Sharing the burden of strife in chronic illness:
A praxiological study of nursing practice in a community context

by

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Abstract

This inquiry is an in-depth exploration of one middle aged woman's, Sarah, experience of strife in chronic illness and her nursing care involving four nurses (including myself) in a community context over a three-year period. The study is praxiological in that the understanding achieved is derived from practice within a 'research as praxis' methodology positioned in the disciplinary perspective of nursing as a practical human science. Five methodological premises inform the research processes: reflexivity, dialogue, moral comportment, re-presentation in narrative and critique. They emanate from an eclectic ontological praxiology based on the research framework constructed from Gadamerian philosophical hermeneutics, components of other philosophical praxiologies evolved from an exploration of the practical discourse in philosophy and my preferred health and nursing assumptions.

The research processes include researcher journalling; summaries of Sarah's nursing record, dialogical meetings with Sarah and the nurse co-participants to collect the research material and then co-construct it into narrative form. The narrative is developed around what Sarah viewed as the overall nursing contribution to her care; the 'sharing of her burden of illness'. This, she maintained, enabled her to live safely in the community. Finally there occurs a critique of the narrative within a discursive framework.

Three themes, embedded in particular discourses, emerged from the narrative both in Sarah's and the nurses' experience; paradox, moral meaning and metaphor. Sarah's experience is interpreted as taking place in the 'in-between space' of the disease and health-illness discourses. Two main concepts which depict the tension experienced in this space are the 'the ontological assault of illness' and 'entrapment in the disease discourse'. We, the nurses, 'pushed the boundaries' to create a space for the nursing as a caring practice discourse on the margins of nursing as a functional service discourse. Within the nursing as a caring practice space many 'fine lines' were walked with Sarah. Walking the 'fine line' of an 'intense relationship' was seen as advanced nursing practice.

The research highlights important implications for a person and/or families who live with chronic illness and practice and educational issues for advanced nurse practitioners. Further, it promotes praxiological methodologies as advantageous for expanding nursing knowledge. This inquiry makes a twofold contribution to the discipline of nursing: it progresses the understanding of living with strife in chronic illness and it expands the practice of praxiological inquiry within nursing.

For
Oscar

May your curiosity and desire to learn, evident at three years of age, stay with you always

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Glossary

Praxis: the reflecting and transforming process involved in the meeting and melding of ideas, ways of knowing, action and outcome.

Practice: the knowledge and conduct directed towards the ‘good’ of another. Choices and decision making derive from practical experience, knowledge and the context pertaining to them. A practice is embedded within a community and tradition and continually evolves from pursuing understanding in what it sees as ‘the good’ and how it is enacted in practice (Bishop & Scudder, 1991; Gadamer, 1981; McIntyre, A. 1981)

Praxiology: the ideological underpinning of particular social, cultural or philosophical views associated with the way the concept of praxis is considered and developed. It is the apriori derivative knowledge and values informing praxis. A particular praxiology is embedded in this study which informs the praxiological methodology.

Praxiological: pertains to the concepts of praxis and praxiology. Its meaning will differ in accordance with the praxiology in use. Praxiological endeavours are often connected with practice disciplines that seek to expand their practical discourse,

Practical discourse: the development of knowledge within philosophy, and currently in other disciplines, which takes into account how people live their lives in the day to day world and how decisions are made to enhance individual and common ‘good’. The knowledge develops from practices within a cultural milieu.

Phronesis: the practical moral reasoning used in judgements involving the intersection of general principles and/or theories and particular situations. It has no predetermined end. The outcome emerges from the deliberative process.

Strife in chronic illness: strife is when people living with chronic illness find themselves in frustrating situations that complicate their health-illness circumstances. These frustrations, arising from individual or family tensions and person/family interactions with the health care system, are manifested in a struggle to achieve their desired goals.

Pakeha: a Maori term that describes people of European tradition living in New Zealand.

Whanau: a Maori word used in New Zealand to describe an extended family. It includes ancestors and can include significant people outside direct family relationships.

Chapter one

INTRODUCTION AND OVERVIEW OF INQUIRY

introduction

This inquiry explores the prolonged nursing practice engagement between one woman client, Sarah, and the nurses, including myself, who cared for her. It reveals the meaning made of the client's experience of strife associated with a chronic respiratory illness and the nursing response to her situation. Strife, in the context of this research is when people living with chronic illness find themselves in frustrating situations that complicate their health-illness circumstances. These frustrations, arising from individual or family tensions and person/family interactions with the health care system, are manifested in a struggle to achieve their desired goals. Suffering, vulnerability and a sense of chaos with loss of control are integral components of strife. Repeated hospitalisations are frequently an outcome of the strife.

I have practised as a nurse within a community setting over many years. Professional encounters with people living with chronic illness have led to a particular interest in their broad health-illness circumstances. I have not specialised in nursing people with any particular medical condition but what has interested me is the phenomenon of day to day living with an illness. Chronic illness is a general term for the many multifaceted illnesses that exist in contemporary society. Chronic illnesses are increasing in western society and affect the way of life for approximately a third of the population (Thorne, 1993). Exact statistics on illness are hard to establish because of the way individuals see themselves or attach meaning to living with a diagnosis of illness that does not inhibit their day to day living (Senior & Viveash, 1998).

The inquiry is a retrospective examination of a practice episode and makes a twofold contribution to the discipline of nursing. Firstly, it furthers understanding of the personal experience of strife in chronic illness and what constitutes an effective nursing practice response to a particular situation, through in-depth study of the engagement of client and nurses over a three year period. Secondly, it offers a unique praxis oriented research

methodology evolved from Gadamerian philosophical hermeneutics (Gadamer 1960, 1975a, 1975b, 1981) and a deconstruction of the praxis discourse in philosophy and nursing. (As Gadamerian philosophical hermeneutics is a phrase used consistently throughout the text of this study it will from now on be referred to as GPH).

A significant contribution of this study to the expanding understanding of nursing a client in strife from chronic illness comes from combining the experiences of the client and the nurses who cared for her. These experiences are re-presented in one integrated narrative; a story constructed by all participants. This design strategy facilitated a sharing of the meaning made by each participant and then a fusing together of individual meanings within a co-construction process. Thus all participants were co-participants. Most practice oriented nursing research examines either clients' or nurses' experiences. Even where there is a combining of experiences, research seldom pertains to the reciprocal responding of the same clients and their nurses. Allen (1994), in referring to Benner's research on nursing expertise, cautions readers about claims to the contribution to client care made by nursing where there is no client voice presented to confirm the claims. Moreover, an in depth study such as this research which spans a three year period, has rarely been discussed in the nursing literature.

Meaning made of the practice situation is evident from the reflections of all those involved in the experience. To me, it is reflective practice 'writ large'. Nevertheless, reflective practice rarely involves the exploration, interpretation and understanding of such extensive reflections, including the client's own perspective, as is presented in this research. The first major insight for both the client and myself emerged from the metaphorical understanding she gave to her illness as a burden that weighed heavily upon her and at times overwhelmed her. In relation to this meaning the nursing contribution to her care was elucidated as a 'caring gaze' under which her health circumstances were co-constructed and emergent from this process her burden was shared. Further discursive illumination of her experience as residing in an 'in between' space of what I term the health-illness and disease discourses explicated a tension between 'illness as an ontological assault' and 'entrapment in the disease discourse'. A

discursive analysis of the ‘caring gaze’ of nursing demonstrated that it was embodied in a space named the nursing as a caring discourse, created though ‘pushing the boundaries’ of what I term the nursing as a functional service discourse. The walking of ‘fine lines’ was viewed as constitutive of the ‘caring gaze’. A significant ‘fine line’ was tread in the creation of an ‘intense relationship’ seen as advanced nursing practice.

I believe in the importance of the development of nursing knowledge from the formal accounts of distinctive nursing praxis episodes. Nursing praxis always take place in a particular situation. From my perspective, it is especially important in this instance when, according to the nurse co-participants, it illuminates particular components of advanced nursing practice.

The research objectives emerged from a conjunction between earlier research undertaken by me, and consequent practice. The methodology of my previous study involved five client participants and myself within a pilot project set up for the research. In the present study the co-participants comprise one client and four nurses from a regular community health service within the New Zealand public health service. The present inquiry, although praxis oriented like the previous study, required a methodology that fitted with its distinctive features.

My ongoing commitment to the notion of praxis both as an important concept in practice development and at a formal methodological level brought me to the notion of praxiological inquiry. Praxiological inquiry is research that has as its purpose the development of practice knowledge: knowledge emanating from theorising about practice, which is often referred to as practice theory. Well known research methodologies such as grounded theory, phenomenology or critical social theory, can be praxiological (Pearson, 1988). However, with my position as both the lead researcher and a practitioner in the nursing situation under investigation a particular methodology, taking these distinctive features into account, was needed. I, as a key practitioner in the practice situation not only initiated the reflexivity process of the research but also continued to be involved as a practitioner in the ongoing care of the client participant.

Research of this nature is rare and brings with it particular contextual and ethical considerations that need to be addressed within an appropriate methodology.

From the outset, this study embodied hermeneutical intent in seeking an expanded understanding of the nursing practice with a person experiencing strife in chronic illness. However, the relationship between hermeneutics and praxis was not clear. The dominance of emancipatory praxis in the nursing literature on praxis research appeared to overshadow other notions of praxis and assign them to the margins. Thus I reviewed the evolution of the concept of praxis in philosophy and in nursing, constructed a research framework from GPH and proceeded to configure a praxiological methodology. This became a process of justification and demonstration of a hermeneutical praxiology as valuable in enhancing reflexivity and transformation in nursing praxis. As such it makes a significant contribution to researching nursing practice.

The hermeneutical knowledge that unfolds in this report illuminates a particular challenge in my ongoing personal quest to deepen my understanding of nursing practice. It is an expansion of my earlier knowing (Connor, 1995). Concomitant with the present pursuit is a search for a methodology equal to the task of capturing the meaning of the particular practice episode. This inquiry, then, can be seen as double praxiological quest. As the study progressed each strand developed together and became thoroughly interwoven in order to meet the research objectives. As I addressed the development of each thread there were shifts in the foreground and in the background as each, in turn, took centre stage in particular chapters.

In my previous post graduate research the strife experienced by one co-participant stood out as significantly more complex than the strife of the other co-participants. When seeking the meaning of experiences is central in ongoing praxis, such an outstanding difference is likely to generate continued reflection. If the opportunity arises to inquire into a similar experience there can be an extension of earlier research, the asking of different research questions. A similar situation did come into being in my practice and became the point of departure for this inquiry. As I was the primary nurse in the practice

episode to be investigated I entered into this research in the full knowledge that my practice would be under scrutiny but not knowing what would surface as its strengths and weaknesses.

research objectives

Two research objectives guide this study. The first is framed to further enhance qualitative understanding of strife in chronic illness and how a particular relationally oriented nursing response to one person's situation had aided movement out of strife. At the commencement of the research it was evident that nursing had made a significant contribution to reducing the strife of the client co-participant. But, the components of the contribution were not clear. It appeared that a sense of what was involved in the overall circumstances would only be achieved in reflecting back on the experience. The second objective flows out of the first. It pertains to the design of the praxiological methodology required to achieve the first objective. The two objectives are:

- a) to explore the meaning of prolonged strife in chronic illness from a client perspective and the nursing practice associated with it as experienced by the client and the nurses involved;**
- and**
- b) to construct a praxiological methodology which will enable the development of substantive understanding of the client and nurses' experience of strife in chronic illness in a particular practice situation.**

These two objectives are interwoven within a hermeneutical view of reality emanating from the theoretical philosophical research framework constructed from GPH (Gadamer, 1960/1975/1999, 1976a, 1976b, 1981). Pervading the inquiry is the key assumption of knowledge as a human construction intimately tied to the persons of the knowers who are part of the world they are interpreting. All the co-participants are subjects in the interaction of interpretation and for this reason the emergent understanding is termed intersubjective. Nevertheless, as I am the main narrator of the constructed understanding, my voice and my subjective lens will have a greater influence on the

final construction than that of the other co-participants. For this reason my voice will appear in the first person throughout the report. Moreover, my use of the first person allows for my overt positioning in the research text (Thompson, 1990) providing an audit trail of my location and decision making throughout the research process. The understanding generated from the research objectives can also be termed practical knowledge (Gadamer, 1960/1975/1999, 1981; Habermas, 1972); knowledge contributing to the practical discourse of the discipline of nursing.

discovering the practical discourse in philosophy

The intertwining of the practical discourse in philosophy with the practical discourse in nursing became clear to me as my research journey advanced. In my 1995 study I made an initial foray into the work of Bernstein (1971; 1983) as an aid to explicating a broader understanding of praxis. It provided a preliminary understanding that answered my then questioning of the increasing and varying use and claims about praxis in nursing triggered by Holmes' (1993) critique of Newman (1990). The opportunity to take up further research involving earlier interests became an occasion to pursue more fully the richness of Bernstein's work on praxis in philosophy and to see where that might take me.

Bernstein (1983) disputes the fruitfulness of the philosophical conception of rationality as it is shaped within the epistemological constructs of objectivism and relativism. In moving beyond these epistemological concepts Bernstein charts new ground in advancing the concept of rationality through his in-depth exploration and re-conceptualisation of the interlinking of praxis and hermeneutics. This contribution to the evolving practical discourse in philosophy has been extremely helpful in deepening my understanding of the evolution of the practical discourse in philosophy. I will further explore Bernstein's thinking in chapters two and five when I discuss his view of post empirical research and his contribution to the practical discourse in philosophy, respectively.

The practical discourse developed as a particular thread in philosophy in order to distinguish it from what is known as the contemplative or theoretical discourse (Bernstein, 1983; Gadamer, 1960/1975/1999, 1976b, 1981). Development of knowledge from lived experience rather than from an act of contemplation has been a defining characteristic of the practical discourse since it was first articulated in ancient Greece. The theoretical and practical distinctions of that period are not as clear cut in today's world. According to Bernstein and Gadamer, the practical discourse refers to the development of knowledge that expands understanding of how we live our daily lives in the world as individuals and communities. It takes account of the individual and common good within changing understandings of the world, and the moral imperatives of communities within this ongoing change. It is within this evolution of knowledge, I believe, that we live and practice our professional disciplines.

Hermeneutics is credited with reclaiming the ancient practical tradition of involving the centrality of human conduct towards the 'good' of an-other (Bernstein, 1983; Gadamer, 1960/1975/1999, 1976a, 1981). There has been a revitalising of this tradition, in which Gadamer has been an important influence; a tradition that had become obscured because of the ascendancy of science in the modern era. Hermeneutics abandons the modernistic approach of applying theory to practice in favour of theorising from practice (Gadamer, 1981). In both books Gadamer claims that moral practice can only be judged wise or other-wise in the application of general principles in particular situations, which is the practice of moral practical reasoning or *phronesis*. Cissna and Anderson, (1990 p. 127) sum up the current understanding of the practical discourse in philosophy as encompassing "oral, particular, local, and timely issues, ... anchored in contemporary experience". From my perspective, hermeneutics, in this framing, is an appropriate paradigm in which to embed my deepening understanding of strife in chronic illness from a practice situation.

My discovery of the practical discourse in philosophy via Bernstein's (1983) linking of praxis and hermeneutics has supported the decision to make a nursing practice episode the touchstone of knowledge development. Thompson (1985; 1990), a nurse scholar who

has drawn on the work of Bernstein, including his earlier publication (Bernstein, 1971) and Gadamer (1960/1975/1999) in her writing about the practical discourse and hermeneutics in nursing, has clarified my transposition of these philosophers ideas into the nursing arena. Praxiological is not a specific term used by Bernstein, Gadamer or Thompson but praxiological intent is apparent in their work. It is a descriptor appearing in the lexicon of the practical discourse of philosophy and appears in some nursing literature.

practice as the touchstone of knowledge development in the discipline of nursing

The pivotal premise of my current position within the discipline of nursing assumes that nursing is a 'practical human science' (Bishop & Scudder, 1991, 1997; Polifroni & Welch, 1999). It is evident in the writings of these authors that their dialogue with the practical discourse in philosophy influenced their identification of nursing as a practical human science. Nursing is a practical human science providing knowledge not only about particular ways of responding to persons experiencing chronic illness, but in all the health-illness related encounters between nurses and their clientele. Bishop and Scudder assert the key tenet of the practical discourse when they maintain that nursing practice should be the centre stage for the development of nursing knowledge. Furthermore, these authors argue that in making nursing practice both the beginning point and end point of expanding nursing knowledge, the discipline of nursing can move beyond its preoccupation with the theory-practice gap. The conception of nursing as a practical human science is a move from the construction of nursing as an applied science to that of nursing as a practical science.

In accepting the view of nursing as a practical human science I have moved on from my positioning within the discourse of nursing mooted in my earlier research. In that study I located myself within an apriori theoretical position, albeit a nursing theory developed by nurse theorist, Margaret Newman (1986, 1994). She developed her theory with knowledge of practice, but not from practice experience, so it can not be described as praxiological or a practice theory. The main reason for my different location within the discipline comes from my practice experience after my 1995 study. Many challenges

were presented to my practical moral decision making in episodes of complex care. I wanted a greater understanding of the what and why of my professional judgements than I possessed at that time. Situating myself in the view of nursing as a practical human science gave me a location in which I could explore challenging practice issues.

Decision-making in practice always needs to take full account of the particulars of each situation. It was a timely reminder for me as my renewed enthusiasm for theoretical ideas arising out my 1995 research had me bordering on the belief that clarity in theory made for a smooth path in the messy swamps of practice (Street, 1990). Theory assists the thinking through of decision making in accord with values and evidence but does not remove the challenge or risk taken in the establishment of the moral meanings of particular circumstances. Instead, I came to believe even more strongly that theorising on particular practice situations must always inform praxis. This kind of theorising enables the theory-practice nexus of nursing to evolve together as a mutual quest.

As I entered into this study I saw that many of the assumptions about human being in the world that I had valued in Newman's (1986, 1996) theory were present within GPH. This influenced my decision to construct a research framework from the hermeneutical viewpoint. The positioning of the study on the broader stage of philosophy facilitated a step back from my earlier position and a critical reflection on it. The critique has enabled my move into a place that is right for me at the present time. Much of this critique is explicated in chapters two and six. Rather than following the methodology of Litchfield (1993), who at that time was in dialogue with Margaret Newman, I have 'pitched my stake' in new ground; the ground of philosophy.

constructing a theoretical-philosophical framework from Gadamerian philosophical hermeneutics

The intention of this inquiry is hermeneutical. Bearing in mind this intention and working through a process of elimination of what hermeneutical framework was most appropriate to my praxiological purpose and epistemological premises I chose GPH philosophy (Gadamer, 1960/1975/1999, 1976a, 1976b, 1981). The major reasons for this choice was the consistency between Gadamer's view of hermeneutics and my designated

view of nursing as a practical human science, the links between praxis and hermeneutics made by Gadamer and Bernstein (1983) and the inherent assumptions about how people live and learn as social beings.

As part of finding the most appropriate framework I reviewed the hermeneutical schema of Heidegger (Benner, 1984; Benner, Tanner, & Chesla, 1996; Grondin, 1994; Heidegger, 1953/1996) and critical or radical hermeneutics (Caputo, 1987; Thompson, 1990). This latter exploration added clarity to the practical intention of the research. My intention was not emancipatory as described by Habermas (1972, 1973). Discursive critique, a common feature of an emancipatory research interest, is included as one component of my methodology rather than constituting the cognitive knowledge interest. Gadamer's (1960/1975/1999, 1976a, 1976b, 1981) philosophy, which builds on Heideggerian phenomenology, was also consistent with my relational practice and inquiry values. The fit with Gadamer's view of understanding appeared stronger than with Heideggerian phenomenological hermeneutics.

In the initial proposal for this inquiry I outlined only three major premises as my epistemological position, plus its praxis oriented nature. The premises were reflexivity, dialogue and re-presentation in narrative. A strong element of uncertainty relating to the praxis nature of the study was an attendant issue from the outset. Because of this I termed my methodology emergent. This granted me the possibility of changing direction in my methodology if changes to the inquiry circumstances occurred. In the initial stage of the research I was using tenets from GPH because I related positively to its inherent assumptions of human being and understanding in the world. As I advanced the research I moved to construct a more explicit framework from GPH. The framework then led to a greater expansion of the initial three epistemological premises and the adoption of two more: moral comportment and critique. Dialogue as a premise within the theoretical-philosophical framework embodied an assumption of open mindedness to the unfolding process of understanding and a flexibility in following what questions and answers emerge. As such it was consistent with the idea of an emergent methodology. The character of methodological premises are expanded further in chapters three and seven.

GPH is constructed around two fundamental tenets: effective historical consciousness and language. In making effective historical consciousness a key tenet Gadamer (1960/1975/1999, 1976b, 1981) was drawing on the turn to historicism in philosophy. His nomination of language gave new expression to his understanding of the Platonic dialogues and the linguistic turn taking place in philosophy. The latter is often referred to as ‘everyday language’ philosophy (Thompson, 1990).

Interpretation and understanding for Gadamer (1960/1975/1999, 1976a, 1976b), are essentially ontological happenings. In choosing to construct the theoretical-philosophical research framework from GPH I chose to give the methodology ontological primacy. What had begun as epistemological premises then became ontological-epistemological premises or simply a set of premises to govern the praxiological methodology. The fundamental importance of effective historical consciousness and language within GPH, also termed a moral science by Gadamer, gave the premises of reflexivity, dialogue and moral comportment both a general and a particular application in the study. They are general in the sense that all reflective and dialogical contributions to understanding in a hermeneutical study, usually described as background material, are inherent constituents of the inquiry. Their particular application is in the way they shape the praxiological methodology underpinning the systematic pursuit of the first research objective.

This inquiry contains three interweaving circles within the overall hermeneutical circle of the study. Considerable background material informing the praxiological methodology is discussed in chapters two to six which constitutes the first hermeneutical circle. The praxiological methodology and the findings re-presented in narrative, the material of chapters seven and eight, can be seen as the second circle. Chapter nine begins the third and final circle. It contains a return to the methodology and literature in order to develop a discursive framework for a critique of the narrative. The shape of the critique was not predictable before the construction of the narrative, because of the methodological challenge to remain open to what would emerge from it. The identification of these circles alerts readers to the shifts that will be encountered in

reading this thesis. Nevertheless, the shifts are linked together by three horizontal threads, the exploration of strife in chronic illness, practice as praxis and research as praxis. These threads are discussed in chapter two.

summary of chapter one and overview of subsequent chapters

In this chapter I have introduced the topic of the research as an investigation of the meaning of strife in chronic illness from the perspectives of an individual living with it and a small team of nurses caring for this person. The first research objective pertains to an exploration of this particular nursing practice situation. A preview of the essential constructs, which emerged from the exploration, is cited. The second objective, relating to the construction of an appropriate praxiological methodology for the achievement of substantive understanding of the topic, is also stated. I claim that the fulfillment of these objectives makes two distinct contributions to the discipline of nursing; it expands the understanding of the nursing practice of people with strife in chronic illness and furthers the development of praxiological methodologies.

A preliminary justification for further research on the topic is outlined. My discovery of the practical discourse in philosophy, which is characterised by knowledge development from experience, is presented as the basis of my position in nursing as a practical human science. In order to give the research a theoretical-philosophical underpinning I signal a claim to the appropriateness of the construction of a theoretical philosophical framework, to underpin the inquiry, from GPH and some implications of this for the overall research and the systematic investigation of the research topic. The study involves the seeking of new levels of meaning within three circles which constitute one hermeneutic-praxiological quest.

In chapter two I discuss my personal and professional context from which my interest in strife in chronic illness emanated. Within this context, practice as praxis and research as praxis, the two other horizontal threads of the research are addressed. My position as a clinical nurse specialist in a regular public health community nursing service is outlined. It was from within the parameters of this role that my engagement with Sarah, the client

co-participant of this research and the collaboration within the nurse co-participants of the study took place. Recent movement in my thinking about practice as praxis and research as praxis is the common thread of this chapter.

Chapter three shifts to the explication of the theoretical-philosophical research framework from GPH. The main primary and secondary sources informing my interpretation of Gadamer's work are noted followed by a short commentary on hermeneutics as a human science. Construction of the framework around the two key tenets of effective historical consciousness and language then follows with a section on the implications of the assumptions and ideas for the inquiry. The framework is selective and does not attempt a full analysis of Gadamer's writings. A critique of Gadamer's position is included as a caution to the partiality of his view of the world. Chapter three closes with a discussion of the criteria from which the research can be judged as authentic knowledge. This discussion is placed in this space because I argue that the major premise of authenticity arises from the inquiry's faithfulness to its philosophical underpinnings.

The substantive material in chapter four extends the historical traditions, in Gadamerian terms the effective historical consciousness, informing the research. There is an examination of what is known as the New Zealand health reform, which commenced in the late 1980s, and continues in the present time. The evolution of the contemporary phenomenon of chronic illness is also discussed in this chapter. These two traditions overlap and are significant in the knowledge development of the study.

Chapter five further extends the background informing the inquiry by examining the tradition in which praxis as the practical discourse in philosophy has evolved into the multiple variations that are currently encountered in philosophy and other disciplines. The chapter explores the evolutionary development of praxis in western philosophy from the time of Aristotle. Important proponents of praxis who progressed its evolution are identified and their particular praxiologies are outlined. A comment on the historical setting of each proponent is offered to demonstrate that each praxiology is influenced by

the ontological and epistemological thinking of the time of its construction. Shifts from the overtly political nature of praxis to interpretations of personal and life praxis are shown and summed up in the feminist proposition of ‘the personal is the political’. Some post World War writers are strongly critical of instrumental praxis and reclaim the authenticity of the practical through their reference to Aristotle. The material in this chapter clarifies some queries I had experienced in relation to claims about praxis and simultaneously expands the horizontal thread of research as praxis.

In chapter six the appropriation into nursing of the differing praxiologies present in philosophy is discussed. Here I substantiate my assertion regarding the close connections of the practical discourse in philosophy to the same discourse in nursing. The discussion demonstrates that there is no one claim to the correct use of praxis in nursing. Instead there is an ever widening use of the concept within differing praxiologies where particular aspects are extended and others abandoned. These are praxiologies that are not overtly classified as such and subsequently can lead to some difficulty in tracking with different nurse writers who offer claims and counter claims to the ‘correctness’ of the expression of praxis. Emancipatory praxis or the praxiology informed by emancipatory theory emerges as the most dominant praxiology in nursing. I conclude that this has happened because emancipatory praxis has been consistently embedded in emancipatory theory, its praxiology. Other claimants have not linked their particular theoretical knowledge so clearly with the concept of praxis and consequently have not demonstrated such a clear praxiology. This reflexive exercise gave me greater clarity in developing my own praxiology and the methodological premises which inform the research processes used to meet the first the first research objective. This chapter completes what I have nominated as the first circle of the research. Because of this I have provided an interim summative statement on this circle at the end of chapter six.

Chapter seven describes the systematic praxiological methodology and research process set up to achieve the first research objective of exploring the meaning of strife in chronic illness from the perspective of Sarah, the client who lived with it and the small team of nurses responding to her experience. The chapter commences with an articulation of my

praxiology. The configuration is laid out of the methodological premises of reflexivity, dialogue, moral comportment, representation in narrative and critique, drawing on the understanding acquired in chapters three, five and six. A second section of chapter seven describes the processes inherent in the carrying out of the systematic praxiological methodology. The discussion covers the preparatory period, the distinctive attributes pertaining to my position as lead researcher and research co-participant and my relationship with the co-participants. The complexity of these features is not common in nursing research and because of this a dialogue was commenced with the co-participants and my local Ethics Committee prior to formalising the processes. This section proceeds to describe the dialogical meeting with co-participants, my journalling of ongoing issues, re-presenting the material gathered into narrative form within a continuing co-constructing exercise and an indication of what is involved in critiquing the narrative.

In chapter eight I present the meaning generated from the dialogical meetings within a co-constructed integrated narrative. It is the outcome of the application of the first four of the methodological premises. Re-presentation in narrative brings to life the poignant pathos of the client's experience of strife in chronic illness and issues encountered in the nursing care. The narrative provides a vivid example of practice as praxis from which the practical discourse in the discipline of nursing can be examined and expanded. In order to demonstrate the experience as a unitary whole the complete narrative is presented in this chapter, which as a consequence is detailed and lengthy. A key meaning generated within the dialogue was Sarah's theoretical metaphorical understanding of her illness as a 'burden that weighed heavily upon her and which at times overwhelmed her'. Sarah saw her life as an ongoing 'battle' to achieve what she described as 'a normal way of life' and to be acknowledged as a suffering vulnerable human being. For her, the overall contribution made by the nursing practice was in 'sharing the load of her burden', which in turn enabled her to breathe more easily. The 'sharing of her burden' was embodied in 'the caring gaze' of nursing where a 'co-construction' of her ongoing health circumstances happened. The notion of an illness as a journey was implicit, therefore, I took the metaphor of journey as the organisational fulcrum of the narrative material. Two metaphors stand out in the meaning we, the co-

participating nurses, gave to our experience. They were ‘pushing the boundaries’ of the practice usually enacted in the particular context and the ‘fine lines’ walked to accomplish ‘the caring gaze’. ‘Pushing the boundaries’ of practice and ‘walking the fine line of an intense relationship’ were identified as advanced nursing practice. The narrative closes with a demonstration of the outcomes for Sarah from the transformative interval of the research period and beyond. Chapter eight concludes the second cycle of the three cycles of the inquiry.

Chapter nine is used to structure a discursive framework in which to critique the narrative. To do this it returns to the methodological premises and provides a background to the identified discourses in the narrative from the literature. As such this chapter constitutes a bridge from the narrative in chapter eight to its deconstruction in chapter ten. Paradox, moral meaning and metaphor are explicated as the main themes in Sarah’s and the nurses’ experience. Once I began to examine these themes I discovered their discursive construction. Two sets of discourses are identified; one set, the health-illness in juxtaposition with the disease discourses is seen to be influencing Sarah’s meaning; the second set, nursing as a caring practice and nursing as a functional service discourses was detected as impacting on the meaning generated by the nurses. The themes and the discursive effects led me to describing the practice episode as postmodern nursing practice. Each set of discourses, as they are illuminated in the literature, are described separately and a table summarising the assumptions of each set is provided in the conclusion of the chapter.

The critique of the narrative as a process of deconstruction is reported in chapter ten. As is consistent with a post modern or post structuralist view of analysis I readily admit that the critique I have constructed is one of many possible critiques that could be made. It is a critique that emanated from within my own effective historical consciousness, influenced by the research framework premise of language and my dialogue with the narrative. Sarah’s situation was embedded in what I describe as an ‘in between’ space of health-illness and disease discourses where she experienced the push and pull of both these discourses. Key concepts of the ‘ontological assault of illness’ and ‘entrapment in

the disease discourse' are used to give another level of meaning to many of the issues constituting Sarah's experience in the narrative. My critique of the nurses' meaning revealed that the caring relational practice that I had endeavoured to implement for Sarah, could be described as a discourse on nursing as a caring practice situated on the boundary of the nursing as a functional service discourse. The tensions of implementing a relational ethic of care and the 'walking of fine lines' in an 'intense relationship' highlight the nursing issues identified in the narrative. The level of meaning surfaced in this chapter embraces many significant insights about Sarah's and the nurses' experience. Rather than smoothing out our human inconsistencies into a ready made theory I have chosen to discuss them as our practical experience of living and practising nursing in the contemporary world. A final summative statement, which describes the achievement of the two research objectives and the unique contribution to the discipline of nursing made by this inquiry, is presented at the end of this chapter.

In chapter eleven the full cycle of hermeneutical reflection that is advanced through out the inquiry within the general methodological premises of reflexivity, dialogue and moral comportment is completed, together with the third circle of the research. The headings of practice as praxis and research as praxis are employed to structure the key insights and implications of the study. Some suggestions for expanding research on the topic are included. The chapter discusses the implications of the expanded understanding of strife in chronic illness for Sarah and person's/families living with strife in chronic illness and for nurses who might identify this phenomenon. Particular indications are stated for the practice and education of advanced nurse practitioners and for health policy. An analysis of the importance, benefits, weaknesses and future potential of praxiological inquiry for progressing knowledge development from nursing practice, particularly advanced nursing practice, is offered. A concluding statement sums up the inquiry and its contribution to the nursing of people experiencing strife in chronic illness and nursing research methodologies.

Chapter two

PERSONAL AND PROFESSIONAL TRADITION AS CONTEXT OF THE INQUIRY: RESEARCH AND PRACTICE AS PRAXIS IN THE QUEST TO EXPAND UNDERSTANDING OF LIVING WITH STRIFE IN CHRONIC ILLNESS

introduction

People living with chronic illness and disability have become a professional interest of mine in both the practice and research contexts. The focus of this interest is on people living with chronic illness at the general level rather than on any specific illness. My practice with these people has been in the community as a district nurse and as a community based liaison nurse for people with physical disabilities. The latter work was an extended role of the district nursing service. Since undertaking a one year full time post registration academic nursing diploma, approximately 30 years ago, I have had an enduring interest in expanding my understanding of nursing as theory-practice. I now call this praxis. The parenting of three young children took priority at one stage of this period and added to the person of the nurse that I have become. My nursing career has straddled practice and education settings. Both areas of work have reinforced my passion for nursing. Since the term praxis, a term I had encountered earlier in liberation theology and in Marxist critique in sociology, entered into my nursing lexicon approximately 10 years ago it has become an increasingly significant concept for me. It has provided a conceptual touchstone for the advancing of my practice-theory understanding in nursing practice, research and education.

As I moved to give my practice a clear theoretical foundation I chose to incorporate the nursing theory of Newman (1986, 1994, 1997) into my disciplinary thinking. Her paradigmatic positioning helped me express the relational aspects of practice, which I had considered the core of nursing since my first encounter with post registration study. An interest in relational nursing practice as opposed to instrumental or technical nursing is a constant focal point in my background. Thinking and researching in the unitary-transformative paradigm constructed by Newman, Sime, and Corcoran-Perry (1991) was reinforced in reflective conversation and as a research team member with my colleague Merian Litchfield (Litchfield, Connor, Eathorne, Laws, McCombie, & Smith 1994) in the

early 1990s. Litchfield was, at that time, developing her research in dialogue with Newman.

Because of my interest in long term illness and the liaison experience I was invited to join a research team investigating family nurse practice in a nurse case management scheme (Litchfield, Connor, Eathorne, Laws, McCombie & Smith, 1994). Families who had one member with a physical disability and at least one child under the age of 16 years, who were deemed to have complex health circumstances by a nurse already working with the family, made up the research participants. One descriptor of complex health circumstances developed in the 1994 research was that of “a predicament of strife” (p. 36). Since my experience of that research I have continued exploring the notion of strife within chronic illness. This concept is not recorded on Cinahl and Medline databases. However, the nurse case management literature (Etheridge & Lamb, 1989; Rodgers, Riordan & Swindle, 1991) does talk of people with complex health circumstances and I would place people living with strife in this grouping.

I have chosen to continue to use the concept of ‘strife’ as I find it a useful descriptor for identifying the particular pattern of circumstances in which some vulnerable and high risk people become enmeshed. In the body of this chapter I will trace my influences and experience as the context of this inquiry. The discussion begins with my initial postgraduate study which influenced my move to a new practice position in a community health nursing service. I will then describe what I have encountered as the experience of strife in chronic illness and how this shaped the setting up of a ‘web of relationship’ with Sarah, the client co-participant in this study. The decision to investigate the practice experience with Sarah led me to further reflect on and move beyond the horizon of Newman’s (1986, 1996) theory and claim this study as a unique expression of practice and research as praxis.

initial postgraduate study

My participation as a research team member in the family nurse project (Litchfield, Connor, Eathorne, Laws, McCombie & Smith, 1994) stimulated the research question of my initial postgraduate study (Connor, 1995). I commenced this study towards the end of

the family nurse project. My research question asked ‘What is the nature of the client nurse relationship in a nurse case management model of care?’ It was informed by the assumptions of Newman’s theory (1986, 1994) which are synthesized in table 1.

Table 1. Synthesis of assumptions in Newman’s theory of Health as Expanding Consciousness.

People are greater than the sum of their parts.

Health is the pattern of the unfolding whole of the person with their environment.

The pattern of the whole changes while enfolding in space and time: it shows and can give meaning to the uniqueness of their circumstances as they live day to day.

Choice points occur during life when people can choose to change the way they act and therefore their pattern.

The way and time people will change is unpredictable.

Change is unidirectional and leads to transformation in the life process; there is always a moving on rather than a return to a stable state. (Connor, 1995, p. 180)

Many of these assumptions continue as important constituents of my view of human being in the world. However I have moved away from the particular tenets of Newman’s theory. Although I still hold that health as human wholeness unfolds in a unitary, unidirectional manner, I do not use her particular concept of pattern.

To answer the 1995 research question I set up a small pilot study of five client co-participants where strife in chronic illness was the main criteria for entry to the scheme. Using the researcher-practitioner praxis-oriented methodology developed by Litchfield (1993) I worked with five client-participants as a researcher-practitioner and evolved a model of care titled ‘The web of relationship’. Four overlapping and interweaving themes constituted the model: constructing context; the art of speaking to one another; building up and moving on; and changing and transforming. I called the nursing philosophy in my web of relationship model a relational ethic of care. It viewed caring as a moral imperative involving a commitment to the uniqueness, humanness and dignity of all

persons. A caring relationship connects the person/s of the client to the person of the nurse. Such an ethic provided the ethical framework of my practice.

At the commencement of my 1995 research I believed that case management as a health delivery model provided the structure needed for a primarily relational nursing practice to be developed without the constraints of other service delivery systems. However, within the research-practice process I came to see that clarity of the practice was more important than the scheme of service delivery. A supportive service enhances clarity of practice but is an empty shell without a skilled practitioner. This idea was evident in the family nurse study (Litchfield, Connor, Eathorne, Laws, McCombie & Smith, 1994) but I did not fully comprehend it until I had engaged in the process of my own research. My 1995 research was significant in the career move I made shortly after its completion.

taking up a new practice position in a community nursing service

I was working in nursing education at the time of the 1995 investigation. The transformation I underwent within that research was a deciding factor in returning to nursing practice. I had searched for a joint practice-education appointment over a number of years prior to this shift but such a position had eluded me. The family nurse practice study team had endeavoured to obtain an ongoing provider contract for the research model of care. Negotiations for the contract were with the new purchaser organisation known as the Health Funding Authority (HFA). If the contract had eventuated I would have sought work within the new service. (Chapter four provides a general overview of the New Zealand health reform). I was not prepared to return to practice unless I could find a position with potential to further develop my knowledge of people experiencing strife in chronic illness. My move, when it came took me into a newly created position within a community based nursing service of a public health provider of primary, secondary and tertiary care. It was in the district nursing service where I had previously worked. The newly created position, together with other new nursing positions created at that time recognised that nurses needed leadership and practice development in the field. Prior to the commencement of the New Zealand health reform in the late 1980s the charge nurse of a service had been seen as the nursing practice leader. As a result of the

restructurings of the reform period most charge nurse positions had become primarily managerial. Consequently, a gap in practice leadership had been identified.

The service I joined was an evolving multidisciplinary community health service. The nursing component was experiencing change influenced by the new contractual pressures and expanding nursing developments. In addition to the district nurses (generalist nurses) who worked in teams in particular geographical areas there were numbers of nurse specialists who worked across community-hospital boundaries nursing people living with oncology, stoma, respiratory, continence and diabetic conditions. In addition, a small team of nurses undertook general discharge planning with hospital wards for clients who were being referred to the community service. The service was managed by a former non-nurse health professional but a nurse adviser did exist. As part of the health reform the move to practice leadership positions in the service had emerged from a pilot career pathway model set up within some services of the provider agency. I was to be practice leader to a number of district nursing teams.

The position encompassed three main components: working with a small assignment of complex clients, working with the nurses to develop their practice and preparing written material for articulating practice and specific clinical protocols. My title was ‘Nurse Specialist – Community’. As I believed that nursing in the community was generalist or comprehensive in nature, as opposed to specialist, I came to call myself ‘the generalist nurse specialist’. This was also to distinguish my role from other nurse specialists with whom I worked who had roles directly linked to the above stated medical specialties.

My position description asked me to provide clinical leadership through developing innovative practice. Research was spelt out as a specific responsibility of the role and I was challenged to initiate, undertake and/or support research in my area of practice. The ability to establish partnerships with colleagues and demonstrate expertise and knowledge in nursing practice were the features that gave the position credibility and authority. Direct practice gave me opportunities to become involved with clients experiencing strife in chronic illness and to be exposed to and reminded of the realities of practice and the day to day concerns of both nurses and the clientele.

In the field I found that many clients experienced higher acuity and complexity in their situations when they returned home from hospital to convalesce, than had been the case in my previous experience. This was an effect of the health reform shift to shorter hospital stays. Another consequence of the reform was the move of what were considered to be simple nursing tasks to unqualified carers. The focus of the registered nurses had changed to working with clients experiencing greater acuity and complexity in their health-illness situations. What had been a traditional district nursing service was now more of a 'hospital at home' system. Prior to the health reform emphasis on streamlining delivery of health care, the scope of a district nurses' practice had been broader. Health promotion and illness prevention together with disease treatment were integrated components of the practice. The service now appeared to me to be an extension of secondary care with a focus on the functional needs of the clients rather than enacting primary health care philosophy. In fact, as health promotion did not feature in the contract nurses were discouraged from mentioning it, although it still went on as a component of their practice.

One of my early projects in the new position was the development and writing of a model of nursing practice with other senior practitioners. Exploring and describing the nature of professional nursing practice in a system of ongoing health reform was, I believed, a critical responsibility of practice leaders in an increasingly functionalist health care environment. Configuration of the model arose from what were evolving as lists of competencies and standards that were required for career path advancement. The career path philosophy was calling forth a greater sense of professional nursing practice that was to rest on the identification of varying levels of competencies and a core of clinical standards. This was part of a shift from the functional task orientation that had been the accepted organisational mode in the past to what was considered a more professional model of nursing. Nurses were expected to practice autonomously and be responsible for overall episodes of care as primary nurses. Constructing a model of practice was seen as a way to give coherence to the new professional thrust and a stronger sense of nursing work as a practice. Where nursing care is viewed as a series of tasks rather than responding to a person with particular health needs, getting through a workload takes on

greater significance. Completion of a workload tends to be reinforced when management is based on a functional philosophy. In this latter functional framework nurses are drawn into meeting service goals which stress efficiency and throughputs more than comprehensive person centred care. Thus the intention of professional practice was being proclaimed and efforts to set up an organisation that supported it were afoot. However all reporting authority remained with management whose brief was functionalist. A tension in the pull and push of the professional model of practice and the functional approach of management affected my role and what the nurses could achieve.

The community nursing section was part of an independent Crown Health Enterprise contract with the regional Health Funding Authority covering a number of professional multi-disciplinary community services. The contract evolved each year as the purchaser became clearer about the core services it would purchase. This process of streamlining the contract had flow on effects in the service. It led to two major restructurings taking place in the three year period of the study; exercises that took time to collect data and to organise new service structures. It was a time of 'reorganisation fatigue' (Somjen, 2000), a condition where nurses and other health professionals became tired from the energy expended in constant structural change. In such situations nurses either leave the system or go into survival mode, which means that quality time is not then available for practice development. The constant restructuring created a paradox around my position. There had been recognition of the need for innovative practice and practice development of the nurses within the service but the ongoing demands of time and energy diverted into service restructuring deflected energy away from innovative practice and practice development. It was within these service tensions and the assignment of complex clients with whom I had begun working that I encountered Sarah, who had experienced severe strife in chronic illness, the person who became a the client co-participant in this present inquiry.

the experience of strife in chronic illness

‘Predicaments of strife’ in the family nurse study (Litchfield, Connor, Eathorne, Laws, McCombie and Smith, 1994) were manifest in the participants’ family relationships; their frustration with numbers of health professionals involved in their care and many of whom were seen not to have their interests at heart; and in them having no sense of a future beyond surviving in the present. The people in strife in my 1995 study were people I described as having strong spirits and with a resolute sense of what was right for them. These attributes combined with reduced control over their health circumstances increased their vulnerability and frustration. At the same time, it was their strong spirit, manifested in courage and determination that kept them going through the cycles of repeating patterns. The issues constituting their strife, but in unique individual configurations, were “vulnerability, frustration, abuse, anxiety surrounding discharge from hospital, medication, work roles, family networks and tensions, satisfaction/dissatisfaction with health care [and the] effects of the socio-economic climate” (Connor, 1995, p. 144-5). A phrase used by two of the clients in that study and one I hear from other families experiencing strife is ‘It’s a nightmare’.

Mhairead was one of the five co-participants in my research-practice process. Mhairead had shifted out of her strife only tentatively within the eight months of our participant client-nurse researcher engagement. Her experience of strife had existed for over five years and her hospital admissions reached a total of 70 during my engagement with her. Living with strife, for Mhairead, flowed out of the treatment with steroids of her primary disease, chronic asthma. A cascade of several disease conditions including pulmonary emboli, osteoporosis, cataracts and intracranial hypertension with accompanying treatments compounded the little control she had over her life and kept her in a repeating cycle of hospital admissions. Mhairead used highly descriptive images and metaphors to describe her experience. One of these was the following “I feel like a dog that is running around and everyone is kicking it. And it doesn’t matter where it goes there is someone there to kick it” (Connor, 1995, p. 146). It was an image of abuse, helplessness, demoralisation and loss of control.

If our 'web of relationship' had continued there may have been a consolidation of the changes made by Mhairead. In retrospect, I believe the research agenda overtook the practice agenda of the research-practice methodology. Mhairead already had a district nurse involved but this nurse worked differently to me. My research-practice had centred on active listening, trust and reciprocity. I see continuity of care by a knowledgeable nurse as crucial in assisting movement out of strife. It is also more apparent to me now that, as a general rule, the longer a person has been in strife, the longer it will take to build up a renewed sense of coherence in their life. Mhairead did need someone to work with her to assist the integration of her strife into her life and to facilitate the ongoing integration of her health services. A particular form of case management or integration of care delivery scheme involving attending to the meaning of her strife and co-ordinating health services could have achieved this result.

The strife of the other co-participants in my 1995 study was of shorter duration or had been of lesser intensity. It appeared that the shorter the length of strife the easier it was to move on within a 'web of relationship'. Indicators of movement out of strife for the participants in my 1995 study and those in the Litchfield, Connor, Eathorne, Laws, McCombie and Smith (1994) study, were greater positive interactions with family and friends, a renewed view of their future and more participation in their local communities. Simultaneously there was a decrease in dependence on health services. Nevertheless, the moving on from strife, the changing and transforming that is possible, is unpredictable.

There was considerable interest in case management health delivery models of care at the national health policy level and in nursing circles during the time of my 1995 research. At that time I envisaged these models of care would develop further. However, the emphasis of case management in New Zealand shifted to be on the management of fiscal resources rather than providing a space for the integration of the client's complex experience and facilitation of services (Malcolm, 2000). A case management service making the client experience the focus of care was seen as an expensive, resource intensive service and lost favour in the cost containment health service climate of the time. Furthermore, I had developed and expressed reservations about the term case management in my study. I knew people did not see themselves as cases, a term that implies a disembodied person

(Liaschenko, 1997). Moreover, people, although they did want assistance in moving out of strife, did not want to be 'managed'. In the belief that more attention would become focussed on the vulnerability of people who experienced strife, whatever the structure or term used to describe their care, I made several suggestions for enhancing the quality of their experience. These were suggestions I drew upon in my new position.

setting up a 'web of relationship' with Sarah

Sarah was referred to me in the early months of taking up my new position. She had been experiencing severe strife over the previous two year period involving repeated and sometimes very long stays in an acute medical ward. I recognised immediately that there were many similarities between Sarah and Mhairead. The new position did present me with an opportunity to work with people in strife; to practise what I had learned from my research but this was not to be in a structure that was designed especially for the integration of care for people in strife. I endeavored to put my suggestions into practice, particularly for Sarah who was experiencing severe strife. In the opening of our relationship I did not know how her health trajectory would unfold but I was committed to bringing all the knowing I had developed from earlier experience to our relationship and to allow her to be my teacher in furthering this knowing.

I believed continuity of care would be critical for Sarah but also knew that I would not be able to attend Sarah as much as she might need, at least in the first instance. Therefore, I organised with Mary, one of the researcher co-participant nurses to be involved in Sarah's care with me. Mary was someone that Sarah had requested to be part of her care. My involvement and the approach I wanted to take were discussed with Sarah and she consented to working with me. In addition to continuity, the approach included focusing on the client experience, providing space in time and in the right setting for her (most often the home), supporting control in her decision making and assuring confidentiality. These were all strategies learned in my initial research. In terms of confidentiality Sarah understood that if we wanted to share a particular revelation with another health professional we would seek her permission to do so. My goal was to provide a safe place for the facilitation of reflection on her experience.

Setting up an associate nurse who would work with me was part of how I organised my practice leadership role. I envisaged that I could set up a particular approach, model that approach to the nurse working with me, then gradually move out leaving the associate nurse as the primary nurse. Another associate nurse could be appointed if deemed necessary. This way of working freed me to be available for another situation needing a creative approach. However this method did not actually eventuate for Sarah. I stayed working as the primary nurse throughout the first year of our engagement because of the complexity of her circumstances. In the second year Mary decided it was time for her to move out of the partnership.

Another proposed strategy from my initial postgraduate study that I put in place was the use of narrative notes that focused on the client experience. These stayed in the house. After a period (weekly when we were visiting daily) they were summarised for the service record. The summaries were read and signed by Sarah who was encouraged to write in the narrative notes and summaries, as she felt inclined. Sarah certainly noted and changed details seen to be unclear or inaccurate in the summaries but rarely wrote in the narrative notes. I also encouraged her to use a journal, which she did at times, but did not find it as useful as verbalising her experience with Mary, other health professionals, or myself. Having access to notes not only promotes some control and assists the process of building up trust, but also adds another dimension in which reflexivity can take place.

Clinical supervision for nurses working with people experiencing strife was also recommended in my 1995 study. Although Mary, Rose (the other nurse in the first stage of the research) and I shared reflections on Sarah's situation at regular levels I also felt the need for more structured reflective practice from someone outside the service. Even though I was charged with the task of developing innovative practice, and did endeavour to negotiate supervision into my contract, my manager did not see it as necessary. So I was not provided with clinical supervision for my practice.

The final contribution from my earlier research that I will mention here is flexibility of work hours. Flexibility in time of day and in days of the week is needed in order to respond appropriately to people in strife. However this was not part of Mary's or my

position description. Both Mary and I gave Sarah our home phone numbers but she rarely used them. In fact, I initiated calls to Sarah from my office or home if I was concerned about her condition. We also provided a back up service from on call district nurses available at night and on weekends. Sarah never initiated using this support. When Sarah had progressed to interacting in the community more both Mary and I sometimes invited her to participate in our off-duty social activities, which she did occasionally.

The approach we were enacting appeared to be working for Sarah as she became more active within her family and participated more in the community. There had been a turnaround in days spent in hospital from 164 days in 1995, the first year of the severe strife prior to our engagement and 158 in the second year, 1996, to 43 hospital days in the first year, 1997, of our engagement. However her life continued to be full of happenings and it was as we were entering the second year of working with her that I began to see that setting up the present inquiry would complement and extend the knowledge development of the earlier study. It is hard to obtain an overall view of what it all means when you are still enmeshed in such a complex situation but by setting up a structured study I believed I would be able to ascertain a great deal more understanding of the experience. Thus, I commenced thinking about what praxis oriented methodology would be appropriate for such a study.

moving beyond the horizon of Newman's theory

In setting up this inquiry I returned to reflect more on Newman's (1986, 1994) theory and research as praxis methodology. Constitutive of expanding my knowledge in terms of the research question asked in my 1995 inquiry I had also begun a journey into understanding the historical roots of the concept of praxis. The stimulus for travelling along this path came from the Holmes critique (Connor, 1998; Holmes, 1993) of Newman. Newman (1990) had appropriated the construct of 'research as praxis' from Lather (1986, 1991), a United States feminist, neo-Marxist and postmodern educationalist and researcher, without acknowledging the emancipatory theoretical positioning of her work. Holmes critiqued Newman's appropriation from what he assumed was the rightful position of praxis within the emancipatory paradigm. This led me to believe that there was more to this debate than I understood. I then examined Lather's claim that research as praxis

necessitated apriori emancipatory theory e.g. Marxist, critical social theory or feminist theory. This helped me understand that Newman had, in fact, adopted Lather's epistemology to support the ontology of her own theory. But she had not given any audit trail of her thinking other than to state that her phenomenological oriented methodology required apriori theory and that research as praxis fitted this prerequisite (Connor, 1995, 1997).

Newman's theory was an important stepping stone in my development but I began to see a wider horizon than was portrayed in her ideas. In order to critique the Holmes and Lather claims I shifted to the work of United States philosopher Bernstein (1971, 1983). Bernstein's deconstruction of the impasse created by objectivism and relativism within the empiricist inquiry tradition has helped me clarify my own positioning in this study.

critique of apriori theory as epistemological foundationalism

Thompson (1985) draws extensively on Bernstein's (1983) dialectical framework of advancing empiricist epistemologies. She calls for nursing investigators to become more 'self conscious' about the epistemological assumptions in their work and move beyond empiricism. I believe her prophetic call is still relevant to the community of nurse inquirers in the 21st century. Thompson's application of Bernstein's framework parallels the ways of coming to know in nursing research with those in the history of the philosophy of science in the twentieth century.

Bernstein's (1983) framework involves four phases and is organised around primary epistemological foci. The first phase involves a 'single term' as the focus. It aimed to demonstrate how the term provided a correct grounding for 'real' knowledge. The second phase takes 'propositional statements' as its focus and the third phase moves to discuss 'conceptual schemes' as the foundation. All phases assume foundational knowledge that can be discovered and/or built upon. Thompson relates each stage to examples of nursing research. The fourth phase moves the focus to examining ambiguities and contradictions in research programmes. This phase challenges nurses to improve their understanding of nursing research traditions (Thompson, 1985). A challenge to become more creative in our research endeavours is also issued in the fourth phase.

The third phase of Bernstein's (1983) framework, which Thompson (1985) links to the use of nursing theories and conceptual models as foundational units in research, is of particular interest to me. It has increased my awareness of weaknesses in researching nursing theory and explained my discomfort in further use of Newman's theory to inform my practice and research. My discomfort also applies to Parse (1995a, 1995b, 1997), another nurse theorist from whom I have drawn many insights. Parse developed an even more structured approach, than Newman, for the use of her theory. Both these nurse theorists hold the view that their theories are foundational. Bernstein (1983) and Rawnsley (1998) both use the term 'suspect' to describe their disquiet with foundationalist or universalistic assumptions in conceptual schemes. Rawnsley argues that giving such schemes a transcendent reality will lead to reification while Bernstein raises issues regarding the distinguishing of schemes from each other and their epistemological evolution. In my view Newman's and Parse's theories and research methodologies have much in common.

In employing apriori theory the researcher embodies the theory (Newman, 1994, 1997; Parse, 1995b, 1997) which in turn frames the view of the findings. The frame of the theory is doubly reinforced when the findings are poured back into the theoretical vessel that informed them (Lather, 1991) as is recommended in the Newman (1994) and Parse, (1995b, 1997) methodologies. Bernstein (1983) sees that formalising the research data back into the theory that informed it risks distorting the data and curbs any creative construction of the findings. He further asserts that returning to the theory fosters a tendency for an univocal meaning to be perpetuated. In Bernstein's view this is a characteristic of natural science rather than human science, where equivocal language, always in the process of expanding is more the norm.

Parse (1995a) does classify nursing science as human science, but not as practical human science. Neither Newman (1994, 1997) nor Parse (1993, 1995b, 1997) talk of 'testing' their theories but claim ongoing research with the theories as an indicator of their usefulness. However, Allen (1994) is skeptical, as am I, of the need to use a theory over and over again to determine its usefulness. Newman (1997) qualifies her methodology

and tells readers that nurse researchers can choose to use her theory as they see fit. There is no such qualification from Parse (1997) According to Parse the use of her research methodology enables researchers to discover a greater understanding of the human health experience from the universalistic perspective of her theoretical propositions. However, I question whether nurse researchers are expanding their own horizons in relation to their own praxis, when they pour their findings back into these theories rather than creating their own local or personal theories.

In accepting that knowledge is socially constructed and all research is theory laden I have no problem with research informed by theory, that of Newman, Parse or other theorists. I honour the enormous contribution made to nursing science by both Newman and Parse. However what is problematic for me is the closing off of potential knowledge development in the requirement to pour the findings back into the theory that informed them. Apart from issues regarding who gains the most from this approach, this is where reification can occur. It appears to me that if the interpretation process remained open; if there was a letting go of what Rawnsley (1998, p. 3) calls “ontological commitment” and the development of congruency between their ontological and epistemological assumptions, there would be a more authentic expansion of consciousness or human becoming. Both Newman (1997) and Parse (1997) acknowledge the ideas of Martha Rogers (1970) as a stimulus for developing their theories. If Rogers had provided a methodological protocol asking them to pour their research back into her theory, their own theories would not have developed. This critique in no way reduces my appreciation of having Newman’s theory as the starting point for theorising my practice which was greatly extended in my earlier academic research and the informing capacity of Parse’s theory from which I have drawn many ideas. I believe we honour our traditions in making the effort to critique them. I will now address other tensions that influenced the evolution of my praxiological methodology.

research as praxis and practice as praxis

In my search to find an appropriate methodology for the distinctive features of this study I also reflected on a tension I had experienced in my use of Newman's (1991, p. 100) concept of the dialogical nature of the research conversations as "the *form* [sic] of practice". Litchfield (1993) enacted this concept. It is also present in her later research (Litchfield, 1997, 1999) where it is expressed as 'researcher as if practitioner'. I was never entirely comfortable in the dual role. For me, Newman's idea of research as 'the *form* of practice' did not go far enough in practice terms as is expressed above in relation to the research agenda overtaking the practice agenda in Mhairead's situation. If I positioned myself as both practitioner and researcher with the client participants, I believed I needed to be equally practitioner and researcher; not offering a limited 'form' of practice; a form that was secondary to the intention of knowledge development in research. Thus, I recommended that practice be brought into a more equal relationship with the research in future similar studies (Connor, 1995). I now see more clearly that, for me, giving each agenda equal value in such a methodology would always create tensions between the goal of research as knowledge development and the goal of practice as 'the good' of the client. Other research methodologies, such as action research, when expressly employed to improve practice knowledge may have less conflict of research and practice agendas, but I knew this approach was not appropriate for my current study.

Through my reflections in this present study I now see that the praxis orientation of my 1995 study was also present in the practice that followed and is present in this inquiry. My mode of knowing in practice is praxis oriented in the same way as my mode of knowing in research, which can be termed research as praxis. Moreover, the expression of research as praxis that I have come to in this current project is hermeneutics as praxis or hermeneutical research as praxis. I began by rejecting this process way of expressing praxis, i.e. praxis as research or praxis as health (Litchfield, 1993; Newman, 1990). There was rarely any explanation accompanying its use. They appeared to me to be 'catch phrases' that had caught the imagination of nurse writers and were used as an inadequate descriptor of a complex concept. However, the more I reflected on the concept of praxis the more I appreciated its ubiquitous process nature. My improved understanding enabled me to view it as a useful way of expressing the process orientation, and as such the action

orientation, of the concept under consideration. I now enthusiastically embrace this way of expressing the praxis orientation of concepts.

The increased appreciation of the process nature of praxis has led to an expanded landscape in the use of praxis in the literature (see chapters five and six). At the same time, there are continued claims that the praxiology of praxis is restricted to the emancipatory paradigm. From the experience in my 1995 research and the ongoing praxis orientation of my practice, which I do not situate in the emancipatory paradigm, I believed that praxis had a wider application. Writers using praxis outside the emancipatory paradigm do not appear to trace their use of it to any particular sources (Litchfield, 1993; Watson, 1999). Conversely, nurse writers who I see as having an overt praxis orientation do not use the term praxis (Benner, Tanner, & Chesla, 1996). I personally felt that my use of praxis outside the emancipatory paradigm needed more justification than when used inside the emancipatory paradigm. Therefore, I chose to explore the evolution of the praxis in philosophy and nursing. What I have referred to as the practical discourse in philosophy and in nursing in chapter one is an outcome of my investigations. In fact, the practical discourse in both these disciplines is also the praxis discourse.

This current study is one of the multiple expressions of praxis oriented research. I decided that the best option for uncovering the meaning I sought from the situation that had already taken place would be through the construction of a methodology for a retrospective examination of the practice. As all co-participants probed their experience of an earlier period, Sarah continued to need nursing care; nursing care that I continued to be involved in (see chapter seven for the discussion of my ongoing practice involvement with Sarah). In this study then, I was also enacting a researcher practitioner role, albeit in a different way from my earlier research. I visited with a research intention on certain days and a practice intention on other days. In this way they were played out as more or less separate roles. Sarah, as is demonstrated in chapter eight, saw them as quite separate, but for me there was an intertwining and overlapping. What I learned in the research role influenced what I did in the practice role.

conclusion

Chapter two contains a miniature portrait of my practice and research experience with people experiencing strife in chronic illness and the reflections informing the shaping of this inquiry. The shifts in my expanding understanding of nursing practice and research are set out to provide the reader with an understanding of the motivation, interests, work role expectations and tensions, and philosophical assumptions informing the overall hermeneutical reflection of this present study. I also intend that the deconstruction of some of the complexities I encountered as a practitioner and researcher to demonstrate my commitment to expanding nursing practice and research.

This study is an expression of praxis as practice and research. These two concepts together with the quest of achieving an expanded understanding of strife in chronic illness are integral components within the overall hermeneutical reflection of this inquiry. They form a spectrum of three horizontal threads weaving through each chapter in a greater or lesser degree. As such they provide chapter to chapter linkages.

The shift beyond accepting Newman's theory as a theoretical position informing research led me to search for a philosophical position that was consistent with my present situation. As indicated in chapter one, GPH is a position that embodies many of the assumptions that I value in respect of human being in the world and is closely allied to the practical discourse in philosophy. Because of this, I have chosen to construct a theoretical-philosophical framework from it in which to embed this praxiological investigation. The next chapter provides an overview of this framework.

Chapter three

THE CONSTRUCTION OF THE THEORETICAL-PHILOSOPHICAL FRAMEWORK FROM GADAMERIAN PHILOSOPHICAL HERMENEUTICS

introduction

In chapter two I described the practice and research context from which my research objective of expanding understanding of strife in chronic illness emanated. In order to explore this objective in a coherent way I searched for a theoretical-philosophical framework that would be consistent with my methodological objective. Positioning this study within Newman's theoretical and paradigmatic perspective, as I had in my earlier research, was no longer tenable. The outcome of my search was the establishment of a framework from Gadamerian philosophical hermeneutics (GPH) (Gadamer, 1960/1975/1999, 1976a 1976b, 1981, 1991). It is a philosophical-theoretical perspective that embodies interconnections between hermeneutics and praxis in its development of understanding as an ontological, action oriented process.

In constructing a philosophical-theoretical framework to undergird this praxiological methodology I am mindful that it may be seen to negate my claim to the praxiological nature of this inquiry. The distinguishing characteristic of the practical discourse from the theoretical discourse in philosophy, as discussed in chapter one, is the development of knowledge from experience. However, discussions of this characteristic were undertaken before the proposition of the theory and value-ladenness of all inquiry was generated (Guba, 1990; Lather, 1991). I accept this proposition and acknowledge that there is no theory or value free knowledge development from experience. A consequence of this perspective is the summons to researchers in the interpretative paradigm to overtly position themselves so that readers can understand influences in their knowledge generation. Therefore, I have chosen to construct a framework from GPH, which I have determined to be consistent with my position in this research and to provide a structure for the theory and value ladenness of the inquiry. I am aware that the framework will colour and place limitations on what knowledge is generated from within the meaning made of the practice situation under investigation but accept some structure is necessary

for working with what Lather (1991, p. 62) calls “the awesome complexity of the world”. Further, I believe that the expanding of my view of world through my study of Gadamer’s ideas, more than compensates for the limitations.

Gadamer’s (1960/1975/1999, 1976a, 1976b) claim to the universality of understanding as the ontological condition of our social reality is an extension of earlier hermeneutical positions. People come into a world where common ways of understanding the milieu are in operation and these ways soon become familiar. Commencing with learning to understand the familiar, everyone, children and adults the world over, come to know and understand the world differently as they encounter something new or alien to their experience. Gadamer is concerned with the general human process of understanding and it is this universality that gives his hermeneutics its philosophical basis (Madison, 1991).

The purpose of this chapter is to expand the introductory comments on GPH made in chapter one. I commence with describing the relationship of GPH (1960/1975/1999, 1976a, 1976b) with human science and nursing as a practical human science as a demonstration of the consistency of the interconnections. Selected ideas, which constitute my framework, from what is a complex comprehensive philosophy are then presented. The ideas include assumptions about human being in the world which embrace, extend and re-language my earlier view of social reality. The assumptions are extrapolated from Gadamer’s key tenets of effective historical consciousness and language. Subsequent to the constitution my framework is a review of its integration into this inquiry. I will then include a brief personal critique, an overview of what is known as the Gadamer-Habermas debate and a feminist analysis as an alert to the limitations of GPH. The critique is followed by a discussion on the authenticity of the research. The latter is positioned here as I argue that a major premise of authenticity in this study relates to its faithfulness to the theoretical-philosophical framework of the inquiry.

The main ideas that constitute my framework are taken directly from the second revised edition, first published in 1960 and translated into English in 1975, of Gadamer’s ‘Truth and Method’. Other important sources are ‘Philosophical Hermeneutics’ (Linge, 1976), a

group of essays written by Gadamer after the publication of 'Truth and Method', and edited and translated by Linge; and 'Reason in the Age of Science' (Gadamer, 1981), another later collection of essays that contain his most overt interlinking of GPH and the practical discourse in philosophy. Further Gadamerian writings and interviews with him that support and clarify his thinking are also used.

The main general secondary sources I have used are Bernstein (1983), Grondin (1994) and a book edited by Silverman (1991) with contributions by other scholars on 'Gadamer and Hermeneutics'. The latter book was put together as a tribute to the 30th anniversary of the first publication of 'Truth and Method' and as a celebration of Gadamer's ninetieth birthday. Nursing commentaries found helpful in transferring Gadamer's ideas into nursing inquiry include Allen (1994), Koch (1996, 1999), Koch and Harrington (1998), Pascoe (1996) and Thompson (1990).

GPH is ontological. Ontology and epistemology have historically been elements of metaphysical philosophy (Rawnsley, 1998). In the historical context ontology was concerned with the ultimate reality of existence and became interchangeable with metaphysics. However, Rawnsley notes that contemporary understanding of ontology is often associated with a particular philosophical view of reality or our being in the world. It is this latter perspective of ontology that infuses my present inquiry. GPH argues for a movement beyond epistemology as understood in metaphysics. Understanding, for Gadamer (1960/1975/1999, 1976a, 1976b, 1981) is a reasoning process as it is how we exist in the world. How we come to know our world emanates from how we are in the world.

Gadamer (1960/1975/1999, 1976a, 1981) did not identify any particular hermeneutical method. He was concerned with the process of human understanding and strongly critical of the over emphasis on method in scientism. In this sense he was anti-foundationalist. His ontological assumptions bespeak a non-objectivistic methodology. My beginning praxiological methodology was interpretive and fitted with the tenor of GPH as a human science. The framework developed from GPH then expanded and gave an ontological

structure to the methodological premises. As the interconnections of human science, GPH and my position in nursing as a practical human science were central to my choice of the theoretical-philosophical framework I will now discuss the relationship of these sciences as a context to the explication of my framework.

hermeneutics as human science

Gadamer (1960/1975/1999, 1976a, 1981, 1991) positions himself as a philosopher in the European phenomenological hermeneutical school. From this perspective, and after much disillusionment with the technical rationalistic science of the day, which he believed to be a factor influencing the development of World War One and Two, he made the expansion of philosophical hermeneutics a life long task. Gadamer saw that the emphasis on scientism reduced attention to the moral knowing present in the human science view of the world. Greater development in the human sciences would, he believed, balance the dominance of scientism. According to Gadamer, Bernstein (1983) and Mitchell and Cody (1992), human science, a collective label for disciplines such as art, classics, history, literature, philology and more recently hermeneutics, is attributed to the nineteenth century German philosopher, Dilthey. Practice disciplines such as nursing which claim the human experience as their focus, have also claimed affiliations with human science. Mitchell and Cody are nurse scholars who discuss the ontological and epistemological assumptions that inform nursing as human science. According to all the above authors, human science views as central, knowledge arising from unitary human experience within its cultural context. As such it views knowledge as a human construction. Gadamer asserts that his notion of universal hermeneutic understanding embodies an explanation of how this knowledge is achieved. Human science, including GPH, takes account of the human ability to reflect, to think, and to channel that reflection and thinking into responsible moral decision making which contributes to a more humane view of the world. In 'Truth and Method,' Gadamer notes that the English philosopher John Stuart Mill was the first person to nominate human sciences as 'moral sciences'.

Human sciences incorporate the values of the humanistic tradition (Bernstein, 1983; Gadamer, 1960/1975/1999, 1976a). The knowing in hermeneutical human sciences

involves the knowers reflecting on their being, their humanness in the world and advancing in their own self understanding in relation to the world. Gadamer returned to the writings of the ancient Greeks and traditions prior to the modernist era, to seek out perspectives that would speak with more moral authority to the contemporary world. He claims that in contemporary human science people know themselves as active beings and this kind of knowledge does not establish a transcendental reality about what is. Rather it is aware of human becoming. The knowledge of the human sciences informs judgement and conduct in our day to day lives, which in turn informs the practical discourse in philosophy. I believe that nursing science with its purpose of facilitating human wellbeing is a moral science. Human science, philosophical hermeneutics and nursing as a practical human science bring together theoretical and practical knowing for the purpose of enhancing personal-professional moral development; a development emanating from practical moral reasoning or phronesis. Phronesis involves judgements emanating from the use of general theories or principles in particular circumstances such as those inherent in the practice situation under investigation in this research.

construction of the research framework

understanding as an ontological event

For Gadamer (1960/1975/1999, 1976a, 1976b) the process of hermeneutical understanding, as an ontological event, has its own mode of being. The metaphor of play is used to describe the hermeneutic mode of being. He highlights the essence of play as the 'to and fro' movement between players. Players are integral to and vitally engaged in the play but once initiated the 'to and fro' of play takes on a life of its own, a particular mode of being. Thus, when a person, or in the case of research, the researcher, sets out to understand something new and alien they engage with it in such a way that the understanding itself becomes the force directing those involved. In this study it means maintaining openness to the direction of emerging understanding which is consistent with the praxiological nature of this study.

