

AN EXPLORATORY DESCRIPTIVE STUDY
OF THE NEEDS OF PARENTS
AFTER THEIR YOUNG CHILD IS DISCHARGED FROM HOSPITAL
FOLLOWING AN ADMISSION WITH AN ACUTE ILLNESS
by
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ABSTRACT:

In New Zealand there are concerns about the high numbers of preventable admissions of young children with acute illnesses. These admissions are concentrated in the under five age group, with higher rates of admissions for tamariki Māori and Pacific children. This study sought to address these concerns by focusing on what happened once these children were discharged. Its aims were to find out what the expressed needs of parents were, as they cared for their child, once home. Whilst there has been a small amount of international research undertaken in this area, there is little known about expressed parent need in the New Zealand context. This exploratory descriptive study involved parents of under five year old children, who had been admitted to a hospital, with one of five acute illnesses. Eighteen parents were surveyed over the telephone.

This study found the parents expressed a need for reassurance and advice once home, and that they worried about their child getting sick again. It highlighted gaps in discharge planning and support. None of the parents had received a written discharge plan for their child. Only five parents had received either a contact number for advice or a referral back to their primary care provider. This study found that whilst some parents considered their discharge needs had been met, others considered that they had not.

Four local discharge practice opportunities to support these families were recommended, these included, providing parents and caregivers with an individualised written discharge plan, giving a contact number for advice after discharge, offering a follow-up phone call in the first 48 hours, and ensuring that all children have a referral back to their primary health care provider. Areas for further research were highlighted, including the need for a larger study to explore and compare the needs of rural and urban parents, and Māori and Pacific parents

Key Words: discharge planning, acute disease, child, parents, telephone survey, descriptive

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CHAPTER ONE: INTRODUCTION

Most parents in New Zealand would probably expect their child to have the occasional acute illness during their early childhood years. However, these illnesses are usually of short duration and most parents, if asked, would not expect that their child would need to be hospitalised as a result of one of these illnesses. Yet as a country, New Zealand has definite cause for concern for the high hospital admission rates for acute illnesses in children (Baker, 2007; Craig, Jackson and Han, 2007a; Dowell and Turner, 2007; Ministry of Health [MOH], 2004b). Of particular concern, are the group of acute illnesses that are referred to as the Ambulatory Sensitive Hospitalisations (ASH). These are defined by the MOH as “admissions to hospital that are potentially preventable by early treatment in primary health care” (MOH, 2004b, p.79).

These ASH conditions include such diseases as respiratory infections, gastroenteritis, asthma, cellulitis, or urinary tract infections (MOH, 2004b). Many of these acute illnesses are particularly concentrated in the under five year old age group (Craig et al., 2007a). Whilst there are concerns about the overall ASH rates for this age group, there are also inequalities in these admissions, with tamariki Māori and Pacific children, as well as those children living in more deprived areas, being disproportionately represented (Craig et al., 2007a; MOH, 2004b; New Zealand Child and Epidemiology Service [NZCYES], 2005; Robson and Harris, 2007; DHB, 2007). These inequalities in health outcomes for children from less socio-economically advantaged families, indicate that the causes of ambulatory sensitive hospital admissions are far deeper and more complex than simply whether or not primary care services are accessed early enough.

Given the ‘primary care preventable’ and ‘socioeconomic determinant’ nature of these ASH admissions, most interventions have understandably been focused on making primary health services more accessible, affordable and acceptable. However there are also interventions that can take place during the hospitalisation process itself which can improve the health of these children. One of the most crucial is to ensure these children leave hospital with parents or caregivers who are

confident, well supported and that they are reconnected with primary health care services. Looking at these families' expressed needs following discharge could ensure that discharge practices are meeting their needs and are maximising opportunities for children's health and wellbeing. These admissions and discharges can be seen as 'windows of opportunity' which can be used to better support parents or caregivers, in order to make a real difference to children's health (MOH, 2004b).

1.1 RESEARCH AIMS

This research study therefore is focused on describing the expressed needs of parents and caregivers after their young child has been discharged from hospital, following an acute illness. The rationale for this study was based around the concerns at both a New Zealand and local DHB level, about the rates of ambulatory sensitive hospital admissions in the under five year old age group, and for the inequalities that exist with these admissions. This is a study based around the premise that although having a child admitted to hospital is stressful for parents and caregivers, it is important to recognise that this stress on families is not just limited to the inpatient stay. Returning home to care for a recuperating child can also be stressful (Smith and Daughtrey, 2000; Snowden and Kane, 1995).

This exploratory descriptive study aims to describe the discharge needs and concerns, expressed by parents and caregivers¹, as they care for their recuperating young child, once home from hospital. It also seeks to describe if there were any differences in the needs expressed between rural and urban parents and caregivers, and whether there were any differences related to their ethnicity or age of their child.

The study involved parents/caregivers of children under five years of age, who were admitted to the children's medical ward at one hospital, with one of five specific acute illnesses. This ward provides the only paediatric specialty inpatient services, and therefore caters for children from across the entire District Health

Board (DHB) area. This particular DHB², with a high rural population, provided a unique rural and urban context thus supporting the comparative component of this study. Five particular acute illnesses, that are common in the under five year old age group, were selected for the study. These were respiratory infections, acute asthma, gastroenteritis, skin infections or febrile convulsions.

A survey tool was developed for this exploratory descriptive study that had both qualitative and quantitative facets. The survey was completed using a telephone interview approach with parents/caregivers, once their children were home from hospital.

1.2 MY INTEREST AS THE RESEARCHER

I have had a long-standing interest in the area of parental needs after discharge. This is based on my previous work experience, particularly my work as a clinical nurse leader and as a public health nurse working with children and their families. I am currently employed as the nurse co-ordinator for a child and youth health service. This role has a strong focus on the primary/secondary health care interface and provides many opportunities to strengthen the continuum of care for children and their families. This research grew out of the result of both this long-standing interest, particularly in the area of individualised discharge planning and my experiences of working with children and their parents/caregivers. This has led me to consider how the support provided to parents and caregivers after their child's ambulatory sensitive hospital admission might be maximised.

The need for this study is based on both the concerns for the ambulatory sensitive hospital admission rates for this age group, as well as the gap in New Zealand based research in this particular area. It is anticipated that this study would provide local health practitioners with an insight into the needs of the parents/caregivers after discharge following their young child's ambulatory sensitive hospital admission. At a local DHB level, there is the potential opportunity for this study to inform

¹ For the purpose of this study, use of the term parent or caregiver acknowledges the diversity of families and whānau, and allowed them to determine who would be involved in this study (Wepa, 2005).

² Refer to the confidentiality statement for this study report (see section 1.3).

discharge practices for both rural and urban parents/caregivers. Ultimately the study sought to look at an opportunity to support parents and caregivers and make a difference to the health and wellbeing of young children.

1.3 THE CONTEXT OF, AND JUSTIFICATION FOR THE STUDY

In the New Zealand context, children's health status is seen as an important indicator of the health of future generations. This is supported within both the Ministry of Health (MOH) strategies and other child health documents (MOH, 1998a; MOH, 2004b; MOH, 2006; NCYES, 2005; The Paediatric Society of New Zealand (PSNZ), 2002; DHB, 2006). This study is set within one district health board (DHB) area of New Zealand. In order to protect the anonymity of this DHB, the name of the DHB has been removed from all cited references that identify it. All DHB documents used in this study were publicly available.

Whilst the need to strengthen the focus on young children's health and wellbeing to support their long-term health gains as adults, the reality is that as a group, they represent a relatively small percentage of the overall population and therefore a small share of the health care dollar. The current population of under five year olds represents only 6.8 percent of the overall New Zealand population (Statistics New Zealand, 2006).

There are several principles embedded in recent New Zealand child health documents. One of the key principles is the importance of taking a family-focused approach to improving the health of children (MOH, 1998a; MOH, 1998b; MOH, 2002; MOH, 2004b; Ministry of Social Development[MSD] 2002; PSNZ, 2002; Standards New Zealand, 2004; DHB, 2004). The need to raise the visibility of child and tamariki health, and to support parents and caregivers through using this 'family-focused approach' to children's health care, is by no means a new concept. Alongside this proposal was concern expressed about the increasing rate at which New Zealand children were being hospitalised. This rate increased by five percent between 1988 and 1995 (MOH, 1998a). This particular report also emphasised the need for early interventions for the reduction in inequalities for tamariki Māori;

Pacific children; children with high needs; and children from families with multiple social and economic needs (MOH, 1998a).

