

**ADVOCATING PRACTICE:
THE ROLE OF THE COMMUNITY ONCOLOGY NURSE**

by

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ABSTRACT

The oncology nurse, along with many other expert practitioners, has a vital role within the community, and due to the many changes within the health system, it will be an even more crucial role in the future. Little is written about the role of the community oncology nurse, which may endanger its very existence. Several nurse scholars as Benner (1984) Johnstone (1999) and Taylor (2000) support and encourage nurses to tell their stories and increase public awareness of their practice.

The primary aim of this research was to advocate for, and make known, the role of the community oncology nurse, and to bring alive the hidden but real issues of nursing people in the community who have active cancer treatment. This study is also about my journey from novice to expert in developing the role as a community oncology nurse. The research also aimed to identify and understand practice that community oncology nurses do and often take for granted.

To capture the essence of this study the method of reflective topical autobiography was utilized, which gave the opportunity to gather advanced nursing inquiry, and generate new nursing knowledge. To obtain insight into the highs and lows in everyday interaction with patients, reflective practice stories are presented.

The thesis generated by this research is that care required by cancer patients at home goes beyond the scope of traditional community health. It requires nurses to be competent in technological skills as well as bringing in-depth expertise to the practical and human needs of people experiencing cancer. The role involves holistic, family-centered care; anticipating patient and family needs; educating; managing symptoms; advocating; confronting ethical issues; coordinating complex care; and monitoring progress.

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CHAPTER ONE: INTRODUCTION

Preamble

Throughout my nursing practice, some of the most valuable lessons I have learnt have been through listening to other nurses' oral narratives or stories. However, it is important to get these oral stories written down so there is a rich source of documentation defining nursing, or the essence of nursing care. Stories have the power to inspire, inform and honor the practice of more seasoned nurses; stories nurture both the storyteller and reader. A sense of community is created, reducing invisibility and the isolation of daily nursing practice (Heinrich, 1992). Stories also highlight the complexity of nurses' professional lives.

There are still many people in the general public who do not know what a nurse's job entails, and in general have a poor understanding of what nurses do. People may still view nurses as women in white, carrying out clinical and technical tasks, such as taking patients' temperatures, giving injections and doing dressings, within the hospital setting (Haberman, Germino, Maliski, Stafford-Fox & Rice, 1994). Therefore, this project acknowledges the need for people to have an understanding of what nurses do and to provide a personal account of my perspective on being a community oncology nurse.

Contemporary undergraduate programs teach students to journal and reflect on their practice experiences, teaching them the skill or art of storytelling with the intention of forming deeper insights into themselves and their practice (Barry, 2001; Heinrich, 1992, Price, 1995). Stories have the power to be therapeutic, inform social policy, facilitate change in organizations, and allow marginalized groups to have a voice (Koch, 1998). Storytelling uncovers deep feelings and layers of meaning in the lived experience. The richness of stories that nurses tell about their practice is testimony to the reality of nursing practice, and therefore

nurses are able to better state their place in the health system (Price, 1995). Storytelling also makes known the importance of having skilled and experienced nurse practitioners. Storying is critical to nursing today, as our role will continue to change. If we do not become pro-active about what we do and believe, it may be to our detriment. Nurses must protect the standards of nursing care provision and be a voice, advocating patients' rights.

It has been through reading the words of Benner (1984), Johnstone, (1999) Richardson (1994), Taylor (2000), and many others, that I have become inspired to tell my story, about my journey in nursing practice. This journey has taken me from being a novice to becoming an expert, and highlights events that constitute my development as an advanced community oncology nurse practitioner. Haberman et al (1994) claim that a better understanding of what oncology nurses do will help the specialty align itself in a changing healthcare system. I now present and discuss the aim of the study, an overview of the method of reflective topical autobiography. Finally I provide an overview of each chapter within this thesis.

Aim of the Study

The purpose of this research was to make known the role of the community oncology nurse, and the 'behind the scenes' care, service and experiences that take place in the community.

Overview of the Approach

Several authors have discussed the nurse's role in the oncology ward (Deatrick & Fisher, 1994; Haberman, et al, 1994; Steeves, Cohen & Wise, 1994) and patients' experiences of having cancer (Davis, Cowley & Ryland, 1996; Herth, 1993; Lynam, 1995; Shepherd & Markly, 1995), but little has been written about community oncology nurses' roles and practices (Barker, 1997; Howell, Fitch & Caldwell, 2002).

To capture the essence of this study the narrative method of reflective topical autobiography, and stories of practice are used. This method will inform the reader of the lived experiences of cancer from a nursing perceptive. Reflective topical autobiography presents opportunities for advancing nursing inquiry and to generate new nursing knowledge. It also gives opportunities to explore the highs and lows in everyday interactions with patients, including lived experience and self-discovery (Moustakas, 1973). Reflective topical autobiography is a distinctive research method in its own right, and its use is commended (Johnstone, 1999) in searching for meaning and the essence of human experience, with ones self-being the principal author of the experience.

Explanation of Style

- Oncology is a specialty area that has its own language and jargon. Therefore, to convey the role and experiences of community oncology nurse practice, I have chosen to write in a personal style, using a language that can be understood by the layperson or health professionals from other disciplines. This style is appropriate within qualitative research (Roberts & Taylor, 2002).
- I use personal pronouns as the research is a reflective topical autobiography. Therefore, it is appropriate to use ‘I’, ‘my’, and ‘me.’
- The stories of practice are in italics so that they are easily identifiable to the reader and so they do not interrupt the flow of the research.
- Bold font is regularly used throughout this thesis to provide direction and flow to the research project.

The Influence of Benner's (1984) *Novice to Expert: proficiency in nursing practice*

I have been influenced by Benner's (1984) work '*From Novice to Expert*,' to gain an in-depth understanding of this theory, as it aligns with my practice. It is only now, 21 years later in practice, that I can identify with the process of developing my own expertise. I can look back over the years, and read comments in my journal writings that give support to Benner's theory. Benner's work is based on the Dreyfus and Dreyfus (1980) model of skill acquisition. They state that in learning a practice, changes in four general aspects of performance take place which are: movement from a reliance on abstract principles and rules to use of past; shift from reliance on analytic rule based thinking to intuition; change in the learner's perception of the situation to an increasingly complex whole; and lastly, a move from standing outside the situation, to a position of involvement and full engagement in the situation. Benner has extended the ideas of Dreyfus and Dreyfus and identifies five levels of clinical proficiency in nursing, novice, advanced beginner, competent, proficient, and expert. Benner also identifies that learning from experience shapes the clinical world, and that narratives of nurses who have differing levels of practice, reveal different clinical worlds (Benner, Tanner, and Chesla, 1992).

As a novice nurse I was caught up in tasks and procedures in clinical situations. The focus was on what needed to be done for the patient, not feeling full responsibility for advanced planning, or of preventing maladaptive situations from happening. Because I was a novice and coming to terms with being a nurse in a new environment, I could only cope with immediate situations and was not ready for the responsibility of such concepts as advanced planning.

As an advanced beginner I was trying to master the 'nuts and bolts' of the job, and worried about forgetting to do tasks. When I saw for the first time an emergency situation it was exciting. In a clinical situation I was more interested in what it was like for me, instead of what it was like for the patient.

Advanced beginners move to competence as part of a crisis, through which they have learnt practice insights (Benner, Tanner & Chesla, 1992).

Competent nurses question their trust in the work environment, and they question other staff members' actions. By now from experiences and watching other nurse's practice I was deciding for myself what was good competent practice. I started to feel a new level of obligation to know about, and to manage clinical problems myself. Safe practice is developed as the nurse gains more knowledge. Consistency, predictability, and time management became important. I now felt more confident to start interventions when the patient was ready. Competent nurses cope with increased responsibility by checking on the patient more often. However, they still struggle to 'read' a situation, failing to see changing relevance. At this stage I considered a good nurse as being one who accomplished their goals, and completed the tasks of the day.

Proficient practice is marked by an increased skill in seeing changing relevance. At this stage I started to develop the ability to 'read into' a situation, and noticed when the patient's condition was changing. I moved away from numbers and structured recordings to looking at the patient in a more comprehensive manner. I also went from analysis and interpretation, to a direct understanding of situations as they unfolded. Anxiety became less as I felt confident in my ability to notice and report important changes in the patient's condition (Benner, Tanner & Chesla, 1992).

Expert nurses grasp situations immediately and directly when in familiar contexts (Benner, Tanner & Chesla, 1992). They use evidence to pick up what is really important, and what can stay in the background. Their narratives show a good grasp of situations and have a wealth of knowledge and experience, and they also have insight into emotion of the clinical situation. There is the ability to recognize patterns in situations and change things as they happen for the better of the patient. Expert nurses coach others to see practice in the same way.

There is confidence that makes them proactive in patient advocacy, and forethought, as they have the 'know how' and experience to anticipate what lies ahead if action is not taken. Expert nurses' concerns differ from other nurse practitioners, and they have ease of insight and wisdom in dealing with rapidly changing, complex patient situations. They use a phenomenon of caring to invest emotional interest in patients and families, and uphold the standards of good practice (Benner, Hooper-Kyriakidis & Stannard, 1999). This I can identify with and believe it to be the way I practice today in the role of community oncology nurse.

At first I did not feel comfortable with the title of expert nurse, but have since found some definitions to ease my discomfort. Hampton (1994) explained that expertise is not something reserved for the elite few, but individuals who pursue, capture and master knowledge in a specific field or specialty can attain expert status. Expertise includes experiential and theoretical knowledge. Experts are people from whom peers seek advice. Johnson (1983) states that the expert is one, who because of education and experience, functions both proficiently and efficiently in a confident and competent way.

Two other skills that are seen as very important to have within the expert nurse role are intuition and thinking in action (Benner, Hooper-Kyriakidis & Stannard, 1999). The intuitive nurse often senses when situations look right or wrong, or they just know something should be done. This discernment is often on a subconscious level, as an automatic response. Intuition comes from seeing similarity with a previous experience, and Hampton (1994) refers to this as a sixth sense, that encompasses tacit or embedded knowing.

Thinking in action is the skill of reasoning, thinking ahead to possible benefits or consequences of treatment and care, or the lack thereof. Thinking in action refers to habits of thoughts, actions and styles of practice. Expert nurses use understanding from past narratives or past situations to help respond to a

situation and make a reasoned judgment. Expert nurses continually ask themselves questions regarding the patient's condition and care, through the process of ongoing clinical problem-solving, sorting through information, and categorizing events into categories and priorities. In addition, because of a broad knowledge base, expert nurses can single out relevant information from irrelevant, and have a vision of what is possible (Benner, Tanner, & Chesla, 1992).

The role of a community oncology nurse includes the skills and cognitive processes of expertise, intuition and thinking in action. The role includes managing risks and identifying crises in patients before significant clinical changes are evident. Literature shows that these specialty-nursing roles are cost effective (Kai Cheung Chuk, 1997). An example of cost effectiveness is decreased hospital admissions as the nurse identifies a problem early enough to implement treatment in the community, thereby avoiding hospital admission. Kai Cheung Chuk (1997) states specialization in nursing practice is for promoting productivity and quality of product, in terms of health outcomes.

Quilting My Philosophy of Nursing

Over the past four years I have been studying at a postgraduate masters level, and have found it to be a journey of self-discovery. During this time I have had the space to reflect on my practice and confirm what nursing is and what it means to me. Although I kept a journal during this time I did not necessarily reflect on it, and I took for granted what I did as a nurse. Being a more practical person I could not put into words immediately my nursing philosophy, so I turned to one of my hobbies, patchwork, and decided to start reflecting on my practice in aesthetic form. I cut out nine squares and sewed onto each one an event that symbolized my nursing journey (refer p.12). An overview of what each block symbolises is provided on p.13.

From the completed quilt I was then able to express my nursing philosophy. A photograph of this quilt is used as the opening curtain of this thesis. The colours I used to frame the quilt are those of the New Zealand Registered Nurses' medal. Red signifies giving of self. Blue represents loyalty and devotion to the sick and aged. The gold background symbolizes faith, consistency and wisdom (Hosking, 1982).

As a quilt is carefully thought out and pieced together, so is my personal philosophy of nursing. Nursing is a creative craft that we weave together based on the knowledge and skills we have. For me, nursing is about touch. The gift of the healing touch is the art within nursing care. Nursing is not just the undertaking of technical tasks, but a human interaction that occurs alongside, within, or after the moment, where no words have to be said, but are understood by touch and eye contact. An art requires organization, practical and scientific education. The act of nursing is ever changing to meet the patient's individual needs. Like the making of a quilt, nursing requires matching, balancing and a structured framework.

When I speak of touch, it is in a broader sense, not just physical touch. For example, the experiences that touch my life influence my nursing practice. These experiences are part of me as a person, and therefore will effect me as a nurse. The art is not learnt solely through nurse education, but is learnt by life experiences, events, and at an advanced nursing level, through which I will continue to learn in a lifetime of nursing. I agree with Gullo (1997), that other life events, such as birth of a child, courtships, love, and weddings are all prevalent in nursing's caring art. Sometimes nursing care requires skills not learnt in nurse education, but in the wider forum of life.

The following exemplars indicate the gift of the healing touch for a client.

As a patient lies ill on bed rest unable to shower, I fill a bowl with hot soapy water. I place the bowl on the bed and tell the patient to put both feet into it. In acknowledgment the patient says, "Nurse how did you know it would feel so good?" How did I know? Was I taught? I knew the comfort this brought, because many years ago when I was very ill in hospital, a nurse did this for me. Who would have known such a simple measure could bring such comfort and pleasure? I guess the answer is that even though you can be taught to do such a task, there is nothing like having had the experience yourself. It helps to know exactly what it is like to be in that situation, and the things that bring comfort, making a difference for you in such a situation. I remember wanting a bath or shower so badly but too weak to attempt it, and when the nurse put my feet into the bowl of water, a soothing feeling ran through every nerve in my body.