Gadamer (1960/1975/1999) interlaces two clear themes into philosophical hermeneutics; effective historical consciousness and language. Both of these themes emerge from

earlier hermeneutical developments and are an extension of Heideggerian hermeneutics (Grondin, 1994).

effective historical consciousness

Effective historical consciousness calls us to examine our past, the tradition of which we are part. Gadamer (1960/1975/1999, 1976a) challenges us to identify our prejudices in order to reveal and understand how we have been shaped by tradition. According to Gadamer, prior to the Enlightenment, prejudice did not have the negative connotations that it has today. He states that the main prejudice of the Enlightenment “is the prejudice against prejudice itself, which denies tradition its power” (1960/1975/1999, p. 270). Gadamer argues for the identification of prejudice as a positive aspect when people seek understanding; an exercise that will assist the separation of enabling prejudices from blind prejudices that could distort the coming into being of authentic meaning. I see this as a reflexive process critical to deepening consciousness of the world we live in and are shaped by. As acknowledged, the explication of this framework constitutes both an enabling and a limiting prejudice in this inquiry. The identification of prejudices is a reflexive process which increases self-knowledge by expanding an individual’s horizon from their gaze on present circumstances. As a personal horizon expands and the knowledge of the horizon of the circumstances under question or study expands, in GPH there is a breaking open of the separate horizons resulting in a ‘fusion of horizons’. The effective historical consciousness of the researcher meets with and penetrates the horizon of the situation.

Unfolding understanding involves application. According to Gadamer we are always applying understanding in some way. His reclaiming of application as an integral component of understanding from the pre-modern era, rather than accepting it as a separate component as in modernist hermeneutics, connects hermeneutics, more specifically, with the practical discourse in philosophy. Bernstein (1983) sees this connection as giving human conduct or praxis a privileged place and opening the way for the move beyond the modernist preoccupation with objectivism and relativism in philosophy.

The main emphasis in GPH is on understanding texts, as was the custom in earlier expressions of hermeneutics. However, Bernstein (1983) and Thompson (1990) claim its application to institutions, practices and forms of life where understanding is sought. In addition, Allen (1994) broadens the notion of historical texts to include research interviews, surveys and observations. Moreover, Gadamer himself, in writing the preface to the book by Grondin (1994) reflects on its application to people's life experience.

Expansion and fusion of horizons makes the hermeneutical experience one of ever increasing openness to the world and what it has to teach us (Gadamer, 1960/1975/1999, 1976a, 1976b). Ongoing learning from life experiences becomes enfolded into effective historical consciousness and is the hallmark of an experienced person. Experience is never repeated. Life is unidirectional; with each experience life moves forwards. People come to know the world as continually evolving and new experiences bring new truth that is always contingent. People realise there are no final answers to life's questions and with this comes the realisation of the finitude of human existence. People's historical traditions and effective historical consciousness are embodied in language.

language

Language is the second major tenet of GPH. The notion of dialogue is central to the Gadamerian discussion on language (1960/1975/1999). Gadamer explains a dialogue between an inquirer and a text. An inquirer comes to know the subject of the inquiry via an engaged dialogue with it and the subject "expresses itself like a 'thou'" in the sense that it is not an object but "relates itself to us" (p. 350). 'Thou' becomes a partner in the dialogue with the one seeking understanding as in Buber's I-thou relationship. Thus, I interpret hermeneutical reflection as an existential relational experience. Understanding emerges in the 'to and fro' movement of the dialogue of the 'I and Thou' in a relational ontological event.

The dialogue commences with development of an inquiring demeanour (Gadamer, 1960/1975/1999). People expand their horizons by becoming questioning persons. The

question gives perspective and shapes the understanding that is to proceed from it. It places that which is in question in a state of indeterminacy. The question leads us into a mode of questioning; with each answer there are further questions. Gadamer is not referring to any sort of question but to genuine questions that when answered will play a role in transforming history in some way (Thompson, 1990). According to Gadamer, a genuine question always points to several possible answers.

Questioning and answering constitute a dialectic in GPH and stimulate expanding understanding within a hermeneutical circle. In this context dialectic is “the art of conducting true dialogue” (Gadamer, 1960/1975/1999 p. 367). As persons enter into a dialogue they become drawn into the ‘to and fro’ movement of the evolving understanding and follow the direction in which it moves. I interpret this as a bringing to birth of what the subject matter is saying. The question, for Gadamer, moves a person forwards as their horizon expands and fuses with the subject of the inquiry. Questioning opens up possibilities and meanings and thus what is meaning-ful becomes integrated into a person’s own thinking. Therefore, participants in an authentic dialogue cannot remain the same. The understanding process is both transforming and productive (Madison, 1991).

Understanding comes into being “through the medium of language” (Gadamer, 1960/1975/1999 p. 375). The standpoint of the ‘I’ is incorporated into the dialogue and moves with the dialogue. Historically effective consciousness can only be manifested in spoken or written language. A text is created in language and transcribed into written form. Written texts provide some detachment from the author and as such can also acquire a life of their own. It is the above two components of GPH, the I-Thou encounter of understanding and the summons to remain open to ‘authentic dialogue’ in texts that constitutes moral comportment in an inquirer.

At all times Gadamer (1960/1975/1999) is concerned with how language provides a unity of meaning for what people are attempting to understand. He asserts that “language is the medium where I and the world meet or rather manifest their original belonging

together.... Being that can be understood is language” (p. 474). Therefore language is much more than correspondence of words with what they represent or signify. Gadamer acknowledges that an element of mystery is retained in the unifying purpose of the person who speaks, the word and the thing it represents; the word becomes part of the being of the image it exists to portray.

The meaning of words is associated within particular discourses and is intricately tied to our thinking (Gadamer, 1960/1975/1999). A discourse provides the relational and unifying structure for expressing words. Each word or idea can also provide a link to the whole discourse, as the meaning of certain words can only be meaningful when located within the discourse of which they are part. However, it is my observation of contemporary language that when a word catches the attention of different disciplines it tends to be used in a variable sense outside of its original discourse e.g. praxis and paradigm are such words.

According to Gadamer, the immediacy of speech overrides the imagery that it implies. In explicating this idea further Gadamer (1960/1975/1999) draws on the notion of the inner word; a notion developed within biblical hermeneutics. The ‘inner word’ attests to the finitude of what is expressed in speech because our understanding does not comprehend what it knows in “a single inclusive glance ... it must always grow what it thinks out of itself” (p. 422). The hermeneutical event involves an inner momentum of the action of the subject matter on itself. Gadamer is not saying that the subject is separate from our thinking but he exhorts those seeking understanding to actively listen to the ‘thou’ of the subject. Within the finiteness of meaning that emerges in language there is also an infiniteness of what is not said and a continuing expansion of what is understood. In this way hermeneutical understanding is speculative and embodies what I would describe as tacit knowledge.

How a thing is thought about and how it is spoken about is all part of the meaning that issues forth in words. As such, concept formation is integral to meaning (Gadamer, 1960/1975/1999). Concepts depend on correspondences and transferences within

thinking which leads Gadamer to state “the genus of verbal consciousness is fundamentally metaphorical” (p. 429). In making this assertion, Gadamer berates the marginalisation of metaphorical expression that occurred within modernism. Verbal forms express the view of the world within traditions or cultures from which people emerge. As such they express the significant values and ways of living of those people within their environments. Gadamer expresses this notion in “the language speaks through us rather than we speak it” (p. 463). As our experience of the world expands so does our language. With the interweaving of language and cultures in our present global village I am aware of many fusions of horizons when listening and attuned hearing to the voice of the others takes place.

Gadamer’s construct of understanding developed within the tenets of language and effective historical consciousness are inextricably interwoven in the above sketch of my interpretation of what is a comprehensive philosophical position. These concepts now provide the theoretical-philosophical framework of this inquiry.

integration of the framework into the inquiry

The praxiological nature of the study became a given in the early stages of my quest for an appropriate methodology to fulfil the first research objective. However, I believed a theoretical-philosophical framework embodying and expanding my ontological assumptions into a coherent worldview would give structure to the methodology. These assumptions constitute the basis of what I describe as my praxiology in chapter seven. What commenced as epistemological premises in this inquiry changed when I appropriated an ontological theoretical framework from GPH. When using an ontological framework, as stated earlier, epistemological premises become ontological reasoning processes and are described as methodological premises; a descriptor I use in this study.

An advantage in framing the praxiological methodology in an ontological worldview is its accord with the primarily relational nursing praxis under scrutiny in which ‘being with’ rather than ‘doing for’ is primary. Practice as praxis and research as praxis meld together as ontological postulates in the Gadamerian worldview. Expressing research as

praxis in an ontological framework is innovative as it is most often expressed as an epistemological postulate (Lather, 1990; Litchfield, 1993; Newman 1990, 1994).

Effective historical consciousness views all understanding as conditioned by the particular cultural milieu from which it emerges. In this view there are as many different understandings as there are cultural milieu. Moreover, Gadamer's belief that a genuine question always leads to a number of possible answers, increases the number of possible potential meanings that can arise. These assumptions, together with the transformative potential in an expansion of horizons and the notion of unidirectionality convey that the meaning generated from this praxiological methodology is one of many possible contingent meanings. There can be no one true or final meaning generated in answering the research question. Paradoxically, the framework from GPH illuminating this praxiological methodology influences and limits the meaning generated from this research material.

The whole inquiry, not only the chosen methodology, is seen as hermeneutical reflection when accepting the tenets of effective historical consciousness and language as all the reflection informing the methodology and proceeding from it is involved. Therefore, I have chosen to nominate three premises to act at a general level to inform the overall hermeneutical reflection and at a particular level within the praxiological methodology. They are reflexivity, dialogue, and moral comportment. These premises have a particular meaning, which is inherent in the framework, and as such, throughout the inquiry. Gadamer's notion of dialogue as an existential relationship between two subjects when interpreting texts overlaps with moral comportment in interpreting texts. It challenges me as researcher to respect the inherent dignity of a text as I would that of a person, to be genuinely open to what it can teach me and move forward within this unfolding learning rather than frame it within an already preferred theory. It does not mean that I, as researcher forgo any position I have, but that there is commitment to expanding that position from the questioning and answering interplay of the dialogue. Thompson (1990) sums it up as a particular way of conducting oneself, an entering into practical moral reasoning or phronesis. The implications of these assumptions for human research

participants are spelled out in my explication of dialogue as praxis and moral comportment as praxis in chapter seven. The ‘to and fro’ of the dialogical questioning process gives the study a dialectical character.

Reflexivity, dialogue and moral comportment as general premises are already present in the exploration of my personal and profession tradition in chapter two. They are intrinsic in personal reflections on my practice as praxis and research as praxis including the advancement in my understanding of empirical research. These premises also shape the exploration of the traditions explored in chapters four, five and six. The three premises take on a systematic and specific function complemented by two other premises, representation in narrative and critique, within the specific praxiological methodology. To keep with the process orientation of Gadamerian understanding as an action oriented ‘to and fro’ event and to make the nexus of hermeneutics and praxis overt I have added the phrase ‘as praxis’ to each premise within the praxiological methodology.

Gadamer’s ideas about everyday language, including metaphors and discourses speaking our being in the world, reinforced the attention I had begun paying to language as I commenced construction of the narrative. I also became more mindful that words used in texts and dialogical meetings are only a shadow of meaning that is not or cannot be described. Therefore, the meaning generated in research and the meaning of the research journey to me, as conveyed in this report, will only be a glimpse of the rich inner meaning. Furthermore, the articulating of a meaning at a particular time enables a comprehension of that meaning not experienced prior to the articulation, which in turn allows a moving on to an expanded meaning. Inherent in this process, then, as it is enacted in this research, is the transforming potential for the client co-participant to expand understanding of her strife and in so doing take steps to move out of it. In addition, there is the opportunity for a deepening understanding of nursing practice for the nurses involved. However, the moral imperative of remaining open to expanding my position in the research, does not challenge other participants in the same way. Another consequence of moving to a new position after articulating meaning at a particular

moment is the likelihood that ambiguity will appear in transcripts of our dialogical meeting as a participant straddles the old meaning and the new meaning.

I have found Gadamerian hermeneutics exciting and helpful in expanding my thinking about research at a general level and in this study. However all grand narratives have their weaknesses and Gadamer's narrative is no exception. My discussion will now move to examine some of these weaknesses in order to balance my acceptance of his ideas used within this inquiry.

critique of gadamerian philosophical hermeneutics

In this section I will firstly comment on some weaknesses I became aware in GPH. Following this I will outline the critique that emerged in a debate between Gadamer and Habermas and close with a particular feminist critique.

weaknesses identified in my reading of GPH

A weakness that stands out to me is Gadamer's (1960/1975/1999, 1976a, 1976b, 1981) championing of historical consciousness but little account is given of how his effective consciousness shapes his philosophy. In a letter written by Gadamer and published in Bernstein (1983), he acknowledges that the assumptions of the German Romantic School may have acted as a limitation to his own horizon. With this influence and a life spent in academia, he can be seen to have lived a cosseted existence in which to contemplate his ontological expression of understanding; an existence without any challenges to its exclusiveness from other views, such as feminism. It appears to me, that Gadamer's belief in a subject to subject relational 'I Thou' dialogue and the unitary transformative nature of people in their world are consistent with the values of the feminist ontology as discussed by Campbell and Bunting (1999). Gadamer and a group of feminist philosophers could have found much in common if a dialogue in which both were open to learning from each other, a tenet of GPH, had been established. Further, I believe there should have been acknowledgement of the context and his adaptation of Buber's 'I-Thou' construct.

Two other weaknesses are evident to me. Firstly is his preoccupation with verbal language and lack of acknowledgement of non-verbal language, probably related to his association of hermeneutics as textual interpretation. I believe an appreciation of non-verbal language in person to person encounters can enhance the meaning associated with words. Secondly, particularly in his later work (Gadamer, 1981) where he expands the positioning of his philosophical hermeneutics within the practical discourse of philosophy, there is an implicit recognition of his ideas as a praxiology but he fails to name it as such. I believe this omission provided a space for emancipatory praxiologies to be seen as the 'rightful' home of praxis. Habermas (1972), a critic of Gadamer, and an early protagonist of emancipatory praxis does use the term praxiology but it is not developed in commentaries on his work. My explorations support my belief that it is not a term that has caught the imagination in the way praxis has. The significance of praxiology as a concept is discussed more fully in chapter five.

I will now outline Habermas' critique of Gadamer in what became known as the Gadamer-Habermas debate.

the Gadamer-Habermas debate

In opening my summary of the Gadamer-Habermas debate it is important to state that Gadamer and Habermas had much in common (Aylesworth, 1991; Bernstein, 1983; Misgeld, 1991; Nicholson, 1991; Outhwaite, 1994). According to Nicholson their commonalties were greater than the polarity of the debate infers.

Bernstein (1983) ascribes the significant differences between Gadamer and Habermas to their age gap. Gadamer is 26 years older than Habermas. As is explained below this gap in ages positions them differently in Western history and in the history of science. In a letter written to Bernstein and included in his 1983 publication, Gadamer notes the influence on himself of nineteenth century German Romanticism and its inclination for seeking truth within tradition. In the same letter he observes the omission of social science and the postmodern attitude of skepticism toward philosophy from his view of the world. Bernstein describes Gadamer's experience within tradition and philosophy as

characterized by continuity as compared with Habermas who experienced the upheavals and destruction in 20th century Germany as discontinuity. According to Bernstein, critical social theory became seen by Habermas as a medium whereby social structures could be analysed for inherent distortions of power and in so doing provide a future counter force to the development of similar happenings in Germany. Gadamer's emphasis is on understanding within cultural conditioning while Habermas focuses on communicative action. Their differences in hermeneutical positions have been described by Ricoeur as clustering around the notions of 'faith' and 'suspicion' (Outhwaite, 1994; Thompson, 1990). Gadamer's work sits in the faith cluster and Habermas' in the suspicion cluster.

The debate began in 1967 when Habermas challenged Gadamer's acceptance of the truth and authority of tradition (Nicholson, 1991). Habermas insisted that any comprehensive hermeneutical stance should include an explicit goal of uncovering distorted communication, communication that rests on power imbalances. This issue remained the core substance of the debate, which according to Nicholson continued until 1972.

Gadamer acknowledged the value of Habermas' philosophical purpose but declared it not to be his agenda. He articulated his unwavering conviction that practical philosophy relies on the practical moral reasoning of phronesis for its ongoing efficacy. He sees that Habermas distorts phronesis by subjecting it to the axioms of materialist science. Conversely, Gadamer can "imagine a scientific approach disciplined by phronesis" [letter to Bernstein published in Bernstein, (1983, p. 263)]. Moreover, Gadamer is of the opinion that it is not critical social theory that will save the world from corruption, but the common sense of people. This will bring them together in some form of solidarity directed towards overcoming the distortions and abuses of power thereby creating a new moral order. It is an expression of faith that honours the practical moral reasoning of ordinary people. He rests this assertion on the history of European revolutions. Nicholson (1991, p. 157) sums up Gadamer's view as "rationality moves where light and dark are mixed".

Bernstein (1983) describes some ironies that developed as an upshot of the debate. He expounds that the explication of Gadamer's work and ideas in the debate rendered both a clearer grasp of Habermas' theory and his vision for critical social science. At the same time Bernstein values Habermas' articulation of our historical cultural situatedness as better than that of Gadamer.

Gadamer (1960/1975/1999) records his appreciation of the debate with Habermas in the 'Afterword of Truth and Method', written in 1972. In this text and in his essay Gadamer, (1976a) claims the emancipatory potential of his ideas. It is erroneous to describe Gadamerian hermeneutics as completely uncritical (Outhwaite, 1994) but it does not have the emancipatory interest of the more structuralist and materialist worldview of Habermas (1972, 1973). Indeed, Gadamer's whole hermeneutical reflection in 'Truth and Method' is built on a deconstruction of the distortion of scientism and a reconstruction of a philosophical hermeneutical position that can be employed to achieve greater 'self consciousness' in scientific inquiry. Madison (1991) points to deconstruction as implicit in hermeneutics but not as a method or technique as Gadamer is not concerned with epistemology. Gadamer's argument with Habermas was about keeping meaning and understanding as the goals of hermeneutics reflection, not emancipation; making emancipation central would narrow the field of hermeneutics.

In terms of my situation in this research I support Gadamer's position in the debate, but I do not believe it needs to be an either/or supporting of one against the other. Some research questions will be better answered within a Habermasian framework. At another level there can be a transcending of the differences by a concentration on their strengths as Bernstein (1983) has demonstrated. In constructing the narrative of this research I became aware that subjecting it to critique would expand the understanding I was seeking. Initially I considered critique inconsistent with GPH, possibly associated with reading accounts that emphasised the difference between Gadamer and Habermas. However, in further reading and in deepening my understanding of Gadamer's ideas I came to a different view. His call for a questioning posture in relation to understanding as our mode of being in the world and the summons to go where the dialogue leads affirms,

for me, a critical component in expanding understanding. In my praxiological methodology critique works as a component of expanding understanding within hermeneutical reflection, rather than the cognitive interest (Habermas, 1972, 1973) of the reflection.

I will now summarise Schott's (1991) feminist critique of Gadamer's ideas. Her main criticism is what she sees as Gadamer's failure to recognise that women can experience a different existence to men.

feminist critique

Schott (1991), a United States professor of philosophy and a feminist, also critiques GPH. She found this work problematic because Gadamer had not identified his own prejudices; a practice he urges in others, as I have already identified. Schott noted examples of these prejudices in the metaphors he used. Gadamer's reference to play in explaining his notion of the 'to and fro' of understanding does not account for gender difference in play revealed in research. According to Schott, his concept of language fails to recognise inherent power relations between western men and women. Gadamer makes the assumption that everyone is equally 'at home' in language meaning it is a comfortable place to be. In questioning this, Schott observes that being 'at home' for some women is not a comfortable place if they are abused by male partners. Schott argues that Gadamer's metaphors imply a normative way of being in the world and maintains that those who do not fit his norms are marginalised. She sees that Gadamer is trapped into his assumption by his desire to shift from the subjective to the intersubjective conception of understanding. Feminist valuing of subjectivity enhances the effect of gender difference at work in our experience of the world. I agree that Gadamer's work lacks sensitivity to woman's being in the world even though he professes that hermeneutics is about dialoguing and listening to each other. However, I believe an intersubjective notion of understanding advances either/or epistemological divisions between subjective and objective.

The above critiques demonstrate a number of weaknesses in GPH. They confirm an assumption present in Gadamer's (1960/1975/1999) concept of language, which asserts that understanding progresses from what is known. As already mentioned Gadamer's knowing of 'others' in the world was quite limited. It is possible for people to expand their horizons and move to qualitatively different understandings but not to be all knowing about the future. Gadamer's notion of an expanding horizon implies, and he explicitly states that his hermeneutics will continue to develop. My awareness of the limitations of Gadamerian hermeneutics, particularly its claim to universality of understanding, expands my comprehension of it but does not detract from its usefulness as a framework in this research.

A contemporary criterion for judging the authenticity of an inquiry is its faithfulness to the theoretical-philosophical framework in which it is embedded. For this reason I have chosen to discuss authenticity of the study in association with the construction of theoretical-philosophical research framework.

authenticity of study

Koch (1996) and Koch and Harrington (1998) assert that an inquiry's trustworthiness and plausibility comes from staying true to the philosophical and theoretical assumptions underpinning the research. To confirm my fidelity to this premise I have identified a number of philosophical assumptions relating to the hermeneutical and praxiological nature of the inquiry, which I have endeavoured to make integral within the report. Since GPH implies that all reflection involved in the study is hermeneutic reflection, the whole research text should be seen to be authentic and trustworthy, not only the systematic methodology designed to meet the first research objective on exploring the meaning of strife in chronic illness.

the philosophical framework

The primary assumption in the research comes from Gadamer's (1960/1975/1999, 1976a, 1976b, 1981) claim of understanding as ontological. It is a claim that rests on his conception of understanding as a 'to and fro' dialogue that has an 'I-thou' character within a subject to subject encounter. This dialogue can take place between an interpreter and a text when the text is related to as a subject rather than as an object; a researcher dialoguing with the metaphorical text of her effective historical consciousness; or between human participants in dialogical conversations who are seeking an expansion of understanding. Dialoguing in this way infers that the mode of being in the research precedes the mode of knowing. This inquiry is informed by all three of these dialogues and I am a co-participant in each. These conversations also represent 'reflexivity' and 'dialogue' as an important component of authenticity (Koch, 1996).

Two strategies indicate the Gadamerian (1960/1975/1999, 1976a, 1976b, 1981) assumptions of knowledge as a human construction and the findings of the research reflecting the finder. The first is in placing myself 'in front of the text' (Thompson, 1990) by using the subjective pronoun 'I'. A description of several traditions inherent in my effective historical consciousness is the second strategy. These include my personal and professional context, the New Zealand health reform, chronic illness as a contemporary phenomenon and the evolutions of praxis in philosophy and in nursing. The two strategies illuminate the decision making steps throughout the research project and at the same time provide a 'thick description' that can be used if another researcher is motivated to carry out similar research (Guba & Lincoln, 1989). In this sense the research methodology is transferable but is not generalisable.

By embodying the methodological premises of reflexivity, dialogue and moral comportment, both general and specific, I am staying consistent with the ontological form of understanding as a human happening. Within the generation of these premises is Gadamer's challenge to remain open to the research objectives by continuing to address the questions and answers that arise throughout. I believe this is demonstrated in the search for clarification of the concept of praxis within the evolution of the practical

discourse. Secondly, remaining open is implicit in the configurations of own praxiology and set of methodological premises rather than following a ready made design. Finally, I believe my theorising about the issues that spoke to me in the narrative rather than imposing a ready made template over the narrative or using it to re-conceptualise my earlier practice model is a demonstration of openness. This openness is evident in the evolving nature of practice as praxis and praxis as research through my location in the research both as researcher-practitioner and practitioner-researcher.

The ‘usefulness’ of the research product can also indicate authenticity (Koch & Harrington, 1998). ‘Usefulness’ in this research is apparent three different ways. It further develops the concept of strife in chronic illness. The meaning generated has transformed my understanding of nursing practice with people experiencing strife in chronic illness. It will improve my practice and hopefully the practice of other nurses in this area. Lastly, my new understanding is opening up an opportunity for me to propose a unique model of care in health service delivery for people experiencing strife in chronic illness. These forms of ‘usefulness’ are discussed in chapter twelve. I believe an important reason for carrying out praxiological inquiry is its future ‘usefulness’. Pearson (1988) infers this in his index of the characteristics of praxiological research.

Pearson’s characteristics of praxiological inquiry

Pearson (1988), a nurse academic and practitioner, has expanded the notion of

Table 2. Pearson’s characteristics of praxiological inquiry

Is future oriented - in that it seeks to transform

Is collaborative - in that it seeks to involve

Is developmental - in that it seeks to build and grow

Is concerned with generating theory that is ground in action , rather than vice-versa

Is agnostic - in that it seeks to re-examine and reformulate, rather than prescribe

Is situational - in that it seeks to recognise contexts and their full meanings.

(Pearson, 1988, p. 136)

praxiological inquiry in nursing. His contribution is discussed in chapter five. He outlines particular features that he believes characterize praxiological inquiry. These characteristics are presented in Table 2. I believe these features are all present in this research and as such give it praxiological integrity. Furthermore, my use of GPH has made me more conscious of the moral posture required throughout praxiological inquiry involving human participants. Therefore, I have added another characteristic to Pearson's (1988) schedule. Using Pearson's form of expression it reads:

it is moral - in that it honours the personhood of participants in the way their contributions are constructed and theorised about.

The research is future oriented and useful in that it demonstrates advanced understanding in the nursing practice of people with strife in chronic illness while at the same time expanding the dialogue on nursing practice as praxis and research as praxis. Collaboration is evident in the participation of nursing colleagues to join my exploration of the practice situation. Moral comportment is present within both our dialogue and the way I worked with their contributions. At a more specific level, the reflexive cycles of returning my construction of the story to the co-participants in order for them to become co-constructors with me is an expression of collaboration and moral comportment. If I had misrepresented anyone's contribution or generated inauthentic meaning in the way I shaped the narrative this exercise in ongoing reflexivity would have brought it to my attention. In addition, the study is both developmental and future oriented in that both earlier research and a practice situation provided the impulse to undertake the study, in advanced understanding of the practice situation and in that further research ideas are suggested for ongoing development.

Consistent with my exploration and findings about the evolution of the practical discourse in nursing I nominated my view of nursing in this research as a practical moral science. Such a view holds that disciplinary knowledge emanates from practice, not from a particular theoretical view. In taking this position I made a commitment to theorising

about the meaning generated within the research rather than using any ready made analysis format.

Re-examining and re-formulating the understanding of nursing practice was central to this hermeneutical praxiological inquiry. There was never any intention that a prescriptive or normative model or theory would be devised. Moreover, the in depth nature of the inquiry into a three year bounded episode of nursing care brings the full situatedness of that care in all its contextual nuances into focus. Thompson (1990) recommends the contextual backdrop of research should include a portrait of the socio-cultural situation of the co-participants, which would inform the meaning they share in hermeneutical dialogue. A mini portrait of the co-participants is presented in the background to the narrative in chapter eight.

The above discussion presents several indicators arising out of the philosophical and theoretical framework and the praxiological perspective of this study from which the authenticity and trustworthiness can be judged. Readers can now keep these in mind as they progress through this research report.

conclusion

This chapter commenced with the claim and justification for a framework constructed from GPH as appropriate for this study. A discussion on GPH as a human science affirms its relationship with nursing as a practical human science. The ideas constituting the framework were then configured together beginning with an explanation of the universal and ontological nature of understanding which infuse the two main tenets of effective historical consciousness of language. The discussion of these overlapping tenets embodies particular assumptions of human beings and how they come to understand their world. These assumptions as they constituted in my framework give form to the theory and value-ladenness of the study. Effective historical consciousness, which comes into being through language, requires that the traditions that inform the context of the research objectives to be apparent as influences in the shaping of the generated understanding. This tenet establishes the basic structure of the methodological premise of reflexivity.

Language developed and expanded within effective historical consciousness has particular influence in shaping the ontological expression of the methodological premise of dialogue and how the language of the co-participants in the study is interpreted. The premise of moral comportment takes its shape from the nature of dialogue and the posture of openness to expanding understanding through the fusion of my horizon of effective historical consciousness with that of the texts and co-participants in the inquiry. Representation in narrative as a methodological premise has a less direct association with GPH, but is compatible as is discussed in chapter seven. Critique as the fifth methodological premise emerges from both Gadamer's challenge to be a questioning person expanding effective historical consciousness of the way language forms the way people are in the world. These interpretations and the framework will be used in the proceeding chapters as manifestation of the structural underpinning of the inquiry.

The critiques of GPH derived from my personal observations, a summary of the Habermas-Gadamer debate and the feminist arguments of Schott are included in the chapter to demonstrate weaknesses which I need to be mindful of as I integrate this framework into the study. These critiques open up a space for the expansion of the methodological premises with material from other praxiological positions which form the substance of chapter five and six. The extrapolation of the theoretical framework will now provide coherence to the ongoing development of the concepts of research as praxis and practice as praxis as horizontal threads unfolding throughout the study. Moreover, GHP, complemented by more specific praxiological criteria, provides a rationale for determining authenticity of the whole inquiry.

Chapter four

FURTHER TRADITIONS ENFOLDED IN THE CONTEXT OF THE RESEARCH: NEW ZEALAND SOCIAL AND HEALTH POLICY REFORM AND THE CONTEMPORARY PHENOMENON OF CHRONIC ILLNESS

introduction

Chapter three introduced the theoretical and philosophical framework of this study which I constructed from GPH. Within the framework concept of effective historical consciousness is the imperative to reflect on all the traditions that inform the systematic investigation of a research topic. The reflexive gaze in this chapter involves a discussion on the New Zealand social and health reform which has taken place over the last fifteen years and a brief overview of the literature on chronic illness. In the first instance these two traditions informing the hermeneutical understanding of this research may appear as diverse threads. However a significant component of the health reform relates to the increasing numbers of people living with and needing ongoing care of their chronic illnesses. At the same time the effects of the health reform have impinged significantly on these people and their carers. The material of this chapter emanated from a reflexive dialogue with my own experience and several texts relating to the different issues.

Firstly I will critique the New Zealand social and health policy tradition with emphasis on the health reform programme at work and its implication for nursing. This provides a background to the practice position I took up following my earlier research and the setting for the exploration of strife in chronic illness and practice as praxis. Secondly, I will discuss my professional observations and present a brief literature review on the contemporary phenomenon of chronic illness as further contextual background to the research topic.

New Zealand social and health policy reform

My belief about health services as a national and community responsibility underscores the following discussion. I have no difficulty with the choice of a private or public health service being available to citizens but health services as a market driven commodity is

anathema to me. I view health services as part of the 'common good' of a society and therefore I see universal access to basic services as a government responsibility.

A change of the nation's government took place in 1984. It marked the beginning of a move away from the birth to grave social welfare system initiated in the Social Welfare Act of 1938. Extensive social welfare had been part of New Zealanders' expectations and experience since that time. Top down reform of social policy began, including health and education systems, as social spending was seen to be adding to the burden of increasing national debt. The driver of the 1984 turn in social policy was a neo-liberal ideology which had gained ascendancy in the new government (Cheyne, O'Brien & Belgrave, 1997; Kelsey, 1999). It was all part of a government agenda of de-regulation of markets, privatisation, corporatisation and globalisation. The accentuation of individual rights and free choice replaced previously accepted policy based on collective responsibility undergirded by state intervention. Major restructuring of government agencies began in earnest and large bureaucracies were dismantled rapidly. The new thinking viewed universal social welfare as responsible for reducing personal motivation and self-responsibility in chosen life styles, which for some had resulted in a dependency on the state.

Critics of New Zealand social policy of the 1970s and early 1980s did exist. However, many did not see the post 1984 direction as the answer to the much needed reform of the health bureaucracy. Politicians claimed that the burgeoning national debt required a rapid turn around or imminent collapse of the economy was likely. Crisis intervention took place under a political rhetoric known as the TINA refrain (there is no alternative) (Cheyne, O'Brien & Belgrave, 1997; Kelsey, 1999). The juggernaut of change advanced at great speed with little deliberation of consequences or alternatives. A merry-go-round of legislation began to alter the social tapestry. Opponents of the change were pushed aside and described as promoters of vested interests or resisters of individual choice and responsibility.

Private enterprise, emphasizing competitive commercial values became the way to respond to local community needs. It assumed that all individuals had the same ability to

make choices and little attention was paid to the social constraints experienced by large numbers of citizens. Government aid to the disadvantaged in society became targeted according to income and need and was administered via provider contracts with purchaser agencies. All funding of social projects was to be contestable and transparent with built in accountability systems. Much of the expanding cost of services was seen to have been poor management within prevailing provider and professional interests (Cheyne, O'Brien & Belgrave, 1997). Good management would solve the problem. Managerialism with its corporate values of efficiency, cost containment and measurable outputs was introduced into social service government departments. Quality of outcome, although given some lip service, became secondary to cost containment.

A number of special issues and dilemmas characterised the health reform. A summary of these issues appears in table three. They were issues that only a thorough, thoughtful

Table 3. Summary of health system issues at the commencement of the New Zealand health reform from the work of Bloom, (2000a), Cheyne, O'Brien, and Belgrave (1997) and Somjen (2000)

Yearly increase in vote health with no apparent improvement in health outcomes
 Increasing sophistication and cost of health technology
 People with chronic illness living longer and consuming increasing services
 Evidence of inequity of access throughout the country
 Surfacing of some unethical practices and lack of evidence based care
 Responsiveness to consumers being overridden by provider and professional capture
 Centralised expanding public health bureaucracy becoming increasingly unable to meet the diverse needs of consumers.
 Absence of costing mechanisms for the many and varied state funded health services

review and restructure of the system might resolve. Moves to confront some of the identified concerns had begun in the 1970s (Bloom, 2000). Change based on the United Kingdom reform, which was evolutionary, had been commenced. However, by the late 1980s a report, infused by the new ideology, recommended a model similar to more

competitive and privatised health system in the United States as the answer to the special issues and dilemmas of the health system (Gibbs, Fraser, & Scott, 1988). No recommendations from this report were implemented immediately but they reappeared three years later.

Another change of the nation's government occurred in 1990 and with it a signal of radical health reform (Upton, 1991) based on the recommendation of the Gibbs, Fraser and Scott (1988) report. A new act instigated a funder purchaser provider separation. The Ministry of Health (MOH) as funder, four regional health authorities as purchasers of personal and disability care and three main group of providers: traditional hospital and associated services which became Crown Health Enterprises (CHE's), community trusts and private/voluntary providers. It was believed that competition between provider groups would ensure more efficient distribution of resources. These changes bought with them numbers of 'unbundling' exercises as an endeavour to establish the costs of health services and the education for the services. A Public Health Commission was set up (public health vis a vis personal health), independent of the MOH with overall responsibility for policy and purchasing of public health services. Other primary care remained dominated by General Practitioner (medical) owned, fee for service practices with a schedule of government subsidies. A new Health and Disability Commissioner, charged with guardianship of consumer rights, came into being. General management systems went into place in CHE's and part charges for services was implemented as a signal for individuals to take more responsibility for their health (Cheyne, O'Brien & Belgrave, 1997). 'Managed care' of the cost containment variety became a much heralded catch phase. A national Core Health Services Committee was set up to consult with the public about the establishment of a list of health conditions worthy of state funding. Many small hospitals closed and bed numbers and lengths of stay in large hospitals dropped rapidly. Some targeted assistance was available for low-income groups and frequent service users. Fully subsidised elder care in nursing homes and private hospitals was put under stringent asset testing which lead to an anomaly between the care for the elderly given in public hospitals and that given in nursing homes. In my view, much was promised by the drivers of the new system, in terms of choice for consumers and the development of a more appropriate health service, but little was delivered.

Increasing resistance to the TINA principle and its consequences in health care was evident by 1996. Protest groups were more organised and were assisted by the introduction of a new Mixed Member Parliamentary (MMP) electoral system (Cheyne, O'Brien & Belgrave, 1997). The competition between state funded and private providers had not eventuated (Somjen, 2000). Modification of the political direction began. The four health purchaser agencies became one Health Funding Authority (HFA). The profit requirement of CHE's, including user part charges, was removed and the stringent asset testing of elders for continuing care was modified. A change of name from CHE's to Hospital and Health Services (HHS's) occurred to signal the move from corporate values. Selecting a list of core services had failed as the Core Health Services Committee came to the decision that context and particular circumstances needed to be taken into account when determining worthiness of public funding. Meantime purchasers continued to streamline their contracts with public providers and only short term acute and rehabilitation care became core services for HHS's. According to Somjen, most of the executive managers who were appointed with no health system experience, departed their positions. Furthermore, layers of middle management kept being removed as ongoing restructuring occurred to fit in with purchaser contracts. Thereafter managers with clinical experience and knowledge about health system organization became preferred appointments. The belief in good general management by a professional manager without health service experience as the remedy of many problems was laid to rest. Little account had been taken of the inherent complexity of the system.

Health care costs were contained and some gains were achieved (Malcolm, 2000; Somjen, 2000). These gains included Maori, the tangata whenua or original settler group in New Zealand, obtaining numbers of service contracts (but major discrepancies still remain in their health outcomes), improvements in home support in personal and disability care and moves to capitation of funding to independent medical practitioners associations (IPA's) in primary medical care. Malcolm observed a change from a 'managed care' health delivery model to an 'integrated care' model involving greater attempts to streamline links between primary, secondary and tertiary services.

Nevertheless some cost containment was accompanied by significant human distress. What is known as 'The Gisborne Inquiry' took place between 1999 and 2001 (Health Funding Authority, 2001). It revolved around incorrect reading of cervical smears and the distress and death of numbers of woman. It highlighted the results of cost containment without quality assurance. In fact, many providers had little option but to 'cut corners' in their services to fit the purchase price (Cheyne, O'Brien & Belgrave, 1997).

The public remained disgruntled and health was, once again, a major topic in the campaigns of the general election in November 1999. The new millennium brought with it a change of government and new legislation for moving the health funding authority into the Ministry of Health, shifting to district health boards with consumer representation similar to the pre 1993 changes and a bill designed to monitor health care professionals' competencies.

implications of the health reform for nursing

Nurses working in hospitals experienced the highest level of disruption. Most senior nurses in top administrative positions were moved aside as the shift to managerialism took place. Little acknowledgement of their years of service occurred as they slipped away. With them went large amounts of institutional wisdom and the control over the employment of general nursing staff. As managers found they needed nursing advice a number of new senior nurse positions appeared for this purpose. However some nurses in these positions found their brief difficult (Ministerial Taskforce on Nursing, 1998). Generally speaking, all nursing positions above ward charge nurse or unit manager were disestablished. Nurses became redundant as small rural hospitals closed and bed numbers fell in larger hospitals.

Associated with the continuous change was the diagnosis of a new condition, mentioned in chapter two, called "reorganisation fatigue" (Somjen, 2000). Experienced nurses became afflicted and left the system. They reported dissonance in the moral endeavour of nursing and restrictive working conditions. In the early stages of hospital reform new graduates of nursing found positions difficult to obtain and sought work in other countries or outside of nursing. When they did find work there was little support and

orientation to service areas. A common expectation existed that new graduates would be work ready; able to function like an experienced nurse. The stress of this was too much for some and they also exited the system. It was assumed the market would rule and settle the requirements for a nursing workforce without any overall planning. National nursing organisations could see that the unfolding situation would lead to a nursing shortage but their outcry was ignored. As predicted, a serious nation-wide shortage of nurses occurred in the late 1990s. The idea of a national health workforce planning committee came back on the agenda and was established in 2001.

The reform period coincided with the inception of clinical career pathways in New Zealand; a strategy where nursing practice expertise is valued and rewarded, and is believed to consequently reduce attrition of nurses. Introduction of these pathways had begun in the late 1980s as a response to streamlining the health care system prior to the 1993 reforms. The aim of clinical career pathways is to identify levels of competence among nursing staff and honour these as the rationale for career progression rather than years of experience. This also brought with it a much more systematic and transparent appraisal strategy that had not existed previously. However hospital and service restructuring often impeded progress (Ainge, 1993).

A promise of the new environment included the possibility of nurses contracting to provide particular health services, especially within the primary care context. Some initiatives did develop and have been sustained in certain areas, particularly in woman's health and in rural nursing. Nevertheless, obtaining and maintaining contracts was not an easy task. My own experience as part of a nursing group endeavouring to obtain a contract for a 'family nurse' primary health care initiative, as referred to in chapter two, did not come to fruition. Many nurses had not developed skills or confidence in contracting or in overall accountability and managing risk in their practice. Early structures of nursing leadership had been dismantled and new forms were emerging only slowly. There was little or no assistance available to nurses to develop contracts

In the latter part of the 1990s two nursing initiatives came from the MOH. One in nursing leadership (Ministry of Health, 1996) and the other was a ministerial taskforce set up to

review barriers to releasing the potential of nursing and make recommendations for overcoming them (Ministerial Taskforce on Nursing, 1998). The former stressed the importance of leadership in nursing at several levels and outlined strategies for evolving it. The latter, a much more high profile exercise and report, made wide ranging and radical recommendations. The report states “tinkering at the margins will not be enough” (p. 27). It called for a change of attitudes and structures involving many health funders, nurses, the medical profession, post graduate education and research. In addition it recommended considerable seeding funding to enable new initiatives to develop. Unfortunately, a major nursing group, the New Zealand Nurses Organisation with both a professional and a union voice and representing the largest group of nurses did not agree with some recommendations and distanced themselves from the report. This signaled nurses’ divisiveness in the national arena and did not support the advancement of nursing. Nevertheless various government agencies and other nursing related groups have begun working on the recommendations and I am optimistic that advancement of the nursing profession will occur albeit at a slower pace because of the divisiveness.

In summary the New Zealand health reform with implications for nursing practice and those living with chronic illness commenced in the 1980s and continues into the new millennium. The major driver of the early reform was the political ideology of the period with its emphasis on cost containment. However, the complexity of the special issues and dilemmas as outlined in table three were not readily resolved in the radical reform commenced in 1993 and modification of this model of health care began in the latter half of the 1990s. During this period nursing has undergone much disturbance, grief and restructuring. However, new opportunities for innovative nursing initiatives have accompanied the changes, and I remain hopeful that, in particular, the potential nursing contribution to the health-illness experience of people living with chronic illness will be realised. I will now discuss the emergence of chronic illness as a social phenomenon in the contemporary world.

chronic illness as a contemporary phenomenon

As previously stated I have developed a professional interest in people living with chronic illness and disability. Chronic illness, at the commencement of the twenty first

century, is emerging as an increasingly complex phenomenon challenging the practice of nurses and all health professionals. The descriptor of strife in chronic illness is an expression of the increasing complexity of this phenomenon. Over time I have observed great variations among people's experience of illness. See the following table for an overview of my observations

Table 4. Observations of the effects of living with chronic illness

For some illnesses, there is a reasonably predictable trajectory, for others there is not
 From some illnesses, there is an extensive and visible disability, for others there is not
 For some people, there is ongoing pain and suffering, for others there is not
 For many people, life goes on in a more or less normal manner, for others it has many disruptions
 For some illnesses, there are medical treatments that enable life to be managed with few disruptions, for others there is not
 For some people, a change in ways of living will ameliorate the consequences of the illness, for others it will not
 For some people, illness leads to transformative experiences that enrich their lives, for others it is an ongoing battle to exist
 For most people, there is no cure or 'fix it' but an ongoing companion that calls forth attention, in one way or another, to its existence according to its manifestation

Strife in chronic illness is often a composite of several of these effects. It involves many disruptions even when the primary disease may have a reasonably predictable trajectory; visible or invisible changes may be present; pain, vulnerability and suffering increase along with an increase in medical treatments which are often without demonstrable efficacy; and day to day living can become a constant struggle.

Modern illness is often referred to as psycho-somatic. It is a way of locating the cause of illness in the mind that is consistent with Cartesian mind-body dualism and generally not helpful to those living with chronic illness. Benner, Janson-Bjerklie, Ferketich and Becker (1994 p. 226) believe it is more helpful to understand that "symptom perception, treatment and emotional responses to illness are shaped by personal concerns and social

responses". I have observed that resorting to psycho-somatic causes simplifies the complexity of situations and can lead to a 'blame the victim' mentality. Modern western society's emphasis on personal responsibility for wellness stresses the moral components of self control, self responsibility and accountability that can infer personal failure and shame when illness spirals beyond an individual or family's control. Accounts of death in spite of exemplary self responsibility for illness are less easily explained. Benner et al remind readers that all illness experiences leads to a questioning of ones-self within ones embodied existence. These authors believe that this should be the starting point of nursing care.

These introductory comments on the contemporary phenomena of chronic illness provide an indication of the complexity of health-illness circumstances that people and families might live with. I will now outline the chronic illness tradition as developed in the literature. The intention of this overview is to provide a context for the topic of strife in chronic illness as it unfolds in the narrative of this research. A greater explication of the health-illness discourse from the literature is undertaken in chapter nine for the purpose of constructing a discursive framework to give structure to the critique of the narrative.

the chronic illness tradition in the medical, sociological and psychological literature

Early studies of chronic illness appeared in the sociological and psychological literature (Strauss, 1976; Strauss, Corbin, Fagerhaugh, Glaser, Mains, Suczek & Wiener, 1984; Senior & Viveash, 1998) as efforts were made to understand the social and psychological consequences of long term illness for society. These studies demonstrated a commonality of experience in the overall situations of individual sufferers and their families, knowledge that had not been available from studying disease entities. Senior and Viveash highlight the different perspectives that underpin the socially constructed models of illness. They include functionalist or structuralist approaches often associated with the medical model such as Parson's sick role theory (Parsons, 1951, 1978); feminism where gender issues affecting women in health and illness are stressed (Burgan, 1994; Webb, 1986); and symbolic interactionism which examines meaning and relationships within social interactions. There are also post modern models that caution readers about the

weaknesses of metatheories, powerful discourses and claims to truth. The latter two models are expanded below as they inform this inquiry.

Several medical practitioners have written on approaches informed by variants of symbolic interactionism (Brody, 1987; Kleinman, 1988; Pellegrino, 1982; Pellegrino & Thomasma, 1988; Toombs, 1993; Viney, 1983). These studies seek the meaning of health and illness and are shaped either implicitly or explicitly by cultural, phenomenological or particular philosophical assumptions. The perspective taken emphasises listening to the story of the client experience and working with it in partnership with the client rather than focusing on the disease. Frank (1995) and Zaner (1982), sociologists, whose writing was stimulated by their personal experience of illness, concur with the medical perspectives. Frank describes these approaches as postmodern in that they counter the limitations of modernist medicine. These studies provide important insights into my quest of seeking the meaning of strife in chronic illness.

Post modern models using discursive approaches to contemporary health and illness are illustrated by Yardley (1997), a British health psychologist and Herzlich and Pierret (1987), two French psychologists. Yardley's emphasis is on the difficulties associated with behavioural approaches such as reification and objectification emanating from particular theoretical constructions such as personality theories. Yardley's response to these approaches is the use of socio-linguistics analysis, which she believes, is more congruent with everyday practice of the health disciplines. As such it relates closely to the everyday experience of the client and the nurses in my research. Herzlich and Pierret, canvas the span of illness models from the ancients to contemporary society. The models range from illness as a consequence of the wrath of the gods and fatalism to present day ideas about the evolution of illness within the way we live our lives. Their discussion describe the cycle of the uncertainty of illness in earlier times to the certainty offered by medical science at its peak to the uncertainty of chronic illness in today's world. These authors provide a discursive analysis linking dominant social constructions of illnesses with the experience of illness of a given period. According to Herzlich and Pierret, the present collective consciousness, informed by images from literature, carries within it explanatory models that have served the understanding of people of past generations.

These authors do not believe these past images are helpful in the understanding of illness for the contemporary western population. For me, their discussion demonstrates how dominant past constructions of illness are readily accessed when people of today are suffering from encounters with the uncertainty and limitations of the modern medicine expressed in phases like “I must have been bad in a past life to be suffering like this”. Furthermore, it shows the multiplicity of views of illness that make up our post-modern age and how these might contribute to the experience of strife. In a similar vein, Sontag, (1977) in a sociological historical overview of illness maintains that many images of illness are no longer useful, if indeed they ever were. Her analysis centres on the many images associated with Tuberculosis and Cancer.

the chronic illness tradition in the nursing literature

Equally important in this inquiry are the nursing contributions to the chronic illness tradition. Burks (1999), Morse and Johnson (1991b) and Thorne (1993) theorise about illness at a general level. However nurses, more often, write about an aspect of chronic illness. Benner, Janson-Bjerklie, Ferketich and Becker (1994), Daly, (1995), and Maeve (1998) highlight moral dimensions for people experiencing illness and the nurses involved in their care. Madjar and Walton (1999) have edited several phenomenological accounts of peoples’ experience of varying conditions. Carson and Mitchell (1998) focus on chronic pain while Daly, Morse and Carter (1996), and Younger (1995) write of suffering. Mishel (1990) and Small and Graydon (1993) look at uncertainty and Thorne, Nylin and Paterson, (2000) examined client expertise in respect of their own illnesses. All these nurse writers advance understanding of the complex health circumstances and nursing contributions that can be made to a person’s situation either within a hospital or in the community. Nevertheless many of these contributions to nursing knowledge do not address the complex contextual interactions of the focal concept of the studies (Paterson, 2000). Thorne and her colleagues (Lindsay, 1995; Paterson, 2000; Thorne & Robinson, 1988; Thorne, 1993; Thorne, 2000; Thorne et al. 2000) appear to be building up a comprehensive programme of research into chronic illness.

Thorne’s (1993) study published in book form is particularly pertinent to my research. She claims that much policy and organisation within a medical framework works better

for professionals than clients with chronic illness – the provider and professional capture issue identified in Table 3 (see p. 61). Like the studies informed by symbolic interactionism, Thorne argues for a shift away from the vested interests of those who gain materially to a genuine listening to the stories of those who struggle with the system. Furthermore, she mourns that the assumptions of the disease model have become so ingrained in the general population e. g. the expectation of a medical fix irrelevant of the personal or fiscal costs. A change of this nature would certainly reduce the experience of strife in chronic illness.

One of Thorne's (1993) recommended changes include the co-ordination of services function which nurses with appropriate education, attitudes, authority and working conditions could undertake. For Thorne, co-ordination would take place within a committed person centred approach, an approach that values the ongoing relationship and trusts the expertise of the person or family concerned. From my perspective, the technico-rationalistic term co-ordinator or case manager belies the therapeutic benefit of such a role. The nursing practice implications of such a role have been spelt out explicitly in some nurse case management literature, particularly in nursing studies in New Zealand (Connor, 1995; Litchfield, Connor, Eathorne, Laws, McCombie & Smith, 1994).

The Litchfield, Connor, Eathorne, Laws, McCombie and Smith (1994) study examined the practice of a family nurse in what some writers might term a co-ordinator role. By focusing on the practice rather than the role, a description of the complexity of the interaction was made explicit. Furthermore, it demonstrated the high level relational skills required for such a practice. The family participants of the study reported qualitative improvements in their health circumstances, arising out of their partnership with the family nurse practitioner. The research setting of the study was a nurse case management scheme. Schemes of this nature were being set up to provide a liaison or facilitation of services to high risk, vulnerable people using numbers of health services; people who were using large amounts of health dollars without good outcomes at that time (Connor, 1995; Rodgers, Riordan, & Swindle, 1991). The Litchfield et al study undertook some costing to indicate effectiveness of their model as was the expectation of case management schemes of that period (Etheridge & Lamb, 1989). Savings in health

care were apparent and even greater savings were estimated if the family nurse had commenced her contact with some family participants at an earlier stage. My research (Connor, 1995) was informed by Litchfield (1993) and the Litchfield et al. (1994) study. It also showed health gains for the participants through a particular way of practising nursing. Reductions in numbers of hospitalisations could have been extrapolated from the health gains to show fiscal gains, but the study did not attempt a fiscal analysis.

The observations and literature discussed in this section demonstrate the multiplicity of theoretical constructions that are emerging in the chronic-illness tradition. This accentuates complex phenomena of long term illness in contemporary society in which numbers of differing configurations and meanings, much greater than an exploration the disease entities can illuminate, are possible for the people experiencing it. In the nursing literature a particular approach in what is generally named case management of integrated health care delivery schemes, which claims positive outcome for clients and a reduction in fiscal costs is advocated. As a reduction in health costs has been a major motivation of the New Zealand health reform the potential contribution of nursing into the health-illness experience needs greater appreciation in health care policy.

conclusion

In this chapter I have discussed the traditions associated with the New Zealand health and social policy reform of the last fifteen years and the contemporary social phenomenon of chronic illness. The expanding numbers of people living with long term illness and disability who require ongoing medical attention was a factor in the burgeoning health budget which the government sought to contain in the health reform. The brief overview of the literature, focusing on health-illness, rather than specific disease demonstrates the complexity and nursing issues associated with long term illness.

The model of health system which was put in place in the early 1990s was not seen to be the answer and successive governments have modified it. Some gains have occurred for people living with chronic illness but services staffed by personnel who respond to the complexity of client's situations and provide integration of the services the client's require needs further development. As discussed in the nursing literature, it is a

contribution to the health care system that nurses with appropriate skills, education and authority can make. This inquiry provides a demonstration of both the complexity of living with long term illness and the contribution that can be made by nursing which will support the development of the nursing potential in this area of health care.

As is already indicated in chapter two my position in the public health community nursing service had emerged within the flux of the health reform. Ongoing effects for Sarah, the client co-participant and the team of nurses are evident in the narrative in chapter eight and critique in chapter ten.

I will now examine the evolution of concept of praxis within the cultural tradition of western philosophy as an exercise to assist clarification of how it has been appropriated into the cultural tradition of the discipline of nursing.

Chapter five

PRAXIS AS THE EVOLVING PRACTICAL DISCOURSE IN PHILOSOPHY

introduction

The gaze in this chapter shifts to the historical tradition of the concept of praxis, otherwise known as the practical discourse in philosophy. At the commencement of the inquiry I felt challenged by the various meanings of praxis I had encountered in the nursing literature. In particular, I was puzzled by claims that praxis belonged within the emancipatory paradigm (Connor, 1998; Holmes, 1993; Thompson, 1990). Therefore, I set out to clarify and deepen my own praxiological position through a reflexive dialogue with praxis as it evolved throughout western history. In this chapter the general premises of reflexivity, dialogue and moral comportment apply to the texts used to explore the evolution of the practical discourse.

This exploration has highlighted the notion of praxiology. Praxiology refers to the theories, values and beliefs which underpin the thinking and action of praxis; a notion that is not commonly used in the contemporary nursing literature around praxis. Nevertheless, it is a concept that has, for me, shed considerable light on the multiple uses of praxis. In any given epoch the premises of these praxiologies will take into account the nuances of the philosophical dialogue/s of that age. My probing of the practical discourse in philosophy has enabled a fusion of horizons between the traditional understandings of praxis and how I am using it today.

The following commentary is a sketch of the contributions generated by some important proponents in the evolution of the practical discourse in philosophy, and in contemporary theory, research and education. Those included are listed in the timeline presented in Figure 1. I have chosen these contributors because the majority of them are the names I encountered most frequently in my dialogue with the nursing literature. Kant, Cierzkowski and Kotarbinski are exceptions. Kant was a very significant philosopher of The Enlightenment period who revitalised the practical discourse in philosophy after the Middle Ages and influenced the thinking of several of the Young Hegelians, including Cierzkowski and Marx, as well as many of the post World War Two contributors. The title ‘Praxiology: an introduction to the science of

Figure 1. A time line of the contributors to the practical discourse in philosophy used in this section

Aristotle (384-322 b.c.e.)

Kant (1724-1804)

The Young Hegelians

Cieszkowski (1814-1894)

Marx (1818-1883)

The Post World War Two revival of praxis

Sartre (1905-1980)

Gadamer (1900-2002)

Arendt (1906-1975)

Habermas (1926-)

Kotarbinski (1886-1981)

Bernstein(1932-)

Freire (1921-1997)

The feminists

Lather (dates unavailable)

Stanley (1947-)

efficient action' of Kotarbinski's (1965) book brought the term into the public realm in a more conspicuous manner, particularly to academic readers. However it inferred there was one praxiology. It was from this source that the term entered the realm of nursing. Names missing from my list that some readers may query are Hegel, Husserl and Heidegger. Hegel undoubtedly contributed to the practical discourse but I found it difficult to summarise his praxiology and settled for mentioning the Young Hegelians who were quite specific in their conceptions of praxis. Husserl and Heidegger also advanced the practical discourse in their development of phenomenology. Phenomenology affirms knowledge development from experience and existential praxis. However, it was the goal of my exploration to clarify my understanding of the various uses of praxis in the nursing literature, rather than undertake a full philosophical review, so I chose to omit them. Many of the ideas I have followed in this journey have come from the work of Bernstein (1971, 1983). Nevertheless my search for people and material for inclusion in the commentary has gone well beyond the explication of Bernstein.

In the discussion each identified praxiology is formed from what I have extracted, from both original and secondary sources, as the main claims of each proponent. To present more than a short synthesis from my broad reading on the subject would, I believe, make this chapter too extensive and overarching within the overall context of the research. My position in relation to the claims of the writers will be stated at the close of each synthesis. However, when there is a specific claim I want to challenge this appears within the synthesis. Also included is a summative comment on what I see as their major contribution to the evolving practical discourse.

My exploration of the evolving moments within the practical discourse in philosophy aided and confirmed my selection of Gadamer's praxiology as the most appropriate praxiology in which to embed my praxiological methodology. This preference, does to some extent, influence my comments on the other praxiologies. At the same time the exploration enables me to appreciate that Gadamer's view, like the other views, is partial. This insight allows me to draw on the strengths of the alternative praxiologies in elucidating my praxiological methodological premises in chapter seven.

The word 'praxis' entered into the philosophical lexicon from its use in Aristotle's text, 'Aristotle's Nicomachean Ethics' (Eterovich, 1980). In this text Aristotle was essentially concerned with the nature of 'the good' in terms of human activity. It was Aristotle's explanation of a subject that had been explored by many of his ancient Greek predecessors. Praxis complemented the Greek notion of *theoria*, which was an ultimate philosophical exercise in providing explanations of the world we inhabit. According to Eterovich, praxis in Aristotelian terms meant deliberate, responsible human action. It continues to be used today in academic circles and is generally interpreted as some form of the integration of theory and practice.

Contemporary philosophers and translators (Bernstein, 1971; Habermas, 1972) point to difficulties in the use of the word practice as a direct translation of praxis. In the English language there are different uses of the term practice or practical. Bernstein speaks of them as the 'high' and the 'low' use of the concept. I would prefer the descriptors 'philosophical' or 'lay' use. The 'high' use is where practice is considered to be informed action and practical describes this application as is expressed in the 'practical discourse' in philosophy and nursing. The 'low' use of the term practical is used to describe people who are clever with their hands and not in need of a theoretical understanding of their work. Both these understandings are seen in nursing as many nurses in the past, and currently, still think of themselves as practical people not in need of ongoing knowledge development (Street, 1995). Notwithstanding the various uses of the word practice and practical, praxis has become a word in its own right in both the German and English language which refers to the "high" or 'philosophical' meaning of practice, action and conduct. The philosophical meaning of praxis as informed action or human conduct is the interpretation of the term used in this research.

Further ambiguity in the use of practice and praxis is seen in the English translation of Habermas' (1973) book titled 'Theory and Practice'. The translator, (John Viertel), explains that when practice is juxtaposed with theory it is a right use of practice in German. However, in the English translation he encountered the multiple meanings of the word practice so he chose to retain the word praxis to ensure clarity of intent. Conversely, the translator, (Jeremy Shapiro), of Habermas (1972) declines to use the word praxis as for him practice in German and English mean the same. This translator

explains that in this book Habermas is evolving his own concept (praxiology) of practice/action and other connotations or interpretations of praxis might prejudice his efforts. Furthermore, there is a difference in the translation of the first and second edition of Habermas' 1972 book, 'Knowledge and Human Interests'. Kortian, (1980, p. 117) uses a direct quote from the second edition, which is paraphrased from the first edition. In the second edition the word praxis replaces the word conduct. What follows in the body of this chapter is the outcome of my exploration.

From Aristotle to the Enlightenment

Aristotle (384-322 BCE)

The book 'Nicomachean Ethics', written by Aristotle between 335 and 322 BCE (Thomson 1953), sets out his claims about praxis. Many present books written in English, which are a translation of this book, are not considered to be translations in the strict sense but are what I describe as representations. The two sources used here, Thomson and Eterovich (1980), are in this category. Their titles indicate this status e.g. Thomson's work is titled 'The Ethics of Aristotle'. Thomson's writing is the earlier of the two. His intention is to make 'Nicomachean Ethics' accessible to general readers. It is strong on context but does not use the term 'praxis' which perplexed me initially. Possible explanations for this omission could be its intention for a general audience and that the post World War Two revitalisation of praxis which was still to receive public attention. Eterovich's representation was published during the increasing philosophic developments of the practical discourse and its application to practice disciplines. He does use the term praxis. Eterovich's representation is a more academic rendering of the subject with extensive notes which I found very helpful. It also demonstrates knowledge of the original ancient Greek language as is also evident in the commentary of Lobkowicz (1967). Lobkowicz' work was also very helpful in my interpretation of Aristotole's ideas. The other main commentary on Aristotole I used is Bernstein (1971) who draws extensively on Lobkowicz and a small number of philosophers from the continental school of philosophy.

Aristotle sees ethics as a science, not an exact science like mathematics, but one drawing its principles from the experience of living. It is a science arising from how ordinary people conduct their lives. Ethics, from this perspective was the reflective

study of what was ‘good’ and ‘right’ in society (Geering, 1991) developed for the purpose of providing a moral code. Although often used interchangeably, the words, ethics and morals, are different. According to Geering, the term moral refers to accepted codes of behaving while ethics reflects on those codes in the light of what it means to be a ‘good’ person at any given time. Ancient Greek ethics had as its goal the absolute standard of conduct, the ultimate good to which all things would aim i.e. the telos. Ethics therefore emerged out what is known in order that we may know absolutely. As such, it was seen as a practice discipline, a sub-discipline of politics. For Aristotle, to act rightly is a moral virtue, the disposition of which is formed by a pattern of right actions that evolves from habit (ethos) and is therefore capable of development and change. Ethos is acquired through the practice of a virtue. Aristotle talks of finding the middle road as the ethical road. Excesses or deficiencies in human conduct diminish moral agency. The ultimate in life is the achievement of happiness: not happiness as it is mainly understood in our contemporary world but as achievement of the good and moral life.

‘Nicomachean Ethics’ (Eterovich, 1980; Thomson, 1953) lays out an ideal ethical pathway which, when traveled by free men, leads to happiness. The ideal trajectory for free men to achieve happiness was through political participation in the affairs of the polis. It was not an individual personal journey of transformation but a communitarian one. The good of the nation, city or community was more important than individual good. Political activity had a greater value than an individual going about their personal business. e.g. a physician. The free man became a good person by behaving like one and from his behaviour he came to know what true goodness was. Aristotle believed that in behaving well the happy man would inevitably model goodness in his action. The political or practical pathway to happiness sat along side the contemplative pathway to happiness in ancient Greece. However, Aristotle asserted that the pursuit of *theoria* through the contemplative life by the philosopher was the ultimate way of life.

Aristotle’s ideas were visionary for his time but hold within them the assumptions of the ancient Greek view of the world, which I believe need to be taken into account when reading his works. Lobbkowitz (1967) reminds his readers of the context of these assumptions. Approximately half the population was slaves. Most of the commercial

people and artisans were foreigners so did not have citizenship. The artisans were held in higher repute than the traders. Free men were in turn free from the day to day work of a community. They had others who provided the infrastructure that enabled them to pursue the noble life of politics.

It is within this social fabric of ancient Greece that Aristotle's use of the word praxis is set. In book six of *Nicomachean Ethics* (Eterovich, 1980), the discussion ranges over five intellectual virtues seen as the core of ethical knowing. Three relate to what was considered unchangeable, the ultimate order of things: science (episteme) wisdom (sophia) and intelligence (nous). The other two relate to what was considered changeable, the unfixed matter of life, and are embedded in the deliberative intellect (logos). They are practical wisdom (phronesis) and art (techne). Deliberative, responsible, human-moral action (praxis) emerged from sense perception and desire inserted in intellect (nous). In short, right perception, right desire and right reason come together in deliberating well in order for human praxis to achieve 'the good' or happiness for oneself and one's community. This process was known as practical wisdom (phronesis), an essential component of praxis. Phronesis is not about ends in themselves but about the process of wise judgement informing praxis. In ancient Greece phronesis served both the personal and the political life; good men were good in the way they lived a communitarian life. Art (techne) and making went together in Aristotle's schema of the intellectual virtues. In art the end was seen to be more important than the act of making or producing (Bernstein, 1971; Eterovich, 1980; Lobkowitz, 1967; Thomson, 1953).

Aristotle clearly distinguished between *theoria* practised by philosophers, *praxis* as the prerogative of free men and *techne* as the province of artisans. However, Lobkowitz observes overlaps between them, which I also see. Lobkowitz, once again, uses Aristotle's example of a physician (Aristotle's father was a physician), to demonstrate the overlap. At one level s/he is seen as an artisan practising *techne* as it produces health. To the extent s/he practises well s/he is using *phronesis* as a component of *praxis*, and to the greater extent s/he is interested in a health discourse on how nature is part of healing methods s/he is in fact participating in philosophical contemplation. It appears to me that the clear boundaries between *theoria*, *praxis* and *techne* declared by Aristotle have broken down within the evolution of western

knowledge. A tension between praxis and techne is threaded into commentary on this evolution and becomes most overt in the post World War Two discussion on praxis when the advances in science and technology are seen to have pushed the principles of ‘individual and common good’ to the margins.

In my opinion, the fact that we in the contemporary world are still finding Aristotle’s separation of these intellectual virtues helpful in discussing what is ‘good balance’ in human advancement, is testimony to Aristotle’s wisdom in distinguishing between them. Furthermore I disagree with the opinion of writers who critique Aristotle’s notion of praxis as non credible in present times because his praxiology, his beliefs relating to mathematics, the logos and metaphysical reality, are no longer relevant. They fail to recognise that the praxiologies informing different moments in the evolution of the practical discourse in philosophy shift with the philosophical understanding the cosmos and the human relationships to it of each period. I believe that the essential tenets in Aristotle’s beginning articulation of theoria, praxis and art have transcended the changing beliefs about the order of the world and remain helpful today.

Changes in the politics of ancient Greece, the fall of the Roman Empire and the advent of the Dark Ages led to a submerging of Aristotelian scholars (Thomson 1953). In the 13th century Albertus of Cologne led the revival of the practical discourse in philosophy (Lobkowitz 1967). Translators use the term practice and practical when translating the writing about Albertus. Lobkowitz notes the diminishing separation of theory and practice as further philosophising unfolded; practical disciplines were increasingly seen to have theoretical underpinnings. From the middle ages until the present the recovered writings of ancient Greece have been core material in the studies of most European students of philosophy. Immanuel Kant, a great enlightenment philosopher, was one of these students.

Kant (1724-1804)

During the enlightenment period Kant (Habermas; 1972; Kant, 1793/1974; Korton, 1980; Lobkowitz, 1967) created a new praxiology within his radical reconceptualisation of the philosophy of that time. In his drive to rationalise all knowledge he categorised all science and knowing pertaining to the sense

interpretation and appearances as theoretical philosophy. He then adopted all knowing associated with moral endeavour as practical philosophy. This moment included a change from the Aristotelian concept of men pursuing happiness as their ultimate goal. For Kant, whose praxiology contained Christian values, the ultimate goal was to become worthy of happiness, and all action directed towards this goal took place in an ethical legal framework. Praxis for Kant became human conduct governed by choice but judged good or bad in terms of the rules of practical philosophy. Kant's intention appeared to be related to saving moral action from the clutches of relativism (Bernstein, 1983). Personal and group deliberation was reduced to examining good in accordance with the ethical and legal framework. I see this as a more instrumental or technical view of praxis lacking the Aristotle's component of phronesis. For this reason, I believe, the Kantian praxis is rarely cited as significant in discussions on the contemporary practical discourse.

praxis captures the imagination of the Young Hegelians

The next significant moment in the expanding practical discourse examined is one that emerged within the philosophical ferment of the post Hegelian period. Hegel (1770-1831), a philosopher of the stature of Kant, reconceptualised European philosophy once again. His philosophy was so extensive that his followers believed that there was nothing more to add. Their mission would be to act out what Hegel had contemplated and speculated (Bertstein 1971; Lobkowitz, 1967; Kitching, 1980). Hegel's followers became known as the Young Hegelians. As the Young Hegelians refined their positions from the vast work of Hegel they were known as being right, middle or left of the political continuum. It appears to me that the Young Hegelians were the first to appropriate the Greek word, which translated as praxis, into the German vocabulary. Cieszkowski, a Polish Count who studied in Berlin, developed a new praxiology and simultaneously another praxiology was evolving in the voluminous writings of Marx.

Before I describe the praxiologies of Cierzkowski and Marx, I will refer to the context in which the Young Hegelians lived and wrote, which I believe provides insights into their thinking, as outlined by Outram (1995). Europe was preoccupied with the ideas and freedom associated with the enlightenment. The aftermath of the French revolution was pushing French socialism beyond the borders of France. Middle

classes were emerging, particularly in France and England. Ideals were becoming translated into action possibilities directed toward claiming a world free of feudal and elite power. It was a time when greater numbers could read and thus access printed material. Social institutions such as coffee houses and salons were gathering places for men and women to debate and critique ideas of the day. The Young Left Hegelians were one manifestation of an evolving liberal movement in Germany (Lobkowitz 1967). However, government officials of the time were of a more reactionary persuasion and commenced a silencing of the radical ideas of The Young Left Hegelians.

It is interesting to note that Lobkowitz (1967) and Bernstein (1971) differ in their constructions of the importance of praxis to Hegel. Lobkowitz maintains that Hegel subjected practice to theory so therefore was truly a spectator philosopher. Bernstein asserts that praxis is inherent in Hegel's notion 'spirit', which is acted out in the material forms of life. Nevertheless, it appears that the Young Hegelians understood that speculative philosophy had had its highest point in Hegel. The task, for them, was to apply it, to act in a way that would realise Hegel's ideal society.

Cieszkowski (1814-1894)

Cieszkowski's contribution to the evolving practical discourse as described by Lobkowitz (1971) is summarised in the following outline. According to Lobkowitz, Cieszkowski was the first to advance Hegel's concept of history. Cieszkowski argued for a futuristic perspective to complement the retrospection typical of Hegel's view of history in proposing that the future could be known "by imagination, by thought, and by action" (p. 197). His thinking transcended the separation of art and philosophy. Cieszkowski did this by nominating social action, the living of a life of civil duty, as the ultimate act. The development of humanity was his prime concern, not the Kantian ethics of his epoch, nor personal salvation. Human action was to be preceded and proceeded by consciousness as developed in the Hegelian concept of Absolute Knowledge. Action could not take place without conscious thought. Rather it was an action conscious of itself. In this construction I see reflexivity as a central part of Cieszkowski's praxiology. In remaining within the major tenets of Hegel's philosophy Cieszkowski was seen as a right or at least middle of the road Hegelian. Nevertheless his imperative was to make absolute knowledge achievable by all

people, including the masses, for influencing their conscious actions, which he believed, would ultimately transform the world. Future emancipation was to be evolutionary not revolutionary. I view Cieszkowski's contribution as helpful in that he both includes the word praxis and the historicist turn into the evolving practical discourse. What is known now as the historicist turn was beginning to enter beginning European philosophy at that time. In hindsight, if the enormous energy and writings of Marx had supported an evolutionary perspective, rather than a revolutionary drive for human development, Cieszkowski's contribution might have become a more acclaimed and better known.