Three of these key groups (tamariki Māori, Pacific children and children from families with social and economic needs) are particularly relevant to this study. As one of twenty one DHBs in New Zealand, the DHB in this study is unique in terms of its geographical size and population distribution. Forty two percent of the DHB's population live rurally, compared to around 25 percent nationally (DHB, 2005). In the area in which this study takes place, seven percent of the population are under five, which is similar to the overall New Zealand population of children (DHB, 2005). The DHB needs assessment predicts an increase in the ageing population for this study area, with more than a doubling of the over 85 year old population by 2026. For the same period the under five year age group is predicted to actually decrease overall. However the percentage for tamariki Māori in this age group is expected to increase (DHB, 2005). This overall projected increase in the number of young tamariki is also supported by Robson & Harris (2007).

Various health reports for this DHB, have used a range of different definitions to determine which areas are defined as rural or urban (DHB, 2005; DHB, 2007). The Statistics New Zealand definition includes three levels of urban area. These are the main, secondary and primary urban areas. Although, using this definition in this DHB would mean that the main urban area extends far further than the actual city boundary, as it also covers a substantial part of two largely rural territorial authority areas (DHB, 2007). This broad urban definition also extends out to include some of the nearby towns, and therefore, the areas outside these generous urban boundaries or 'zones' are defined as rural areas of this DHB. Using this same definition would also mean that one rurally located town in this DHB is also included as a secondary urban area. More children live rurally in this DHB, than New Zealand overall (NZCYES, 2005), and it is these rural areas that also have very different socioeconomic needs. Using the NZDep01 scoring, this DHB's needs assessment (2005) showed nearly one quarter of its rural population lived in the highest deprivation quintile. This same document showed that families with high socioeconomic need also face the greatest distance to travel to get to either primary

health care, or to one of the five hospitals within this DHB to access secondary care. The DHB rural plan (2003), classified those people who have the ‘greatest distance’ to travel, as being isolated (that is living more than 30 kilometres away from the first healthcare). Babryn and Barnett’s (2004) New Zealand study highlighted the accentuation of accessibility to healthcare issues for people living in remote areas, when combined with socioeconomic deprivation.

For the purpose of this study, a more simplistic definition of rural and urban for this DHB was therefore used. This determined that participants residing within the city boundary were considered urban, and all other participants were defined as rural. This decision was based on the fact that the study site (the children’s medical ward at one hospital), was based in this city. This study made the assumption, that access to a range of primary health care services (including after hours), may have been more consistently available to participants living in the city, than those living rurally.

Although there is a focus on preventing these ASH admission rates in the first place, the fact remains that there seems to be very little known about the needs of these parents and caregivers *after* their child’s ambulatory sensitive hospital admission. This limited knowledge is further highlighted by the fact that whilst searching the literature for this study, it seemed that areas surrounding the needs of families caring for children with complex and chronic health conditions is a reasonably well researched area. The Lewis and Noyes (2007) study and the local National Health Committee (2007) document, are two recent examples of work in this area. There has not however, been an equivalent focus in the research around the discharge needs of parents and caregivers for children following an acute illness. It is also these children, who are less likely to have any follow-up in place, after their discharge.

When comparing the needs between rural and urban children in this DHB, it was the report produced by Graham, Leversha and Vogel (2001), that provided a comparative analysis for these children and young people. It included comparing the health and wellbeing of the 0-24 year old age group in the DHB, with those living in the three other DHB’s. This report included the top ten causes for

potentially avoidable hospital admissions. This study's DHB, was divided into rural and urban reports on health status, with these differences "being determined by a complex interplay of ethnicity, socioeconomic status and whether they live in rural or urban communities" (Graham et al., 2001, p.3). This same report highlighted concern for the poorest health and socioeconomic status that rural children in this DHB had. Whilst presumably those families living in the urban area of this DHB, have easier access (in terms of distance) to a range of primary health care services, urban children in this DHB did not fare any better. The more recent epidemiology report NZCYES (2005), showed that the overall increasing ambulatory sensitive hospitalisation (ASH) rates in this DHB, were higher for both tamariki Māori and children living in urban areas.

It is the high numbers of acute admissions for the under five year old population in this study's DHB that are also a definite cause for concern. It is these admissions that could provide what is best described as a "window of opportunity" to better support parents/caregivers with children's health and wellbeing (MOH, 2004b).

It is interesting that Flores' (2005) study, argued that some of these admissions were not avoidable, but also that there were other factors outside of accessibility and socioeconomic needs, that affect the preventable hospitalisation rates for children in the United States. These factors included missed opportunities for both parental education and children's follow-up care. At a local level there is a clear need for further study around the actual ambulatory sensitive or preventable hospitalisation rates for children. There is also a broader need to include looking at socioeconomic status of individuals and the New Zealand realities before making assumptions about the differing rates for ASH between urban and rural areas. There have been particular concerns raised about the ASH rates for both urban children (NZCYES, 2005) and rural children (Graham et al., 2001), in this DHB.

1.3.1 Tamariki Māori and Pacific children

There are many documents that highlight the health inequalities for Māori and Pacific children in comparison with all other ethnicities (MOH, 2003). These inequalities at a local level are reflected in the fact that both Māori and Pacific

children have higher hospitalisation rates for both respiratory infections and asthma (DHB, 2005). At a national level, between 2000 and 2004, Pacific infants were admitted with bronchiolitis at five times the rate and tamariki Māori at 3.2 times the rate of European children (Craig et al., 2007b).

The Pacific population in this DHB, at just over three percent, is small in comparison to New Zealand's overall Pacific population of approximately six percent (DHB, 2007). Using the broader Statistics New Zealand (2006) definition for urban areas in this DHB, seventy five percent of this Pacific population live in an urban area. However, of this group, 57 percent live in areas that are defined as most deprived (DHB, 2006). Thirty eight percent of this DHB's under five age group are tamariki Māori and 43 percent of these children live in the most deprived areas in comparison to around 20 percent of non-Māori (DHB, 2005). A higher percentage of tamariki Māori and Pacific children grow up with families and whānau with high socioeconomic need. In the Craig et al. (2007) report, they showed that the level of socioeconomic need clearly impacts on ASH admissions, with rates nearly four and a half times higher, for those living in poverty. Baker (2007) also expressed concerns about these persisting inequalities. The concept that "healthy children would grow into healthy adults" (MOH, 2004b, p.ix), should strengthen health professionals resolve to view a Māori or Pacific child's admission to hospital, as providing a very real 'window of opportunity' to maximise the support for these families and whānau, based around their needs on discharge from hospital.

1.3.2 Ambulatory Sensitive Hospital Admissions

Whilst the accessibility of appropriate health services for families in rural areas may be an issue, as reported by Brabyn & Barnett (2004), the fact remains that all children are reliant on their parents or primary caregivers to provide both care for their health and wellbeing and access to health services. The cost of accessing primary health care has been a potential inhibiting factor for many families. However since the New Zealand primary health care strategy was introduced (MOH, 2001), the costs for primary health care have gradually reduced to support access for people in areas of socioeconomic need throughout the DHB. This was

through the provision of opportunities for families to enrol with a low cost Primary Health Organisation (PHO). However, whilst the financial barrier for under five year olds should now be significantly reduced for all children, in some areas there are still additional costs for after hours medical care.

In 2007, the Ministry of Health announced that they were increasing funding for doctors visits for children under six, the Minister of Health at the time, stated that “we don’t want any parent to think twice about taking their young child to the doctor because of how much it costs” (Hodgson, New Zealand Herald, 2007). Early this year, the Government released the number of primary care practices in each DHB, opting to provide free healthcare during ‘normal hours’ for the under sixes. This showed that 91 percent of all practices in this DHB have joined this initiative (MOH, 2008). Although, this means that it may still cost families to seek after hours primary healthcare for their sick child.