A patient with cancer lies in bed crying. Sharing feelings and fears about her diagnosis, treatment and an uncertain future, I hold her hand and reassure her and acknowledge that these fears and anxieties are normal and that she isn't going mad, as she thinks. How do I know this? How do I know it is best just to listen, as there are no magic words to say? I have read in books and articles about what cancer patients feel and experience in this life changing illness, but I also learnt this through the terminal illness and death of my sister-in-law. She touched my life more than she knew. Watching and listening to her as she shared her experience of cancer, and being family made it all very real. She showed me the feelings of being out of control, feeling anger, and of asking. "Why me? What have I ever done? Why can't it be someone else, who has nothing to offer life?"

A wife, mother, and school teacher who was not ready to die. Once starting treatment there were even more issues like losing her hair, not being able to function properly as a wife and mother, and having to give up work, of living one day at a time, and being unable to make future goals. There were issues around keeping up appearances and being bright so people would visit, even though she felt dreadful. I asked her once why she did this, and she said; “ I don’t what to frighten people away.”

There is a young woman numb in the chair. The expression on her face is as though her heart has been torn out. The baby she has inside her is very unwell and going to die, and tomorrow she is going to theatre to have a termination. This is the baby for whom she has always dreamed, it is her first baby and it has to be taken from her. I hold her tight as her tears flow and my heart starts to ache, as memories flood back of a similar situation I had. A chill goes through me as I remember too well my own experience that ended in empty arms. Numbness takes over to protect body and soul, and your heart physically hurts. For the medical profession, it may be an embryo or fetus, but from the moment a women finds out she is pregnant, she is having a baby. This is an experience that is more distressing than people realize, as other mothers have their babies when you would have been due, and as their children grow up, you wonder what your child would have been like at that age and stage.

These experiences are but a few of those that have touched my life, that are part of me, and that influence me in my everyday practice as a nurse. Through these life experiences I develop closeness with my patients and a remembrance of what it is like ‘to be in their shoes.’ I do not mean that I share my experiences necessarily with them and impose my experiences on them. Through such experiences in life I have gained an appreciation of where they ‘might be.’ I

have insight, caring for them only, as I would like to be cared for myself in that situation.

Like music, touch can have a huge influence in setting the mood. By mopping a brow, rubbing an arm, or holding a hand I am saying, “I am here for you. I support you and understand. I will be your advocate until you are well enough to care for yourself again. I am here to listen and to provide you with the knowledge you need to make informed decisions about your health and treatment.”

Like the body, a quilt is made up of many parts, the creative fabric pieces, front, back, batting, and binding, each needing the other (refer p.12). All these blocks are part of me and what has touched my life that I bring to my nursing practice. The presents on the quilt symbolise the gift of the healing touch. We care for patients and touch their lives, and in return they often share with us lessons in life, giving us the gift of insight.

Figure One: My Nursing Philosophy

The following are the definitions for what each block in the quilt symbolises.

1. New Zealand Enrolled Nurse medal, 1985-1996.
2. The cross symbolises my spirituality, a belief that comes with me, and is part of me. These underlying values influence my nursing practice.
3. The butterfly symbolises my-sister-law who died of breast cancer three years ago. The butterfly is from Kubler-Ross's (1997) theory that when we die we shed our cocoon and turn into a beautiful butterfly and return home to God.
4. The rose, Loving Memory symbolises the loss of our baby.
5. The print in the middle of the quilt is that of John Morton's, The Red Cross. The nurse is mopping a soldier's brow, which to me symbolises the healing touch.
6. The little girl in the nurse's uniform symbolises how I spent a lot of my childhood, playing nurses.
7. The block of blue fabric was given to me by my quilting group in remembrance of winning the Cancer Society Nursing Scholarship to start my Master's studies, which is what the Mortar Board symbolises.
8. The wedding bands symbolise my marriage relationship, as this is also fundamental to who I am.
9. My mother's handprint symbolises her major influence, support and comfort in my life. She taught me that we are not on earth for ourselves, and what we will get the most pleasure out of in life is giving to others.
10. Musical scores, symbolise my love for music and the importance it has in my life. I use music to switch off work at the end of the day, and I also find solace in music, and use it to help refocus.
11. The patient in the bed symbolises my experiences of illness over the years, and that I bring to nursing understanding of what it is like to be a patient.
12. The New Zealand Registered Nurses medal 1996 was awarded when I did the bridging program to Bachelor of Nursing.

Physical, social, psychological, spiritual, and sexual are all dimensions of the person, each intertwining and affecting the other. Nursing is about holistic care. A patient's recovery may depend on it. How can they get better if they are worried or concerned about issues happening in their life?

To be effective in providing holistic care nurses must care for themselves, physically, psychologically, socially, and spiritually. By looking after themselves they can do their duty to society. To be comfortable in assisting others in these areas they need to be comfortable in where they stand. Nurses own underlying values will govern the moral basis of their care (Bradshaw, 1996).

As nurses touch the patient's life, so patients touch nurses. It is like a continuum. I make a patient feel better, and in return I feel good and rewarded. At times in my nursing career I have received more from the patient than I have been able to give. These people have taught me lessons relevant to my life. Often when nurses listen to other people it is as though we are hearing about ourselves. When patients touch my life it gives me fulfillment in life. We all desire the feeling of needing to be wanted, and seek for purpose in life. Fulfillment in life is to experience love, faith, hope, peace, joy, and to leave a legacy (Covey, Merrill & Merrill, 1994).

This project represents the work of the community oncology nurse as more than just a job. There are multiple ways of knowing, in order to understand the complexity of nursing situations. This project fostered for me reflection and a deepened understanding of what nursing is, and will communicate what I value about nursing to others. "Humanizing health care must begin with teaching nursing through the lens of caring" (Barry, 2001, p.28).

Definition of Key Terms

The reason for providing definitions of key terms is to make it easier for the reader to engage with the stories in this thesis, so they can understand the textual language used. It is important so the reader is not made distant from the text.

Oncology	The study, care and treatment of cancer.
Palliative	The care of patients with progressive cancer, not receiving active or curative treatment.
Chemotherapy	Cytotoxic drugs mostly used in the treatment of cancer.
Radiotherapy	Radiation treatment mostly given in the treatment of cancer.
Neutropenic	When the white blood cells known as neutrophils are low or depleted, making the patient very prone to infection.
Terminal Care	Nursing care of a dying patient.

Overview of the Thesis Chapters

Chapter One provided an introduction to the project's aim, approach and background interests. It also explained styles, defined key terms and overviewed the thesis chapters.

Chapter Two is a literature review, focusing mainly on the work of Barker (1997), Howell, Fitch and Caldwell (2002), and McEnroe (1996). All three articles have similar findings and support the need for the community oncology nurse, although their research is looking at the patient's perspective, rather than a nursing perspective of the necessity of the role.

Chapter Three outlines the method used in this research. For the purpose of this project reflective topical autobiography has been chosen, due to its ability to reveal the real day-to-day nursing practice and its complexities. As reflection is a key part to reflective topical autobiography, I discuss the appropriateness of using three stories of practice in order to give voice and meaning to my

experiences as a community oncology nurse. I also want to bring my practice alive for the reader. Issues of trustworthiness are explored, and ethical issues are considered.

Chapter Four discusses the role and practice of the community oncology nurse, in relation to carrying out clinical tasks, and in the role as educator, liaison, co-coordinator, advocate and support, including the nursing competencies required within this role, and issues around truthtelling and 'being there.' I have chosen to discuss advocacy, truthtelling and being there, as I am confronted with these issues most days in practice.

Chapters Five, Six, and Seven are practice stories, telling the stories of my practice, using a reflective topical autobiographical approach. The practice stories are oriented to three topical key issues that community oncology nurses often face in their day-to-day work, including truthtelling, which is considered essential for the development of an effective nurse/patient relationship; patient advocacy, and being there for patients. To protect the identity of the patients within the practice stories pseudonyms are used.

Chapter Eight concludes the study, highlighting key points and insights made throughout the study, and implications for nursing practice and education.

CHAPTER TWO: LITERATURE REVIEW

Introduction

Using CINAHL, PUBMED, and several other cancer information websites CancerNET, and CancerWEB, I searched for existing literature on the role and practice of the community oncology nurse. What kept coming up in abundance was literature on the role of the palliative care nurse in the community. This role is what is known as the McMullin Nursing Service in England, which is different from that of the community oncology nurse (Jones, 1998; Jones, 2001). All databases used, identified community cancer care as palliative care, with no recognition of patients in active cancer care or treatment. There was also an abundant amount of literature on the patient's experience of cancer, and the nursing perspective of working in an oncology ward setting (Deatrick & Fischer, 1994; Haberman, et al., 1994; Krebs, Myers, Decker, Kinzler, Asfahani & Jackson, 1996; Steeves, Cohen & Wise, 1994).

When I started to type in cancer treatment in the community and chemotherapy in the home, many articles appeared that were inappropriate, but in doing this I found three articles from the United Kingdom and Canada by (Barker, 1997; Howell, Fitch & Caldwell, (2002) and McEnroe, (1996). These articles describe the importance and relevance of the role of community oncology nurses through research and literature review, and even though this was helpful, they are not from a nursing perspective. On the whole my research looks at what it means to the patient to have the care and support of the community oncology nurse. What the literature has done is confirm the lack of literature and research on the role of the community oncology nurse, particularly from a nursing perspective, and so supports the aim of this project. This chapter looks at the types of literature written on the cancer experiences. Then it looks particularly at the research findings of Barker (1997) Howell, Fitch and Caldwell (2002) and McEnroe (1996) relating to the role of the community oncology nurse.

The Cancer Experience

The cancer experience creates a sense of uncertainty, apprehension, fear and anxiety, and often disrupts every aspect of the patient's and family's life. It also challenges their psychological, social, spiritual and financial resources (Fitch, 1996). Newly diagnosed cancer patients try to make sense of what is happening to them. They struggle to integrate the demands of cancer treatment, and to make small to large adjustments to their everyday lives in the face of disruption that the disease brings (Corner, 1997). These adjustments may include changing the way they view themselves, their lives and their relationships, and re-examining values. Barnard, Towers, Boston and Lambrinidou (2002) weave together many narratives of the patient experiences of cancer, bringing alive the day-to-day challenges with which they are faced. The personal cancer experience is also depicted well by Armstrong (2000), Clark (2000), Nathan (1998) and Wilber, (1991) who acknowledge what a cancer diagnosis does to a person, and how it changes their life. With all these changes and challenges, one must then look at the role of the community oncology nurse and how their expertise and support can help, and be crucial at this time.

The Need for the Community Oncology Nurse

Care required by cancer patients at home goes beyond the scope of traditional community health nurses. The acuity level and complex care needs of cancer patients at home requires home care nurses to be efficient in high-technology skills such as nursing assessment, identifying potential problems and initiate appropriate action, and giving chemotherapy. In an effort to optimize continuity of care and influence positive patient outcomes, oncology nurses are needed to implement community health strategies directed towards promoting health and managing chronic illness (McEnroe, 1996).

Barker (1997) undertook a qualitative study to investigate the research question: Does home support by community oncology nurses improve psychological

morbidity during and after treatment? Barker (1997) acknowledged that the role of the community oncology nurse is fairly new and not well researched. The study involved two groups of participants. Group A started with traditional support and then after four months they were changed to having community oncology nurse support. Group B started with community oncology nursing support and then at four months changed to having traditional support. The Rotterdam symptom checklist was used as the measurement tool for the study. This measurement tool has eight psychological subscales, which the patient is scored from 0 (not at all) to 3 (very much). The maximum score a patient could receive was 24 and patients were seen 'at risk' if they had a score of 11 or more. The questions the patients were asked are not stated in the report, but they focused on aspects of the patient's quality of life.

The research findings were that Group A participants' anxiety decreased once they had the support of a community oncology nurse, and Group B participants' anxiety increased as they lost the support of the community oncology nurse. The research rigour was consistent with similar research done by Greer, Moorey & Baruch (1992), who found that visits from the community oncology nurse created a degree of safety for the patient. The results of Barker's study justified the benefits of the role of the community oncology nurse, from the patient's first clinic appointment until completion of treatment.

A criticism I have about Barker's (1997) research is that the recommendations were very generalised and not personalized to individual patient needs. For example, patients were told at the beginning of treatment the duration of care. Radiotherapy patients were to have one visit half way through their treatment and then again at the end of treatment. Therefore, a problem with the research design was that visits and length of support depends on individual needs, and that not everyone is the same, nor do they fit in the same box, even for research purposes.

McEnroe (1996) undertook a literature review and a case study to bring alive the real life issues of caring for a cancer patient at home, and what it means for the patient and their family. The case study also represents the complexity of care needs within the home setting, and identifies the role of the family and issues that are potentially stressful and fearful for them. McEnroe states the family is vulnerable to physical, personal and social disruptions due to demands and role changes. Therefore, the family, community support and resources are essential for positive patient outcomes in caring for them at home. Continuity of care is maintained when patients are nursed at home and community nurse service provides a pivotal communication link between patients, doctors, pharmacy, and laboratory. The research identified advantages and disadvantages of caring for patients in their home, and nurses' expanded roles in patient advocacy.

Howell, Fitch, and Caldwell (2002) carried out a qualitative research project that explored the impact of expert oncology nursing support in the community. The care was provided by an independent nursing service called Interlink. The study was guided by hermeneutic phenomenology to gain understanding and insight into the experiences of the participants receiving care and support from community oncology nurses. The sample involved 18 women and two men aged between 28-78 years with a variety of cancer diagnoses and living circumstances. The aim of the research was to capture the richness of the participants' stories through audiotaped interviews. Howell, Fitch, and Caldwell were the only ones to emphasize the ethical considerations of their research, for example, how they sought ethical approval, obtained consent and how participants confidentiality was ensured. Seven core themes were revealed through the research. Patients felt supported by the oncology nurses, in that the nurse was there for them (being there), throughout the cancer experience. The nurses took time to address all their needs, and the patients had opportunities to unburden themselves of their thoughts because the nurses showed understanding. The Interlink nurses made the patients feel safe and secure even

in the face of death. The nurses also provided essential information and resources. Patients felt that their ability to get through the treatment, adjust to living with cancer, and their well-being was due to the support received by the community oncology nurses. In summary, the research showed that the role of community oncology nurse had a significant impact on the patients' experiences; well being and survival, and the skills and knowledge of these nurses were critical to positive patient outcomes.