Both Bernstein (1971) and Lobkowicz (1967) were uncertain about any connections between Cieszkowski's and Marx. However, they did reveal that men who were in dialogue with Marx were also in dialogue with Cieszkowski. Bernstein argues that Marx came to evolve his praxiology from his engagement in the complete works of Hegel.

Marx (1818-1883)

My interpretation of Marx's ideas about praxis comes from the commentaries of Bernstein (1971), Lobkowicz (1967) and Kitching (1985). According to Bernstein, Marx's commitment to praxis is most overt in his 'Theses' on Fierbich's materialism. The Theses although written in the 1845, were not published until after his death. It is interesting to note that Lobkowicz was of the opinion that the theses were not as important to Marx's view of praxis as Bernstein and Kitching believed them to be. In my explication of Marx's contribution to the practical discourse Bernstein and Kitching view has been favoured as they give a wider context to their position. All these authors agree that the outcome of action is what mattered to Marx and because of this emphasis, his praxis is seen as essentially instrumental; a view shared by Habermas (1972) and Gadamer (1960/1975/1999). However, it is also evident to me that Marx valued the process of deliberating or reflecting well in order to achieve a particular outcome. Therefore I interpret his praxiology as an example of an interlinking of the separate concepts of praxis and techne as developed by Aristotle. Marx's praxiology is embedded in his social theory known as historical materialism.

The process oriented dialectical framework, developed by Hegel, is used by Marx to expand his own idea of praxis from Hegel's philosophy. Marx also takes the Furbachian concept of 'species-being' to differentiate humans from other species and show the inherent needs and the potential of our humanness. For him, human activity, not speculative thinking, achieves the ultimate realisation of humanness. However, Marx believes that human alienation is necessary in order for transformation and the realisation of our humanness to happen (Bernstein, 1971). Alienation occurs when what man does is separated from his self or is not available as potential for transformation. For Marx, alienation took place in a social system that saw products as more valuable than the producer. Therefore alienation has its roots in socio-economic-political structures. In the pursuit of a new world order Marx's task was to bring alienation into the consciousness of the people through educational processes. He saw capitalism as the main social alienation to be overcome via revolutionary praxis for the achievement of a better society. Marx saw this ideal society in the form of a communist state but not, the authors believe, as manifested in the many communist states of the early twentieth century.

Bernstein (1971) uses the descriptor praxis as relentless criticism, to describe another expression of social action in Marx's work. According to Bernstein, critique of political institutions, was most important to Marx. This is what I see as the beginning of what developed into critical social theory praxiology. I am also mindful that the critical discourse in philosophy had its main beginning in Kant and was extended in Hegel (Thompson, 1983). The understanding of social relationships through criticism would be effective when it became part of the thinking and indignation of the masses, inspiring them to assert their rights. This is similar to the goal of Cieszkowski (Lobkowicz, 1967). Thus Marx acknowledged the reflexivity impulse as central in revolutionary praxis. He believed philosophy was actualised in praxis when the masses began to understand their situation and used their understandings to inform action to change it. Marx believed that the imperative of the philosopher and teacher was to transform the consciousness of exploited workers via the orchestration of a reflective process that would in turn incite the workers to revolutionary praxis.

According to Kitching (1985), Marx's early followers emphasized the theoretical and ideological components of his work and neglected his philosophical framework. His

later work, which focussed on economic and political theories, became more ideological. Kitching (1985, p. 35) maintains that the reduction of Marxist theory to propositions about objective truth is in fact “a supreme irony” as it became a theoretical pursuit of abstract questions. Kitching believes that it misses completely that Marx's life's work was about acting in the world to bring about human transformation. Kitching's insights are interesting but from my perspective he fails to fully discuss the implications of the publication of Marx's early more philosophical writings after his death. Marx's revolutionary drive inspired by the context of the French Revolution and carried along within it appears to me to have precluded an earlier appreciation of the philosophical underpinning of his praxiology.

What we think of today as emancipatory praxis, a radical transformation of earlier praxiologies, evolved from Marx's commitment to action. The revolutionary drive in his work threatened the political powers in northern Europe making Marx's continued presence there untenable. Nevertheless, in the period from Marx's death until the second half of the twentieth century, a period when Marxism became the informing ingredient of most Eastern European governments, its philosophical development remained slow. The continued prevalence of the Marxian praxiology, in a variety of different expression, present in numbers of international governments, as a component of several international liberation movements and as a sub-discipline in academic institutions, is confirmation of his significant contribution to the evolving practical discourse.

a revitalisation of praxis in the post World War Two period

The political events in the early decades of the 20th century challenged Marx's vision of the future. However, Marxism remained a strong ideological movement and had a philosophical renaissance in the post World War Two period. Influences from the multi-faceted philosophy of Hegel were also in revival (Bernstein, 1971). Sartre, an influential Existential philosopher and playwright of the middle years of the twentieth century, firstly developed a highly controversial form of Existentialism and then juxtaposed it with the writings of Marx himself, rather than with the many forms of Marxism that were current.

Sartre (1905-1980)

Existentialism was first shaped by Kierkegaard but was named by Sartre (Bernstein, 1971). Unlike Kierkegaard, Sartre denied any metaphysical reality. His key ideas are outlined in his essay – ‘Being and Nothing: an essay on phenomenological ontology’ (Sartre, 1964/1956) written in the pre world war two period. A shift in his thinking is evident as Sartre became familiar with the writings of Marx, but his schema of Existentialism remained firm (Sartre, 1968). Sartre notes that positive critique of Marx was frowned upon in his early studies. Later, he saw that Marxism, with some modification, could provide a broad enough schema for true philosophical advancement. Sartre believed there was too much emphasis on social structures in Marxism which obliterated the reflexive, choosing, acting, existential person. Groups are collections of individuals, according to Sartre, and whatever the collective project, there is always a possibility that an individual’s reflexivity will lead to action that is out of synchrony with the group because of her or his existential circumstances. In doing so the outcome of the collective action may be unpredictable. The way the collective project may be altered will depend on any number and configuration of factors e.g. the individual’s standing within the collective, timing within more global events or internal dynamics of the collective. Thus Sartre saw Existentialism and Marxism as complementary.

Existentialism as a foundation knowledge within the schema of Marxism connecting personal praxis with social praxis, is the basis of Sartre’s claim to Marxism advancing the quest of philosophy (Sartre, 1968). I see this connection as Sartre’s main contribution to the evolving practical discourse. From Sartre’s perspective, the true role of existentialism is to remind advocates of the human sciences that the comprehension of themselves and their existence is foundational knowledge. This is knowledge arising from reflexivity of their mode of being in the world. Sartre maintains that a truly practical philosophy will evolve out of the acceptance of the existing individual “as a practical organism producing knowledge as a moment of *praxis* [sic]” (p. 179). My view is that Sartre’s praxiology took account of the way individuals can create change as an evolutionary praxis balancing Marx’s emphasis on revolutionary practice. It opened the way for praxis to be seen as personal transformation as well as social transformation.

Another European philosopher, studying and teaching in Germany within the phenomenological discourse at the same time as Sartre, was Gadamer. Although Gadamer's work displays an Existential influence, he chronicles his major influences as the German Romantic and post Romantic period (Gadamer, 1960/1975/1999).

Gadamer (1900-2002)

The ideas of Gadamer (1960/1975/1999, 1976a, 1976b; 1981) that provide a philosophical framework for this inquiry are presented in chapter three of this text. A critical factor in choosing Gadamerian ideas as my framework related to the framing of worldview within the reclaiming practical discourse in philosophy. This section will focus more specifically on Gadamer's contribution to the practical discourse than is present in earlier discussions. The writings of Marx and Sartre are not significant influences on his work. Gadamer was more preoccupied with a deconstruction of what he saw as the inadequacies of modern science and a reconstruction of a model of understanding that would act as a counter to its shortcomings.

As part of Gadamer's (1960/1975/1999, 1975a) mission to present hermeneutics as a counter to the excesses of science and technology he critiqued Aristotle's 'Neomachean Ethics' for its contemporary significance. In doing so he came to see the deformations of praxis and phronesis in the evolution of the practical discourse, including the instrumentality of Marxist praxis. Within this critique Gadamer asserts that today's science and technology is heir to Aristotle's construct of techne and hermeneutics is heir to Aristotle's construct of praxis. From my perspective it appears that Aristotle's emphasis on the separateness, rather than overlap of these two concepts, enabled Gadamer to expand his construction of praxis as an ingredient of contemporary human science. The omission of the critical component of moral reasoning in scientism concerned Gadamer. Lack of moral reasoning was also associated with Sartre's expression of Existentialism (Bernstein, 1971). The reclaiming of the moral component, according to Gadamer, would counter the hegemony of science and technology. He believed it would bring the contemporary contributions of the human and physical sciences into a more productive balance.

Gadamer (1960/1975/1999) extends Aristotelian phronesis as a mode of understanding by inserting it into his philosophical hermeneutics. Phronesis thus

becomes the ontological, moral reasoning process inherent in Gadamer's notion of universal understanding. He sees that expanded understanding arises from the reflexive questioning of the world in which we live; questioning that will effect the tradition in which we live and/or work (Thompson, 1990). According to Gadamer, Aristotle's practical-moral action, praxis, and the moral being of our human becoming shape phronesis and is shaped by it within language. Phronesis involves applying the universal or general principles or a schema to a particular situation for the purpose of guiding action.

In reclaiming the separation of praxis and techne in order to balance the physical and human science contribution to human development Gadamer elicits and articulates how each is shaped by different knowledge premises. These knowledge premises are also drawn attention to in Bernstein (1983). The table below is my demonstration of the different knowledge premises, articulated by Gadamer, between technical and practical (practice) moral knowledge.

Table 5. Differences between technical knowledge and practical knowledge (Bernstein 1983; Gadamer, 1960/1975/1999)

<u>Technical or instrumental knowledge</u>	<u>Practical moral knowledge</u>
Changes constantly and can be easily forgotten	Not easily forgotten
Knowing the end determines the means	Is concerned with the means involved in doing what is right as demanded by the situation
Can proceed without involving people	Always embraces involvement with and understanding of the other

According to Gadamer (letter written by Gadamer and published in Bernstein, 1983), it is the expanding of practical moral knowing in conjunction with technical knowing, that will avoid the cataclysmic events of twentieth century Germany happening again. Gadamer's idea of practical moral knowledge is central to my understanding of praxis and phronesis in this research.

Gadamer (1960/1975/1999, 1981) takes advantage of Aristotle's separation of *techne* and *praxis* in order to further expand *praxis* as a counter to the lack of moral knowing in science. His integration of this into contemporary philosophical hermeneutics is, I believe, his major contribution to the evolving practical discourse. Within this contribution Gadamer makes the reflexivity inherent in *praxis* equally applicable to personal or group action. Gadamerian philosophical hermeneutics further contributes to the practical discourse through advancing *phronesis* in the broader schema of understanding as an ontological event thus linking existentialism and hermeneutics. His development of several layers of connection between hermeneutics and *praxis* affirms my descriptor of hermeneutics as *praxis*.

Although Gadamer, was evolving his philosophical position at a similar time to Hannah Arendt I have found no evidence of communication between them. However, I see commonalities in their writing in their return to Aristotle to reclaim his notion of *praxis* for appropriation in the contemporary world, their experience of being students of Heidegger and in their passion for the redemption of practical-moral reasoning in the open space created from disillusionment with the over emphasis on the instrumentality of scientism.

Arendt (1906-1975)

Hannah Arendt is another person who lived through the chaos of Europe in the first half of the twentieth century. This background influenced her theoretical position (Bernstein, 1983). She was a contemporary of Gadamer, Sartre and Habermas and spent some time studying with Heidegger. Her major treatise first published in 1958 (Arendt, 1958/1998) sets out her praxiology. She used the ancients and modernity as reference points and included Christian theology, and ideas from Kant, Hegel (to a lesser extent), and Marx. Arendt distinguished between labor, work and action (*praxis*) all of which she acknowledged as part of the *vita activa*, the active life. I see an overlapping of the concepts of *techne* and *praxis* in her exposition rather than the separation stressed by Gadamer.

Arendt's (1958/1998) major strategy in evolving her position was to examine the concepts of labor work and action within the changing historical and social circumstances of different periods, especially the changes that have occurred between

the ancient Greek world in what was known as the public and private realm. Labour in ancient Greece equated with the obtaining of the necessities of life and went on in the private household. I see it as the infrastructure that allowed free men and philosophers to pursue, respectively, praxis and theoria. In the Marxian extrapolation of labour as the overt manifestation of the industrial revolution, labour had become centre stage in the public realm. Furthermore, Arendt argued that by the twentieth century society was characterised by a working population she termed 'jobholders'. Her notion of work holds with the Gadamerian knowledge premises of *techne* or technical knowledge as described in Table 5 (see page 89) Action is the interpersonal activity of people with each other; it does not require a material conduit. As such it is our highest form of activity. According to Arendt it does require plurality, acknowledgement of the 'other' in our individual differences and preferences, along with language/speech. She holds with the Marxian stress on action as social praxis emerging from the reflexive impulse within public human gatherings. Moreover, praxis assumes an equality of the actors. Within her framework, Arendt highlights a major reversal in values that have occurred since the life of the ancients. Firstly she notes a change from valuing the *vita contemplativa* as the highest expression of living to our present valuing of the *vita activa*; secondly, she explicates a shift in value from a communitarian achievement of happiness to individual rights and expression governing community development. These shifts occurred with the rise of our technologically based society, which she considers has eclipsed people's valuing of interpersonal praxis.

Persons are conditioned by how they labour and work but it is action that enables them to condition the world they inhabit (Arendt, 1958/1998). Human beings are always in a state of becoming within these processes. Their birth into the world is their first action. Arendt uses the image of natality in a many layered way to demonstrate action potential. For her, every time a person acts anew there is a new beginning of possibilities. Like Sartre she believes that praxis can occur spontaneously and begin a new way of being in the world. Action, for Arendt, becomes the 'in between'. It is similar to the 'to and fro' of the event of understanding in Gadamer which takes on a life of its own. She captures this intangible reality with the metaphor of " 'the web' of human relationships" (p. 183). People are born into existing webs of relationships and advance their lives within multiple different webs

of relationships. Within these webs new processes emanate. These webs appear to be a metaphoric description of Gadamer's tenet of effective historical consciousness. According to Arendt action stimulates reaction which is a new action taking on new processes. Action and reaction set in motion a multitude of possible boundaryless effects. Therefore, for Arendt, unpredictability and uncertainty are important characteristics of action.

Arendt (1958/1998), like Gadamer (1960/1975/1999), was concerned with what constitutes a moral life. She believes moral codes emerge out of tradition and changing social mores but are more than these components. For Arendt, 'the good' is best achieved in the giving and receiving of forgiveness and promises. Goodwill arises from these commitments and fosters communities where new beginnings, which interrupt the repeating patterns of daily life, are fostered. In this type of community people "are not born in order to die but in order to begin" (p. 246). Transformation, according to Arendt, as it is for Cieszkowski, Sartre and Gadamer, will be evolutionary rather than revolutionary.

Taken together, Arendt's metaphors of birth and webs and her emphasis on the interpersonal, the needs of the other, forgiveness and equality all appear to me to foreshadow feminism. However, this is denied by Margaret Canovan who has studied Arendt's schema of ideas extensively and who wrote the introduction to the 1998, second edition of her book, originally published in 1958. From my perspective, the above factors characterise her work as different from that of male commentators discussed in this chapter. Moreover, these factors, in my view, constitute Arendt's original contribution to the evolving practical discourse.

The events in Germany in the third and fourth decade of the twentieth century which disturbed Arendt (1958/1998) also alarmed and influenced Jurgen Habermas (1972, 1973), a philosopher who has been significant in the development of emancipatory praxis.

Habermas (1926-)

Habermas is commonly associated with the development of the Institute of Social Research in Frankfurt, one legacy of the Young Left Hegelians, in particular Marx

(White, 1988). The purpose of the Institute was to critique “economics, politics and culture of western societies” (p. 4). The term ‘critical theory’ as coined by Horkheimer emerged as a descriptor of their theoretical stance. As the events in 1930 Germany unfolded the protagonists of critical theory distanced themselves from Marxism and became exiled in the USA. White describes their return to Germany post war to re-establish the Institute at Frankfurt and continue the development and application of critical theory. Their intention was to keep critical theory socially grounded and versatile enough to be applied across several disciplines.

The unfolding of Germany as a democratic state post World War Two strongly affected Habermas’ view of the world (Bernstein 1983) and made him a major critic of Marx (Habermas, 1972). According to Habermas, the major limitations of Marx’s thinking related to his inability to extricate himself from positivism and thus move to an understanding of communicative action/praxis. Habermas sees Marx’s notion of social praxis, within historical materialism, as instrumental or technical praxis.

Praxis as revolutionary activity, according to Habermas (1972, 1973), needs to be complemented by the critical function of a reflective science to avert any return to fascist government. Reflexivity, then, is a key tenet in Habermas’ critical social theory. Any institutional domination, which hinders his view of communicative action, potentially slows the process of self transformation. Moreover, Habermas cautions interpretations of labour acquiring meaning as life world. He relates this interpretation to a phenomenological interpretation using Husserl’s notion of life world that is echoed in Sartre and Heidegger. According to Habermas, the dialectical interaction of a knowing person involved in social praxis is the essential ingredient of a critical theory, not personal praxis. In this interaction a space exists for the reclamation of practical moral decision making. Korten (1980 p. 1270) values Habermas’ advancement of Kant’s notion of practical philosophy giving primacy to action/praxis “which is constitutive of all theory”. Habermas set out to create a social theory with practical intentions on the presupposition that action is *a priori* to wanting to know. He remained committed to the notion of personal and political emancipation but believed it came through the conceptualisation of rationality, not understanding as argued by Gadamer (1960/1975/1999).

Integral to Habermas' communicative action theory is his well-known cognitive human interests associated with knowledge development; the technical, the practical and the emancipatory (Habermas, 1972, 1973; Ray, 1999). Habermas claims that the emancipatory interest, as the critique of political positions, is the most important as it demonstrates a distortion at work within people approaches that continue the oppression of particular groups. He also stresses that the effectiveness of practising critical social theory is to be seen in the action of the audience who co-participate in its development. Success is achieved when the audience reflects that the theory is a good description of their social political position and worthy of informing their action.

Kortian (1995) reminds critical social theory researchers that within their critique of distorted social situations there must be an awareness that there may be a distortion of reality in their own thinking. Kortian is raising the notion of 'false consciousness' in the researcher; a concept that is, I believe, most often applied to the researched but should be meticulously uncovered in the researcher's own position. False consciousness as discussed by Lather (1991) involves our denial of the disempowering effect of political constructions inherent in our everyday world. She acknowledges the difficulties such a concept raises but accepts that "most people to some extent identify with and/or accepts ideologies, which do not serve their best interests" (p. 68). The difficulty I have with the construct of 'false consciousness' relates to who decides what is actually a person's 'best interests'.

I also have difficulty with the way Habermas (1972) has separated out the emancipatory knowledge interest as a separate category from his ideas on the practical knowledge interest. It appears to me to be more of a sub category of the practical interest. His privileging of the emancipatory interest is also problematic from my perspective. He appears to have fallen into the same trap as the positivists who see their approach as the way. In this age of pluralism, I believe there are many ways to achieve emancipation and transformation and the best approach is that which best answers the research question posed. An approach, that in today's milieu, may involve all three interests. Furthermore the three cognitive interests of Habermas have been critiqued as transcendentalism (Bernstein 1983; Nicholson, 1991). I see them as human constructions, which have helped many researchers give a specific location to

their inquiry, but as human constructions they can be deconstructed when used as foundationist premises.

Habermas, like Gadamer, has reclaimed a moral stance characteristic of earlier praxiological positions. He reminds readers of the moral imperative that exists when groups of people enter into a dialogue to improve communication. His praxiology, and he does use the word praxiology, to describe his position, is an intricate weaving and expanding of the critical discourse initiated by Kant and advanced by Marx (Habermas, 1972, 1973), which when used with practical intent, becomes a component of the practical discourse. As such, Habermas' praxiology makes an enormous contribution to understanding of the political arena in the evolution of the practical discourse.

At the same time as Habermas, Gadamer and Arendt were developing their praxiologies, a quite different praxiology emerged from the Polish philosopher, Kotarbinski (1965).

Kotarbinski (1886-1981)

Kotarbinski (1965) developed a theory of efficient action using Aristotle's idea of *techne* as the foundational unit. He named it 'Praxiology' which implied to me that he considered it 'The Praxiology'. There is no reference in his work to the other Polish philosopher, Cieszkowski. Kotarbinski claims that his praxiology is a new discipline with trans-disciplinary application similar to the claim about critical social theory by the Institute of Social Research, Frankfurt (White, 1988). It has Marxian overtones and is linked with Habermas' (1972, 1973) reductionism notion of purposeful rational action. It also incorporates logic and mathematics. Its goal is to set up a rational approach to discovering techniques and practices that will lead to efficient and effective work. Kotarbinski postulates that it will have its greatest application in business management but also maintains that it has broader philosophical pertinence. It is a praxiology that does not incorporate a strong moral imperative. Therefore, I believe it is a good example of what Gadamer (1960/1975/1999) and Habermas (1972) describe as the de-formation of praxis within modernism. Further, Kotarbinski inference of one praxiology, could have influenced other authors, I believe, from claiming their work as a praxiology.

Bernstein (1971, 1983), a current US philosopher has progressed the concept of praxis by focusing on a contemporary notion of phronesis that goes beyond the ‘Cartesian anxiety’ in the either/or approach to rationality.

Bernstein (1932-)

Bernstein (1971, 1983) has been an important guide in my journey through the evolving moments of the practical discourse. He has also made a unique contribution to that discourse. Bernstein’s style is to seek commonality and conjunctions in the world of philosophical inquiry rather than stressing differences. The broad spectrum of Hegel’s philosophy is his starting point for discussing the revival of praxis through the Young Hegelians. He then focuses on Marx, Sartre, and the early United States analytical philosophers and United States pragmatists. Bernstein applauds the efforts of Marxism, Existentialism and Pragmatism for evolving the practical discourse by holding to the broad paradigm of praxis initiated by Aristotle and highlighting its relevance to contemporary life. However, he is more skeptical about the contribution of analytic philosophers. It is Bernstein’s belief that they have stayed with the Hegelian notion of explicating the ‘is’, rather than responding to Marx’s challenge to act and bring about change.

In 1983 Bernstein (1983) continued his dialogue on praxis within an overall objective of going beyond what he called the ‘pernicious dichotomy’ between objectivism and relativism. He set out to disrupt this binary and reconstruct a new conceptualisation of rational thinking. Bernstein used the explication of practical reasoning or phronesis first developed by Aristotle, and reclaimed in Gadamer, to evolve his praxiology. The either/or arguments around objectivism and relativism were, he proposes, a result of the Cartesian Anxiety. Bernstein believed a new way of talking about rationality was needed. According to Bernstein, praxis and phronesis, as developed in GPH, together with some strengths from the many writings of Habermas, and Arendt (1958/1998), provided a new perspective from which rationality could be viewed. Bernstein uses the metaphor of a cable that combines the intertwining of several strands, when describing his melding of philosophical strengths, to make a greater conduit than is possible in each strand. His extended model of phronesis contains strands of “dialogue, conversation, undistorted communication, communal judgement and the

type of rational wooing that can take place when individuals confront each other as equals and participants” (p. 223). The new model transcends the either/or of objectivity and relativity. I do see elements of personal praxis in Bernstein’s praxiology but his general emphasis is on social praxis emerging from communities.

From my perspective, Bernstein’s (1983) concept of rational wooing or persuasion is disputable. It has overtones of the old discipline of rhetoric (Gadamer, 1976a; Pellegrino & Thomasma, 1981), which makes a virtue of persistence and male rationality that would put many woman at a distinct disadvantage because of their preference for a more mutual decision making processes. Furthermore, there is a fine line between persuasion and subtle coercion. In the context of my inquiry persuading the co-participants to come to a consensus about meaning would be anathema to my intention of honouring and working with their individual meanings. I am more comfortable when praxis takes place within pluralism (Arendt, 1958/1998) where acknowledgement of individual difference and preference is taken into account.

Communities who endeavour to provide the ideal notion of solidarity can be fragile (Bernstein, 1983). He is also mindful that much of humanity has never experienced such a community, which Bernstein believes, cannot be bought about by social engineering. Bernstein advises people to grasp every opportunity to act on initiatives that offer a sense of mutuality and solidarity, rather than give up on the progression of humanitarian quests in the light of such difficulties. He completes his hermeneutic circle on an optimistic reminder that a paradox in history does show that power has its own point of vulnerability where a space for resistance from particular communities can lead to what is considered an unpredictable turning point. The idea of an unpredictable change in direction is also expressed in the praxiologies of Sartre and Arendt

Bernstein’s contribution to the practical discourse, I believe, comes from his commitment to uncover commonalties among a number of praxiologies, providing a clear critique of them and weaving their strengths together in his cable metaphor.

While Bernstein remained within academia in the United States evolving his praxiological position in conversation with his European and national contemporaries,

another praxiological position was taking shape from grassroots experience in the third world barrios of Brazil and Chile. Freire (1970/1983) 'walked the talk' of a liberation pedagogy.

Freire (1921-1997)

Paulo Freire, (1970/1983) was born into a middle class family. The depression of the 1930s triggered the loss of his family effects and, for Freire, bought with it a direct encounter with poverty. Tertiary education enabled him to be emancipated from poverty. At the same time it gave him tools to help others do the same. He became a teacher of the poor and oppressed. Freire learned that adult education, practised in particular way, could be emancipatory. His book 'Pedagogy of the Oppressed' is a refinement of his beliefs about education and the effects of poverty. So threatening to the politically powerful was the effect of his teaching and dissemination of his beliefs that he was jailed in Chile for inciting unrest. Freire left South America after his discharge from jail to continue his work without threat of further imprisonment. Later appointments at Harvard University and at the World Council of Churches followed.

The voices of Hegel and Marx resonate in Freire's (1970/1983) writings. However he also tells of the influences of Husserl, Marcuse, Mao Tse Sung, and Martin Luther King. Thus, his pedagogy, where praxis is the central concept, is also informed by Humanism and Existentialism. The praxiological struggle of the oppressed led him to define praxis as "reflection and action upon the world in order to transform it" (p. 36).

Freire's (1970/1983) pedagogy brings together the praxis of the teachers who facilitate the reflection of the students on their world. A dialogical partnership is set up where the revolutionary knowledge of the teacher meets the contextual knowledge of the student. The intention of the reflection is to inform the student's praxis. For Freire, the teaching or leadership practice must have as its goal the humanisation¹ of the people. This is expressed as "becoming truly human (is every person's) [sic] ontological vocation" (p. 61). Freire is clear, as was Marx that a leader cannot carry out the revolution without the people. To this end Freire encourages revolutionary leaders and teachers to live in communities with the students and participate in a

¹ Freire differentiates between humanism and humanisation

dialogue as both teacher and student. Furthermore, according to Freire, authenticity for students involves a double praxiological struggle. First it is the coming to know of the power relations in their situation and the confrontation of that reality. Secondly, it involves the action required to transform it. Theorising is an outcome of the reflection on the action taken and expands the original emancipatory theory.

The strength of Freire's praxiology, to me, is its groundedness in practice. It is truly experiential and demonstrates the realities of practising an emancipatory praxiology as pedagogy. His authenticity in practising what he preached is inspirational.

Other emancipatory praxiologies include those developed by feminists. Some of these embrace ideas developed by Freire.

feminist praxiologies

Campbell and Bunting (1999) point out that women's issues are always the focus of feminist research. According to these writers, the feminists have a world view involving values of relatedness, unity, the unitary nature of actions within a local context and subjectivity that provide clear epistemological guidelines for praxis research. Moreover, feminism highlights and critiques the male dominance of western philosophy (Solomon & Higgins, 1997). It declares the privileges experienced by male philosophers throughout western history in their freedom from being caught up in providing the necessities of life, much akin to the free men in ancient Greece and what I sense was the experience of Gadamer. Lather (1991) rejects the claim of the universality of most western philosophical schools of thought. In Lather's view, women and people of other cultures do not feature in the traditional philosophical notion of universality as is made overt in the critique of Gadamer, by Schott (1991), recorded chapter three.

Two women who are proponents of praxis oriented research within a feminist frame are Lather (1986, 1991) and Stanley (1990). They translate feminist values into clear epistemological premises demonstrating their commitment to the emancipatory power of praxis. Lather, is a teacher and professor of Educational Policy at the Ohio State University, United States, and Stanley is a lecturer and researcher in Woman's Studies at University of Manchester, United Kingdom.

Lather (dates not available)

Lather's (1986, 1991) fundamental stance is that our knowing is evident in our action as we live, speak and work in a political space. She claims a multi vocal framework for expressing her position. The framework arises out of "conjunctions of feminisms, neo-maxisms and postmodernisms" (1991, p. xv). Her mission is to embed praxis into post modernism in order to insert the emancipatory ingredient that she sees as lacking; a mission that she acknowledges as a praxiological quest.

Research, for Lather (1986; 1991), is a practice in addition to her teaching. As with Habermas (1972, 1973) and Freire (1970/1983) Lather cedes that emancipatory theory that makes the research or teaching intent overt is apriori. Using theory in this way, according to Lather, is likely to "protect us from the awesome complexity of the world" (1991, p. 62). She sums up her epistemological premises as "interactive, contextualized and humanly compelling because they invite joint participation in exploration of research issues" (1991, p. 52). Lather also joins the proponents from Habermas onwards who adhere to the notion that the research empowers the participants to claim their emancipation and supports them in their ongoing praxiological endeavours.

Stanley (1947-)

In discussing the creation of knowledge in academia Stanley (1990) uses Marxist terminology. The academic mode of producing knowledge, she contends, is characterised by a particular association between relations and the forces of production. Stanley asserts that present western academia turns knowledge into a commodity where gatekeepers, mostly male academics, assign it a greater or lesser value according to traditional conceptions of valuing knowledge. She argues that when emphasis is on knowledge as product there is a separation and alienation of researcher and researched; an intolerable separation according to the Feminist approach which emphasizes process and the inextricable link of finder and findings.

Stanley further outlines important epistemological premises of participatory inquiry that combine in Feminist praxis research. She stresses reflexivity of the research process as part of the product of the research. This avoids both the production of

alienated knowledge and provides an audit trail from which authenticity of the research can be decided. Another premise, Stanley sees as critical, is the grounding of the researcher in the actual research context. In her final premise she urges that research participants be treated as subjects, not objects. Stanley asserts that objectivity is an intellectual exercise separating people from their subjectivity. According to Stanley, these three premises, informed by a feminist ontology, provide the epistemological framework for Feminist praxis research.

The values of feminist praxis further expand the practical discourse in alerting researchers, like me, to weaknesses in the praxiologies that assume a freedom of human development that has been taken for granted by many men but one that is often difficult to achieve for women. This difficulty arises out of the different social expectations of gender roles. Consequently, I understand the appeal of a feminist emancipatory praxis to many women researchers. Some of praxiologies I have described acknowledge the importance of 'other' views of the world. This is implicit in Gadamer's universality of understanding, in Habermas' emphasis on the hegemony of political institutions and Freire's ethic of listening to other perspectives. However, I do not interpret any real sensitivity to women's positions. Likewise, Arendt, who I believe expresses the assumptions of a feminist ontology without awareness, does not acknowledge that women's view of the world might be different from that of men. At the same time, I think that it is time for feminists to let go their preoccupation with comparing their epistemologies with those associated with objectivist research, as is evident in Stanley (1990).

conclusion

The examination of the practical discourse in this chapter identifies that philosophical praxiologies evolve within the currents of thinking and philosophising of the era of their development. As an evolving concept praxis is not the prerogative of any one ideological perspective. In the multi vocal world of post modernism different praxiologies constituted from the varying values, theories and prevailing ideologies will sit side by side. Praxis in the work of Aristotle took place within an overt political community. Over the subsequent two and half thousand years praxis has taken on a personal focus while at the same time retaining the social orientation of its origins. This shift is consistent with the changes in the private and public realms and

movement from a strongly communitarian to a more individualistic value system (Arendt, 1958/1998). At the same time feminists remind us that the ‘personal is the political’ (Campbell & Bunting, 1999) in that individual lives are shaped by the ideology underpinning political decision making. Furthermore, Gadamer (1960/1975/1999) challenges us to reflect on questions where the answers will transform our understanding of the world and make a difference to future traditions. It appears to me that fostering a nexus between the political and individual foci of praxis will contribute to an expanded and more useful praxis tradition in the future. Research as praxis, in this inquiry, commenced with a focus on personal praxis and through the adoption the methodological premise of critique, the influence of particular discourses in the generation of meaning became apparent, which brought out political perspectives.

Reflexivity and transformation are two constant threads throughout the evolution of the practical discourse in philosophy. These are not always expressed in the same way and are more evident in some praxiologies and less in others. Critical social theorists using Marxian, Habermasian, Freireian or Feminist models all express an emancipatory political intention as the purpose of the reflexive exercise. For this reason they are what Campbell and Bunting (1999) call a family of theories. Gadamer, Sartre and Arendt talk more of the transformative potential of praxis available in the expanding of horizons of individuals and/or groups rather than praxis as an explicit emancipatory task. The purpose of the methodological premise of reflexivity as praxis in this inquiry centres on its transformative potential.

A characteristic of the practical discourse is its development of knowledge from experience but differing views of how theory and experience are moments of praxis are evident. These vary between the grand narratives such as critical social theory to how personal values and theories might be embedded in our effective historical consciousness. What is now evident to me is the fact that a particular praxiology, whether explicit or implicit, does influence the direction of the transforming potential of praxis. As discussed in chapter three the selection of GPH influenced what my gaze rested upon in the research material and coloured what I chose to extrapolate for discussion and critique. However, the meaning generated is not returned to my

research framework. Had such been done it would have made theory development, rather than praxiological expansion, the goal of this research.

Aristotle's separation of praxis and techne and the implications of their overlapping tendencies, drawn by some contemporary commentators, is a thread in my commentary. Techne or instrumentality of action is most overt in Kant and Kotarbinski. Marx's praxiology is critiqued as being primarily instrumental but I see it as representing an overlap of both concepts. The main criticism of an emphasis on techne, as in contemporary science and technology, is on its eclipsing of the importance of rational moral reasoning or phronesis. Much of the post World War Two philosophy has been preoccupied with reclaiming the Aristotelian moment of praxis in order to counter balance the instrumentality of science. These contributors to the practical discourse have found it more helpful to stress a differentiation between praxis and techne rather than commonalities. This separation has enabled me to focus on building up praxis as the relational component of nursing in this study, which I believe, is endangered by the instrumental or functional drive of the New Zealand health reform as described in chapter four.

The more common expression of praxis has been in an epistemological form; it has been a way of coming to know rather than a way of being from which we come to know. However, with Gadamerian hermeneutical philosophy where application becomes a moment of understanding the Aristotelian concept of phronesis, a core component of praxis, takes on greater significance as contemporary practical moral reasoning. It becomes the ontological happening of understanding that determines our acting wisely or other-wisely in the world. In this sense it is known as practical wisdom and is enacted as such in this inquiry.

In the expansion of my horizon of the practical discourse in philosophy, as illustrated in this chapter, I now have greater clarity of the various uses of praxis in nursing. In chapter six I will examine the multiple praxiologies present in the discipline of nursing from an informed background.

Chapter six

APPROPRIATION OF PRAXIS WITHIN THE DISCIPLINE OF NURSING**introduction**

In this chapter I discuss the praxiologies identified in chapter five which have entered the discourse of nursing and the 'to and fro' movement among these praxiologies within nursing. As in the previous discussion, this exploration will involve an outline of the overall terrain. To structure the discussion I have chosen a number of particular groupings that represent the main discussions on praxis in the nursing literature. Within each section will be the voices of nurses who have appropriated and applied the form of praxis under discussion. The groupings are praxiology in nursing, emancipatory praxis, hermeneutics as praxis, the theory practice gap, nursing as praxis, and praxis in nursing theory. The discussion continues my clarification of praxis within the general premises of reflexivity, dialogue and moral comportment with nursing texts. Within this clarification I nominate my own praxis position. The texts used come from a literature search, including an internet exploration of praxis and nursing, followed by the use of references from identified texts and references given to me after discussions with research supervisors and colleagues.

Consolidating the material from the references into this discussion has expanded my horizon of praxis as an action oriented concept and the multiple ways it can illuminate nursing practice, research and education. The discussion also demonstrates that the various terminology used to describe the praxiological quests in nursing has led to disjunctions in the development of praxiological nursing knowledge. The two concepts, praxis as practice and praxis as research, associated with my praxiological quest of expanding understanding of strife in chronic illness, are the foreground of this discussion. The chapter closes with an interim summative statement on the inquiry so far.

praxiology in nursing

The concept of praxiology was first introduced into the nursing lexicon in the early 1970s (Walker, 1971). In her attempt to clarify nursing theory Walker appropriated the idea of

praxiological inquiry from an educational perspective which had been informed by the praxiology of Kotarbinski (1965). His is the most technico-rationalistic of those praxiologies outlined in the last section. Its focus was on rational purposeful human action or working efficiently rather than the deliberation about what should be done and why (Street, 1995).

Walker (1971) was writing in a period when nursing was clamouring for professional status, particularly in universities (Pearson, 1988). It was believed that attention to theoretical expressions of nursing would gain respect and sustain the discipline within those institutions. The purpose of Walker's article was to contribute greater clarity to the emerging conceptions of what constituted nursing theory; what I call the theoretical discourse in nursing. In order to achieve this clarity she coined the term *nursology*. Within *nursology* she developed a number of theoretical positions that were assigned value on a hierarchical ladder. On the top rungs of the ladder are what she terms nursing theory and nursing science. Walker drew on and expanded earlier notions of practice theory (Dickoff, James & Wiedenbach 1968a, 1968b) which she linked to praxiology. Praxiology or practice theory, for Walker, is not 'real' theory and is placed on the lower rungs of her ladder.

According to Walker (1971, p. 428) praxiological inquiry, is a mode of investigation that "provides a description and explanation of what are effective practices in a given endeavour" (p. 428). This definition implies an acceptance of nursing as an accumulation of techniques, rather than a coherent practice. Walker's differentiation of theory and practice is associated with her view of what was 'good theory' not fitting with context bound, action oriented knowledge (Pearson, 1988). A consequence of Walker's belief in theory as higher than practice is, according to Pearson, the reinforcement of the separation of doing and thinking; a separation that emphasises 'the gap' between theory and practice. I see Walker's linking of practice theory to philosophical praxiology as a strength of her work. However, her use of Kotarbinski's praxiology with its emphasis on *techne* or instrumental practice, precluded, I believe, movement to include reflexivity of

practice and the balance of instrumental practice with the nuances of person centred decision making processes (Orlando, 1961; Peplau, 1952/1988).

An immediate critique of Walker's ideas came forth in a response to her article (Wooldridge, 1971). Wooldridge was a social psychologist with a particular interest in disciplinary practices (Wooldridge, Skipper & Leonard, 1968). In his 1971 critique he proposed a different typology that subsumed praxiological inquiry into scientific empirical inquiry. He accepted Walker's link of practice theory as praxiological theory and nominated "praxiological inquiry as the special province of nursing science" (p. 495). For him, praxiological knowledge was critical in the development of nursing as a practice discipline. He espoused a theory/practice nexus rather than a gap within a behavioural science paradigm. For Wooldridge, praxiological inquiry was crucial, an idea whose time had come, as it best explicated the practice of nursing. In his critique of Walker's rigid adherence to the canons of good theory, Wooldridge challenged the reign of scientism in nursing by asserting that "no completely valid tests of theory exist" (p. 495). It was a view that was gaining momentum in the human sciences (Gadamer, 1960/1975/1999, 1976a, 1981). No acceptance of the interlinking of practice theory as praxiology apparent in the nursing literature of the 1970s. What Walker named nursing theory and what I call the theoretical discourse in nursing, continued to gather momentum particularly in US nursing academia (Pearson, 1988; Thompson 1986). The terms praxiological and praxiology did not surface until again until 1988. However, practice theory continued to exercise the minds of nurse scholars (Beckstrand, 1978a, 1978b). This author argued that all practice theory could be reduced to "science, ethics and logic" (1978b). Therefore, for her, practice theories were redundant.

Seventeen years later Pearson (1988) drew on and expanded the work of Walker (1971) and Wooldridge (1971). This was a time when disillusionment with the primacy of the theoretical discourse was being voiced. A nursing academic and practitioner, Pearson believed in the importance of praxiological knowledge for the development of the discipline. He maintained that theorising about nursing is tantamount to thinking about nursing, something all nurses do. Pearson pointed to the confusion about the use of the term theory in nursing which had also been a central concern of Walker's (1971), and

constructed yet another framework of how different theories could be ordered. The lack of attention to local contextual theory i.e. praxiological theory, irked Pearson as did 'the gap' between theory and practice. To Pearson, nursing as an action-oriented practice, always embodies knowledge, and as such theory. In an expansion of his early paper Pearson (1992, p. 213), states that "nursing is simply a practice, but its practice is far from simple". Johnson and Ratner (1997, p. 16) echo this complexity of nursing saying that "it is a genus of many species".

Pearson (1988, 1992) reiterated Wooldridge's call that the time of praxiological knowledge development had come. However, Pearson talks of nursing as a practical science, but not in these words, while Wooldridge talks of nursing as an empirical science. The expansion of praxiological theory, which is evident to me in Pearson's writing, is associated with the emancipatory views of praxis of Carr and Kemmis (1986), on which he draws. Nevertheless, I see that Pearson kept to a broad promulgation of praxis rather than situate himself in the emancipatory paradigm. He favours practitioners developing their own local specific theories. This view was initially posed by Ellis (1969) and termed action theory. Moreover, Pearson favours a view of practice as a world of action and theoretical endeavour that opens up a postmodern vista of multiple horizons, which can be scanned by the nurse thinking about nursing. Pearson envisaged reflexivity and transformation in the contextual world of the nurse. In my understanding, Pearson supports multiple praxiologies. The grounding of praxiological inquiry in hermeneutics is included in his discussion; the choice of philosophical-theoretical perspective in which this inquiry is embedded.

Twenty six years after Wooldridge's (1971) comment that the time of praxis in nursing had come Thorne (1997) reflects the same sentiment in the first nursing book to be devoted to the subject of praxis, "Nursing Praxis- Knowledge and Action". There is no mention of Walker, Wooldridge or Pearson in her references. The linking together of practice theory and praxiological theory had not been maintained in the nursing literature. Two parallel paths had evolved to describe the practical discourse in nursing. Taking hold of the concept of praxis, Thorne believes, will open up dichotomies that have become

ingrained between practice, theory and research in nursing. In doing so, according to Thorne, more efficacious modes of reflective practice and inquiry, will arise. Thorne does not use the term 'praxiology', nor do Johnson and Ratner (1997), who wrote an overview on the evolution of nursing knowledge in which they quote Walker's (1971) article. However, Thorne talks of praxis theory wherein praxiological knowing emanates from within a dialectical relationship of theory, research and practice. Emancipatory praxis is one of the multiple ways of knowing explicated in the Thorne and Hayes (1997) book.

emancipatory praxis

In between Walker's (1971) and Wooldridge's (1971) discussion of praxiological inquiry and Pearson's (1988) expansion of it, praxis was entering nursing research and education via particular praxiologies from the practical discourse in philosophy. In the initial stages the major influence was from critical social theory. Interestingly, Habermas (1973) does use the term praxiology, but only incidentally. As a term it appears to have lost ground in the expansion of critical social theory. One factor could be Habermas' choice to transpose the term praxis for human action as is mentioned in the introduction to chapter five. In addition to critical social theory, or sometimes in association with it, is the increasing use of Freirian and Feminist theory, and to a lesser extent neo-Marxist theory as apriori in nursing research. It is research that has emancipatory intent. Emancipatory praxiologies are used to examine hegemonic practices within the health and education systems pointing to nursing views of reality and structural issues that hinder the development of nursing.

In the earlier 1980s, two nursing studies by university teachers, informed by critical social theory, were evolved almost simultaneously but separately in the US and New Zealand. These were the work of Thompson (1983) in the US and Perry (1985a, 1985b) in New Zealand. Thompson's thesis provides a critical nursing praxis in which she exhorts nurses to become reflexive in order to become more conscious of the ideological influences in their world. A theoretical framework drawn from Habermas is used to undertake a critical tracing of the development of the emancipatory discourse in philosophy and points to the increasing technical rationalistic governance of society.

Thompson favours recent frameworks like her own and that of sociologists Berger and Luckman (1967) as apriori theory for nursing praxis. Furthermore, Thompson cautions nurses about accepting normative beliefs arising out of nursing theories as empirical statements of fact. She recommends that all theoretical abstractions are for use in a reflective practice where they can be judged helpful or unhelpful within a particular context. Thompson's caution sits well with Gadamer's (1960/1975/1999, 1976a, 1981) stress on allowing the situation to call forth the knowledge most appropriate to make the judgements needed, the *phronesis* component of praxis.

Perry (1985a) also uses a theoretical framework constructed from the writings of Habermas but her focus is on the inductive process of first year graduates into the bureaucratic health system. She favours the term action and talked of the nexus of theory and practice. Like Thompson (1983), Perry draws attention to the technical controls embedded in the world of practice. Her focus is on the functional organisation of both education and health systems that hindered her participants' ability to practice nursing as the curriculum had prepared them to do i.e. to have a praxis approach where theory is embodied in their nursing action or to 'think nursing'. Perry (1985b) expands the concept of 'thinking nursing'. Her participants experienced paradoxes and contradictions from their preparation programmes and their goal in their first year was to fit into the system.

The research methodology of Perry (1985a) held within it a reflexive process in which the possibility of transformation and emancipation could occur. A beginning transforming process was evident in the stories of some participants, but not all. Perry asserts that the distorted separation of theory and practice, evident in the participant's stories, diminishes the growth of a professional culture which would hopefully bring together an ability to enact the practice of nursing as opposed to fulfilling the demand of a bureaucratic service. The investment of authority in positions within bureaucratic institutions was stressed as a factor which limited the embodiment of nursing knowledge in practice and its expansion through reflection on practice. The ongoing praxiological thrust of research participants in this study is not clear. The stronger potential lies with the researcher and how she develops her teaching, research and writing practices. Less

potential lies with the beginning nurses as they grapple with contradictory messages in a bureaucratic system where values about performance differ. Furthermore, with the advent of the contract driven environment in New Zealand there has been increasing emphasis on technical-rational management. A commitment to make opportunities available for New Zealand nurses to examine their nursing praxis saw Perry involved in the establishment of a refereed journal named 'Nursing Praxis in New Zealand'. Perry's (1985b) notion of 'thinking nursing' has also been further extended in dialogue with Jones (1993, 1997).

Some vigilance is recommended when locating practice, teaching or research interests in the emancipatory paradigm. In discussing the potential of post modern feminisms, Millar (1997), comments that proponents of emancipatory praxis can uncover an awareness of their own hegemonic practices. It is discovering what Lather (1991, p. 10) describes as a "complicity in what one critiques". Awareness and transformation in this area may well be the most fruitful outcome of the teaching or research. Furthermore, emancipatory praxis as described by Grundy (1987) reveals that it is the task of adherents of the emancipatory interest to promote the freedom of all groups to act in a way that allows control of their situation.

curriculum as praxis

A major use of emancipatory praxis by nurses is its contribution to nursing curricula transformation. Disenchantment with traditional curricula that affirmed the technical rationalistic bureaucratic values, rather than practice values, drove the search for curricula that would produce graduates capable of critically evaluating hegemonic influences in practice environments. This quest is apparent from the late 1980s in New Zealand, Australia and in the United States. The New Zealand-Australian model involving the ongoing praxiological thrust of Perry, as referred to above, and her Australian colleague, Moss (Perry & Moss, 1989), draw almost exclusively on critical social theory and Freirian pedagogy as their praxiology. In the United States, early protagonists of curriculum as praxis, Bevis and Watson (1989) built their praxiology of caring from Freirian pedagogy and feminist praxis. The latter writers assume nursing to

be a moral discipline concerned with realising the humanness of people. The Australian initiative concentrated on the transformative processes that enable students to critically evaluate the hegemonic influences likely to disempower their translation of knowledge into practice. Threads in the New Zealand-Australian expression of the ‘curriculum as praxis’ discourse appear to be closely linked to a robust dialogue among educationalists at Deakin University, Geelong, Australia (Carr & Kemmis, 1986; Grundy, 1987; Pearson, 1988). Pearson headed the nursing faculty at Deakin in the 1980s and with his faculty was part of the ferment generated in the dialogue with the educationalists (Moss, personal communication, 2000; Street, 1995). Perry and Moss assume that faculty members are enlightened and well placed to enact emancipatory curricula but Bent (1992) notes that the emphasis of change should be with the faculty rather than the students. The latter author believes that Freire’s (1983) ‘banking concept’ of teaching and learning where teachers provide knowledge and students accumulate knowledge is still prevalent in many nursing faculty staff. An implication of Bent’s argument is that too much time spent on changing curricula, without as much or more investment in changing faculty attitudes, is misguided.

Drawing directly on Grundy’s (1987) work, but by-passing the work of Perry and Moss (1989), Canadian educationalists in the discipline of nursing, Ford and Profetto-McGrath, (1994) explicate a model of critical thinking which they believe will enhance the effectiveness of ‘curriculum as praxis’. In my view, the ignoring of the nursing contribution, even if not seen to be helpful, undervalues nursing. Another Canadian writer on emancipatory curricula is Varcoe (1997). She asserts the necessity of moving the focus of empowerment to the client to enhance more collaborative relationships between clinicians, educators and students. As Varcoe states, the client in whatever form or context, is the *raison d’être* of all the efforts. Within the collaborative enterprise of all parties Varcoe, like Pearson (1988) and Rolfe (1993) want clinicians valued as clinical theorists. Furthermore, Varcoe cautions about the exposure of students to emancipatory praxis without the development of skills to challenge injustices and the lack of the modelling of moral comportment in educational and nursing practice. Without these

highly refined skills, not always seen in educationalists, she believes new graduates will succumb to survival in the dominant discourse.

Owen-Mills, (1995), a New Zealand nurse educator committed to ‘curriculum as praxis’ in her research and teaching practice describes the implementation of a curriculum synthesizing caring praxis within a critical social theory framework. An evaluative schedule is integrated into the curriculum implementation and early evidence from this evaluation gives hope for the achievement of the stated goals. Within this curriculum model is the call for educationalists to uncover any power relationships they might be involved in; an overt recognition of Millar’s (1997) caution. Another New Zealand view, not as optimistic as that of Owen-Mills, examines the curriculum revolution and the barriers to achieving it’s aims (Spence, 1994). She summarises these within the tensions of oppressive health service structures. Spence questions how changes in curricula can ever be fruitful if there are not concomitant changes in practice. Like Perry (1985a), she sees that the technical rational demands made by the education system and the health system hinder both educator and practitioner from achieving their potential. Spence records a catalogue of strategies that may help to overcome present barriers.

My investigation of the use of praxis in nursing has certainly highlighted that the emancipatory paradigm is the one most often cited in the literature in the last decade. I believe its strengths are the way it works the theory praxis nexus and the attention it pays to technico-rationality with nursing and the health and education systems. This discussion has expanded my understanding of why nurses like Holmes (1993), who worked with Pearson at Deakin University, claimed it as an exclusive praxiology. It is an irony that a praxiology with overt emancipatory intent should have become so dominant that it has limited the expression of other praxiologies. Nevertheless, I am aware that the emancipatory praxiology was not readily accepted in the early days of its appropriation into nursing (A. Dixon and C. Moss, 2000, personal communication). A strategy to support and expand the benefits of the emancipatory paradigm was implemented by the establishment of yearly conferences titled ‘International Critical and Feminist Perspectives in Nursing’ in the late 1980s by key United States nursing academics

(Seventh Annual International Critical and Feminist Perspectives in Nursing Conference, 1996).

While appropriating the emancipatory praxiology into nursing research may have taken considerable effort it is now time to foster the insertion of other praxiologies that will be useful in the development of nursing as a practical moral science. This research project makes a contribution to this endeavour in asserting, justifying and demonstrating that a hermeneutical praxiology is valuable in enhancing reflexivity and transformation in nursing.

hermeneutics as praxis

There is now evident in nursing, a debate that challenges the exclusivity of praxis within the emancipatory paradigm. From the philosophical lens, Gadamer (1960/1975/1999) and Bernstein (1983) opened up a space for viewing hermeneutics as praxis or the development of a hermeneutical praxiology. Lutz, Jones, and Kendall, (1997) exemplify my discomfort with the ownership claims to praxis by adherents of the emancipatory praxiology. Like myself, these authors argue that praxis, involving reflexivity and transformation is possible in the hermeneutical paradigm and is not always fulfilled in the emancipatory paradigm. Moreover, in using the writings of Benner to support their view, they claim both emancipatory and hermeneutical praxiologies make significant contributions to clinical practice. These authors also affirm my position on the origins of the exclusivity of emancipatory praxis emanating from the transcendental status given to the cognitive knowledge interests of Habermas (1972).

Furthermore, viewing praxis as the 'to and fro' movement of understanding in both emancipatory and hermeneutical praxiologies has potential to move praxis to an ontological status that is beyond the usual view of praxis as epistemology. As such there can be a moving on from a paradigmatic purity emanating from epistemological assumptions. Emphasis can be on their complementarity rather than their difference. At the same time ongoing critique should be fostered in order to expand and move towards a new horizon.

At the time emancipatory praxis with its research possibilities for understanding the practice culture was entering the discipline, Benner (1984), acknowledged by Pearson (1988) as developing praxiological knowledge, had begun a focus on the knowing in practice via the hermeneutical pathway. Benner situated herself in the phenomenological mode of inquiry influenced by Kierkegaard and Heidegger. Her original 1984 work and contemporary research interest (Benner, Tanner, & Chesla, 1996) is based on an ontological premise that theory and practice are embodied in the nurse as s/he responds to particular situations. Benner et al. are clear that expert nurses make clinical judgements via a responsiveness to the situation and what needs to be done rather than what a particular theory dictates. Simultaneously, these authors acknowledge the importance of theory and assert that a clinical dialogue with theory is necessary in the practice knowledge of experts. The research tool used by Benner in examining skill acquisition comes from her academic colleagues, Dreyfus and Dreyfus (1996) – one of whom is a philosopher and the other a mathematician. These colleagues are part of a community of inquirers working with Benner and other nurse researchers. Benner et al's 1996 work involves a critical perspective of the technical-rationalistic approach exemplified in the nursing world's preoccupation with the nursing process. However, I see that Benner's early work could be critiqued as involving much of that approach in her development of competencies and her acceptance of technical-rationalism within her competencies of organisational work roles. Competencies are constructs that fit with the bureaucracy's notion of 'good' rather than a practice notion of 'good' (Bishop & Scudder, 1991). Bishop and Scudder critique administrative systems, which they assert, are preoccupied with 'external goods' that hinder the achievement of the 'internal goods' of practice, the reason for which nurses exist.

Nevertheless, Benner and her colleagues (Benner, 1984, 1990, 1994; Benner & Wrubel, 1989; Benner, Janson-Bjerklie, Ferketich & Becker, (1994); Benner, Tanner & Chesla, 1996) have contributed enormously to the knowledge development in nursing practice. Their view of theory as an abstraction giving the practitioner knowledge about a wide range of possibilities that may present in any particular situation is consistent the work of

Gadamer (1960/1975/1999, 1981) and Bernstein (1983). It also supports Thompson's (1983) warning about the normalising potential of theory. The work of the community of inquirer where Benner appears to be a leader, promotes the nexus of theory and practice. It is a picture of phronesis where knowledge sits within the practitioner's personal way of being in the world and constitutes a way of responding, making judgements and acting from a positions of engagement and attunement to how a person/family is in their world. In drawing on the early work of Polanyi, Benner et al (1996) calls this personal knowing 'connoisseurship', an existential skill underpinned by a relational ethic of care.

Benner, Tanner and Chesla (1996) continue to expand their commitment to the development of practice based knowledge. In their recent interest in unbundling the practice of expert nurses, however, they have not expanded their contextual horizon beyond intensive care situations. They do not use the term praxis in their discussions on enacting the theory practice nexus. Possible reasons are that the book on Aristotle's Neomachean Ethics (Thomson, 1953) quoted in Benner et al's references, does not use the term. Or, similar to Habermas (1972, 1973), they may see that using praxis would align them with a view of praxis (the emancipatory paradigm) which would not be appropriate. In fact, the community of inquirers associated with Benner has been critiqued for not including emancipatory intent (Thompson, 1990). In response to Thompson, Benner (1990) argues, as I argue, that hermeneutics can include critique without being openly emancipatory in intent and at the same time censures the privileging of emancipation to within the critical paradigm. Too much emphasis on rational procedural approaches that depend on equality in the balance of power, Benner charges, overlooks the vulnerability of persons dependent on ongoing health care, particularly those with chronic illness. Benner and her associate inquirers have done a great deal in advancing the theory-practice nexus in order to overcome the 'gap' between theory and practice as discussed under the 'praxiology in nursing' section of this chapter.

the theory-practice nexus

Allmark (1995), Jones (1993, 1997), Rolfe (1993) and Street, (1990, 1991, 1995) mourn the theory practice gap and hold that theory and practice are intertwined and developed

reflexively. Allmark, Rolfe and Street are mindful of the influences of ‘scientific theory’ in our thinking about theory as in my discussion of the ‘canons of good theory’ in relation to Walker. They agree that this residue can send confusing messages to nurses about what constitutes theory and on the potential of theory to normalise practice. Street, a member of the Deakin circle and researcher of clinical nursing, is a strong critic of the nurse scholars and theorists who have allowed the theory practice gap a place in nursing. The idea that theory was developed primarily to give nursing curricula a congruent nursing focus is acknowledged by Street who is an educationalist, but not a nurse. She believes that the language of the theoretical frameworks taken on so readily in curriculum development is a ‘switch off’ for students. Curriculum as praxis sits more comfortably with her.

Allmark (1995), a strong advocate of phronesis, reminds readers of a central premise that all practice relies on understanding, not on theory per se. He believes that there are as many modes of understanding as there are ways of knowing. This emphasis is consistent with the view of practical reasoning as a component of praxis explicated by Gadamer (1960/1975/1999), Habermas (1973), Arendt (1958/1998) and Bernstein (1983) and is an important concept in this thesis. Allmark sums up the three major concerns present in the theory-practice gap debate. Firstly he asserts that practice, which fails to line up with theory, can be interpreted as theory that has failed to normalise practice. Another difference is that educators are seen to value theory more than clinicians. The third concern relates to the irrelevance of theory to practice or what might be described as the pursuit of theory for its own sake. Allmark, like Street (1995), sees that language and ivory tower status of academics can create disjunctions with practitioners. Street uses the metaphor of ‘high hard ground and messy swamps below’ to highlight the separation of nurse academics and educationalists from the complexities of practice. By continuing to allow this separation and the research mentality that arises from it, Street believes that nurse researchers will be part of a vicious circle in continuing to undertake more and more similar research projects in order to bridge the gap. Paradoxically, this is likely to increase ‘the gap’.

Street (1995) ‘walks her talk’ in working as a researcher in a clinical unit. She assists nurses to examine their work culture and relates examples of emancipatory praxis as outcomes of this exercise. Research questions come out of reflection and are questions clinicians have a vested interest in solving. Praxis research as a form of action research inquiry is the methodology used by Street. Her approach is a demonstration of Arendt’s (1958/1998) notion that we are conditioned by how we labour and work but it is action that enables us to condition the world we inhabit. The recent innovation of nurse researchers being attached to clinical areas has been developing in Australia in the last decade. It is a beginning phenomenon in New Zealand and also exists in other countries. In my view, this trend along with the appointment of nursing consultants who have a brief to undertake practice research, has real potential for an expansion and valuing of praxiological inquiry advocated by Pearson (1988).

The problem of the theory practice gap is seen to be located within the attitudes and technical–rationalistic culture of the practitioners who can choose liberation from oppression or maintain the status quo (Jones, 1997). Jones promotes the reflexive relationship of emancipatory praxis in bringing theory and practice together but does not appear to situate herself as both learner and teacher in this praxis as is the summons of Freire (1983). Jones fails to see that the same ideological critique that she applies to practitioners can also be applied to her own situation; that she may also be oppressed by the ‘false consciousness’ of the ivory tower world. I see that the assumption of right knowledge will keep educators and practitioners apart and is the very stuff that encourages the gap between theory and practice.

Rolfe (1993) proposes a circular model of nursing praxis commencing with theory generated from practice, enacted and reflected upon in practice and the generation of new action theory as the process expands. Within this view Rolfe proposes that all practitioners are theorists and action researchers. It is a role of “practitioner-as-researcher” (p. 176). Rafferty, Allcock and Lathlean (1996, 1997) take a different view to Rolfe and those who promote a closer nexus between the theory practice gap. Rafferty and associates propound that the assumption about perceived harmony between theory

and practice has not been productive. They propose that emphasis on a tension between theory and practice will keep clinical practice up to date. Further, they assert that there are no standards to judge what is legitimate knowledge and therefore find Rolfe's differentiation between informal and formal theory problematic. I believe that working a theory-practice nexus is more productive than maintaining a tension between them.

Another process oriented expression of praxis exists, which is closely associated with the promotion of working the theory-practice nexus for the reflexive development of nursing knowledge. It can be termed nursing as praxis. Nurses in practice are at the centre of this category.

nursing as praxis

Reflective practice, or the development of reflexivity in practice is central to nursing as praxis. Two books published in the 1990s, Gray and Pratt's (1991) 'Towards a discipline of nursing' and Palmer, Burns and Bulman's (1994) 'Reflective practice in nursing' both contain a focus on reflective practice, a significant notion in nursing over the last fifteen years. In addition, the ideas of Rolfe (1993, 1996) can also be termed nursing as praxis. Gray and Platt's examples are set within the development of nursing as a discipline in Australia while Palmer and co-writers primarily examine the experience of developing a practice oriented curriculum. Both books favour knowledge development in nursing emerging from what they call the practice-theory-practice model. They acknowledge faculty practice that models reflective practice as essential but problematic, and recognise reflective practitioners need for maturity and a commitment to advancing their practice. Palmer, Burns and Bulman's book draws extensively on the writings in Gray and Pratt's book as well as the work of Street (1990, 1991, 1995) who is a strong advocate of reflective practice. The majority of authors in both books acknowledge the seminal work of Schon (1983), which proposes that development of personal understanding and concomitant action emanate from reflection rather than emancipatory praxis. However, the Australian contributions in Gray and Pratt's book mainly positions reflective practice within the emancipatory paradigm.

Emden (1991a, 1991b), Gray and Forsstrom (1991) and Cox, Hickson, and Taylor (1991). present the Australian experience of reflective practice. Emden and Cox and Hickson and Taylor explore the development of reflective practice firmly embedded in the emancipatory paradigm. However, Gray and Forsstrom focus on the process required for the development of practice theory from faculty practice and draw on an Australian writer on reflection called Boud, rather than situating themselves in the emancipatory paradigm as fully as their colleagues. Fitzgerald (1994) talks of reflexivity as the goal of reflective practice and positions reflective practice in the emancipatory paradigm. In taking this stance she is mindful of the pitfalls that might befall students in pursuing emancipatory praxis; pitfalls also outlined by Varcoe (1997) (see page 111). In acknowledging the position of Schon, Fitzgerald poses a complementary relationship between understanding and emancipatory paradigms. In my view, Schon's model of reflective practice has a greater fit with GPH than with the emancipatory paradigm. Furthermore, Schon's notion of reflection in action has strong similarities to the notion of phronesis. As such, my position on praxis in this inquiry is closer to Schon's than to the emancipatory praxiology.

Holmes (1992), also a member of the Deakin circle, has made, in his PhD thesis, a unique contribution to nursing as praxis. He undertakes a discursive analysis of nursing ethics using a Habermasian framework. His thesis argues for transcending the present ethical discourse with a metatheory on ethics as praxis; a theory that is at the same time normative and ideal. In reaching this conclusion Holmes draws on the work of Yugoslavian praxis theorists, Stojanovic and Markovic, who extend Marxism. He proposes that their praxis theory, based on humanistic principles and therefore moral in its purpose, bridges the tension between personal and social praxis. Holmes takes their descriptor of humans as "beings of praxis" (p. 213) as an important component of his theory. Within this construct praxis, our action towards human fulfillment via personal and social transformation, is the most significant of all human conduct. In moving this construct into an ethics of critical praxis Holmes makes the nurse and her/his relationships with clients and organisations central.

In a process reminiscent of Gadamer's effective historical consciousness, Holmes (1992) charges the nurse with becoming increasingly 'self conscious'. Furthermore, the nurse is challenged to take up an emancipatory stance and work towards overcoming all the oppressive structures of the health care system. Holmes does recognise that the main problem in reaching this ideal is a mutual understanding of what is 'the common good' in our present post modern society where multiple views of the world are prevalent. However, he does not address any of the issues that were part of Varcoe's (1997) challenge, issued some years later, that it is not effective or moral to expose students or practitioners to emancipatory praxis without the development of skills to challenge the injustices they encounter. Moreover, in conceiving nursing as an art Holmes describes nursing as aesthetic praxis. Tantamount to Holmes' vision is the increasing practice of encouraging reflection and reflexivity amongst nurses. I would add that this is a realistic first step in achieving ethics as critical praxis.

Other Australian writers who were colleagues of Holmes as faculty members of Deakin University, Geelong campus, talk of too much emphasis on the theory component of praxis (the prattle) and not enough on the practical application (Penny & Warelow, 1999; Warelow, 1997). These authors describe nursing as praxis evolving in the reflexivity practitioners as personal knowing and personal practice/action theories similar to the beliefs of Rolfe (1993). Furthermore, these authors, looking through an emancipatory lens, stress that becoming aware of what shapes their knowing as in Gadamer's (1960/1975/1999) effective historical consciousness, will raise consciousness of practice. Warelow's 1997 paper talks of the strengths and weakness of the concept of nursing as praxis, which he terms discursive praxis. In focusing on different contributions from the emancipatory school of thought he exposes the technico-rationalistic discourse (the weakness) in nursing. He sees the main strength of discursive praxis and critical social theory as vehicles for changing our language and becoming more aware of our political influences and constraints, thus gaining a voice from within the reflexive process.

While emancipatory praxis draws on emancipatory theory another form of praxis in nursing draws on nursing theory.

praxis in nursing theory

caring as praxis

In the late 1980s, Watson, an important theorist on the moral imperative of caring in nursing, associated herself with praxis in the curriculum as praxis initiative. This has direct links with feminist praxis. Soon after Watson (1990) talks of praxis as a dimension in the advancing of the science of caring separate from epistemology, ontology and methodology. It appears as a 'add on' in the study of caring practice that did not fit well with her notion of research. However, in the evolution of her theory she views praxis as central in a caring healing science. Without "caring healing praxis" in what she calls ontological competencies there is only theory (Watson, 1999, p. 7). Moreover, Watson declares that caring without action will not have any meaning in postmodern nursing or beyond.

health as praxis

Newman (1990, 1994) an important theorist who I have already discussed in chapter two appropriated the construct of research as praxis and at the same time proposed that her theory could be termed health as praxis. She used the flexibility provided by process oriented theorising. Her process oriented ontological theory of 'Health as Expanding Consciousness' holds that the human living of health is manifest in the pattern of a person's existential life process. "Pattern simply *is* [sic]" (Newman, 1986, p. 31), is how she describes health as an inextricable component of our being in the world. A person's awareness of their pattern within a reflexive process becomes health as expanding consciousness. In her search for an epistemology consistent with the ontology of her theory she appropriated research as praxis from the emancipatory paradigm of Lather (1986, 1991). Her goal was to achieve a methodology capable of affirming the usefulness of her theory. Newman claimed that her theory provides an emancipatory vehicle within the world of nursing for articulating a nursing approach that can be both transformative for the nurse in practice and for the client nursed. As explained, there is a very fine line between what Newman and other nurse theorists do in testing their theories explanatory value for practice and the advocacy of normalising theory. It is a pitfall of theories

intended as contributions to the theoretical discourse in nursing and not conceived via praxiological inquiry.

I have found the explanatory power of Newman's theory (Newman, 1986, 1994) helpful in articulating my practice. Moreover, it was in the ambiguity and critique surrounding her appropriation of research as praxis from Lather (1986, 1990) that encouraged my questioning of the claim of the 'rightful' place praxis in the emancipatory paradigm. Newman does note the fit of her theory with phenomenology but did not see using her theory in an apriori position was compatible with it as a research methodology (Allen, Benner, & Diekelman, 1986). In the most recent update of her theory, Newman (1997) does not mention research as praxis or health as praxis. Instead she states

To satisfy questions about what method was being used, I settled for the descriptors of "her-meneutics [sic] dialectic". Hermeneutic to reflect the meaning and understanding and interpretation inherent in the researcher's embodiment of the theory; the dialectic because both the process and the content were dialectic. The process is the content. The content is the process. (p. 23).

The hermeneutics mentioned in this quote is not linked into any reference in her article even though there is an evolving hermeneutical discourse in nursing. There is, however, a reference to Guba and Lincoln (1989) in the 2nd edition of her book (Newman, 1994). Guba and Lincoln talk of hermeneutics in a general sense and do not link it to any philosophical perspective. I fear that Newman's preoccupation with her own theory has blinded her expanding consciousness of advancing understanding of research approaches in human science. Interestingly, Newman does refer to Walker (1971) in her 1994 book but does not comment on her notion of praxiological inquiry. The interest at work in Newman's discussion on research appears to be development of her own theory; what Street (1995) refers to as more of the 'high hard ground'. I see that her theory does have potential to emancipate practitioners from a technical-rationalistic model of practice, but it also has potential to affirm the theory practice gap because of its high level of abstraction.

The suggestion that the findings of research using her theory be poured back into the vessel of the theory and its values (Newman, 1994), I believe, subsumes the practical discourse into the theoretical discourse. In so doing, Newman privileges the theoretical. Theoretical abstractions can be helpful in everyday praxis as long as they are not allowed to normalise practice. My world of practice called forth much more from me, in terms of moral reasoning and clinical judgements, than broad abstractions could inform.

Litchfield (1993) enacted praxis oriented research in dialogue with Newman, to examine the process of health patterning in families of children experiencing repeated hospitalisation. In this research she expanded both the health as praxis process and the praxis as research idea. She became a researcher-practitioner and concluded that the informing capacity of the practice and the research came together as a complete praxis project. In relational practice, Litchfield highlighted that health for clients-participants is a co-construction of the researcher-practitioner interaction. From this, she concluded that nursing is the practice of health or expressed as health as praxis; health in this instance being Newman's theory of 'Health as Expanding Consciousness', the pattern of the life process. In her research, Litchfield used a dictionary definition of praxis, thus distancing herself from the praxis dialogue in the discipline. In discussing her evolving understanding of research as praxis (Litchfield, 1997, 1999) describes the purpose of her 1993 study as the articulation of practice informed by an exploration of Newman's theory and the evolving of methodological approaches for affirming its usefulness for nurse practitioners. I used the methodology designed by Litchfield in her 1993 project in my 1995 research and found it helpful in answering my research question.