According to the MOH (2004b), it is not only about affordability issues as ASH rates for children indicate either a lack of early intervention, or an actual attendance at a primary care level. As a result, sick children are presenting later with more complications requiring hospitalisation. The MOH acknowledge that there are a range of underlying socioeconomic determinants that may also impact on early access. The inequalities in ASH admissions for tamariki Māori may perhaps indicate as Robson & Harris (2007) suggest, that Māori are not receiving adequate health care. There is also the issue of actually having primary health care facilities available, in the first place, as it is this lack of primary care availability that can be a barrier for some families. The MOH (2006) report on implementing the New Zealand Health Strategy, acknowledged that not having primary care services available at all hours can be a problem.

As part of quarterly health target performance reporting, the MOH (2007a) requires that each DHB also report on their avoidable admission rates. This includes reporting on their ASH rates for the under five age group. Although this reporting requires DHBs to report on these rates by ethnicity grouping, the focus is very much on reducing the need for the ambulatory sensitive hospital admission in the first instance, as opposed to looking at the needs of those admitted with an ASH.

Some examples of these ASHs for young children include gastroenteritis, rheumatic fever, dental conditions, respiratory infections, cellulitis, or kidney infections (NZCYES, 2005).

1.3.3 Local inequalities

Whilst in the total New Zealand population, under five year olds have the highest rates of ASH, within this DHB, these rates are highest for both tamariki Māori and urban children. The NZCYES (2005) data showed differences depending on the ambulatory sensitive hospital condition in the under five year olds. Whilst gastroenteritis had higher rates of admission for both urban and European children, pneumonia and serious skin infection admissions had higher rates for both Pacific children and tamariki Māori.

These local differences were also highlighted during the initial planning stages for this study. This involved collating the local admission data for approximately 200 children who had been admitted with any of five specific ambulatory sensitive conditions, during a three month period in 2006 (DHB, Casemix, June 2007). Analysing the demographic details of these children showed that, whilst tamariki Māori represented 38 percent of the under five population in this DHB, the admission rates for tamariki were 55 percent. Using the definition of rural and urban for this DHB, this data showed that there were higher admission rates for rural young children (47%). It also showed that the highest rate of admissions were for the under one age group (48 %). A respiratory infection was the most common reason for admission during this period, accounting for 47 percent of all five acute illness admissions. Local disparities in the admissions for an ASH are a cause for particular concern for young children in this DHB. This does however, provide an insight into the possibility of some differing needs for these families, depending on their geographical location (rural and urban) and their ethnicity. This supports the opportunity to explore whether there are actually any different needs for these parents/caregivers after their child's acute admission.

1.3.4 The under fives

Whilst we know that acute illness admissions are higher in the under five age group (NZCYES, 2005), it is these child admissions to hospital for an acute illness that provides a crucial opportunity to support the parent/caregiver(s) with their child's health and wellbeing. Whilst this admission to hospital in a young child may be an 'illness focused' event, it may be turned into a 'wellness focused' opportunity through engaging with the parent/caregivers, meeting their individual discharge needs and encouraging and supporting strong primary care links for children and tamariki.

In order to reap the benefits for long-term health gain (their future health as adults), the need to focus on their health right from early childhood, is well supported (Dowell & Turner, 2007; MOH, 2004b; MOH, 2006; NZCYES, 2005). Whilst these reports share familiar themes about the future implications that young children's health have, this is perhaps best summed up by Dowell & Turner (2007). They state that the opportunity to "ameliorate or prevent the impact of the most significant long-term health problems begins in childhood, when risk factors are developing, rather than in adult life, when they are established"(p.153). It is this relatively recent recognition of the long-term benefits that serves to reinforce the health gain opportunities that could result from turning the focus towards these young children admitted with an ASH.

1.4 SUMMARY

This chapter has provided the background around ambulatory sensitive hospital admissions for young children in both New Zealand the local DHB contexts. There are some particularly concerning inequalities for tamariki Māori, Pacific children and children from families with socioeconomic need within this area of child health. At a local level, this review has also highlighted some of the additional concerns in relation to the geographical nature of this study's DHB, and the higher rurality of the population. An overview of the Ministry of Health's focus on reducing actual ASH admissions in the first place, through timely primary health

care, also serves to reinforce the opportunity to strengthen the continuum care links for these children during these admissions.

Now that this chapter has provided the local context for these children, this leads to chapter two which examines the research that currently exists in this area. This extends further into the area of discharge planning and provides an overview of previous research studies around the discharge needs for families as they care for their acutely ill child at home. Before moving on to the next chapter an outline of the structure of this thesis is provided.

1.5 STRUCTURE OF THIS THESIS

Chapter two provides an overview of both the existing literature and the international studies in this area, and draws upon key themes within the literature which inform the design of this study. Chapter three then provides an overview of the design for this exploratory descriptive study and of the methods used. It includes an explanation of the survey tool developed and the research approach which was a telephone based interview. Then chapter four presents the findings from the study, which describes the characteristics of the population and their expressed needs. Chapter five discusses these findings in relation to the literature. The thesis then concludes with recommendations for practice and for future research.

CHAPTER TWO:

A REVIEW OF THE LITERATURE

The admission of a child to hospital is stressful and creates many uncertainties for parents and caregivers as they cope with their child's ill health and the complex hospital environment (Snowden and Kane, 1995). This stress is not just limited to the time the child was in hospital, as the discharge home and the early time at home can also be difficult (Smith & Daughtrey, 2000; Snowden & Kane, 1995; Suderman, Deatrich, Johnson and Sawatzky, 2000). Whilst there is a substantial amount of research that examines the needs of parents whilst in hospital (often in comparison with staff perception of their needs), there is a much smaller amount of international research that has focused specifically on the needs of parents after their child has been discharged home from hospital. There is an apparent absence of New Zealand based research that has focused on these parents' discharge needs.

This chapter provides an overview of the literature around the discharge needs of parents of children with acute illness admissions. This includes looking at the difference between staff and parents' understanding of discharge needs and what structured discharge planning entails. A summary of the four research studies that exist in this particular area is provided. It then concludes with the implications for this research study.

Literature searching strategies

The literature search for this study, utilised the MEDLINE, PUBMED, CINAHL and PROQUEST databases. Due to the small amount of literature specific to the needs of parents after their child is discharged that was uncovered, the search was extended to include the needs of parents during hospitalisation, as some studies may have included small aspects of parent's discharge needs. The search also involved accessing secondary references, related paper links via electronic searches as well as checking for further research from the seminal authors. Library databases and journals were accessed through the University of Victoria, the local tertiary, and the District Health Board libraries. The New Zealand Nurses Organisation's daily research e-journal network was also accessed. The following

key search terms were used: child, discharge, discharge planning, discharge to home, parents, needs, children, hospital, parental needs (and extended to) acute illness, young children, preschool children, needs, parents.

The need for this particular study was also strengthened by the fact that there was such a small amount of existing research in this area. Whilst there were four studies located that looked specifically at the needs of parents after a child was discharged from hospital after an acute illness, these were all carried out overseas.

2.1 NEEDS AFTER AN ACUTE ILLNESS:

Within this local DHB, there are services that meet the needs of families of children with chronic health care and/or complex health needs. This is usually through the provision of home visiting from specialised staff, overview and support with specialist staff in secondary and/or tertiary health care and the referral to additional support services (personal knowledge).

However, for the majority of young children, their admission to hospital will have involved a relatively short stay following an acute illness, and may not obviously have involved further support services. Shields, Hunter and Hall's (2004) study of parental needs whilst in hospital, found a negative difference between the needs of parents with a child admitted with an acute condition, who felt they did not have their needs met, in comparison with the needs of parents who had a child admitted with a chronic condition. It is this potentially 'unsupported' care that both the Darbyshire (2003) and Smith & Daughtrey (2000) raised as a concern. They stated that parents were expected to take on the sole responsibility for care once the child came home from hospital. In order to better support parents/caregivers on discharge, we need to actually ask what their needs are. This approach is supported by Hayes, Marino and Marino (2000).