Main Points about the Role of Community Oncology Nurse from Articles

Barker (1997), Howell, Fitch and Caldwell (2002) and McEnroe (1996) showed similar findings in relation to the role of the community oncology nurse, who not only provided traditional 'hands on' care, but brought in-depth expertise in oncology nursing to bear on the practical and human needs of people experiencing cancer. They provided patients and families with information, education, psychosocial, and psychological/emotional support, thus meeting the challenges of cancer and its treatment as early as possible in the cancer continuum. These nurses paid particular attention to assisting patients and families in dealing with the physical effects of the disease and its treatment, dealing with actual symptoms of the disease or treatment, as well as potential health problems (Howell, Fitch & Caldwell, 2002).

Pain and symptom regulation were also a significant part of the overall nursing role of community oncology nurses, who also led patients to cancer resources, organized transport to clinics and treatment, and accessed counselling for patients and families as needed, to promote the patients' optimal level of wellness. Nursing activities to achieve best outcomes are centered on secondary prevention strategies, facilitating early diagnosis of health problems and prompt intervention to limit disabilities, providing assistance to families and overseeing coordination of community resources (McEnroe, 1996).

Barker's (1997) study also found that followup after appointments or treatment, and emotional support, were imperative to the patients. Community oncology nurses were often relied on by the patient to translate, or confirm information given by the doctor at the appointment. They also had a key role in advocacy and acted as a link between services and other health care providers involved in patient care. Ley and Spelman (1965) showed that shortly after visiting their doctor or clinic, outpatients forgot approximately one third of what they were told during consultation, 20% of patients forgot prognosis, 48% forgot the statements about treatment, and 56% could not recall the instructions. Therefore, the role of community oncology nurse in advocacy and confirmation of information is crucial.

Community oncology nursing is about autonomous independent practice, comprehensive decision-making, multidisciplinary coordination, and collaboration. Such roles strengthen the nurse's ability to meet the care needs of the patient in the community. Nursing care is to promote self-care competence, nutritional adequacy, and effective symptom management by teaching, encouraging and supporting the patient and their family (McEnroe, 1996). Dawson (1999) found that home is nearly always the most appropriate and preferred setting for individuals with cancer and most people would rather be cared for at home, than in hospital.

Patients found it beneficial to talk in the relaxed environment of their home rather than in hospital. They said: "It was more personal" (Barker, 1997, p.37). The patients and family found it helpful to have an oncology expert nurse visiting them at home to explain in layperson's terms the journey they were about to undergo, because this helped them to understand the disease and face treatment. The patients stated that the knowledge and experience of community oncology nurses differentiated them from the general community nurses. Trust was quickly instilled when they had a weekly visit; they remained less anxious

and were confident knowing that contact was easily assessable either by phone or another home visit.

The psychological support of having support at home alleviated depression and loneliness and patients felt secure (Barker, 1997). The nurse was guaranteed to be there through it all, when other people were not. In some situations the community oncology nurse was the only support a patient had in dealing with the realities of living with cancer. The nurse shared the journey giving the patient a feeling of being 'held up,' in the sense of being supported. Even if nurses did not have the answer, they still could be counted on to get one quickly. The nurses had the ability to provide practical information in managing complex situations, with handy hints and suggestions. Howell, Fitch, and Caldwell (2002) state that nurses play a significant role in facilitating the patients' ability to make the adjustments to meet the challenges of cancer and treatment. The nature of the interaction between the nurse and their patients has a profound influence on shaping the cancer experience.

Expert oncology nurses' support may be an important factor in patients' adjustments to cancer and may have the potential to significantly affect their experience of living with cancer. Patients were able to meet challenges of living with cancer and find the hope, courage and strength to survive. Healthcare systems that provide access to expert oncology nurses support for patients in the community are essential. They must be recognized as part of the fabric of supportive care (Howell, Fitch, & Caldwell, 2002).

Conclusion

Review of the literature indicates that there is a need for the community oncology nurse, as patients face a cancer diagnosis and a journey into the unknown. The three key articles reviewed contained similar findings, acknowledging the expertise required by the community oncology nurse to support patients and to provide them with complex care as they undergo

treatment. Barker (1997), and Howell, Fitch and Caldwell (2002) also identified that the role of community oncology nurses is under-researched and encouraged the reader to explore similar research in the relationship between the community oncology nurse and their patients. Therefore I felt challenged to embark on research in this field as a community oncology nurse. I want to share my experiences, and tell my stories to inform, and build on nursing knowledge.

CHAPTER THREE: RESEARCH INQUIRY

Introduction

This chapter describes the method used in the research including ‘narrative,’ ‘storytelling’ and in particular Johnstone’s (1999) method of reflective topical autobiography. Researchers have tended to use the words ‘story,’ and ‘narrative’ interchangeably (Roberts & Taylor, 2002). Polkinghorne (1988) differentiates story and narrative. A story is a single account reviewing life events in time or imagined form, and a narrative is a scheme of multiple stories, which organises events and human actions into a whole (p.18). Rice and Ezzy (2000) refer to narrative being either the process of making a story, to the cognitive scheme of the story, or to the result of the process, the written stories (p.123). Because of the different view points and definitions with regard to ‘narrative’ and ‘stories,’ I need to make clear at this point that these terms will be used in this research synonymously and interchangeably as have Toombs (1992) and Hunter (1991). They used narrative / story telling to convey clinical and medical practice, and felt that in this form it provided therapeutic dimensions. I see reflective topical autobiography as a reflective narrative of self-life-story.

What is Narrative ?

Narratives are views or stories that capture and make sense of peoples’ real experiences, and gives them meaning (Sandelowski, 1991). This methodology is considered as one way of providing meaning or making sense of a disruption or deviation in life, and makes the reader mindful (Diekelmann, 2001; Polkinghorne, 1988). Narrative inquiry is a powerful vehicle for communication, making visible activities within nursing practice that are usually taken for granted. Under the umbrella of this qualitative methodology come methods such as, life histories, oral history, biography, autobiography,

ethnography, phenomenology, grounded theory and research interviews, or in any approach requiring sets of accounts that describe life experiences (Roberts and Taylor, 2002). There is no rigid recipe of what counts as a story (Robinson & Hawpe, 1986). Even so, Bruner (1990) suggests stories have two main components that must be grasped in order for the meaning of a narrative to be understood. Firstly, a narrative should have a configuring plot, and an overall structure, which makes sense. Secondly, the plot is constructed out of these parts, out of a succession of events, and the power of the story derives from understanding this sequence of events.

Narrative research has become a much more popular and respected method in recent years, particularly within nursing, giving nurse researchers an opportunity to reflect on an event or practice (Benner & Wrubel, 1989; Harker, 2000; Taylor, 2000). Vezeau (1995, p. 169) claims that, “the power of narrative is that it moves us not only to think and evaluate, but to live in a place, smell the smells, and feeling the full impact of human experience.” Narratives change depending on who tells them and they can convince the audience through gripping drama. Story telling is not new to nursing as everyday in practice we are telling real stories as we hand over the care of a patient to oncoming staff. When nurses tell their clinical stories they invite others into their practice world (Lumby, 1993).

Research is a careful search or inquiry (Sykes, 1976). Nursing research is a systematic process of investigating phenomena of interest, with the purpose being to add to the body of knowledge about nursing practice. Carper (1992) acknowledges aesthetics, the art of nursing and a component of personal knowledge as one of the four fundamental patterns of knowing in nursing. She acknowledges the contribution of such patterns of knowing in increasing nurses' awareness of the diversity and complexity of nursing knowledge. All forms of knowing have their place, and none of them are mutually exclusive (Carper, 1992). Like many other research methodologies narrative inquiry has an

important and valuable role to play in adding to the body of knowledge, through nurses sharing their knowledge and experiences with other nurses. Narrative gives the opportunity for nurses to share what they know in a variety of ways and forms, for example poetry, painting and quilting. These methods are all ways of knowing about the complexity of nursing practice.

Why Use Narrative Inquiry?

Narrative inquiry is a useful methodology to teach others what it means to be a nurse, about death and dying, and about empowering the patient. Personal narrative is particularly focused on everyday life and moments that have special meaning (Richardson, 1994). "Narrative inquiry is useful as it provides a way of understanding human experience that is consistent with the way that people make sense of their own lives" (Rice & Ezzy, 2000, p.122). Self - narrative recreates the lived experience and evokes emotional responses (Richardson, 1994). Through narratives, nurses can tap into a rich supply of nursing practice, which has remained unspoken and invisible, like the role of the community oncology nurse. Darbyshire (1994, p.33) says that "through contributing to nursing narratives, nurses can demonstrate that there is infinitely more in nursing that unites us, than divides us." I believe other nurses will be able to read this thesis and relate a lot of the findings to their own practice in other health settings and specialties.

While causal methodologies and mechanistic metaphors of physics and economics can offer a great deal, they cannot capture the richness and complexity of human lives. This can only be sought through narrative inquiry (Polkinghorne, 1988). By using personal narrative I believe I can provide a true account of what it means, and what is involved in being a community oncology nurse. This method allows the freedom to write on everyday life within practice in a language that is familiar to the reader.

Limitations of Using Narrative Inquiry

As with all other methodologies, narrative inquiry has both advantages and disadvantages. As I have already pointed out many advantages for using narrative inquiry, it is only reasonable to also discuss the limitations of this approach. First, some forms of narrative inquiry cannot be easily codified and systematised, because they focus on the ambiguity of meaning and interpretation. Second, narrative inquiry requires high investments of time and energy, because of the focus on careful analysis of meanings and interpretations. This attention to detail may frustrate researchers with tight time lines or intolerance of complexity. Third, as a consequence, narrative inquiry is not useful for studies of large numbers of nameless, faceless subjects (Riessman, 1993, p.69). Narrative inquiry looks into the meaning and feelings of people's experiences. In this research I look into the meaning of my nursing practice and discuss my feelings and experiences. This is why I have chosen reflective topical autobiography as the research method for this project.

Reflective Topical Autobiography

A particular method of autobiographical inquiry described by Johnstone (1999) is reflective topical autobiography, which she defines as a 'snap shot' or 'fragment' of a person's life story, which is of some topical interest. The story is told by that person, as a self-life-story. Johnstone (1999) states that Moustakas's (1961) classic work, 'Loneliness' is an example of reflective topical autobiography, although it is not recognised as such.

Why use Reflective Topical Autobiography?

Rice and Ezzy (2000) suggest there are three main paradigms that have been predominantly used in nursing research and they are empirical-analytic paradigm, Heideggerian phenomenology, and critical social theory. When studying and researching the experiences of nurses' and patients' perspectives of care, nurse researchers have used methods from the positivist and post-positivist paradigms. An assumption inherent in the positivist paradigm is that

there is only one truth and one reality. Within the post-positivist approach reality is seen as complex and holistic. The emphasis and focus of this inquiry is subjective human experience and therefore sits within a post-positivist approach. This means that rather than making overall specific statements and universal claims of truth for everyone as in positivist inquiry, subjectivity refers to personal experiences and personal truth that may or may not be so for everyone (Roberts and Taylor, 2002).

Reflective topical autobiography allows nurses to reflect and write about our practice and experiences, which is not otherwise amenable to investigation by other research methods. Johnstone (1999, p.134) suggests “it adapts a heuristic and phenomenological research approach as it searches for meaning and essence of the human experience, and rejects theoretical imposition such as Marxism, Feminism and Post structuralism.” In this thesis I am not retelling the story of another, or translating someone else’s experience, I am telling my story of what it is to be a community oncology nurse. To use other research methodologies such as critical social theory and phenomenology would be less appropriate, as I believe the story would lack flow and become disjointed, rather than having a seamless appearance (Speace, 1982). I have also not chosen to inform my work from a critical or phenomenological perspective as it would become too big and out of the scope of a two paper thesis.

In this research the stories of my practice experiences as a community oncology nurse, (from novice to expert) are shared to illustrate levels of practice. Also shared are my life experiences that have influenced practice. Nurses are ‘who’ we are, not ‘what’ we are, therefore, whatever happens in our personal life affects our professional world. This is why reflective topical autobiography is the appropriate method to use in this research (Johnstone, 1999).

Self-narrative can bring alive the nurse’s role, and the lived experiences of practice and relationships with patients during a cancer diagnosis and treatment.

It provides opportunities to explore the highs and lows in everyday interaction with patients, and lived experience and self-discovery. In searching for meaning, and the essence of human experience, the people who live the experience are in the best position to talk about it, therefore, the self – narrative of a reflective topical autobiography is written from deep involvement of self and life discovery (Moustakas, 1973). Reflective topical autobiography makes the person whose life story is being narrated the subject, instead of the object of inquiry.

Reflective topical autobiography is a rich and valuable research approach for the nursing profession today, as it has the ability to advance nursing inquiry, and provide new nursing knowledge. The use of reflective topical autobiography is not an easy option, and nurses have been warned that this method is just as demanding as any other interpretive research (Johnstone, 1999). This method does not claim to give an absolutely true account of the experience; rather it presents an account or reconstruction of the subjective human experience, for as Johnstone (1999, p.132) says, “it tells a story but never claims to have told the whole story.” Certain characteristics that are important, are that carrying out a reflective topical autobiography is a creative and informative piece of work, and that it is written in simple human language with no specialized jargon.

Reflective topical autobiography is a favourable method to use in nursing research, for the rich source of information it has to offer. This method works towards providing a realistic account of patient and nurse experiences in care, practice and life, through capturing ‘turning point experiences,’ and existential moments. As a research method reflective topical autobiography provides opportunities for nurses to write expressively and creatively, and it is also user friendly for the novice researcher (Johnstone, 1999). It is up to nurses to shape the future they want, preserving and influencing nursing practice, upholding the vital principles underpinning the moral of quality care. Reflective topical

autobiography reflects what nursing is all about, through direct accounts of the nurse as storyteller reflecting on practice.