The purpose of Litchfield's (1997, 1999) study was to further explore the praxis framework evolved in her first study. As in her 1993 study, a co-construction of health took place in the research dialogue and became what she called "health as dialectic" (1999, p. 70) which incorporated the multiple and expanding meaning given to health by the participants. Other descriptors of this process as the practice of health or health as praxis are also maintained. Furthermore, she points to the intertwining of research and

practice within a praxis approach when knowledge development underpins both endeavours. Within this weaving together of both endeavours, the reflexivity component, or practice wisdom emanating in the process becomes centre stage. Litchfield then moves to conceptualise the knowing of research practice in the construct ‘praxis as practice wisdom’.

Litchfield’s (1993, 1997, 1999) use of praxis as a broad interactive process in knowledge development, where the residue (new knowledge) of the process is the praxis outcome, enables her to theorise the process in multiple ways i.e. health as praxis, health as dialectic and praxis as practice wisdom. As an academic exercise in process oriented inquiry it is novel and interesting but possibly presents as a confusing jigsaw to a novice researcher. The interactive processes at the heart of Litchfield’s theorising, I believe, can be likened to Gadamer’s (1960/1975/1999) notion of the ‘in between’ of play or the ‘to and fro’ of hermeneutical understanding. In her 1997 dissertation Litchfield takes up the hermeneutic–dialectic turn present in Newman (1997). Like Newman, Litchfield does not reference her work to any particular hermeneutical perspective or to any accounts of phronesis in the philosophical or nursing literature. In her later work, Litchfield talks of a ‘turn’ to practice in the last decade as something new in nursing knowledge development. A strength of her work is the acknowledgement of the influence of Newman’s theory in her construction of a personal praxiology rather than inserting her findings back into Newman’s theory.

Cowling (2000 p. 18), drew on Newman’s definition of praxis as “thoughtful reflection and action that occurs in synchrony” and developed a praxis methodology for the purpose of healing through attention to the unitary pattern of the whole within a person–environment context of the human health experience - relational nursing practice. He calls his focus “healing as appreciating wholeness”. The practice he describes is a faculty project within which he positions himself as a scientist/practitioner. He asserts that as a healing praxis approach it “can be used for research or practice, or combined research and practice intentions...” (p. 19). His positioning is similar to that of Litchfield (1993, 1997, 1999) as researcher–practitioner but, in my view, he achieves a better balance

between the goals of practice and theory development, through a commitment to ongoing practice, than is apparent in her work. Litchfield appears to hold to research as a form of practice, in which theory development in nursing is the purpose of her praxis research endeavour. Cowling's appreciation of wholeness in clients, like Litchfield's attention to the story of the research participant, gives rise to action potential which can be noted in the way in which the participants get on with life.

conclusion

This chapter has discussed the presence of multiple expressions of praxis in the discipline of nursing. Links have been made with the praxiologies described in chapter five where these have been evident and between the different expressions of praxis in nursing. Evolution of praxiological inquiry within particular paradigms, similar to the evolution of the practical discourse in philosophy, is apparent. Walker's explication, within the technico-rationalist paradigm emphasized 'the gap' between theory and practice whereas all the other nurses quoted, except the nurse theorists, have inserted themselves in the practice discourse where a nexus rather than a gap is paramount.

The discussion on evolving praxiologies in nursing counters the claims to exclusivity of praxis within emancipatory theory. Habermas' (1972) concept of the three distinct human cognitive interests undergirding knowledge development as transcendental categories is evident in appropriations of emancipatory praxis into nursing. It appears to me that they are more or less distinctions. Emancipatory research, most often, is also interpretive research. Rather than continuing to separate the practical and emancipatory categories I believe it would be more fruitful to see them as different emphases for obtaining different goals. Bernstein (1983) believes we can shift beyond our differences by concentrating on similarities, and in seeking practical solutions within a dialogical community. I endorse this approach and proffer this inquiry, using Gadamer's hermeneutics (1960/1975/1999, 1975a, 1975b, 1981) as an example that brings together understanding and critique.

Resistance to the use of theories of nursing as normalising strategies, as inferred in the theoretical discourse of nursing, is apparent. In the practical discourse nursing theories

and other empirical knowledge is used to inform judgements that take account of the special circumstances of the situation. This is the phronesis component of praxis where the outcome emerges from the interaction of what is known and the particular encounter. In favouring the approach of the practical discourse I am also mindful that practitioners who are not expert nurses do have a need for theory that frames their practice but does not normalise it. If there are not models that assist nurses to 'think nursing' (Jones, 1997; Perry, 1985) it is very easy for a nurse to succumb to the dominance of the medical discourse.

Praxiological inquiry as a research methodology in nursing, in whatever form it takes and in whatever context it happens, has the potential, I believe, to provide major insights into the contribution of nursing to the health of individuals, communities and populations. It acknowledges an important shift in knowledge development from the praxis of nursing as opposed to the application of the 'canons of good theory' that has been the preoccupation of the theoretical discourse. In this study hermeneutics as praxis is used to investigate practice as praxis with a person experiencing strife in chronic illness.

interim summative statement on inquiry

Chapter six completes the first hermeneutical circle of the inquiry which has included extensive discussion. Therefore, I have chosen to summarise the material at this point. The first objective of my inquiry is to expand understanding of a particular practice situation; a situation that I have described as practice as praxis. In relation to this objective I positioned myself in nursing as a practical human science. The second objective relates to the first in that to explicate understanding of the unique practice context I chose to construct a praxiological methodology, which took account of the notion of praxis as practice within a distinctive context. To give the methodology structure, a consistent language and to expand my own philosophical assumptions about human being in the world I created a theoretical-philosophical framework from GPH to underpin the study. I argue its compatibility with my positioning in nursing as a practical human science and praxis as practice. Furthermore, the key concept of research as praxis, which is central to this study, can be expressed as 'hermeneutics as praxis'.

A consequence of setting the inquiry in a framework from GPH is that all of an inquiry becomes an ontological hermeneutical reflection. In accord with this I determined that three general premises of reflexivity, dialogue and moral comportment which emanate from the explicated framework, would be inherent in my explication of the historicist component of GPH. This component, effective historical consciousness emphasises understanding of traditions informing a methodology. The hermeneutical reflection thus far has identified the tradition within my personal and professional context, the New Zealand health policy context and chronic illness as a contemporary phenomenon which inform practice as praxis and the understanding of strife in chronic illness. The traditions within the evolution the practical discourse in philosophy and nursing dispel a quandary I had relating to claims about the exclusivity of praxis within the emancipatory paradigm. This expansion of research as praxis highlights the notion of praxiology as a body of assumptions and knowledge informing praxis and supports my claim to a hermeneutical praxiology as my ontological positioning of research as praxis.

Material from the research as praxis discussion will now be woven into the praxiological methodology which fulfills objective two. Chapter seven commences with the praxiology that I have constructed to inform the methodological premises. A full explication of the research processes enacted to gather the research material then follows.

Chapter seven

PRAXIOLOGICAL METHODOLOGY OF THE STUDY**introduction**

This chapter presents the methodology constructed to explicate an expanded understanding of the experience of strife in chronic illness of the person, Sarah, living with it and the nurses involved in her care. As the purpose of the design is to reveal understanding of a practice situation through the concept of research as praxis, the methodology is described as praxiological. The methodology is informed by a nursing praxiology configured from assumptions taken from my philosophical-theoretical framework and extended with ideas from other praxiologies and my beliefs about health-illness and nursing. My use of the framework, developed from GPH, as a medium for consistent structure, language and assumptions gives the methodology an ontological character. From this flows an ontological expression of research as praxis rather than the more common epistemological formulation.

My journey into the practical discourse in both philosophy and nursing enabled a clearer understanding of the evolution and diverse use of the concept of praxis in the contemporary world. It confirmed for me, that praxis is often used to talk about thinking and acting and the transforming inherent in this but seldom, except in the emancipatory paradigm, does it allude to the praxiology on which it is based. The exploration of the practical discourse is an example of Gadamer's concept of a fusion of my personal horizon with that of the knowledge in texts. This fusion opened up the notion of praxiology, the ideas or ideological position, values and beliefs that inform and govern how praxis is enacted. As Gadamer (1960/1975/1999, 1975a, 1975b, 1981)) indicates, understanding proceeds and governs human praxis and new understanding emerges from it. Understanding seen in this light according to Gadamer, is a moral endeavour as it determines how we are and how we act as human beings in the world. The seeking of understanding within this praxiological methodology uses Gadamer's notion of understanding and as such is a moral endeavour.

My new understanding regarding all praxis being in-formed by a particular praxiology has enabled me to see why the emancipatory paradigm is so often considered the only authentic basis of praxis. As I am not using emancipatory theory in this praxis oriented research it was important to configure my own praxiology based on hermeneutical reflection. My practical intention does not exclude emancipation, nor rule out any space for transformation to occur. I believe that emancipation and/or transformation can be an outcome of hermeneutical reflection. In construction of my praxiology and methodological premises for this research I have drawn ideas from emancipatory theory into my research as praxis position. Thus, I have situated the research in a space that unsettles the Habermasian (1972, 1973) knowledge interests in research with practical intent and that with emancipatory intent. In pursuance of an expanded understanding for myself I did hope for movement in my own praxis journey and in doing so to provide an opportunity for the co-participants to move on in their personal and/or professional praxis journeys. Moreover, by including the methodological premise of critique I surfaced what can be described as political hegemony within dominant discourses and in so doing have brought together personal and social praxis.

This chapter is divided into two major sections. A nursing praxiology and five methodological premises, which embody the assumptions of the praxiology, constitute the first section. I extend the general premises of reflexivity, dialogue and moral comportment into this praxiological methodology and add two more, re-presentation in narrative and critique. The second section actualises the premises in a full description of research processes carried out to gather and analyse the research material.

praxiology of the study

The praxiology of this research is eclectic. It is situated within the framework taken from GPH but also draws on other traditions. It is a praxiology in-forming a nursing inquiry configured for the purpose of researching a particular nursing practice situation. Therefore, it also takes account of the view of the world that underpins my ideas, values and beliefs about health-illness and nursing practice as the lead investigator. The following is an explication of my praxiology.

People are existential beings who live day to day in their worlds. Furthermore, people exist as embodied beings always in a process of becoming (Gadamer, 1960/1975/1999, 1981). There is no compartmentalisation of mind body or spirit as they unfold from day to day in a unitary way. The process of human becoming means that people are unidirectional beings always moving toward the future and never returning to any previous stable state. According to Gadamer, human reality and meaning proceed from how people understand their world as self interpreting beings. This reality and meaning is enfolded within people's experience of their unfolding within particular cultural traditions; their effective historical consciousness. People's horizons are expanded with new understanding and new experience. Each experience is a new experience, enfolding all past experience, or all earlier webs of relationships (Connor 1995, Arendt, 1958/1998). As Gadamer and Arendt state, the world and cultural traditions we live in shape us but we also shape them via our day to day praxis. Moreover, these latter authors emphasize that people and the cultures they are embedded in, are evident in the language used and how we speak. Choice points exist in people's lives which lead to conscious praxis (Sartre, 1968) that can, as proposed by Arendt, take people beyond their earlier shaping and open up new possibilities for themselves and others in the world. New possibilities bring with them more choice points.

Engagement in a reflexive process about what has shaped individuals and groups is the process of personal and social praxis. Identification of both enabling and blinding prejudices within particular traditions is the hoped for outcome of the reflexive process leading to greater authenticity in understanding (Gadamer, 1960/1975/1999). When people enter into a personal or group praxis they bring about change or transformation in their world. Thinking and acting well is phronesis or practical moral decision making (Bernstein, 1983; Eterovich, 1980; Gadamer, 1960/1975/1999, 1981; Lobkowitz, 1967). Phronesis embraces uncertainty and unpredictability (Arendt, 1968/1998). It is about achieving personal 'good' and 'the common good' and, as described by Arendt, Gadamer, and Habermas (1972, 1973), it is a moral imperative.

However, an individual's persona and the world that shapes it incorporates constraints that can inhibit personal and social praxis. These can be constraints that prevent the person from achieving the full expression of humanness (Bernstein, 1983; Campbell & Bunting, 1999; Habermas, 1972, 1973); constraints that are not acknowledged by Sartre (1968) and only indirectly by Gadamer (1960/1975/1999, 1981). Furthermore, in the light of what Bernstein describes as the type of communities needed to support praxis, I am mindful of the idealism of such a view of the world when many of the world's population will not experience such support. On the other hand, for some, the lure of individualistic or hedonistic pursuits, or what Gadamer calls blind prejudices, detract from the reciprocity involved in achieving both the personal and the common good.

Newman, Sime, and Corcoran-Perry (1991 p. 3) assert that "nursing is caring in the human health experience". I find this overview phase helpful for capturing the essence of nursing. The health-illness experience, as I prefer to call it, is an intricate part of embodied wholeness, not fragments of invading diseases. Change in one part of the body is change in the whole person when people are viewed as unitary holistic beings unfolding in their world. Health-illness manifestations or patterns are part of people's wholeness and are shaped by the traditions in which they live and interact with their environment. Internal rhythms, energy and relationships interconnect with external rhythms, energy and relationships and in this way people are connected with all phenomena of the cosmos. This view of health-illness is the residue of the many tenets of Newman's theory of health (Newman, 1986, 1994) which underpinned my earlier research (Connor, 1995), and which I still accept.

The ontological term 'well being' is often used to describe a personal sense of being in the world, which encompasses a full range of health-illness circumstances. It captures a sense of unitary wholeness in which people are getting on with their lives in the day to day world either living with or without an illness, and is a useful descriptor of health-illness. However, for someone living with a chronic illness it can belie the turmoil of the ontological assault (Pellegrino & Thomasma, 1981) or disruption of a person's being in the world that is often the experience of serious chronic illness at some stage of its

trajectory. Such an assault or disruption is experienced as de-moralisation or de-humanisation diminishing well being. It is the experience of ill-being but not often referred to in this way. The term health circumstances, developed by Litchfield, Connor, Eathorne, Laws, McCombie and Smith (1994), acknowledges the presence of a particular medical condition but sees its manifestation in relation to all the dynamic relationships within the life process. A wide angled caring lens in nursing practice is needed to take account of the breath of the dynamic relationships manifested within what I now prefer to describe as health-illness circumstances.

Constructing a relational ethic of care within a web of relationship (Connor, 1995) provides a medium for caring for the existential being of people. It is the building up of a relationship where listening, trust and reciprocity are core features. Watson (1999 p. 290), calls this “caring healing praxis”. It is a relational ontology that aims to provide a growth opportunity in terms of quality of life for the person-family experiencing health-illness and an expansion of professional- personal understanding for the nurse. Manifestations of health-illness have commonalties and differences in individual people, families and communities; however the experience of these manifestation is always unique and subjective. Therefore phronesis as a process of coming to understand and judge a unique situation, within an I-Thou dialogue, is critical.

The expression of this praxiology is an integrated summary of several of the ideas expounded in the background chapters of the methodology. Assumptions from it will now be translated in the methodological premises I have chosen to support the processes designed to gather the research material. I will now discuss the premises.

methodological premises

Five key premises inform the research process. Each one has the supplementary phase of ‘as praxis’ added to indicate its process and action orientation. The five premises are reflexivity as praxis, dialogue as praxis, moral comportment as praxis, re-presentation in narrative as praxis and critique as praxis. Like the articulation of the praxiology, each premise begins with its explication in Gadamer’s work (1960/1975/1999, 1975a, 1975b,

1981) and is then extended with ideas from other praxiologies. The first three premises, reflexivity, dialogue and moral comportment are inextricably intertwined and are present within the last two, re-presentation in narrative and critique. In the following explication of the premises the implications for human participants will be accentuated.

reflexivity as praxis

Reflexivity is most overt in the concept of effective historical consciousness (Gadamer, 1960/1975/1999) which is a summons to become questioning persons who expand self knowledge or self consciousness. It is the self knowledge that comes from examining the social and cultural context or what Lather (1991) calls the discourses that shape our view of the world. Similarly, reflexivity is the medium of mutual and active listening leading to expanding our horizon about our own place, and that of others, in the world.

The stress on reflexivity as a component of praxis directed towards future change in action, from new understanding, has been evident since the time of Marx's praxiology. It is central in critical theory, Freire's pedagogy, feminist research, hermeneutics in nursing (Benner, 1990) and in health as praxis (Litchfield, 1993, 1997, 1999; Newman, 1994). As Street (1995 p. xiii) states, "the process of engaging in practices informed by reflection is *praxis* [sic]".

The process of reflexivity in this inquiry began with my stepping into a hermeneutic circle at the outset of the research and is manifest in particular processes of the methodology. In line with the whole research involving hermeneutical reflection Koch and Harrington (1998), argue that reflexivity when sign posted throughout a project can become an important audit trail indicating the rigour of the inquiry.

Lather (1991) acknowledges the layers of reflexivity taking place in the research relationship where they operate in particular ways for the lead researcher and the co-participants. She discusses the possibility of critical theory or other imposed theory developing its own vested interests and ideology without rigorous self reflexivity of the lead researcher, which will enable an open mindedness in how data is analysed. This is

tantamount to Gadamer's (1960/1975/1999) summons to remain open to the happening of understanding and follow where it leads. It is also an alert to the shaping of understanding in this inquiry by GPH. Simultaneously, Lather appreciates that a never ending self critique can be paralysing. A reflexive mode of being of all research co-participants is present throughout the unfolding methodological journey of seeking understanding and meaning in relation to the research question. Reflexivity pervades several layers or cycles of the research dialogue.

dialogue as praxis

Dialogue is a central premise in GPH (Gadamer, 1960/1975/1999, 1976a, 1981). It is the conversational and questioning medium in which the happening or event of understanding occurs. As an event it is participatory, involving the engagement of participants in co-constructing the dialogue, but is more than general participation in that it acquires a life of its own that calls forth participation in its own unfolding. The dialogue of this methodology is enacted in multiple ways. It involves self dialogue calling forth a critical reflection of my social, cultural and professional positioning, most overt in my journalling; an ongoing conversation with co-participants to gather the research material then co-construct narratives; and a continuous dialogue with texts to enlighten the self dialogue and the research objectives.

The purpose of the different forms of dialogue is the expansion and fusion of horizons that can occur within a reflexive posture. The dialogues are governed by the research objectives but commence with a series of questions according to the particular stage of the research being addressed. Questioning continues as answers emerge and more questions arise. In this process, co-participants need to remain open to where the dialogue will take them. A consequence of following this type of dialogue, together with the inherent unpredictability of the research co-participants circumstances, is that the methodology must remain open to change and emerge or be consolidated as the research progresses. As such it requires the co-participants to live with unpredictability until each step is accomplished.

Dialogue is manifest in language (Gadamer, 1960/1975/1999). Gadamer's discussion of language has some commonalities with Lather (1991) who also stresses the importance of language in praxis oriented research. Both agree that language speaks the being of the speaker. They also concur that people are shaped by and can shape their traditions and therefore their positioning in the world is always contingent. Lather extends Gadamer's view in her explication of the multiple positions often illustrated in a person's language, which can be interpreted as conflicting discourses. She contends that we represent ourselves in ambiguous and contextually contingent stances. Therefore, for this reason, it is likely that ambiguity will appear in the transcripts of our dialogical meetings. It would be inappropriate for me as the main constructor of the narratives to edit these ambiguities out in order to demonstrate a consistent point of view.

The movement possible in a reflexive dialogue (Gadamer 1960/1975/1999, 1976a, 1976b; Lather 1991) when it entails the telling of one's story about illness, provides an opportunity for healing (Vezeau, 1993). The meaning made in the act of reflection allows a more coherent new view of possibilities to emerge. Any retrospective articulation of the meaning associated with a particular illness is a new understanding of that situation; an expanded horizon with greater potential for new choices and actions. Furthermore, the context of the articulation will shape how the articulation is formed (Bowers and Moore, 1997). These authors discuss the construct of dialogical consciousness as conceived by the Russian philosopher, Bakhtin, and make direct applications of its value to nursing. They reinforce the potential of dialogue for the co-creation of meaning, meaning that emerges in interaction within a complexity of circumstances. An expanded understanding of Sarah's is present in the narrative.

Freire (1970/1983) uses dialogue as the medium of his pedagogy. His emphasis is on the listening stance within the reciprocity of the 'to and fro' of understanding. In genuine dialogue, as with Gadamer, Friere expects a commitment from all participants in the dialogue to be open to hearing the perspective that each brings and to move forward in understanding from that listening. Bernstein (1983) stresses the solidarity of communal dialogue where plurality is acknowledged and acts as a beginning point of the discussion

but is not allowed to predominate over an ethos of working towards a common goal. Freire and Bernstein remind me that active listening and allowing different perspectives to emerge are critical aspects of this research dialogue.

A reflexive dialogue in research, which maintains openness to following where the conversation leads, has considerable ongoing moral implications. Because of this and the need to provide a safe environment for all co-participants I consider moral comportment to be a significant methodological premise.

moral comportment as praxis

The ethical implications for human participants require the construction of a research design. However, in Gadamerian hermeneutical inquiry where the researcher is charged with following where the dialogue leads it does mean that a proposed design is subject to change. All participants must be consulted about and agree to any changes.

Gadamer's emphasis on hermeneutics as a moral science treating the text as 'thou' within an engaged relationship alerts researchers to the ethical responsibilities of attending to the vulnerability and human dignity of the co-participants, of honouring the 'thou' in the engagement. It calls forth a moral comportment that parallels the ethical comportment, which Benner, Tanner, and Chesla (1996) propose to be in clinical expertise. These authors describe ethical comportment as an inherent way of conducting oneself; a responsiveness to the 'good' of clients. Moral comportment as praxis requires paying attention to protection from possible destructive consequences that might occur through an ongoing reflexive posture within the unfolding dialogue. The gaze of moral comportment then, also includes what Gadamer (1960/1975/1999) calls a tactful stance for attending to cues which may indicate intrusiveness or presumptuousness that could destroy co-participants confidence in revealing them-selves. Gadamer in talking about commonsense as part of the humanist tradition sums up tact in the following way:

By tact we understand a particular sensitivity and sensitiveness to situations and how to behave in them, for which knowledge from general principles does not

suffice. Hence an essential part of tact is that it is tacit and unformulable inexplicitness and inexpressibility. One can say something tactfully but that will always mean that one will pass over something tactfully and leave it unsaid, and it is tactless to express what one can only pass over. But to pass over something does not mean to avert one's gaze from it, but to keep an eye on it in such a way that rather than knock into it, one slips by it. Thus tact helps one to preserve distance, it avoids the offensive, the intrusive, the violation of the intimate sphere of the person.

(Gadamer, 1960/1975/1999, p. 16)

Timing and tact are of the essence when sensitive issues are being explored. Moral comportment is a way of being in the research that precipitates both a revealing and a concealing. If the dialogue becomes too intrusive, aggressive or intense a person's soul or inner self is likely to remain hidden (O'Donohue, 1997). Moreover Arendt (1958/1998) cautions, that when people reveal who they are in the telling of their stories, a potential for alienation exists. Authentic dialogue as the medium of understanding that expands the horizon of each participant is advanced in attending to the everyday 'good' of the co-participants. As such, it creates a space for a transformative process for all participants.

Arendt's (1958/1998) praxiology provides some important ethical principles that informed the moral comportment of my praxiological methodology. Her notion of 'webs of relationships' is clearly a relational ontology, a view often expressed in feminist thinking (Campbell & Bunting, 1999), and links well with my own 'web of relationship' (Connor, 1995). Praxis, for Arendt, is the inter-personal action of people with each other involving plurality of opinion and preference. This view conforms well with my research process as the co-participants brought their particular opinions and preferences into the research dialogue. Arendt stresses that many unintended consequences of praxis cannot be known at the time but will unfold in the future. Arendt's emphasis on seeking forgiveness for unanticipated consequences provides a counter to their effects. It will not undo the effects but will set new possibilities in motion. She also advises that contractual agreement be set up to provide a thinking through of likely consequences. The informed consent procedure undertaken at the commencement of the study is an example of

Arendt's contractual obligations. However, the gaze of moral comportment is as necessary throughout the research as it is at the commencement of any project.

Moral comportment as a way of conducting myself throughout the research is also inherent in the way I initiated the co-constructions of the research narratives. Re-presentation of the dialogue into a narrative form required close attention as its construction had potential to increase the vulnerability of participants.

re-presentation in narrative as praxis

The material of the dialogue in this research is re-presented in narrative form. My praxiology does not include anything specific about narrative formation. However, Gadamer does infer that the understanding that comes from a reflexive dialogue, where people have been listening to one another, is in fact a story (Gadamer's foreword in Grondin, 1994). In addition, Koch (1996), points to Gadamer's conception of the interpretation of text as an indication that narrative forms of dialogue as texts are valid research strategies in hermeneutical inquiry. Re-presentation in narrative is useful for demonstrating personal experience and the meaning associated with it (Riessman, 1993).

A narrative is not about predictable or causal events but enables an impression of a "patterned totality" (Polkinghorne, 1988, p. 116); a holistic understanding of a unique person and/or in a unitary way (Vezeau, 1993). I constructed the narratives of this inquiry in such a way as to illuminate the participants' experiences as an exploration of the research topic. In so doing re-presentation in the narrative functions as a story that illustrates rather than one that provides a particular point of view consistent with a research question (Lather, 1991). It captures the plurality of the participant's positions. According to Vezeau, narrative truth emanates from the personal knowing of the participants. It is a particular knowing which can then be backgrounded by a more general knowing. Background knowing of the context is incorporated in the final integrated narrative of this methodology. However the background knowing from the literature is not included because I chose to have the particular knowing speak directly to readers. The latter is provided in the critique phase of the methodology.

Opie (1992) and Lather (1991) argue for the incorporation of voice as integral to a narrative text as it can be empowering for the participants across several planes. These narratives retain considerable components of direct quotations from research participants in line with the position of these authors. Giving voice to all participants is also consistent with the co-construction of a narrative and is said to enhance meaning and transformation in participants. In the narratives of this research there is no silencing of any voices.

Narratives in nursing practice can be personal, general or relational (Gadow, 1996). Gadow favours the relational narrative with uncertainty at its core but encompassing “the particularity and vulnerability inherent in clinical situations” (p. 9). For her, a relational narrative is a story that is co-created by nurse and client together. It combines views while at the same time transcends the individuals involved but not their relationship. Thus, it provides an ethical context but is not a solution to ethical dilemmas. I have adapted Gadow’s relational narrative into research as praxis in this methodology.

Three main narratives are constructed within a reflective dialogue with participants in this methodology, one of the client experience, one of the nurses’ experience and finally an integrated narrative is composed from the first two. Chapter eight renders a full account of the integrated narrative. It is the longest chapter of this report as I have deemed it important to keep this material as a unitary whole. The process of forming the narratives from my dialogue with the research material was another layer of the reflexive process as it offered multiple opportunities for reflection.

Re-presentation in narrative created a nexus of Sarah’s and the nurses’ experience. It offered an opportunity for “a profound weaving of human context and human responses that is a solid base for knowledge development in human care nursing” (Vezeau 1993 p. 212). It was in this layer of reflexivity that my critique of the material began.

critique as praxis

Another focussed cycle of reflexivity, dialogue and moral comportment began after the co-construction and reflection on the integrated narrative. It was a continuation of the question and answer dialectic of GPH involving an examination of the effective historical consciousness within the narrative through a dialogue with the literature. The study of narratives of practice, in all their contextual complexity, is important when locating nursing as a practical human science (Bishop & Scudder, 1991; Bowers & Moore 1997). Both Benner, Tanner and Chesla (1996) and Bishop and Scudder contend that the personal and moral knowing of practice becomes evident in narratives where covert meanings of the human experience can be explored. Bowers and Moore highlight the recognition of participants as subjects, not objects in narratives; a feature that requires the researcher to engage as a subject rather than an objective observer as in my framework underpinning the methodology. The I-Thou concept fosters the mutual regard necessary for moral comportment in this study. Furthermore, Bowers and Moore support Bakhtin's ethical dialogical narrative as a methodological mode entailing ongoing interaction between and among meanings, which are simultaneously effecting each other.

As mentioned, both Gadamer (1960/1975/1999) and Lather (1991) agree that the relational structure of language is identifiable as discourses. Riessman (1993) confirms these beliefs in her observation that narratives contain many discourses and evidence of power relations. Lather proposes that the ambiguity of people's multiple positions are illustrated in conflicting discourses. Therefore, a discursive framework was constructed for critiquing the narrative. Discourse illumination in this methodology is a continuation of hermeneutical praxiological process of the dialectic of question and answer.

The five methodological premises have been discussed as separate entities but I have endeavoured to demonstrate their overlapping nature. They are a manifestation of the assumptions of my praxiology and form the theoretical structure of the research process. Their translation into the research process is now presented.

the research process

This inquiry began with a tentative proposal. As I worked through the complexity of formal retrospective exploration of a practice situation in which I was involved the distinctiveness of my intended inquiry emerged. It was a distinctiveness that needed careful thought and management of methodological strategies designed to explicate the understanding that was the objective of the inquiry.

The exploration covered a three year period beginning in December 1996 and finishing in November 1999. However, the initial proposal was designed to examine material from the first two years only. As Sarah required ongoing nursing care in the year in which the retrospective reflections on the initial two year period took place, 1999, I decided, with the approval of Sarah and other authorities, to include reflection on the experience of that further year, turning the research time period into three years. This addition increases the complexity of reading about the steps in the research process which is why I have summarised these steps into a timeline in Figure 2. The time line commences in December 1996 when I first commenced nursing Sarah. It then moves to highlight the various steps and times in the development of the research process. As is indicated in the timeline the idea of researching the practice episode began in the second year of our engagement and the actual meetings commenced in the third year of our engagement. This outline is then extended in the following discussion. Firstly I will specify the distinctiveness of the research and the procedure of obtaining ethical approval from my local health ethics committee. I then move to a description of the multiple research strategies involved in the process of obtaining and generating meaning within the research material. The multiple strategies were lead researcher journalling, dialogical meetings, summarising the nursing documentation, constructing the narrative, and critiquing or looking behind the narrative.

distinctive features in my vision for the inquiry

In 1998 I began to think about researching the specific practice situation in this inquiry in order to expand the knowledge on strife on chronic illness. Possible research options to achieve my goal were included in my considerations. During this time I made tentative

Figure 2. Timeline of research process

<u>Year and month</u>	<u>Activities</u>	<u>Meeting content</u>	<u>Journalling</u>
1996 November	Sarah is discharged from hospital. Prolonged engagement in the community commenced. Mary and I involved.		Experience is part of the journalling of overall practice. ↓
1997 March	Rose becomes involved.		
1998 April	Proposal for research constructed and refined.		Journalling of practice with Sarah became more specific, included preparatory phase of research
↓			
December	Approval to commence research granted		
1999 February	Dialogical meeting with Sarah commenced.	Meetings 1-3 Sarah recalled her experience.	Nursing care of Sarah continued.
	Summary of nursing record developed.	Meetings 4-5 reflected on nursing record	Research journal commenced.
April	Construction of preliminary narrative of Sarah's experience.	summaries.	
June/July		Meetings 6-7 reflected on preliminary narrative.	
August	Dialogical meetings With Mary and Rose commenced.	Meeting 1-general recall of experience. Meetings 2-3 informed by summary of record. Meeting 4 informed by Sarah's preliminary narrative.	↓
November			
November	Approval for 1 year extension of research granted.		↓
November/December	Three meetings with Sarah. Summary of 1999	Meeting 1-2 reflect 1999 experience. Meeting 3 informed by	

<u>Year and month cont...</u>	<u>Activities cont...</u>	<u>Meeting content cont...</u>	<u>Jounalling cont...</u>
	nursing record.	record summary.	
	Meeting with Kim, new nurse in Sarah's care.	Meeting informed by summary record.	
2000 January/April	Construction of two separate narratives. Sarah's preliminary extended and refined. First full draft of nurses' narrative.		↓
April/May	Narratives returned to Sarah and nurses respectively.	Meeting with Sarah to reflect on narrative. Separate meetings with each nurse co-participant to focus reflection on separate contributions. Meeting of all nurse co-participants- reflected on the whole of the nurses' narrative	↓
July			
July/August	Integration of two narratives and returned to Sarah and nurses		↓
August/ September	Organisation of meeting to include Sarah and nurses	Reflection on integrated narrative. Closure of meetings	↓

approaches to Sarah and the nurse co-participants, Mary and Rose, to establish their willingness to join me in a reflexive exercise about the experience. The outcome of these first tentative steps was positive. Nevertheless, I had been clear that my discussions were provisional and in no way committed them to what might eventually gain approval by my academic supervisor and the local ethics committee.

Consideration and planning continued and the inquiry developed into its present form. The methodology differs from the way that research often commences where a topic is selected and a target group, which usually has some flexibility in how it is put together, is then sought to assist the researcher to answer the research question. Only those involved in the situation could assist me in uncovering a deeper level of meaning of the prolonged engagement of Sarah and the nurses. Thus, in a sense, the research process began before any formal procedure was in place.

Although this praxiological inquiry has some of the usual characteristics of participatory inquiry as described by Reason (1994), it is different in that I, as lead investigator, decided the research topic and invited others to assist in exploring it. Most participatory inquiry invites a group interested in a particular topic to come together and the research question is decided after deliberation within the group. I was aware that the client's condition could change and prevent her from participation and that the nurses could move away from the area or their own more pressing concerns could take priority, inhibiting the sharing of their story. Taking this risk into account I decided to proceed in the belief that the potential understanding and knowledge development that could accrue in terms of my own praxis journey and as a contribution to the discipline was worthy of pursuit. In the event of one or both of the above stated risks crystallising I would re-appraise how I might proceed depending on the effects of the change at the time of its occurrence. It seemed that the worse that could happen was a complete impasse and a return to writing a new and different proposal for my academic qualification.

Double insider status

Another major issue was my location within the inquiry. I would be the lead investigator but also a practising nurse with the client and a colleague to the nurses who I was inviting to participate. My position would be that of a double insider researcher; an insider from the perspective of being a nurse investigating a topic of interest with other nurses but also an insider as a nurse who had been involved in the complex situation that was under investigation. I believed that the participation in this type of reflexivity could be helpful as is discussed under the premise of dialogue as praxis. However, a risk existed in

relation to the possibility of an episode surfacing in the research dialogue which might trigger a crisis; an exigency that I would not be able to deal with; an event that might aggravate Sarah's chronic illness. I needed to acknowledge this unpredictability without making it sound so ominous that it outweighed any of the unpredictable benefits.

Risks were also involved for the nurse participants. I came to the research employed in the same service as the nurse participants. One participant was of similar rank in the service to me but the other was a colleague who could perceive me as her superior, even though I did not have any managerial responsibilities for her performance. She could have perceived that she should participate. Furthermore, there was the intention that my nursing practice would be under investigation alongside that of other nurses. Moral comportment as praxis was being called forth in this pre-formal phase. I was keen to undertake the inquiry but did not want to exert any pressure on my limited circle of participants to cooperate. It was to be a time for reflection where all contributions would be honoured in assisting our expanding understanding of what was a complex situation with many nuances.

Participants would be able to exit the research at any time without having to justify leaving. My trust in the human agency of the participants in the choices they would make about joining the research and what they would choose to reveal about their experience was critical. The Health Ethics Committee who approved the study also needed to know that the risks would be managed safely.

The dual insider status remained a tension that I needed to manage throughout the research. The strength of this position lay in my familiarity with the situation and thus the ability to gently probe into areas that may not have surface otherwise. However, there were two main negatives. The first was what I call the 'pleasing me' effect where participants may want to talk of the good aspects and conceal the negative. I did make it explicit that I wanted to hear all sides of their experience and listened for cues that could probe further for any negatives. In addition, I endeavoured to promote an environment where all aspects of the experience could unfold. The second issue of insider status is my

challenge to make overt my values and beliefs so the reader can see the connection and influence of these within the research. These are explicit in my praxiology.

dialoguing with the health ethics committee

Ethical approval for this study came from the local health ethics committee and was submitted afterwards to the university ethics committee for noting. I knew the identified issues would be a challenge in terms of gaining approval. Before submitting my proposal for the initial two year period, I set up an appointment with chairperson to talk about the ethical implications of the research distinctiveness. She was supportive of the study. The proposal was duly considered by the committee and then returned to me for more consideration of how I would ensure the safety of the client co-participant and myself. In dialogue with my supervisor additional strategies for this purpose were drawn up and submitted to the committee (see appendix one). The additional strategies are incorporated in the following considerations.

managing the nexus of practice as praxis and research as praxis

As Sarah and I were in a practice relationship she could have felt pressured to participate; either to assist me achieve my research goal, when in fact she was not interested in participation, or out of gratefulness for the assistance I had given her. Or, she could have considered her care to be threatened even though she had been given assurances regarding ongoing care. However, these assurances did not take into account that I had been a significant person in her care in the two year period I wanted to investigate. This professional relationship had been what came to be called in the research meetings ‘an intense relationship’ but had reduced in intensity at the completion of the two year period. Moreover, it was possible that Sarah would not need a nurse if she continued to move out of her strife. These considerations were explored as I entered into the formal explanation process prior to her giving written consent. The name of an independent group of advocates was given to her for the talking through of any issues she may have had as well as the name of my academic supervisor and a contact number of the local Health Ethics Committee.

During the formal information session, Sarah, with Ethics Committee approval, was given the choice of an ongoing practice relationship with me if she still required nursing input at the commencement of the study. Another nurse would have been asked to be available if she preferred this option. If health improvements continued and a consequent discharge to independence from the nursing service occurred, her vulnerability would be decreased. If, however, she was readmitted the former would apply. My position was also subject to possible change or dis-establishment as the service was once again restructuring as a consequence of the New Zealand health reform as discussed in chapter four. Sarah chose to have my ongoing practice involvement but this was complicated by Sarah's relocation to another area. This, together with service restructuring from the ongoing health reform at the time of her move, meant that I no longer visited her new location. However, because of other health reform upheaval in the nursing service in the new area I stayed in contact until the new nurse, Kim, was oriented to her care.

informed consent

Issues of consent and confidentiality were addressed as per information sheets and consent forms and the correspondence with the Health Ethics Committee in appendix one. Furthermore, a running consent form was given ethical approval. This is a space on the initial consent form that allows for participants to give written consent to more minor changes as the research process unfolds. These are changes that had not been discussed in the 'information sheet' but did not require ongoing dialogue with the Health Ethics Committee. I was asked to return to the committee if major changes were envisaged which did happen with the addition of the extra year. I will return to this issue later.

clinical supervision for research project

The ethics committee challenged me to consider my own vulnerability in this research journey. Until that time I had tended to believe that I was an experienced nurse and becoming an experienced researcher in co-participatory research. My issues had been more about being controlling than about being challenged or hoodwinked by the co-participants. I did feel that I had known and worked with the prospective co-participants for two years and believed any deception was highly unlikely. Nevertheless, once I

considered this as a possibility I volunteered to enter into what I termed clinical supervision, to distinguish it from my academic supervision. It would be a confidential space for me to discuss issues regarding Sarah's and my own vulnerability during the research process. The clinical supervisor probed my moral comportment within another layer of our reflexive dialogue as praxis and aided me in addressing any concerns. As part of my moral comportment I also undertook to connect with my clinical and my academic supervisor within a week of a meeting with Sarah in order for identified risks to be addressed promptly. Furthermore, as a strategy for enhancing both Sarah's and my safety I gave my clinical supervisor permission to take any identified concerns she might have about my conduct to my academic supervisor. As it was, this was not an issue. The clinical supervision proved to be most fruitful for me as I am a person who moves in my thinking via talking through what is going on. I audio-taped my clinical supervision sessions and always listened to the tapes and journalled about the sessions shortly after.

lead researcher journalling

The journalling I undertook as a strategy to inform this research process was another layer of reflexivity, dialogue and moral comportment as praxis. It was a dialogue with myself, in which I endeavoured to remain open to the informing potential of all the research happenings. Journalling also commenced before the formal beginning of the research; it covered all the issues of the preparatory phase. During this phase I had commenced journalling my practice with Sarah in a more extensive way from the general way I already journalled my overall practice. This material became the early entries of what consequently became my research journal. My dialogue with the journal emanated from encounters with the literature, co-participants, clinical and academic supervisors and PhD schools held at the university twice a year where accounts of significant progress were presented. Impressions and feelings from meetings, tensions, dreams, ideas and insights were written down.

I would often commence with an experience of a conundrum and as I dwelt with it and wrote about its main characteristics, I was able to move in my understanding of what had gone on. For some topics there was a multiple revisiting through repeated entries at

different times; something I had read or a conversation would trigger another thought about it. I commenced journalling on the computer but moved to have an exercise book that I carried with me for those flashes of insight that came out of the blue. If I didn't write these down as near to the time as possible life moved on and they could be forgotten. In the early stages of journalling I kept both a computer journal and the exercise book. However, I moved to use only exercise books and filled up several.

I can look back now at some of the entries and think 'Why was that such an issue for me? For example in my journalling about my practice with Sarah there are numbers of entries where I reviewed my visits looking for cues that would indicate her movement out of strife and the non directive stance I was endeavouring to maintain. From the multiple insights I have achieved throughout the research it now appears I should have either trusted the process more or believed in the notion of what I now call 'phronesis'. I can see also that there was a lesson for me about being patient with Sarah and with myself. In relation to those type of entries I would often return to a reading that I had written in my journal and found helpful over a long time. It was

Remember that you are facilitating another person's process.

It is not your process. Do not intrude. Do not control. Do not force your own needs and insights into the foreground.

If you do not trust a person's process, that person will not trust you.

Imagine you are a midwife; you are assisting at some one else's birth.

Do good without show or fuss. Facilitate what is happening rather than what you think ought to be happening. If you must take the lead, lead so that the mother is helped, yet still free and in charge. When the baby is born the mother will rightly say: 'we did it ourselves!'

(Heider, 1986, p. 33)

These entries were not expressing anything about being caught up in the immediacy of Sarah's situation but were indicating that I, too, was travelling an uncertain road.

Another journal topic I look back on now related to my apprehension about getting my proposal through ethics committee. I had experienced difficulties in this area in my 1995

research and was trying to anticipate reactions this time. In hindsight the ethics approval was relatively smooth. I decided that a major aspect contributing to the smooth process of approval was the early commencement of my dialogue with the chairperson within a direct encounter. She was able to draw on our discussion in order to guide the committee, as well as have some sense of who I was and what I was trying to achieve as was indicated in her subsequent letters.

I did not follow any 'how to' journalling strategies that are available in books on reflective practice. My entries were a stream of consciousness process commencing with deliberation on a particular event, a research meeting, or starting with a question in my mind and proceeding to work with it. I encouraged Sarah to journal also, but it was not an activity that came easily to her. The journalling process expanded my horizon and helped my movement from one step to the next. Material from my journalling informed my proposal, the dialogical meetings, constructing the narratives and writing this thesis.

research meetings

As is discussed under the methodological premise of dialogue as praxis, I set up the research meetings to be conversational in character. It was to be an environment where the meaning given to the situation could be revealed and reflected on within a 'to and fro' dialogue from the subjective stance of each co-participant. Reflexivity, dialogue and moral comportment as praxis were embedded in the meetings. I made a decision to have separate sets of meetings with Sarah and the nurses. This decision was based on Sarah's vulnerable position; a position that was likely to become more threatened if she was trying to give voice to her experience in a group situation where others were also talking of their experience. Because I wanted to capture Sarah's experience in the first instance as there was potential for a change in her condition, I set up the first series of meetings with Sarah and then followed on with a series of meetings with the nurses. The research meetings commenced shortly after the consent forms were signed. All meetings were taped and the majority of conversations were fully transcribed. Participants were assured that they could rescind, change or develop contributions within the over all construction of the findings within a co-construction of the narratives.

The first group of seven meetings with Sarah recorded her experience. In the first three meetings Sarah told of her experience with only a few prompts from me. Prompts such as ‘tell me more about ...’, ‘What did it feel like at that time? I remember such and such situation, would you like to talk about it?’ This latter type of question, was I believe, a benefit from my insider status. I used it mainly to expand the conversation on an event that was already under discussion. Nevertheless, I had to be aware of emphasizing material that had no significant meaning to her. At the end of each meeting we would take a few minutes to recapitulate what had been covered and decide what might be some events that we would focus on in the next meeting. Sarah was invited to have a family member/s or friend present at the meetings but chose to participate on her own. In the nursing practice period it had been evident that her children were her main support network so I suggested that her children be involved in one of our meetings to reflect on their experience of her illness. Although Sarah was agreeable to the suggestion, their busy lives made it difficult for them to get together, so such a meeting did not eventuate.

Meetings four and five with Sarah used a summary of her nursing notes as prompts for her reflections. Following these two meetings I constructed a preliminary narrative in chronicle form from the transcribed material and sent this to Sarah for her comment. The sixth meeting centered on discussion of the preliminary narrative and in the seventh meeting we discussed some patterns, themes, and paradoxes that I had identified and how the process of telling her story had been for her.

Only on one occasion did I become uneasy towards the close of a session. Sarah had been recounting her period of severe strife in the two year period prior to the three year research period, and became completely involved in it. Her distress was evident so I used the last part of the dialogue to move away from it and then, with her permission, after turning off the tape, I went through some ‘letting go’ strategies with her. She was expecting some members of her family to visit and stay the night soon after I left and I phoned her next day to inquire into any after effects. Sarah appeared to have moved on from her distress and was enjoying the company of her family by that time.

The seven meetings ranged over a period of four months after which Rose, Mary and I began our dialogue on our nursing practice experiences with Sarah. The first meeting with the nurse co-participants involved an open discussion on how we became involved with Sarah and any outstanding memories of the experience. Summaries of the nursing notes were used as prompts for remembering the experience at the following two meetings. Sarah's preliminary narrative and what we had learned from the practice experience were the focus of our fourth meeting. In addition, we considered what would be important in future nursing practice that could prevent strife occurring or in any engagement with a client experiencing prolonged strife. At the close of each meeting we decided what would be the main content for the following session. The meetings always included any further reflections co-participants might have had on the previous sessions. The completion of the above four meetings coincided with obtaining ethical approval for the extension of the third year of the study period. However before I discuss this extension I will relate what I believe were two interrelated lapses that became apparent at the close of the meetings with the nurses.

As mentioned I had created a preliminary narrative of Sarah's experience from our early meetings as a tool for giving her experience coherence not apparent in the transcripts and for enhancing her reflexivity. I requested and received verbal permission to share it with the nurses following our reflection and further expansion of on it. I should have used the running consent form rather than verbal consent. The narrative contained what could be interpreted as an ambiguous statement relating to Mary's practice. I was aware of the ambiguity and meant to make Sarah aware of it and provide an opportunity for her to clarify it but did not get to do this before I gave the narrative to Mary and Rose as part of our reflections; the second lapse. Mary did experience some discomfort with the statement. I apologised for not having made the effort to give Sarah an opportunity to clarify her meaning, as is a facet in my praxiology for dealing with untoward effects of praxis. It had been tactless on my part. In talking with Mary sometime after the event she reassured me that although it had caused her some uneasiness in her first reading she had taken it as an opportunity to reflect more fully and had come to a comfortable resolution

of the issue. Following my acquaintance with the discomfort experienced by Mary I brought the ambiguity to Sarah's attention and the said passage was reworded to clarify her intent. It emerged in this encounter that Sarah had forgotten she had given me verbal consent to share the narrative. I discussed my lapses with both my clinical and academic supervisors. They affirmed my subsequent actions and my learning from the incident. One cannot undo the discomfort but one can recognise it as a consequence of action and commence a new path through acknowledgment and taking steps to make amends for the damage done.

The above meetings with Sarah and the nurses took place in 1999, the year following the initial two year period of our prolonged engagement, as per the timeline Figure 2 and the my discussion of the timeline. At the completion of this two year period her illness trajectory was still unpredictable. Progression from her early severe strife was apparent and might have proceeded to her independence from nursing care. As it happened Sarah made some major changes in her life that slowed her progress. I came to see that adding a third year, 1999, to the study time period would enhance the research material. In fact, this provided a conclusion that was not apparent at the close of the two year period. This extension required ethics committee approval, which was readily achieved. (see appendix one for approval of this extension)

Another series of meetings began forthwith in November/December 1999 to capture the experience of that year. These involved a further three meetings with Sarah. The initial two focussed on her recollection of 1999 and one was centered on the summary of the 1999 nursing record. Sarah had very clear recollections of that year. This appeared to me to be associated with two things. Firstly although she had experienced ups and downs, overall there had been continuing movement out of strife and secondly reflecting on a year in the immediate past appeared easier than looking further into the past.

One meeting was held with the new nurse, Kim, in December 1999, who had become involved with Sarah during that year. There was an opportunity for a second meeting but Kim decided one meeting was adequate for her reflections. A summary of the notes was

sent to Kim prior to the meeting to be available as prompts throughout the meeting. I did not set up another meeting with Mary and Rose. Mary had not been involved in Sarah's care in the third year and Rose did not see that she had anything more to add about the third year. Furthermore, there was to be another opportunity for reflection when they received a draft of the narrative.

Two narratives were formulated from these three series of meetings. The earlier narrative of Sarah's experience was refined and extended to encompass the material from the additional year. It was sent to Sarah and I subsequently met with her to discuss it (see letter in appendix two which accompanied her draft narrative). The nursing narrative included the material from initial meetings of Mary and Rose and myself and the material from the meeting with Kim. First drafts of these narratives were sent to the co-participants in April/May 2000 i.e. Sarah received the draft of her narrative and the nurses received a draft of their combined narrative, as per Figure 2. (see letters which accompanied draft narrative in appendix two). Another series of meetings began with participants to capture reflections, and changes or development in their thinking about the experience. Four meetings took place for this exercise, one with each participant. I considered nurse participants would want to concentrate on how their own contribution now looked within the overall narrative. Individual responses were incorporated into the nursing narrative and this was then sent to the nurses with an invitation to attend a joint meeting to dialogue with each other on the nursing narrative (see letter in appendix two). The nurses' narrative was fine tuned again following this meeting and then combined with Sarah's narrative to form what I term the integrated narrative that is the substance of chapter eight. The nurses and Sarah were then invited to a meeting, which all attended, to reflect on the integrated narrative in draft (see letters accompanying the draft of the integrated narrative in appendix two). A summary of this meeting is located at the end of chapter eight.

I had originally intended to request the permission of the nurses to send the draft of our final narrative to Sarah for her reflection and then bring her reflection back to the nurses for their further reflection. However, it was proving difficult to get all the nurses together

because of differing days of work, geographical distance and personal happenings in their lives; one had a death in her family and another one was moving house and getting married. Furthermore, Sarah would get an opportunity to reflect on the nurses' narrative, albeit in a shorter form, as it existed in the integrated narrative.

Sarah and the nurses were invited (see letter in appendix two) to attend a joint meeting to share reflections on the first draft of the integrated narrative. I was particularly concerned that the draft integrated narrative might trigger discomfort for Sarah. Therefore, I forewarned her about its contents and offered to sit down with her when she read it. The latter offer was declined but she did agree to ring me if she experienced any difficulties with it. I did receive a phone call where she raised one or two queries in relation to particular issues but they were not distressing her. I encouraged her to write her questions down and raise them up at our joint meeting. Bringing all the co-participants together took careful organising. There were issues of distance to travel and a time in the day that would be suitable for all. Moreover, the narrative material did hold some differences of opinion that had the potential to be contentious.

All research co-participants chose to attend the joint meeting. A facilitator was organised to enhance the dialogue between the participants; to bring a fresh approach and make sure that all participants had their voices heard adequately. The co-participants were asked to respond to their reading of the integrated narrative and for comment on their satisfaction or dissatisfaction with the re-presentation of their contributions. The participants recapitulated their part in the practice as expressed in the narrative, much of this was addressed to Sarah. Some general dialogue then took place on the overall research process and the usefulness of the joint meeting. The meeting provided a natural closure to the co-construction of the research material and of their involvement in this research.

A total of 21 meetings with participants had been held. Each one ran for the time the participants had put aside or until natural closure occurred. I was concerned about the meetings tiring Sarah and checked this aspect at times during each meeting. The duration of these meetings varied from forty-five minutes to 90 minutes. Most were approximately

one hour. Copies of the tapes were offered to participants after each meeting. In fact Sarah recorded the first meeting on her own recorder. However, she had difficulties with her recorder and she did not record any further meetings. Copies of tapes were given after the next three to four meetings but her interest in listening to them began to wane. I stopped offering them to her when it was apparent that it was no longer a helpful activity. The nurses declined my offer of the tapes. They felt they had significant access to the material through reading the documentation summaries and the meeting transcripts. I listened to the tapes while driving home from meetings and/or shortly after a meeting. I journalled immediate thoughts about the meetings and the material that emerged from them. Once the meetings were transcribed by an outside transcriber, I read the transcripts and again wrote insights and impressions in the margins and in my journal.

The transcripts of all meetings were sent to the participants. An exception to this was the cycle of individual reflections on the nurses' draft narrative. Further reflections were entered into the narrative after each interview but I waited until the round was completed and then returned the updated narrative to the nurses for further reflection before we met as a group. The final meeting was summarised rather than fully transcribed as the discussion contained considerable material already in the narrative. The synopsis was sent to all co-participants.

summary of nursing documentation

All the written nursing documentation on Sarah's nursing care was summarised to provide prompt material for the meetings. These summaries supplemented and complemented the reflexivity, dialogue and moral comportment of the meetings. I initially dialogued with the documentation to establish a framework for the summary. Once a framework of headings covering the most outstanding issues was determined I proceeded to make notes under the headings in monthly columns that covered the 36 months of the study period.

The summaries were given to Sarah after our first three meetings in my first round of meetings with her and after the initial two when reflecting on the third year. Withholding

the summaries was deliberate, as I did not want them to shape her story. The summaries were given to Rose and Mary at the end of our first meeting and to Kim prior to our first meeting as I recognised they would need some prompts for remembering this particular practice episode in the early stage of our dialogue.

The nurses found the documentation summaries particularly helpful in aiding their recollection of the practice experience and triggering memories of particular events. They provided their first glimpse of the event as a whole and certainly were used within our dialogue for clarification and expansion of reflections. Although Sarah found the summaries interesting they did not trigger significant material about her experience.

re-presentation in narrative as praxis

Re-presentation in narrative form was a reconstruction of the stories extrapolated from the meeting transcripts. I attempted to capture the spirit of their story telling to provide a unitary whole of the experience. To achieve this I listened to the tapes and read the transcripts several times to obtain an overall sense of the material. I marked areas on the transcripts and wrote notes in the margins about links within the material and thoughts on the material. Sarah's initial and final narrative emerged as a chronicle of her experience. Both she and I had come to understand the theoretical/metaphorical meaning of her illness as a burden that weighed heavily upon her all the time and at times overwhelmed her. This meaning emerged in the dialogue on the third year of the research period. Arriving at this understanding was a very significant moment. Many fragments that had seemed disparate came together. It seemed so obvious that I berated myself for not having comprehended it in earlier practice. From this meaning I used the notion of journeying with the burden of illness as a framework for her final narrative, dividing it into significant aspects of the journey. Excerpts were arranged and rearranged in a process of testing and searching for coherence and an understanding of the pattern of the whole in the revealed experience. I used quite large quotations from her tapes and provided the linking narration with summarised material.

Creating the nurses' narrative was a more complex task as there were four voices to position. I use the same process of listening to tapes, reading transcripts and writing notes. The notion of journeying with the client provided a framework and I gave this narrative the title of 'Walking alongside'. In analysing the transcripts I was looking for major themes under which I could group material. It commenced with many themes and in a final analysis was reduced to six as I regrouped and broadened the dominant theme to account for material from minor themes. The themes were then rearranged in the journey framework. Excerpts from the transcripts were then placed under appropriate headings and refined as each voice was linked together. Material from different time periods appeared in most of the framework headings. In the nurses' narrative I kept my voice in the third person in order to project myself as a voice of a team member along with the other three voices. I was also the narrator providing the overview and the linking throughout.

The process of developing the narratives held reflexivity, dialogue and moral comportment as praxis within it. This was especially so for me in the constructing procedure where I came to know the material well and commenced looking behind the text where I began to uncover another layer of meaning. Nevertheless, it was also a reflexive process for the co participants in their ongoing co-construction of the findings. Sarah did comment that each reading of the narratives bought back a sense of vulnerability about what she had been through. However, this sense did not proceed into any destructive effects. Overall the process of telling her story and reflecting on the narrative/s appeared to have therapeutic effects and complemented her movement on from strife.

Interestingly, all participants found reading their quotations in the transcripts challenging. They found their speaking voice did not sit comfortably with their notion of the written word. Kim rewrote some of the larger quotes that I had transposed into the narrative from her transcript and Sarah commenced writing her own story in order to increase her comfort with it. The writing of her narrative remains incomplete at this stage. However, Sarah gave permission for me to go ahead with the integrated narrative using material from my construction of her narrative. Rose and Mary asked that I tidy up their

quotations as I refined the material further for the integrated narrative. In line with keeping the integrated narrative a manageable size I had intended to reduce the size of the quotes and extend the narration to capture what might have appeared in quotes in the separate narratives. The intention in my use of the larger quotes was to allow the co-participants to see what I was foregrounding from the transcripts.

In constructing the integrated narrative I stayed with the notion of journey and for each major heading I provided a sub heading on the focus of Sarah's experience and the nurse's experience. Wherever there was a direct relationship of the material from the separate narratives I placed them together, otherwise material stood alone under a variety of sub headings (see chapter eight). No further comments were forthcoming about comfort with quotations in the meeting reflecting on the integrated narrative. Sarah contributed some explanatory notes and made some minor corrections to a small number of passages in the integrated narrative. She also came to the combined meeting with her questions regarding some areas of the nurse's experience. The nurse participants offered no changes to the integrated narrative.

I highlighted the issue of confidentiality for all participants in each letter that went with draft narratives. The use of pseudonyms assures some confidentiality. However the participants and I recognised that even with pseudonyms certain material would identify them especially when read by personnel who might know them. This is a particular issue with studies involving a small group of participants. Blurring of details in the report e.g. change of age, gender, family numbers was an option for Sarah. Sarah and Rose considered using their real names. However, after discussing that their use of real names might reduce the confidentiality of the other people talked about in the narrative, they agreed to use pseudonyms.

A fusion of Sarah's horizon with the horizon the nurses involved in her care is apparent in the integrated narrative. Within the dialectical process of constructing the narratives I became aware that a structured critique would generate another level of meaning which lay below the surface.

critique as praxis: looking behind the text

In the course of constructing the narratives certain themes and patterns began to emerge. In Gadamerian terms the narrative began to dialogue with me. Therefore I began a structured critique of the narrative text in order to develop the emergent patterns and themes from a dialogue with the literature relating to them. At this stage I was fortunate in being able to leave my usual domestic responsibilities and move to a quiet and environmentally beautiful location to dwell with the narrative and literature relating to it. This dialectical questioning and answer process set off a new hermeneutical circle with the methodology.

Each participant's contribution to the overall narrative from their individual narrative is their personal perception of the event at the time of narrating their story and the reflections that went on in the reflexive re-construction. The perceptions were shaped within the dialogue and cannot be measured against any objective reckoning. Some ambiguous and paradoxical positions of participants caught my attention in the initial examination of the narrative. The critique began with attending to evident paradoxes and a reading of the discursive literature on illness, suffering and caring in nursing. As this path proceeded the metaphors used and varying moral meanings in the narrative stood out as significant and together with paradox, were employed as linking concepts. In writing a first draft of this critique I realised that many of the paradoxes represented in our contingent positions were embedded within the different discourses identified in my examination of the literature on chronic illness and caring in nursing. I then proceeded to summarise these different discourses from the literature to act as a framework in which to embed the critique.

I utilised the discourses in a heuristic sense only. I was very conscious that setting up binaries might take me into the trap of the Cartesian anxiety so well exposed by Bernstein (1983). The negating of binaries is typical of a post modern position where a more or less emphasis is all that can be argued. All participants, including myself, displayed paradoxes in what we revealed as is also typical of standing in a postmodern space

(Lather, 1991). Our positions are always contingent. We are always in a more or less process of clarifying how we view the world and trying out new lenses for the accommodation of new ideas.

The critique embedded in a discursive framework emerged from following my questioning of the narrative, which is consistent with Gadamer's exhortation of following the lead of a dialogue with a text; of remaining open minded to where the dialogue might take an interpreter. I had originally believed that a dialogue with the narrative would lead me into a re-conceptualisation of my earlier practice model – 'the web of relationship' - or to a new practice model. My dialogue with the text did not point in this direction. This critique completed the generation of meaning sought in both the research objectives. Chapter nine discusses the construction of the discursive framework and chapter ten presents the outcome of the critique.

conclusion

Chapter seven describes the construction of the praxiological methodology sought in the second research objective. It is the methodology used for the systematic investigation of the first research objective and further expands the axiom of research as praxis in the inquiry. An explication of my personal nursing praxiology was presented. The praxiology includes assumptions about how people live and learn in the world from the research framework, from other praxiological traditions my position in nursing as a practical human science. This explication together with the five methodological premises embodying the assumptions provide a summary of my positioning in the methodology from which readers can determine influences on the shape of the understanding generated. The research process is then fully described, commencing with the considerations relating to its distinctive character that preceded the formalising of the inquiry to the final critique. This thick portrayal of the processes was undertaken to demonstrate the enactment of the premises and furnish an audit trail of decisions taken throughout the collection and analysis of the research material.

I was profoundly grateful that the preliminary design of the process came to fruition without any major upheavals. The addition of the third year of research material to my study, more than fulfilled my initial hopes, which were tempered by the high degree of unpredictability and uncertainty within the research process. Without the material of the third year I may not have had the significant insight about Sarah's metaphorical construction of her illness. Moreover, capturing the happenings of that year added substantial material that contributed to a wider understanding of strife and prolonged engagement. The extension of the research to cover the third year gave me a greater sense of satisfaction and closure than I had experienced after the collection of the research material at the close of the first two years.

The report now shifts to present the findings in the form of the co-constructed integrated narrative. It is a vivid and living example of nursing practice as praxis. Moreover, it is a practice situation that captures the pathos of living with strife in chronic illness and the moral endeavours of the team of nurses (including myself) who worked with Sarah in all the nuances and complexity of her situation. Movement on from the strife and suffering she was experiencing at the outset of the three year research period is evident.

Chapter eight

SHARING THE BURDEN IN A JOURNEY THROUGH STRIFE IN CHRONIC ILLNESS: NARRATIVE AS PRAXIS

introduction

This chapter presents, in narrative form, the generation of the meaning made of Sarah's experience of living with strife in chronic illness and her nursing care. It is research as praxis at work in uncovering practice as praxis. The voices of the co-participants, Sarah, Mary, Rose and Kim are interwoven throughout. These names are pseudonyms that were negotiated with each co-participant. My own dual role in the research as participant and narrator is enfolded in the narrative. The three years of the practice episode under investigation began in December 1996 and continued to December 1999.

The narrative is the result of all co-participants entering into a co-construction process involving the methodological premises of reflexivity, dialogue and moral comportment as praxis. It encompasses the stories of all co-participants who occupied different positions and viewpoints. The co-participants consented to share experience and beliefs with the intention of contributing to nursing knowledge. In particular, the narrative is a contribution to an expanding understanding and deepening consciousness of the client experience of prolonged strife in chronic illness and the nursing practice that evolved in response to it. The narrative sits within a premise that values subjectivity and intersubjectivity, so as lead researcher, a practitioner in the nursing team and narrator of the account, my voice appears in the first person.

From the dialogue there emerged significant metaphorical explanation, given by Sarah, to the nursing contribution to her health-illness circumstances. It was expressed as 'sharing the burden of illness' and aiding 'safe passage' for getting on with her life'. The moment of insight relating to this meaning is amplified in the latter stage of the narrative. These concepts are used within the metaphor of journey to give the narrative a coherent expression. Kleinman (1988) alerts practitioners to pay attention to the explanatory model that people assign to their illness. It is the overall perception they have of the situation they find themselves in. Moreover, many nurses writers, Gadow (1980b) Newman (1994,

1997) Parse (1995, 1997) and Younger (1995), have exhorted nurses to uncover what the meaning of illness is for a person and/or their family. As I reflect now there were hints of Sarah's explanatory model in the first two years of our practice engagement. In that period I had come to understand that she needed a rest from herself but did not appreciate why. Therefore, the explanatory model in which my practice insight could be understood was a major revelation for me in terms of the search for meaning related to Sarah's experience.

What is about to unfold is the outcome of integrating the voices of the client and the nurses into one narrative. It contains four sections making up a framework that covers the journeying of the client and the nurses within notable time intervals within the research period. Nevertheless, there is overlap and blending of each interval within all the sections. This is a long chapter as I wanted to be faithful to the co-construction process and because attempts I made to break it into smaller chapters fragmented the unitary nature of the story. Only minor editing and the addition of some summarising comments and statements has taken place since the co-participants verified the narrative as a faithful re-presentation of their positions. I have placed the direct quotations of the co-participants in italics to aid the reader's sense of the different voices in the narrative. The narrative stands in its own right as the intersubjective reality of the co-participants, the story of our being and knowing in the world shaped by our individual historical consciousness, in a particular time and place. Therefore, there is no analysis of the narrative undertaken in this chapter. An analysis in the form of critique as praxis appears in chapter ten. I believe the narrative stands alone as a poignant story of a nursing practice situation and this poignancy could be missed if interrupted by ongoing analysis.

The headings for each section are made up of phrases that cover an overall sense of what is about to unfold from the client focus and from the nursing focus. The client's phases and the nurses' phases are separated with the symbol $\Leftrightarrow$. Within each section are a number of sub-headings to guide the reader through the exploration of different issues. The four sections in the framework are presented in Table 6. The chapter concludes with a summary of comments from the meeting where all co-participants came together to

share their reflections on the draft of the integrated narrative. This combined meeting provided an opportunity for the client and the nurse participants to talk with each other

Table 6. Four sections of narrative framework

<u>Client focus</u>	<u>Nurse focus</u>
1 Going from one step to the next to get through each day	Beginning to journey together and share the burden
2 Learning to live with uncertainty while beginning to look ahead	Walking alongside while pushing the boundaries of care and caring
3 The great leap into living alone with some stumbling in a roundabout	The wake up call and upping the ante for change while introducing a new nurse
4 Carrying the burden of illness into the future while extending her engagement in the world	Reducing the nursing input and examining options for Sarah's future, and that of others with strife in chronic illness

and clarify the positions of both themselves and the other participants. Previous reflections from within the co-construction process were incorporated into the narrative. However I chose to keep the final reflections separate in order for these to be seen as a whole and as a completion of our cycles of reflexivity. Furthermore, the meeting provided a time for closure in the co-constructing of the narrative that appeared to be a natural conclusion to the co-participant's extremely valuable contribution.

Before I begin the narrative proper I will provide some background relating to Sarah's experience and that of the nurse co-participants as each one entered into the three year period under study.

background of research co-participants

Sarah's journey into illness

Sarah was born the third child in a Pakeha (European) family of six; five girls and one boy. On entering the research period Sarah was 41 years of age and had four young adult

children and four grandchildren. The names of her children who are mentioned in the narrative are Anita, Toby, and the twins Sam and Oscar. Sam's partner is Michelle. Sarah's journey into illness began in childhood. She remembered spending much time at the local major hospital, a significant distance from her home, attending clinics related to her asthma. Fear became associated with the clinic visits as they appeared to her to be a series of nasty experimental treatments. Towards the end of primary school (year 8) her parents stopped the treatment. Fear, which is so deeply embedded in her adult illness, appears to have become established in from her childhood. *"I had a real hang-up with it"* Sarah commented. She remembered that when she was 12 years of age she had a hospital stay of three months.

Interruptions in schooling led, for Sarah, to a sense of difference from other children. A sense of being non-normal and feeling not *"as good as the rest of them"* remained with Sarah as a memory of that time. Limitations on physical activity compounded the sense of difference. *"It was my whole being that was different"* she noted. A special relationship developed with her mother, who was the main sharer of her childhood illness burden. The years at secondary school passed more smoothly. Her main goal at secondary school was to become a normal adolescent, to fit in with her peers. This is known as a task of adolescence but it took on exaggerated proportions for Sarah. Part of achieving this task for Sarah was taking up smoking. Although asthma attacks continued she learned to hide any overt signs of illness and appear more normal. This sense of being normal was further developed after leaving school and beginning work as a hairdresser. Sarah relates *"I was all right after that for a while and I felt pretty much normal except for the moments that I had"*. Sarah married and had four children. *"When I was pregnant that's when I was really well"* she asserted.

Sarah experienced a severe pneumothorax in 1976, with accompanying hospitalisation. Her twins, Sam and Oscar, were then aged one year. From then on hospitalisations occurred approximately every two years supplemented by attendance at her local health centre. In the 1980s the busyness associated with young children and the stress and grief in her life with the break up of her marriage and court proceedings over custody of her children took its toll financially and emotionally. Compounding the stress of this period

was her mother's sudden death in 1987, at age 54 years. *"I don't think that even now that I've got over it"* Sarah reflected. From 1990 onwards Sarah perceives that the emotional aftermath of these years led to deterioration in her health, a sense that *"when it all eases off or finishes that's when it hits you"*. During the reflexivity process Sarah noticed that this is a recurring pattern in her health circumstances.

When life began to settle again Sarah moved into a new home and began working outside the home. However, this did not last long. After the suturing of a pneumothorax in 1990 Sarah experienced ongoing and increasingly severe pain in her chest wall. Repeated visits to her surgeon were not helpful. Finally, three years later in 1993, after hassles in obtaining a second opinion, a suture left in situ following the 1990 surgery, was discovered and removed. The suture had caused intercostal nerve entrapment over the three year period. Sarah felt this had led to *"everything that's happened to me since ... I feel like it ruined my life"*. Hopes of returning to work as before the surgery were diminished. *"Since then I haven't been able to work, just live a normal life"*.

a time of severe strife

The impact of the events of the early 1990s resulted in a time of severe strife where between 1994 and 1996 Sarah spent long intervals in hospital. Some admissions were six to seven weeks long. The longest was three months. The worst one was in 1994 and is what Sarah terms *"42 days of horror"*. Sarah became paralysed and experienced severe pain. This experience still remains without a particular medical diagnosis. *"They (the doctors) came and stood over me and just looked at me as if, 'Well, we don't know what's going on'. I felt really like a freak ... in the end I discharged myself"*. At this time she was involved in developing a case of medical misadventure with a lawyer regarding the undetected suture. Compounding this was a particular conflict that developed with a medical registrar who did not take her experience seriously. *"I was just like a wild animal at times with this pain and the way this [medical] registrar was behaving"*. That admission was so difficult that Sarah asked her sons to bring additional pain medication from her home. It appeared to her that *"I was either going to die of that or die of my breathing ... I took a lot digesics"*. Sarah reacted badly to this overdose but managed to survive.

Sarah recalled that some of her fear at this time came from the “*headmistress and pupils*” disposition of the charge nurse. She believed that this attitude dominated the culture of the whole ward and made it a very “*unpleasant*” place. A particular nurse, whom Sarah believed could have helped her at that period but did not, became the focus of her anger. On approaching the nurse some years later Sarah discovered she was remorseful. The nurse had wanted to help her but found “*her hands were tied*”. A referral to a psychiatric registrar who was “*a good listener*” and an advocate for her assisted her through this time.