There is a small amount of internationally based research looking at the needs of parents after discharge, which includes studies from Canada, the United Kingdom (UK) and Australia (a summary of these studies is provided in section 2.2). There is sufficient concern for the health status of local young children (with inequalities,

the rural/urban split and ASH rates as examples) to warrant a local DHB study, and therefore to provide a small New Zealand based study. The research which this thesis reports looks at the potential opportunities to better support *all* parent/caregiver(s) after their acutely unwell children are discharged from hospital

2.1.1 Hospitals as stressful learning environments

Having a child admitted to hospital is stressful and creates uncertainties for families as they try to both navigate the complexities of the hospital environment and to adjust to the immediate impact on both their child and the wider family (Smith & Daughtrey, 2000; Snowden & Kane, 1995). The emphasis on having a family-focused support approach throughout a child's admission which extends into discharge planning is well supported (Sarajärvi, Haapamäki & Paavilainen, 2006; Snowden & Kane, 1995; Suderman et al., 2000).

However, as hospitals become busier, and acute admissions shorter, the time to prepare a parent for their child's pending discharge can be limited. The nursing literature often looks at the impact this has on nurses, in terms of nurses having a limited amount of time to 'prepare families' for discharge and how best they 'manage' this (Anthony and Hudson-Barr, 1998; Atwal, 2002; London, 2004; Maramba, Richards and Larrabee, 2004; Robinson and Miller, 1996; Sarajärvi et al., 2006).

The busy atmosphere of the hospital is just one of the multiple stressors on the parent/caregiver as they try to care for their children. They are also very concerned for their sick child while at the same time facing a very foreign environment. Within this environment they are seeking and attempting to absorb important information. All this contributes to making hospitals difficult learning environments (Robinson & Miller, 1996; Smith & Daughtrey, 2000; Snowden & Kane, 1995).

Nurses have an essential role in engaging and communicating with the parent/caregiver and in using family centred discharge practices in order to facilitate learning in this challenging environment (Griffin and Abraham, 2006). Communication with families also needs to be flexible. This is demonstrated by the

Suderman et al. (2000) study of parents' perceptions of discharge, which identified three specific learning styles of parents. These included parents with past experiences in health (more likely parents of a child with chronic health needs), those parents who were proactive in seeking out advice and, perhaps most pertinent for nurses and discharge planning, are those parents who are the 'silent parents' and therefore did not ask questions.

The need to involve parents with discharge planning is by no means new as this 'need' was highlighted in an American nursing resource on discharge planning some thirty years previously (Bristow, Stickney and Thompson, 1976). The New Zealand Child Health Strategy clearly states that child health services need to support parents and whānau as the primary caregivers of their child (MOH, 1998a). This supportive role is vital for discharge planning. Both Smith & Daughtrey (2000) and Snowden & Kane (1995) point out that although going home from hospital can be difficult, there is a significant reduction in this stress and anxiety when parents are actively involved in discharge planning,

2.1.2 An ASH admission - a brief opportunity for discharge planning?

For many parents and caregivers at the time of discharge, the 'step outside' the hospital door signals the end to their child's health care by health professionals and a return to taking on the sole responsibilities during their child's recovery at home (Snowden & Kane, 1995). The international literature indicates that it is increasingly likely that this stay in hospital will be brief (Anthony & Hudson-Barr, 1998; Darbyshire, 2003; Dokken and Sydnor-Greenberg, 1998; Maramba et al., 2004; Robinson & Miller, 1996; Smith and Daughtrey, 2000; Snowden and Kane, 1995). This is reflected at the local level, where the length of stay for acute admissions in children has reduced over the past 15 years. Local strategies such as collaborative guidelines (used by primary and secondary care) for the early best practice management of acute asthma and gastroenteritis in children, have managed to keep many children out of hospital (unnamed, personal communication, April 23, 2007). This impact at a local level would mean that children actually admitted with an acute illness, are most likely to be very unwell.

In addition, at discharge, children may be going home at a more acute phase of their illness. The expectations are then placed on the parent or caregiver to take on the responsibility to care for their child during the recuperation phase but also during the later part of the acute illness. Darbyshire (2003) questions the direct effects that these early discharges have on families. He challenges nurses to consider what this means in relation to preparing for discharge.

The reduction in length of hospital stay and discharge preparation time, could serve to strengthen the increasing need for health professionals to actually *hear* what parents and caregivers discharge needs actually are. Hearing these needs and taking an individualised approach to discharge planning might enable optimum partnerships between nurse and patient (*or the parent/caregiver*).

2.1.3 Structured discharge planning

In their paper on applying an evidenced based model for discharge planning Maramba et al. (2003) defined discharge planning as “the process of identifying and preparing for a patient’s anticipated healthcare needs on discharge” (p.123). Despite the increasing recognition within the literature of the need for an individualised approach, there has been a tendency towards the development of more structured discharge planning processes. This may be through the use of guidelines and checklists to assist staff (Dokken & Sydnor-Greenberg, 1998; Langan, 2006), through the use of written resources (Robinson & Miller, 1996), or a more formalised process (Wesseldine, Mc Carthy and Silverman, 1998).

Wesseldine et al. (1998) carried out a randomised controlled trial of the use of a structured discharge package compared with standard discharge care for children with asthma. They saw readmissions as a failure of opportunity for intervention at the first admission. Their UK based study was effective in their aim to reduce children’s asthma readmission rates. They argue that standard discharge care relies on parents enthusiasm, staff experience and time available. Their structured discharge care only took 20 minutes to deliver and could be ‘taught’ to nurses to use with families. Their structured package included an education component and

an asthma management plan. This is similar to what we could use in the New Zealand context.

Whilst there are advocates for the use of structured discharge planning, there is still recognition of the need to individualise the plan. Darbyshire (2003) reinforces the importance of flexibility as opposed to an overly rigid pathway. He also stressed the importance of having a caring dialogue rather than just the handing out of a pamphlet.

Under the 1994 New Zealand Health and Disability Consumers Act (Health and Disability Commissioner, n.d), receiving an individualised discharge plan for their child, and having their discharge needs met as parents and caregivers, could be seen as a consumer right. It is this act that ensures that the rights of all people accessing health or disability services are protected. The Code of Health & Disability Services Consumers' Rights (Health and Disability Commissioner, n.d) involves ten specific rights. Two of these rights have particular relevance to the area of discharge planning. Right five is about communication and ensures that people have a right to information "in a form, language and manner in which you understand" (p.1). Right six relates to the right to information and this states that they "have a right to request and receive a written summary of information" (p.2) (Your rights when receiving a health or disability service, n.d).

The New Zealand code of rights for consumers and the well supported need to use a family-focused approach to children's health care (MOH, 1998a; MOH, 1998b; MOH, 2002; MOH, 2004b; MSD, 2002; PSNZ, 2002; Standards New Zealand, 2004; DHB, 2004), strengthens the need to look at what parents and caregivers actually want, with regards to discharge planning.

2.1.4 Expressed needs of parents/caregivers & staff perceptions of their needs

Currently there is a tendency for health services to assess how well they are meeting needs of patients (or parents) via customer satisfaction surveys, although Heyden (1993) argues that these only measure the extent of patient's agreement

with what health professionals assume are the patient needs. (in Armitage and Kavanagh, 1998). They are not asking what patient's actual needs are but are assuming that they know.

Research that has looked at the needs of parents whilst their child is in hospital, has often compared parent's needs with staff perceptions of their needs (Sarajärvi et al., 2006; Shields, Kristensson-Hallström and O'Callaghan, 2003). Both these studies showed differences in what staff perceived the support needs of parents were and what parents actually expressed as their needs. These study findings can assist nurses to see potential for practice and gain new insights into parent needs, in their setting. Robinson & Miller (1996) suggest that mismatch between nurse's and patient's perceptions of need, arise as nurses perceptions can be informed by pre-conceived assumptions and by previous experience.

Needs, can be also defined either as expressed needs or perceived needs. From a 'discharge needs' approach, *expressed needs* are the needs identified by actual service users. Therefore, these are the discharge needs that parents identify as important to them. *Perceived needs*, are those that health professional 'assume' are the discharge needs of parents. Discharge planning practices may be based around those perceived needs.