Disadvantages of Using Reflective Topical Autobiography

While there are many advantages to using reflective topical autobiography there are also some disadvantages. Like most qualitative research, its main disadvantage is being accepted as credible 'research'. The second disadvantage is that the researcher opens their personal lives into the public arena, which makes them vulnerable and that is a threatening experience.

Rigour and Reflective Topical Autobiography

The criteria for rigour in research is related directly to the underlying assumptions of what constitutes knowledge and truth, and how these are best generated and proven (Roberts & Taylor, 2002). Quantitative and qualitative research are different, and so too are their assumptions, methods and processes. It is unreasonable to judge a qualitative research project against the criteria designed for quantitative investigations. This is why rigour in quantitative research is judged by validity and reliability, and qualitative research is best judged by trustworthiness to reflect the people-oriented nature. In other words, the research findings must reflect 'the truth' of the matter (Roberts and Taylor, 2002, p. 378).

Trustworthiness is a process used to determine the usefulness of qualitative research including the criteria of credibility, fittingness, auditability and confirmability (Roberts & Taylor, 2002). These criteria originated from Guba and Lincoln (1981) who used this process of rigour in qualitative research in general, and in particular nursing research.

"Credibility means the extent to which the readers of the research recognise the lived experiences described in the research as similar to their own."

"Fittingness refers to the extent in which the readers of the research find it has

meaning and relevance for their own experiences” (Roberts & Taylor, 2002, p.380). Credibility and fittingness are assured in reflective topical autobiography, which is in line with concerns about other qualitative research approaches (Johnstone, 1999). Storytelling is unscientific to some and the researcher can be accused of fabrication. There is no agreed upon method for ensuring rigour (Johnstone, 1999). For reflective topical autobiography the main evidence of credibility and fittingness is when readers feel as though they are reading about themselves, and find something in common, giving them a depth of understanding about their own lives. In other words, it resonates with them, finding something in common with the story told, helping to broaden their own horizons of insight, providing them with a deep understanding and meaning of their own lived experience (Johnstone, 1999).

Koch (1998) claims that careful reflective, systemic study of phenomena or experience to advance human understanding can count as research. As part of the appendix transcripts, portions from a diary or journal, or photographs, provide credibility and ‘evidence,’ by showing the process of reflection.

“Auditability is the production of a decision trail which can be scrutinized by other researchers to determine the extent to which the project has achieved consistency in its methods and processes” (Roberts & Taylor, 2002, p.380). Within this project to try and ensure auditability I used clear simple language so the reader does not have to make assumptions or pause to interpret what I have written. I have endeavored to write in a way that makes the project straightforward and understandable so the reader immediately understands what is being said. Where possible I have used other literature and theoretical assumptions written on the matter or point being made, to support my experiences and findings. In doing so the story should ‘ring true’ and be believable, and if another researcher decided to do a similar research, they may possibly arrive at a similar conclusion.

Confirmability is when the project achieves credibility and fittingness, and auditability can be demonstrated (Roberts & Taylor, 2002). The use of reflective topical autobiographical approach allows for personal and transparent processes, which readers can examine for proof of confirmability. Stories are also left open to interpretation.

Reflection and the use of stories of practice

As reflection is the key part to reflective topical autobiography I consider it appropriate to include three stories of practice (Chapter Five, Six & Seven) to give meaning and voice to my experiences as a community oncology nurse.

Humans as living beings have the privilege to be able to reflect. Knowing how to reflect is a process of making sense out of all life experiences, which is of great value (Taylor, 2000a). As the word reflection has other meanings it is important to state the definition for reflection within this research. Taylor (2000a, p.3) states “Reflection means the throwing back of thoughts and memories, in cognitive acts such as thinking, contemplation, meditation and any other form of attentive consideration, in order to make sense of them, and to make contextually appropriate changes if they are required.” Boyd and Fales (1983) define this type of reflection as the process of creating and clarifying the meaning of experience in the present or past, and in terms of self in relation to self, and self in relation to the world.

Schon (1987) talks about two different types of reflection, reflection in action and reflection on action. Reflection in action refers to professionals in their daily practice, as they encounter a situation, which is out of the ordinary in some way, and deal with it by ‘thinking on their feet’ in order to find a solution to the situation. This is thought to be an almost subconscious process and closely allied to intuition, where the answer to the problem ‘just presents itself’ (Conway, 1994). Schon (1987) suggests that the answer to the problem is not merely a process of trial and error, but drawing on our experiences of similar

but different situations. An example of this is in Chapter One; within my nursing philosophy I discuss drawing on experiences within my personal life to assist me in understanding and communicating with patients in my care.

Reflection on action is a process of looking back on events and what was done. One ponders on the event or experience, making sense of it, and learning lessons from what did or did not work. Reflection on action can also occur during an event, when the practitioner stops and thinks What shall I do? (Arendt, 1971). Reflection links the art and science of nursing (Benner, 1984). Reflection on action is used within this research project in Chapters Five, Six and Seven.

Nurses in their day-to-day practice are constantly ‘thinking on their feet’ while delivering patient care. However, Conway (1994, p.116) contends that “what nurses have not traditionally been good at doing is recording these reflections and using them as a basis of theory building and education.”

Taylor (2000a) identifies three kinds of reflection, technical, practical and emancipatory, which are categorised according to the kind of knowledge they involve and the work interests they represent. She says that:

Technical reflection is based on the scientific method and rational, deductive thinking, will allow you to generate and validate empirical knowledge through rigorous means, so that you can be assured that work procedures are based on scientific reasoning. Practical reflection leads to interpretation for description and explanation of human interaction in social existence. Emancipatory reflection leads to ‘transformative action’ which seeks to free nurses and midwives from taken-for-granted assumptions and oppressive forces which limit them and their practice (p.4).

For this research only practical reflection will be utilised. The questions practitioners ask in practical reflection are about creating a better understanding of what it is like to experience, and to make sense out of living a life in relation to other people and events (Taylor, 2000a). The quilt in Chapter One is an example of practical reflection (refer p.12). I used this process to gain growth and interpersonal understanding by piecing together things that are important to me in my personal and professional life. Once it was pieced together I stood back and was able to make sense of what nursing is, and what it means to me, and to create my own philosophy of practice. A whole story was depicted in the quilt, meaning more came out of the project than I expected, as it raised my awareness about my values and action, and how they related to other people.

Taylor (2000a) suggests that there are many strategies for reflecting, which can be used alone or in combination. These might include writing, audiotaping, creative music, dancing, drawing, montage, painting, poetry, pottery, singing, videotaping, and quilting. Mazloomi (1998) provides an amazing example of the creative use of narrative and reflection with 'The Spirit of the Cloth' is a collection of 150 contemporary African American quilts, each telling pictorials, 'slice of life' compositions of African heritage. The quilts are personal aesthetics that have been inspired by personal experiences, childhood memories and daily observations. Mazloomi's role in inspiring this freedom of expression cannot be overstated and can be classified as research.

Reflective Process of the Practice Stories

The idea of practice stories was to make my nursing practice visible and to give voice to the caring moments that make a difference, but are often taken for granted. I chose these three stories because 'advocacy,' 'truthtelling' and 'being there' are very topical in my daily practice as a community oncology nurse.

My thought processes, and the way I decided what stories of practice I would tell, were influenced by Moustakas (1990) six phases as a basic guide to heuristic research design. These include: initial engagement, immersion, incubation, illumination, explication and creative synthesis. For the purpose of this research I used four phases immersion, incubation, illumination and creative synthesis. Moustakas (1990, p.43) states that heuristic research methods are “open-ended,” that there is “no exclusive list” for all heuristic investigation and “each research process unfolds in its own way.” The heuristic process is the way in which the investigator comes to know, is informed, or a way of knowing fully what something is and means (Moustakas, 1990).

During the immersion phase I could not stop thinking about what practice stories to use, as there were so many. I kept a pen and paper by the bed so if it came to me in the night I could quickly write it down. But it was in the shower that it all started to take shape; I knew the stories I had to tell, but why? What was their significance? In the incubation phase I decided what stories I would tell, I then relaxed and put them aside for the time being, and continued to write the beginning chapters of the thesis. Illumination occurred while writing the chapter on the role of the community oncology nurse. Then it came to me: advocacy, truthtelling and being there, are all very topical issues within the oncology setting, and I am continually confronted with these issues in everyday practice. Then thinking back over the practice stories I realised they were about these very issues. John’s story is about ‘truthtelling,’ Molly’s story is about ‘advocacy,’ and Chloe’s story is about ‘being there.’ Moustakas (1990) states that getting to this point is a breakthrough into conscious awareness.

Lastly I engaged in creative synthesis, this involved writing and re-writing as I reflected time and time again on the practice stories, and what they meant to me, and for my patients. I kept writing until I knew the stories would ‘ring true’ with the reader, in other words, nurses reading the stories would recognise similar practices and experiences. This in turn gives the reader a depth of

understanding about their own lives and helps to broaden their own horizons through insight.

Conclusion

Reflective topical autobiography enabled me to reflect and tell my stories of practice, as a personal narrative of community oncology nursing. This chapter described the method of personal narrative in the form of a reflective topical autobiography. Reflection is a key part to reflective topical autobiography and to nursing practice. Therefore, reflection on practice is used within this project in the form of stories of practice (Chapter Five, Six & Seven) to increase the visibility and meaning of events and experiences in my role as community oncology nurse.

CHAPTER FOUR: THE ROLE OF THE COMMUNITY ONCOLOGY NURSE

Introduction

This chapter explores the role and practice of the community oncology nurse, and it also advocates and justifies the importance of such a role from my perspective as a community oncology nurse. Nursing competencies are discussed displaying the level of knowledge and skills required by a nurse within this role, and to also identify what makes the role of community oncology nurse a specialist role. This chapter also identifies the many ‘hats’ the community oncology nurse wears. Not only do they monitor and assess patient’s physical needs, but they also provide education, support, and coordination of care, and act as liaison and advocate.

Preamble

When people ask me what I do for a job they usually follow with: “What does oncology mean?” Once I explain that it means I care for people with cancer, the next statement made is, “Gosh, that must be depressing and sad.” To their surprise I reply, “ Yes it can be, but I mostly enjoy my work, as there is high satisfaction, and it is very rewarding.” To paraphrase the words of Charles Dickens (1960) ‘ it is the best of jobs, it is the worst of jobs.’ Although many people view oncology nursing as being depressing, caring for people with cancer has been described as both stressful and satisfying work (Cohen, Haberman, Steeves & Deatrck, 1994). There are inherent rewards in this work and the ability to have close relationships with patients and their families (Cohen, et al, 1994).

The role of community oncology nurse was set up during the late 1970s at the hospital in which I work, after two oncology nurses went to a conference, and were inspired by other community oncology nurses and the role they played.

Through very hard work they managed to convince their employers of the need to set up and have as part of the cancer service, the role of community oncology nurses. The role started quite differently to what it is today, because the newly created position involved mainly caring for palliative and terminal care patients in their homes. Over time the service changed from patients staying in hospital for days and even months, while they received their chemotherapy and or radiotherapy. For some people it meant staying in hospital from diagnosis to remission. Chemotherapy treatment was becoming more refined. Large volumes of fluid were no longer needed, patients were starting to have their treatment in a day ward setting, and then going home the same day. New antiemetic medication for nausea improved recovery from treatment.

Other factors that now have to be taken into consideration is that cancer is on the increase; the age limit for treatment is no longer relevant, in that if a patient is 75 years old, but in otherwise good health, they too are offered treatment, and more treatment advancements are being made with decreased side effects. Most radiotherapy patients are receiving their treatment as outpatients, and they only go into hospital if there are complications. Patients are now also offered palliative chemotherapy and radiotherapy for disease control to give longer and better quality of life.

Today the focus is to keep patients in the community, maintaining as near as possible a normal life. Neutropenic patients who were once kept in hospital and in protective isolation are staying at home provided they do not have an infection. At home they are more likely to get common, easy to treat infections, rather than harder to treat hospital infections.

Cancer is becoming a chronic illness with which people can live for some time, before it becomes life threatening. There are now many drug trials in progress, some being oral tablets taken by the patient at home. Some patients are ambulant in the community with their chemotherapy being slowly infused into a

special line called a port-a-cath, and the chemotherapy is in a plastic container that is worn on the waist in a 'bum bag'. Beside the use of chemotherapy and radiotherapy there are other procedures that are now being used, such as embolisation (cutting off the tumor's blood supply) to inhibit metastatic disease from growing, and immunotherapy.

Oncology is a rapidly changing specialty. Therefore, it is important that nurses do not lose sight of their role within this area of expertise. It is crucial that nurses advocate for the role of community oncology nurse by developing and documenting practice guidelines. Specialty areas identify knowledge and skill competencies of what a nurse should be able to do and know within the role of community oncology nursing. With the assistance of literature such as Haberman et al. (1994) and Steeves, Cohen, & Wise (1994) I compiled competencies required by a community oncology nurse (Southgate, 2001). These competencies are presented in the following section and include evidence based practice, symptom management, planned care, treatment, team dynamics, ethics, safety, emotional support, and education.

Oncology Nursing Competencies

Evidence Based Practice

The nurse must be able to demonstrate a knowledge base of anatomy and physiology, oncology pathophysiology, carcinogenesis and nursing management of oncological emergencies. S/he also needs a sound knowledge of the principles of cancer diagnosis and treatment.

Symptom Management

The nurse must have the ability to use clinical and theoretical knowledge of cancer care and treatment to anticipate complications, monitor progress, interpret clinical signs and observations and minimize side effects especially pain, infection and sepsis, bleeding, nausea, vomiting, and anorexia.

Planned Care

The nurse must be able to coordinate complex care, e.g. oncological emergencies, and giving of home chemotherapy. The nurse has the ability to plan care in partnership with the patient and family, and has the ability to be flexible in planning for care in a variety of environments. The nurse should be able to demonstrate effective time management skills.