Fear and pain, including the treatment of her disease and the invisibility of some symptoms together with de-humanising effects, evident in her metaphors, that made her think life was not worth living were all deeply embodied in Sarah’s memory as the research period commenced. These and her losses and grief constitute her strife. Within this her drive to be normal, to do what other people are doing was apparent, as was the importance of acknowledgement of her experience.

the nurse co-participants

Each nurse met Sarah at different times encountering her in a different space. We as nurses also enacted different roles shaped by our previous experience, nursing philosophies and positions within the service. Moreover, we were all mature pakeha women who had undertaken our basic nursing education in hospital based programmes. Subsequently we had all participated in a number of ongoing education initiatives, some with a primary clinical focus and others with a more academic focus.

Mary entered the project with an extensive nursing background. She was an experienced district nurse working in a team serving the geographic area where Sarah lived. Prior to her move into district nursing Mary had gained extensive nursing experience in a variety of roles and services within a hospital. Her involvement in Sarah’s care continued for approximately 2 years. Mary was the first of the co-participants to meet Sarah.

Rose, and nurse specialist in respiratory conditions worked across all district nursing teams covering a greater geographic area than Mary or I. Her role crossed the boundaries of hospital and community. Rose worked with an assignment of 150 clients. She visited Sarah at her home approximately ten times in the two years and nine months of her involvement in the research period. In addition she saw Sarah during hospital admissions. Rose has extensive experience in different community nursing positions.

Kim commenced nursing Sarah and being involved in the research at a later stage than Mary and Rose. She has many years of practice experience, including ten years with people of differing age groups in rehabilitation situations. She was a newly appointed first time district nurse, working in a team that serves the locality of Sarah's change of address. Kim worked with Sarah for approximately 8 months at the end of the research period. She was not part of the dialogue of Mary, Rose and I and expressed a sense of discontinuity in the research process because of her lack of early involvement. The discontinuity occurred with the adding of the third year to the research period. After she had read the record summary and the first draft of the nurses' narrative Kim grasped a greater sense of Sarah's history.

My own history is already outlined as part of my personal and professional tradition informing the knowledge development of the inquiry in chapter two. I resigned from my position in the community health service at the end of August 1999, three months before the closure of the research time.

The way our differing personalities, positions and experience are portrayed in responding to Sarah are demonstrated in differing approaches in practice.¹

approaches in practice

As nurses we all manifested many commonalities in our practice but differences were also apparent. Our differing work position descriptions called forth a different emphasis in knowledge and our differing philosophies of practice, when enacted, meant variations

¹ When Sarah, Rose, Mary or Kim use the term 'you' they are referring to me as facilitator of the dialogue unless stated otherwise.

in approaches. As Mary and I were most involved with Sarah, initial indications of our approaches were more evident in the dialogical conversations.

Acceptance, respectfulness, non-judgmental understanding, confronting issues, inspiring hope and discovering strengths were attributes of Mary's practice with Sarah. Identifying options, clarifying issues and problems, informing Sarah about other available resources and monitoring symptoms and treatments were all strategies Mary used. She assigned half an hour to her visits and liked to move through presenting issues systematically. Time was often a factor in her busy schedule of home visits. Mary did not "*pontificate*" about Sarah overdoing physical activity as "*I couldn't stop her doing all those physical things and I didn't have a right to really. ... I've always ended a visit with 'Well let's go and look at your garden' or 'What are you doing? What have you made?'*"

Mary remembers that her approach began to change from observing my practice with Sarah. "*You came along and taught me a different way really and I then learned from you. ... Very early in the piece where it was this giving of not just your time but of your presence and also acknowledging her as a person and validating her feelings*". Mary saw that it could be easy to down play a person's circumstances if they are "*in the too hard basket. We do have clients with anxiety and it's something that you see in all shades and shapes in different personalities*". In observing my approach Mary considered that she had a different role. Mary recalled that "*as soon as I established all that it became very clear to me that my role with Sarah was totally different to Margaret's role*".

I did not see them as totally different, but as complementary roles informed by similar values. While Mary learned from me, I learned the specifics of asthma treatments and clinical tests from Mary and Rose. Mary had a long-standing interest in working with people with asthma and believed that nurses assisted these people more than doctors. She noted an emphasis on contemporary science in this practice but added that "*unless you have a wider picture ... that expanding of knowledge, ... it's really important that patients like Sarah get a really balanced overview*".

My primary approach was relational. I listened to Sarah and what was going on with her and worked with her to find solutions that might work for her. At that stage I did not realise that I was extending the ‘listening role’ of the psychiatric registrar. I took notes as Sarah talked to aid clarification of issues. Sarah had access to all that was written about her. Reminding myself that I was working to facilitate her life process, not my own, was an ongoing challenge for me. This involved coaching Sarah in making her own decisions, particularly about judging her condition. Honouring her personhood while promoting hope in the future was also central to my approach.

Rose made a deliberate choice not to practice in a primarily relational way with Sarah as Mary and I were already in this mode. *“I would be her resource person, and it’s worked that way”* said Rose. Nevertheless, Rose built in a person to person aspect at the closure of her encounters. Although Kim came into the nursing of Sarah in the third year of the research period in 1999 she found a relationship between them developed readily. *“We have a trust there and I feel quite comfortable with her”* reported Kim. However, in the light of Sarah’s lack of need for physical care Kim doubted if she fitted the service contract, which had been tightened at the time of her commencement with the service, as an ongoing effect of the health reform. Kim found it difficult to justify her visits to Sarah.

This introduction to the similarities and difference in our nursing roles and approaches is expanded in the narrative in how we responded to particular events in Sarah’s health circumstances. It is also a historical portrait of the co-participants that Thompson (1990) recommends as important in hermeneutical inquiry.

the narrative proper

going from one step to the next to get through each day ⇔ beginning to journey together and share the burden

impressions from early encounters

The research term began after Sarah’s discharge from a long hospital stay at the end of November 1996. At that time, her son, Oscar, lived at home with Sarah and her other children and their partners visited regularly. It was a chance to normalise her life again, to

get out into the community but oxygen cylinders went everywhere with her. In looking back Sarah recalled both excitement and fear about coming home; *“I really did want to come home but in a way when I got there I didn't want to. I was so scared”*. She had developed a sense of safety in hospital. Nevertheless, Sarah set out to learn to live again. She remembered the community health services beginning. She felt as if her house had been *“invaded”*. However the personnel and equipment came together to aid her safe passage in the community.

Sarah recalled meeting Mary and me. *“When you came on the scene it was more formal to start with ...but it quickly turned around and became very different. ... I did get better after what felt like a long time. ...I quickly got to believe in you and I felt that it wasn't going to be as bad as I thought first of all. You got the guts of everything that was going wrong. Its taken me a while to get my confidence back but I felt quite free, ... without being judged in any way. ... I could vent out a lot of anger and frustration”*. Sarah found that Mary and I were different in our approach. *“I felt that Mary would come and if there was anything physically wrong and she could put it right, she would. She had her way of trying to lift my mood when I felt low At a later stage she took me out, that was marvelous ... because I hadn't been anywhere with anyone except my kids. To go with her I felt safe. I felt if something happened I'd be right. She actually broke that barrier for me. I did feel safe”*.

My first visit to Sarah was at the end of November 1996. It was a busy period for her with Christmas approaching, the twins 21st birthday on the 29 December and her son Toby's wedding in February. Sarah reflected *“It was kind of special and I wanted to do as much as I could for them towards the Christmas celebrations. ...I remember being pleased with myself because I was able to make it there [for the birthday party]*.

Mary had only recently moved to be part of a new district nursing team at the time of her first encounter with Sarah. It was a few months before the three year research period commenced; the time when Sarah was still having frequent hospital admissions. Information from Mary's team members emphasised Sarah's 'lack of fit' to their norms for a respiratory client, in that Sarah's physical exertion and continued smoking were

seen to compound her situation. On visiting Sarah, Mary found a sick woman taking a cocktail of medications, driving herself to achieve home tasks. Within a few days of that first visit Sarah returned to hospital. Her personal drive, or will to achieve particular ends, was apparent to all the team and became a challenge we all needed to work with. We all admired her drive but believed it had both positive and negative repercussions. Sarah reflects about her drive. *“Perhaps there is something there that drives me but I can go for so long and then I collapse. Probably at times I feel like I pushed myself to the limit or over and I pay for it. But I manage to get through and get done what I want to do”*. In the latter part of the research period Sarah came to see that her drive was associated with her *“deep inner self”* which kept her surviving the ordeals of her illness burden.

Another aspect of our human drives is associated personality preferences. All nurse co-participants were familiar with different personality typologies. Sarah had a strong drive to get out and about and to be with people even when feeling ill which led us to believe she was an extrovert. Mary and I also detected impetuosity associated with her extrovert nature. This impetuosity was, at times, part of the family tension. Furthermore, Sarah’s drive for justice also came to the fore. We remembered that she was not afraid to put things on paper to make constructive comment. Sarah wrote letters of support and letters of complaint when she saw an injustice in the system.

We, the nurses, observed early in our relationship that Sarah had a strong sense of family values. Family co-operation and sharing of burdens was important to her. It had been an important value in her early life. On the whole Sarah enjoyed co-operative and mutually supportive relationships with her four children and their partners. However Sarah’s extended family became a significant factor during our engagement. Arguments, tensions and attempts at reconciliation often resulted in a series of mini crises.

My partnership with Sarah began following a request from the community-hospital liaison nurse that I become involved because she knew of my previous experience with people in strife in chronic illness. I met Sarah approximately three months after Mary’s introduction. Sarah’s multiple and lengthy admissions had challenged the hospital staff. A nursing home was under consideration by the hospital respiratory team. Sarah and her

family did not want this option and Sarah requested that Mary remain involved with her in the community. At that time the district nursing service had an organisational method of the nurses changing from one group of clients to another every two weeks. This was about to change to a primary nurse system. It was clear to me that Sarah needed consistency of nurses, probably over a long period, if we were going to be able to assist any movement out of strife. I believed that inconsistency of nurses and nursing contributed to Sarah's strife.

I found a woman with lots of issues. Sarah's loss of confidence in judging changes in her condition was her outstanding concern at that first visit. Increasing Sarah's confidence in judging symptom fluctuations became our first goal. If Sarah was likely to go off to hospital in a couple of days, we needed to be in there coaxing her through, building up her confidence which in turn would show her that she could get through her low cycles.

It was four months after I commenced working with Sarah that Rose made her first visit. In her early visits Rose encountered a lonely woman with low confidence in managing her condition. Furthermore, Rose detected in Sarah a need for nurturing and acceptance, a need to have someone walk alongside and share her load. Before Rose's first encounter with Sarah at home, she had heard about her in discussions at hospital respiratory team meetings. Impressions from these discussions resulted in a picture of a complex person, not in need of 'high tech' care, who did not fit well in the busy acute ward. Sarah's response to this when she read the first draft of the integrated narrative was a sense of being judged and penalised in relation to outward appearances. She commented: *"I can look OK but in fact the opposite is happening"*. It was the tension of visible and invisible effects of her illness, which Sarah had encountered in her admissions, and which continued to frustrate her.

At the end of 1998 Sarah moved to a new house some distance away from her previous one. This move coincided with more major changes in the Community Nursing Service precipitated by the HFA (Health Funding Authority) contract. Kim commenced working with Sarah in April 1999, after only a few weeks working as a district nurse. I remained in contact during the transition time. Kim encountered a person *"having quite a good*

space” but also recognised that the earlier part of the year had not been easy for Sarah. At this stage Kim saw her visits as “*primarily social*”. Her colleagues queried what she was doing for Sarah. To help Kim answer this question and decide what she could offer Sarah she asked Sarah if she could describe what she got from the visits.

Sarah remembered this episode as Kim “*asking me to justify her visits and I thought that this is it*”. Sarah couldn’t answer her. “*I felt that because there was nothing visible at this stage*” and as Kim had not seen her at her worst “*she probably thought she could spend the time elsewhere. I thought ‘from total involvement to nothing! ...Mind you looking back I am nowhere as bad as I was but I still feel frightened*”. In hearing her say ‘from total involvement to nothing’ I posed the question ‘Would it have been fairer not to have become so involved if I could not guarantee a continuation of the kind of relationship established?’ Sarah reflected “*No. I think that’s just life anyway. ... I thought that with Kim coming while you were here that she saw what was going on and if she didn’t think she could carry on it was up to her to say that*”.

At each encounter Mary and I found that Sarah’s body language also spoke volumes about the space she was in. Her body language talked of poor sleeping, of having pain that often moved from site to site at different times and of distress following difficult encounters with her sisters, father and stepmother. I described her life as pain-full in the early period.

Fear in a variety of forms, often exacerbating the pain, was seen to be deeply ingrained in Sarah’s day to day living. I coined the term “*anticipating the worst scenario*” to describe her fear about past symptoms recurring again in her future. She also had a fear of dying from a heart attack like her mother. This latter fear was reinforced in the development of an acute situation in her new location because of the longer distance needed to get to hospital. It had also diminished her confidence in judging changes in her condition that had been increasing. Sarah did not have any ambulance trips to hospital in the 1997-98 period but these commenced again in 1999 after her move.

Rose drew attention to the grief that appeared to exacerbate Sarah's illness; a chronic ongoing grief that commenced as a child with the loss of a 'normal life'. Mary observed that these multiple faces of grief appear to "*propel Sarah into a helplessness and downward spiralling of her spirits until she reached a place of 'I can't do this I can't do that and life's not worth living'*". Furthermore Mary observed "*very acute anxiety at times, and very, very fluctuating moods*".

Nevertheless through all the pain, suffering, demoralisation, distress and anxiety Sarah demonstrated "*her creative outlets of which she has many*" stated Mary. These were evident in her house decorating, cake decorating, handcrafts and gardening.

All the nurses' impressions added up to Sarah not fitting any text book norms. Major reactions occurred when people or events threaten her sense of what was right. Sarah became very angry, fearful and had a tendency to become what she called her '*stubborn self*'. She resisted complying with health professionals' images and lived life according to her values. Rose had a picture "*of someone who actually knows very clearly where she's going and what she wants*". In her reflections Rose observed that we as health professionals "*have defined the norm*"; the 'norm' to which we expect clients to accord. However, Kim believed that nurses made considerable efforts to plan care that fitted with a client's needs. I noted that people who didn't fit the system were often labeled as manipulating the system. I agreed with Rose that we have often defined the 'norm' which could result in people with different expectations fighting to be recognised as vulnerable human beings. Mary asserted that building trust and consistency avoided manipulative behaviour when it is a foundational value in the practice approach.

Sarah's drive, family values and tensions, fluctuations in both pain and her respiratory condition with associated treatment, smoking, fear, anxiety and grief all form ongoing horizontal threads throughout this story. Altogether these co-exist within her personal attributes of warmth, courage, creative expression and a strong moral imperative of reaching out to others in need. All nurses encountered a woman who welcomed us into her house, graciously offered refreshments during the visits; a woman comfortable talking to us.

harnessing confidence

Daily visits from Monday to Friday occurred initially to support Sarah's vulnerability and harness some confidence in getting through short periods. Her family were more available at the weekend but a weekend nurse would phone Sarah and was available to call if necessary. It soon became apparent that Sarah could get through the weekend with family support. A move to have her call the service if she needed professional nursing support was then made. In reading this in the draft narrative Sarah commented "*I didn't like to bother anyone. I have felt like this way all my life*". Sarah found that she could manage though the weekends with family support even though she often felt unwell. Her strategy was to keep going and ventilate concerns to Mary or I on the Monday. Sarah was choosing to have known nurses, nurses already engaged with her, who had begun to share her load. As confidence in managing the fluctuations in her condition increased the frequency of visits decreased until a weekly visit became viable in the latter part of 1998.

Sarah described her confidence in the earlier period. "*To start with, it was just nothing. ... I didn't really trust myself; I didn't want to do anything. ... It slowly built up and mainly because I think you [Mary & I] would visit every day, you would show me or talk me through my fear. If I was particularly uptight or worried about how I was actually feeling that particular day, we would talk it through and I would get through it. ... I was pushing myself to the limit to get by and I did. It felt to me like my body was not doing what I wanted it to do. ... After all the really bad things that had happened it was a like a new experience of going from one step to the next and it was frightening. I was coming from the hospital, a sort of a safe place to home where it was open*". Sarah referred again to her confidence in going out with Mary and continued "*I was really dependent on you but in time you have taught me to stand on my own two feet but I can't always do that. If I had come out of hospital and been totally on my own I could not have come as far. ... I knew that if things were really bad, you would be there next day just to ride me over that period and I felt safe cause I knew you were keeping an eye on me*". I interpret these comments as the caring gaze of our active listening and support in which a co-construction of Sarah's health circumstances went on leading to an increase in her confidence.

learning to live with uncertainty while beginning to look ⇔ walking alongside while pushing the boundaries of care and caring

a major crisis

Pain was the dominant issue for Sarah in the winter of 1997. Three of her hospital admissions that winter were for investigations and relief of pain. The MST had crept up from 40mgms twice a day at November 1996 to 120mgm twice a day². Side effects were being becoming increasingly evident. Concern about the effects on her breathing were voiced by the hospital personnel. The Physician, GP and Chronic Pain Clinic doctor were all involved. At an October 1997 admission the MST was cut to 60mgm BD over a short period. Sarah was discharged after a few days of adjusting. Rose had been part of this hospital event from the ward perspective and remembered some confusion about how much morphine Sarah was taking. Ward personnel tried various strategies to obtain some pain control including increasing the morphine. In doing so Sarah had become drowsy with slurred speech and after consultation with the pain specialist a decision was taken to reduce the morphine rapidly.

On discharge from this October 1997 admission Sarah remembered *“one doctor was telling me to go home ...there was nothing else that they could do. ...I was pretty low as far as feeling that I didn't want to carry on, didn't want to be around and burden the kids anymore”*. The cutback of morphine had left Sarah feeling *“high and dry and I had to just suffer and accept it, which I felt I couldn't do”*. Sarah was anticipating Oscar being away from home the next weekend. She was worried about being alone as she remembers *“I really didn't trust myself”*.

Mary was first to visit after this hospital discharge and noted Sarah's suicidal state. She asked me to visit as soon as I could. Sarah had come home informed of the cut back in morphine but not well enough to grasp its significance. I remembered observing the effects of withdrawal and an aura of deep sadness. Sarah talked of her life having no purpose and how she might end it. My offer to call the psychiatric crisis intervention team was declined but Sarah gave her permission for me to talk with the psychiatric registrar. Rose and I conferred and consulted with the physician and psychiatric registrar.

I stayed in phone contact with Sarah over the weekend. No real progress had happened by the next week so I organised a visit with the psychiatric registrar and went with her as a support person. An admission to the psychiatric unit was advised but declined by Sarah so admission to her usual medical ward was arranged for the meantime. Following the weekend Sarah was persuaded to go to the psychiatric unit.

Her plan of care, on arrival in the psychiatric ward, included access to nebulisers through the night, *“which I never got. I felt really agitated there and I needed to be up. I couldn't stand being locked up in the room and having to be in bed. ... I needed to walk round, I needed to go and make a drink and I needed to have a smoke and they wouldn't allow it”*. Most things had been taken from her, including her cigarettes but not her phone, which she thought had been overlooked. Sarah *“kicked up a bit of a fuss”* and was told to be quiet and stay in her room. She felt *“caged in, ...so, I sort of demanded my rights”* and a confrontation developed between her and the staff. Sarah announced she was leaving but assumed she was not believed. *“I just pulled out my phone and rang Oscar. This was about 3 o'clock in the morning, and said for him to come up and get me”*. Sarah heard him arrive and feared he wouldn't be allowed in so she created more fuss, *“rattling doors and banging them”* to make sure he heard her. *“I really did sound like a real raving lunatic [but] I finally got out and Oscar took me home, I didn't feel like a human being”*. The next day Sarah spent with her daughter, as she was concerned that there would be repercussions. Mary expressed disappointment about the psychiatric personnel not taking Sarah's particular coping mechanisms into account and failing to achieve a satisfactory outcome. The same metaphors that were used to describe her experience of demoralisation in her time of severe strife reappeared again.

Sarah's memories of her suicidal feelings during this time included *“I always knew what I wanted to do, or was going to do”*. However she was mindful that her children might blame themselves for not having done enough. This moral obligation *“stopped me going ahead with it. I had always intended to when I couldn't cope with it anymore, that there was a way out. I still feel that way to a degree, although it hit me harder back then”*.

² MST continuous is a morphine sustained release analgesia

Effects of the major crisis rippled into Sarah's extended family. Sarah remembers *"having my Dad come back on the scene. ... I wrote a letter because I really wanted support there for my kids and I felt that they didn't get it"*. A surprise visit from her father and sister Edna followed. Shortly after he visited again with her stepmother, Agatha, and another sister. Sarah felt frightened and panicky when they came but her son, Oscar, supported her through the visit. She saw the visits as the family re-establishing contact and treating the relationships as if nothing had happened. However Sarah believed there could not be a return to the past. Feeling connected to her sister Edna pleased Sarah but she did not want contact with her other sister, Nell. Moreover she was philosophical about her stepmother, Agatha, as *"deep down I knew that if I had anything to do with Dad, Agatha came along as part of the bargain. I never really had him back how I had him before she was on the scene"*. The family reconciliation continued for a few months. The nursing team reflected on the crisis and continued their input.

reflecting on our differing ways of responding to suicide

Responding to clients considering suicide brought out a different positioning of team members. Mary's approach included negating *"suicidal feelings"*. She believed suicide is destructive and not *"a good choice"*. We all agreed that suicide was a cry for help and exploration of the situation should be the first course of action followed by seeking further assistance. Mary said *"I didn't think I could rescue Sarah but certainly I think I could have given her a better choice"*. It shocked Mary to hear me talk of suicide as a choice people might make especially when she considered me to be a wise nurse. *'Margaret, we really differ on this, you know, I don't think she has a choice. I think life is terribly precious and to be preserved at all costs'*.

A belief that influenced my view was that most people who are going to take their lives will do so no matter what we do. We may be able to stave it off for a period of time and this may be a really important thing to do. I always walk a fine line when I put to people that they do have a choice. Moreover, I always support it with a rider that I would hate to see them take that choice and I endeavour to look for alternatives with them. This view fits the importance I place on peoples' self-determination in my practice. I like to respect it in the many ways that it becomes evident. Rose expressed a fear of *"missing a serious*

threat to someone's life" but acknowledged that she has known people who had chosen suicide and felt they had made an informed choice that she felt comfortable with.

I recognised that when Sarah felt de-humanised she did slip into a space of 'life is not worth living'. I acknowledged her feelings and worked with her to problem solve possible options. These episodes often involved loss of control over her situation. Her first line of action is to seek a 'fix it' from medication, often an increase or change in her anti-depressants. Sarah's pattern is to 'come out of it' but this does not mean she will not choose suicide as an option at some time. The cultural expectation of 'a fix' for all our health problems is strongly embedded in Sarah's thinking. However, it is often an unreal expectation for people living with chronic illness.

life moves on and is full of happenings

Following the initial aftermath of the crisis Sarah did improve and proceeded to have a reasonable 1997-98 summer. She remembered *"I got through that Christmas time and next thing it was February"*. Her daughter Anita, had offered her tickets to the Dateless and Desperate Ball that was being run as a charitable event in the city in February. *"I was really scared about going and thinking, 'Oh, couldn't do this', and I thought 'well I could cope with it if Edna came with me'"*. However Edna, her sister, did not get a matched date in the computerised organisation. Nevertheless, the family discovered a male friend who was attending so Sarah went with him. Although not feeling very well Sarah rose to the challenge and she found *"it turned out it was all right"*. Mary noted that Sarah did have the confidence to go to the ball. *"I think it would be quite difficult to go and meet a blind date and she looked absolutely gorgeous"*. We all observed that Sarah placed great importance on her body image. Sarah always made an effort to look good. Fluid retention from steroids embarrassed her.

Around this time Oscar announced he would leave home in approximately a year. It triggered Sarah into looking ahead. She saw that she needed to *"make the most of that transition, try and plan things because I didn't want to feel how I was feeling"*. Sarah began to consider buying another house that she could manage better when on her own and *"saw a house that needed quite a bit of work doing to it but inside, I liked it"*. After

much negotiation a sale did not eventuate. Sarah believed this entree into moving set the scene for the change that took place at the end of 1998.

In early May 1998 family tensions heightened once again. These were triggered during a hospital admission. At the same time her younger sister, Nell, had a baby in the maternity ward, which happened to be near her ward. Sarah encountered her sister and other extended family and friends in a lift where they ignored her. Edna, the sister Sarah most wanted to stay in relationship with, also ignored her. Sarah reflects that *“since then the family [her siblings] hasn't had any contact”*. Sarah's father had an operation in June. The tensions with siblings that developed in May continued. They did not speak to each other when meeting while visiting their father which left Sarah feeling *“really hurt and lonely again”*.

Over the winter of 1998 Sarah commenced legal measures to place her house in a trust. *“I'd decided that I had to secure the house for the kids. ... I thought well, if I go into hospital and they decide to put me in care, which they had decided once before and took me to the place. ... I just couldn't risk that, maybe something would happen that I couldn't look after myself or be at home”*. Her father's decision to seek the return of some money Sarah believed he had given her several years earlier, intensified her actions. *“There's no way I could pay it back', there's no way I could get the money”* said Sarah. The legal work was to cost money Sarah did not have so her children worked with her in setting up a garage sale to help pay the bill. For Sarah *“it was a lot of planning. It was a lot of work”*. The proceeds covered a significant portion of the bill but it remained a stress until paid off in April 1999. Securing ownership of the house for her children pleased her. Sarah talked of the major struggle undertaken to re-establish a home after her marriage break up. She managed to buy a house but had no furniture initially. *“They went without too, to get that. I felt they deserved it and they'd looked after me more than most kids would have done I think.... They've been through a lot of heartache for their young ages”*. Sarah consistently expressed a moral obligation to her children for their support of her.

Running the garage sale and accomplishing the family trust took its toll. Sarah remembered experiencing severe chest pain in August /September. The GP arranged for clinical tests, which did not show evidence of a heart attack, and told Sarah she was too young to have one. *“All I know is it [the pain] was shocking and I never want to have that again. ...That was the worst that it's ever been”*. The episode undermined Sarah's growing confidence but did not stop her having some good moments.

On a positive note Sarah recalls the garden course she attended. Interruptions occurred because of a hospital admission and the move to the new location. *“So even though I only saw half of that through, at least I felt I attempted it anyway. I wanted to have things going on in my life”*. Another major event in 1998 was the birth of Anita's third son at the end of October. Sarah had been involved throughout her daughter's pregnancy and had looked forward to attending the birth. She remembered *“he arrived and I remember touching his head before he actually was born. ... I was there and this time I wasn't wheeled into the theatre [as she had been for the birth of Anita's second son], I walked. ... I was going to do it come hell or high water, but I was feeling physically a lot better than before, so it was easier to cope with”*. Anita returned home within a few hours of the birth and Sarah spent much of the first few days with her. *“I enjoyed it, I enjoyed it. I was tired but I enjoyed it”*. Sarah also reflects that *“the better I get the more I want to do”* which is another confirmation of reducing strife. Sarah took a 'complex medication cocktail' to help her through the day. However the nursing team were concerned that this medication cocktail was a two edged sword.

the medication cocktail

Morphine and anti-depressants are central components of an extensive poly pharmacy prescribed for Sarah. Not all of Sarah's symptoms could be related to a direct cause as demonstrated in clinical tests associated with the severe chest pain described above, another experience of invisible causes. Sarah liked to be able understand exactly what she was experiencing, to be able to give it a label but *“everything that I seem to get, no-one can explain what it is, and that's another thing that I can't stand. I'd rather have some really dreaded disease that at least they can put a name to it, but having all these mysterious things, it makes me feel like a real freak (a non-person)”*. Mary and I thought

there were more subtle interactions going on as in what was named ‘idiopathic oedema’. This certainly could be seen as mysterious interaction, but did have a label, which was a reassurance for her. The pain specialist physician believed much of her pain related to osteoporosis, which was a side effect of the steroids used in treating Sarah’s asthma. Mary noted. *“a lot of what Sarah is suffering is not only her condition but it's the effects of the medication to treat that condition, she's into that bind now.* Mary saw that many the *“aches and pains and diarrhoea and indigestion and nausea”* were linked to the polypharmacy. It was a paradox that treatments for alleviation of symptoms actually caused more suffering.

As mentioned Sarah yearned for a ‘medical fix’ for her distress and suffering. This, I believed was associated with her ongoing acceptance of the polypharmacy and its side effects. However we were all aware that the physician couldn’t provide ‘the fix’. All he could provide was ongoing review of the medication. Rose remembers *“he would have said to Sarah several times, look I don’t have the answers to this”* which would be followed by a plea for Sarah to reduce her smoking. Both Mary and I encouraged Sarah to seek review of her medications with the psychiatrist and physician but understood her belief in them. When Sarah talked of feeling better I encouraged her to discuss cutting back on her MST with her physician. My disquiet about the morphine related to her pattern of fluctuating pain and having room to move without getting into the dilemma of the major crisis again. In addition many of her discomforts came from side effects associated with morphine. Furthermore, I queried the effects of the medication cocktail on Sarah’s day to day problem solving but realised it was not easy to comprehend these effects when you feel low.

Sarah did talk about coming off medication at times after a ‘wind up’ from doctors about her smoking. In some instances she stopped taking a number of medications for a brief time but it was usually a response in asserting her control. At times she wondered what her real self might be minus the medication. At these times I cautioned her about the likely withdrawal effects if there was not a structured cut back with medical oversight. At the same time I affirmed her desire to reduce the cocktail. Hospital admissions and visits to the physician were the main times when medications were reviewed.

hospital admissions

The hospital admissions of 1997 and 1998 did not feature to any great extent in Sarah's telling of her story. After the hassles of 1994 –1996 they appear to have been seen as necessary intervals in getting through the year. Sarah appeared keen to go to the hospital. It was a chance for her to hand over her load to someone else for a short period. However, we nurses remembered that admissions were not always a good experience for Sarah. Sometimes she perceived she received minimal attention. Other times staff lacked sensitivity to her circumstances and a second level nurse was assigned to this complex person. From her go-between standpoint Rose observed that the hospital admissions could sometimes end up as a "*battle*" for survival for Sarah. I pondered the term "*battle*" which is a metaphor of living in Sarah's story. In this instance it explained why Sarah, at times, returned from hospital worse than when she went in. Here was another paradox, she went into hospital for relief of symptoms but came out worse than when she went in.

During 1998 I had some discussion with the physician about arranging an admission for Sarah before acute situations arose. The discussions did not achieve any agreement as there was increasing contract pressure to admit only acutely ill persons and for short stays only. I had come to understand that, from time to time, Sarah needed a rest from herself and her day to day coping. Sarah would express that she needed someone else to care for her for a period to enable her to keep going on her own. My understanding of her explanatory model had emerged at that time. I explored alternatives to the acute hospital but there were very few available in the region. We discussed the alternatives but Sarah's preference remained that she go to the acute ward.

Rose and I had at an earlier time, discussed my insight about needing a rest from herself. Mary had not been part of those discussions but affirmed alternatives to acute hospital as a good option for Sarah; a place to go when feeling low but before the development of a troublesome chest infection. We imagined an alternative where Sarah could be nurtured, have the burden relieved for the period and carers who would act as her friends. It would be something akin to the European spas attended by people in nineteenth century

historical novels; not an option that is highly regarded in the increasingly functional public health system.

The length of time in Sarah's hospital admissions decreased from approximately twenty three weeks each year in the 1995-6 period to approximately six weeks the 1997-8 period. Nevertheless Sarah did not see this as a good indicator of her level of wellness. Life at home continued to be a struggle much of the time. However, having things to do and professional friends aided her progress.

sharing our interests and ourselves: facing inherent dilemmas

The notion of traversing a fine line through particular layers of care with Sarah came up several times in the team's research conversation. Mary observed "*I think there's this very fine line, ... between being a nurse and being a counsellor, being a friend, it's not a black and white thing, is it? It's part of nursing*". After Christmas in 1997 Sarah's family all went away for six days. She had known about it earlier and although nervous did some planning. "*I had arranged with you that I went into your place one morning and had morning tea with you, and another day I went to Te Papa with Mary. ...I remember going up and I had a meal at Edna's place one night, and things weren't as bad as I thought they'd be because I had things to do and I was busy*".

Mary and I confirmed that our approach did take on being a friend to Sarah so it was consistent to have contact outside the Monday to Friday 8-4.30pm work hours. Mary felt comfortable with her approach but was mindful of having observed nurses who had become over involved, creating dependence on themselves, rather than extending work time therapeutics with some out of work therapeutics. "*I guess I checked whether I was too deeply involved when I invited Sarah to Te Papa and invited her home for a coffee, but I had another friend there so it wasn't a therapeutic visit*". In actual fact this was another paradox as it had been very therapeutic for Sarah.

Rose offered an observer perspective on inviting Sarah into our personal space. Her first reaction on hearing about it had been "*Oh stepping out of boundaries*". However, Rose decided "*you did it in a way that wasn't overstepping the boundaries, just caring. I*

suppose it's the difference between confining your therapeutics, given that you are both significant people to Sarah's life, to her care, confining that to eight hours, forty hours a week, and then if Sarah has a need, like you were able to see the bigger picture". Rose saw that it wasn't a response to our needs, as it would have kept on going if this had been so. *"You also weren't so clinically focussed that you sort of said 'Oh there is no way I can stretch my care to that, the loving caring person that I am ends at 4.30pm'. So you both went into that fully aware of what you might be getting yourself into. A junior nurse might not have been able to do that. It takes an experienced nurse to be able to do that".* Nevertheless, Mary and I were in firm agreement that clinical supervision is a must when we are pushing the boundaries of our caring gaze.

Sarah took interest in what we did in our lives and shared what happened in hers. These interactions helped Mary see that loneliness was a major concern for Sarah. Mary tells of the time Sarah reported to her *"Margaret's having a grandchild, and Sarah really loved it, because she's so family oriented herself"*. Another time when I had shared an anecdote concerning one of my daughters, Sarah responded that I needed to take some of my own medicine and believe *"change is possible, anything is possible"*. Sarah had been very pleased with herself catching me out. Rose remembered sharing a snippet of her life and how that delighted Sarah. *"I wondered whether I'd stepped over there. But I wasn't unhappy that I had"*. Sarah had reciprocated with a sharing of her life. *"We've started talking about life things rather than sickness things now over time"* Rose mused.

Additional 'fine line' issues for me related to my role of therapeutic listener. Did it effect further strife too much dwelling on the illness or did it encourage dependence? I believed that I was facilitating Sarah's process of moving out of strife and hoped at some stage she would find that her burden had become light enough for her to get on with life without the need for so much nursing involvement. Mary saw it this way *"I see it as giving her time for emotional ventilating. Sarah's got insight, she's a very intelligent lady. She's unable to change the way she sometimes thinks, feels and behaves. I don't think it's something that happens quickly or without a lot of professional input. ...I don't see the relationship between you and Sarah as a dependent or co-dependent relationship"*. Mary

believed I had the practice wisdom to navigate this fine line and recommended a gradual withdrawal rather than an immediate cutback related to lack other support there for Sarah.

Sarah did have access to home phone numbers but was never encouraged to call at any time. Sarah never misused this in any way. We acknowledged that when a vulnerable person knows assistance is only a phone call away, it often works to reduce anxiety that may develop otherwise. In actual fact Sarah was sensitive about not intruding into our private lives. I initiated phone calls between visits from my home or office, when I believed Sarah was quite at risk of deterioration, until improvements were evident or an admission arranged. Sarah's feedback on the use of phone calls in between visits affirms this strategy as helpful. *"It helped in the way that I could vent it rather than building it up in a sense"*. If Sarah felt bad on a particular day she knew help was at hand without having to request it or wait a week. *"I personally had the support today and I could tell you, like giving it to someone else, hand it over. And I had some feedback on it, had some suggestions to cope with it and someone there caring for me was a big thing. Some days when I was feeling so bad ...I couldn't wait for you to ring. It was an urgent feeling. It (the phone call) was good"*. The caring gaze or the ventilating of her burden could go on without being physically present to each other. This, I believe, had evolved from consistency and trust within the relationship.

responding to multiple symptoms and discomforts

All nurses responded to the exacerbations of Sarah's different symptoms like anxiety, respiratory distress, interrupted sleep, tiredness, oedema, loss of appetite, constipation. Practical strategies that might mitigate them were offered.

Rose saw the big part of her role as *'my in-betweeness'*. She represented Sarah to the respiratory service and represented the respiratory service back to Sarah, Mary and I. Her primary focus was to assess Sarah's respiratory function. Rose recalls that most of the time Sarah's tests were within normal limits. Sarah kept her own record of peak flows that was monitored at each visit. The peak flow results varied from very low, under 100

to something reasonable for Sarah that was between 300-400³. Mary revealed how hard it was to gauge Sarah's breathlessness in relation to peak flow readings. She learned not to panic, as they needed to be taken into account with all other aspects of Sarah's day to day living. I noted that Sarah understood that she functioned below what was considered to be peak flow norms but not without a struggle. Kim talked of the distress that breathing difficulties must incur for Sarah and related it to her experience of a bad cold, "*it would be 10 times worse for her*".

Sarah's physician always took a firm line on Sarah's smoking. Rose related a story about her discomfort when she was asked to attend a 'wind up' he gave Sarah on smoking. After these sessions Sarah often became fearful and angry hearing above all else a statement about the physician not being able to do anything more for her. Rose and I visited Sarah together after this particular episode to clarify what had been said and clarify our positions in relation to smoking. Rose put it this way " *'we're here to support you if you want to make any efforts to stop' ... because we presume Sarah would very much like to not need her cigarettes, she knows the role that they play*". We were clear that our practice with her did not involve policing her smoking. There were times when I reminded Sarah that smoking was part of her distress. At the same time Sarah reminded me how stressful it would be without it. Smoking was another paradox in Sarah's strife; it added to her burden and was a comfort in relieving her burden.

The need for Sarah to use oxygen decreased over time. In early 1999 Sarah commented "*I thought perhaps I've got to a stage where I might not need it and I tried the night of Sam's wedding*. Sarah discovered she still needed it at night. However it helped her see that "*before I couldn't go anywhere without it. ... I felt like I was caged in but needed to get out as well at the time... I've come a long way since then*". Her life had become more 'normal' than before when it had felt 'abnormal' and 'caged in'

Interrupted sleep and restlessness appeared to be deeply embedded in Sarah's life. These resulted in a general fatigue and falling asleep whenever she became relaxed, which

³ Norms for an adult female are around 400-500. However these always need to be read in relation to what a person's special circumstances are at any given time.

bothered Mary as it posed risks to her physical safety. Both Mary and I put considerable effort into promoting relaxation, rest and sleep. Mary recounted *“Sarah would fall asleep at the table early, burn the tablecloth at some stages, and then she'd go to bed and miss TV”*, something she had often looked forward to enjoying. In dialogue with Sarah both Mary and I worked hard at endeavouring to improve these patterns. However, Sarah could only work at them for a limited time and then something else took priority. This also happened with other suggestions we made. We believed that Sarah, like us, would want to feel rested. I needed to remember my commitment to her process, not my own.

Sarah remembered the attempt to change the rest and sleep pattern. *“I didn't have the energy then. I was too agitated to rest. Instead of sitting down for a moment I would go and walk in the rooms. At night when I get up now I don't sit down I keep standing. ... In the middle of the night I feel I could be doing other things. While I am just standing here during the day I feel, whether I deserve it or not, I feel I can't do that I might be lazy. I know I have become lazy in certain things and I don't want to become totally lazy”*. A strong work ethic is another value constituting Sarah's strong drive to achieve her goals.

The experience of severe oedema, at times, interfered with Sarah's daily living. One such episode occurred after a hospital admission in the latter half of 1998. A range of nursing measures were of limited help. Her physician reluctantly increased her diuretic and eventually the oedema subsided. Sometime after the oedema reduced I observed that the diuretic dose had not been decreased. I discussed it with Sarah who talked to her physician the next time she visited and it was cut back. It appeared to me that prescribing the 'medication cocktail' always seemed easier than ongoing close monitoring of responses. I did not want to be in a medication surveillance role as Sarah had regular outpatient's visits to her physician, but I did want the best outcome for Sarah.

Mary discussed the value of pet therapy with Sarah and helped set up trialing a puppy. Sarah recalled this initiative. *“Mary took me out to get this dog, which I was quite keen on having. I brought her home, and we had her for three days. I found she had to go back because I was just wheezing and coughing every time I went near her, which was sad*

because I enjoyed it". This was another example of Mary's 'pushing the boundaries' of the service to provide therapeutic care.

Once when Sarah was experiencing a 'better time' Mary thought she might be able to manage a small job. Mary put considerable time into finding out possible options. She contacted various agencies and talked to a friend who ran a hairdressing salon about some temporary reception work. *"Sarah would have been really good and my friend would have loved to have had her even for just an hour on a Friday but I never quite got her there"*. We discussed Sarah's lack of readiness for this type of stepping out. Rose reflected *"Sarah doesn't respond when we suggest jobs or other things because in actual fact at some stage she would probably do it herself"*. I now understand that as long as Sarah is heavily burdened with her illness she will not be able to consider options like stepping out into a job. It is as Rose comments *"Sarah's not actually asking us to live her life or to solve her problems"*.

walking along together with the interdisciplinary team

Mary, Rose, Kim and I were all mindful that other health personnel also walked with Sarah sharing her burden in different ways. An interdisciplinary dialogue was occurring throughout our journeying. Rose, the physician and I were a continuous presence but others came and went.

Mary expressed disappointment in the six monthly change of psychiatric registrars⁴. This meant each new psychiatric registrar grappled with Sarah's complex history then moved on. It also demonstrated several different approaches to care. Mary believed that my active listening to how her illness burden was affecting her day to day experience was as instrumental in assisting Sarah as an appointment at the psychiatric clinic approximately 20 –30 kilometres away. *"Sarah trusted you with her intimate detail, she was really bearing her soul at times"*. I can see that this was likely but also observed that Sarah found the psychiatric input more helpful when we had reduced our visiting regime to once a week or fortnight.

⁴ medical doctors who are undertaking their psychiatric clinical experience for credentialling as a psychiatrist so rotate around different areas of psychiatric services.

Mary recalled “*there was no real psycho-dynamics, as I saw it, being done with Sarah, no crisis counselling*” which led into too much emphasis on the ‘medication cocktail’ rather than finding the right counselling approach for Sarah. I saw that Sarah had been offered some of these specifics but she had not liked the approach or felt ready to take them up. Rose remembered the physician clearly delineating Sarah’s need for psychiatric expertise as outside his respiratory expertise. He also talked to me about his hope that the psychiatric input would help move Sarah out of some the conflicts she had with her family.

When I had concerns for which I believed a medical opinion was required I would either talk with Rose who presented the material to the physician or I would talk directly to him. Occasionally I went with Sarah to her appointment with the physician if there was an issue Sarah wanted help in working through. However, I decided this could be disempowering of Sarah telling her own story so held back from further joint visits. I encouraged her to write the things down that she wanted to discuss and assisted her prepare this list at times. Mary affirmed my decision not to attend the appointments as she believed my presence might interfere with the relationship that Sarah had with her physician.

In the course of the research time period I had two significant differences of opinion with the physician regarding Sarah’s care. The first one related to cutting back on the morphine (MST). I was concerned about the many side effects from morphine which were part of the ongoing discomforts experienced by Sarah plus the fluctuating nature of her pain. If it could be cut back when her pain was settled it could be increased again when the pain was more difficult. Sarah was loathe to let go of her morphine elixir as it gave her control of fluctuating pain but at times appeared agreeable to cut back on MST. However the physician saw that her pain treatment fitted the palliative care model where MST is increased to cover break through pain and reduction is made in the use of the elixir. I argued that Sarah did not fit that model and was prepared to cut back her MST. The physician’s response was to refer Sarah back to the chronic pain specialist who left things as they were. The second difference in opinion related to getting Sarah admitted to

hospital when she was beginning a downward spiral in order to prevent the development of an acute episode and the aggressive pharmacological treatment that went with it. I was told that the medical ward was not a respite ward. Nevertheless, I did achieve some earlier admissions when Sarah was deteriorating that I believe prevented the onset of an acute attack.

My need to communicate with the GP decreased after the crisis with the morphine withdrawal. The physician had concluded, after the crisis, that it would be best if he kept the overview of prescribed medications. Sarah still attended her GP for any concerns in between her appointments with the physician and the GP would talk with the physician directly. I did not need to be involved in this loop of communication very often.

After her initial assessment of Sarah Mary made a referral for her to have community physiotherapy. At the community health base building the physiotherapist's office was close to that of Mary and me. This allowed us to work closely together and share our ongoing insights. The first physiotherapist attended Sarah for approximately a year and was replaced by a second in 1998. Sarah became very fond of both these women even though there was a period of adjustment to the style of the second physiotherapist.

Sarah also had home help from an outside agency. Mary or I became involved in this from time to time in relation to Sarah's expectations of the service. Sarah had high standards in household upkeep and the workers didn't always share these standards. I also made a referral for a new assessment for home help when there was a change in the providers of this service.

maintaining an informed nursing approach

Keeping each other up to date with Sarah's condition was done with both verbal and written exchanges. As the primary nurse I set up the written documentation system which Mary found effective. *"I always got feedback from you and the notes were so well written"*. Notes from each visit sat in the house until they were summarised, in the early period once a week and later once a month. Sarah had access to nursing notes and summaries and was encouraged to write in them. She would read the summaries and add

or correct things before signing her agreement with them. This encouraged involvement in her care and openness to what was written about her. This is the system that Rose referred to in saying *“I went in there absolutely nervous because I’d heard about these screeds in the notes that you guys wrote ... I just wrote clinical notes”*.

Other times the focus was on feedback from Sarah. There were several times that we structured informal feedback. Mary and I went in at the end of the first year and evaluated her long term goals and set new goals with her. I repeated this exercise at the close of the second year. In addition, I often asked Sarah if she was happy with Mary and me or if she would like someone new. In the winter of 1997 I went to the hospital ward where Sarah went when she was admitted to hospital to talk with the nurses about the approach we were practising in the community as an endeavour to obtain consistency across boundaries between the hospital and community.

changing along the way

Sarah’s movement out of severe strife was taking place ‘along the way’. Mary observed Sarah processing her feelings verbally, using oxygen effectively, resting when breathless, being aware and accepting some limitations, reciprocating warm relationships with her children and neighbours. *“Sarah made big strides in some ways, now and again she had a step backwards but not the huge, huge impact it used to have before”* noted Mary. Encouraging change is something that Mary saw as needing careful consideration. She regarded timing and *“in-depth knowledge of the client and the workings of that family”* as vital. The most notable change, according to Mary, was improvement in Sarah’s decision making.

Rose wondered about the notion of changing in relation to care being offered and given versus a person seeking care. *“It always seems to me that there’s a stage of depression where you actually can’t do the simplest little thing to move yourself out of it, ...I think it’s something to do with her motivation or belief in it, I think she’s low enough in her mood to not take that move to let go of something that’s been part of her life”*. Rose discerned that the burden of illness would continue as long as Sarah lived with her huge grief. Rose’s theory is that grief needs to be replaced by new significant event in a

person's life "a *reason for being or loving or touching or whatever*". Sarah understood this notion as expressed in a response regarding developing the new garden. "*I've lost so much in the way of family that I've got to love something else*".

When working with people experiencing strife another 'fine line' judgement is required in closing a professional relationship. In 1998 Mary came to see that her role in Sarah's care was no longer necessary. The visits had decreased to weekly consultations and it appeared one generic nurse, myself, would be appropriate. After some initial dialogue with me, Mary began to look for the right moment. "*I wanted to withdraw because I wanted Sarah to be more independent ...and she was*". I knew Mary, carrying Sarah's history, would be there to be a backup if needed. Mary commented that she has retained a friend role with Sarah visiting her at the new home and taking an interest in her garden.

Sarah's move to the new locality became imminent. Oscar decided he would be leaving home earlier than originally planned. Her other son Sam, twin of Oscar, decided he and his partner Michelle, would move to the new town. Sarah reflected "*I knew I really couldn't stay and look after that house on my own. So, with that in mind I decided it was time for a change*". She would have preferred to stay in her former locality but that was not to be. After a number of negotiations within a short period during October/November 1998, her former house was sold and her present house purchased. As it happened Sally, Sarah's friend, was also looking to move and bought a house in the same location.

Threaded through the events of this section of the narrative is a continuation of the metaphor of Sarah's venting or ventilating her burden as an effective way of reducing her strife. A co-constructing of her health circumstances, involving the caring gaze of nursing, happens within this process. Nevertheless, paradoxes within her circumstances are evident. There is also ongoing evidence of the de-humanisation or de-moralisation metaphors of 'caged in', 'freak' and 'raving lunatic'. Threats of suicide are closely associated with her sense of these meanings in her life. These are countered to some extent by her drive in achieving positive experiences. In addition new metaphors of practice have emerged; 'pushing the boundaries' of practice and 'walking fine lines'. There is also an alert to the difference in Sarah's norms and our nursing norms.

The big step into living alone with some stumblings in a roundabout ⇔ changes in nursing approach and in the nursing service

consequences of the move

The move to the new location in early December 1998 and learning to live on her own involved Sarah in some unforeseen consequences in the roundabout of change. She talked of her first few months in the new home as a “*nightmare*”. She had cut herself off from Mary, the physiotherapist and me. “*I’d made this decision, I’d made this move, and I’d put myself at risk. I didn’t know how to fix it. It just seemed to get worse and worse. ... I don’t know whether it was a combination of the move and the stress that I was in hospital four times*”. It was the repeated admissions; out for a few days then in again that worried me. I saw the possibility of a repeat of the 1994-1996 interval.

More community health changes, related to the streamlining of the contact by the regional health purchaser of the service, had occurred in February 1999. These changes altered my geographical boundaries and officially put a stop to my working in Sarah’s new area. At the same time the changes brought with them considerable disarray in the district nursing team in the new location so I continued to visit Sarah, albeit less often, after the settling down period from the repeated hospitalisations. Sarah recalls “*even though you still came here, you weren’t as easily accessible. I couldn’t ring you and say, ‘Well, if you’re around can you just pop in. ... I actually feel really bad but am I really as bad as I feel’*”.

A new district nurse in the new locality was assigned to Sarah but as it turned out in the disarray of the change this particular nurse moved from the area soon after this contact. Asked if more nurse visits or phone calls might have staved off admissions Sarah responded “*I don’t know whether it would have stopped an admission because I felt pretty bad and I wasn’t coping with the heat*”. The stumblings did not aid Sarah’s fragile confidence. She experienced confusion about the inconsistency emphasised in only being admitted if in acute distress and some ward staff saying she should have come earlier. She didn’t like to get to the hospital and have it said “*we’ll keep you for a few hours and go home*’. *I know that’s not going to fix it; ... I can still feel it, that one day I think I’m going to die on the motorway. I feel I’m stuck*”. Sarah talked of a shift in house as easing

her son Oscar's leaving home, but it had not. Moreover she "*felt that I'd issued my death warrant*". This all combined in Sarah "*feeling quite panicky*".

I acknowledge Sarah's fear about not making it safely to hospital but remind her that hospital isn't always a safe place today with MRSA, the notion of admitting only really acute people and how, at times, she comes out more distressed than when she went in. Nevertheless hospital is acknowledged as a resource for Sarah who relates it to emergencies; "*especially because things can happen so quickly. Like I have been in ICU, things happen so quickly, that's when I think it is safe to be there*". I mention that Sarah has not been in ICU in the 3 years I have worked with her but note that it had been considered at one of the January admissions. Sarah's hardest time is feeling ill but being uncertain if she will come out of it or deteriorate. "*I suppose that when I am going that way there are so many factors that come into it. They are fighting one another: I have got the distance to travel, may be they are full up there, may be they won't take me, maybe I should stay at home*". Her vulnerability and burden is exacerbated by the uncertainty.

Sarah recalled a session about her smoking given by her physician at one of those January 1999 admissions. She reflects "*I rely a lot on him and I do get upset when he does that ... it hurts more. Where, if it was some other doctor that said that to me, I would be angry and that would be it*". Sarah goes on to talk of this episode in the context of her major change of living on her own. "*I know that they keep going on every now and again to me about it but I can't do it. ... I'd got the impression that I was told if I didn't stop smoking they weren't going to treat me.... I couldn't do what they want, and I needed to smoke because it was the only thing I had anymore... and it's not just a pleasure thing, I've got to have it. I feel desperate for it.... I can totally understand how he feels, but I can't do anything about it*". Sarah believed that her physician and others in the hospital didn't understand her side of the story, her present context, and how difficult it is to stop smoking. Furthermore, the determination of the hospital staff had the opposite effect as it brought out "*her stubborn self ... with some people the way they go on makes me all the more determined in a way ... (but) I would give anything to not want it*". Sarah tried ceasing smoking in structured programmes; "*I have been to hell and back with it but also it is a comfort to m.... It would certainly save me a lot of money.... Sometimes when I am*

feeling really sick with the illness I think I have just got to carry on because I want all this over quickly". Sarah clarifies this last comment when asked as *"smoking will bring about the end more quickly. It's going to happen. I'm just speeding it up"*.

Sarah cogitated further on her setback in January and February, 1999, *"I did things on the spur of the moment, which a lot of them I do.... At the moment (December 1999) I feel that I'm trying to get through the best way I can, coping with one of the worst decisions of my life. ...I don't know when it was that it really hit me, or how long I was here before deciding it wasn't me"*. Simultaneously Sarah was working on settling into the new place. *"I like the house but I don't like where it is ... I'm trying all sorts of different things to make it feel like home"*. Sarah experienced ambivalence about the move and appreciated the paradox of her smoking both alleviating and exacerbating her burden of illness.

a grand effort

February saw the preparations for Sam and Michelle's wedding come to fruition. *"I just didn't feel I could cope with it all. I didn't have the physical energy to cope with it because I was just zapped. I felt that I had to push myself a bit, which was one of the times that I ended up in hospital"*. Sarah was involved in baking the wedding cake, embroidering the bridal outfit and other preparations for the wedding. Over this time she was also experiencing vomiting and diarrhoea, probably associated with antibiotics, which compounded her low energy. A particular achievement was the speech she prepared and presented. *"Everything that I had I put into that day, because I felt I had to do that, I owed it to them to do it. ... I felt I've let them down a lot of times in what they've gone through for me... I made it through that day anyway but it did catch up"*. The three week honeymoon time meant that Sarah had no family nearby. *"I felt terribly insecure"*. However, Sarah's daughter Anita, her partner and three children moved to the same area at the end of March 1999 as the newly married couple returned. So now two of her children and their families were now in close proximity and provided company and a sense of security for Sarah.

a change in nursing approach

I always encouraged Sarah to make some changes that could reduce some of the hassles in her day to day living. But it was after my alert from the January-February 1999 admissions that I actively encouraged change. I had now shared her illness journey for two years and believed she trusted me to work with her. In addition the research had commenced and I was under clinical supervision for the research. I used part of my supervision sessions to work out strategies and evaluate effects. I did not confront the smoking issue, as I knew its role in her life. I believed small changes can have big consequences as they help people see that they can change. In the dialogue Sarah and I had about incorporating strategies to help her move out of strife she noted that change would be very scary, but agreed to participate in some structured exercises. I used affirmations, encouraged journalling (writing issues down to help get them out of her system or to remember them for another time), accentuating the positive and enacting some mini rituals on transformation. At the same time I appreciated that inviting Sarah to view her world differently in the midst of the burden of illness could be threatening.

March, April and May 1999 were reasonable months for Sarah and this was the time when the major component of the structured work on change went on. In a research meeting I encouraged Sarah to comment on the changed approach. *“To start with sometimes it used to annoy me ... I was feeling what’s the point of all this? What’s this going to do for my physical condition? And yet sometimes through it, it was all right and it made me clear on different things from the past and when I was actually seeing different patterns come out through the years. The part I didn’t like about it at times was that it was too hard for me. It felt like I had an enormous amount of homework to do, ... because it’s my life, it’s hard.... I might have felt lousy some particular days and I couldn’t see the point, ... but other times I enjoyed it. ... It gave me a lot to think about. It was digging deep into me”*. Sarah recalls the difficulty and effort that goes into each day. *“ Since I’ve been really unwell, the things you take for granted, getting up, getting ready for your day ahead or having a shower takes ten times the effort or even more. So anything else on top was just so much harder for me”*.

Some positives did emerge. *“It showed me that I can keep going, the different strategies and ways that I could cope with things, and different ways of applying them. Ways of getting through being on my own. If it was last year when I was down at the other place, when I was feeling unwell down there, I would think that I could never get through it on my own or without someone being in the house. I know now there’s no choice, there’s nothing else you can do but do it. ... Sometimes I could apply them, sometimes I didn’t want to. Sometimes I couldn’t. Probably I felt too low. This here like’ my deep inner strength is keeping me going’*, (Sarah was referring to an affirmation in the nursing notes summary in front of her) *I knew before, all I could think is there’s a drive there. Putting it down there, well it’s more real and I can see it a bit more. ... When I’m in the right space and right frame of mind, it’s giving me a bit of support, a bit more confidence. ... In thinking about the Court case I probably would have thought, ‘I can’t do it, I can’t do it’. I can now think - Well, ‘I’ve got to do it’. ... It’s given me different ways of looking at my fears emotionally but the physical ones they’re in far deeper when I’m ill”*. I was pleased to hear her impressions some time after the event as I had wondered if I had been too directive. I had walked another fine line.

consequences of an intensive primary relationship for other nurses

In April 1999 as the initial disarray of community health change began to settle Kim was asked to attend Sarah. Kim and I had discussed her history with the new clinical nurse specialist in Sarah’s locality. In our research reflection on these changes Rose raised the issue, for other people in the team, of difficulties that may follow the setting up of an intensive relationship. For Rose it was *“the crux issue of prolonged engagements”* and one she saw that would be different in particular circumstances. Rose, entering Sarah’s care some months after me had observed the focussed relationship that Mary and I had with Sarah. She saw that I had eased Mary into the relational way of ‘being with’ Sarah. Rose had felt some trepidation about her ‘fit’ in the established relationship as she had enjoyed relational nursing in the past. Nevertheless, Rose made a decision to keep a clinical focus. On reflection, she was seeing that it was hard for Kim commencing with Sarah when movement from the severe strife had occurred; hard for her to appreciate the history and purpose of what we had set up, especially if she didn’t feel the same way.

Kim attended three visits to Sarah with me as a strategy for easing her into the care. It was the time I had been working on structured strategies to assist Sarah deal with her cycle of hassles. Kim was impressed with the structure but remembers “*I made it quite clear to you that I could not be you.... I knew I couldn’t just step in and continue where you had left off. You and I had a talk and I said ‘I would be happy to continue as a visitor, nurse, friend’.*” In observing the focussed relationship Kim interpreted it as a therapist role with Sarah. The major question for Kim was not about the difficulty of picking up the relationship or establishing one as a professional friend but a moral one, a philosophical one. It was “*What did I believe was right for Sarah?*”

Another one of the fine lines I walked was my ‘staying in’ or ‘being there’ for Sarah after I left the nursing service at the end of August 1999, three months before the close of the research period. Did my continuing presence, albeit it on a friend/researcher basis of seeing her approximately fortnightly for approximately three months inhibit the development of a relationship between Kim and Sarah? In response to my query Kim noted that she has been pleased I was there and recalled “*I was apprehensive that when you went that Sarah was going to change but she hasn’t.... She had that bad patch with the difficulties with the family. Also her friend died and she went to hospital*”. Kim returned to her philosophical concerns. She had hoped that Sarah would demonstrate some of the skills she had been taught by me and other nurses and didn’t see these in action. “*It was the telling point for me. It made me question the nursing input up to that point given that Sarah still seemed dependent*”. From this viewpoint Kim’s preference for Sarah was “*skilled counselling from an appropriate professional, qualified to practice in this area, rather than from individual nurses who lack expertise and do not necessarily have an integrated approach to management of care*”. Kim wondered if we had unwittingly encouraged dependence. However Mary, Rose and I saw that our approach had assisted Sarah’s movement out of strife and the dependency that was associated with it.

My closing of the professional relationship was less clear cut than Mary’s had been. Leaving the service could have been a time of closure for me but I offered to keep in contact for a period if that was what Sarah wanted, as Sarah had just experienced a low

time. I did not want to move right out if it was going to knock Sarah back. On the other hand I did not want to foster dependence or stop Sarah getting on with life. In early August I told Sarah that I would be leaving the service at the end of the month. Sarah looks back at that time. *“I felt awful but I felt pleased for you for what you were doing and although you had arranged with the service up here to continue I was counting down till the time came”*. Sarah remembers feeling bereft at the time. *“You had said to me that you would keep in touch and see me if that was what I wanted”*, which had helped alleviate her sense of loss. However Sarah recalls *“I didn’t want to interfere in your new path but I knew that if the worse came to the worse I could phone you. ... I don’t think that I could have coped with the transition with Kim and what has gone on if I hadn’t had contact with you. You haven’t stopped me getting on with my life. ... We have done other things, had lunch, gone to garden centres, that is taking another step it has made me feel more normal. ... I think now I am more independent, I am”*. I affirmed how good it was to hear her say she was more independent.

I commented that it was hard for Kim to come in after our in-depth relationship. Further, I remarked that our relationship could have created a double bind situation in which it created difficulties for someone else to continue and left her without the support she needed. Kim had seen that she could not work at the level I was working at. Sarah saw it more of *“a non clicking as far as knowing what has gone on for me. ... As far as the involvement with you, other people might think you were too involved but I don’t think that. I don’t think I would have come as far if I hadn’t had your support”*. Sarah also acknowledged the support she had from others like Mary and the physiotherapist in her former location and noted *“I had had a new person up here with Pip ... she fits in with me and I fit in with her”*. Pip was her new physiotherapist. This discussion confirmed, for me, my decision to offer Sarah ongoing support after leaving the service.

Sarah referred to rises and falls in her confidence in the discussions. One of my goals from day one had been to assist Sarah build up her confidence in judging her health situation. I ask to what extent this had occurred. Sarah reported a loss of confidence following the move. The new environment *“was so scary”*. It brought back all the uncertainty of her making it to hospital when acutely distressed. With this, plus all the

1999 issues Sarah said “*I lost some of the confidence I gained. ... I can’t help feeling that I am being punished for something. ... My kids have stood by me and if they hadn’t I doubt whether I would have been here today*”. As she noted above, the fear associated with her physical illness is deeply ingrained and rises to the surface readily when there is a serious threat from her disease. Major disease exacerbations do increase Sarah’s burden of illness and slow down movement out of strife.

Sarah continued about the stress her children have experienced with her illness. “*They are too young to have gone through what they have been through. They don’t deserve it. I have become a bit of a burden*”. She sees that by ventilating her emotions to me “*it has lifted that stress from them.... There wouldn’t have been the same outcome cause I was very conscious of putting that stress on them*”. From her perspective not only could she breathe easier but “*they could breathe a bit easier*” also. I am mindful that ventilating her stresses to other health professional also assists lightening the load for her children.

A short time into July 1999 bought the sudden death of Sally, a special friend. “*I was so involved and I wasn’t really with it*” Sarah recollected. She realised that busyness and some denial got her through the “*utter chaos*” of that time. Sarah remembered “*I had been without (medication) because I was in the hospital with her. ... I was in agony. It was absolutely dreadful and right through my body*”. The GP gave her a tranquilizer that “*knocked me out, I needed it because I had all the arrangements to do. ... I felt that the only friend up here that I had, other than my kids, had gone. I just felt so alone. In the weeks around the time I was involved with all her personal affairs*”. Sarah told of visiting her friend regularly for the company and comfort of their relationship. It helped diminish her load. “*I think it probably hurts more with this family thing going on. I haven’t got support from them when I felt I needed it*”. I affirmed the marvelous contribution Sarah made during the process of Sally dying and afterwards and acknowledged the further loss and grief for her.

Sally had also lived with family tensions so Sarah had a special empathy in relation to this and felt obligated to advocate for her friend’s wishes. It was a time when Sarah really would have appreciated some sharing of the burden with her father but a few days after

the funeral he visited to ask for the money. *“I felt I was getting kicked while I was down.... All of a sudden I had this big dilemma and it has been going ever since. I hadn’t time to finish the grieving”*. Legal negotiations over the money ensued and a court case was pending. The combination of living close to her father and the sense of having made a poor decision in buying the house led to Sarah to placing it on the market for a short time but after consideration of all her issues she decided not to sell at that time.

Sarah had attended the CORD (chronic obstructive respiratory disease) group with Sally in the first half of the year but had not managed to keep it up. She had visited the psychiatric clinic more often and it fell on the same day as the group met. The person who ran the CORD group happened to visit Sarah in hospital in August. They had talked about Sally’s death and Sarah felt she had got to know the field officer more as a person. Sarah expressed a desire to return to the group but observed *“I haven’t had a link again and it is going to be hard for me to go back on my own as I always went with Sally so that’s going to be a challenge if you like”*.

distracting herself from ‘the huge awful thing’

After Sally’s death and an August hospital admission Sarah then had to deal with the threat of a court case initiated by her father. Sarah planned distractions from the *“huge awful thing. ...The thought of it all happening and it being my father is churning my guts up”*. She visited her son, Toby and family, at the weekends. Her thinking was *“I’m putting all my physical energy into a physical activity and I know at times I’m going overboard. It might be affecting me physically but it’s a protection for me from going insane and I can’t get that fine balance. But also going from my past that if I can do it today I’ll do it because I don’t know what it’s going to be like tomorrow”*. Sarah remembered that in the past *“I had got to the stage where I couldn’t walk. I was in a wheelchair because I couldn’t breathe to get up from the chair to the table”*. I observed that it is a good philosophy to live day to day but overdoing it can be part of not being able to finish a task the next day. However, Sarah saw it differently. She maintained that the memory of paralysis made her take every opportunity to do normal things *“... I’ve been doing sort of normal things with people. ... It’s just made me feel a bit more human being able to go and do something like that”*. In fact, the physical activity at her son’s

place did not precipitate an exacerbation of her disease. The sense of normality obtained from it appeared to re-moralise her from the de-moralising effects of the pending court case and counter any onset of acute disease.

the ongoing struggle

Within Sarah's suffering was an endeavour to make the most of her home situation. "*I'm doing what I can to try and make it more me. The boys put up that fence to make me feel a bit more secure, that I'm not just wide open to Dad and the family. That's made me feel a bit better*". Threats to her security brought back the feeling that suicide was an option that will end her burden. "*I feel that I don't want to know about anything and those times have been pretty strong lately. When they've come they have involved a lot of planning, [but] I'm not ready to tell anyone about it because it's going to be my way out*". It was a time of more uncertainty as the court might make her sell her home. "*I don't know what my life holds. ... I am really frightened about that outcome. I feel like a little kid that wants to run to their parents for support to protect me but I've got nowhere to run to, so that's hard to take. ... It's me and I don't want that, I want somebody else to take it from me. I'm not strong enough to keep going. ... I couldn't have got this far without them (the children) but I also know that I need somebody else other than my children to share it with because I don't want to burden them*". Sarah was clearly articulating her circumstances; the times when she felt overwhelmed and wanted to hand over her burden to others and her ongoing need to share her burden with a therapeutic listener.

We talked about Sarah's goal to develop the garden at the new house. I had not visited for some months and saw a transformation in the garden. It looked beautiful. Sarah reflected "*I have been here a year now.... I have to get in there and do it because I don't know what is in the future. ... I don't notice it being a big change*". Sarah stated she could not stand another upheaval of the proportions of the last move unless it was a return to her former area. However she also knew "*that life can't go backwards*". I encouraged Sarah to enjoy and relax in the garden. However it was a difficult exercise for her. "*I am still feeling like when it's a nice day and it would be good to sit out there. I still feel uncomfortable doing that ... I need to have someone there to do it with me. ... I have to go out. I quite often just go to the kid's place. I often sit down outside with them*".

Our discussion moved to Sarah's pain. She noted that her pain has been somewhat better "*I've had moments when it has flared again but on the whole it has been much better*". Nevertheless there had been some gall bladder pain that coincided with a call from the hospital about it. "*They are just going to keep in touch with me about it*". Her pain did flare again and the MST was increased to 100mgms twice a day during a May 2000 hospital admission.

Sarah remarked on a new friend she had made in the new area through the land agent. The woman arrived at her door and they commenced a weekly contact. She described the friendship. "*I look at houses with her ... She tells the land agent I have to get my friend to come along and see this as she's an interior designer. ... So I have had the privilege to go along and have a look at it and she has wanted input from me ... which I felt was good.*" I affirmed this as another step in her 'normal'. Her feeling 'good' countered the many de-humanising things in her life.

This section has focussed on the last year of the research period. The upheaval of Sarah's change of location within her continuing struggle to live with the effects of her burden of illness is apparent. As is the continuation of her increasing clarity about her need for a therapeutic listener. Strategies that Sarah uses to reduce her burden, to normalise her life, are more overt in this section than in earlier sections. The invisibility of Sarah's burden also continues to be problematic for her. Changes in the organisation of the nursing service and introducing a new nurse raised the issue of the consequences of my 'intense relationship' with Sarah for other team members and in particular for Kim, the new nurse who began nursing Sarah. Having worked closely, and I believed fruitfully, with Mary in the previous location I had not given much thought to it. I had endeavoured to ease Kim into her role knowing that nurses develop their own particular relationships.

carrying the burden of illness into the future while expanding her engagement in the world ⇔ reducing the nursing input and examining the options for Sarah's future care, and for others with strife in chronic illness

Sarah's need for ongoing support

Sarah acknowledged that she was getting on with her life better than in the past but maintained she would still like ongoing support in the sharing of her illness burden. At the close of my role in the service she saw her main service support coming from Pip, the physiotherapist. Pip had encountered her having 'a breathlessness turn' and had been instrumental in arranging an overnight stay in hospital a few days after discharge from a six day admission in August 1999. Some tension arose in relation to this overnight admission. Sarah had asked the new medical general practitioner (GP), to be her primary doctor after an earlier 'wind up' from the physician in January-February 1999 and renewed this request after the August admission. Sarah reported his decline of her request. *"I was quite stunned with that, angry. He said he would be my GP for anything else but when it came to that (her respiratory condition) he didn't want responsibility. ... With that news I felt I was definitely on my own. ... I still feel stubbornly angry. I won't go back so really I am without a GP. In a way I should be grateful that he was honest"*. In addition the GP had repeated an earlier admonition about what he saw as her ill-conceived move further away from the hospital. Kim had reassured her he would continue to care for her, but it triggered Sarah to consider returning to her former location because of familiar people being there to help share her load. At that time, it appeared to Sarah that nobody in the new location wanted to share her load.

Nonetheless, Sarah worked at building up her life. *"I suppose that some days are better than others. For a long time there I didn't think I could get through the next day. I think with another change of medication for the depression, I virtually had to beg them to do something because it wasn't working. I think the change has helped but it hasn't cured it, it is still a battle. I try to think like you, think more positive, but quite a lot of time I am on the down side of it all. I feel sorry for myself. Out of the 3 years, this year [1999] would have been the year I have had the most happen beside health things, a mentally challenging and emotional year. ... A lot of the time I am fighting it [her battle] and because my health is alright at the moment [December 99] I am coping, I have survived"*.