Learning about parents experiences (their expressed needs) of their child's discharge and what it was like for them after they have returned home, could help balance staff's perceptions and inform local discharge practices. Grinnell and Unrau (2005) comment that expressed needs are revealed when the people talk about how the problem impacts on them and perhaps suggest what might be done.

It is often the opportunity for hearing these expressed needs in relation to discharge planning that is missing. Snowden & Kane's (1995) study questioned whether discharge information was based on staff's perceptions. The Suderman et al. (2000) study found that involving ward nurses in the interviews with parents after discharge, actually allowed nurses to "unfreeze" their previous beliefs about discharge planning. This further supports the importance of contributing to the gap in New Zealand research around the needs of parents and caregivers after their

child's discharge. Hearing the expressed needs of parents/caregivers around their child's discharge would be very beneficial and may play a role in informing local discharge for these families.

2.2 THE CURRENT RESEARCH ON THE NEEDS OF PARENTS AFTER DISCHARGE

There were four studies located that looked specifically at the needs of parents after a child was discharged from hospital with acute illnesses. These studies were published between 1995 and 2003. They were two Canadian, one UK and one Australian based study. A brief summary of each of the four studies will now follow.

Snowden & Kane's (1995) study looked at the needs of parents after their child's discharge. In this exploratory descriptive study, the researchers interviewed parents of children discharged with an acute illness from one large acute care hospital in Canada. They specifically looked at parents of children aged twelve years and under, who were admitted for at least 48 hours. This study was based on two questions: what is the nature of parents needs following discharge, and what are their perceptions relating to the effectiveness of a discharge follow-up programme designed to meet their needs.

They interviewed sixteen parents who were both urban and rurally based (although these were not compared in their study). The parent's needs related to wanting more information specifically about their child's illness/treatment and recovery. They also identified the need for support in relation to stresses once home. The second part of the research involved nurses working with the parent to address their individual needs. This was then followed up by the researcher, using a telephone interview with the parent to establish how useful the discharge programme was. On follow-up at home, parents identified a need for information relating to their child's acute illness and medication, as well as the need for support. This study recommended discharge planning based on individual needs.

Suderman et al's. (2000) Canadian based study used an action research approach to explore parental perceptions in relation to discharge. They used open-ended interviewing with 20 parents. There were fourteen urban based parents and six rurally located parents. The children in this study had been hospitalised for at least 48 hours with a respiratory problem and were not chronically ill. The children were twelve years of age and under, and 65 percent were aged under six years. The researchers also completed a written survey with 25 parents who chose not to be interviewed. The findings identified three categories of parents as learners. The first category was the experienced parent, who required minimal information to support their caring for their child after hospitalisation. The second was the proactive parent, who actively sought out information and then there was the silent parent who didn't ask questions. Whilst most parents in this small study were satisfied with the information they received about their child, a few parents raised concerns in relation to conflicting information, or to deficiencies in the discharge information.

Parents also wanted to be informed well ahead of discharge timing, in order to allow them to plan. This study reinforced that going home was stressful for families, with lack of sleep, adjustments to their work and the need for close monitoring of their child's health as the identified stress factors. The authors commented that the findings provided insight for nurses that could be used to better inform their discharge practices. In particular it noted the need to recognise the differences between the learning style of parents.

Smith & Daughtrey's (2000) UK study used a qualitative approach to explore discharge preparation from one hospital. They completed a telephone survey with 164 parents of children aged three weeks to eleven years, who were discharged following an acute illness. Questions looked at discharge preparation, the discharge itself and any support needs required following discharge. The researchers then used semi-structured interviewing with 20 parents who had identified that they had needed the support of a health professional within the first 48 hours of their child being discharged. This study showed that planned discharge negotiated with the parent was important in reducing stress. However, both isolation and anxiety were

identified as issues. The need for reassurance and advice was also important in the first 48 hours (from someone who knew their child's situation). Parents wanted to have a choice of contacting either the primary care service or the hospital for follow-up advice and support. This study recommended using an individualised approach to discharge, including providing written information for families. In line with their 'seamless care' approach, they encouraged good communication between health sectors and recommended linking families with primary care.

Darbyshire's (2003) Australian based study used an interpretive design to provide insight into the meaning of recovery from the parent's perspective. Ten mothers of children aged six months to fourteen years who had undergone day surgery, or had only spent a few days in hospital, participated. Eight were interviewed in small groups and two were interviewed individually. The findings showed that the mothers considered all aspects of their child's illness impacted on how they managed recovery at home (including admission, hospitalisation and discharge). Mothers felt that written information, including pamphlets, were less important to them, than knowing that staff really cared about them and their child. They wanted a contact phone number for advice and knowledgeable help following discharge. They also found that mothers would have appreciated a follow-up phone call from the hospital.

2.3 THE IMPLICATIONS FOR THIS RESEARCH

This literature review has provided the background that has supported the planning for this study. The emphasis on the need to use a family-focused approach to children's health care was well supported and has direct implications to meeting the discharge needs of parents and caregivers following their young child's admission with an ASH.

Whilst the need to have an individualised and family-focused approach to a child's discharge care is evident in the literature, what is also clear is that the discharge needs of parents after a child's acute illness have not been well studied to date. There is reference to the difference between parents expressed needs around discharge and of health professionals' perceptions of their needs. There is also

evidence to suggest that discharge planning is often based on what staff perceive parents need.

The four existing research studies that looked at the discharge needs of parents (Darbyshire, 2003; Smith & Daughtrey, 2000; Snowden & Kane, 1995; Suderman et al., 2000) used different research approaches. They all focused on children under fourteen years of age, and with the exception of one study, the focus was on children admitted with an acute illness. Two studies mentioned urban and rural parents, but there was no comparative analysis for either of these variables. Three of the four studies used face to face interviewing with one using a large telephone survey as one component of the research. There were three common findings that came through from summarising this research. These were that discharge to home was stressful for parents; that there was a need for a contact number for reassurance and knowledgeable advice and having individualised well planned discharge approach to meet their needs, were all important to parents.

Although only four research studies were located, these were not recent studies, as they ranged from 1995 to the most recent study completed in 2003. The needs of parents after discharge, following their child's acute illness admission, is not a well researched area. This lack of current research may be due to the assumption that, as Rennick (1995) states "the effects of acute illness are often regarded as having faded within a few months post discharge, studies have focused on fostering a healthy hospital environment for the child and parent, but have seldom moved beyond this" (p.260). It is possible that, as many of these children with an ASH move through the hospital system relatively quickly, these parents' discharge needs are presumed to have 'faded' and therefore are not seen as needing research.

This research is informed by this review of the literature. As an understudied area, it also seeks to provide some much needed local research in this DHB's context. The focus is on the expressed needs of parents or caregivers after their young child (under five years of age), has been discharged from hospital, following an admission to hospital for an ambulatory sensitive condition. The intention is to support the MOH's (2004b) 'window of opportunity' for these children and their parents/caregivers.

This study seeks to provide some much needed research around the discharge needs of parents/caregivers. It will be a local study based in one New Zealand DHB's hospital setting. Its particular strength will be to provide some local evidence that may inform local discharge practices for children and their parent/caregiver, after an ambulatory sensitive hospital admission, at this DHB.

2.4 SUMMARY

This chapter has looked at the literature around the discharge needs of parents after their child's acute illness admission. This included an overview of the literature in relation to hospitals as stressful learning environments for families and the implications for discharge practices. The summary of the current research studies that have been done in this area highlighted some of the key findings and also the research approaches used. This was then followed by the implications for this research. The information presented in chapter two has helped to inform this study design and this will be reflected in the detailed research design, contained in the next chapter.

CHAPTER 3: RESEARCH DESIGN

This chapter provides both the rationale for choosing the exploratory descriptive research design to meet the particular research study's aims, and also provides a complete overview of the method used.

The research approach section includes the study's aims and objectives, and is then followed by the background for choosing the descriptive comparative approach. As it is the discharge needs as 'expressed' by the participating parents and caregivers that is central to this research study, this chapter also provides some discussion about 'expressed needs' in contrast to 'perceived needs'. This then leads onto the rationale for choosing to use a structured survey tool with a telephone based interview approach. The process used to develop the survey tool specifically for this study is then provided. The study's inclusion and exclusion criteria are followed by a discussion on both the representativeness of the study sample and the sampling processes used. In the research process section, both the study setting and the processes involved for gaining participants are described. An explanation about the telephone interview process is provided. This section then concludes with the data analysis processes used.