Treatment

The nurse must have well-developed technical skills in the delivery of chemotherapy, the care of radiotherapy patients, and in the management of central venous access devices. The nurse has the ability to demonstrate confidence in their approach to new technology, knows the purpose of treatment given, e.g., curative, palliative, and adjuvant, and knows the principles of staging, and common sites for metastatic disease.

Team Dynamics

The nurse must have the ability to function by contributing at multidisciplinary team meetings and education sessions, acknowledging skills of all team members, accepting individual responsibility within a collective, and be open to constructive criticism.

Ethics

The nurse must have a theoretical understanding of ethical principles and codes, and be able to apply these principles to practice, e.g., in resolving ethical issues and dilemmas in treatment decision-making, securing informed consent, clinical trials, issues in palliative care, shifting from cure to palliative therapy, and questioning methods.

Safety

- The nurse will practice in a culturally safe way, which includes maintaining / upholding the principles of the Treaty of Waitangi.
- The nurse will have a sound knowledge of radiation precautions, exposure to cytotoxic agents, coping with grief and loss, and know the signs of emotional burnout.

Emotional Support

The nurse must to be able to provide emotional support to the patient and family, and have an understanding of the grieving process. S/he will have knowledge of support services available and how to access these services. The nurse will have developed listening and communication skills to provide effective support and empathy for patients and families affected by cancer. S/he will be able to provide the right environment for patients and family to express feelings and concerns, be able to make provision for the psycho-social aspects in cancer care, and acknowledge the patient as a whole, physical, psychological, spiritual, and sexual being.

Education

The nurse will be able to use clinical and theoretical skills in patient and family education in cancer diagnosis, treatment, drugs, procedures and precautions. S/he will have the ability to empower the patient by fostering independence and self-responsibility, be able to provide a good learning environment, and be willing to educate students and other nursing staff in care of the oncology patient.

These competencies reflect the minimal role activities and behaviours required of a community oncology nurse. Although I did not plan it this way many of the key competencies required by the community oncology nurse line up with Benner's(1984) definition of an expert nurse (refer p.4). For example the competencies outline that the community oncology nurse must have the ability

to use clinical and theoretical knowledge of cancer care and treatment to anticipate complications, monitor progress, interpret clinical signs. The nurse must be able to coordinate complex care and plan care in partnership with the patient and their family.

The role of the Community Oncology Nurse 2002

The role of community oncology nurse has changed over the years from predominantly providing care to the palliative and terminally ill patient, to more focus on the management of patients having active cancer treatment. In the last three years due to medical advancement some chemotherapy drugs are given in the community setting, for example oral chemotherapy tablets (such as Xeloda), and infuser pumps worn by patients on a belt. This is just the start as new drugs come onto the market that are immunotherapy agents which attack cancer cells alone (for example, Gleevac).

Therefore, care that is required by cancer patients at home goes beyond the scope of traditional community health. The acuity level and complex care needs of cancer patients at home requires nurses to be efficient in high technology skills to optimize continuity of care, and influence positive patient outcomes. The community oncology nurse needs to have in-depth expertise of practical and human needs of people experiencing cancer in the community (as can be seen in the previous section on oncology nursing competences)

Although the Cancer Center is the main source of referrals in the service in which I work, I can also get referrals from the surgical wards, before patients have been seen by one of the oncology doctors. This is often because it has been identified that the patient and family are very anxious and are going to need support as soon as possible after discharge. I am also sent referrals from the patient's GP, indicating the patient is home and has a cancer diagnosis, and is requiring immediate support and monitoring. The service can help to reduce anxieties by informing patients and families of what is likely to follow. For

example, I can help them to write out some questions that they need to ask at the first oncology appointment.

Therefore, the art within the role of community oncology nurse is that of patient education, liaison, monitoring and assessing, advocating, coordinating and support which I will discuss in the next sections. It is also about 'being there', caring holistically for the person, remembering that their interpersonal dimensions are all closely linked, and one part affecting the other. It is not just about carrying out of technical tasks it is also human interaction.

Patient Education

Before starting treatment it is often helpful to patients if the community oncology nurse visits them at home to introduce them to the service, and to start with some education. Although the nurses in the day unit and the ward are effective in educating these patients, it is interesting how little patients actually hear and remember when they are visited later at home. There is so much happening for patients in hospital they simply forget what they are told. They are often still consumed and overwhelmed by emotions and feelings related to their cancer diagnosis, and they are bombarded with information and education that they will need in the next stage of treatment. When I visit them in their home they are in their own environment and more at ease, and they are not having therapy, such as having a needle put into the back of their hand for chemotherapy.

I give the patients books on the diagnosis and treatment that have been put out by the Cancer Society especially for patients and their families. After reading these books often generate's more questions to ask. Education is also given on how to take a temperature, and channels that they can use to seek assistance, help or advice, and what to do when needing help after hours. Because a diagnosis of cancer gives a feeling of lack of control and powerlessness, it is important to put the groundwork into education, helping patients to feel fully

informed and back in control as soon as possible. This is empowering them, giving them responsibility in their health care. The ideal outcome is each patient is happy, feeling supported and safe in the community.

Liaison for Patients

Often, patients ring after their appointment anxious and upset that they did not understand what the doctor was saying to them, and did not like to admit that to the doctor. In this situation I ring the doctor concerned and explain the situation, and we discuss what was said. Then I relay it back to the patient, thereby lowering anxieties and misunderstandings. It is not always that easy though, because once patients understand what was said, they have questions, some which I cannot always answer. This necessitates phoning the doctor again with the questions and relaying the responses at an appropriate level of comprehension.

Liaisoning is also keeping informed other health providers involved in the patients' care. For example, I keep the GPs involved in the patient's care, as they are often the one who put all the hard work into the diagnosis. It is important that the GP continues to be involved. Most patients have a good relationship with their GP so it is important that it is maintained.

Monitoring and Assessment of Patients

Unlike radiotherapy, chemotherapy has the potential for many side effects and toxicities that can be experienced by the patient, as the treatment is systemic. When I visit patients at home I assess them by 'walking' visually through their body, from head to toe covering all possibilities. I cannot always rely on the patient to tell me all I need to know, as they can think some things are not worth mentioning, or are not important. It is important to try to support the patient through the treatment time with as few side effects as possible. The community oncology nurse's role is centered on secondary prevention strategies facilitating early diagnosis of health problems and acting promptly to limit disabilities.

Through the first few days post chemotherapy I work towards managing symptoms such as nausea and vomiting. For some patients it is back to work as usual, but for others it is not so easy. Sometimes while visiting I can find the reason things are not going well, for example, the patient is not taking the medication correctly. Many people have not taken much more than a paracetamol (pain relief) all their life, so they are feeling overwhelmed by all the medications they have to take and when. Writing out a timetable is a great help, as it gives them back control. For others it means rearranging medication, or getting the doctor to prescribe another antiemetic, and reminding them to drink plenty of fluid.

The aim of prompting patients about self care through this time and supporting them is to get them through this stage by minimizing effects, so they are feeling better towards the middle of the cycle when other effects from the treatment can be expected. Side effects such as mouth ulcers, oral thrush, and a drop in the blood count (myelosuppression) causing anemia, which often presents as extreme fatigue, shortness of breath and neutropenia, making them susceptible to infection. Much education is needed to prevent possible effects and to maintain the patient's physiological safety. At this time I am supporting the family as well, because often they feel great responsibility for their loved one's well being.

Some patients get 'into the swing' of their treatment cycles and require little support and input, but there are also many patients and families who need a lot of monitoring, requiring attendance in their homes two or three times a week, or even daily for a while. Also in the first two cycles of treatment, patients are often experiencing hair loss, so they require support and reassurance. In particular, the female patient's hair loss is one of the most overwhelming effects of chemotherapy, and a source of major anxiety (Cope, 1995).

I often make contact the day before patients are due back for their next treatment to make sure they are feeling well enough to attend. Sometimes patients are anaemic, so I organize blood tests the day before, and if a blood transfusion is necessary this can be arranged before treatment to avoid delays. Patients also ring the service regularly, to update me on their progress, or to ask questions. Dressings are often needed on radiotherapy skin reactions, and injections such as GCSF (Napagen), a drug used to stimulate the bone marrow to produce new white blood cells in patients who are profoundly neutropenic, or to avoid neutropenia. Patients are educated to give their own injections, but they still need monitoring for drug side effects, such as flu like symptoms and badly aching bones, for which they may need pain relief. They may need the drug stopped if the pain is too severe, as it often means the bone marrow is being over stimulated.

During all these phases of treatment as a community oncology nurse I am communicating with the doctors, informing them of patient progress or seeking advice from them. This is often done through the weekly meeting of the service with doctors, during which they tell me who they have seen in clinic and how they think they are progressing. This is interesting, as often patients can present a very different picture in clinic to what I see at home. Some patients having palliative chemotherapy are worried that if they tell the doctor how things are really going for them, the doctor may stop treatment. So they apply the wig and make-up and go in smiling sweetly at the doctor, proclaiming that all is well. Without being too disloyal to the patient, I inform the doctor how the patient is progressing from my perspective, if I am concerned. In conclusion, the community oncology nurse pays particular attention to assisting patients and families in dealing with the physical effects of the disease and treatment, dealing with actual symptoms, as well as potential problems. Pain and symptom management and regulation are a significant part of the overall role. I am 'the doctor's eyes' in the community.

Advocating for Patients

Advocacy is pleading the cause for another in this case, the rights of the oncology patient (Parkinson, 2000). Recently I was phoned by a patient who was 'beside himself,' saying that if we did not do something about his pain, he was going back to the surgeon to see if he could help him. He expressed that he felt his oncologist was not listening to him, or taking him seriously. We talked at length, and my aim was to try and calm him down. We talked about the pain and his medication. I tried to gain a clear picture of what was going on. He was not due to see the doctor again for two weeks. Therefore, I rang the doctor and explained the situation. I managed to get the doctor to agree that things were not satisfactory and that there were a few other tests that could be done to find the underlying cause of what was happening. The doctor agreed to see the patient the next day and do another full assessment, and the patient was very relieved and grateful. These situations are never easy, and I have to be very tactful and maintain a good relationship with the doctor. The situation needs to be handled in a way that will not jeopardize the doctor-patient relationship, the nurse-doctor relationship and the nurse-patient relationship. Oncology nurses are responsible for ensuring that the patient receives the best care. I function to promote and safeguard the interests and well being of patients.

If oncology patients are not happy with care, it is very difficult for them to complain as their treatment goes on for a long period of time, and they have to keep coming back. Whereas, a surgical patient who has an operation usually goes home not to return. Therefore, the oncology patient feels uncomfortable with 'rocking the boat,' and this can make the situation very stressful.

Coordination of Patient Care

Coordination is another key part to nursing practice, assessing the need for other health professional's involvement, such as physiotherapy, occupational therapy, care assistants for home help, assisting with hygiene needs, and counselling for patients, families and children in cancer affected households.

Social worker involvement for counseling or to assist with finances is often an issue for many patients, especially if they are unable to work throughout their treatment. Unfortunately life does not 'go on hold' when a person is diagnosed with cancer and the bills still keep rolling in. Coordinating also involves making appointment times, or bringing these forward if there are problems or complications in the patient's condition. There is also a need to arrange transport via the Cancer Society volunteers for some patients who do not have a car, or should not be driving after treatment. Other coordination activities involve organizing GP visits, and having prescriptions faxed through to the patient's pharmacy.

Support Person for Patients

A support person is crucial for patients. It often amazes me how timely my visits can be. I knock on the door, not knowing that for the patient I have come at the right time. The door opens, and sobbing into my arms, may come a woman newly diagnosed with breast cancer. She has been brushing her hair and it has started to fall out. Over coffee I become the 'listening ear' and share a little of what other patients' experiences are, to give her some reassurance. These times can often end in laughter. There are a lot of 'behind the scenes' events that community oncology nurses see which is not seen in the ward or outpatients department. When working in an oncology ward I took for granted what happened to the patients once they were discharged, to when they returned for the next treatment. Now working in the community, I get a very full picture of what it means to the patient and their family going through a cancer diagnosis and treatment. It is important to remember that there are times when there is nothing I can say, but just to be there to listen and learn as patients share their feelings, stresses, anxieties, family dynamics, relationship issues, and fears.

Being There

There are times when the patient's family needs me more than the patient themselves. The patient may lie asleep in the next room unaware of the distressed relatives or friends pouring their feelings and emotions out to me in the kitchen. I provide a listening ear, hold their hand and acknowledge what they are going through is real and the way they are feeling is normal. I remember the privilege it is for patients to open their homes, and sit and share their private lives with me. It is important that oncology nurses protect that information as much as possible disclosing information only on 'a need to know' basis to other health professionals.

Clearly, one hallmark of the community oncology nurse as support person is using one's self as primary intervention, being present, in the moment, and 'being with,' no matter what the outcome. Swainson (1993) defines 'being with' as being emotionally present with the other, in a way that conveys to the patient that they and their experience matters to the nurse. This means that I am often there with the patient at their most private moments of suffering (Haberman et al., 1994). I consider this to be one of the most important nursing interventions, which unfortunately is fast disappearing within nursing in the hospital setting, which could be due to less nursing staff with heavier work loads. This situation makes it very difficult for the nurse to 'be there' for the patient outside implementing clinical tasks, for example, doing the patient's dressing or maintaining intravenous (IV) therapy. I believe this jeopardizes the nurse/patient relationship that is essential in facilitating best patient outcomes.

Nursing, as already discussed in this project, is not just the undertaking of clinical tasks, but having an effective relationship with the patient so therapeutic healing occurs (Taylor, 2000). Nursing is about human interaction and nurses are there in people's lives at birth, or death, or at times in between. Taylor (2000, p.35) state's "regardless of whoever else may be present, the chances are that a nurse will be there, as a helper, a healer and a friend." Taylor,

(2000, p 35) goes on to say, “Nurses are present and active throughout people’s lives, and nurses roles, responsibilities, and ways of being are as many and varied as the situations in which they find themselves.”