Once again Sarah repeated her desire for a ‘medical fix’ but at the same time was trying to develop an emphasis on the ‘positive’ that I had encouraged. She was also distinguishing between her health (disease) and the emotional aspects of her burden.

insight into the contribution of nursing to her care

At the end of 1999, I told Sarah of my major insight about the nursing contribution to her health/illness experience as a ‘sharing the illness burden and aiding safe passage’. Sarah reflected *“Yes it has been like that for me ...all the way through really when particular things have happened. ... Earlier on it was getting through each day with how I felt with my illness and to voice that to you was halving it for me. I was protecting myself in a way through sharing it, that you could decide whether you thought things were good or bad from what I told you and take it from there. ... Also I can get a different view from you if my thinking is particularly screwed up about a certain thing. You bring a different perspective into it that I just can’t see myself at the time until it is mentioned. Sometimes when it is mentioned I can’t see it even then but it is just getting a balance. ...* Sarah continued to talk about the overwhelming nature of her burden at times and recalls *“it used to get on top of me just overwhelm me and I couldn’t function. When I felt like that I thought ‘I’m it, I’ve got it all’, decision making, everything. ‘I don’t want it, I have too much’, ... its overload”*. Sarah talked of the advantage of having someone close to share her load in the way partners do in a close relationship; a supportive partner would advocate for her in particular situations, such as in hospital admissions when there is a ‘battle’. The concept of co-constructing her health situation is also present in this discussion.

did it need to be a nurse sharing Sarah’s burden?

I asked Sarah if my role could have been performed by another health professional e.g. a social worker? She responded *“looking back over the whole, no, because a lot of it had to do with my health. I wasn’t sure or I was really upset. Somebody like a social worker couldn’t have helped and I would have felt ‘what’s the use of saying anything to someone who hasn’t got any medical knowledge?’ ... While I am well its OK, but as soon as things start to go wrong for me that’s the support I really need. No one else could do that”*. Sarah again mentioned the confidence she gained from going out with Mary as an

example of her belief that a nurse was necessary and added; *I have to have faith in you, which I have, like with you and Mary. ...Like you demonstrated to me that you know what you are doing, but it's a bit more as well because no one is the same with their illness."*

Sarah continued *"I don't react like a lot of people would expect an asthmatic to act and you know that, so therefore I have confidence in you. A lot of people don't know that. What you have shown me is that I can be safe, you know how I particularly work. ... Yes, it is definitely that sense of safety, ... people are different, I am not a textbook case"*. I acknowledged Sarah lacked 'fit' with the textbook and noted that less experienced people find it difficult to function outside of particular norms. However she responded *"But even a lot of experienced people... they don't seem to catch on to that sort of thing. I have been through that journey with you and we have encountered different things that come up. I know that if you are not happy it won't be long before you are in contact with me again and I can feel safe about that.... You feel really vulnerable and when you get people like yourself who know it all you tend to latch on there"*. The co-construction of her health status had imbued Sarah's sense of safety and at the same time reduced her burden. I assured Sarah that I did not know it all but I always try to focus on the person and not on the condition; how a person lived with an ongoing chronic illness. These comments lead to a discussion on what is health and quality of life for Sarah. I explain my concept of health-illness. Sarah liked this idea as it summed up how she felt. Her quality of life was about having the health and happiness to join in life with her children. It was doing things with them *"that normal people can do, be a normal grandmother. ...And at times someone to look after me, a rest from being responsible and being 'I'm it' all the time"*.

reflecting on the research process

The research meetings were closed with my asking how the research experience has been and any difficulty there may have been with my researcher and practitioner role. Sarah saw the roles as *"totally different"*. The research provided an interesting opportunity, for Sarah, *"to look back at something (that) at any other time I would not see about myself. ...It has helped in the sense of what I have gone through and has been put down and come back to me. Like when there is a time that has cropped up again I can express it*

more easily ... and knowing that if I do have a flare up it will be easier to relate to how I feel. ... It has given me insight. ... Your reaction, my reaction has been involved.... I can now relate to it easier and when it happens again it will be is much easier to let people know how I feel". On the other hand the practice was seen to focus on her ongoing health needs.

However, from my perspective, the difference in practitioner-researcher role was not so clear. I found that once I had commenced the research in early 1999 it informed what I did in practice and what I did in practice came into the research. A good example of the latter was at the last research meeting when I invited Sarah to talk about the three main positive experiences of 1999, a strategy I used in practice. Sarah, not seeing any incongruence between my practice and research role, spoke of the dissipation of a tension she had experienced with a daughter in law enabling better all round family interactions, news of a new baby expected in 2000 and the development of the new friendship. Nevertheless, Sarah commented *"I feel I have lost heaps ...I think what I am trying to say is that the losses have been so deep so hurtful and ongoing that its hard to appreciate the pluses that's how I feel - I am trying"*.

Sarah kept trying and when we reflected on the first draft of the narrative in June 2000 expanding participation in the world was observed. She had joined her family in staying out of town for a few days over the celebration of the new millennium. Her son Toby had begun his own business and Sarah was working the accounts system for him. This challenged her at times because if she wasn't feeling well it affected her ability to concentrate. It had been a time of connecting with her brother in another city and in February 2000, accompanied by members of her family, she flew to that city and had a few days with him. Easter had brought the wedding of her daughter and much activity involved with it. However, the price of all these activities was to be paid by the subsequent occurrence of a low time. Sarah saw, that at this stage, support from a nurse would have been valuable. In May 2000 a 16 day hospital admission took place nine months after the previous one. For a short time after it Sarah felt well but the events in her life kept coming. A new grandson was born with her attending the birth and she had upgraded her car. The court case stayed simmering the background. Sam and Michelle,

her son and daughter in law and their new baby were planning to stay with her while their new house was in construction. An anxiety in this plan related to a particularly robust dog that would be with them and likely to cause havoc in her garden. After contemplating this quandary for some time Sarah found a solution in asking her daughter to mind the dog. Furthermore, she had renewed her desire to sell the house and move further away from the prying eyes of her extended family. I see these activities as an indication of a reduction of strife in living with chronic illness.

learning from the experience and reducing the nursing care of Sarah

In looking ahead to how we might identify clients who get into strife in their chronic illnesses the conversation included Sarah's experience and ranged over a number of areas.

Mary considered that people most at risk of strife in chronic illness are those with no or limited community support. She affirmed the blessing of Sarah's children assisting her but conceded "*they have their own life in their own relationships*", something that Sarah was aware of. Another group of people 'at risk' that Mary identified are those whose inner balance is upset and "*everything is affected, their relationships, their physical health, their confidence, their ability to cope and their attitude to life.*" Mary stated that "*an up to date care plan is absolutely invaluable in this situation, a long term plan. ...Making a care plan that client takes an active role in, and we did all those things [for Sarah], not what I want in a situation but what she wants.*"

I observed that in my experience, anyone who has a history of illness from childhood and ongoing contact with the health system, especially if poly-pharmacy is involved, could also be at risk of strife. Included are those who commence having repeated hospitalisations in any age group. The other factor I had learned from my earlier research was a 'lack of control' syndrome; a struggle developed to maintain some control and people can end up in strife.

In considering future options for Sarah and others who may experience strife Mary noted the importance of a belief system. She recalled that Sarah did value her spirituality and

saw it could be nourished in creative expression “*music, dance, drama, ... Sarah is a very creative lady*”. Sarah had commented that “*I have always been spiritually aware*” and told of an experience of leaving her body when she was resuscitated. She had been calm, peaceful and without pain, then she had to struggle down a rope to get back into her body. This had led her to believe “*there is somewhere to go, it is not finished here*”. It is interesting to note Sarah’s ‘struggle’ in this experience as it is central in her strife. Mary also sees that “*sublimation*” can be helpful. I recalled that it is quite common for people who are ill who belong to a religious group, to either renew or increase their participation in that community. People see they can hand over their suffering to God on a day by day basis, which is tantamount to having someone there to share the burden.

Other strategies discussed were journalling, mentioned by Mary and books and programmes for people living with fear as discussed by Kim. Community volunteers or friends was an option posed by Rose which she had experienced in an earlier palliative care nursing role. Rose also remembers that the Asthma Respiratory Foundation is a resource that may assist people similar to Sarah. They run information sessions and Sarah had attended some of these. We agreed that any support groups available in the community should always be explored as potential assistance to persons living with chronic illness.

I offered the notion of ‘nursing beds’ or a family nurse practitioner. ‘Nursing beds’ are particular beds set aside from medical beds in a hospital where nurses are responsible for the overall care given and refer to other health professionals as required. I had discussed this option with a local charge nurse from an acute ward who had written a business plan for such a unit. The charge nurse saw that an acute ward in the present climate was not a therapeutic place for people. She thought there were numbers of people with ongoing chronic illness whose needs would be better met in such ‘nursing beds’ where nurses admit and discharge clients. The family nurse practitioner, discussed in chapter four, has been mooted for our health system but like the ‘nursing beds’ it has not eventuated as yet.

Another option that Mary hesitantly considered was that people living with strife in chronic illness should be under the umbrella of a psychiatric team. Her reservation was

that the label of having *“a psyche problem will then shape their behaviour”*. Mary sees that the ritual of taking pills reinforces the notion of illness. She added, *“I still believe there is an unacceptance of Sarah’s type of condition”* and believed a building not associated with a psychiatric institution would be a good option for clinics and care.

advanced nursing practice for people experiencing strife in chronic illness

The conversation shifted to the skills needed by nurses to work with clients in strife and prolonged engagement. Mary posed that *“a nurse needs to know her strengths, skills and have previous experiences, to enjoy long term clients. ... You certainly need to know a bit about crisis intervention work or know how to access the team”*. In addition Mary believed that the ongoing restrictions associated with purchaser contracts in the service were likely to limit the care of these clients. She also envisaged a gap in anyone taking a similar role to me in the service. Mary expressed that *“with the right person you can go anywhere. I would enter into something like this again with such a complex client if there was an experienced practice leader to support and work with me. ...I saw something that I was interested in originally and then could see the enormity of the issues, not just the complexity of her life and her illness. It was her events, there was always something coming at you, not put purposefully, but always coming”*.

In responding to Mary’s comments I questioned whether a credentialled advanced nurse practitioner should care for clients in prolonged strife. Mary had some doubts about nurses’ with advanced qualifications currency in practice but I explained advanced nurse practitioners would only be credentialled if they were current in their chosen area of practice. Kim was clear that nurses who practiced with vulnerable clients like Sarah needed both advanced qualifications and service boundaries that would provide protection for both client and nurse. Further, Kim believed, that at present, district nurses did not have supervision so *“who knows what’s going on? Who knows if it is a good structure that will bring about a positive change in behaviour? What you are talking about is relationship counselling with a person like Sarah”*. In relation to this belief, Kim endorsed my contribution to Sarah’s care. *“You obviously are a skilled interviewer and practitioner. I was particularly impressed with the plan of action you had in place for Sarah. It demonstrated sound application of theory to practice....”*

I had believed that if I modeled primarily relational care as is described in this narrative then district nurses would learn from me and then be able to practice it with my support. Therefore, it was a revelation to discover that if nurses were to lead the practice with people experiencing strife in chronic illness, they needed advanced skills and knowledge.

does Sarah still need a nurse?

The other question raised was “Does Sarah still need a nurse?” Kim’s initial reflection on this question was in relation to what she saw as Sarah’s greatest need; someone to work with her on her deep-seated fear, not a skill that she or other nurses in her team had. Furthermore, Kim seriously questioned the role of the nurse in assisting Sarah when she was in fact getting on with life without apparent difficulty. By the time of reflecting on the narrative Kim had not seen Sarah for some months. A series of events had resulted in Kim asking Sarah to contact her if she needed help. There had been no contact between them in the first half of 2000. Sarah had contacted Kim in the middle of the year and a monthly visit was re- established.

Kim and I talked about a case co-ordinator/care facilitator, as described in chapter four, as an option for Sarah. Kim reflected that a professional person holding the overview of the health circumstances and care providers involved with Sarah could work. *“I think that if other people are going to be involved in that care they too need to be linked with that person [the co-ordinator]. Maybe there needs to be regular reports sent in, some dialogue some kind of accountability to a case co-ordinator”*. Kim pondered further that the many current different funding streams for care in the community actually fosters parallel paths of client care in service provision. This is a weakness of our re-formed health system that professed considerable rhetoric about improving integrated care. No care co-ordination system for people like Sarah existed in the present region.

During our reflection on the narrative Rose and I continued the conversation on the question of Sarah’s need for a nurse. We agreed that Sarah is not likely to call the service unless it is for a technical request. The physiotherapist had aided her May 2000 admission to hospital. Some discussion ensued regarding other health professionals

filling the role I had taken with Sarah in the past in obtaining an admission before she collapsed into an acute stage of disease. I believed that part of Sarah's anxiety was related to not knowing if she was going to get help when she needed it. A major part of my practice was to coach Sarah's confidence in getting through lows that in her past (particularly in the 1994-6 period) had resulted in hospital admissions. Assisting the admission process only happened after an ongoing decline that Sarah had been supported through at home. I perceived that 3-4 periods, of approximately a week within a year, in hospital or another nurturing place (not yet found), would diminish her fear of constraints of access. Moreover, in my opinion, it would accommodate her low times, often related to her drive to achieve, which compounded her burden of illness. It would, I believed, enable a sense of security and better quality of life at home and would need close monitoring.

Rose recalled her awareness of being the primary nurse, the main nursing link, at her last visit in the first half of 2000. *"I am aware that I don't go there so much for respiratory expertise anymore. ...I made a decision to call three monthly and if Sarah needed anything in-between she could call me"*. Rose related that her role of primary nurse would be different to mine. I responded that Sarah's needs are different now to what they were in 1997 and 1998. As I saw it she didn't require the earlier intensive input any longer. Rose continued *"Sarah trusts me and she knows that I will do what she needs. I think she feels that I care about her so would be quite happy to connect with me"*.

We, the nurses, conceded that uncertainty and unpredictability would be associated with Sarah's circumstances. Rose commented that this period could be a turning point. A good interval in Sarah's life could have lasted nine months but there is always potential of change for the better or for the worse. Any change would be difficult to ascertain with large gaps between visits. I recommended that negotiation with Sarah be undertaken regarding a schedule for visits.

This section has addressed the final reflections on Sarah's experience of living with strife in chronic illness and accompanying nursing care. Uncertainty remained a feature of Sarah's experience and is embodied in the nursing decisions regarding what nursing

support should be available to Sarah in the future. Lessons from Sarah's experience were identified and a recommendation was made that nurses who are responsible for the care of people living with strife in chronic illness have advanced knowledge and skills. The narrative does not have a tidy conclusion. Responding appropriately to Sarah's health-illness situation remained an ongoing challenge.

final research meeting – September 2000

The organisation of the final research meeting is described under the heading 'research meetings' in the previous chapter. As stated a nurse from outside the practice situation facilitated the meeting.

All nurse co-participants conveyed their satisfaction with their re-presentation in the narrative and indicated expanded learning from their participation in the research. Rose saw the research as reflective practice. Mary thanked Sarah for the sharing of herself and what she had learned from her. Kim restated her difficulties with entering the care and research in the later period; her practice dilemma about not knowing what she could contribute when Sarah appeared to be getting on with her life. Her approach was not to be '*protectionist*' or '*interfering*' in what was working but she believed Sarah's health care would benefit from co-ordination. Furthermore, Kim had moved to a position of now understanding that she had experienced lack of clarity about her role because of my continuing presence with Sarah after leaving the service. A shift in Sarah's understanding of Kim's role had also happened. She understood Kim's dilemmas better and confessed she had felt '*pippy*' with her earlier. Sarah felt their relationship, at that time of the meeting, was working. Kim apologised for any distress she may have unwittingly caused Sarah in her early approach.

Rose expressed satisfaction with what had been achieved for Sarah by community health nursing and considered there were others who could benefit from such partnerships. Rose reaffirmed her concern that the establishing of an intense relationship had implications for someone else entering the care. Nevertheless, she believed it had been the relationships that had been the main influence on the good outcome.

Sarah recapitulated her story. She responded to the ‘invisibility of symptoms’ issues in the narrative and the ongoing frustration it caused her, especially on hospital admissions. Sarah emphasised her tendency not to request help. Kim’s note in the box that read ‘call me if you need me’ did not sit comfortably with her while Kim had interpreted the lack of response as Sarah getting on well without nursing support. Sarah stressed that visits where the nurse ‘listened’ to what was going on for her were really helpful in aiding her living with chronic illness in the community. Sarah asserted that she had relied on Mary and I and believed we had ‘aided’ her in getting to where she was at that time, September 2000. The possible negative effect of ‘dependency’ as discussed in the narrative had not been her experience. Sarah reinforced how significant it had been for her going out with Mary in the earlier period. The discussion of the ‘fine line’ issues in the narrative was an ‘eye-opener’ for Sarah and she hoped she had never misused our goodwill. We assured her that this was not the case as our approach had been consistent with our nursing values.

Some small corrections and additions to the narrative had been made by Sarah and were given to me in written form. She talked about the vulnerability she experienced when reading about her life. It had brought back the ‘*nightmare*’ of the ‘*horror*’ admission in particular. At the same time it had helped her see that that she had achieved things that she had never thought would be possible after that experience. When she reflected on what she was doing now it seemed ‘*amazing*’.

The meeting closed with Sarah sharing her current achievements. She had completed a course on interior design. Although she had felt ill at times she had persisted and was pleased. Going out at night without dire consequences was something never envisioned at commencement of the research period. Not only had she completed a course, she had commenced attending a 200 hour computer class with her daughter. Furthermore, Sarah was involved in planning the design of a new house and selling her present one. A closing quote from Sarah is a reminder for all nurses working with people with chronic illness:

“When you [a nurse] are dealing with someone with a chronic illness you become part of their family.

Whether you like it or not, you become part of our lives and become our friends”

conclusion

The record of the meaning made within the movement, events and nuances of a three year period of the prolonged engagement of Sarah and nurses in a complex situation has resulted in an lengthy narrative. Bringing the voices and different perspectives of nurses together with the voice of the person receiving their care is, I believe, a unique and interesting contribution to the understanding of strife in chronic illness. The meaning emerged within a co-construction process from the enactment of the methodological premises of reflexivity, dialogue and moral comportment. It is re-presented in narrative as praxis. The establishment of a dialogical consciousness meant that the sharing of individual meanings were shaped in the questioning and answering dialectic of the conversation. All co-participants co-operated in a spirit of solidarity and were transformed in the process. The nurse co-participants were not explicit about their transformation but Sarah’s was inherent in her descriptions of participation with family and community; in what she experienced as ‘amazing’. This transformation arose from practice as praxis and was complemented and extended in research as praxis.

Sarah was clear and consistent in her message about the de-moralising circumstances that increased her burden. Equal explicitness is presented about what reduced her burden; acknowledgment of her vulnerability and humanness within a caring relationship where active listening lead to a co-construction of her illness. This assisted her sense of safety in the community and enabled some movement out of strife.

A primarily relational nursing practice involving an intense relationship between Sarah and myself, had constituted ‘the caring gaze’ of nursing. The intense relationship was seen to have consequences for the nursing team, but it was also seen as the main fulcrum, by Sarah and the nurses, in the achievement of her movement out of strife. The nurse co-participants described the establishment of our ‘caring gaze’ as the ‘pushing of boundaries’ and the navigating of ‘fine lines’. As such it was viewed as an innovation in

the context of the particular community health service in which it took place; an innovation identified as advanced nursing practice.

Throughout the narrative is the presence of paradox, moral meaning and metaphor. These themes operate within the push and pull of different discourses. Several references are made to the constraints of the New Zealand health reform, the tradition of which is discussed in chapter four. I now see this as part of what I have named as the nursing within a functional service discourse. A tension resides between this discourse and what I now call nursing as a caring practice discourse, the discourse that is present in my praxiology in chapter seven but not named as such, which also involves the 'caring gaze'. Another identifiable tension is between a focus on Sarah's disease, the disease discourse, and her broader health circumstances, the health-illness discourse.

This conclusion completes the second hermeneutical circle of the inquiry. The third and final circle takes up the themes of paradox, moral meaning and metaphor within a discursive framework as an enactment of the methodological premise of critique as praxis. However, before generating the critique I return to the research methodology in order to construct a discursive framework as a structure for the critique.

Chapter nine

THE CONSTRUCTION OF A DISCURSIVE FRAMEWORK FOR CRITIQUE AS PRAXIS: PARADOX, MORAL MEANING AND METAPHOR AS THEMATIC THREADS

introduction

In the course of co-constructing the narrative I began to pay attention to particular themes within it. These were paradox, moral meaning and metaphor. Initially they captured my attention in Sarah's narrative. Soon, they also became apparent in the nurses' narrative. When first I identified these themes, I was not aware of any schema influencing my selection of them. They were components of the narrative that had been included in my illustration of the overall contextual complexity of the practice situation; not components that I had deliberately chosen as particular features. The assumptions within the methodological premise of dialogue as praxis encouraged a dialectic posture of continued questioning and answering in order to expand understanding. Inherent in this premise was the challenge to follow where the dialogue led. I had remained open to what a dialogue with the narrative might bring forth rather than apply a particular template over it to aid and shape further interpretation. Nevertheless, my openness was limited by my effective historical consciousness.

In retrospect I see that the methodological premises of reflexivity, dialogue and moral comportment had moved me into a new hermeneutic circle of understanding the experience of living with strife in chronic illness and the associated prolonged nursing practice. It was an understanding that was shaped by the traditions informing the research. At that stage of the research journey my effective historical consciousness encompassed the framework taken from GPH, my praxiology based on the framework but extended by constituents of other philosophical praxiologies and my values about health-illness and nursing. The assumptions from my praxiology had been translated into the methodological premises. In my praxiology I had nominated my preference for certain discourses present in the health-illness and nursing literature. Therefore, I realised

that my reflexive dialogue with the narrative was taking place within preferred assumptions about health-illness and nursing.

The first theme I focussed on was paradox. In the methodological premise of dialogue as praxis I discussed the possibility of ambiguities appearing in the sharing of our stories. This possibility emanated from Lather's (1991) belief about the contingency of the multiple discourses that make up the post modern world in which human praxis takes place. For me, the paradoxes pointed to the pluralism inherent in the practice as praxis. As my reflexivity continued I began to uncover more fully, linkages between the discerned paradoxes and the discourses which I began exploring in a return to the health-illness and nursing as a caring practice literature. Discourses, according to both Gadamer (1960/1975/1999) and Lather evolve from the clustering of concepts and language into related groupings underpinned by a particular view of the world. The research framework concept of language, 'everyday language' was at work in my consciousness.

Moral meaning in a number of forms was the second theme of the narrative on which my attention rested. In positioning myself in the disciplinary viewpoint of nursing as a practical human science and in accepting the assumptions of my research framework I had increased my awareness of nursing as a moral science. Gadamer (1960/1975/1999, 1981) believes that moral knowing or moral consciousness is the essence of phronesis. It is self knowledge learned from making moral decisions and reflecting on them as a process of expanding one's own horizon. It is about grasping what needs to be done in particular situations. In retrospect I understood that my decision to assign moral comportment the status of a methodological premise would have focussed my attention on moral meaning. Moreover, within this process, a connection between moral meaning and the different discourses emerged.

The third theme identified in the narrative was metaphor. As the methodological premise of dialogue included ideas about 'everyday language' from the research framework, I saw that a focus on metaphor could expand the meaning I was seeking. Metaphors are commonly used in everyday language. According to Gadamer (1960/1975/1999) the life

of language advances from our expanding conceptual formation. Part of this process is the recognition and transference of the meaning of one event to another event with similar features. Our verbal and dialogical consciousness brings the two or more events together. For Gadamer, there is an inherent paradox in this consciousness. He expresses the paradox as follows:

It is obvious that the particularity of an experience finds expression in metaphorical transference, and is not at all the fruit of a concept formed by abstraction. But it is equally as obvious that knowledge of what is common is obtained in this [abstract] way (Gadamer, 1960/1975/1999, p. 429)

practice as praxis and research as praxis in a postmodern space

As with the paradoxes and moral meaning, my reflexive attending to the metaphors demonstrated an association with the identified discourses. I realised that I had captured much of the ‘messiness’ of present day nursing practice as described by Street (1990). On the surface, the narrative demonstrated the multiplicity of views as well as fragmentation, characteristics of a postmodern or post structuralist framing of the world (Lather, 1991). Therefore, I chose the term ‘post modern practice’ as a descriptor of the practice as praxis described in the narrative.

I also used the term postmodern to describe research as praxis. I was working in a space where the discourses of health-illness and nursing as a caring practice were accentuated rather than assumptions of the disease or the nursing as a functional service discourse. The latter two discourses were based on modernist assumptions of the world which I discuss below. However, in my postmodern space they were influences from the non-preferred discourses but nevertheless the dominant discourses. As a consequence the critique represents multiple views of the world where paradox and ambiguity reside. It is a good exemplar of Lather’s (1991) construct on the contingency of multiple discourses in the post modern world.

Critique of the narrative was undertaken to illuminate meaning and expand understanding of the whole experience under investigation. Rather than to fragment and disrupt

meaning, as is the intention in some post modern approaches (Caputo, 1987). Moreover, some postmodern analyses delete any sense of moral intention. The moral imperative of practice in the health-illness and the nursing as a caring practice discourses derives from the practitioner's interaction with the suffering and vulnerability of the ill person. It is central in this post modern space and best described as a practical, moral imperative. Frank (1995) uses the metaphor of 'crossing the divide' between modernism and post modernism. He believes the move to focus on a person's experience, to reclaim their voice in the form of illness stories, is an indication that the divide has been crossed. This is consistent with the assumptions of the health-illness and nursing as a caring practice discourses. Frank sees a paradox in our drive to analyse narratives. According to this author, it is part of our modernist baggage. It is his belief that narratives can and should stand alone in a postmodern space. Nevertheless, his justification, which is also my justification, is that a framework can increase awareness of the truth narratives already hold. Furthermore, I am mindful of my praxiological positioning in regard to theory emerging from practice and Pearson's (1988) characteristics of praxiological inquiry. Pearson warns that over theorising will subordinate the narrative into an abstract state of generality and diminish the voices of the participants. In addition, according to Frank, the process orientation of the inquiry is postmodern in that the nature of the meaning generated evolved within in the course of carrying it out.

The discursive illumination of the themes of paradox, moral meaning and metaphor could not have occurred prior to the co-construction of the narrative as I did not know what was going to emerge from it. This is a similar strategy to that employed in grounded theory inquiry. However, unlike grounded theory, I have decided to discuss the literature that is used in my backgrounding of the themes and discourses before its use in the critique. This discussion of the literature relates particularly to the discourses present in the narrative, as it was difficult to convey the assumptions of the different discourses in the critique without disrupting or overshadowing the voices from the narrative. Therefore, I have decided to use this chapter as a methodological vehicle to create a bridge from the narrative to the critique as praxis. Thus it can be interpreted as a chapter devoted to

explication of a discursive framework containing the traditions of the discourses in which the critique proceeds.

Before I discuss the discursive literature from which the framework is taken I will outline how the concepts of paradox, moral meaning and metaphor have been used in the nursing literature. This is followed by an explication of the main ideas of the health-illness and nursing as a caring practice discourse as they exist alongside the disease discourse and nursing as a functional service discourse respectively.

paradox, moral meaning and metaphor

paradox

In living, practising and researching in a postmodern world there is a challenge to understand the paradoxes and complexity manifest within it (Spitzer, 1998). Spitzer observes the complexity that is manifest in social systems with their ever increasing parameters of interactions and ongoing transformation of structures. Positions are always contingent. According to Spitzer, a dance of chaos and order is instigated from which more paradoxes emerge. At one level paradox infers difference; at a deeper level it demonstrates that things are not quite as they seem. Spitzer's discussion, like that of Lather (1991) encompasses the way we are in the world as unfolding human beings, never entirely consistent, but ambiguous and incongruent at times and always in a process of transforming. This is described as human becoming (Parse, 1995a, 1995b) and expanding consciousness (Newman, 1986, 1994).

What unfolds in the identification of paradox in my theorising can be viewed as a paradoxical or dialectical dance or 'to and fro' interplay as events and their opposites are pursued to a stage of uncovering deeper moral meaning. The steps are never the same but on close observation patterns emerge and a consistency is often detected. Paradox, as a concept that is helpful in understanding the human condition is used in Parse's theory of Human Becoming (Parse, 1995a, 1995b, 1997). Parse developed several very abstract paradoxes, which are intended as an apriori foundation for nurses using her theory to inform their research. I am not using paradox in this way. Rather, paradox as an

important theme in this study is identified and discussed within the unfolding of the methodology that led to the construction of a discursive framework, together with the themes of moral meaning and metaphor.

moral meaning

Carper (1978) made moral knowing in nursing practice prominent in a seminal article on patterns of knowing in nursing. She linked her observation of nurses' ethical judgements in the complexity of clinical situations to the *raison d'être* of nursing as attending to the human health experience. Carper noted the limited assistance of ethical codes in the everyday conduct of caring for people. Normative standards may work in some instances and not in others. Each situation, she believed, called forth a deliberative judgement according to the circumstances encountered. Her notion of moral knowing "includes all voluntary actions that are deliberated and subject to a judgement of right or wrong, including judgement of moral value in relation to motives, intentions and traits of character" (p. 18). Carper's description is close to *phronesis* as first developed by Aristotle and expanded in contemporary philosophy by Gadamer (1969/1975/1999, 1976a, 1976b) and in nursing by Benner, Tanner and Chesla (1996). Furthermore, Carper argued for nurses to be cognisant of differing positions regarding what is good or right in the post modern clinical world of uncertainty and unpredictability and practitioner accountability.

More recently Watson (1990) proposed that informed passion arising from reflexivity on nursing as a caring moral science awakens the nurse to the relational contours of the contextual landscape of practice. In short, it is a passion that keeps the gaze of the nurse on the person of the client's human being in the world. Another nurse researcher (Maeve, 1998) supports Watson's position in contending that nurses who embody the suffering of their clients are more likely to pursue the moral possibilities for humanising their care than those who disembody the suffering. This embodying by nurses takes place in a layer of reflectivity, not in a layer of feeling. Maeve's research clarifies how nurses come to know and do "the right thing/the good thing" via an experiential path involving "competency, commitment and courage" (p. 1139). Reflection on moral ambiguities in

which they have experienced discomfort in not standing up for their beliefs had brought Maeve's participants to their stance of moral commitment and courage.

The characteristics of 'competency, commitment and courage' are components of everyday ethical comportment (Benner, Tanner & Chesla, 1996). According to these authors, knowledge of 'right' and 'good' flow out of the community in which people reside. Furthermore, Benner et al. differentiate between quandary and/or procedural ethics and a relational ethic of care. The former tends to be brought into play when an ethical dilemma is present. A procedure is put into place to determine the 'right' approach to take. In the view of these authors, this approach does not deliberate on what will be 'good' within the person's life. In bringing together ideas about a relational ethic of care, put forward by several nurses, Benner et al. see the core components as a stance of responsiveness and responsibility to the other. Moreover, embodying a relational ethic of care has positive health outcomes when attending to the human health experience. Health outcomes that

may involve the alleviation of vulnerability; the promotion of growth and health; the facilitation of comfort, dignity or a peaceful death; mutual realisation; and the preservation and existence of human possibilities in a person, family a community or tradition.

(Benner, Tanner & Chesla, 1996, p. 233)

I believe that these health outcomes can be hard to measure as they evolve within the relational ethic of care and the particular situation. Moral meaning as it became evident in the narrative refers to what is seen as 'good' and 'right' from Sarah's perspective and from the perspectives of the practitioners involved in her care. For the latter it arises out of their discursive position at the time of passing their judgement. The metaphors that Sarah uses to describe her severe strife are indications of how de-moralising the experience of severe strife was for her when she had been subjected to a view of what was seen by practitioners to be 'good' for her.

metaphor

Interpretation of the human health situation involves listening to how a person, family, community or tradition expresses their health experience; listening to their conceptual constructions and paying attention to the metaphors used in these constructions. Metaphors as part of our language in nursing knowledge development are accepted in nursing (Banonis, 1995; Gadow, 1995b; Watson, 1999). Gadow asserts that they provide a vehicle for the illumination of meaning which factual objective descriptions do not. For both these authors metaphors provide a linking of the personal interior view with an exterior view through the use of imaginative descriptors and thus a narrative or story is created. Watson draws our attention to transformational relationship between metaphor and metamorphosis. At another level, Watson notes the dominance of particular metaphors in certain historical epochs. She sees the battle metaphor, strongly evident in Sarah's experience, as one that has penetrated our collective conscious in the twentieth century.

In the critique of Sarah's experience in the narrative the concepts of paradox, moral meaning and metaphor are given coherence in a 'to and fro' dialogue between the disease and the health-illness discourse. These same concepts continue to be core axioms in the nursing experience and are presented within a 'to and fro' dialogue of the discourses of nursing as a caring practice and nursing as a functional service. I will now shift to explicating the traditions involved in the 'to and fro' of the health-illness and the disease discourse. This literature illuminates current understandings of illness that differ from understandings of disease processes. These discourses have been chosen because of the emphasis in the narrative on chronic illness as an ongoing burden intertwined with the diagnosis and treatment of the disease process. Later in this section a similar explication of the nursing as a caring practice and nursing as a functional service discourses is presented.

the 'to and fro' of the health-illness and disease discourses

The disease discourse has been associated with the development of science over the last 300 years (Pearson, Vaughan, & Fitzgerald, 1996). Influences from the Cartesian

separation of mind and body advanced the reduction of the body into systems and has progressed to the current preoccupation with the analysis of DNA. The assumption of the body as a machine is widespread, where the fixing of individual parts has become both the answer and the expectation of western populations. Illness as a discourse emerged in the western world in the second half of the twentieth century with the dramatic rise in people living with chronic illness. It takes account of the personal and the environmental effects a person may suffer that stem from any disease, injury or disability and from their treatment (Benner & Wrubel, 1989; Brody, 1987; Capra, 1982; Cassell, 1991; Ferguson, 1980; Kleinman, 1988). It is similar to what I intend when I use the term health circumstances and because of this I am using the term health-illness discourse. Health and illness dwell together in people's experience of chronic illness as they live day to day in their worlds. Moreover, my praxiology informing this analysis talks of the health-illness experience as integral to embodied wholeness. Change in one part of the body is change in the whole person when people are viewed as unitary holistic beings unfolding in their world.

As mentioned in chapter four the discourse on health-illness initially appeared in sociological, psychological and medical literature. An example of this is a book edited by Kestenbaun, (1982b), a philosopher and educator. In his book named "The humanity of the ill" he asserts the importance of knowledge development of the subjective experience of illness and claims that a phenomenological frame of mind can bring this perspective into focus. Furthermore he acknowledges the work of nurse academics, Paterson and Zderad, Gadow and Watson, in this area. Among contributions to his book from philosophers, medical doctors and a sociologist is a paper written by Gadow, a nurse philosopher who is extensively quoted in this study. Other writers outside of philosophy or particular health related disciplines who applaud what they call the new paradigm of health and with it a new approach that considers the person and their environment as central are Capra (1982) and Ferguson (1980). Capra also affirms the work of many nurses in advancing the new paradigm approach.

Nevertheless, it is also important to note that sociological explanations also reinforced the disease discourse. Parson's (1951, 1978) sick role theory, an example of a functional explanation of illness, has been very influential in shaping the thinking of many health professionals. Brody (1987) and Frank (1995) critique the sick role theory. Brody, a physician and philosopher, points to its reductionist focus within the disease discourse, its emphasis on abnormality of disease and the way it portrays one way to be sick when we know that there are as many ways to be ill as there are people with illness. Frank, a sociologist, draws on his own experience of illness and the stories of many ill people. He critiques Parson's notion that some ill people enjoy the attention they receive and their release from particular social responsibilities is seen as secondary gain from being ill. This explanation of healthy people imposing a purpose on behaviour is anathema to Frank. For this author, not only does it suit the medical view of the world but it releases its practitioners from the challenge of entering the world of the other and working with them to create meaning of the illness experience.

Brody (1987) and Kleinman (1988) an anthropologist and a psychiatrist, state that their patients taught them much about the human condition and in particular about living with illness. These authors agree that the dominance of the disease model, even though there is little evidence of its success, distracts practitioners from seeking the meaning of illness with the people who seek help. Brody prefers the term sickness as opposed to illness. Kleinman discusses the importance of assisting ill people to construct a narrative of their experience; a similar exercise to the co-contraction of Sarah's health circumstances in the narrative and akin to co-constructing a relational narrative from within a relational ethic of care (Gadow, 1996). Kleinman and Gadow claim the therapeutic nature of such an exercise. However, they issue a warning of the need to enter into the uncertain world of the ill person to achieve such an endeavour, and of the uncertain outcome. Kleinman sees chronic illness and its treatment as a symbolic "bridge that connects the body, self and society. The network interconnects physiological processes, meanings and relationships so that our social world is linked recursively with our inner world" (p. 40). This is a broad view of the health-illness discourse similar to my notion of health-illness circumstances.

Both Brody (1987) and Kleinman (1988) discuss at length, the social and cultural factors that play a role in the illness experience. Furthermore, they assert, as do Morse and Johnson (1991b) and Thorne (1993) that the illness experience is not always tied to a manifestation of disease. It is an ontological view rather than a reductionist view (Cassell, 1991; Pellegrino & Thomasma, 1988) and as such is consistent with Sarah's view of her illness burden. So, although it is important to understand or have knowledge of disease processes, it is equally as important to be knowing in a wide range of areas if the rhetoric of person centred humane care is to be achieved. Health-illness within an ontological lens requires knowledge of people and personalities, cultural and social contexts, family dynamics and communications styles, organisations and politics. It is about everything that effects human being in the world. I see this as a big challenge in a world that bows to the supremacy of empirical knowledge in medical specialties; the disease discourse.

suffering in health-illness

At the same time as the health-illness discourse was evolving a related discourse on suffering was also unfolding (Cassell, 1991). Cassell, a medical practitioner, defines suffering as “a state of severe distress associated with events that threaten the intactness of the person” (p. 32). Although suffering as a discourse pertains to a wider range of human experience than illness it will be treated here as a component of the illness discourse. Brody (1987), Frank (1995) and Kleinman (1988) discuss suffering within illness which links closely with what Cassell associates with suffering. These authors see suffering as a common component of illness narratives, which cut across all ages and cultural conditions. Furthermore, Toombs (1993) uses the term ‘suffered illness’ to capture a person's existential experience of being ill.

The nurse co-participant, Mary, introduced the term suffering into the narrative to describe Sarah's situation. It is a descriptor of Sarah's condition that all nurse co-participants agreed upon. Cassell (1991) found that suffering was a concept that had lost currency in the medical world even though persons seeking care were clear that it was part of the doctor's role to alleviate suffering.

The loss of currency in using the term suffering was also my experience when involved in teaching and practicing nursing in the late 1980s and 1990s. In my work with people with physical disabilities it was considered politically incorrect to say that they were suffering with quadriplegia or multiple sclerosis as it connoted a medical and victim status, when in fact many were getting along well in their lives. To use the term suffering as in the common everyday framing of it, was countering the trend to normalisation and accentuating the positive. This view possibly veiled my gaze from the suffering that may have been present in the people I cared for. In the reign of the ‘nursing diagnosis movement’ more precise objective descriptions, nominating what was going on such as pain, fear, grief or anxiety, were encouraged (Bishop & Scudder, 1991). Another explanation for the reluctance to use the term suffering is that medical science supposedly had conquered disease and with it suffering in illness. So, to acknowledge that people still suffered was to concede the limitations of the disease discourse. Even in palliative care people do not suffer unto death; they are assured that their pain can be relieved. I now see that this view limited my understanding of suffering as part of the existential human condition.

Media attention continues to report intensively the breakthroughs in finding a cure for cancer and other degenerative illnesses which encourages lay people have a high expectation of a cure and if not a cure at least ‘a fix’ of some sort. This expectation, when thwarted, adds to their suffering as was the case for Sarah. Expecting ‘a fix’ is often an anticipation of both client and practitioners and accepted as the norm. This may work for episodes of acute disease that settle rapidly but it can cause frustration when applied to the contemporary phenomena of chronic illness.

Pellegrino and Thomasma (1988) and Thorne (1993) discuss what they see as the contemporary dilemma in relation to the choices available in disease treatments. According to Pellegrino and Thomasma, this dilemma involves “what is *right* [sic] in the sense of what conforms scientifically, logically and technically to the patient’s needs and a choice of what is *good* [sic] and worthwhile for the patient (p. 211). These authors highlight the public expectation of ‘a fix’ in what is termed the rationing debates on

health services. Pellegrino and Thomasma see a tension between what is morally right in terms of how a limited health budget should be spent and what is technically possible but increasingly expensive and often of dubious gain. Further tension exists for people living with illness in what is often described as a separation of the body from the self.

A disruption of the body and the self happens when a person experiences the ontological assault of illness (Pellegrino & Thomasma, 1988). This assault influences the way a person lives in the world (Brody, 1987; Cassell, 1991; Frank, 1995; Gadow, 1980a; Kleinman, 1988). Such disruptions are a threat to the sense of wholeness and normality of the person. The complexity of a person is multifaceted. Ignorance of some of these facets, especially spirituality, may cause suffering according to Cassell, Frank and Gadow. The spiritual or metaphysical realm of peoples' lives is accommodated within the wide angled lens of the health-illness discourse. This realm has been advanced from a greater understanding of the eastern spiritualities (Capra, 1982) and the new understandings of mind and emotions within what is called the psycho-neuro sciences (Greenfield, 1997). At the same time suffering is still seen as the road to salvation in some spiritual and religious beliefs (Herzlich & Pierret, 1987). The broader the knowledge base of the practitioner working with people the greater will be their ability to understand the effects of the ontological assault of illness.

Cassell (1991) cautions that we can never fully know the person and the person can never fully know their own self. However, this is not as important as knowing the meaning the person gives to their suffering or illness (Kleinman, 1988). To enter into this meaning is to enter into the mystery of the existential subject (Gadow, 1980b; Gulino, 1982; Newman, 1986, 1994; Parse, 1995a) at any given moment in time and pay attention to their unfolding narrative of life. Suffering is what the person experiences (Younger, 1995). It is person-al and can extend into the significant others, family and community. For some, it may become a special commitment and the life work, but for others, it may overwhelm them and create a distancing. If a helping professional fails to at least begin to understand the meaning of these possibilities a person's reality can be left beneath the surface and compound the suffering.

Morse and Carter (1996) examine endurance and suffering as related concepts. These authors distinguish the concepts in noting that endurance is devoid of emotion while suffering is an emotional response in relation to what is being endured. Explicit in Morse and Carter's rendition of suffering is that nurses are the alleviators of suffering when persons are in bed. There is no acknowledgement that nurses can contribute to suffering, especially when practising in institutions with a dominant disease model lens and little understanding of the complexity of ongoing illness. In my view, Morse and Carter's work tends to both normalise and objectify suffering. Rawnsley (1996), in a response to the Morse and Carter article, censures their abstraction and assumptions. For Rawnsley, the assigning of abstractions "to people's struggles seems at best, premature closure; at worst, it is a betrayal of trust" (p. 67). She believes nurses benefit from an expanded view of suffering rather than a reductionist approach.

Pain and suffering are linked in the experience of chronic illness (Carson & Mitchell, 1998; Cassell, 1991; Kleinman, 1988). Linking pain and suffering too closely can keep our gaze on the physical. Kleinman devotes a chapter of his book to a discussion on the vulnerability of pain and the pain of vulnerability. This is not to undermine the reality of physical pain which does cause suffering but to give voice to other facets that contribute to suffering in the experience of illness. In my experience there is a tendency among nurses to describe facets as emotional pain, moral pain, mental pain, spiritual pain or in some attempts to be less reductionist to call it 'whole pain'. This language has enabled us to avoid terms of anguish and suffering. It is timely to heed Younger's (1995, p. 55) counsel that "suffering does not happen to people, they happen to suffer". I now understand that to talk of manifold pain or use the expression 'people suffer from a particular illness', is a medicalisation of suffering. It moves the focus to aspects that might be 'fixable' and can be a deterrent from entering into the mystery of the person (Gulino, 1982).

assessment in the disease and health-illness discourses

assessment in the disease and health-illness discourses

Gadow (1995b) develops a heuristic tool for clinical assessment that bridges the disease discourse and the health-illness discourse. She identifies five stages in clinical assessment and uses the notion of dialectic in the proceeding from one to the other in a clinical assessment: The stages are vulnerability and engagement; disengagement; reduction; holism; and a return to engagement. In the first stage the nurse engages with the person and assesses the immediate distress and works to relieve it, such as distressed breathing and/or pain. In the second stage, disengagement, the nurse steps back and looks for an objective empirical understanding that will assist her/him develop a long term plan of interventions to relieve the distress. Reduction, the third stage, continues the phase of objectivity when there is examination of cellular changes (reading the laboratory reports) that may or may not point to 'the cause'. Gadow alerts nurses to the equally likely possibility of other single causes being embraced in the same way as cellular changes. These may include personality types, developmental or nutritional theories or the sick role theory posited by Parsons (1951, 1978). Any one of these can provide clarity can become the answer in nurses' quests for understanding of what is going on. According to Brody (1987), Kleinman (1988) and Gadow, relying on a single answer is a trap for the unwary. The single answer does provide certainty in the short term and if it turns out to be the answer it relieves the suffering associated with the initial period of limbo. If however, no medical diagnosis is made, as was often Sarah's experience of particular symptoms, then uncertainty exacerbates the suffering and increases the pain.

In the fourth stage of Gadow's (1995b) clinical assessment, holism, the gaze is broadened to include the illness and suffering in all its possible guises, all that the embodied person brings to the situation at a particular moment. Diversity, uniqueness and complexity all shine through and are configured into an overall tapestry. In this tapestry no privileging of foreground or background information occurs initially, as this can easily lead to an attitude that 'blames the victim' e.g. the cancer personality, which in turn diminishes the responsibility of cigarette companies or other polluting industries. Gadow also warns that

widening the gaze does not by itself reduce objectivity. The nurse is still in a position of making an unilateral decision unless there is dialogue with the person. The nurse is challenged to return to engagement, the last stage of Gadow's theoretical construct. In this last stage there is a dialogical search for meaning within all the material with the person/s concerned, the creation of a 'web of relationship' (Connor, 1995). It is within this final stage of engagement that a relational narrative is developed and the person can find "safe passage" some shelter in her/his storm of suffering, a "habitable home" (Gadow, 1996, p. 31),

I find Gadow's (1995b) recommendation of opening up each phase of the assessment and leaving it open in order to reduce the closing off of any options, useful. However, there is some inconsistency in Gadow's dialectic in opening up the first stage as engagement and keeping it open with stages of disengagement and then returning to engagement as the final phase. If all stages remain open from the beginning, which I believe they should, there would not to be any need to return to engagement in the final phase. From my perspective disengagement is unnecessary and likely to increase suffering. Nonetheless her notion that the clinical epistemology arises out of the process rather than the outcome is a timely reminder for those of us working with people with chronic illness. Moreover, her phases helped in my understanding Sarah's plight as will be articulated in chapter ten.

nursing studies about living with chronic illness

A number of nursing studies with people experiencing chronic illness are mentioned in chapter four. However, publications from two nursing studies on living with chronic illness (Benner, Janson-Bjerklie, Ferketich, & Becker, 1994; Thorne, 1993; Thorne & Robinson, 1988) have particular significance to Sarah's experience in the health-illness discourse. Thorne reporting separately and with a colleague [Robinson] presents a Canadian study, undertaken in the late 1980s, involving 77 people living with chronic illness either as individuals or within families. The study assumes that people with chronic illness, whatever the varied manifestation, have much in common. These authors' focus on personal experience demonstrates that the complexity of living with illness over time is far greater than the management of signs and symptoms. It takes account of all the

relationships and social happenings in day to day living and as such documents a profound social phenomenon that health professionals can no longer ignore. It is a phenomenon embedded in the broader culture and values of society. In accord with Brody (1987) and Kleinman (1988), Thorne notes that the interest of health professionals in acute care makes them ill prepared for the complexities of chronic illness. In fact, the participants in Thorne's inquiry saw themselves as 'troublesome' in a health system culture embracing the 'fix it' mentality.

In eliciting greater understanding of illness, Benner, Hanson-Bjerklie, Ferketich and Becker (1994) investigated the particular experience of chronic asthma. These authors chose this condition in the belief that chronic asthma is often not seen as a 'real disease' as the cause is not clear and many social factors influence its manifestation. Benner et al. maintain that chronic asthma is a condition where the Cartesian division of 'mind over matter' remains strong. Thus moral responsibility for staying well is laid heavily upon those who live with it. The study categorised participant's responses into attitudes towards their illness. These responses ranged through acceptance, transitional, non-acceptance and adversarial. The largest group, the category 'non acceptance', saw their condition as separate to them-selves and if those people were in adversarial mode, they believed the condition needed to be fought. This is a demonstration of the deeply embedded battle metaphor associated with disease. Inherent in this expression was a sense of moral weakness if the fight was not being won; shame and blame become significant experiences within this scenario; a moral burden to be borne within the complexity of the circumstances of the illness territory as is demonstrated in Sarah's experience.

the 'battle' in health-illness and disease discourses

The metaphor of 'battle' has been particularly dominant in the consciousness of people in the twentieth century (Watson, 1999). Prevailing ideas osmose into our consciousness and view of reality. The connotations of battle relate to fighting for the necessities of life and fighting for our country that will provide these. It now incorporates and carries with it notions of greed, conquest, expansionism and exploitation and control over our-self and others (Zukac, 1990). These notions are indicators of external power as opposed to what

Zukac nominates as internal power. There is a deep penetration of the 'battle' metaphor within the disease discourse with the use of the surgeon's knife or an armoury of drugs and other technical devices in its fight against disease (Ferguson, 1980). When the emphasis is on this lens it rules out a seeking of the meaning of disease or illness and/or suffering in the overall life of the person (Newman, 1994). The question 'What is this disease, illness or suffering telling me about my-self and my life?' is not asked.

The above discussion is a broad outline of the main assumptions of the disease and health-illness discourse from the literature pertaining to that discourse. These assumptions are summarised and illustrated in Table 7 in the conclusion of this chapter. They are assumptions in which the themes of paradox, moral meaning and metaphor are seen to be embedded in further generation of meaning in the narrative. I will now discuss the assumptions of nursing as caring practice and nursing as a functional service discourses.

the 'to and fro' of nursing as a caring practice and nursing as a functional service discourses

Early influences of nursing as a functional (technico-rationalistic) discourse affecting the practice of nursing are evident in Wooldridge, Skipper, and Leonard (1968). These influences are part of the initial debate regarding the place of theory in nursing (Walker, 1971; Wooldridge, 1971). The purpose of Wooldridge et al's book is the development of nursing practice theory (praxiological theory) within a behavioural scientific model. The term praxiological theory, introduced in Walker's paper and used in Wooldridge's response to it, came into nursing shortly after the publication of Wooldridge et al's book. Kotarbinski's (1965) praxiology had been appropriated into education, and from there into nursing by Walker. Prior to 1971 practice theory was the preferred term and it was seen as beneficial "to predict the effects of socially permissible practitioner activities on the welfare of clients" (Wooldridge et al. 1968, p. 32). These authors believed that the practice of nurses could be identified in their work of meeting the psycho-social needs of clients as nurses were seen to have a particular jurisdiction in this area. The physical tasks that nurses performed were seen to be supervised by medical practitioners.

The view of Wooldridge, Skipper and Leonard (1968, p. 22) heralded what is known today as evidence based practice in what they called the “rationalization of practice”. It was a term evolved from empirical research to describe effective practice. If a positive result was achieved in testing the casual relationship of a ‘good’ outcome with a particular procedure, then that procedure became known as ‘good practice’. Furthermore, this type of research also became the vehicle for affirming the professional status of nursing in delineating particular aspects of care as the province of the nurse. In keeping with the dominant functional discourse of the time Wooldridge et al. used the terms ‘diagnosis’ and ‘treatment’ to describe the nurse’s practice in responding the psychosocial needs of clients. Nursing practice then, became well embedded in the functional discourse of science which led on to the full manifestation of ‘The Nursing Process’ or what is still known as ‘The Nursing Diagnosis Movement’. It began as a movement, paralleling the medical model, designed to give nursing its own language and from this would flow jurisdiction over its practice (Bishop & Scudder, 1991). According to Bishop and Scudder this view is an objectification of the human condition and as such a deforming of practice. Nursing practice, for these authors, is responding to the moral ‘good’ of the person and is constituted as caring practice.

The embedding of nursing in the behaviouralist model was at the same time an embedding in a social organisational structure. In this structure it became shaped by the sociological concepts of “role, norm, profession, collective responsibility, and complex organisation” (Wooldridge, Skipper & Leonard, p. 34). Ironically, nursing in seeking to distinguish itself from the disease model of care and claim its own professional ground took on a different but similar functional structure as the disease model. Herein lies the reason for the many similarities of nursing as a functional discourse with the disease discourse. In my view this double functional perspective, reinforced within the New Zealand health reform, exemplifies the tensions experienced in my endeavour to embed Sarah’s ongoing care within the health-illness and nursing as a caring practice discourses.

symbolic interactionism in the nursing as a caring practice discourse

Wooldridge, Leonard and Skipper (1968) acknowledge the appropriation of symbolic interactionism, arising from social psychology, into the lexicon of nursing. Symbolic interactionism is the study of the social construction of the meaning of social interactions (Crotty, 1998). As symbolic interactionism also informs the health-illness discourse, similarities between it and the nursing as a caring practice discourse are evident. Symbolic interactionism had appeared in nursing well before the Wooldridge et al. publication in the form of interaction theories of nursing (Orlando, 1961; Peplau, 1952/1988). These theories, in fact, announced the arrival of the nursing as a caring practice discourse in the discipline of nursing. Nursing interactions were seen to have symbolic significance which needed to be understood outside of or alongside of the functional approach. Thus, two significantly different threads of nursing came to be recognised as the instrumental and the expressive. Later, more nurse researchers published work with a distinctive existential phenomenological approach (Gadow, 1980b; Paterson & Zderad, 1976; Watson, 1985). These works further affirmed the expressive thread and gave it a greater relevance and weight alongside the instrumental thread. For some nurses the expressive and instrumental threads were seen as parallel threads and for others they were intertwining threads.

What became known as the person centred or humanistic approach emanated from the existential focus, known as the expressive thread. Within this approach the emphasis on organisational structures of the instrumental or task and team orientation within nursing became problematic. Sociological concepts of role, norm and team, shaped within the nursing as a functional service discourse were seen as anachronistic in the move to a person centred model of care. Primary nursing developed as a solution to overcome this problem. Primary nurses would be responsible and accountable for the person centred care of small groups of clients throughout their admission to a health service.

Emergent from the influence of symbolic interactionism and the introduction of phenomenological research methodologies in nursing was the development of the concepts of care and caring in nursing and with it the claim of nursing as a caring practice (Bishop & Scudder, 1991). It was also the beginning of a dialogue with the practical

discourse in philosophy. These writers assert that viewing nursing as a caring practice does not exclude the use of technology in nursing. According to Bishop and Scudder there is a major shift in perspective from viewing nursing as a caring practice where technological skills are part of nursing to viewing it as “a practice structured by technology” (p. 49). Furthermore, these authors assert that if a practice is reduced to the application of physical science or an applied science, emphasis on the technical will replace responding to the moral good of the person.

caring as a moral imperative

The nurse writers who initially established caring as a moral imperative in nursing as a human science were Gadow, (1980b) and Watson (1985). The substance of their ideas drew on a strong existential base, including the work of Sartre (1956/1964). They asserted the importance of a metaphysical dimension in the practice of nursing. These writers spoke of caring taking place in relationship. Thus what had been known as the expressive function of nursing now became known as a relational process. Fry (1988, 1989) sought to develop a theory of nursing ethics where the foundation is formed from values practised in the client nurse relationship. In her theory, caring is a foundation value. Fry sees that caring in the client nurse relationship has moral value and is an ethic of care when it involves a view of 'the good' of others and guides the nursing actions of all people. Furthermore, according to Fry, an ethic of care has preferred values e.g. partnership and compassion.

In drawing on Gilligan's (1982) work, Cooper (1991), differentiates between principle-oriented ethics and an ethic of care. Principle oriented ethics involve establishing a set of ethical principles and then measuring a nurse's performance against them. It involves both objectification and normalisation and as such fits with the nursing as a discourse. Cooper contends that in an ethic of care the moral concern is "with needs and corresponding responsibility as they arise within a relationship" (p. 26). In this view unpredictability is the norm as opposed to the more prescriptive and predictable approach of principle-oriented ethics.

The derivative knowledge informing a relational ethic of care can come from different theoretical or philosophical, or a mix of these perspectives, as is demonstrated the work of the following authors. Benner Tanner and Chesla (1996) saw the primacy of caring as synonymous with 'the primacy of the moral'; Roach (1987) drew on a Christian humanist philosophy; Fry, (1988, 1989) used ethics theory while Cooper's (1991) ethic of care derived from both ethics and feminist theory; and Bishop and Scudder (1991) together with Poslusny (1991) acknowledged influences from the practical discourse in philosophy, feminist theory and caring science. Watson (1985, 1990, 1999) initially worked with existentialism, caring science, feminism and nursing theory and has now moved to incorporate ideas from postmodernism and beyond. Finally, Marck (1990) used her own construct of therapeutic reciprocity. However, only those of the authors who deliberately use the emancipatory aspects of feminism pay due attention to what may be de-moralising facets in the person's story or how these might influence their ability to change. As moral meaning was identified as a theme in both Sarah's and the nurses' experience in the narrative of this research, it became important for me to explore its significance in the 'in between' of nursing as a caring practice and nursing as a functional service discourses also present in the narrative.

My own journey in coming to see the importance of an ethic of care as the moral imperative of nursing came through my exploration of Newman's theory of health as expanding consciousness (1986, 1994). The assumptions of this view of health and person pointed to the need for an ethically based, primarily relational practice, so that health viewed from this perspective could be facilitated. I would now say that my relational ethic of care is informed by the praxiology I constructed for the informing of this praxiological methodology. It still contains some remnants of Newman's theory but is now more grounded in human science assumptions of the world and an eclectic view of care and caring in nursing.

I do not believe that care and caring are restricted to nursing but I do see that caring as the substantive underpinning of an ethic of care informed by a variety of derivative knowledges to be a critical axiom of nursing. Therefore, I do not agree with Morse,

Solberg, Neander, Bottoroff, and Johnson (1990) who argue that the caring dialogue present in the nursing literature is repetitive and shows little agreement about care and caring as a foundational value in nursing. For me, conformity of knowledge is not as important as the outcomes of caring. There are many pathways to achieving the same goal.

It is one thing to theorise about caring as a moral imperative, it is another thing to practice it in particular situations still dominated by nursing as a functional service. Halldorsdottir (1997) reminds readers that caring needs to be demonstrated and experienced as well as proclaimed. Moreover, she reminds us that we have a professional obligation to examine the rhetoric of caring professed by the theorists. Theoretical knowledge can stimulate mindful practice but it is important to remember that *phronesis* within 'everyday ethical comportment' (Benner, Tanner & Chesla, 1996) demands high level judgements taking the complexity of the context into account. Warelow (1996) agrees that caring as an ethical ideal needs to be demonstrated and that demonstration will then be seen to be 'good' in the context of responding to the health of a person. He argues that the context or situatedness of the caring practice will always determine the expression of caring and as such will negate any general consensus about what informs caring as an ethical ideal in nursing.

the New Zealand health reform and the nursing as a functional service discourse

Crowe (2000) confirms the influence the New Zealand health reform, as identified in the narrative, on the nursing as a caring practice discourse. She sees that the emphasis on managerialism has turned health care into a commodity requiring nurses to be mechanistic functionaries in achieving measurable and standard outcomes. As already expressed, Crowe affirms the double functional perspective of the disease and nursing as a functional service discourses, as problematic in realising the potential of nursing as a caring practice. An additional factor discussed by Crowe is the social images of women and women's work. She describes images of womanly nurturance, embedded in passivity, obedience, self effacing conduct and a penchant for 'good' works, which she believes infuse the caring work of nursing. These images not only place the caring relationship of

nursing in opposition to the managerial approach but also render it invisible and therefore of little value within that discourse. According to Crowe, the nurturing of others has traditionally been done in the private realm of the home and is difficult to commodify as a real practice in the nursing as a functional service discourse. This discourse's emphasis on technical skills, tasks, routines and predictable responses of both nurse and patient lead to the view of a nurse as a replaceable unit of a team. If team members are deemed to have similar technical competencies used to achieve standard outcomes then one nurse is as good the as next one.

Another effect of the dominance of the nursing as a functional service discourse, as discussed by Crowe (2000), is the establishment and valuing of hierarchies. As the disease discourse has been dominant, the medical practitioners who exercise authority in terms of diagnosis and treatment of disease, occupy the higher rungs of the health professional hierarchical ladder. In this positioning of authority, according to Crowe, nurses are subject to medical control in term of diagnosis and treatment of disease and therefore are inferior. Compliance of the nurse and the patient with a medical practitioner's clinical orders is expected. An outcome for the nurse in this situation, viewed through the lens used by Crowe, can be a disassociation from the patient as a person. She reminds her audience that discourses both shape us and are shaped by us. In accepting the disease and nursing as a functional service discourses we continue to be shaped by it. However, in choosing to practise assumptions from the health-illness discourse and value nursing as a caring practice we can, in fact, alter the effect of the disease and nursing as a functional service discourses.

This section outlined the 'to and fro' influences in the tradition of the nursing as a caring practice and nursing as a functional service discourses. Attention was drawn to the similarities between the disease and nursing as a functional service discourses which can increase tensions in the endeavour to practice according to the beliefs of the health-illness and caring as a nursing practice discourse. Instead of acknowledging the importance of all these discourses the New Zealand health reform has increased the tension by its

acceptance of the disease and nursing as a functional service discourse as dominant as is evident in the narrative in chapter eight.

conclusion

In this chapter I have identified and discussed the themes of paradox, moral meaning and metaphor as the major themes of the narrative in both Sarah's and the nurses' experience. These themes were seen to be embedded in the an 'in between' tension of two sets of discourses evident in the narrative; the health-illness and disease as one set of discourses and the nursing as a caring practice and nursing as a functional service as the second set. The ongoing influence of the methodological premises of reflexivity as praxis, dialogue as praxis and moral comportment as praxis were paramount in this explication. These themes and discourses had not been specifically sought in a deconstruction of the narrative, but spoke to me in the Gadamerian sense of a dialogue with the narrative. I had not explicated the traditions of these discourses earlier in the research. For this reason and to enhance the flow of the critique I chose to develop a discursive framework from a review of the literature informing the different traditions of the discourses, which provides a bridge from the narrative to the critique.

The assumptions of the health-illness discourse alongside those of the disease discourse and those of the nursing as a caring practice discourse beside those of the nursing as a functional practice discourse are summarised in tables 7 and 8. The purpose of the tables is to act as a reference point in reading chapter ten where meaning in the narrative is generated from the 'in between' tension of the different discourses. We live and work in a modern space inhabited by multiple discourses, which impinge on our effective historical consciousness in different ways, often resulting in our being located in ambiguous positions. The tables are presented as a heuristic reference strategy for the reader as s/he engages in the discourse illumination of the narrative in chapters ten. They are set out in order to understand the tensions when practitioners operate from the assumptions of discourses which are inadequate in understanding the complexity of the circumstances of a person like Sarah and in responding to her health situation. In the practice situation we

are situated in ‘the in-between’ of the discourses and experience ‘to and fro’ pulls from one to the other in whatever we are trying achieve. Further, the tables provide a visual image for all clients and nurses’, like all the co-participants in this study, who are situated in ‘the in-between’ of these discourses.

Table 7. Summary of the assumptions in the disease and the health-illness discourses

<u>Area of difference in:</u>	<u>Disease discourse</u>	<u>Health-Illness discourse</u>
Disease illness perspective	Entity that is given a medical label Meaning is sought in specific symptoms Reductionist -fragmentation – separation of body, mind, emotions and spirit Physical science Relies on quantitative information Breakdown in body machine – can be treated and fixed Emphasis is on the instrumental - means of coming to know and act is determined by the ends	Disease that affects person, whanau, community and tradition Meaning is sought in day to day life Dynamic pattern of unitary unfolding Physical and human science relies on both quantitative and qualitative information Person as whole - disease may point to underlying chaos or conflict that may need attention Emphasis is on the relational - means of coming to know and act emerges out interactive process
Client perspective	Dependent on expert Follows orders - compliance with prescribed regime expected - trust of expert expected - can have struggle to have experience believed Lack of voice Disease is to be fought	Involvement with practitioner in co-construction of meaning Expertise of self, whanau, community and tradition is involved in therapeutic partnership - dialogue and mutual trust Voice is heard Disease is reflected on and its meaning is co-constructed within life process

	Side effects of medication treated with more medication - co-morbidities expand	Alternatives to medication sought e. g. relaxation or nutrition therapies
Suffering and Vulnerability	Treated as pain, anxiety or depression	Answers sought in reflecting on meaning in order to find
<u>Area of difference in: cont..</u>	<u>Disease discourse cont..</u>	<u>Health-illness discourse cont...</u>
		coherence for person, whanau, community and tradition
Practitioner perspective	Expert and specialist in body systems, disease entities and treatments	Generalist shares expertise and acknowledges expertise of person
	Authority derives from expertise and specialism	Authority derives from shared expertise and ability to work with person, whanau, community and tradition, to find appropriate solutions, including treatments
	Emotionally neutral – relationship with person is secondary to treatment	Relationship is primary and integral in the outcome - engaged caring involvement with person, whanau, community and tradition
	Moral imperative is to fight disease	Moral imperative is to caring in the human health-illness experience
	Mystique in expert knowledge is revered	Mystery of human unfolding is honoured
Social perspective	Vested interested in disease - companies sponsor research in disease	Social iatrogenesis - reduced ability to achieve life plans from dependence on treatment

Table 8. Summary of assumptions in the nursing as a caring practice and nursing as a functional service discourses

<u>Areas of difference in:</u>	<u>Nursing as a caring practice</u>	<u>Nursing as a functional service</u>
Ethic and ethos	Concerned with internal ‘goods’	Concerned with external ‘goods’

	the well being of the client-person Values based Caring for the whole person	how to get the greatest good for the greatest number Fiscally based Getting the work done
<u>Area of difference in: cont..</u>	<u>Nursing as a caring practice cont..</u>	<u>Nursing as a functional service..</u>
Values	Needs of the person Human becoming and quality of life Effectiveness from person's view Relationships - attributes of the nurse Being with Nurses' individual practice Healing environment	Needs of the institution Fixing disease or illness Efficient use of time Inputs and outputs Competencies, nurses with same competencies are interchangeable Doing for Roles and teams Neutrality of environment
Focus of interaction	Clients	Professionals
Approach	generalist	specialist
Accountability and Authority	Client group Practitioner is autonomous Authority in expertise Continuity of practitioner important as is integral component of healing environment	Institution Authority invested in roles of managers and health specialists within hierarchies Algorithms to follow and checklists of competencies
orientation	Process and relational I-thou - subjective	Product and Instrumental I-it - objective
View of health	Subjective - what it means to person	Absence of disease or improvement in function
Measured by	Difficult to measure as relates to personal goals and outcome	Health status indicators based on ideological construction
Documentation	Practice philosophy Client experience and movement towards goals	Competencies, protocols Inputs and outputs

The two sets of paired discourses exist in the relationship of the different sets of assumptions that inform them and set them apart from each other. However, this is the construction of a theoretical device that draws attention to difference and should be interpreted as a more or less emphasis rather than a distinct cannon of truths. The binary differences of the discourses only exist in relation to each other and sit within the postmodern premise that “every truth is partial, incomplete and culture bound” (Millar, 1997, p. 142). In addition, the setting up of distinct boundaries between discourses holds within it the possibility of developing rivalry between them. This is not part of my intention. It is a theoretical construction that can be de-constructed at any time. The separation of the assumptions of discourses, though useful at a theoretical level, can become a Cartesian sword of either/or, setting up a duality, which can detract from keeping open to new ways of knowing and acting.

It is not correct or helpful to infer that all health professionals who see the world primarily through a disease discourse are not people who care about their clients. However, I see that there is a strong human drive to privilege certain assumptions, which in turn decrease the ability of keeping an open gaze on the strengths and weaknesses of both discourses.

Chapter ten uses the discursive framework constructed in this chapter to present critique as praxis. It extends the meaning made in the narrative in the examination of Sarah’s and the nurses’ experience. Paradox, moral meaning and metaphor are common themes in the explication of both experiences.

Chapter ten

MEANING IN POSTMODERN NURSING PRACTICE: CRITIQUE AS PRAXIS**introduction**

This chapter enacts critique as praxis in order to construct further meaning from a deconstruction of the narrative. I use the term deconstruction to describe a deeper penetration into what other meaning might lie below the surface. To do this I explore both Sarah's and the nurses' experience using the themes of paradox, moral meaning and metaphor within the discursive framework constructed in chapter nine. Sarah's experience is placed in the 'in-between' space of the disease and health-illness discourses. The nurses' experience is placed in the nursing as a caring practice discourse which occupies a space on the boundary of the nursing as a functional service discourse. The summary tables in the conclusion of chapter nine highlight the different assumptions associated with the two sets of discourses as a reference for understanding the 'pull and push' of each discourse. The literature used to illuminate the traditions of discourses in chapter nine is further expanded as I apply and interweave it into the particularities of the practice situation.

The theoretical construction that follows is one of many constructions that would be possible about the narrative. It looks behind the level of meaning achieved in the co-construction by the research co-participants. It is my theorising, within my effective historical consciousness. The triad of horizontal threads permeate the entire hermeneutical reflection of the research. They are living with chronic illness, practice as praxis and research as praxis and have influenced the shaping of the meaning constructed in this chapter. An understanding of why Sarah's illness became such a burden for her and continues to be a burden emerges in this critique as does the influences that affected the 'caring gaze' of the nurses involved in her care.