The next section discusses the validity and reliability of the survey instrument and of this research study. Generalisability is also discussed in this section. The chapter then concludes with an overview of both the relevant ethical issues and the ethical requirements for this particular research.

3.1 THE RESEARCH APPROACH

Whilst the discharge needs of parents caring for a child with a complex chronic health condition may have been well studied, there has been a limited amount of research that has actually looked at the needs of parents caring for their young child once home from hospital following an admission for an acute illness. Add to this, the fact that this research has only been carried out overseas, there is an apparent gap in the New Zealand based research in this area. It was therefore both a

particular interest in this subject area, along with this chance to provide some locally-based research that became the driving force behind this research study.

This study provided an opportunity to ask parents and caregivers of young children, admitted with an identified acute illness, what they felt were their main concerns and needs once they were home from hospital caring for their recuperating child. This included getting them to rate how they felt these needs had been met, and to include any ideas and suggestions they may have, that could support any needs.

Being able to share the study's findings with local health professionals was fundamental to this research. Staff in the clinical setting will not know about these families' experience of discharge and their needs once they have left the hospital. This study intends to provide an insight for staff, into these families' needs and concerns after discharge. It is anticipated that this insight may also help inform future discharge preparation practices to ensure that the needs of these parents and caregivers within this particular DHB, are met.

3.1.1 Aims and Objectives

Using an exploratory descriptive design, this research aimed to describe the expressed needs of parents/caregivers in supporting their young child's health care once discharged home from hospital. This research also sought to describe if there were any differences in these identified needs after discharge within three key areas. These included, comparing any differences in the needs expressed between rural and urban parents/caregivers, if there were any differences in need between the parent/caregiver's based on (self-identified) ethnicity, and finally, if there were any differences in the needs expressed by parents/caregivers, depending on the age of their young child.

3.1.2 Research as exploratory description

This exploratory descriptive study utilised two research approaches. As an exploratory study, it focused on studying a relatively unstudied area. The exploratory approach is supported by Nieswiadomy (2008), as the method to use when there is limited knowledge in the topic. This research also utilised a

descriptive approach which is best suited when there is limited existing information available on a topic. The choice is supported by Bickman, Rog and Hedrick (1998), who state that the descriptive approach is used “when the researcher is attempting to answer ‘what is’ or ‘what was’ questions” (as cited in Bickman and Rog, 1998, p.15). This research sought to answer the one central ‘what are’ question by asking what the needs of parents/caregivers are, when caring for their young child at home as they recuperate from an acute illness. Through using a comparative context, the research objectives were to describe the ‘what were’ component. In this case what were the differences (if any) between these needs of the parents and caregivers, in terms those residing in rural or urban areas, the differing identified ethnicity of the parent/caregiver and the different age of their young child.

Whilst descriptive research has its limitations, in that it cannot, as Bowling (2000) says, be used to identify a cause and effect relationship, it does however, play an important role in highlighting a phenomenon of interest that is unknown. Steinberg (2004) referred to descriptive research “as corrective experiences precisely because they help us correct our perceptions, which are too often inaccurate, if only because we rarely have the chance to see a picture in total” (p.48). Health professionals working in the inpatient clinical ward environment will not usually know the experience for these particular families once they leave the hospital. It is exactly that missing piece of the total picture that this particular research intended to describe, thereby to finding out what the needs of parent/caregivers were once home from the hospital and whether there were any components of discharge preparation that health professionals could be doing better to meet these needs. It is this potential ability to adjust services or to “stimulate social action and provide the basis of well-targeted social policy interventions” that De Vaus (2002, p.19) says is a key role for descriptive research. It was anticipated that this research study would offer an insight into the discharge needs of those caring for their recuperating young child, once home.

3.1.3 Expressed needs versus perceived needs

It is through the use of a descriptive designed survey tool, that this study aimed to create the opportunity for participating parents/caregivers to express *their* own needs. It is their *expressed* needs as service users, in this case the parents' or caregivers' needs that may be different to the *perceived* needs that health professionals think are parents/caregivers' needs, and upon which existing discharge planning practices may be based. This reinforces Steinberg's (2004) support for descriptive research being able to correct previous held perspectives, in this case perceptions around parental discharge needs that health professionals might have. In addition to expressing their needs, this study also sought to hear any ideas that participants may have, in relation to future discharge preparation for families (Grinnell and Unrau, 2005). It is the opportunity to find out the needs of parents and caregivers, that would ensure that local discharge practices for children and their families, are based on a balance of both the expressed and perceived needs.

It was important that this study design was able to include all discharge needs that were expressed by the parents and caregivers in this study, as their needs were to form as large part of the descriptive findings. In order to capture the diversity of expressed needs a survey tool was developed specifically for this study (the development of the survey tool will be explored in section 3.1.6).

3.1.4 Choosing the survey approach

Despite the desire within research to want to explore an ever increasing range of questions within an area of interest, the need to curtail this enthusiasm within descriptive research was essential in order to avoid what DeVaus (2002) stated as ending up "as an exercise in mindless fact gathering" (p.19). Therefore, the use of a structured format which allowed for the inclusion of both open and closed questions, whilst also maintaining a concise nature, became the rationale for choosing the survey approach for this research. The choice of the survey tool also supported the data analysis phase which needed to be consistent with a descriptive research study.

It was important to use a structured framework for the questions around parent/caregivers needs after discharge. This was essential to ensure that the findings would be both useful to practice and also to support the comparative objectives particular to this study. It was the use of the structured approach, for consistent data collection, in order to enable comparisons that were supported by both Kumar (2005) and Parahoo (2005).

Although a structured survey can be used for either self-completed questionnaires or interviews, it was the personal perspective and nature of this study (seeking to describe parents/caregivers needs when first home from the hospital), that meant an interview approach would be more appropriate. It was determined that this approach would provide the opportunity for the participant (and interviewer) to seek further clarification about any question. Although the use of structured surveys utilises a standard format approach (using consistent questions and order), the structured interview can allow the interviewer to ask what is referred to in Parahoo (2005) as ‘non-directive probes’ such as “In what way?” or “How do you mean?” (Cartwright, in Parahoo, 2005, p.319). This is unlike the self-completed questionnaires for example, the postal survey, where there is no opportunity for any clarification, and “rely on the respondents understanding and answering *the* questionnaire” (De Vaus, 2002, p.123). Whilst structured survey interviews are suited to being carried out either through the face-to-face or the telephone-based interview method, this study chose to use telephone-based approach.

3.1.5 Choosing the telephone-based approach

A major contributing factor involved in choosing the telephone-based interview approach for this study, was the particular rural-urban geographical nature and population of this DHB. It was anticipated that there would be a substantial number of rural participants in this study, and therefore to be representative of the population being studied, it was really important to be able to include participants who lived anywhere within this DHB’s catchment area. This geographic advantage of using telephone interviews was supported by Barribal, Christian, While and Bergen (1996). It could be argued that a postal survey could have met this need, however, achieving a good response rate to postal surveys is reputedly more

difficult (Babbie, 2007; Barribal et al., 1996; DeVaus, 2002; Mc Murtry, in Grinnell & Unrau, 2005; Parahoo, 2006). Regardless of this issue, the self-completed survey approach was not considered for this study. This was because the potential benefits to be gained from the researcher–participant interview, such as enabling more clarification to be sought and the qualitative nature of the topic, (participants expressed needs) meant that the telephone interview approach was considered more suitable.