Being there when patients are told their condition of health, and being supportive, sharing the grief and laughter with patients is important and special. Unfortunately, this is often a time when patients learn who their real friends are, which they find understandably very upsetting. Many people, even some family members will shy away at this time, as they do not know what to say. This is very lonely for the patient, and why the nurse can find themselves being a helper and friend, as well as a healer.

Truth-telling

I have positioned truth-telling at the end of the chapter, not because it is not an important issue, but because I believe it is not a role on its own. Truth-telling is a basic moral principle and an underpinning factor in all the above roles of the community oncology nurse as educator, liaison, monitoring and assessment, advocacy, coordinator and support person. Moral principles are standards that a society can use as a guide to do what is right or good. Moral principles are important for our day-to-day living and decision making (Thompson, Melia & Boyd, 1988). Although truth-telling is paramount in all patient care no matter what service they are in, I have found myself being more confronted by truth-telling within my role as community oncology nurse.

Trust is the basis for a relationship and needs to be present so nurses can work with the patient to meet objectives that the patient themselves set. By trusting the nurse the patient will share with you personal information required to maintain holistic care. If we withhold information from the patient, and fail to tell the truth, we risk losing the relationship, and patients cannot make decisions about their health without sufficient information.

When visiting, some patients request as much information as possible, and have also sourced some literature for themselves, while other patients exert their right to the information for the time being. In this situation I only give them the information they need in relation to treatment and side effects, to maintain their safety in the community. Once a patient is further down the track in treatment and adjusting to their diagnosis, and the relationship between us is less formal, they start to open up and ask more questions, such as, “Will this treatment cure me? What are the chances of the cancer coming back? What is my prognosis? How will I die? Will I die in pain?”

Often questions are not asked directly, but I assess the conversation what the patient is trying to say, so at the next doctor’s meeting I tell the doctor so s/he can address the issues at the clinic appointment if it is appropriate. This brings me to the issue of whose role is it to answer such questions, as in the past there have been conflicting opinions. Some would say it is the doctor’s role, and the second view is whomever the patient questions, should answer truthfully (Bradshaw, 1996). In hospital it is easier in the sense that both doctor and nurse can be present. In the community, this is not possible. Mostly, I will answer the patient, which is not always easy if it means being the bearer of bad news. If I do give this information, then I make sure I tell the doctor so s/he is fully informed. Sometimes though it has been appropriate to say, “These are questions that you are best to ask the doctor at the next clinic appointment.” For example when patients are asking questions like, “If this treatment does not work, what next? What are the chances of this treatment working, or not working?”

There are two conflicts here. Firstly, the patient’s right to know, and second, the response of the health professional to protect the patient from news that may shock or distress them. The patient may be distressed at first but I do not really know how they might respond to the situation. They may give up, but then again they may fight with all they have. If the patient is fully informed they

may decide to do the things they want before they die, to fulfill 'secret desires.' They may decide to stop treatment and go home to die, and enjoy the time they have left. If I do not tell the truth I could be cheating them from these secret desires or dying wishes. Doctors cannot expect nurses to lie and run the risk of jeopardizing their relationship with the patient.

Conclusion

The community oncology nurse's role is about: assessing multiple body systems for symptoms of the patient's disease and side effects of treatment; supporting patients; minimizing their suffering; teaching patients and their families; facilitating decision-making so the patient is empowered; managing pain; administering treatment; maintaining hope; building relationships; and, managing psychosocial needs. It involves caring for the whole person, anticipating the patient's needs, and providing comfort and support to the patient and their family. It is also about family-centered care, presenting options, managing symptoms, being patient and family advocate, confronting ethical issues, co-ordinating complex care and monitoring progress.

The art within the role of community oncology nurse is that of patient education, liaison, monitoring and assessment, advocate, coordination, and support person. Community oncology nursing is about being there, caring holistically for all parts of the person, that are closely linked, one affecting the other (much as making a whole quilt from multiple parts). It is not just about technical tasks, but human interaction.

Chapters Five, Six and Seven that follow describes the important aspects of truth-telling, advocacy and being human, which are pivotal to a community oncology nurse's role. Practice stories illuminate the necessity for these three pivotal acts, and demonstrate how I have been able to reflect on my own practice as a community oncology nurse using a reflective topical

autobiographical approach. To protect the identity of the patients in the practice stories, pseudonyms will be used.

CHAPTER FIVE: TRUTHTELLING

Truth-telling has long been an issue of concern, especially for the oncology nurse. Since the 1960s, the health care culture has gone from one in which patients were given very little information regarding their diagnosis and treatment, to today where patients are given extensive information about their condition, treatment and prognosis. Despite this trend, informed choice remains a difficult issue, and the nurse's role in this needs to be identified.

Our duty is to tell the patient all the information pertaining to their health. Patients have the right to know the truth. How can patients make decisions about their health without sufficient information? Truth telling is a basic moral principle (Rumbold, 1986). Zerwekh (1994, p.34) says that "truth and choice are important to everyone, but particularly to the person who must rely on others for the critical information needed to make difficult decisions."

The following story from my practice exemplifies the need for truth-telling.

Winter is coming upon us and there is now a chill in the air, and one of the many patients I have been caring for is a gentleman with cancer of the esophagus, which had already locally metastasized since diagnosis. Therefore, the treatment he underwent was palliative chemotherapy and radiotherapy. From this treatment he unfortunately only got about 7-8 months remission, possibly even shorter. As there was a period of time, the symptoms of recurrence were obvious to the medical team, but the patient chose for a while to deny there was anything wrong again. I believe he knew, but didn't want to talk about it. He was a little cagey when I visited to re-heparinise his port-a-cath. He would look at me, as though,

“Don’t you say anything.” But that was okay. Over the years in my practice I have become comfortable in playing the game of pretence. Through experience I have come from thinking that the patient is in denial and needs to be talked to frankly, to now knowing that many of them do know their situation and will talk about it and acknowledge it when they are good and ready. So, this is where Bill was and it was okay, although the doctors didn’t think so, and they wanted me to have that frank talk with him. My experience told me to talk to him ‘all in good time,’ a right time, and that wasn’t yet.

As the weeks went on symptoms were starting to overwhelm Bill such as nausea, and no appetite, and being unable to swallow due to the pain. In discussion with Bill it was decided to insert a subcutaneous pump so he would have a constant 24-hour cover for nausea and pain relief. Best of all, he didn’t have to attempt to swallow all his medications. In this discussion with Bill and his wife, he also expressed a wish to die at home, and he didn’t want the hospice service involved.

Bill had his good days where he would sit up in the lounge and drink tropical smoothies that had been made with so much love and enthusiasm, as his wife was trying desperately to tease Bill’s appetite and nurture him. She felt good and comforted if he was able to tolerate food and fluids. Then Bill had his bad days when he would lie huddled up in bed consumed with nausea and pain, as we worked hard to get the cocktail of medicines right in the pump to ease his symptoms and maintain his dignity. Also during these times his wife and children needed just as much support, as well as knowledge on how to care for him, and more importantly, to know what was to come.

This is where it is so different from caring for dying people in a hospital or hospice, because there are trained staff present 24 hours a day to provide instant support in acute episodes. With metastatic esophageal cancer there is always a risk or chance that a patient may bleed. Sometimes it is a small bleed, sometimes it is a large bleed, and sometimes it doesn't happen at all. My last experience in caring for a patient in this exact situation was they bled. So, my gut feeling was to tell Bill's wife about this possibility in a gentle way, although I know I can never prepare people for what can happen. Hopefully by having the knowledge of this possibility fear and anxieties would be less if it did happen. So I told them and they thanked me for my honesty, and we talked about what they could do in such a situation. They agreed they would stay with Bill supporting and reassuring him until nursing support arrived.

The weeks went by and Bill slept more and more, and needed more assistance with hygiene and toileting, which was very difficult for him as he was a very private person, and he found it very embarrassing. But he did enjoy the light humor I introduced tastefully to make it a little easier for him, such as when he became very weak and unsteady on his feet and required assistance with showering, I would tease him about being drunk, and I was going to check under his bed for the bottle. Once he was toileted, showered and settled back to bed and the pump was refilled with medication, much of the visit involved talking to Bill's wife and family, listening to stories about Bill and sharing fond loving memories they had. I also listened to their hopes and wishes of how the end of life events would be.

Bill continued to have little to ask or say, but he always verbalized his thanks for the care and concern shown towards him and the family. One thing he did express to me was that he didn't accept what was happening to him and he felt bitter about dying. He seemed amazed or shocked and smiled when I acknowledged his feelings and told him it was okay, and that he didn't have to accept what was happening, because I wouldn't accept it either.

Later, during the course of his illness, Bill developed a chest infection and he became very septic. At one visit I sat on Bill's bed and talked about this new development. We could try oral antibiotics, but it was more likely he would need IV antibiotics, which involved a hospital admission. I left Bill and his wife to think about it, and talk further. As I was leaving, Bill said to me, "If I don't have the antibiotics will this possibly be the way I will die?" As hard as it is to reply to such a question I replied, "Yes". I could see that Bill was beginning to give up, he had had enough. Bill had not just been fighting to live over the past two to three weeks, but over the last eighteen months, since his diagnosis and treatment started.

His decision was not to have the antibiotics after conversations on the phone with the oncology consultant and GP. I reassured him we would keep him as comfortable as possible. We started four hourly paracetamol suppositories and educated his willing wife to give them with Bill's full approval. This worked really well at keeping his temperature down and stopping the rigors.

Then it came, a few days later when I visited Bill, his wife greeted me at the door in tears and holding an ice-cream container in her hand, "Look at this," she said. I looked into the container and not

to my surprise it was ¼ full with bright red blood. I took the container off her and lead her into the dining room, I sat her down. She looked up at me and said, "This means it is going to be soon, doesn't it?" I replied, "Yes, it probably does." We talked for a while and then went into the bedroom to see Bill. He was waiting for me as he had seen it and wanted to talk. Bill was sitting on the side of the bed. He looked at me and said, "Have you seen what is in the bowl?" I replied, "Yes Bill, I have." Bill said, "What does this mean?" I was on the spot. He trusted me and I respected him. I owed him the truth. Trust is the very basis for a relationship between the patient and nurse. By the patient trusting their nurse he / she will share with you personal information you require to maintain holistic care.

It was me he was asking and me who had to reply. I sat on the bed beside him and put my hand on his back, "Bill it means the cancer has broken through a vein or vessel." He promptly said, "Can you do anything?" "No Bill, I'm sorry we can't." "That's ok, I thought as much," he said. Bill then said, "Will it be long now?" I replied, "No Bill it probably won't, maybe a few days and we will do our very best to keep you as comfortable as possible." And like a lot of patients say at this stage, "I'm not worried about me now, I'm only worried about my wife. I will be gone and she will be so alone." I acknowledged this and reassured them that the children and the nursing staff would be there to support her.

As I walked out of the room, he grabbed my hand and said, "Thank you so much for your honesty, I feel more at peace now. I know it wasn't easy for you to answer my questions with straight answers." I smiled.

As a left Bill's home my emotions were such that I could have vomited in the garden. I felt physically sick. It doesn't matter how many times I have been in that situation, I still am not used to it. I know I had answered correctly, but I found myself doubting it. I knew if I were in his shoes I would want straight honest answers too. He asked and it was his right to know. My dilemma here was not that I thought he shouldn't know the truth. It was the feeling of wanting to protect him from news that may shock and distress him, but then I never under-estimate how patients will handle the situation.

I got back to the car and phoned the consultant for reassurance that I had done the right thing and answered correctly. He confirmed that I did, and then he asked me if I was all right. I really appreciated his support and concern, as I knew I had paged him in the middle of a busy clinic.

Later on in the week Bill's wife told me how grateful Bill was that I told him the truth and that night they sat as a family and talked about many issues. Two days later in the early hours of the morning, Bill died peacefully in his wife's arms. They lay together in bed for an hour or two, before she rang to say he was dead.

Reflection

As hard as it is to tell the patient the truth it is important that I do. As well as listening to patients, nurses have to also answer them truthfully. For too many years death and dying issues have been shrouded in mystery, and contemplated in fear and envisioned as an experience of great suffering. So it is up to nurses to educate and support patients and their families through this time. Many people want to die at home and many families want to have the patient at home,

but they can only do this with a nursing service that can provide the back up and support.

By visiting the patient and family regularly the community oncology nurse creates time for continuing dialogue and increasing familiarity through interpersonal communication, which is essential for the development of an effective nurse/patient relationship. Nurses bring their ordinary human qualities and activities into their work world. Patients are pleased when they find the nurse caring for them is human. Nursing is a human service, because “it facilitates humanity of both parties as they negotiate the illness experience together” (Taylor, 2000, p 246).

This chapter provided a story that exemplified truth-telling, which is an important aspect of the role of the community oncology nurse. Literature acknowledges that it is not a pleasant task to tell patients their prognosis is poor or their condition is terminal, so it is understandable why many doctors and nurses shy away from this duty (Bradshaw, 1996). It is not easy to be the bearer of bad news, but it must be done by picking the right time and with sensitivity. As nurses we can share patients’ grief, anger, shock and depression as a support to them. Being honest with them and being there can enhance their trust in us, and also means the family can make plans for their future. Truth-telling is another intervention that pieces together into the bigger picture in making a foundation for an effective, therapeutic nurse/patient relationship. In the quilt metaphor, truth-telling is the gold, which symbolises faith, consistency and wisdom.

CHAPTER SIX: ADVOCACY- BIDDING ON BEHALF OF OUR PATIENTS

Pleading the cause for another is otherwise known as advocacy (Parkinson, 2000). A considerable amount of the community oncology nurse's role is advocacy, being a moral voice for the patient's sake, and keeping their best interests in mind. Advocacy has particular relevance in caring for cancer patients, because due to the nature of their illness, they are vulnerable and already have enough anxieties, and are often unfamiliar with the situation. Advocacy is essentially an ethic of caring (Rich, 1995; Tschudin, 1993).