In referring to the particularities of the experience documented in the narrative I will use the abbreviations N = narrative and FM = final meeting. With these abbreviations are the page number/s in this report where the references can be found. They are present as an

audit trail in relation to the generated meaning. The chapter is composed of two distinct sections. The first deconstructs Sarah's experience and the second embodies the deconstruction of the nurses' experience.

focussing on Sarah's experience

The deconstruction of Sarah's experience reveals multiple factors that have contributed to her burden. If the person's explanatory model of their illness is not respected and understood by practitioners the therapeutic efficacy will be undermined and ongoing strife will continue (Frank, 1995; Kleinman, 1988). Associated with Sarah's metaphors are paradoxes and moral meaning which underpin her existence in the world. Her paradoxes and moral meaning interweave with the assumptions of health illness and disease discourse. The deconstruction commences with the concept of the ontological assault of illness and then moves to examine Sarah's entrapment in the disease discourse. The concept of the 'in-between' space of the health illness and disease discourses is then used to examine her medication cocktail; her fluctuating bodily symptoms; moral meaning within the threat of suicide; the separation of body and self; family tensions and the temporal element of suffering. The section concludes with the creation of an extended metaphorical meaning of Sarah's burden and the implications for practice as praxis in the nursing care of people experiencing the suffering of strife in chronic illness.

the ontological assault of illness

Sarah's illness burden and suffering began in her childhood with the diagnosis of asthma and what she experienced as "*nasty experimental treatments*" (N p. 166). These precipitated fear and a real "*hang up with it*" (N p. 166) compounding into a strong feeling of being "*not as good as the rest of them*" (N p.166). Moreover, with this demoralisation she sensed a difference about her 'whole being' (N pp. 166-203). Pellegrino and Thomasma (1988) describe such a response as the 'ontological assault' of illness. It disrupts people's sense of being in the world, can lead to an understanding of not being them-selves (Cassell, 1991) and a sense of separation between the self and the body (Gadow, 1980a). The ontological assault of illness, then, penetrates the very being of the

person and affects how they view the unfolding of their life. It disrupted Sarah's childhood and in so doing she failed to build up a 'good' self concept.

A particular manifestation of the ontological assault for Sarah was dis-ease in breathing. Her 'battle' for breath to get through the day became synonymous with her battle for life in general. The 'battle' metaphor that has pervaded our collective consciousness (Watson, 1999) became a leit motif in Sarah's life. Fighting for what she perceived was a normal existence and for her right to be recognised as a vulnerable human being became ingrained in the way she lived from day to day.

The burden of illness and suffering that had begun for Sarah in her childhood turned into what Rose termed "*chronic ongoing grief*" (N p. 175). Her sense of an abnormal childhood with the accompanying loss of normality became a continuing metamorphosing in and out of grief and varying degrees of feeling 'normal' and "abnormal". For Sarah, normal was how other children got on with their lives without apparent disruption. Sarah battled to achieve a sense of the 'normal' even when it meant hiding the abnormal (N pp. 166-167-203). Adolescence brought with it a very overt search for the 'normal'. Fitting in with her peers and learning to smoke gave her a sense of belonging she had not experienced in earlier years. It also gave her a sense of control over her life. This carried on for some time in her work, marriage and caring for her children.

Sarah's experience of vacillating between normal and abnormal is consistent with that of the participants in the Thorne (1993) study. In Thorne's study experiencing the normal and abnormal meant living a paradox. It was about fitting into the social setting in a normal way while accepting an inherent abnormality. Being normal for the participants in the Thorne research became an ideal that they measured themselves against. It was the same for Sarah (N pp. 166-167-203). It could be taken on as a social pressure calling forth conformity and thus increasing the complexity and stress of her situation. The tendency to normalise had both advantages and disadvantages. In the study by Thorne normalisation was advantageous in assisting the 'fitting in' process and minimising the

illness limitations. Nevertheless, too much accentuation of the normal negated the reconstruction of an identity that takes limitations into account. Furthermore, the Thorne study demonstrated differences in visibility compounding the sense of normal. Invisibility of abnormalities and symptoms such as pain, intensified their experience which was inherent in Sarah situation (N pp. 167-174-182-183; FM p. 215. The Benner, Janson-Bjerklie, Ferketich, & Becker (1994) study supports this latter observation. For participants in both the Thorne and Benner et al. study invisibility raised the issue of the legitimacy of their illness, as was Sarah's experience (N pp.167-184). Such labels can bring forth moral judgements about attention seeking and/or shirking responsibilities, as is promulgated in Parson's (1951, 1978) theory of the sick role, causing greater distress. In addition, Benner et al. noted that when medical science failed to locate pain or other symptoms, health professionals negated chronically ill people's experience in the same way as lay people tended to do. In my experience the normalising of the lives of people with disabilities and chronic illness was motivated by the humanitarian intention of advantaging people and granting their rightful claim to participation in society but holds within it possibilities of the disadvantage of professional normalising which I saw happening with Sarah.

Sarah's sense of having control over her life coupled with her experience of normal as a young adult was short lived. While still in her twenties more suffering occurred. This arose from loss and grief related to a broken marriage and threats of losing her children. (N p.166). Ending the marriage was not her choice so this episode was a double threat to the control she experienced in her life and as such was highly stressful. Her life plan (Brody, 1988)¹ was arrested. The one thing she could do to retain some control was fight to keep her children. Her battle to keep them was won but with financial and personal costs as her being took another assault. Sarah's suffering and illness burden at this time was shared by her mother and to a certain extent by other members of her family. There was an interval of tentative normality before her loss, grief and disruption was extended with the death of her mother. Exacerbating this ontological assault of the grief of a lost

¹ The notion that we have within our minds, ideas and personal goals that we have decided are achievable within our lifetime. The lifeplan is inextricably linked to our self esteem.

parent was the loss of the main sharer of her burden. “*I don’t think even now I have got over it*”(N p. 166). From this period on her dis-ease became more troublesome.

entrapment in the disease discourse

A three year period of disabling physical pain from the “*the intercostal nerve entrapment*” (N p. 167), when her distress was not taken seriously, precipitated another period of suffering; her sense of being abnormal was compounded by the apparent invisibility of a cause. This period of strife symbolises her ‘entrapment’ in the disease discourse. Clinical tests did not demonstrate clinical abnormality so all the surgeon and general practitioner could do was fob her off with pain relief medication when she knew within her being that something was seriously amiss. Her modified life plan was seriously eroded. It felt like her life had been ruined and her ‘normal’ (being able to work outside the home) was out of reach. Informed by this understanding it is not surprising that a two year period of severe strife ensued.

In the following two years Sarah became more and more ‘trapped’ in the disease discourse resulting in ‘*horror*’ and a sense of her pending death (N p. 167). It is a story of humiliation, de-humanisation and de-moralisation. Similar experiences are noted in the Thorne (1993) investigation and are what she describes as “a destructive side of humanity incarnate in the health care system” (p. 153). It is analogous to Frank’s (1995) image of the wounded storyteller caught as a mute witness in a chaotic world; a world of horror. Frank talks of the illness story coming out of a sense of wreckage where any path to the future is lost. The grief, loss and feeling of abnormality in relation to the effects of the disease experienced by Sarah can be interpreted as wreckage but the most vivid sense of wreckage came in the two year period of her time in severe strife (N p. 167) between 1994 and 1996.

Gadow’s (1995b) heuristic tool for clinical assessment illuminates the 1994-6 period of severe strife. Her discussion on the reduction phase gives meaning to Sarah’s period of strife and consequent hospital admissions. Gadow asserts that relying on a single answer, in Sarah’s case the reductionist phase of looking for disease, lacks openness to other

possibilities. It does provide certainty in the short term and if it turns out to be the answer it relieves the suffering associated with the initial period of limbo. If however, no medical diagnosis is made from the suffering of particular symptoms, as was Sarah's experience (N pp. 167-183), then the uncertainty exacerbates the suffering and increases the pain. Even when disease is discovered it presupposes that medical science can 'fix it'. When this is not possible, as is the case of many symptoms associated with chronic illness, yet more weight is added to the burden of suffering. Such a weight can lead to paralysis (N p. 203). The voice of certainty becomes the voice of uncertainty.

According to Gadow (1995b) an impasse arises when nurses and other health professionals remain in the reduction phase where disease provides the only answer. It is what Gadow (p. 29) describes as "the endless and fruitless search for the diagnostic touchstone". I see this as an explanation of what happened in Sarah's situation. Any understanding of the health-illness discourse was completely missing. Pain becomes true suffering when it is "overwhelming, uncontrolled, and unexplained" (Brody, 1987, p. 29). Brody also asserts that the disease discourse, when practised as the only approach neglects the moral. Entrapment in the disease discourse produced extensive demoralisation for Sarah; loss of her sense of personhood and standing in the world. It provoked a repeating pattern. Her words to describe this time bring this phase of demoralisation into stark focus, "*she felt a freak [and] a wild animal*" (N p. 167), images of non-persons. She had metamorphosed into the abnormal. Herein lies a major paradox. It was not Sarah who was primarily stuck at this time, as I had originally conceived, but her doctors and nurses. This culture of objectivity, as described by Gadow, was exacerbated by the attitude of the charge nurse (N p. 167), or in fact set by it.

Kleinman (1988, p. 9) likens a too rigidly held empirical view to an encircling effect of an "oppressive iron cage". Health professionals who continue "the fruitless and endless search for the diagnostic touchstone" (Gadow, 1995b, p. 29) are encaged and by association entrap or isolate the suffering person in a separate oppressive cage. Sarah's metaphors mirror this imagery (N. p. 167). She felt "*caged in*". A wild animal when entrapped by humans is caged. Likewise, "*freaks*" (N pp. 167-183) and "*raving lunatics*"

(N pp. 178-179) were historically put behind bars. Sarah had become completely alienated in an existence of suffering (Younger, 1995). According to Kleinman (1988), when the broader lens on illness and its meaning is taken, both the person with the illness and the health professionals are liberated from their cages. A partnership can be forged where both work together. Frank (1995) also talks of cage imagery in his illness stories. However, for Frank the image is of the body as a cage of the self, an image also embodied in Sarah's story (N p. 177). Benner, Janson-Bjerklie, Ferketich and Becker (1994) see this experience as culminating in what they name "a discourse of suspicion that fuels an entitlement discourse in relation to disease treatment" (p. 252). Physicians become suspicious of the client experience when it is not validated within disease discourse assumptions. It is labeled as 'not real disease' and the symptoms are seen to be 'all in the mind', therefore these people are not entitled to treatment. It is a sub-discourse of the disease discourse, which furthers the righteousness and authority of the professional over the client. Furthermore, Senior and Viveash (1998) comment that 'blaming the victim' for her or his situation is likely when they do not fit these functional discourses. With this sort of justification there is no motivation to move from their iron cage of empirical knowing.

The nurse whose hands were tied (N p. 167) could not reach out of the cage in order to touch Sarah with the warmth of her humanness. Doctors hands are also tied when in their iron cages. There was little the hospital health professionals could do for Sarah (N p.178). They offered three options: she could help herself by stopping smoking (N pp. 188-196), the psychiatrist could 'fix it' (N pp. 167-168-206) or she could go to a nursing home facility (N p. 181).

Gadow (1995b) also warns that widening the gaze does not automatically reduce objectivity. The nurse, unless there is dialogue with the person, is still in a position to decide what should be foreground or background issues. Moreover, Gadow's conceptualisation of the clinical epistemology arising out of the process rather than the outcome is a timely reminder for those of us working with people with chronic illness. Nevertheless, her challenge to keep all phases of assessment open can be much easier

said than done, especially in prolonged engagement. My own experience was to stay with a holistic engagement and put empirical matters to the back of my mind because, for me, they were the brief of the medical people or the respiratory clinical nurse specialist.

I now ponder the questions; What control does one have behind the bars of a cage? Who can win a battle from within a cage or when positioned in chaos and wreckage? Notwithstanding the entrapment Sarah's "*deep inner strength*" (N p. 199) was not obliterated and she discharged herself home (N pp. 167-178). No wonder she thought she was going to die and took additional pain relief '*the digesics*' (N p. 167). When the reduction phase becomes an end in itself it can become a "dead end" (Gadow, 1995b, p. 29). Death of the person becomes a possibility as is seen in Sarah's resort to the possibility of suicide (N pp. 167-177-178-203). Death is the ultimate disruption of illness (Brody, 1987), the ultimate metamorphosis or transformation. Taking extra pain relief was the only medical remedy supplied that might ease the pain of her incredible suffering. Frank (1995) notes that when the reality of ill people is denied they remain recipients of care not participants in their care. Like a chronic wound that resists healing because of an underlying pathology, healing for Sarah did not proceed readily while the meaning of her burden of illness and suffering was ignored.

the 'in-between' space of the health illness and disease discourses

the medication cocktail

The polypharmacy that we, the nurses co-participants, had concerns about was well established when we began our engagement with Sarah. She was taking medication to treat symptoms and medication to treat the side effects of the medication that treated the symptoms (N pp. 172-177-183-189-190-191). In establishing polypharmacy the medical practitioner enters into the paradox of prescribing therapeutics that have untherapeutic effects (Kleinman, 1988). I saw that Sarah's pharmaceutical cocktail increased her suffering and fostered a reliance on the medication and her medical practitioner. In so doing it reduced the control she had over her life and her life plan. As Thorne, Nylin and Paterson (2000, p. 304) propose "qualities of compliance and self reliance become mutually exclusive".

Paradoxically, Sarah actually stopped taking some medications and talked of coming off medication (N p. 184) when she was frustrated with the doctors. This appeared to me to be a quest to be in control. She acknowledges that this is an irrational response and relates it to her stubborn self (N pp.175-196). It seems she was saying 'I will stop taking the medication you ask me to take to spite you, I won't be compliant and this will make you angry which will be my pay back after you have made me angry'. It is an example of the power struggles that develop in the prolonged relationships of health professionals and clients who live with chronic illness, as discussed by Thorne (1993). Moreover, it exemplifies Sarah's paradoxical situation of self reliance and dependence on the health system (Benner, Janson-Bjerklie, Ferketich & Becker, 1994).

The concept of non compliance, according to Gadow (1980a), fits with the notion of paternalism. The person declines what is seen as 'the good' of the parent as it does not fit with the value system of the person. It is seen to be a lower 'good' than the person is actually pursuing. Sarah's response, irrational or not, actually got her through her time of frustration. At the same time Sarah genuinely wondered about what her real self might be without the medication (N. p 184) Any reduction in medications would need care-ful consideration because of the suffering of withdrawal that was likely to occur. A indication of this is captured when Sarah missed taking her medications when attending to her dying friend, Sally (N p. 202). Morse and Johnson (1991b) suggest that the illness experience, the ontological assault of illness, can be so devastating and irrevocable, that the persons concerned will never move to a position of trusting themselves fully again.

In my discussions with the physician I expressed my concern about the use of the long lasting and short lasting morphine extracts (N p. 191). He was reluctant to accept that Sarah 'did not fit the palliative care model' or to trust her judgement as to what might work for her. He referred back to the medical pain specialist which generated another cycle of "the endless and fruitless search for the diagnostic touchstone" (Gadow, 1995b, p. 29).

fluctuating body symptoms

In addition to disease symptoms and side effects of medication, other bodily symptoms are inevitably associated with chronic illness (Kleinman, 1988) The medical term for these is “somatisation” (p. 59). They can manifest in a number of ways. We all have aches and pains in our day to day living. However, a person like Sarah who lives with chronic illness and who is charged to be ‘responsible’ in monitoring her disease symptoms, is caught on the horns of a dilemma or paradox. She is asked to be both vigilant and at the same time distance herself from them (Morse & Johnson, 1991b). Is what she is experiencing a disease alert? is it a symptom of everyday aches and pains exaggerated by medication but something she can ignore? is it both of these magnified by stress? The doctor is also caught in this dilemma as s/he finds it hard to distinguish these symptoms. Kleinman reminds us about the bodily manifestations of the physiological effects of stress², some of which are very close to symptoms of asthma. His reminder is a good reason for keeping open all phases of a clinical assessment (Gadow, 1995b). Panic, an understandable reaction to threatened breathing, heightened Sarah’s symptoms (N p. 196).

With all the happenings in Sarah’s life there is ongoing stress, in varying degrees, contributing to the burden her suffering. Sarah talks of the third year of the study period as the time she lost so much. This included the “*nightmare*” (N p. 195) of the move into living alone, the death of her friend (N p. 202), and increasing tension with her father and stepmother who had become her near neighbours (N. p. 203). When chaos remains at the center of one’s experience it is accompanied by a sense of being overwhelmed, exacerbating a continuous series of happenings in one’s life (Frank, 1995). He notes that when the chaos settles more control in life’s happenings reappears.

Judgment of her bodily fluctuations (N pp. 170-183-205-206–207; FM p. 215) causes Sarah ongoing angst. However this lessens at times when her health is “OK” (N pp. 206-

² “increased pulse and breathing rates, difficulty sleeping, dizziness, tingling’ of hands and feet, ringing in the ears, headaches, abdominal discomfort , constipation or diarrhoea, frequent urination, dry mouth and throat, difficulty swallowing, dyspepsia, tightness in the chest, changes in menstrual patterns ...” (p58)

207). ‘OK’ health is a time when she is breathing more easily and when pleasurable events are enjoyed. (N pp. 175-181-182-197-198-204-205-209; FM p. 216) Nevertheless making decisions about the best time to seek intervention when she is in a downward spiral is at best confusing and at worst a ‘*death warrant*’ (N p.196). It is what she sees a nurse can help her with most; co-constructing her health situation (N pp. 177-188-195-198-206-207; FM p. 215).

the hospital paradox

Hospital allowed Sarah to hand over of the judgement of her illness fluctuations that she undertook day to day. It was seen as a safe place (N pp. 177-184-196). However, paradoxically it was the place she encountered staff in their iron cages who de-moralised her and a battle often ensued to be recognized as a vulnerable person seeking relief from her suffering. It was a situation akin to the vulnerability of pain and the pain vulnerability (Kleinman, 1988) that was mostly treated by pain relief medication. The effects of any non-medicated therapeutics used in the community were weakened. I think that Sarah would relate to Frank’s (1995 p. 107) personal illness experience of hospital when he says “I both hated the hospital and found it was the only place where I felt I had a place”.

On the other hand, hospital was a legitimate place to rest and catch up from the outpouring of energy in her day to day life. In Sarah’s frame of reference it is legitimate for ill people to rest in hospital but if you are well enough to be at home the normal expectations of getting on with the activities of daily living and moral obligations to others become her focus. These took priority over resting and caring for herself at home. In retrospect I see that all the efforts Mary and I put into establishing what we thought would help Sarah attain her ‘normal’ were not effective (N p. 189). The goal of our work was to normalise but we lacked understanding of Sarah framing of ‘normal’. It was another paradox in our partnership.

moral meaning in the threat of suicide

Sarah’s inner drive to have a safe place for a home appears on the surface to be paradoxical to her contemplation of suicide (N pp. 167-178-203). When she spiraled

downwards, a period of severe suffering and de-moralisation, death became a 'good' option for her. In her metamorphosis into the abnormal (N pp. 167-183-188) death is seen as a 'good' choice. It offers a sense of control, which appears to relieve her suffering, and it offers final relief from her suffering and the battle of life. Sarah holds no fear of death. She believes from an earlier near death experience and her spiritual awareness, that there is somewhere to go after death (N p. 210). A somewhere that becomes an attractive option, a safe home, when all around her is suffering and chaos. *"I don't know what life holds, I am really frightened of the outcome. I feel like a little kid that wants to run to their parents to hide ... I'm not strong enough to keep going"* (N p. 204). Death is the final metamorphosis that promises peace and harmony. At the same time, however, it is her sense of moral good that stops her suicide. Her children would have blamed themselves for not being there for her (N p. 179) and the last thing she wants is to let her children down because of what they have been through with her (N p. 201). Moreover, holding suicide as an option appeared to give her the energy to fight on. Knowing that there is an option, a way out, if things get too 'bad' seems to work like having someone to call if anxiety spiraled up (N p. 187). The knowledge that help or relief is at hand actually decreases the need to utilise it.

Frank (1995) discusses how we witness to the testimony of the chaos (strife) in an illness journey when we set out to discover what illness means to the person experiencing it. He see this witness as someone to walk alongside the wounded storyteller without any particular instrumental purpose e.g. keeping them out of hospital or monitoring certain signs and symptoms. It is someone who listens to what constitutes their chaos, the haunting nature of their experience, their encounters with self destruction because of de-moralisation and de-humanisation; someone who facilitates the giving voice to chaos and acts as witnesses to that chaos. Furthermore, Frank asserts that a world of possibilities for the person experiencing the chaos remains closed unless the chaos story is witnessed and honoured. If the possibilities remain closed the wounded storyteller is denied the care s/he desperately seeks. According to Frank the less assistance a person experiencing chaos gets the greater is their need to talk about their chaos. Frank sees the witnessing and honouring of the chaos story as a moral imperative. It is an imperative that assists the

people to recreate themselves recursively. In doing so wounded storytellers integrate the chaos into their lives and are able to move forward in creating a new or modified lifespan. Their story becomes a gift to be offered to others as testimony and witness to the existential experience of chaos or strife in illness.

separation of body and self

Another ambiguity often associated with chronic illness that was part of Sarah's burden is the concept of a disruption of the body and the self. "*It felt to me that my body was not doing what I wanted it to do*" (N p. 177). She was caught in the moral dilemma of mind over matter highlighted in Benner, Janson-Bjerklie, Ferketich and Becker (1994). Sarah drives her body beyond 'normal' limits and she manages to get through and gets done what her-self wants, then her body exacts its toll – increased physical pain or distressed breathing in "*at times I pushed myself to the limits and over and I pay for it*" (N p. 172). This is akin to an observation in Frank's (1995) discussion on the separation of body and self. Here the body object can be felt to give the self subject a 'hammering'. Furthermore, Frank sees the separation as a survival mechanism for the self. The self can keep going if the 'I' has something to blame for the 'I's sense of chaos.

The separation of self and body is what (Gadow, 1980a, p. 174) calls "disrupted immediacy" in a four stage theoretical construct of a dialectic of body and self. Like Gadow, Frank (1995) sees the body and self as separated into body as object and self as subject. This objective body becomes the existential other to the existential self, different from but similar to seeing the person as object in the disease discourse. Gadow proposes that the medical gaze on the body with its drive to categorise every symptom completes the self-body separation. Frank and Pellegrino and Thomasma (1988) support Gadow's proposition. The body as object should be the servant of the self but becomes a 'constraint' on the self as it does not do what the self asks of it. A sense of opposition develops between the two where the inter-relationship becomes one of struggle or in Sarah's terms 'battle'. Gadow uses the terms "heaviness and recalcitrance" (p. 176) to describe the sense of separation the body holds within it-self. The separation can move to be a "cultivated immediacy" (p. 177) where the body is integrated with the self through

effort and exercise as with an athlete's training programme. This is present in Sarah's attention to her body-image. Her sense of self is bolstered in a good body image created from her endeavour to reduce fluid retention and look attractive for the ball image (N p 181). However a stage of "subject body" (Gadow, 1980a, p. 187) where there is mutual recognition of one with the other and a relationship of intersubjectivity can develop in which a awareness of each other's needs is taken into account.

As part of Sarah's separation of her-self from her body, was the separation of her health from her-self. Health for Sarah is related to her chronic asthma and pain, all the physical manifestations (N pp. 198-206). So when all the suffering during the third year of the study, the nightmare of the change, Sally's death and increasing antagonism with her extended family was looked at, it was seen as part of her-self but not her health. However there was a glimpse of intersubjectivity in "*I don't know whether it was a combination of the move and the stress that I ended up in hospital four times*" (N p. 195). Mary and I often advised Sarah to listen to her body and takes cues from this to rest or relax in some way. It was also part of my discussions about the effects of smoking (N p. 188). We were operating on a 'relationship of intersubjectivity' of body and self. When body and self are in an 'opposing forces' relationship and there is a sense of a recalcitrant body, it is not likely that its message will penetrate the self. The recalcitrant body increases her burden and vulnerability and silences any dialogue that can go on between.

family tensions

Within this cycle of "vulnerability of pain and pain of vulnerability" (Kleinman, 1988 p. 56) is the web of relationships (Arendt, 1998) that make up Sarah's life. Her family (nuclear and ex-tended), her health professionals who become her friends (including the physician) (FM p. 216) and her lay friends. Ordinary relationships come under pressure from time to time in our day to day lives but when they are compounded with the ongoing burden of illness stresses and strains can become apparent and increase the weight of the burden (Brody, 1987; Frank, 1995; Kleinman, 1988; Younger, 1995). Health professionals or family members who view the world through the lenses of functional discourses (Senior & Viveash, 1998) can commence querying the authenticity of the ill

person's symptoms which in turn increases the dissatisfaction of the vulnerable person. This does not appear to happen so much in terminal illness as the period is more defined. I see that this is one meaning that could explain the ebb and flow of tension between Sarah and her father and siblings. In her early strife significant family members supported her and after the major crisis (N p. 179) there was a rallying around her but as her life settled again tensions increased (N pp. 181-202). They increased so much that the symbolic wall separating them came to be a physical separation in the erecting of a fence between the road and her house (N p. 203).

Sarah felt her extended family had begun to threaten her security within the openness of the community and the fence increased her sense of safety and decreased her sense of vulnerability. It quite literally gave her a safer home. The tension escalated into mutual antagonism and a lose-lose situation for all developed. It culminated in her father requesting a return of the money that Sarah believed had been a gift many years earlier (N p. 181) and which she could not repay. The request was followed by an announcement of a '*pending court case*' (N p. 203) while still grieving for her friend; a time when she needed their support in the sharing of her burden. It was a double blow that was "*churning up my guts*"³ (N p. 203). In relation to Sarah's family values including the expectation that members would help share each others burdens the thought of her father taking her to court' became '*a huge awful thing*'. (N p. 203). A countering effect in Sarah's family relations is the constant loyalty, support and contribution to her house and garden development by her children. This is a reciprocal 'good' in her life. As she tells it "*my kids have stood by me and if they hadn't I doubt whether I would be here today*" (N p. 201).

the temporal element of suffering

Cassell (1991) talks of a paradox within the temporal element of suffering. For suffering to be experienced there must be a sense of the future and for it to be minimised the person needs to be grounded in the present. Sarah's experience swung between present and future, both being influenced by the past. Fear arising out of her past experience was her

³ a physiological symptom of stress

constant companion in the present. It appeared to govern any envisioning of a future without the heavy burden of suffering and illness. In our three years of partnership Sarah returned time and time again to this fear. The invisibility of bodily symptoms almost always triggered her fear that her earlier pain and suffering would return (N p. 195). While still in hospital Sarah believed “*I was either going to die of that (overdose of digesics) or die of my breathing*” (N p. 167). Here, she had a sense that the chaos and suffering was going to be so overwhelming that she might die but it is from a perspective of being alive and intact. I named this fear “*anticipating the worst scenario*” (N p. 175). As time went by and her perspective began to change, I believed, she did much more in a day than people without an illness, which appeared to us as nurses to contribute to the prospect of not having a future.

Finding a safe space in the open community, in the early stage of the research period, meant Sarah would not risk doing what ‘normal’ people did (N p. 167) in order to have a future. According to Cassell (1991), the relinquishing of fear of possible future suffering and pain is very difficult even though it is exacerbating the suffering and pain in the present. Cassell sees that success is most possible if the people can ground themselves in the present. As the old maxim says ‘to live each day as it comes’. I believe this is more realisable for people who have personalities who have more of a now focus than a future focus. I understand her future orientation, as I am a person who also tends to live in the future.

Sarah’s other personality traits of the strong drive and impetuosity (N p. 173) do, however, appear to assist a grounding in the present. She works to achieve the goals she sets herself in house and garden development and with her crafts motivated by a moral imperative to be busy but also by the drive to do what is possible today in case she is unable to tomorrow. The times she spent doing hard physical work at her son’s place was an example of living in the present to allay “*the huge awful thing*” (N p. 203) of the pending court case. Sarah does admit to difficulty in finding the right balance and feeling the physical effects when she overdid physical activity (N p. 203) but it was in fact therapeutic for her. Her own wisdom knew that “*it’s a protection for me from going*

insane” (N p. 203). It gave her a sense of the ‘normal’ and made her feel “ *a bit more human*” (N p. 203) which relieved the weight of the burden of her chest and allowed her to breathe more easily. Her ‘good’ of feeling normal and human is being attained and is ‘good’ for her. In practice I tended to see her overdoing of activity more than the understanding the therapeutic aspect but did realise it worked for her (N p. 203). Sarah was pursuing her modified lifeplan and as Sarah says “*the better I get the more I want to do*” (N p. 182). There is testimony to her ‘getting better’ and pursuing more and more activities (N p. 209, FM p. 216). It is a ‘better’ that still involved a struggle at times. However, in the reflexivity that the reading the narrative stimulated, what she was doing in September 2000 was ‘*amazing*’ (FM p. 215)

Sarah's life remains a constant battle, albeit less of a struggle than earlier, to achieve her lifeplan. She is also philosophical about the probability that her illness will shorten her lifespan in years. In the light of this frame of reference her smoking is viewed as instrumental in accentuating an inevitable process. Sarah says it this way, “*smoking will bring about the end more quickly. It's going to happen. I'm just speeding it up*” (N p. 197). As she liked to remind me there was no guarantee that giving up would relieve her burden. Smoking had paid a significant part in the quest to be normal in her adolescence and later it became her way of de-stressing and alleviating her suffering; a comfort (N p. 196). Furthermore, it was something she had maintained control over when she had lost so much control related to her losses and illness. In fact her smoking was a central pivot in the power struggles she experienced with some health professionals (N p. 196). While smoking remains meaning-ful, Sarah is not likely to let it go without something more meaning-ful coming into her life.

Practice as praxis in an extended metaphorical meaning of Sarah's burden

From the above reflections on the health-illness discourse in the literature I have now created an extended metaphorical analogy of what sharing the burden of strife in chronic illness means for Sarah and for nursing. The burden of illness (suffering) that Sarah carries in all her day to day living appears to be a weight or heaviness sitting within her chest. Getting things off our chests is a common way of expressing how we unload dis-

ease or dis-stress. When the weight of the burden is heavy it takes up all available space in her chest and there is dis-ease with breathing. Sarah talked of it weighing her down, “*its overload* (N p. 207), which stops her functioning (N p. 206). Ventilating of air from her lungs is dis-rupted. Disrupted breathing leads to disruption in her voice (N pp. 178-196). When she has little voice then she has little power and calls forth others to speak on her behalf and to co-construct the state of her health-illness circumstances.

In ventilating her burden (her fears and frustrations, the strife within her illness experience) to a caring health professional, the dis-ease of the burden is lifted and space is created for the breathing in of energy for participation in ‘normal’ activities. Sarah’s expressions include “*I could vent out a lot of anger* (N p. 172). It allows her to breath easier and in so doing “*they [her children] breathe a bit easier*” (N p. 202). Sarah equates ease of breathing with a sense of wellbeing in “*When I am well I am OK*” (N p. 207). There is some integration of self and body but in the period of the research time there was always some degree of stuggle and burden. While life continues to be a struggle for Sarah there will be a battle to get enough breath to achieve her lifeplan as “*the better she feels the more she wants to do*” (N p. 182). “That one should bear the burden of the other is the simple and clear call that comes from all suffering. It is possible to help bear the burden (Younger, 1995, p. 67). Younger’s ‘clear call’ is the challenge of practice as praxis when responding to people experiencing strife in chronic illness. The outcome can be the creation of a safe home and greater participation within the community where they live.

In this section focussing on Sarah’s experience of strife in chronic illness the push and pull of illness as an ontological assault and entrapment in the disease discourses is explicated. A deconstruction of several issues from the narrative within the concept of the ‘in between space’ of the health-illness and disease discourses which expands the meaning evident in the narrative is then presented. The new meaning is then used to expand Sarah’s metaphor of illness as a burden and its consequences for practice as praxis.

focussing on the nurses' experience

In this section I re-present the nursing practice as seen through the eyes of the nurses in the narrative as a 'moment' in which "caring-healing praxis" (Watson, 1999, p. 7) was attempted. The context of this moment was within a regular community nursing service in the New Zealand current health care environment and what is interpreted in the narrative as 'the caring gaze' of nursing (N pp. 177-186-187). The re-presentation will examine the practical implications of such a moment where nurses felt the pull and push of the nursing as caring practice and nursing as a functional service discourses.

The discussion begins with addressing the concept of a 'caring healing moment'. It then moves to discuss the relational ethic of care, the intense relationship, the fine line between therapeutic and non-therapeutic approaches and norms normal and normalising. This discussion concludes with an explication of Sarah's transformation process within our 'web of relationship'. As the material of this chapter is the final contribution to the fulfillment of the research objectives a final summative statement on the overall inquiry is included after the chapter conclusion.

a 'moment of caring healing praxis'

A caring moment signifies the togetherness of people within space and time where a mutual connection can occur and where intersubjectivity develops its own web of relationship, its own life (Connor, 1995). It calls for a 'be'-attitude rather than a 'do'-attitude. As such it is ontological in nature and parallels the 'to and fro' movement of understanding as discussed in the framework, constructed from GPH, underpinning the inquiry. The practice viewed through this lens can be termed practice as hermeneutical praxis, which has been captured through research as hermeneutical praxis. Watson (1999) describes a caring healing moment as a transpersonal moment involving higher consciousness in a metaphysical reality. Newman (1994) also uses the descriptor of 'a moment', in the life of people. She acknowledges that her conception of a 'moment' comes from Bohm's notion that 'a moment' is a component of subjective reality that is not limited to space and time. This understanding is also apparent in Watson's discussion where the moment can be anything from a brief encounter of a few seconds to the

possibility of hundreds of years. Such moments are ontological in nature. It is this understanding that informs the notion of moment used within the following section.

To talk of the health-illness experience as an ontological assault (Pellegrino & Thomasma, 1988), calls for an ontological response; a response akin to Watson's (1999, p. 7) moment of "caring healing praxis". To talk of illness as a subjective experience also calls for a subjective approach (Gadow, 1980b, 1995a), which is envisaged in Watson's (1999) moment of 'caring healing praxis' and the web of relationship (Connor, 1995). Watson talks of caring as ontology in that it encompasses two or more beings in existential relationship calling them-selves forth in order to become more fully what is in them to become. I believe my philosophy of practice, a constitutive element of my 'web of relationship' practice model guided my ontological approach in the practice experience of working with Sarah and as a nursing team member. For me, there was a calling forth of my-self in my care of Sarah as I consciously called her self forth. However, the discursive illumination of the narrative in this inquiry has given me a much greater appreciation of the moral implications and constraints in operationalising such an ontological philosophy.

To enter into the mystery of a person assumes deep person-al involvement in an intense relationship (Gulino, 1982; Gadow 1980b; Montgomery, 1993); a walking alongside that means there will be times of walking a 'fine line' (N pp. 180-185-186-199; FM p. 215) and 'pushing boundaries' (N pp. 177-186-189). These two metaphors used to describe the meaning of the prolonged nursing experience in the narrative stood out as significant. 'Pushing the boundaries' referred to the need to create a space for the implementation of the nursing as a caring practice discourse in the prolonged engagement with Sarah. Implementing the caring gaze of nursing led to the walking of several 'fine lines' within this space. The following discussion highlights the tensions and the achievements of realising the assumptions of the nursing as a caring practice discourse in a space that was constructed on the boundary of the nursing as a functional practice discourse. Issues raised in the narrative form the structure of the discussion. These are the moral imperative of the relational ethic of care, the intense relationship as the 'crux' issue of

prolonged engagement, the fine line between a therapeutic and untherapeutic approach, norms normal and normalising, and transforming within a web of relationship.

the moral imperative of a relational ethic of care

To enter into the mystery of a person is to wander in the moral territory that is the home of the other; to tread care-fully in search of their meaning; to honour their personhood, their being in the world and to walk alongside and share the burden of their illness. Sharing the burden of their illness will lighten the load so that room can be created for the energy that enables an existence that is moral in that they can achieve their good and right-ful position in the world. The journeying in this moral territory of the other calls for a readiness to experience all the uncertainty, unpredictability, ambiguity and paradoxes that make up their lives in order to attend to their 'good'. The touchstone in this moral journeying can be both a clear philosophy of practice grounded in knowledge from the literature and from practice reflection where the practice and the philosophy are continually examined in the light of 'the good' of the other. The philosophy should point to the potential contribution that the nurse can make to the health of the other and remain open to transformation from every particular experience.

As I entered into relationship with Sarah, the philosophy I practised, and endeavoured to model to Mary, was described as a relational ethic of care (Connor, 1995). The invitation to nurse Sarah because previous care was not making a difference to her health circumstances was to be a test of my philosophy. Could I practise what I preached? I did preach the assumptions of the nursing as a caring practice discourse but not as clearly as I can now articulate them. Would practising what I preached make a difference? It seemed that I was being called to make a difference in Sarah's strife, which had been compounding until that time. Initiating new ways of responding can provide ventilation into a system (Bishop & Scudder, 1991). This metaphor links to the metaphoric understanding of Sarah's situation. My position, which required me to practise innovatively also required me to open up a window of opportunity, a space on the perceived boundary of nursing as a functional service at that time, a space 'to walk the talk' of nursing as a caring practice discourse. Because of the length of time of our

moment together Sarah summons an intensity of caring from me that had not been called forth before. Hence my reason for wanting to explore more fully what went on from the reflexivity of the research.

On entering the moral territory of Sarah's world, I was aware of needing to be constantly vigilant of an involvement that created a safe place for the healing of her self but was also a safe place for me. It was walking a fine line that meant holding an open attitude to any cues in Sarah's behaviour or my own that might point to the relationship becoming demoralising. I knew she was there to be my teacher about living with prolonged strife in chronic illness and experiencing the uncertainty of her world was the price I needed to pay. Mary referred to my practice wisdom (N p. 187). However practice wisdom is something that is forever evolving as in "to seek wisdom is to begin to find it. To claim to possess wisdom merely indicates you have lost it" (Eastham, 1998, p. 70). Practice wisdom is not something that can be taken for granted but is an ongoing quest, always in the process of becoming. Theoretical expositions of practice wisdom can infer that once this becomes apparent in one or two practice situations the nurse has arrived at wisdom rather than seeking it anew in each situation because in each situation the nurse enters new moral territory.

In a similar way to the theoretical expositions of practice wisdom, theoretical explanations of caring can imply that if a nurse has 'good' intentions and cares long enough, the individual will eventually transcend their suffering (Liaschenko, 1997). It is a view that I believe has potential for coercion. I did want Sarah to be able to get on with her life and hoped she would progress to not having a need for nursing support. Sarah as a person with a deep abiding knowledge of what she needed, was a person who resisted any persuasion not fitting with her explanatory framework as is demonstrated in several places in the narrative (N pp. 167-175-178-181-193-196-197-203). Although I may have been impatient at times throughout our prolonged engagement I always returned to my philosophical statement about facilitating her process and not mine which was a challenge to any 'good' intentions I may have borne.

I interpreted Sarah's comments "*I felt safe because I knew you were there keeping an eye on me ... someone there caring for me was a big thing*" (N p. 177) as the 'caring gaze of nursing. I believed it summed up what Sarah valued in the nursing contribution to her health-illness burden. Illness and suffering had destroyed the co-herece of Sarah's personal narrative (Gadow, 1996), which mirrored what is known as the postmodern disintegration of the person or what Frank (1995) calls the chaos story. Sarah was calling forth caring health professionals to work with her to co-construct her health and a narrative which would give her life a new co-herece, and according to Gadow, build a new safe and 'habit-able' home. It was a narrative that opened up the moral space (Liaschenko, 1997) she needed to get her life together again.

nursing as a caring practice discourse situated on the boundary of nursing as a functional service discourse

the intense relationship in prolonged engagement

Entering into the mystery of a person assumes a deep personal involvement and intense relationship (Gulino, 1982; Gadow 1980b; Montgomery, 1993). Rose raised the issue of my intensive relationship with Sarah and its impact on other members of a team. For Rose, it was "*the crux issue in prolonged engagement*" (N p.199). As such it challenged me to think and theorize about it, to expand my own horizon in order to become more conscious of the implications of such a relationship. Some illumination of the deep involvement and intensity of the situation is discussed by Gadow. It is an illumination that assumes the acceptance of nursing as a caring practice discourse and does not take account of it positioned within a space on the boundary of the nursing as a functional service discourse. Gadow talks of the intensity of the situation being experienced differently by the person and the nurse. The nurse can enter into the person's suffering but is not bound by "the immediacy" (p. 88) of the situation in the way that the person is. Toombs (1993), agrees with this premise in her discussion of existential aloneness, where she asserts that the person with the illness is the only one who can experience the sensations of illness. According to Gadow, a nurse is positioned in an external level while the sufferer is involved in "a radically interior way" (p. 89). This does not deny an authentic attending to the whole person as an embodied person but it does, from Gadow's perspective, imply that the nurse will objectify these bodily manifestations in some way.

Benner, Tanner, and Chesla (1996) also affirm Gadow's (1980b) view in proposing that the positioning of the nurse in a layer of reflection, which acts as liberator from the 'immediacy' of the illness, allows for ongoing attention to the moral position of the person. Gadow sums up these different positions as a divergence in "the form of direction, not the form of intensity" (p. 88). Furthermore, Gadow sees that the intensity aids the reflective process, which in turn provides ongoing effectiveness of the relationship for the person involved. Sarah affirms the effectiveness of the relationship in aiding her movement out of strife, "*other people might think you were too involved but I don't think I would have come as far if I hadn't had your support*" (N p.201).

One could then ask if a nurse or other health professional is required to share the burden of illness? It could be a lay person, a friend or family member, as long as they are able to help move the sufferer out of the immediacy of the suffering. However, it necessitates more than "simply sharing the other's experience" Gadow (1980b, p. 89). This is not to undervalue or negate what family or friends can achieve. It is only when family or friends' caring is unable to attain the alleviation of suffering that can allow the person to move on their lifeplan that professional care can help (Kitson, 1987). This in fact assumes that the professional has an understanding of how their approach can help. It is Gadow's belief that if the nurse is unable to maintain "sustained objectivity" (p. 90) through operating in a layer of reflection, but works in a layer of feeling, then person-al involvement can compound into person-al professional suffering and a depletion of energy. It is a process of being "sucked out" from being "sucked in", as a participant in Montgomery's (1993, pp. 87-8) research colourfully describes it, leading to poor professional judgement and consequent ineffective caring. Gadow argues that this implies that when a nurse becomes bound in the immediacy of the person's suffering there is a contagion that parallels infectious disease.

In developing a person to person, subject to subject, professional relationship to promote effective healing the professional needs to retain "sustained objectivity" according to Gadow (1980b). If this is so it creates a paradox between subjectivity and objectivity.

Montgomery (1993 p. 88) is not comfortable with this paradox and prefers the term "therapeutic perspective". It seems to me that an experienced nurse, working in a layer of reflection, is able to see the person's immediate suffering from different perspectives than the sufferer. The nurse can then offer an alternative view to what the suffering person has arrived at. This is not an objective view in the sense that it is the real or true view of reality that is often inferred from clinical tests, but a different yet subjective and partial view, arrived at from looking at the person's situation from being positioned in a layer of reflection. Sarah demonstrated an appreciation of my 'different but partial and subjective view' of her situation in her responses: *"I had some feedback on it, I had some suggestions to cope with it"* (N p. 187) and *"I can get a different view from you if my thinking is particularly screwed up about a certain thing. You bring a different perspective into it that I just can't see myself at the time until it is mentioned. Sometimes when it is mentioned I can't see it even then, but it is just getting the balance"* (N p. 206).

Rather than use the concept 'of sustained objectivity', Benner, Tanner and Chesla (1996) talk of "emotional attunement to the situation" (p. 114) and "a sense of salience" (p.115) about an expert nurse knowing what is 'right' in a particular context. This embodied knowledge enables a grasp of the bigger picture that takes account of personal concerns, vulnerability and suffering. Benner et al. term this way of responding "moral action" (p. 160) which involves openness in particular ways of being with and doing for persons. Connection with a person, they believe, is not made without these attributes.

However, when wandering in the moral territory of the other there needs to be a safe home for the nurse as well. Acknowledgement is made of the possible 'contagion' from suffering if the development of 'emotional attunement' does not happen within a commitment to a relational ethic of care. Gadow (1980b) and Benner, Tanner and Chesla (1996) envisage times of 'contagion' as the existential skill of becoming involved with a client, is learned in experiential situations and refined through reflective practice. It is a process requiring openness to increasing personal knowing. Gadow sees personal knowing as an attribute that is evoked, not learned. It is evoked by metaphysical questions that can go some way in providing answers to a nurse's reflective questioning.

Clinical supervision as an adjunct of reflective practice can assist making this house of learning, a safe house for the nurse. Benner Tanner and Chesla (1996) and Gadow (1980b) note that supervision is accepted as a 'right' for other professionals such as psychotherapists and psychiatric nurses but not for general nurses. Supervision when working with someone like Sarah, in complex health circumstances was something that Mary and I (N p. 186) believed would be helpful. However, the clinical nurse specialists, nurses deemed to be the practice leaders and charged with initiating innovative practice, were not deemed to need supervision by management. My colleagues and I tried to negotiate having it into our contracts but were not successful. It appeared that there was not an appreciation or understanding of the moral territory in which we wandered as part of enacting the caring as a nursing practice discourse. Cost appeared to be the bottom line in the service where nursing as a functional service discourse was the view held by management. Management did provide counselling for a one off distressing situations.

the intense relationship and the nursing team

Rose's query regarding difficulties for team members who may be required to take up the care, where an intense relationship has been established and when the primary nurse is not available, is not answered in the theorising of Gadow (1980b) or Benner, Tanner and Chesla (1996). Nursing as a functional service discourse affirms the option of not becoming too involved so that anyone with similar competencies can enter into a relationship without any ambiguity. This is what is often described as the view of 'a nurse is a nurse is a nurse' or its corollary 'any nurse can replace any other nurse'. In this lens nursing is a commodity rather than a therapeutic medium (Crowe, 2000). Therapeutics in the functional discourse are interventions that work irrelevant of any 'good' or not so 'good' relationship; a belief that underpins the notion of team or task nursing. Consequently, the functional discourse supports the belief that intensive relationships are untherapeutic as it assumes that nurses work in a layer of feeling where 'suffering is contagious' and leads to poor clinical judgement. The professional knows what is 'good' for the client and relationships, particularly intense ones, do not exist as therapeutic constructs.

In the community service, the context of this research, the assumption of 'a nurse is a nurse' was, in fact, challenged by feedback from the service's clientele in an internal survey. They critiqued the numbers of nurses who attended them within short episodes of care. Moreover, the criticism included the fact that most nurses brought with them different views on how things should be done which confused clients and slowed down movement towards healing. In my interpretation the clients' were requesting continuity of care, which contradicted the perceived wisdom of 'a nurse is a nurse'. Nurses, even though they had well documented care plans, actually did as they saw fit. If a nurse does not have a sense of the 'my-story' of the client, as is more likely in the nursing as a caring practice discourse, it is hard to provide what health reform jargon calls a 'seamless' service.

The nursing as a caring practice and nursing as a functional service discourses, in the research context, sat side by side in paradoxical tension. The functional discourse had supposedly been replaced with the advent of a professional nursing career path supporting the assumptions of the nursing as a caring discourse and a range of expertise within the nursing workforce. My position in the service was a recognition of the latter. Moreover, I interpreted that my position was there to coach nurses into a greater sense of the nursing as caring practice discourse. However, I was very aware that the rhetoric of person centred care and complexity of client needs being matched with the skills of the nurses took second place to the functional discourse of getting through the work.

Maintaining a 'controlled emotional involvement' and having numbers of different nurses involved in her care was not an answer to Sarah's health need. If nurses were not able to enter into a person to person relationship with her there was very little contribution that nursing could make to her healing. At the beginning of the three year research period, Sarah needed daily support and nurses were the only health care professionals who could provide it (N p. 176). Social workers could have been a possibility but at that time there was very little social work time available in the community health service. Moreover, I have not been party to social workers making daily visits in the community. Even if

available, this option assumes that they have the skills that Sarah actually required. Sarah did have a social worker assigned to her in hospital but this person did not figure in her story except to take her to see a continuing care facility when it was considered as an option for her care (N p.181). Mary had begun to connect with Sarah, she respected her personhood and was empathetic to her suffering (N p. 170). However she did not have the skills and knowledge that I had, as was the same for Kim at the later period (N p. 212). Furthermore, Sarah affirms the intensive relationship, “*other people might think you were too involved but I don’t think that. I don’t think I would have come as far if I hadn’t had your support*” (N p. 201). Another team member cannot take up an intense relationship that has been established between a nurse and client (N p.199), but they can support it in a similar way to how Mary supported the relationship between Sarah and myself.

Watson (1999) affirms having two nurses involved with one person requiring continuity of care and a therapeutic relationship over a prolonged period. However, Watson appears to assume that both nurses have the same skills and knowledge. This strategy of two nurses in place worked well with Sarah in 1997, the first year of our involvement. I was certainly aware from the outset, not knowing at that stage what the length of our moment might be, that I could not work with Sarah without backup support. In the second year of the research period Mary withdrew as Sarah did appear to be moving out of strife (N pp. 194-201). At that stage we were visiting Sarah once a week and she appeared reasonably “*independent*” (N p. 201) in managing the fluctuations in her condition. However the change in living circumstances and move away from the area altered her trajectory. I did understand that Oscar leaving home and Sarah living alone would be a wrench but I believed the planning she was doing for this event would ease the transition. I did not envisage what developed as her 'nightmare' or the disarray that would be going on in the community nursing team in the new location. This disarray from the second restructuring of the service within which I worked during the three year research period, compounded Sarah’s transition.

The disarray within the community nursing service in the early days of Sarah's transition adversely affected the introduction of a new nurse who would eventually take over from me if Sarah continued to need a nurse. There was a planned introduction of a new nurse when things began to settle for Sarah and for the new team. I did want to be able to pull back my involvement with the change of geographical boundaries and with Sarah not needing the same intensive relationship of the initial years. However with significant events always coming in Sarah's life there was never a 'good' time. Even with my resignation from the service I did not want to make a clear cut as it was still early days after her 'nightmare' and the loss of her significant friend. The ambiguity of wandering in her moral territory gave rise to my offering to be there for her if that is what she wanted while I was still involved in the research. At the close of collecting the research material for the additional year of the research Sarah appeared more settled than earlier. This was three and a half months after my leaving the service and natural closure of what might be termed my professional role and a move to a friend role took place. Being prepared to walk the uncertain path with Sarah had been constant balancing act on a 'fine line'. Recognising this period as the 'right' time for the change of role appeared to work for both Sarah and me. Kim was initially pleased that I had remained close to Sarah (N. p. 200) but in her later reflections on my staying in a therapeutic role with Sarah, she saw that it had confused her role (FM p. 214).

In reflecting on the option of expecting a district nurse to be able to work with Sarah some tensions arose in relation to the meaning given to her burden of illness. Given that Sarah indicated she is better than in the early period (N pp. 174-201) I believe that continuing to have Mary available, if that had been possible, would have been a workable option. Mary had a good relationship and was mindful of Sarah's deeply embedded fear and how I had worked at coaching confidence in managing her dis-ease fluctuations. Sarah would not have needed to be visiting regularly when she was feeling well and phone contact could have detected deterioration. However with Kim commencing as a new district nurse and not knowing the history from an involved perspective she had a different view.

It is always 'good' to have fresh eyes on a situation where questions are raised that may have become less visible within the familiarity of the situation. Mary and Kim are both experienced competent nurses, albeit that Kim was a beginning district/community nurse. Nevertheless, there is a tension evident in their envisioning of future requirements for Sarah. Mary talks of a careplan that incorporates not what the nurse wants but what Sarah wants (N p. 210) and Kim reflects on what she believes is 'right' for Sarah (N p. 200). From Kim's perspective Sarah needed skilled relationship or fear counseling by a qualified and credentialled practitioner (N p. 212). This need, Kim believed, was not something that she or other district nurses could fulfil. Sarah is saying that ventilating her burden of illness to a nurse who can co-create with her the state of her fluctuating bodily manifestations is helpful in maintaining a safe home in the community. Mary's option is more consistent with what Sarah sees as her need.

In considering the needs of the client and the needs and skills of a nursing team, another 'fine line' is walked in uncertain terrain. Spitzer (1998), discusses the paradox in postmodern nursing where there is an expectation that nurses be more autonomous while at the same time function more as a team. As Spitzer states "workers of health care organisations are, on the one hand, asked to take personal responsibility for being innovative and for managing change, and, on the other hand, expected to be part of a synergistic team and promote group goals" (p. 167). It can create a conflict between commitment to the client and to the organisation. Nevertheless, Bishop and Scudder (1991, 1997) are clear that the service exists for supporting the practice of professionals in achieving 'the good' of the clients. Bishop and Scudder believe that if the bureaucracy and its 'external goods' (nursing as a functional service), takes precedence over 'the internal goods' of practice (nursing as a caring practice), then a nurse becomes a technocrat rather than a practitioner of her discipline.

intense relationships as the work of advanced nurse practitioners

I took the risk of entering into an intensive relationship to provide Sarah a space to find her-self again. At the same time I knew the situation needed a second nurse and coached Mary into the notion of relational practice (N p. 199). She understood what was

happening but did not see that she needed to be in the same role as I. I neglected to think through how an intensive relationship might affect the team other than to demonstrate that it is possible to work differently and in so doing make a nursing contribution to Sarah's health experience. In this instance, a tension in advanced practice and competent practice emerged. Neither Mary nor Kim thought they had the skills to enter into a prolonged intense relationship of this nature (N pp. 199-211-212). In fact, Kim believed it might be the work of credentialled practitioners in other disciplines. I believed that I could model a particular way of being in practice that other nurses would be happy to continue with my support. However, I have learned that entering into intensive relationships is the work of an advanced nurse practitioner. Benner, Tanner and Chesla (1996) support this learning.

Kim was clear that if nurses undertook intense relational work they needed to be safe within credentialled practice that had the imprimatur of the service (N p. 212). The credentialling of advanced nurse practitioners became possible in New Zealand in 2001. The term chosen as the title for these nurses in New Zealand is 'Nurse Practitioner' (NP). The New Zealand Nurses' Organisation [NZNO] (2000, p. 1) position statement states that "the scope of advanced nursing practice is distinguished by autonomy to practice at the edges of the expanding boundaries of nursing". It is seen to differ from expert practice in a particular specialty "in its scope and sphere of influence and its application of advanced nursing knowledge" (p. 1). I believe that my practice in this particular situation did meet this criteria. The credentialling will go some way in providing a safe place for the advanced practitioner but as the above quote implies they will always be some walking of a 'fine line' on the outer boundaries of expanding practice. Uncertainty and unpredictability will be their close companions. Nevertheless, the Nursing Council of New Zealand's (2001) document, which heralded the implementation of credentialling for advanced nurse practitioners, is situated, in my opinion, in the nursing as a functional service discourse. The word caring, or any description of high level relational skills is absent.

The vulnerability of an uncertain future most certainly makes Sarah eligible for ongoing oversight by a health professional. A health professional, who Kim describes as a case co-ordinator, could take on a primary care preventative role. This sort of role, I believe, calls for advanced practice that involves knowledge of the person (Liaschenko, 1997) and the skill to co-create a narrative that is a safe home for the person (Gadow, 1995a, 1996). This is the practice within a nurse case management scheme that is described by nurses (Connor, 1995; Litchfield, Connor, Eathorne, Laws, McCombie and Smith 1994). Liaschenko warns of the limitations of a gaze on the 'case' where the ontological entity collapses into a fragmentation of parts that need fixing. If nurses or other health professionals move into these demanding roles without advanced preparation then they are likely to continue to practice at a level that they know rather than at a level demanded by the role. Unfortunately, in my experience, the co-ordination roles set up by health providers, as a contract with health purchasers have been functional in nature and limited to finding and funding what they see as appropriate services. This type of co-ordination role is not seen to be a therapeutic role underpinned by the assumptions of nursing as a caring practice. Furthermore, it contains limited authority to bring together numbers of health professionals with the client to actually streamline the contribution that is being made by each.

The term 'integration of care' within a service delivery model appears to be replacing the term 'case management' (Geary & Smeltzer, 1997; Malcolm, 2000). A recent book, with the purpose of updating knowledge about case management internationally, edited by Cohen and De Back's (1999) uses case management in its title. My preliminary read of the book reveals that none of the writers embody my objections to the name case management. However it is evident that many writers use descriptors other than case management, to describe this type of work. Integration can describes the practice as well as the service intention. Facilitating the integration of the strife of a health event (moment) into a re-visioned life-plan is, I believe, pivotal in the practice with people experiencing strife in chronic illness.

Litchfield (1998) provides an overview of case management initiatives in New Zealand. She found that it was seen as a service delivery initiative where the co-ordination of care for complex patients was facilitated either in hospital or across hospital community boundaries. The nexus with professional practice was also identified. From the nursing perspective it was seen as a component of the nursing role rather than a nurse stepping into a new and different practice. According to a number of Litchfield's informants the case management component had been added to the present work of nurses without enough consideration of what structural and communicative support and educational preparation nurses might need to be effective in the role. Litchfield highlights the emphasis on the relational practice component in the nursing research studies discussed in her paper. She argues that effectiveness can be best observed through a focus on the practice but does not comment that there is a paradox between the practice described and the term case management. This is yet another instance of using the language of the disease discourse but indicating the assumptions of the health-illness discourse. I agree with Litchfield (1998b) that the effectiveness of case management schemes depends on the practice of the professional. However her paper does not discuss the nuances or 'fine lines' that are the territory of such a practice.

the 'fine line' between a therapeutic and non-therapeutic approach

"Going the extra mile" (Montgomery, 1993, p. 91) or "doing what needs to be done" (Benner, Tanner & Chesla, 1996, p. 118) is an interpretation of our befriending of Sarah to the point of having involvement in activities outside of clinical hours. It was seen as 'pushing the boundaries' of care (N p. 186). According to these authors it takes account of the bigger picture in a committed person to person relationship. Montgomery brings out a paradox in what can be described as stepping out of role. When you step out of what may be deemed the professional role "is when you embrace it the most" (p. 42). I believe that is what occurred when Mary took Sarah out into the community for the first time other than with her family (N pp. 172-207; FM p. 215). Although Mary saw it was a friendly gesture, it had a very significant therapeutic effect as Sarah referred to it several times in the research dialogue.

Kim's analysis of the narrative led to her query that our caring approach may have unwittingly made Sarah dependent as she had not taken on board much of the advice she had been offered. As already discussed, wandering in Sarah's moral territory contains a paradox of the intention of therapeutic approach having the potential to be un-therapeutic. In raising the question Kim was appreciating this paradox. There is a 'fine line' between dependence and dependability. Sarah needed to be able to depend on us as nurses to be there for her health needs. In trusting this dependability (N p. 177) Sarah was able to unload her burden and regain some confidence. Dependence was likely to develop in the absence of dependability. Frank (1995) comments on the need of people experiencing chaos to keep on telling their story until they find some who will witness to their chaos. For the person in chaos this provides the opportunity for the reflection needed to find a way through their chaos to a new or modified lifeplan.

"*Total involvement to nothing*" (N p. 174) was how Sarah experienced my leaving of the service and Kim's unpredictable visits. I see this as a reaction to having experienced a service that was dependable, one she could rely on for help and where the plan of visiting has been co-constructed with her. It was more than the loss of our intense relationship as it had been reducing in intensity as the visits were extended out from daily to fortnightly at the time of my leaving the service. The loss of dependability was a threat to her safe home in the community. Paradoxically, Kim's approach did allow her to discover that she could get by for longer periods without a nurse.

norms, normal and normalising

Movement in independence is endorsed in Sarah's story (N pp. 201- 206-209; FM p. 216) and is associated with a sense of finding a safe home in the open community. However, Sarah's deeply embedded burden from her experience of the 'ontological assault' of illness from childhood blunted the prospect of a 'fix' from our 'normalising' activities. This was particularly so when our view of normal was out of synchrony with Sarah's normal. As Rose stated we as health professionals "*have defined the norm*" (N p.176). Sarah did depend on a service being at hand for when she collapsed into dis-ease. Herein lay another paradox. On the surface Sarah's life demonstrated her ability to be normal

most of the time, albeit as a struggle (N pp. 203-209; FM p. 216). However this depended on having caring practitioners who en-abled this by sharing her burden. For this reason I see that a handing over of her burden to caring professionals for a short period three or four times a year would further increase her confidence in living in the community as her safe home (N p. 213). Nevertheless, inherent in Sarah's situation is the very real possibility that the disease will worsen in the near future.

A paradox in our nursing practice, already mentioned, was the contradiction between what Sarah saw as normal and the nursing actions that were directed at normalising her day to day living. It was our discourse on 'normal' not Sarah's. The practical strategies for managing oxygen given by Rose, the advice on rest and sleep, diet, reduction of oedema (N pp. 188-189) given by Mary and I, were instrumental in that they were directed to particular ends, Sarah's physical comfort and safety. They were normalising in the sense that from our perspective as nurses we believed that Sarah, like us, would want to be physically safe and comfortable. Ironically for us as nurses much of her comfort comes from her smoking (N p. 196); a comfort which places her at high risk for more discomfort. We knew that most of the time Sarah declined our advice and we certainly did not make any judgements about her choices except to offer a particular perspective on them at times. We did understand that somewhere in her being she was doing what was 'right' for her at any given time. Mary's comment on not having the 'right' to reduce her activity (N p. 170) and my belief that I was there to facilitate her life process, not mine (N p. 170) are indications of our person centred and relational approach. Sarah's normal was being her active busy self, keeping her house and garden in order and spending time with her children. As Rose reflected "*Sarah is a person who actually knows very clearly where she's going and what she wants*" (N p.175). I am not sure that she knows exactly where she is going as she treads her uncertain path but as long as she has enough breath to achieve her modified lifeplan in the present she is prepared to pay the price of dis-ease. She had a well established pattern of driving herself to a stage of standstill; a place where her chest becomes filled with dis-ease. This pattern is embedded in a very strong personal value about the 'good' of hard work. Breaching this value is seen to be lazy (N p. 189).

Nevertheless, there were times when Sarah appreciated the practical strategies for promotion of comfort and safety. It seemed that they were interpreted by Sarah as part of the role of the nurse, part of our repertoire of skills to be offered as the occasion arose, part of the caring gaze. It was instrumental caring (Younger, 1995) which supplements ontological and existential caring. We were keeping open the instrumental function in the same way that Gadow (1995b) recommends that we keep open all stages of the assessment process. It is also likely that vestiges of our earlier grounding in nursing as a functional service discourse still influenced our way of working and we considered ourselves in-competent nurses or not real nurses if the invisibility of our being in relationship was all that was observed.

ambivalence about taking the lead

My taking on the task of offering to work with Sarah on structured strategies for changing was an advance of the instrumental advice outlined above. I believe that this work fits with what is described by Watson (1999) as ontological competencies. Albeit that ‘competencies’ are most commonly associated with nursing as a functional service, Watson sees ontological competencies as modalities for healing; advanced clinical skills that are learned and integrated into a nurse's practice ready to be used when appropriate. My initiation of the strategies for change came out of Sarah's experience of the 'nightmare' (N p. 195) and my alert that she had not moved to a position of being able to ride out turmoil through to a settling point without spiraling down in her physical disease. My offer was accepted even though Sarah believed change might be scary. The outcome of these strategies is described in the narrative (N p. 198).

I was ambivalent about instigating a direction that had not come as a request from her. Part of my ambivalence in offering the programme of strategies for change had come from knowing that Sarah had declined attempts of this nature from the psychiatric registrars and as Rose commented she was not requesting help to “*solve her problems*” (N p. 190). However, Sarah was not in a space where she could see any benefits from change. Again as Rose put it “*there is a stage of depression where you can't do the simplest thing to move yourself out of it*” (N p. 193). Frank (1995) discusses this same

idea in less clinical language. He believes that the experience of chaos is the experience of immediacy, a similar immediacy that is described by Gadow (1980a). The experience of immediacy, according to Frank, inhibits any reflective understanding of what is actually happening to a person and as a consequence forecloses any ability to see a path forward. Frank, sees that that chaos imprisons people “in the frustrated needs of the moment” (p. 98). However the life of a relationship can transcend the ‘depression’ or ‘immediacy’ of the chaos and provide a vehicle for reflection and as such a re-visioning of a future. When both person and nurse are engaged with each other there is an integrating of each particular view into a new view that transcends both where “its authority begins and ends with their authorship” (Gadow, 1996, p. 9). Nevertheless, as Gadow warns, it is authority that is destined to be embedded in uncertainty; an explanation for my ambivalence.

I was also mindful that I had experienced this uncertainty in my earlier research. I had initiated a case conference in dialogue with Mhairead who, during later reflection, had affirmed me taking on a more directive role as it had been helpful and as she noted neither she or other staff would have done it (Connor, 1995). My philosophy of practice was to be non-directive but it is not so rigid as to rule out initiating a direction if that is what I see as called for in the situation. The key is not to be coercive and this can be a fine line when someone trusts you. I view Sarah’s acceptance of my initiation of the strategies as a caring gesture although she had difficulty aligning it with her physical health and at times it was too hard (N p 198). Paradoxically they were adding to her burden rather than relieving it. But, at times she enjoyed it so it was reducing her burden. It dug deep into her and awakened her “*deep inner strength*” (N pp. 198-199), made it more real and visible in her mind's eye. She had become conscious of her consciousness (Wade 1998). It gave her some “*ways of getting through on my own*” (N p. 198). So on reflection it did contribute to the sharing of her burden, to what Sarah was actually asking of us as nurses, but could not have been articulated as this at the time. I took the risk of leading the relationship. It was not only that I had skills, as described by Kim (N p. 212) but that it had been co-authored within the establishing of a ‘safe home’ for Sarah (Gadow, 1996).

Furthermore, my initiation of the strategies designed to assist Sarah's movement out of strife also fitted within the paradox evoked in Gadow's (1980b) notion of 'sustained objectivity'. Or, as I would now describe it, the ability of a nurse who works in a layer of reflection rather than in a layer of feeling, to offer alternative perspectives to that perceived by a person caught in the frustration of immediate needs. This is a position that can and should be entered into as it is called forth from the situation. Otherwise it would have been a lost opportunity seeking 'good' outcomes for Sarah. I realise now that it was a great act of faith on her part. Although she found that the psychiatric registrars eased her burden by listening to her 'vent' her fears and frustrations (N p. 190) it had not happened within the context of providing a safe home in the community to the extent achieved by Mary and I.

transforming within a 'web of relationship'

My approach had involved 'being present' to Sarah as she ventilated her fears and frustrations (N pp. 170-187) which seemed to allow her a breathing space for getting through the day expressed in "*I could vent out a lot of anger and frustration*" (N p. 171). Once our web of relationship (Connor, 1995) had gathered momentum in its unfolding I did not have to be physically present to be present to Sarah. Listening and responding to her in a telephone call worked in a similar way as in "*I could vent it rather than building it up*" (N p. 187). Her deeply embedded fear from the past and about the present and future necessitated a continual downloading to create space for moving into the future (N p. 207). As was stated at the outset of this chapter her perception of having "*someone there caring for me*" (N p. 176) underpinned our web of relationship.

Sarah talked about her movement in getting on with her life as a move from "*I couldn't breathe to get up from the table*" (N p. 203), a paralysis emanating from the strife and chaos of her dis-ease in the two years of 'horror' preceding the three year research period. There had been a shift from the abnormal to "*I have being doing sort of normal things with people*" (N p. 203). Nevertheless ambivalence about the future characterised her thinking as she moved forward as captured in "*I don't know what it is going to be like to-*

morrow, if I can do it today I will" (N p. 203). A component of my practice was to assist her balance the positive things in her life and there were numbers of these (N pp.172-180-182-185-209) and to promote hope in the future. When there was space from the reduced load of the burden it did work but other times it was too hard, *"I try to think and sometimes it is only moments but I try... to think more positive but quite a lot of the time I am on the down side of it"* (N p. 206). Best of all she keeps on trying (N p. 208). The question facing the nurses involved in Sarah's care after my leaving the service pertained to what sort of professional support was needed by Sarah in her apparent getting on with life, in her ongoing endeavour to be positive and independent?

The ambiguity surrounding Sarah's need of a nurse (N pp. 212-213) is an ambiguity often experienced in prolonged engagement in the community. In the instance of Sarah's care it became more of an issue midway through the research time period where the community contract for provision of care placed greater emphasis of short term episodes of care as the role of district nursing services. The functionally oriented contract would pay for episodes of care requiring 'specialist' community nursing and assessment associated with high or medium risk in illness. Once assessed as low risk clients were to be discharged or referred back to their GP and practice nurse for ongoing primary health care. Hence Kim's uncertainty about Sarah's fit with the contract boundaries when she did not have any 'functional deficit' and appeared to be getting on with her life (N p.171).

Most literature assumes the client's unchallengeable right to be nursed; usually flowing out of a decision to admit to an institution, mostly made by the medical professional working within the disease discourse. Working within tight contract boundaries and experiencing dilemmas around the eligibility for nursing services is a new experience for many New Zealand nurses. It demands clarity of purpose and an ability to articulate the nursing contribution to the health outcome of the service clientele. Articulating the nursing contribution is not too difficult when a nurse is responding to a 'functional deficit'. However this sort of articulation can often be reduced to a set of tasks or interpreted as a set of tasks and then health service funders look for the cheapest way to purchase the service of these tasks. Articulating the nursing contribution from nursing as a caring

practice when there is no 'functional deficit' is more difficult. In this situation the articulation of the transforming process and outcome is important.

different meanings within one transforming process

The research highlighted two differing views of what was happening within the caring relationship. An interpretation emanating from Sarah's position in the relationship and an interpretation emanating from my position in the relationship. From Sarah's position there was an increasing aligning of her condition with the way I reacted. If I was positive she took this on and felt safe knowing that I would be in touch if I was concerned. I was positive because I believed in her ability to ride out fluctuations and her confidence in judging their severity was increasing as was evidenced in the reducing hospital admissions. As indeed it was (N pp. 185-201). When I did initiate medical involvement I believed this had come out of a dialogue and I was preventing further deterioration in a deterioration process. Sarah saw that I had got to know her illness, which in a way I had, as I knew when she needed medical intervention (N p. 207). What I saw as coaching her through fluctuations to the point of needing medical intervention had been interpreted by her as 'I am safe' and can keep going. This is what I term the co-construction of her health circumstances. Different though the meaning was from our differing vantage points, there was another meaning unfolding within in the life and energy of the relationship, which I believe was evidence of a transforming process taking place. Sarah's sense of safety within the 'caring gaze' led to an unconscious self discovery (Wade, 1998). She could in fact ride out quite long periods with different degrees of symptoms manifesting; she was safe in the open community rather than in the hospital ward and she could do 'normal' things within her community.

In theoretical terms Sarah was experiencing a process of expanding consciousness (Newman, 1986, 1994, 1997); a release of inner power that can move the person to greater harmony and self healing (Watson, 1999) or a moving beyond or transcendence (Parse, 1995). The use of different terms refers to the context of the theories rather than conceptual meaning (Wade, 1998). A moment of "caring healing praxis" (Watson, 1999, p. 7) had taken place. The burden of illness and suffering had been shared. However,

there was not evidence of transformation as is defined in the literature "whereby an individual becomes critically aware of old and new self-views and chooses to integrate these views into a new self definition" (Wade, 1998, p. 716). Nevertheless, Wade describes transformation as an individualised journey of ascending levels of being through layers of self-discovery. In this view, I believe but not acknowledged by Wade, it is inconsistent to talk of transformation and more congruent to talk of being in the process of transforming. Sarah was in a process of transforming from a fear-filled person lacking confidence in her-self to a person spending less and less time in hospital and confidently navigating her life in the community. She stills carries the burden of illness and knows that at times it will become overwhelming. At these times she will need to hand it over to someone there caring for her while she re-energises herself.