There were additional advantages in choosing telephone-based interviewing that suited both the timeframe and size of this study. Telephone interviews are relatively concise in nature, for example Jamieson’s (2002) guideline recommended that telephone interviews should last no more than ten minutes. Whilst the telephone approach requires significantly less time than face-to-face interviewing, it can also be seen as less invasive, in that it does not require the participant to meet the researcher, and therefore, does not involve meeting in their own home or at an agreed venue. An additional advantage also meant that without the need to travel to meet participants it also allowed the researcher more flexibility to be able to complete the interview at a time to suit each participant’s needs (day or night). A suitable time for the telephone interview survey was arranged during the initial phone contact by the researcher. This also recognised the busy nature and context of these families’ lives. At the same time, the researcher aimed to complete the telephone interview within a realistic timeframe to maximise the study participant’s recall of their needs after discharge. It is for this reason that attempts were made to try and complete the surveys within the first two weeks of the participants’ child being discharged home from the hospital.

The telephone interviews took approximately 10 to 15 minutes to complete, the initial phase focused on building and maintaining rapport with participants. This played an important role and was factored into the overall interview timeframe. The importance of this rapport building is supported by the early work of Groves (1979) ‘who said that “first few moments of the interaction should be designed to request no information but rather to attempt to develop trust with the respondent” (Shuy as cited in Holstein and Gubrium, 2003, p.181). In this study the first minute

or two of the telephone interview, involved introducing the researcher, the research and inquiring how things are going for them and their child now. Thereby acting as a standardised dialogue to 'guide' (albeit not to restrict) initial telephone conversations. This study also involved audio taping the telephone surveys. This was intended to further minimise the time required for the participants, in that there was no delay whilst the researcher wrote their responses. But it also intended to help maintain rapport throughout the phone interview by enabling the researcher to 'just listen' during the interviews. Permission to audio-tape the telephone interview was sought from participants in their information sheet, and discussed at both the initial set-up phone call and prior to the survey with verbal consent given first. Although participants had an information sheet (Appendix A) handed out at the ward level, which introduced the research and researcher, the reality was that many parent participants had not read it, or had perhaps since 'forgotten' the information.

Unlike face-to-face interviewing, completing research by telephone interviewing does not involve the cost of traveling to interviews, telephone interviewing does however, involve the research costs with the associated toll calls and calls to mobiles (some families may no longer have a landline). Overall, choosing the telephone approach over face-to-face interviewing had significant advantages for both researcher and potential participants, whilst also providing the opportunity for two way researcher-participant clarification and dialogue. The reduced time involved to complete each interview by phone also meant that this study could involve more participants. It was for all these reasons that the telephone interviewing approach overall was deemed the most appropriate method that suited both the nature of the research topic and the study's survey tool.

3.1.6 Survey design

It would have been ideal to have been able to utilise a survey tool that had already been developed from one of the previous international studies. This also could also have provided an opportunity to compare international study findings with New Zealand based findings. Unfortunately, although three of the four previous studies utilised a telephone-based survey with parents as a component of their research approaches (Smith & Daughtrey, 2000; Snowden & Kane, 1995; Suderman et al.,

2000), there were no pre-existing survey tools available that met this study's intended focus. Whilst the Smith & Daughtrey (2000) United Kingdom study incorporated a large telephone based survey, they didn't actually report on either the telephone survey results or specific detail about the telephone survey tool they used, as the purpose of the large phone survey was to help find a smaller number of parents who had needed support after discharge to interview. Attempts through an internet search using the terms (child AND Discharge) AND (Parent AND Need) AND (survey OR Tool OR Questionnaire) also failed to locate a useful survey format.

However, although the Suderman et al. (2000) study used open-ended interviewing with parents, they did include their interview guide in their research article. The type of questions used did provide some a small contribution towards the development of the open questions and prompts used in this survey tool.

Despite the unsuccessful attempts to locate an existing suitable format, it was possible however, to incorporate two of the previous international research findings into the development of a new survey tool specific for this study. These findings included the parental need for written information, relating to their child's health and care after discharge (Smith & Daughtrey, 2000; Snowden & Kane, 1995; Suderman et al., 2000). The second research finding included, was the importance identified by parents in having a contact person and/or a number to call, should any follow-up advice or support be required, particularly in the first 48 hours after discharge (Darbyshire, 2003; Smith & Daughtrey, 2000; Suderman et al., 2000). These two findings were included as separate closed questions in the latter part of the survey, to determine if these aspects had been provided for the participants in this study.

There were definite benefits in developing the survey tool specifically for this study. It provided the opportunity to 'test' previous research findings in a local context. It also enabled the complete development of a range of both open and closed questions specifically focused towards this research study. As such, any questions that were included, needed to be considered right through to the descriptive analysis phase. The final survey had a total of 11 questions, which were

in five sections, or as Bowling (2002) referred to them as modules, emphasising the importance of grouping similar questions together as being “ more professional and less irritating for respondents” (p.277). Each section of the survey tool, developed for this study (Appendix B), is now discussed.

The baseline data

The first section captured the baseline data from the participant. This included the age of their child, the reason for their recent admission, their length of stay in hospital and how long they had been home from hospital. These questions also served the dual-purpose of both building rapport with the participant, whilst also learning about the context for them and their child.

The open questions

The initial baseline conversation facilitated the move towards the second section of the survey. This included the three open questions, that asked them to recall what they identified as their main needs or concerns in caring for their recuperating child when first home from hospital. This then moved towards asking if they felt that there was anything they felt they needed that could have helped them with their child. A final open question asked if there were any other needs, thoughts or ideas they may have around supporting them at home. There were also prompts (or probes) developed for each question to support any further clarification the participant may require. Sometimes further elaboration about an answer may have been required. The open nature of these questions supported the ability for participating parents/caregivers to express their needs from their perspective. These open questions provided a qualitative aspect to what is otherwise a predominantly quantitative designed study.

The rating scale

The third section involved one rating scale question. This invited the participant to rate on a scale of one to five, how *they* felt their needs had been met (by the hospital and prior to discharge) in order to care for their child’s recovery at home. This ranged from ‘not met at all’ (1) through to ‘completely met’ (5).

The closed questions

The fourth section provided three closed questions that specifically related to the discharge preparation for the parents/caregivers. This included two questions that related to the previous research findings. These asked participants whether they had they received any written discharge information, and if they had been given a suggested contact number for advice. An additional question in this section also asked if they had any follow-up referral to a health professional after discharge. The interviewer asked for more detail if a participant answered yes to any of the three closed questions. It was important to ask these questions because knowing the type of existing discharge information and support that each participant had already received would help to inform the study. This knowledge would help to put their needs and concerns that they expressed in this study into context.

Final demographic questions

The last section of the survey included two demographic questions that enabled the comparative objectives of the study to be met. These included comparing any differences in the needs expressed between the parent/caregiver's identified ethnicity (ies) and between rural and urban residing parents and caregivers. These were asked with a brief prior explanation that the research study was attempting to see if there may have been different needs for parents/caregivers. The demographic questions were asked at the conclusion of the survey. This was supported by both Babbie (2007) and De Vaus (2005), as they encouraged starting with the questions that people are more likely to want to answer. This decision was also based on the premise that asking the parent/caregivers their identified ethnicity (ies), early on in the interview may have made them uncomfortable. Participants were first asked if they were comfortable stating their own identified ethnicity (ies), thereby giving them the option of not answering. The interview questions then clarified whether they lived in an urban or rural locality, based on this study's definitions.

The survey interview then closed with participants being provided with the opportunity to provide any further comment, as well as to be able to ask anything further about the research study. Participants were also offered the option of

receiving a brief report at the study's conclusion. Finally each participant was offered a small token of appreciation (a \$5.00 grocery voucher) for their time and input into the study.

Pre-testing the survey tool

Pre-testing of the survey tool involved different stages in the tool's development. An earlier version was trialed in a telephone interview with a senior nursing colleague, who has worked extensively with children and their families in the community context. This trial had a particular focus on the use of the prompts (or probes), and ensured that the study explanations were adequate. This format was also trialed by phone with a parent of a young child who had recently been in hospital. This enabled the checking of questions whilst also going over the audio-taping explanation, and also ensuring that the final demographic questions, in particular the question about the parent/caregiver's ethnicity was asked in an appropriate way.