Dubler (1992) describes advocacy in caring as acting to the limit of one's professional ability to provide for the client's interests and needs, transferring power back to the patient to enable him or her to control their own affairs. Parkinson (2000, p.23) defines advocacy as “ informing patients of their rights or treatment options in order to reach an informed decision; encouraging patients to reach a decision which they themselves feel is in their best interest; and finally, supporting the patient in whatever decision they reach.”

The nurse's role is to help patients understand the choices available to them in all clinical situations, including research projects, and particularly in clinical trials. The power of cancer can diminish the patient's sense of personal control. Oncology nurses strive to encourage patients to be self-determining with regards to their care by adequately informing them and supporting them through difficult decisions. The following practice story exemplifies the need for advocacy.

Bidding on the behalf of our patients. Just when I thought, “Surely there will be no more referrals for this week,” in rolled another. The surgical team had discharged Molly, and she had presented in Accident and

Emergency Department with an enlarged abdominal mass and weight loss. It was thought at first the mass was a hernia, but after a number of investigations, it was found to be an enlarged liver. It was assumed that the condition was metastatic liver disease and so while in hospital she underwent a coloscopy, which was normal. The family was told the problem was inoperable and the prognosis was not good. They were told that she possibly didn't have long to live and not to worry if she didn't eat much. Molly was discharged home with a prescription for Ensure Plus (dietary supplement drinks).

On my first visit, all I had to go on was an inadequate nursing referral, which had no information or medical letter. The GP had only been given a phone call by the doctor concerned, and no letter either. Molly and I chatted as I wrote up the nursing assessment. Then I asked Molly what she knew about her condition. She said "I have a very large liver (which was visible) and they say it is probably cancer. The doctor spoke to my family not me. I don't know really what is next, and nobody talked about treatment. I would have liked the opportunity to have talked to a doctor about it." I asked her if she had an appointment for the Cancer Center, but she said "No". Molly said, "I don't understand it, nobody has really said where to from here. I want to talk to someone about treatment. I know that I'm 84 years old, but I have been well up until now and it doesn't mean to say I am ready or happy about dying. If there is something to give me longer, I would like to know about it. My son in Australia said there is a radioactive dust they can put into the liver to kill the cancer. He wants me to go over there for it." I felt so sorry for her. I phoned Molly's GP and explained that he really needed to speak to Molly and her family, and to send a referral to the appropriate service being either the Cancer Center or hospice.

So later in the week Molly and her daughter-in-law saw the GP, and after discussion they agreed a referral to the Cancer Center was appropriate. On Monday I was phoned by Molly's daughter-in-law to say that Molly had become very unwell over the weekend. She was unable to get out of bed, and diarrhea with faecal incontinence was a problem. She had no appetite and a painful left shoulder. I told the daughter-in-law I would be there shortly.

What a foul day. The weather was 'only for ducks' and district nurses. On arrival at Molly's I had a chat with her about how her weekend had been. This was a different picture from what her daughter-in-law had said on the phone. It didn't take me too long to work out that Molly was down playing or denying her situation, as she knew these new developments would mean having to go back to hospital. On doing a 'head to toe' assessment, I realised she had a new pain in her left shoulder, which was very uncomfortable. Not knowing where or what her primary cancer was, this could be shoulder tip pain from the enlarged liver putting pressure on her diaphragm, or it could be unknown bone disease. Her liver had not been painful up until now, but it was tender today. Her appetite had depleted, which was unusual. Molly was pale and lethargic. Over the weekend diarrhea had also been an issue and again I was faced with the unknown. Was it really diarrhea or overflow from constipation, as the history for the week was 'bowels not opened for four days.' I then talked to Molly, discussing my findings and what I think needed to happen. Molly needed hospital admission and proper assessment, investigations and discussion around treatment, although my gut feeling was that now, we were beyond that point. However, still Molly needed to consult with the right doctor to discuss her situation. It was her right and I felt determined to fulfill that right. She conceded that she was going to need another hospital admission and I assured her it would be with the appropriate service.

Her daughter-in-law was very anxious and angry about what hadn't happened and the 'laid back' attitude of the GP. She was relieved that I was there trying to sort it out, as she didn't know who to turn to next. I phoned the GP and he said he had written a referral to the Cancer Center, but hadn't sent it yet and would do so today. I told him that he really needed to ring the oncology registrar and talk to him about getting Molly into hospital and assessed today, as her situation was now more acute. We sat by the phone awaiting the GP to call us back with the solution.

A little while later the phone rang, and he said the oncology team was not happy to take her, because there was no histology as evidence of cancer. I thought this was strange. He went on to say that he then spoke with the surgical registrar and that they would take her, and he said I was to ring the registrar and inform him. By now I was seething. I asked myself "What was he doing"? This wasn't going to be of any help to Molly, it was just back to square one for her." We knew her condition was inoperable. I took a big breath to calm myself and ease my frustration and politely said: "Doctor, this is not going to help, oncology is the right and appropriate service. Surgical is not appropriate." In a diplomatic way I said, "Would you mind if I rang and spoke to the oncology registrar and see what I can do." The GP said, " Oh will you, that would be great, I don't want to shirk my duty, but that would be good." He was sounding out of his depth.

I phoned the oncology registrar and informed him in a very frustrated tone of the whole situation, and when I finished, the doctor said to me, "Well, now it has been put like that, yes we will take her. The GP only told me that this lady had an enlarged liver, and a sore shoulder, but now you put it like that yes, send her in." It took an hour of phone calls before I was satisfied and happy with the outcome.

Molly was admitted to oncology, tests and other investigations were done and the diagnosis was confirmed and on discussion with the consultant about treatment, Molly made an informed decision not to have treatment and was admitted to the hospice service for palliative care. Her daughter-in-law rang and thanked me for all I had done. She said “You have gone beyond the call of duty for Molly.” To my way of thinking, I was just doing my job. I was bidding on behalf of a patient.

Reflection

Advocacy empowers the other to be what they want to be, which is the ultimate goal in nursing. Advocacy helps patients to help themselves (Taylor, 2000). Mallik (1998) claims patient advocacy by nurses is good professional practice and an integral part of the nursing role. Benner and Wrubel (1989) have identified advocacy as the base of nursing as a caring practice, and to be with patients in such a way that acknowledges a shared humanity which forms the foundation of the nurse/patient relationship. As nurses we know what the patient is entitled to and the skills needed to advocate. In reality being an advocate can demand considerable personal risk, emotionally and psychologically. One needs to be very careful that in being a patient advocate it does not jeopardize relationships with other members of the multidisciplinary team in the future. This is when it may be more appropriate to involve an independent advocate. Patient advocacy is not always easy and can in fact be very frustrating, but it is important to remember to keep calm, be diplomatic, and maintain relationships. Being an advocate also means crossing the line on behalf of vulnerable patients. Advocacy is another block or piece of the relationship that builds up to a trusting effective nurse/patient relationship. Recalling the quilt metaphor, blue is for loyalty and devotion to the patients well being in nursing care.

This chapter provided a practice story, which is a clear example of how vulnerable the cancer patient can be. The emphasis on facilitating the advocacy process requires the advocate to take responsibility to make sure the patient has all the necessary information to make informed decisions and to support the patient in the decisions they make.

CHAPTER SEVEN: BEING THERE

As already identified in previous chapters much of the community oncology nurses role is about caring for the patients' physical well-being, but I consider it is important not to under value the role that involves just 'being there.' Nursing is not just about 'hands on care,' but human interaction, 'being there' as a helper and healer, and also a friend (Taylor, 2000, p.35) as the patient tries to make sense of this life-changing experience. This chapter is a story about a patient who most of all needed me just to 'be there.'

In the book by Mitch Albom (2001) '*Tuesdays with Morrie*,' Morrie is an old professor who taught Mitch at University many years previously. Morrie is diagnosed with Amyotrophic Lateral Sclerosis (ALS), a brutal unforgiving illness of the neurological system. For the last few months of his life Mitch visits Morrie at his home on Tuesdays, which turns into lessons in how to live. No books are required yet many topics are covered including love, work, community, family, aging, forgiveness and finally death, where no final exam can be given. It is an example of 'being there' for someone.

Using Albom's idea, the following practice story of being human exemplifies the importance of shared humanity in the nurse-patient relationship.

This story reminds me of a patient, whom I will call Chloe, and it is about 'Fridays with Chloe.' Chloe had breast cancer for 16 years, and she had a lumpectomy and refused all other recommended treatment, which at the time was chemotherapy and radiotherapy. For many years she survived with not having these therapies, then four years ago she got recurrent disease in the bone, mainly the ribs. Chloe was given Tamoxifen (hormone therapy) and got on with her life, trying to forget she even had cancer. Chloe was a tough woman; life had made her this way, but the more I had

to do with her, I found a soft, caring interior. She was an elegant woman, whose appearance and mind was way beyond her years. Doctors often questioned her age, thinking her date of birth was wrongly printed in the documents.

Two years ago the tamoxifen became less effective and she was admitted to hospital with back pain, which turned out to be spinal cord compression from further metastatic bone disease, for which she received radiotherapy. Unfortunately, a few months later Chloe developed shortness of breath, which was found to be pulmonary clots, so she was given anticoagulant therapy (warfarin). Through these events Chloe needed closer monitoring and support in the community. She was given morphine,(opiate pain relief) Paracetamol, warfarin and an array of other medications, and she needed a lot of coaching with taking these. She had never taken more than an aspirin most of her life, so she found it all very overwhelming.

Once Chloe got into a routine with her medications, she sought moral support and so this is where I came in. As I identified in my nursing philosophy in the background chapter, nursing is not just the undertaking of technical tasks, but a human interaction, ever changing to match each patient's individual needs. It is holistic care, acknowledging that a person has physical, spiritual, social, sexual, and psychological dimensions, and each affects the other. Healing and wellness are not just about the physical state of a person, but can also be the release of inner pain (Swainson, 1993). I agree with Taylor (2000, p.21) who states, "while tasks are necessary they reflect the biomedical imperative, rather than caring that shows creative healing."

As time went on Chloe requested more visits, so it became a regular event on Fridays around noon, which became lunch. She insisted on serving

soup and toast with silver service. I had built a good relationship with Chloe, in fact, we became friends.

Reflection

Regardless of whoever else may be present, the chances are that a nurse will be there as a helper, a healer and a friend (Taylor, 2000), in the human side to nursing, being human. This does not happen with all patients. This is where I believe Swanson's (1993) nursing theory of caring is applicable to nursing today. Despite the fact that this theory was derived through studies done on perinatal situations, its validity to other areas of nursing have been found. This theory is based on caring intervention rather than taskorientated intervention, caring for people in a way that they feel, valued, loved and belong. The first stage is maintaining belief, which is that a nurse has to have faith in the client to get through the event. In turn, the nurse is then motivated to do his or her best, and endeavors to provide care in a way that in the future the patient and family memories of the event are as pleasant as possible.

The second stage of caring in Swainson's theory is knowing, which is being sympathetic to what the event means to the person. It involved trying to understand how it is for them. This is where the community oncology nurse see the whole picture of the cancer experience. They are privileged to be in people's homes and quietly bear witness to the whole experience, or as Taylor, (2000, p.1) states, "nurses have a front row seat to watch the dance of humanity." The next stage is 'being with,' which in my experience is the most important nursing intervention. It involves just being there for the patient, making myself available to share joyful and painful feelings. Visits do not have to be only about doing dressings, injections, removing sutures, and other physical care. They are also about listening, acknowledging, and supporting. This is not as easy as it sounds either, in fact, it can be very taxing, and exhausting, because it can 'suck

the nurse emotionally dry.’ I realise that it is very important that oncology nurses are aware of this and are active in caring for themselves to recognise their emotional state.

Between visits Chloe would ring if she had a query, or more likely she was lonely, or if I had visited the day before, she would ring to thank me for being there and listening. She would acknowledge she felt a lot better for getting her anxieties ‘off her chest,’ and she almost sounded like she was ‘on a high.’ She would sometimes just phone in a motherly way to check on me, telling me to look after myself.

Reflection

These issues are acknowledged in Taylor (2000, p.235) who states, “it is the small things that matter to the patient, like having a cup of tea with them.” Patients value the time that nurses spend being with them. A trust relationship is built through sharing, talking, listening and being there. Taylor (2000) states that this is essential for developing an effective nurse/patient relationship. “Nurses are not just dispensers of professional help. Nursing is a human service.” (Taylor, 2000, p.247).

Chloe had been divorced for many years and lived in a big old beautiful home full of antiques from the Victorian and Edwardian period, of which she had a lot of knowledge. Due to her failing health she sold her business, which she thought at the time she could not wait to do, but in fact she found herself to be quite a ‘lost soul’ once it had sold. Her purpose to get up out of bed was gone. She loved being busy and having people around her. This only became evident to her once it was gone. In fact, she was a mother to many of her employees, as well as her four children. One daughter lived in Australia; the other married and was living up north in New Zealand. The two boys lived locally, but Chloe kept them at arm’s length, because both were drug addicts and Chloe did

not want them around her, especially now she was on morphine. This is where Chloe needed someone to trust and talk to, as at times cancer was the least of her worries. This is often the case or situation when caring for people with cancer in their homes. As a community oncology nurse I often see, and have to support the patients through the other effects of their illness, with financial issues being possibly the most stressful of them all. There are patients with children, who are not only grappling emotionally with this life changing condition, but they are also having to be mindful of what it is doing to their children and the family structure and dynamics.

Many of the Fridays with Chloe were spent sitting out on the veranda, overlooking Wellington city and the harbour talking through issues like selling the business, how she was adjusting to her new lifestyle, the worry about her boys, and whether it was her fault they turned out the way they had. She would only allow me to briefly talk about her condition and ask appropriate questions to assess medications, pain, diet, and signs and symptoms of recurrent spinal cord compression. I believe that for a long time Chloe ignored her situation. This was the way she was going to cope with it all, so I felt an extra responsibility to watch her closely, as she was not watching out for herself. Chloe kept her knowledge about her illness to a minimum, as I believe underneath the tough exterior, she was really frightened. Many would say she was in denial, but like many other patients, it was just the way she wanted to handle the situation.