Wade (1998) discusses the work of many writers who assert that a particular choice point needs to happen for transformation to occur. But, Frank (1995) cautions about this belief and likens it to the Phoenix story of new life arising from the burning up and ashes of the old life. It is a process that can infer an exaggerated purgation of the past, too complete a transformation. According to Frank people who have experienced the ontological assault of illness, unlike the Phoenix, do not forget their sense of difference and chaos. The expectation that people who have experienced the ontological assault of illness will reach that choice point can discourage those who have been unable to rise from the ashes. It also fails to appreciate the deeply embedded fear that can easily surface when there is a threat to the integration of their delicately balanced self and body (N p. 177). Furthermore, there is the suggestion by Morse and Johnson (1991b) that the severity of the illness experience may make taking on a qualitative different view of life impossible.

It is always necessary to take account of the "material, social and political conditions" (Thompson, 1985, p. 69) that influence the ability to actualise a choice point that involves movement to a qualitatively different view of a situation. For Sarah, these conditions would include the ontological assault of her illness compounded by the hegemony of the disease and nursing as a functional service discourse increasing her suffering rather than alleviating it. Sarah's view of the world did not change in a qualitative way but there is

evidence of incremental change consistent with the building up of confidence. The ontological assault of her being and the ongoing burden of her suffering needs to heal further for a qualitatively different vision of how she can be in the world; a miracle that could happen with ongoing caring and healing.

conclusion

The generation of meaning in this chapter emerged from following where attention to paradox, moral meaning and metaphor led me in a dialogue with the general abstractions of the health-illness and nursing as a caring practice discourse. The meaning comes out of a shift from personal praxis apparent in the narrative to social praxis from a discursive illumination. It involved a continuation of reflexivity and moral comportment as praxis within a dialectic dialogue between the particularity of the narrative and the discursive literature.

The critique identified Sarah's burden as a manifestation of an 'ontological assault of illness'. Her being in the world was experienced as different to 'normal' people. Lack of recognition of this health-illness concept meant a 'battle' commenced to have her humanness recognised together with treatment of her disease. This battle, in my interpretation, led into entrapment in the disease discourse with consequent demoralisation as illuminated in her non-person metaphors. The tension created in the 'in between' space of this set of discourses constituted a major component Sarah's strife, her burden of illness. Issues from the narrative illustrate the tension. This generation of meaning provides a coherent understanding of Sarah's strife that was not available in our practice or on the surface level of the narrative. It is a meaning that was not anticipated in any way but consistent with my praxiology and methodological premises; with an ontological expression of practice as hermeneutical practice and research as hermeneutical praxis.

I knew that the 'caring gaze' that I had initiated as a response to Sarah's strife had worked as there was evidence of some movement out of strife. However, I had not comprehended the why or how of it. Sarah's clear construal of her need to share her

burden within a non-judgmental person to person relationship which, incorporated the broader health-illness and nursing as a caring practice discourse, was evident.

A deconstruction of the particularity of caring for Sarah demonstrated contextual constraints. Following the moral imperative of a relational ethic of care and connecting with Sarah within an intense relationship over a prolonged period required the creation of a space on the boundary of nursing as a functional service discourse. Further, it required that we walk 'fine lines' in uncertain terrain with her. This was seen as advanced nursing practice. The navigation of the 'fine lines' with Sarah, within this space, provided a co-constructed facilitation of Sarah's movement out of severe strife. The research also contained 'a form of practice', hermeneutics as praxis, and in it another level of co-construction of Sarah's situation complementing her transformative process out of severe strife. The movement from paralysis to doing 'amazing' things with her family and her community is evidence of a transforming process. A positive outcome was achieved in spite of the constraints of the nursing as a functional service. The multiple constituents of this practice situation is, I believe, an expression of postmodern nursing practice.

final summative statement of the inquiry

My research commenced with two objectives. First, I sought to accomplish an exploration of the meaning of prolonged strife in chronic illness from the perspectives of Sarah, a particular person experiencing it and the nurses caring for her in a particular context. Consequently the second objective was to design a praxiological methodology which would take account of the distinctive features of the research and my position within it. This was a postmodern, process oriented project in which the nature of the inquiry unfolded within the research. The two objectives worked in tandem as interweaving parallel threads. For the purpose of this summary I have unraveled them and argue that a unique contribution to the discipline of nursing has been made from my attainment of both objectives. Because the first objective was fulfilled within the accomplishment of the second I will begin with the second objective.

The situation of this praxiological methodology is in a nursing disciplinary perspective known as nursing as a practical nursing science. In association with this positioning are three important constructs, which act as horizontal threads, linking the chapters: strife in chronic illness, practice as praxis and research as praxis. At the commencement of the inquiry I experienced some confusion about claims to the 'right' use of 'research as praxis'. The creation of this methodology was an opportunity to clarify my own position about this construct. To this end I explored the evolution of the concept 'praxis in philosophy'. The praxis discourse in philosophy is also known as the practical discourse. Most significantly, this exploration demonstrated that the reflecting and acting inherent in praxis is always based on a praxiology. Historically, the evolving praxiologies were embodied in the paradigm of the particular epoch in which they developed. In the postmodern epoch where there are multiple paradigms within the practical discourse in philosophy, multiple praxiologies sit side by side. I observed a direct link of the multiple praxiologies from the practical discourse in philosophy to the practical discourse in nursing. This exploration, I argue, enabled a clear justification that my position in this research was hermeneutics as praxis and was evidence that the claims limiting praxis to one paradigm in nursing were suspect.

Moreover, in the course of my exploration of the practical discourse in philosophy I discovered that my then unarticulated praxiology was, to a notable degree consistent with GPH, a human science. Therefore to develop a coherent structure and language for the hermeneutical reflection of the inquiry I constructed a framework from GPH. From this decision the course of the inquiry took shape within the ontological assumptions of this framework. I recognised that the framework from GPH was a partial view of the world so I extended its basic assumptions with postulates from other philosophical praxiologies and the health-illness and nursing as a caring practice discourses into a specific praxiology constructed to inform this inquiry. The assumptions of the praxiology were then translated into five methodological premises of reflexivity, dialogue, moral comportment, re-presentation in narrative and critique. The first three premises act as general premises guiding all the hermeneutical reflection of the inquiry. More specifically they are embedded in the researcher journaling, research meetings and documentation

summaries of the research process. They also underpin the last two premises and processes of re-presentation in narrative, achieved within a co-construction process involving all co-participants, and the critique achieved within a discursive framework. Reflexivity, dialogue and moral comportment are the core premises of this inquiry. In the construction of the praxiological methodology I brought together assumptions of the practical cognitive research interest with assumptions from the emancipatory research interest (Habermas, 1972, 1973). The integrating of these two cognitive research interests illuminated both personal and social praxis from the exploration of strife in chronic illness and the nursing practice response.

I therefore argue that the construction of this unique hermeneutical praxiological inquiry expands the construct of research as praxis as an ontological expression within the discipline of nursing.

The first objective was to accomplish an exploration and generate meaning from the experience of living with and the nursing response to strife in chronic illness. The meaning made, although in no way anticipated, was shaped by my praxiology and methodological premises. It was the outcome of the unique expression of research as praxis. The first major insight was Sarah's metaphorical meaning of her illness, and as such her strife, as a burden that lay heavily upon her and at times overwhelmed her. For Sarah, being able to vent the frustrations, pain and vulnerability of this burden within a reflexive dialogue, nursing practice as praxis, with a caring non-judgmental nurse enabled a co-construction of her health-illness circumstances. This is the main nursing contribution made to Sarah's health-illness experience. It is described as 'sharing the burden' of illness. The ongoing co-construction, for Sarah, embodied a transforming process of increasing confidence and sense of safety in living and participating in her local community.

When paradox, moral meaning and metaphor were used as themes in a discursive framework developed from the health-illness and disease discourses, Sarah's burden was interpreted as an 'ontological assault of illness' in which her whole being suffered. Her

inclination to ‘battle’ for recognition of this assault and medical treatment for her suffering self was portrayed by me, as entrapment in the disease discourse. In using the idea of a tension existing in an ‘in-between’ space of the health-illness and disease discourses many issues from the narrative took on another level of meaning. From my perspective as nurse practitioner and researcher this meaning gave consistency to Sarah’s experience not understood prior to the research.

The ‘caring gaze’ of nursing interpreted from Sarah’s language in the narrative and central to ‘sharing the burden’ embodied, in the opinion of the nurse co-participants, some tensions linked to its prolonged nature. Again, using the themes of paradox, moral meaning and metaphor within a discursive framework, the implementation of nursing as a caring practice discourse was elucidated as ‘pushing the boundaries’ of the nursing as a functional service discourse. Within the nursing as a caring practice space many ‘fine lines’ were walked with Sarah to achieve a ‘moment of caring healing praxis’. Walking the fine line of an ‘intense relationship’ was interpreted as advanced nursing practice.

The uniqueness of this substantive knowledge development emerged out the particularity of a specific practice situation from which the horizons of a client and the nurses involved in a prolonged engagement were fused to illuminate a unitary unfolding of ‘a moment of caring healing praxis’. Constraints on this ‘moment’ were exposed through further theorising on the particularity of the contextual complexity. From both the meaning generated from the ‘moment’ of praxis and its critique there is an expanded understanding about the topic of strife in chronic illness with associated nursing practice. There is a growing literature on what I have termed the health-illness and nursing as a caring practice discourses, but there is seldom research on the constraints of their embodiment in practice. Therefore the substantive knowledge that has been generated on this topic makes a unique contribution to the nursing practice of persons experiencing strife in chronic illness.

chapter eleven

INSIGHTS AND IMPLICATIONS OF THE INQUIRY: CLOSING THE HERMENEUTICAL CIRCLE OF THIS INQUIRY

introduction

This chapter completes the third hermeneutical circle of the research within the overall hermeneutical circle of the inquiry. The general methodological premises of reflexivity, dialogue and moral comportment that have shaped the expression of this praxiological research are enacted for the final time in the illumination of my insights and the implications of the study. In this illumination I have identified that moral comportment also pertains to the responsibility of researchers to announce the implications of their research for future situations. Furthermore, I see that it demonstrates the integrity of a future orientation as a distinguishing feature of praxiological inquiry (Pearson 1988). The insights recorded in this chapter represent the transformative journey in which I have participated within the process of undertaking this research.

An appreciation of the action and process orientation of praxis led me to nominate practice as praxis and research as praxis together with my search for expanding understanding of strife in chronic illness as the common horizontal threads linking each chapter of the inquiry text. They form an interwoven pattern in a unitary unfolding throughout, each advancing in the other. In this chapter they provide organisational signposts in which the reflexive dialogue of this study is completed. As expanded knowledge of strife in chronic illness is inextricably tied to practice as praxis and research as praxis it will be integrated into the discussion on each of these themes.

Chronic illness in its many manifestations is an increasing phenomenon in the western world. Science has enabled the treatment of symptoms which untreated in an earlier age would have meant a premature death. In relation to this phenomenon our understanding of the constituents of well being are also advancing. To talk of well being is to give health-illness an ontological focus. Health and illness are lived as an integrated unfolding by the people living with chronic illness in its varied forms and to consider these as

separate components misses the complexity of the experience. It is important then, that both health professionals and the general population continue to understand how individuals construct their unique interpretations of living with chronic illness. This research offers an in-depth focus of the constructions of a unique engagement of client and nurses; it does not attempt to generalise. However, insights and implications emerged that were helpful for Sarah and her family and could be helpful for other families living with chronic illness.

practice as praxis

implications for Sarah and her family and other families living with strife in chronic illness

Sarah's illness began as an ontological assault in her childhood. A longitudinal view of her experience is enfolded in the narrative. The early components of her story aid understanding of how chronic illness can lead into strife and how early strife can become severe strife. In presentations of the research and conversations about the topic of strife I have found that nurses and lay persons alike resonate with the term. A response has been to share a story with me about their own strife or where they have seen it operating. Strife in chronic illness then, could be a term used more to help people understand what is happening to them if they begin to experience the struggle of strife.

A greater understanding of health-illness situations is available if a person's and/or family's metaphorical construction of living with chronic illness is known. Metaphorical constructions of illness, when explored, can enable major insights into the meaning of what is significant in an ill person's or family's life; what they value and how this influences the decisions they make about how they live. Each person or family who has lived with a chronic illness over a prolonged period of time is likely to have a personal construction that shapes their view of the world. Uncovering this construction will allow a greater streamlining of what actually contributes to personal health outcomes. Sarah's suffering, engendered within her illness experience, took on a new meaning for me when situated within the metaphorical construction of her situation.

From the examination of Sarah's story in relation to the metaphors within the accumulated knowledge of the health-illness discourse another clear message is apparent; the strife that people get into comes as much from the narrow lens of the disease discourse as it does from personal circumstances. It arises out of "the endless and fruitless search for the diagnostic touchstone" (Gadow 1995b p. 29) in which practitioners keep repeating the same cycle of clinical activities without effective change in the person's condition. These repetitive clinical cycles actually precipitate the repetitive cycles of hospital admissions that characterise strife. Their entrapment in what Kleinman (1988) calls the empirical cage with its cascade of treatments and the effects of treatments not only reinforces a belief that suffering can be fixed via ongoing interventions but promotes a dependency upon these interventions. Various writers in the health-illness discourse mourn the widespread expectation by many of the general public of a 'a fix' from disease treatment. However, it is the limited horizon of the disease discourse practitioners and researchers that reinforces this view. Much money and publicity is given to potential cures of diseases and members of the general public can be lulled into a false security. It is time to promote a more realistic expectation about the limitations of the disease discourse. This could be done in the form of encouraging reflexive dialogues that promote a person or family's belief in their own expertise and decision making as they navigate a safe home in the community. This, at best, could reduce the suffering associated with strife and enhance more control of their situations. At the same time it could act as a counter to the strong expectation of successful treatment.

personal insights and implications for my future practice and that of other nurses, particularly advanced nurse practitioners, who work with persons living with chronic illness.

Once I had grasped Sarah's metaphorical construction of her illness I became open to discovering the concept of the 'ontological assault' of illness (Pellegrino & Thomasma, 1988) and Frank's (1995) notion of the 'wounded storyteller', both of which expanded my understanding of illness as a burden. When someone's being in the world has been wounded so deeply in childhood, as was Sarah's, the significance of illness, as a burden

that weighed her down, became clearer. The constructs of illness as an ontological assault accompanied by existential woundedness affirm for me, the moral imperative of practice as an ethic of active listening in caring for clients experiencing strife in chronic illness. These constructs also gave me a deeper understanding of Sarah's sense of upheaval and chaos following the move to living alone. Reflecting on these constructs in my future practice will I believe provide for me a greater understanding of people's fear and lack of confidence. In particular, I will refine my anticipation of the effects of major changes in day to day living. I believe these constructs will also be helpful for other nurses working with clients living with chronic illness.

The regression associated with Sarah's move to a new house and living alone motivated my offer to work on some structured exercises to assist changing some of her personal responses which, in my view, perpetuated her strife. My ambivalence about taking the lead while professing a non-directive practice value was my major concern. I am now much clearer about the value of offering different perspectives. I was in danger of taking my general value of being non-directive too literally and failing to take account of what the situation was calling forth. There will be times when taking the lead in order to offer other perspectives is the 'right' approach in a particular context. Not to do so would be failing to summons the practice wisdom. However, taking the lead will always require close monitoring because of the 'fine line' between untherapeutic effects from intended therapeutic action. This, I believe, has important implications for advanced nursing practice.

The insights into Sarah's situation gleaned from the health-illness literature, were only revelations because they connected with her experience. This I believe is the strength of praxiological inquiry. Understanding the apparent paradoxes embedded in her story was an example. Sarah certainly appeared to accept them as part of her existential living with illness. However, my deconstruction of the narrative showed their association with the discursive tensions influencing her world of illness. The deconstruction also showed that I, too, had been influenced more by the functional discourse than I originally thought in relation to the notion of suffering. I had been caught up with the breaking down of this

holistic notion into what was considered ‘better’ descriptors of what was going on within the client experience expressed in a ‘nursing diagnosis’. Most nurses, I believe, will experience some tension between these discourses in whatever way they are constructed. The summaries of the discursive assumptions into table form (tables 7 and 8 pp. 243-5) will enable a ready identification of what particular beliefs underpin nurses’ practice. Hopefully, this identification will improve understanding of what influences the effectiveness of their nursing care, particularly in prolonged engagements, but also in brief encounters.

Understanding differences in temporal interpretations in suffering in chronic illness is also important in future practice. Time spent in coaching someone to work towards what might be considered a sensible outlook on the future, within particular assumptions of what is normal, can be time wasted. It fails to take account of the paradox of being driven to achieve as much as possible in the day to day in case there is no tomorrow.

Sarah’s polypharmacy arose from her entrapment in the disease discourse. It had seemed to me that less medication would enhance the power of Sarah’s ‘inner strength’ to sustain her day to day living. The concepts of the ontological assault of illness and entrapment in the disease model of care gave me a better understanding of her dependence on the medication and its meaning for her survival. Her smoking is in the same category. Medications and smoking provided comfort and have relieved her suffering, while paradoxically increasing it, and fit with the disease discourse trap of keeping people dependent. The allure of the social expectation of treatment, which is embedded in the disease discourse assumptions, was part of Sarah’s reality.

My expanded understanding of the ‘comforting’ role of medication and smoking in Sarah’s life also contributed to the meaning of transformation as a process. I was well aware of transformation as a process but somehow it had become clouded in my hoping and looking for a ‘phoenix type’ of conversion. I had hoped to see Sarah move to a whole new view of life where the past was going to be put behind her as she lived life in a way I considered ‘good’ for her wellbeing. Being alert to subtle ongoing changes, is, I now

believe more helpful than hoping for a major transformation in people who experience the ontological assault of illness. This interpretation can help nurses, particularly advanced nurse practitioners, to understand why it can be so difficult for people to make changes in their life.

Sarah's transforming process had, in fact, begun at the commencement of the three year research period. Sarah's feedback on how the daily visits assisted her transition from hospital at that time was important. She clearly articulated how she was able to get through each day by having someone co-construct her health circumstances. Her response underscored the sense of vulnerability experienced in the transition from hospital to community. Attending to 'existential woundedness' can so easily take second place to more obvious wounding associated with functional needs in a nurse's busy schedule. It is relatively easy to perceive a sense of unsafeness from a functional perspective but comprehending the enormous need at the existential level is more difficult. As such I consider this assessment and co-construction of 'existential woundedness' to be a facet of advanced nursing practice.

Practising a relational ethic of care with people experiencing strife in chronic illness care means being prepared to enter into an intense relationship. It brings with it the walking of 'fine lines' together with 'pushing the boundaries' of the nursing as a functional service discourse now common in the New Zealand contract driven health environment. As the nurse enters into the moral territory of the person with strife, an approach interpreted as advanced nursing practice, s/he will encounter all the nuances associated with the uncertainty and unpredictability of the person's day to day existence in the world. This requires a reflective practice in which it is critical to have the knowledge of how practising a relational ethic of care will aid the person's journey through health-illness. It calls for an advanced nurse practitioner with the ability to create the space needed for the nursing as a caring practice discourse. Creating or fostering ongoing dependency is a risk involved for both the client and the nurse while learning to practice a relational ethic of care. If such dependency occurs, movement out of strife would be limited, and burnout of the nurse could be expected. I strongly believe that the safety and skills of an advanced

nurse practitioner, the refining of the practical, moral decision making and professional judgement of phronesis, can be enhanced by clinical supervision; and that this should be readily available.

Trusting the person of the client is a foundational tenet of a relational ethic of care. This was not always easy to achieve when surrounded by disease discourse assumptions. I wonder now if my trust in Sarah equaled her trust in me. Although my reflections on our relationship always brought me back to the notion that I was facilitating her life process, the fact that I kept returning to this premise, points to my doubts. Sarah's drive in completing physical activities always challenged my trust in her sense of balance in life. However in understanding the body-self disruption and the paradox of temporality in illness this manner of living now has a meaning for me. There is a great deal in the nursing literature about client's trust of nurses and not so much on the nurses' trust of clients. I recommend that more research be undertaken on nurses' trust of clients in complex situations.

Our daily visits in the transition time were, for Sarah, the first demonstration of our non-judgmental dependability allowing her to trust us and begin to envision a better future for herself. Her trust in Mary and me was also consolidated from our making all written records accessible to Sarah. Our dependability appeared to trigger trust in her-self, which in turn inspired her transformative process. It only happened, I believe, because of our ongoing continuity in visiting at that time. Person-held records and continuity as part of community nursing policies are in my opinion, critical in fostering trust and confidence in clients.

Sarah's trust in Mary's ability to keep her safe as she stepped out into the broader community is a lesson in the lateral thinking needed to expand therapeutic effectiveness. A lot of time can be wasted in non-therapeutic activities unless there is a constant dialogue about what is effective for a person or family. Time was a driver of Mary's practice as is indicated in her contribution to the narrative. Other demands on her time diminished the time she had available for Sarah. The busyness of nurses and time

pressures are extensive themes in the culture of nursing, intimately associated with the nursing as a functional service discourse. I believe more discursive research and consideration needs to be given to how time is used, what takes priority and what values inform those priorities. A focus on outcomes can assist an argument, in terms of community nursing policies, to spend the time necessary for primarily relational care.

The moral imperative of a relational ethic of care involves facilitating the ill person's unloading of strife, thus co-creating a new space for the integration of their suffering into some sort of coherence. To deny a person this attention is to deny their personhood leading to a de-humanising and de-moralising experience. Sarah's images of being 'caged in', 'a freak', 'a wild animal' and a 'raving lunatic' are all testimony to her de-moralisation. Paying attention to metaphors that imply de-moralisation has expanded my lens on strife in chronic illness. Before this, my understanding of this term was akin to low self worth or low morale but the illness literature sees practice as a moral endeavour helped me link it to 'the moral'. This particular insight further expanded my understanding of threats of suicide. Failure to give witness to people's experience of de-moralisation is to implicitly contribute to their belief that suicide is the only option whereby their suffering will be relieved. I believe that it is important that more nurses appreciate these connections.

This research could be further expanded in a closer examination of the metaphors used by people experiencing suffering whether in strife in chronic illness, or in acute or terminal illness. It could point to some commonality in their uses. This would be consistent with the practical implications of the meaning of 'everyday language' in practice encounters and could heighten the awareness of how suffering is interpreted by the sufferers. The de-moralisation metaphors used by Sarah in this study drew attention to her suffering in a much more graphic way than any nursing diagnosis could.

A credentialling process for nurses as advanced nurse practitioners became available in New Zealand in 2001. It emphasises competencies associated with the nursing as a functional discourse. There is no mention of competencies associated with nursing as a

caring practice or the ability to support people suffering from 'existential woundedness'. However, an openness to an evolving conceptual description of advanced nurse practitioners is evident. This research supports the ongoing evolution of what constitutes advanced nursing practice through demonstrating the value of practising the assumptions of the health-illness and nursing as a caring practice discourses. I am convinced that these discourses should be incorporated into the constitution of advanced nursing practice. I will work towards making this happen.

general implications of living with strife in chronic illness for the nursing profession and health care delivery

In order to respond appropriately to people experiencing strife in chronic illness nurses need to be able to identify it as a particular health-illness phenomenon. I have extrapolated indicators of strife from Sarah's experience as a beginning structure that can act as signifiers for nurses working with people who may be at risk. The indicators are set out in table nine. I have incorporated indicators from the different discursive frameworks so that nurses working primarily in one or the other or positioned in an 'in between' space can connect with these circumstances when assessing a person living with chronic illness. Moreover, the indicators of strife within the nursing as a functional service will be readily recognised by managers and can be used by nurses in arguing for flexibility to attend to their client's needs. Nevertheless, I do not recommend the use of any standard assessment tools as appropriate when caring for a person experiencing strife. What is required is the putting aside of any judgmental attitudes or nurse shaping structures of the experience as people in strife can be seen as 'the problem' rather than the limited gaze of the health professionals attending them. Intensive non-directive and non-judgmental support was highlighted as the essential ingredient enabling the beginning movement out of strife in this research. What health team members view as normalising and therapeutic is not necessarily seen as such by the client/family. When nurse centred normalising occurs it can become a component of the strife. The broader view of a person's health situation, as demonstrated in this research, is needed in the care of people living with strife.

Table 9. Indicators of strife in chronic illness embedded in Sarah's experience

<u>Perspective of disease and nursing as a functional service</u>	<u>Perspective of health-illness discourse</u>
Repeated hospitalisations	Chronic illness from childhood
Diagnostic Related Group (DRG) status: length of stay (LOS) longer than allocated DRG - does not fit one DRG	Development of a sense of difference from others – 'not normal', not as 'good' as people without chronic illness
Lack of fit with rehabilitation criteria	Can be a mid-life phenomena
Increasing numbers of treatments	Lack of family support or development of family tensions
Increasing co-morbidities e.g. primary chest condition can lead to cardiac, vascular, endocrinological conditions and depression	Life expectations thwarted in some way
Expanding symptomatology e.g. chronic pain, gastro-enterological dysfunction oedema, disrupted sleep	Repeating pattern of disruption between self and body
Needs cannot be met in one medical service	Sense of strife and chaos
Increasing numbers of health personnel involved in care	Considers suicide a better option than sense of de-moralisation
Expanding size of health record	

The gaze of the disease discourse also accentuates a disruption in the person's sense of their body and their-self. It is a disruption that provides a survival mechanism for getting through strife and suffering but at a cost of an integrated body and self where each interacts to provide a sense of balance to foster wellbeing in day to day living. The body-self-disruption alerts nurses to an understanding of why the ill person is unable to hear messages that the body gives the self or to hear any advice given by a nurse who seeks to normalise their day to day suffering within an assumption of the body-self integration. Learning more about facilitating the integration of the split through holding a watching

brief on its fluctuating effects and how a natural process of coming together happens is a challenge for my future practice and that of other nurses.

As time went on Sarah's unloading of her burden and feeling safe from our co-construction of her health circumstances during our visits could be achieved by phone calls rather than our physical presence. The metaphysical life of the relationship held within it all the existential attributes that were needed. This is an important insight from the perspective of health delivery as it can provide time and cost effective practice in meeting health needs provided a relational ethic of care within continuity of contact is firmly established.

comparison of costs of Sarah's care pre and post research period

An important implication of this research is the cost of Sarah's care pre and post introduction of the health-illness and nursing as a caring practice discourses. The high risks to the quality of life for the person and their family plus the high fiscal costs for the service are apparent in the effects of Sarah's strife in chronic illness. Figure 3

Figure 3. Graphs showing change in Sarah's days in hospital and cost of hospital care pre and post research period

demonstrates savings made in hospital costs through a comparison of time spent in hospital in the two years prior to the initiation of the research practice and the decrease in hospital stays in the three years of the research period.

The costing is based NZ\$650 a day in an acute ward given to me by the District Health Board where Sarah's admissions took place. In fact this costing is an under estimate as it does not take account of associated costly clinical tests, use of the pharmaceuticals and the time of other professionals who may have been consulted during stays. Neither does it take account of the number of days that Sarah spent in the Intensive Care Unit (ICU) during the pre research approach two year period, 1995 and 1996, which is now costed out at \$100 an hour. The indicators of strife in chronic illness as set out in Table 9 (page are 302) are costly events in terms of health care delivery. From Sarah's exemplar I would speculate that people who experience severe strife in chronic illness are low in volume but high in fiscal costs. Implementing approaches from the health-illness and nursing as a caring practice discourse can make cost savings. What is 'good' for the client is 'good' for health care delivery.

future integration of care of people experiencing strife in chronic illness

In considering future options for supporting and developing the practice described in the research, I believe it would be best situated in a separate scheme within or outside of regular community nursing services. A suitable title for such a scheme could be 'Integration of health events in complex chronic illness'. Such a health care delivery scheme of care would have many similar characteristics with what is often called case management. However, for me, case management, apart from my discomfort with the language, as it has been generally understood in New Zealand belies the advanced skills necessary to achieve its potential effectiveness. Another reason for the choice of such a title is that it describes the practice as well as the service intention. Facilitating the integration of the strife of a complex health event (moment) into a re-visioned life-plan is pivotal in the practice.

I have been encouraged by a number of clinical managers within my local District Health Board to present a proposal for such a health delivery scheme to the Board Executive.

This is, I consider, an indicator of the usefulness of my praxiological research. If such a scheme of health care delivery is implemented further research on quality of life for clients and decreases in costs of delivery of care would, I consider, be imperative. I also believe that more discursive studies of primarily relational nursing practice vis a vis primarily instrumental or functional practice could further assist nurses to understand the tensions that frustrate achievement of quality of nursing care.

implications of practice as praxis for the education of advanced nurse practitioners

The main practice as praxis implications of this research are for advanced nursing practitioners. Therefore, in this section I will describe what I see as implications from this research for education of nurses, who choose to care for people at risk of or experiencing strife in chronic illness. The Nursing Council of New Zealand (NCNZ) (2001) requires advanced nurse practitioners to have a clinical Master of Nursing qualification. Therefore I recommend that the foundational educational preparation for an advanced nurse practitioner who would work in a 'Integration of health events in complex chronic illness' scheme of care be incorporated into a clinical master's programme.

Such a programme could use a modified model of Gadon's clinical epistemology (1995b) as a framework for knowledge development. The advantage of this model is its acknowledgement of both the disease and health-illness discourses, which point to knowledge coming from both the physical and human sciences. It is a challenging option in which the strengths and weaknesses of both sciences could be debated. This could keep open the option of a high level generalist or specialist trajectory for those who want it and provide nurses who seek to work in the scheme outlined above with the necessary knowledge.

I see that analysis of the discourses inherent in all nurses' scope of practice would be advantageous in the core units of nursing knowledge to be woven throughout the programme. Examining how these discourses entered into nursing and the tensions experienced when caught in the pull and push of each one would be an excellent analysis strategy in units titled 'Reflective practice'. Specific knowledge and skill in seeking the

meaning of the experience of clients through an exploration of the health illness discourse could expand students understanding of the ill person's experience, which in turn informs the nursing as a caring practice discourse. In addition, an exercise in extrapolating the assumptions of the different discourses from their practice could allow students to see where their emphasis lies.

The achievement of clinical experience and mentoring of practice in such a scheme of care could prove challenging in the first instance when no schemes are operating. However, students could identify possible areas where they see a variation of the model at work or nurses who embody the approach that they want to advance. Working with providers of health services to identify clients in strife could provide a clinical option opportunity for students to walk alongside these people for a prolonged period. I also believe that academic institutions have a responsibility to work with other community organisations to create new models of care that respond to the health needs of particular populations which would also provide clinical placements for their students. An example of such an initiative is the Health Action Model in Community (HAMPIC) described by Bunkers, Nelson, Leuning, Crane, and Josephson (1999). This is an initiative where partnerships have been forged between an academic institution, advanced nurse practitioners and community outreaches in order to respond to identified gaps in groups with complex health situations. Such an initiative also provides opportunities for faculty practice for the lecturers in a clinical master's programme. Furthermore the lecturers could initiate praxiological research methodologies within such innovative programmes which could provide a basis for the research module of the master degree. The students would have the opportunity of praxiological learning and research and within this process a chance to develop and refine their own praxiologies.

research as praxis

personal insights and implications

The understanding generated in this inquiry has been through the vehicle of a hermeneutical reflection within praxiological methodology. GPH is described as a hermeneutics of faith (Thompson, 1990). Although not knowing this descriptor of GPH

when I stepped into the research journey I would now describe it as a journey of faith. I risked following my practice question in an unpredictable and uncertain situation. The research design came to fruition because of the generous participation of all co-participants involved in the practice under scrutiny. For me, it was a richly rewarded faith resulting in a new breadth of understanding. The construction of the praxiological research methodology of this inquiry, informed by reflection on my effective historical consciousness produced a unique expanded understanding of the engagement of nurses with person suffering from strife in chronic illness. It elucidated a contextual demonstration of what it can mean to practise the tenets of nursing as a caring practice rather than only proclaiming or theorising about them.

A clear overlapping of practice as praxis and research as praxis is observable in this research. It is apparent in the dialogical reflection with Sarah as the 'form' of practice (Newman, 1991) and in my ongoing practice role with Sarah during enactment of the research. Research as hermeneutical praxis can provide an ethic of active listening which complements practice as praxis. However, unless the intention of the research as praxis is the good of the client together with the intention of knowledge development, as is demonstrated by Cowling (2000), I remain of the opinion that the form of practice embodied in research as praxis is, at best, a complementary adjunct to practice as praxis.

Remaining in the practice role, or what I described as my double insider status in the research, was both beneficial and at times difficult. It was beneficial in that my twofold advancement as practitioner and researcher enabled a richer description of the retrospective happenings and any insights from the research could be transposed into practice immediately. In addition the clinical supervision put in place for the research served to equally support my practice. The difficulty arose in extricating myself from the practice when I left the service. I felt an obligation not to leave Sarah in a non-supportive vacuum but did not want to interfere in the development of new service relationships. A natural closure when the time was right for Sarah did occur. My concern about what a 'pleasing me' effect, raised in chapter seven, was also resolved in a closing conversation I had with Sarah and Mary. They assured me that their contributions came out of their

perception of the experience. Both these issues were further lessons for me in trusting the agency of the participants and the process. The particular insights of this praxiological inquiry were shaped from my double insider research status.

limitations and benefits of praxiological inquiry

In using the term praxiological inquiry to describe knowledge development from nursing practice I have joined a long established tradition in nursing. It is a tradition that has evolved in its expression and characteristics but stayed on the margins of nursing research. Theory development became center stage in much of the late twentieth century in an attempt to achieve professional equity with other disciplines in academia. Unfortunately, the theorists of nursing drew more on theories from other disciplines and then applied them to nursing practice, rather than growing their theory from nursing practice. Theories of nursing are helpful in assisting nurses to articulate their practice for, as stated, I have found the theories of Newman (1986, 1994) and Parse (1995, 1997) useful. However, I have also found that it is productive to move on from the theorist's positions in order to both critique these positions and to creatively advance nursing research methodologies and practice theory. My stepping into a philosophical worldview unencumbered by the informing elements that Newman and Parse had built into their theories enabled me to appreciate the partial view of nursing and research embedded in their theories and methodologies. Their views counter knowledge development within the practical discourse of nursing. The constitutive components of Newman's theory arise mainly from quantum physics, a discipline that contributes much, but one in which I did not find a comfortable home. I feel much more 'at home' in philosophy. Theorising about practice situations does draw on multi-disciplinary perspectives. However, it shapes the perspective to the experiences rather than vice versa. As such praxiological research honours, grows and expands practice knowledge.

I do believe that the time is right for praxiological inquiry to come into its own in nursing. However, the term is not one widely used or understood. The term practice theory is more common in contemporary nursing literature (Thorne & Hayes, 1997). A consequence of this dual terminology means that those who are committed to

praxiological inquiry or practice theory development can be on parallel paths missing and therefore failing to build on each other's contribution. Although the term praxis is well embedded in the lexicon of nursing there has been little exploration of its evolution and the implications of this in our current use of it. This situation presents a paradox, typical of our post-modern world. Many and various operational definitions of praxis are evident and accepted which on the surface demonstrate their usefulness for a practice discipline but at the same time limits any overall coherent understanding from which their potential can be realised.

The praxiological methodology of this research demonstrated a successful research strategy for uncovering knowledge embedded in practice and therefore expanded understanding of the practice situation. I believe praxiological methodologies are significant for advancing practice knowing, particularly for advanced nurse practitioners. They are a formal expression of reflective practice that can enable nurses to grow their practice and at the same time improve their articulation of it in terms of service delivery outcomes. Theorising about practice outcomes is a process of clarifying and expanding understanding. Future pathways and models of care can emerge from confronting all the ambiguity of our practice contexts within the theorising process. At the same time praxiological methodologies can be a vehicle for giving voice to clients and nurses and in so doing have potential to be a transformative reflexive medium for them.

If praxis is deemed important and practice as praxis leads into and out of research as praxis then the notion of the practitioner as researcher and researcher as practitioner could become integral to all advanced nurse practitioner roles. In this way the practitioner stays a student of nursing beyond any formal preparatory programme. Nursing practice as dynamic and continually evolving, increases in worth to the discipline of nursing and to health service delivery systems. Research projects do not need to be the breadth and depth of this one. They do need to emerge out of practice questions that will provide an expanding understanding of the practical issues challenging every day nursing work.

As discussed by Pearson (1988) a number of well known research methodologies can be used in a praxiological inquiry e.g. grounded theory or phenomenology. An advantage, for me, in choosing to create a framework from the assumptions of GPH was its close relationship with praxis within the practical discourse of philosophy. The construction of my five methodological premises; reflexivity, dialogue, moral comportment, representation in narrative and critique, as process and action oriented postulates, was unique to this research. Furthermore, the methodology's ontological character fitted with the relational focus of the nursing practice under scrutiny and made the constructing of a unique ontological nursing praxiology appropriate. In this situation the movement of research as praxis into an ontological framework was innovative and opens the way for other researchers to bring together ontological praxiologies that fit their positions.

This expression of research (hermeneutics) as praxis challenged me to configure together the premises that fitted with the praxiological intent and distinctive features of the inquiry. As a result I was able to bring together premises that are often considered the prerogative of certain established methodologies. e.g. reflexivity with emancipatory inquiry, dialogue with participatory inquiry, discourse analysis with post structural inquiry. Using a theoretical framework from GPH paved the way for this inquiry to develop a distinct praxiological methodology without relying on following a known methodology.

transformative potential of research as praxis

In my research framework, taken from GPH, the ongoing transformative process of being and becoming is foundational to the process of expanding and fusing of horizons. Questioning and reflective persons are always moving to a new place where new possibilities open up for them. It is about the embodiment of a process orientation rather than a product orientation. For all co-participants, the research process involved hermeneutical reflexivity. The main elements of the transforming process apparent in Sarah's experience are extrapolated and discussed in chapters ten and eleven. Transforming along the way is not so apparent for the nurse co-participants. Rose did articulate that the research journey was a reflective practice journey and her major insight

related to movement in being able to ‘let go’ of being the nurse to carry the relational component of a person’s care. Mary and Kim declared they had learned much from the research process but did not articulate specific insights. In fact, Mary believed her significant insights into the enacting of nursing as a caring practice occurred in the practice environment; it had been practice as praxis for her rather than research as praxis. It appeared that their co-participation in the exercise of expanding knowledge about the nursing practice of assisting people in living with strife in chronic illness generally, rather than developing insights into their own practice, was in the forefront of their minds.

I considered offering a draft of the meaning generated in the process of deconstructing the narrative to the co-participants but decided against it. There had been indications that the time and effort of the ‘homework’ required in the participation of co-constructing the narrative had been quite demanding and the final meeting had appeared a natural closing time for their participation. Further, I was aware, that the meaning made came out of my effective historical consciousness, not that of the co-participants. While they may have found it interesting and insightful it did not appear appropriate to begin another cycle of reflexivity at that stage. All co-participants indicated interest in reading this report and another cycle of reflexivity, whether formal or informal will, I believe, take place in relation to the meaning generated from deconstructing the narrative. Therefore, as I have been the main person searching for meaning and the co-participant who dwelt with the research material over the longest period, I believe that my expanding and fusing of horizons has been the most significant amongst the nurse co-participants.

The practice as praxis exploration of this research as praxis was a further hermeneutical circle of reflection triggered by my earlier research and return to practice. As in earlier circles I have experienced an ongoing expanding consciousness about the experience of people living with strife in chronic illness and the nursing practice that is effective in assisting them move from severe strife. In addition this circle significantly extended my understanding of the notion of research as praxis. My journey, like Sarah’s, has not involved any particular choice point where I took on a qualitatively new view of the world. I can look back now and say that for most of my nursing career I have been drawn

towards what I have articulated in this study as the health-illness and nursing as a caring practice discourses. This research has given me the opportunity to articulate them to a much greater extent and depth than ever before.

future potential of praxiological inquiry

It seems to me that the nomination of an inquiry as praxiological; the emphasising of the primary intention of the inquiry as knowledge development from practice, provides a way forward for the development of nursing practice. My experience of praxiological inquiry has made me a committed herald of its possibilities for nursing as a practical human science. I see that it can achieve several benefits in nursing research.

Praxiological research can assist closing the theory practice gap and encouraging a more constructive focus on the nexus of theory-practice. In so doing practitioners, researchers, academics, educators will work more collaboratively for the common goal of ‘the good’ of our clientele and hopefully realise more fully the contribution that nursing can make to the health of the community.

‘Pushing the boundaries’ of our caring practice will become easier when praxiological methodologies are used to demonstrate caring practice as the ground of our knowing. The notion of practical rational reasoning or practice wisdom will expand in tandem in research and practice.

Reinforcing the value of reflective practice that is already demonstrating positive movement in the development of nursing knowledge at the local contextual level, will I believe, be expanded by praxiological inquiry. It is or can be reflective practice ‘writ large’. As such it does not present a major change in thinking for practitioners to become formal researchers or to be part of a research programme team. Areas to be researched will be chosen from practice and then hopefully there will be an investment in incorporating the findings in future practice; a working of the theory-practice nexus to reduce the research practice gap.

Moving away from foundationalist epistemologies that are characteristic of empirical research and achieving what Pearson (1988) calls praxiological inquiry's 'developmental and transformative characteristics' will be made easier. Inquiry will always be based on derivative knowledge or be theory and value laden and acknowledgement of this is important. In praxiological terms this is the praxiology informing the thinking and action of praxis. However it is equally important to remain what Pearson (p. 136) calls "agnostic" in the sense that the goal is to "re-examine and re-formulate rather than to prescribe". In this view theory is no longer applied or foundational. It is lived in practice, examined in the living, and re-formulated in the re-flecting.

New post empirical methodologies can unsettle too strict an implementation of paradigmatic canons no longer useful. Implementation of these canons has led to the erection of boundaries that have benefited researchers in providing assumptions and processes in which their ideas can be structured. But it is equally important to remember that these boundaried positions are human constructions often erected to privilege the perspectives of the original constructors and can be deconstructed. If these boundaries are not subjected to ongoing critique they can be boundaries that become a hindrance in expanding the horizon of creativity in post empirical research.

Multiple and creative methodological configurations are possible for other research questions and similarly alternative theoretical frameworks can be constructed from other than the GPH position. As there is an increasing call for nurses, particularly advanced practice nurses, to articulate how nursing practice contributes to the health outcomes of the populations they serve I believe that praxiological inquiry, in whatever form it takes, has come of age in nursing.

In this section I have addressed the implications and my insights from the expanded knowledge of strife in chronic illness, practice as praxis and research as praxis. Within this discussion I have proposed particular implications from my research for Sarah, families who live with chronic illness, the nursing profession, health care delivery services and myself. In the course of the chapter I have made recommendations for

further research. I have emphasised considerations for advanced nursing practice in relation to the finding that leading the nursing practice of the care of people with strife in chronic illness is a role for advanced practitioners. Implementation of these implications will, I believe, advance the quality of life for people living with strife in chronic illness and increase the benefits of praxiological inquiry to the discipline of nursing.

concluding statement

Sarah, the client co-participant in this study was referred to me as the community nursing clinical nurse specialist in her local community. As I began my engagement with Sarah, I initiated, what is termed in this study, “a moment of caring healing praxis” (Watson, 1999). The nursing philosophy underpinning this moment came from a conceptual model of practice titled ‘the web of relationship’ (Connor, 1995). In the second year of engagement with Sarah I realised that I could expand the knowledge development achieved in my earlier research if I investigated Sarah’s situation. This study has focussed on the experience of the prolonged engagement of Sarah, a person living with strife in chronic illness, and the small team of nurses from a regular state funded, community service involved in her care. Health-illness is manifested in a multiplicity of ways in different people, cultures and traditions. This research provides an in-depth examination of one manifestation as experienced by a middle aged Pakeha woman, Sarah. It explicates a unique view of health-illness responded to by a team of nurses who professed to give person centred care. The study involved a local, boundaried, practice situation spanning a three year period; a situation rich in contextual complexity.

For Sarah, illness had become a burden that continually weighed heavily upon her and at times overwhelmed her. She saw the nursing teams’ contribution to her health-illness experience as sharing this burden. This sharing involved active listening, a co-construction of her health circumstances and offering advice on and assistance with strategies that could be instrumental in promoting her comfort and preventing exacerbations of her disease.

To effectively share Sarah's burden of illness, we, the nursing team 'pushed boundaries' and walked 'fine lines' within the confines of the community nursing service in which we worked. Walking the 'fine line' in what is described as an intense relationship was seen to be the most effective nursing contribution to Sarah's care and at the same time the most problematic for the nurses. This component was seen to be advanced nursing practice. My dialogue with the co-constructed generation of meaning of the three year period, the research in narrative form, revealed the themes of paradox, moral meaning and metaphor as common to both Sarah's and our nursing experience. I then saw that these themes were embedded in particular discursive frameworks.

Sarah's experience is discussed as occupying an 'in-between' space of the health-illness and disease discourses. The concepts of the ontological assault of illness and entrapment in the disease discourse, taken from the health-illness literature, are used to illuminate her situation in this discursive space and provide an understanding of her circumstances. Our nursing position incorporating 'a caring gaze' is described as an expression of the nursing as a caring practice discourse in a space on the boundary of a nursing as a functional service discourse. In this space, tensions related to my intense relationship with Sarah, the 'fine line' between therapeutic and non-therapeutic approaches, norms normal and normalising and different meanings within one transforming approach are discussed. Because of the multiplicity views expressed in the voices of the co-participants and the differing views of the world in the discursive frameworks I used the term postmodern practice to describe this particular prolonged engagement. Substantive understanding and knowledge about the nursing practice with clients experiencing strife in chronic illness is advanced in the melding of the particular with more general abstractions from the literature.

The substantive understanding and knowledge unfolded within hermeneutical reflection on the concepts of strife in chronic illness, praxis as practice and praxis as research. The expression of research as praxis involved the construction of a theoretical-philosophical framework from Gadamerian philosophical hermeneutics, the creation of a particular praxiology using the basic assumption from the framework and the health-illness and

nursing as the caring practice discourses. In accepting an ontological view of the world from Gadamerian philosophical hermeneutics the research methodology became an ontological expression of research as praxis. Furthermore, the whole inquiry became a hermeneutical circle of reflexivity embodying dialogue and moral comportment. In fact, three overlapping and interacting hermeneutic circles constitute the hermeneutical reflection in this inquiry; the exploration of the traditions informing the inquiry, the construction of the praxiological methodology and the narrative findings within the premise of re-presentation as narrative, and the deconstruction of the narrative within the premise of critique. The three methodological premises, reflexivity, dialogue, moral comportment were embodied in the research processes of researcher journalling, a series of meetings with the co-participants from which the research material was collected, and summaries of the nursing documentation. Re-presentation of the research material into a narrative went on within a co-construction process involving more meetings with the co-participants. As lead researcher I undertook the critique of the narrative. My presence in the practice being explored and the research exploring it made for a distinctive methodology.

To deepen my understanding of the concept of praxis and how it would inform my study I chose to explore its evolution in philosophy and its appropriation within the discipline of nursing. The fruits of this exploration enabled me to grasp a new view about the varying uses of praxis in nursing research and the importance of a nominated praxiology when engaging in praxiological inquiry. With this knowledge, I have argued and demonstrated that research as praxis can involve a wider perspective than that of emancipatory research informed by emancipatory theory, which is commonly associated with praxis research. In this instance I have demonstrated that research which is primarily hermeneutical and practical in intent can be informed by a praxiology which melds together assumptions from what Habermas (1972, 1973) described as the practical and emancipatory human interests underpinning knowledge development. The transforming potential of this praxiological view was realised for both Sarah and myself.

Thus, the contribution of this inquiry to the discipline of nursing is twofold. Firstly it provides an expanded substantive understanding of the nursing engagement with a client experiencing prolonged strife in chronic illness. Secondly, it progresses the understanding and application of praxiological research.

Several insights and implications of the inquiry are extrapolated from the generated substantive meaning and the praxiological methodology. Recommendations are also made for future research pertaining to the topic. Several implications pertain to advanced nursing practice. Nursing people with strife in chronic illness within complex contexts was viewed as the work of advanced nursing practitioners. Furthermore, because of the discursive tensions identified in the context of a regular community nursing service a recommendation is made to set up an independent health delivery scheme, akin to, but more than present health related case management schemes.

I have come to the end of this circle of hermeneutical reflection. It had a beginning that involved an act of faith. I did not know where it would lead or what would happen in the unfolding of the research journey. It was a faith that has led to a meaning-ful broadening of horizons for both Sarah and myself and significant knowledge development for the discipline of nursing. The beginning of this research emerged from the ending of an earlier inquiry. It is possible that this study will generate the beginning of new circles of hermeneutical understanding, should I or others, wish to pursue questions that have been raised within it. The outcome of the development of new and various hermeneutical circles from where new and varied expressions of postmodern nursing praxis can evolve will be the continued expansion of nursing as a practical human science.

APPENDICES

Appendix 1

Communications with Health Ethics Committee and Client co-participant at commencement of study

Appendix 2

Communications with Health Ethics Committee and research co-participants during the study

PLEASE
DO NOT
STAPLE

APPENDIX 1.

AN IN-DEPTH STUDY OF PROLONGED NURSING ENGAGEMENT WITH A PERSON EXPERIENCING STRIFE IN CHRONIC ILLNESS:

Client Information Sheet

Principal Investigator
Margaret Connor
Clinical Nurse Specialist
Community Health Services
Capital Coast Health Ltd
Work pH 04 237-2030
Home pH 04-473-5195

Introduction

I am a registered nurse currently enrolled in a Nursing PHD programme at Victoria University of Wellington. I am about to embark on research that aims to describe the nursing practice that assists patients move out of strife within chronic illness. Strife within chronic illness means frustrating circumstances that stop people getting on with their lives in the way they desire in a community setting. It involves repeated hospitalisations.

This is the practice that you and I have engaged in over the last two years. I would like to invite you to be part of my study.

Other nurses who have visited you on a regular basis will also be invited to be part of the study to assist me in describing the nursing practice we have endeavoured to carry out.

I believe future nurses will be able to assist patients who get into strife better if we can write about your particular situation and our response to it.

The research process.

Several meetings will take place. Initially there will be approximately three one hour interviews when you are asked to reflect and talk about the day to day living with your health situation over the last two years.

I intend summarising the nursing notes about your health situation and using this as a basis for another interview approximately three months later. If there is significant material that you may have forgotten I will ask you to comment on this and its significance to you. The nursing notes are the notes you have seen and signed throughout the last two years. I will be looking at your notes after your first reflection because I do not want to influence the initial telling of your story.

I will work with the nurses in a similar way to the process outlined above to describe as fully as possible the approach we were taking.

An in-depth study of prolonged nursing..... client information sheet

Finally there will be one to two interviews several months later, where I ask you to join the nurses involved in order to assist me put your story and our story together.

You will be able to refine or change any of your contributions as the story takes shape.

Possible Benefits

The reflection involved in telling your story of the last two years may assist you to come to a new understanding of the past. It is only after a prolonged period is completed that a retrospective examination can illuminate all that was involved over that period.

You will have a written story to refer to at any time. This may be of assistance as a reference for problem solving in similar situations in the future and a reinforcement of your courage and the abilities you have developed in living with your chronic condition.

Participation

Your participation is entirely your choice. If you do agree to take part you will still be free to withdraw from the study at any time, without having to give a reason and this will in no way affect the standard of your continuing health care.

If the study process changes from the outline in this form you can choose to withdraw or re-consent to continue.

If your health circumstances deteriorate and you choose to leave the study I will ask you to consider leaving what material you have contributed to that time in the study. Again you will be free to decline this request.

If you decide to participate you can choose to have me involved in any of your ongoing nursing care or I can become a researcher only and have other nurses attend to your care.

With your permission I will audio-tape the meetings.

You will be able to choose a venue for these meetings to take place.

Two weeks will be available for you to decide about your participation in this research.

Confidentiality

No material that could personally identify you will be used in any reports on this study without your explicit consent

The information collected will be seen by my research supervisor, my clinical supervisor and the person who types up the audiotapes. All these people will be subject to confidentiality agreements.

An in-depth study of prolonged nursing..... client information sheet

The audiotapes, hard copy of the transcripts and computer disks will be stored in a locked cabinet. The directory on the computer in use will be password protected.

The audiotapes and computer files will be erased five years after completion of the research.

Possible risk

At some stage during the reflection on the past two years you may become upset by something that has been extremely hurtful. If this does occur and you feel you can not go on with the meetings you are free to leave the study. If this happens I will assist you obtain counselling to move through the hurt and to debrief on leaving the study.

More information is available from

My research supervisor

Professor Alison Dixon

Chairperson, Department of Nursing and Midwifery

Victoria University of Wellington. Telephone 471-5363

and

The Wellington Ethics Committee, Wellington Hospital,

Telephone 385-5999 ext 5185

The Wellington Health Advocates Trust will provide independent advocacy for you during the research if you require it. A pamphlet explaining this service will be given to you.
Telephone 5700850

This study has received ethical approval from the Wellington Ethics Committee.

The Clinical Leader of the Community Health Services Capital Coast Health Ltd has given permission for this study to be carried out

Please feel free to contact me if you have any questions about this study.

Date

AN IN-DEPTH STUDY OF PROLONGED NURSING ENGAGEMENT WITH A PERSON
EXPERIENCING STRIFE IN CHRONIC ILLNESS: Client Consent Form

I have read and understand the information sheet dated _____ asking me to take part in the study designed to improve the principal researcher's ability to describe the nursing practice involved in prolonged engagement with a client.

I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I understand that taking part in this study is my choice, that I may withdraw from the study at any time and this will in no way affect my continuing health care

I understand that my participation in this study is confidential and that no material, which could identify me, will be used without my explicit consent.

I understand that if there is any change in how the study progresses I will have an opportunity to give or decline consent for the changes at that time.

I understand that if my health circumstances deteriorate to a level that require me to leave the study I will have the opportunity to give or decline consent to my contribution to that stage remaining in the study.

I have had time to consider whether or not to take part.

I know whom to contact if I have any questions about the study.

I consent to my interviews being audio-taped. YES/NO

I wish to receive a copy of the final report YES/NO

Ongoing material from the narrative development will be available to you but there will be a significant delay from data collection to the publication of the final report

I. (full name) _____

hereby consent to take part in this study.

Signature

date

An in-depth study of prolonged nursing..... client consent form.

If you have any concerns about the study, you may contact:

The Wellington Ethics Committee,

Wellington Hospital,

Telephone 385-5999 ext 5185

If you require some independent advocacy during the study you may contact

Donna Payne

The Health Advocates Trust

Ph 04-5700850

I have discussed this consent form with the person concerned and am satisfied that she fully understands it and that her consent is freely given.

Signature of witness

date

Signature of researcher

date

Ph 04 -473-5195

Project explained by Margaret Connor

date

Ongoing Consent

Signatures

Date

**AN IN-DEPTH STUDY OF PROLONGED NURSING ENGAGEMENT WITH A
PERSON EXPERIENCING STRIFE IN CHRONIC ILLNESS**

Nurse Information Sheet

Principal Investigator

Margaret Connor
Clinical Nurse Specialist
Community Health Services
Capital Coast Health Ltd
Work pH 04 237-2030
Home pH 04-473-5195

Introduction

I am in the process on a piece of research for the PHD nursing programme that I am enrolled in at Victoria University of Wellington. The research aims to describe the prolonged nursing practice that assists clients move out of strife within chronic illness. Strife within chronic illness means frustrating circumstances that stop people getting on with their lives in the way they desire in a community setting. It involves repeated hospitalisations.

This is the type of nursing practice that we have worked at collaboratively in the last two and a half years. I invite you to be part of my study. I believe that the written experience of our particular endeavour will improve the ability of future nurses to prevent and/or assist clients who get into prolonged strife.

One client who has experienced strife that we have worked with together has been participating in the project.

The research Process

Several interviews will take place. Initially there will be two to three sessions for us to recall the significant nursing care given to the client. I will use a summary of the nursing notes and my professional practice journal to act as triggers in recalling the nursing care.

I have worked through a similar process with the client to record her story before I work with you.

Approximately three months later I will ask you to meet with the client and myself in order to put the two stories together into a composite narrative. This exercise will take approximately two one-hour sessions.

You will be given summaries of all the meetings and will be able to refine or change any of your contributions.

An in-depth study of prolonged nursing..... nurse information sheet

It is my intention to create a conceptual model of nursing practice from an analysis of the themes in the composite narrative. You will be invited to examine and offer comment on the initial draft of this model.

You will have ongoing access to research data that you have contributed and a final report will be available to you if you would like one.

Possible Benefits

The reflective practice involved in a retrospective examination of a two-year period of nursing care to a client may help you see more clearly the care that helps or hinders a client's movement out of strife. The process will provide tools for ongoing reflective practice.

Both the process we go through and the conceptual model about prolonged engagement with clients in strife will help you to identify and/or curtail strife in other high risk clients.

Participation

Your participation is entirely your choice.

You do not have to take part in this study, and if you choose not to take part our collegial relationship will be ongoing.

You will be given two weeks to consider whether or not you would like to take part in the study.

I would like to audio-tape the sessions with your permission

You will be able to negotiate a venue for the sessions to take place.

Confidentiality

No material which could personally identify you will be used in any reports on this study without your explicit consent

The information collected will be seen by my research supervisor, my clinical supervisor and the person who types up the audio-tapes. All these people will be subject to confidentiality agreements.

The audio-tapes, hard copy of the transcripts and computer disks will be stored in a locked cabinet. The directory on the computer will be password protected.

The audio-tapes and computer files will be erased five years after the completion of research.

An indepth study of prolonged nursing..... nurse information sheet

Possible risk and inconvenience

If anything does arise in the retrospective examination of our nursing practice that is hurtful to you or makes you feel vulnerable in any way I will support you obtain assistance from the CCH employer assistance program.

I do not see that there will be any physical risk to you.

Giving up your time to participate may be an inconvenience.

More information is available from

My research supervisor

Professor Alison Dixon

Chairperson, Department of Nursing and Midwifery

Victoria University of Wellington. Telephone 471-5363

And/or

The Wellington Ethics Committee, Wellington Hospital,

Telephone 385-5999 ext 5185

This study has received ethical approval from the Wellington Ethics Committee.

The Clinical Leader of the Community health Services Capital Coast Ltd has given permission for this study to be carried out"

Please feel free to contact me if you have any questions about this study.

Date

AN IN DEPTH STUDY OF PROLONGED NURSING ENGAGEMENT WITH A PERSON
EXPERIENCING STRIFE IN CHRONIC ILLNESS

Nurse Consent form

I have read and understand the information sheet dated _____
asking me to take part in the study that describes the prolonged nursing practice
involved with a client experiencing strife within chronic illness.

I have had the opportunity to discuss this study. I am satisfied with the answers I have
been given.

I understand that taking part in this study is my choice, that I may withdraw from the
study at any time and this will in no way affect our collegial working relationship.

I understand that my participation in this study is confidential and that no material,
which could identify me, will be used without my explicit consent.

I have had time to consider whether or not to take part.

I know whom to contact if I have any questions about the study.

I consent to my interviews being audio-taped. YES/NO

I wish to receive a copy of the final report YES/NO

Ongoing material from narrative development will be available to you but there will be a
significant delay from data collection to the publication of the final report

I. (full name) _____
hereby consent to take part in this study.

Signature: _____ Date _____

If you have any concerns about the study, you may contact:
The Wellington Ethics Committee,
Wellington Hospital,
Telephone 385-5999 ext 5185

Signature of researcher date
Ph 04 473-5195

Project explained by Margaret Connor date

29 November 1998
 Sharon Cole
 The chairperson
 Wellington Ethics Committee

Dear Sharon,

Thank you for your letter of 13 November 1998 regarding the research proposal I submitted to your committee

I have since met with my university supervisor to discuss the points you raised for further consideration.

Protection of the client

I spoke with the Health Advocate Trust asking that an independent person be available when I explain the research to the client. However they do not have the personnel to undertake this function but have pamphlets explaining their service and these will be given to the client and her family. The client will be asked to have two people of her choice present when the research is explained. An invitation will also be made for her to have a support person with her during the interviews

Protection of other nurses

If the nurses become vulnerable in any way from what emerges in the research data I will assist them obtain help from the Employer Assistance Programme that is available within Capital Coast Health Ltd.

Protection of self

To protect myself I undertake to begin a programme of formal clinical supervision with an appropriately qualified person for the time of developing the client's story. This will enable me to talk freely and confidentially about any issues that arise. As part of the contract I intend to set up with the supervisor I will give permission for her/him to talk to my research supervisor if it becomes evident that I am part of the strife of the client or at risk in some other way. In addition my research supervisor will see me for de-briefing meetings following each meeting I have with the client

Accompanying this letter are two further letters:

- * one to the client covering the consent process to be put in place and
- * one from my research supervisor, Professor Alison Dixon, acknowledging the concerns outlined in your letter and the processes that are planned to reduce vulnerability of all research participants

Sincerely

Margaret Connor

January 1999

Dear Ms

This letter confirms the initial tentative conversations of last year inviting you to participate in research with me. The date we arranged for the explanation is

I ask that you invite two of your family members or close friends to be present for the explanation. As I have been your main nurse for the last two years I do not want you to think that you have an obligation to participate. In addition the research involves areas of negotiation and it would be helpful to discuss these areas with your family or friend before making a decision. A two week period following the explanation will be available to you to consider participation. The period is available to you to raise questions and seek clarification that will help you understand the implications of participation. Written information sheets with names of people other than myself and a pamphlet describing an independent Advocacy Group will be left with you and your support people at the time of explanation.

Family members or close friends will be welcome to be at any of the interview sessions we have.

The above process is set out to ensure that you are as fully informed as possible before giving consent to participate

I look forward to our meeting

Sincerely

Margaret Connor

APPENDIX 2

26 Norwich Street
Wilton,
Wellington.

29 October 1999

Ms Sharon Cole
Chairperson
Wellington Ethics Committee
Wellington

Dear Sharron,

I write to seek ethical approval of an extension of my research. The original proposal No 98/124 was approved by the committee in December 1998.

I have now completed the first stage of data collection as outlined in that proposal. Overall the data collection, which had potential to increase the vulnerability of the client, has gone well. It has taken longer than I originally anticipated due to longer gaps between interviews if the client was not feeling well or had other priorities for her energy, and the difficulty in getting two busy nurses together at the same time. However this has not been problematic for the research and is minor in relation to the overall unpredictability that was inherent in the research process.

The client has had continued nursing involvement in 1999. I am now keen to include the experience of this period and the experience of a new nurse who became involved with the client this year. It would also involve summarising the 1999 nursing record.

To date I have tentatively posed this possibility to both the client and the nurse. At this stage they are both agreeable.

The consent form signed by the client at the beginning of the research has a place for ongoing consent which can be used. The process for her will be the same as outlined in her original information sheet. However the information sheet designed for the nurses has needed minor alterations to accommodate the nurse coming into the research at this later period. A copy of the modified form is enclosed.

I ask that you consider this request
Sincerely

Margaret Connor

10 May 2000

Dear Nurse Mary, Rose, Kim

Please find enclosed a narrative that I have constructed from the transcripts of our research interviews. I now invite you to give me more input as mentioned in the information sheet given to you at the outset of the research.

In particular, I ask that you read it with the following points in mind:

- feelings that come to you about reading your own voice and how it is represented vis a vis the other voices
- any particular insights or aha's that arise
- any shifting from a the nursing practice view represented at the time of the interviews to your present view
- further discussion in relation to the areas that I have marked and areas that you may mark for your own clarification
- any changes you might like to make to the language you used
- use of pseudonym. I would like you to choose a name you want to be represented by. What I have used in the narrative has been a pragmatic choice to protect your identity at this stage. In addition please consider any other means you would like taken in protecting your identity.
- any general editing advice you may have for me or other comments.

I thought of highlighting your voice to make it easy for you to locate but then decided it may not be helpful. However you may like to do it yourself.

It is my intention to meet with you individually to discuss the above and following reconstruction to invite you to a meeting of the whole group to consider the overall change. My goal is to have a narrative that you are happy for both Sarah and the general public to read.

I will contact you by phone over the next week.

Sincerely,

Marg

1.

2 June 2000

Dear Sarah,

Please find enclosed a new narrative that I have constructed from the transcripts of our research interviews including the second phase of our meetings in November/December 1999. I now invite you to give me more input as mentioned in the information sheet given to you at the outset of the research.

In particular, I ask that you read it with the following points in mind:

- feelings that come to you about reading your own voice and how it is represented in the narrative.
- any particular insights or aha's that arise
- any shifting from views expressed at the time of our meetings.
- further discussion in relation to areas that you may mark for your own clarification
- any changes you might like to make to the language you used
- use of pseudonym. I would like you to choose a name you want to be represented by. Also any other means you would like taken in protecting your identity.
- any general editing advice you may have for me or other comments.

My goal is to have a narrative that you are happy for both the nurses who have been involved in your care and the general public to read. The nurses and I are refining our narrative at the moment and hope to send it to you to read in the near future.

I will contact you by phone over the next week.

Sincerely,

Marg

18 July 2000

Dear Nurse Mary, Rose Kim,

The nursing narrative that I talked with you about recently is now reworked. It is enclosed for any further reflection, clarification and/or correcting that you may care to share with me.

In the re-work I have tightened up the larger sequences of quotations in the earlier version. In addition I have added ongoing reflections, clarifications and corrections from you. This means there is some movement in the positioning of particular participants.

In progressing the research since our discussions I can now see that I will not use this narrative in its current form in the body of the research text. However it may appear as an appendix. I see it as an operational text for clarification and reflection on our nursing journey with Sarah. It is informing my work in progress on an integrated narrative of our experience and the experience of Sarah. It is then my intention to theorise about our combined journeying as it is described in the integrated narrative. At this stage, I envisage that the theorising framework will use paradox and moral knowing as its core components.

In doing the rework of our narrative I have managed to cut off four pages but acknowledge it is still a long read. I now ask you to read it to:

- ascertain that you are represented appropriately
- take the whole into account and how your contribution fits with the whole
- pull out extracts that you would like to explore further in a meeting and
- re-consider issues of confidentiality and anonymity and your acquiescence of material being read by Sarah and eventually entering the public domain.

I invite you to a meeting to share your considerations with the other nurse participants and me as a continuing dialogue. I will phone you in the coming week to arrange this. At this stage I am wondering if we could meet at Kenepuru Community Health base. As I mentioned to you at our last meeting it is my goal to have one final meeting following this one when Sarah will be invited to attend. For that meeting I will have completed the integrated narrative for us all to reflect upon and discuss.

I do appreciate the time and effort you have put into this research so far and I am very grateful for your rich contribution.

Sincerely,

Marg

3 September 2000

Dear Mary

This letter confirms discussion I have had with you regarding the setting up of a final research meeting.

A narrative integrating the client and the nursing experience that has unfolded in the research is now together in draft form. In order to obtain a coherent and reasonably sized narrative I have refined material from our earlier nursing story. My voice now becomes that of the narrator and interpreter. In short I have re-presented your contributions in the story. The draft is enclosed for your reflection, clarification and/or correction that you may care to share with me

I invite you to attend a meeting to reflect on this draft as a group. M will be invited to attend the meeting also. It is the final expression of the concept of partnership and participatory involvement that is central to my research methodology. It will be a chance to dialogue together about our partnership and anything we have learned from it. It also provides an opportunity to sum up any of your insights or concerns relating to the overall research process. The meeting will be lead by a facilitator, Nita Hill. This will enable me to be freer to enter into the dialogue.

If there is anything that arises in your reading of the narrative that you would like to clarify or discuss with me prior to the meeting please do not hesitate to contact me. I ask that you once again consider the issue of confidentiality and anonymity and your acquiescence of material eventually entering the public domain.

Thank you for generously offering your home for the meeting. I accept your offer and appreciate its convenience for those travelling from further north. Moreover, it has the advantage of being outside designated service and client space so is hopefully more neutral ground. The meeting is timed for 3pm on Wednesday, 13 September.

I continue to appreciate the time and effort you have put into this research and I am very grateful for your rich contribution.

Sincerely,

Marg

3 September 2000

Dear Nurse Rose, Kim,

This letter confirms discussion I have had with you regarding the setting up of a final research meeting.

A narrative integrating the client and the nursing experience that has unfolded in the research is now together in draft form. In order to obtain a coherent and reasonably sized narrative I have refined material from our earlier nursing story. My voice now becomes that of the narrator and interpreter. In short I have re-presented your contributions in the story. The draft is enclosed for your reflection, clarification and/or correction that you may care to share with me

I invite you to attend a meeting to reflect on this draft as a group. M will be invited to attend the meeting also. It is the final expression of the concept of partnership and participatory involvement that is central to my research methodology. It will be a chance to dialogue together about our partnership and anything we have learned from it. It also provides an opportunity to sum up any of your insights or concerns relating to the overall research process. The meeting will be lead by a facilitator, (name). This will enable me to be freer to enter into the dialogue.

If there is anything that arises in your reading of the narrative that you would like to clarify or discuss with me prior to the meeting please do not hesitate to contact me. I ask that you once again consider the issue of confidentiality and anonymity and your acquiescence of material eventually entering the public domain.

The meeting is to be at Mary's home. It has advantages of being outside designated service and client space so hopefully is more neutral ground. It is also reasonably accessible for those coming from a longer distance. The meeting is timed for 3pm Wednesday 13 September. The address is A map is enclosed to assist you locating the address.

I continue to appreciate the time and effort you have put into this research and I am very grateful for your rich contribution.

Sincerely,

Marg

3 September 2000

Dear Sarah

This letter confirms discussion I have had with you regarding the setting up of a final research meeting. A narrative that integrates your experience with the nursing experience that has unfolded in the research is now written in draft form. In order to obtain a coherent and reasonably sized narrative I have refined material from your earlier narrative. My voice becomes that of the narrator and interpreter. In short I have re-presented your contributions in the story. The draft is enclosed for your reflection and any clarification or corrections that you may care to share with me.

I invite you to attend a group meeting to reflect on this draft. The nurses are invited to attend the meeting also. It is the final expression of the concept of partnership and participatory involvement that is central to my research methodology. It will be a chance to dialogue together about our partnership and anything we have learned from it. It also provides an opportunity to sum up any of your insights or concerns relating to the overall research process. The meeting will be lead by a facilitator, (name). This will hopefully allow for a freer dialogue for all participants, including myself. It will not be restricted by any directing of the discussion that I might inadvertently do. Please feel free to bring a family member or a friend with you to this meeting as a support person.

I have raised my concern with you about potential for distress from reading a text that describes not only what you have revealed about your life but how we as the nurses have responded to what we interpreted as key aspects of your health circumstances. My offer of sitting with you while you read it is available to you. If you choose not to accept this offer I would appreciate hearing from you on the phone shortly after reading it so as you can off load any feelings that it may have given rise to. Furthermore it is an opportunity for you to clarify or correct anything before the meeting. I ask that you once again consider the issue of confidentiality and anonymity and your acquiescence of material eventually entering the public domain. You will notice that there is the trial of two different pseudonyms for you as talked about. There is also the issue of how we deal with the names of your children and their families and your extended family to be resolved. Any ideas you have about this will be gratefully accepted.

The meeting will to be at Mary's home. It has advantages of being outside your home and designated service space so is hopefully more neutral ground. It is also reasonably accessible for you from your home area. The meeting is timed for 3pm on Wednesday, 13 September. The address is A map is enclosed to assist your location of the address.

Your rich contribution to my research and the time and effort you have given to it is greatly appreciated.

Sincerely

Marg

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