As time went on and the cancer progressed, in the middle of conversations she would pop in the odd question like, “What am I to expect as things get worse?” “How do you think I might die?” So, in many ways I knew she was curious. It was at this time I felt Chloe needed someone else to talk to as well. She knew she was on a steady decline and it was making her anxious. With her consent I wrote a referral for her to see a counselor as

she was displaying unusual characteristics. At the time I was also suspicious of brain metastatic disease.

The next time I visited Chloe it was a horrible windy Wellington day, and in the middle of winter. We sat talking at the table in the kitchen. She was saying that she did not know whether the counseling was helping or not. Then she looked at me and asked, "What is wrong?" Was the look on my face that offensive? I looked at her and said, " You are rolling your tongue as you talk to me." "What does that mean," Chloe asked. "It is probably nothing, but sometimes it can mean there is a neurological problem in the brain." I had to be honest with her and at the same time not alarm her. Besides, it was not my place to diagnose. She had an appointment in two days with the doctor. I told her I would tell the doctors what I observed so they could check it while she was there. I told her that if the doctors were concerned they would possibly do a CT scan. She looked at me and said, " What can they do if there is disease in my brain?" "Sometimes radiotherapy or steroids, or both. Or sometimes nothing." I replied. "Do you lose your hair from radiotherapy?" "Yes," I said, "You do, in the area they radiate." There was a long pause then Chloe said. "I don't think I what to know if there are any problems in my head." This was her decision to make and I told Chloe that I would support her in whatever she decided.

Chloe was seen two days later and the doctor felt brain disease was possible, but Chloe talked the doctor into delaying the CT scan for a few more weeks. I believe Chloe had a gut feeling, but was not mentally prepared to have it confirmed and that was okay, I would still be there for her.

The following week Chloe collapsed off the toilet and was found by her son. She had had a cerebral hemorrhage and she died in A&E. The

registrar knowing the relationship Chloe and I had, phoned me the following morning to tell me. My response caught me totally off guard. I burst into tears. This is when I really realized why I reacted this way, I had not only lost a patient, I had lost a friend.

Chloe became a friend through caring for her and without her realizing, she gave me so much more back, and she taught me so much about life. While I gave nursing care and advice, she unwittingly shared freely her experiences of life. The lesson I learnt was while Chloe had lived a life that many of us would judge, and therefore avoid her, we ran the risk of never knowing the true Chloe, the caring, totally appealing, and open minded lady she was. The healing touch, we touch the patient's life and in return they touch the nurses. In my quilt metaphor, red signifies giving of self. Our relationship with the patient is something that weaves together over time with careful piecing like a quilt. A relationship that occurs alongside, within or after the moment.

Reflection

This story exemplifies the fact that patients are physical, social, psychological and spiritual beings. Nursing is a therapeutic interpersonal process, caring holistically for all parts of the person so healing can occur. 'Being there,' is being emotionally present with the patient in a way that the patient feels that they matter and are understood, which is essential in facilitating best patient outcomes (Taylor, 2000).

'Being there,' reflects creative practice and is underestimated, and it is my experience that patients value the time nurses spend with them, and feel less in debted to you and your service if you accept their offer of a cup of tea. In this way, the tea and talk allows for equal sharing, not only of a drink and conversation, but also of a common humanity as people. Being human in

community oncology nursing makes the illness experience more manageable for patients and nurses and bonds them as human beings.

CHAPTER EIGHT: SUMMARY AND CONCLUSION

Introduction

This research has been about the role and practice of the community oncology nurse from a nursing preceptive. It has identified and discussed the behind the scene care, service and experiences of nursing cancer patients in the community who are having active treatment. Although this research has focused on the role of the community oncology nurse, this thesis reflects what nursing is all about no matter what area or speciality a nurse works in.

This study has assisted me to examine and reflect on my own practice as a nurse, which was possible through using the narrative/story telling method of reflective topical autobiography. I would have to say as well at this point that using this method was no easy option as so much self disclosure was required, which is soon to be in the public arena. I have been able to share my journey from novice to expert (Benner, 1984) and how I developed into the role of a community oncology nurse. I defined nursing, and what it means to me through creating my personal nursing philosophy entitled, 'the healing touch.' This is displayed within this project in the aesthetic form of a quilt.

In this chapter I discuss possible practice changes and ethical concerns in the future for the community oncology nurse, and what it could mean for the nursing profession. I also discuss the aims achieved in the research, key findings, and suggest other possible research that could be done on this topic. As identified within the project there is very little literature on the role of the community oncology nurse, and the literature found was from a patient's perceptive, not a nursing perceptive.

Possible practice changes in the future for the community oncology nurse

Present statistics show that one in three New Zealanders will develop cancer. Cancer incidence rose by 21 percent in the five years between 1991 and 1995. In data gathered in the Auckland area, there has been a nine percent annual increase in the amount of chemotherapy treatment given to new patients. The Cancer Society predicts the incidence of cancer will increase by 40% by the year 2005 (Ministry of Health, 2001).

Chinn (1991) predicts inevitable change in four particular areas. More chemotherapy will be given in the outpatients setting and in the community. As hospitals become much smaller, intravenous therapy in the community will increase. There will be a large palliative care clientele, as people will live much longer with cancer. Cancer will be more like having a chronic illness, therefore, the need for support within the home will be far greater, and problems with finances will see people much more needy if it means long periods of time with little income.

There will be a greater need for community oncology nurses as the care becomes more and more complex. Nurses are going to have to be more proactive, marketing themselves and advocating their worth to general practitioners, private hospitals, and other health care agencies. Nursing and the community have historically worked well together. Nurses are going to have to be a driving force in the future primary health delivery. There will continue to be new cancer drugs and treatments, biological agents, and immunotherapy, as in New Zealand there are breakthroughs in more treatments.

There will also be advancements in technology, for example, TV screens on cell phones, which facilitate patient assessment over the phone, because the doctor is able to see the patient on the screen in his or her home. Nurses will probably be carrying lap top computers, having all patient information on-line. There will

probably be major advancements in surgery with improved techniques, and cancer vaccinations.

This will be a window of opportunity for nursing. There will be an explosion of technology, which we are already seeing, such as computers at the bedside. There will be an evolution of drastic disease trajectories with increase in devastating environmental destruction, waste, and pollution. There will be a pronounced scarcity of resources due to increased demand. Therefore, the search for financial resources, natural resources and profit will be even more a primary motivation in human life. There will be a dramatic increase in complexity in every arena of life, and as people become more 'developed,' they will be more assertive in making their demands.

In practice, nurses need to become prepared and craft their actions, thinking and practice to shape the future they would prefer. They must create images and visions of what they think health and healing could and should be in the future. Chinn (1991) states that nurses need to have vision of interactions that nourish the human spirit and peace in the places they live and work, which brings comfort and healing through touch. She also states that the most important thing nurses can do to prepare for the future is to learn about how to trust their own intuition, becoming fully in touch with their own deep source of inner knowing, which is essential for human connection. Nurses need to be innovative in creating new ways to answer their patients' needs (Loflus & Westen, 2001).

Ethical concerns for the future

In light of the inevitable changes in the future of the health service and care, ethical concerns must be considered. Nurses are going to have to be more than ever, a moral voice for the patient's sake. Our role will move very much towards an advocate role, bidding on behalf of our patients. For some nurses this will be a change in practice. The Cartwright Inquiry (1988) was a huge learning curve and a lesson to New Zealand nurses about patient advocacy, as

the nurses were questioned as to their lack of voice in what was happening. The Cartwright Inquiry (1988) was an investigation into cervical screening research that was being done at the National Womens Hospital without patient consent during the 1970's and 1980's. Nurses have a professional and moral obligation to defend the health related interests of those for whom they care. Therefore, nurses also need to be politically awake, and have knowledge to function as guardians of patients' legal rights. This must be done with compassion, empathy and care, keeping in mind the patients' best interests.

Today oncology nurses are seeing patients being treated to almost the very end of their life. Some patients are spending 'the precious days' having treatment, and suffering the effects of the treatment, instead of spending these days more comfortably. Oncology nurses are starting to see more complex end of life situations due to being able to offer second and third line treatment. I find myself often challenging doctors on this issue, but still there are doctors who do not welcome what they perceive as failure. Alternatively, the other side to that coin is that because new treatments are available, or because patients can source information on the Internet, patients are being proactive in sourcing treatment options when their prognosis is poor.

Another ethical concern that is starting to arise and will be a much greater issue in the future, is the increasing cost of health care. The ability to pay for health care determines the availability and quality of care. Patients are now on priority waiting lists (as to the urgency of their surgery) as now there are more treatment options available, this is outweighing the available resources such as money, time, doctors, and nurses to do the treatment.

The ethical challenge for nurses is knowing when to intervene on the behalf of the patient regarding issues, such as the best site for care, provision of appropriate care, and preparing for death with dignity. To achieve success it is

beneficial that nurses act collectively, and to set or maintain positive values in care provision and practice within the system.

Summary

Nursing in the community is quite different from the safety of the hospital where there are other nurses with whom you can have a second opinion. This is something that is taken for granted when working in the hospital setting. There is a great deal of autonomy in nursing in the community, but at times it is very lonely, with no one to hear the conversation, and your word against the patients. I experience the dread of whether I have forgotten something, and being able to 'read' a situation, is at times a challenge. However, this role shows complexity of what nursing is.

Within the role of community oncology nurse I am able to live alongside the cancer experience by embracing the patient's triumphs and challenges. It is a privilege to care for the patients and families who are facing cancer, and their mortality. Literature states nurses often choose oncology because it fits their personality (Haberman et al, 1994), and in my case, my motivation comes from a personality that is comfortable in caring for cancer patients, and finds real purpose in life caring and giving to these people.

Aim of the Research

Throughout this research I have endeavoured to advocate for, and make known the role and practices of the community oncology nurse. The aim was to bring alive for the reader the lived experiences of being a community oncology nurse, and enlighten them to what it is that nurses do, that is often taken for granted. The aim has also been to advance nursing inquiry and identify the complexity of nursing practice, making it important to have skilled and experienced nurse practitioners in an ever-changing health care system.

Findings

This project represented the work of the community oncology nurse as more than just a job. Nursing activities to achieve best patient outcomes are centered on secondary prevention strategies facilitating early diagnosis of health problems and prompt intervention to limit disabilities, providing assistance to families and overseeing coordination of community resources (McEnroe, 1996). While the community oncology nurse pays particular attention to assisting the patient and family in dealing with physical effects of the disease and its treatment, pain and symptom management, the role is also that of educator, liaison, advocating, coordinating and support, leading patients to resources, organising transport to clinics and treatment and accessing counselling and other services. The care required by oncology patients in the community goes beyond the scope of traditional community health nursing because the community oncology nurse requires indepth expertise and knowledge in caring for these patients.

The art of nursing is ever changing to meet the patient's individual needs. Nursing is about holistic care and sometimes requires skills not learnt in nursing training, but in the wider forum of life. Nursing is a therapeutic interpersonal process caring for all parts of a person so healing can occur. "Nursing is a human service, because it facilitates humanity of both parties as they negotiate the illness experience together" (Taylor, 2000, p. 246).

Nursing is not just about 'hands on care,' but a human interaction, being there as a helper, healer, and friend, as patients try to make sense of this life changing experience. The 'healing touch' is when the nurse touches the patient's life, and in return the patient touches the nurse's life. Patients value the time that nurses spend being with them, and are pleased when they find the nurse caring for them is human (Taylor, 2000). In some cases the community oncology nurse is the only support a patient has when dealing with the realities of living with cancer.

As a community oncology nurse I strive to encourage patients to be self-determining with regard to their care by adequately informing them and supporting them through difficult decisions. Cancer patients are vulnerable and nurses need to be a voice advocating for the patient. As nurses we know what the patient is entitled to, and have the skills needed to advocate. Advocacy is good professional practice and an integral part of the nursing role (Mallik, 1998).

Truth-telling is another intervention that pieces together into the bigger picture in making a foundation for an effective nurse/patient relationship. These research findings are supported by Barker, (1997), Howell, Fitch, and Caldwell, (2002) and McEnroe, (1996).

Maintaining rigour in my research project

Johnstone (1999) states there are no agreed upon method for ensuring rigour in reflective topical autobiography. To maintain rigour within this research project the process of trustworthiness has been used, this includes the criteria of credibility, fittingness, auditability and confirmability (Roberts & Taylor, 2002). Rigour of reflective topical autobiography is about the reader identifying from the research similar experiences in their own practice, making the research plausible. The intention is also that the reader experiences fittingness, in which they find meaning and relevance for their own lived experiences, and feel as though they are reading about themselves. It is also intended that the reader gains in-depth understanding and insight into the role and practice of the community oncology nurse.

I have endeavoured to maintain rigour by using a writing style that can be clearly understood, and the reader does not have to make assumptions. Where possible I have used literature to support findings, claims and experiences I have had.

Future Research

Due to the lack of research and literature on the role of the community oncology nurse I encourage other New Zealand community oncology nurses to write about their practice and experiences. Nurses need to carry out research on their practice, and share their stories and experiences. Many research questions and approaches are possible, requiring quantitative, qualitative or mixed methods research designs. As the area of community oncology nursing is not well researched in New Zealand, nurses could 'brainstorm' possible areas of inquiry, including aspects of practice, education and management.

Conclusion

Community oncology nurses along with many other expert nurses have a vital role within the community, and it will be an even more crucial role in the future as care becomes more and more complex. I find it a privilege to care for patients and their families as they face cancer and all it brings. It is important to be aware of the need for time and trust, just as a quilt can only be complete once all the pieces are sewn together. So it can be when building a nurse/patient relationship. There are many skills and roles required by the community oncology nurse that come together to form an effective therapeutic relationship to facilitate best patient outcomes in their care.

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