The next step involved advice as Bowling (2002) suggests with "experts in the field" (p.275). The advice of the senior paediatrician, whilst not particular to the survey tool, did raise the importance of ensuring that the study focused on children with an acute illness only and did not include young children who also has an underlying chronic health care condition. These parents and caregivers were likely to have had different needs after discharge, which may have distorted the study findings. Subsequently the expert nurse advice for the final survey draft was sought from two very experienced senior children's clinic nurses. This last step involved asking them each question in the survey. The survey tool was also approved as part of the ethics application

3.1.7 Selection of participants

For the purpose of this study, the term parent/caregiver was used to for a parent *or* primary caregiver who was involved with their young child's health care. This involvement included both whilst the child was in hospital and in the following two weeks after their discharge. It was intended that use of the dual term would not

restrict potential participation, but acknowledge the diversity of families and whānau (Wepa, 2005).

3.1.8 The inclusion and exclusion criteria

The five specific acute illness categories studied were an admission for a respiratory infection, acute asthma, gastroenteritis, skin infection or a febrile convulsion. Other inclusion criteria for this study were that the child was under five years of age, they were admitted for at least 24 hours and lived within this DHB's geographical area. Choosing five common acute illnesses that resulted in hospitalisation for young children under five years of age resulted in combining several Ambulatory Sensitive Hospitalisation's (ASH) into themes. This meant, for example, that acute bronchiolitis, pneumonia and croup were categorised as a respiratory infection.

This study excluded parents or caregivers who did not speak English and/or whom would require an interpreter. Interpreters would have made the research both costly but more importantly it would have made the participant consent for involvement both complex and protracted. Parents/caregivers of children, who resided outside this particular DHB, were also excluded from this study. It was possible that participants from outside this DHB may have had differing needs after discharge. This also supported the fact that this study aimed to provide some locally based research in one New Zealand DHB.

It was important to ensure that we did not have children involved in the study who had an underlying chronic health condition, with a subsequent admission for an acute illness. This was to avoid the potential for any distortion of the findings, as these parents/caregivers may have different needs. They are more than likely very experienced with their child's hospitalisation and the follow-up discharge support they require. One example of this is young child with a history of multiple admissions following a premature birth who was admitted with a chest infection. At a potential participant selection level, this was easy to address, the staff member involved in identifying potential participants was the Clinical Nurse Manager, who

would choose not to include to parents/caregivers of children with an underlying chronic health care condition within the study.

3.1.9 Representativeness

Having a study sample that is as representative as possible is defined by De Vaus (2002) as being “one in which the profile of the sample is the same as that of the population (e.g. gender, class, age, race etc)” (p.70). To know what this ‘profile’ might actually look like it was therefore, important to ‘know’ both the size and the demographics of the potential population. This required accessing the clinical coding data for the children admitted with these acute illnesses to this children’s unit. This data was collected using the International Classification of Diseases Code (ICD-10-AM) system (Clinical Coding booklet, n.d).

At the planning stages for this study, it was important to understand the potential number of children who would meet this study’s criteria during the planned study period. It was equally important to find out the ethnicity of the children, their geographical location, the age of the children, and the reason for their admission, to ensure a representative population. This involved looking at these admissions for the same three month period in the previous year. The overall admission data during that period showed that a parent or caregiver of approximately 200 children would have been potential participants in this study. Overall, this showed that if the study population was to be representative then there would be a higher number of participants with a child, who identified as tamariki Māori, were from a rural area, were under one year of age and would most likely have been admitted with a respiratory infection (DHB Casemix report, June 2007).

3.1.10 Sampling

Initially, the sampling approach used was based on the availability of participants. This relied on those parent/caregivers expressing an interest in being involved, however, whilst this was not seen as the best sampling method, as De Vaus, states availability sampling “must be used with caution” as “these samples are the least likely of any technique to produce representative samples” (De Vaus, 2002, p.90).

This study attempted to be representative, particularly given the inequalities that exist for these acute illness and ambulatory nature of these admissions. This representativeness supported the ability to provide a demographic picture to predict the participant population required. It is this ‘picture’ that would play a role in the sampling technique used for this study. The initial availability sampling relied on those participants who would choose to be in the study. As the study progressed it would be possible to change to a more purposive approach to sampling. This is defined by De Vaus (2002) as “a form of non-probability sampling where cases are judged as typical of some category of cases of interest to the researcher” (p.90). This meant that it was possible to ask at the participant selection level for more participants with a particular characteristic. For example requesting a wider sample of parents/caregivers with a child admitted with acute asthma.

These sampling techniques are reliant on potential participants being offered the opportunity to participate in the study, and then actually choosing to participate in this study. However, there are no guarantees that either non-probability technique will provide a truly representative sample. The process for accessing the study’s participants is now discussed.

3.2 THE RESEARCH PROCESS

3.2.1 Setting

Participants were accessed from the paediatric medical ward at the one hospital. This is a 20 bed (24 over the winter period) specialist children’s unit, which caters for children up to the age of 16 years of age from across the DHB area.

Only one staff member, in this case the Clinical Nurse Manager (CNM) was involved in the research. The CNM was responsible for approaching potential participants about the study. Although the researcher had no involvement in the selection of participants, initial preparation included the development of a participant selection resource to assist the CNM. In addition, ongoing contact between the CNM and the researcher was maintained throughout the study, to support this role.

All research (the telephone interviews) was carried out once the parents/caregivers had been discharged home from the hospital. Therefore, the actual study setting was the parent/caregivers home.

3.2.2 Gaining participants

Parents and caregivers of young children who had been admitted and met the study criteria were approached by the CNM to see if they were interested in participating in the study. It was explained that it was a telephone-based survey and was to be completed by a nurse researcher once they were home from hospital. If they were interested in the study, then a participant information sheet (Appendix A) was provided. The CNM then liaised with the parent/caregiver to complete the research participant baseline detail sheet (Appendix C). The researcher collected these detail sheets, directly from the CNM on a weekly basis. The participant selection process only took place during the CNMs days of work. This meant that this occurred during Monday to Friday. Potential participants who had been discharged outside these days were not approached.

The study period initially chosen (August to October), is known as the busiest time of the year for admissions for children in this area. This is supported by Vogel (2005) “The large winter peak in these (*respiratory infection*) admissions has a major impact on staffing needs” (in NZCYES, 2005, p.64). However, the extremely busy nature of the study setting during this period resulted in times when the CNM was simply unable to commit any time towards this study. This resulted in extending the participant selection by a further two months (this is discussed further in section 3.4).

Although only the CNM in this study setting had involvement in the study, it was important that other staff had an awareness of the study taking place. This was to ensure that if a parent/caregiver on this ward had been approached about possible interest in the study by the CNM, and then mentioned the research to another staff member, they wouldn’t feel concerned if the staff had never heard of it. The latter may have caused concern for the parent/caregiver and discouraged potential participation. A simple flyer was developed for the staff notice board, this aimed to

raise staff awareness about the study in progress in this setting. This introduced the researcher, the basic detail of the study and the timeframe (Appendix D).

3.2.3 Sample Size

Using the previous year's admission figures, the potential population of children meeting this study's criteria was approximated to be about 200 children for this study period. This would mean that selecting a minimum sample size of thirty participants, would equate to about 15 percent of these acute admissions to this paediatric unit. Although this percentage wasn't the deciding point, it was more important to remember this studies original intent. This was to provide a small exploratory descriptive study, in an otherwise unstudied topic, focusing on the discharge needs of parents/caregivers for young children following an ambulatory sensitive hospital admission.

Being able to interview parents/caregivers by a telephone- based approach also meant the participant sample was substantially larger than studies that use face-to face interviews. This would support this study's intention, as the ability to have a larger sample would also enable a comparison of the needs between the different groups of participants. A very small sample size would not have supported this.

As an exploratory descriptive study, it intended to describe these parents' needs, as expressed by them. It was Steinberg (2004) who said that in descriptive research "generally a sample of thirty cases is considered the minimum" (p.48). However, as an exploratory study also, it sought to learn about an understudied area and therefore the size of the study is perhaps less important. It is also well recognised that qualitative studies tend to be smaller than quantitative studies (Gillis and Jackson, 2002; Kumar 2005; Parahoo 2006). Although, this study design does include both quantitative and qualitative aspects, it is important to remember that as an exploratory descriptive study, it is a starting point and does not seek to be generalisable at all outside this local study context. It is anticipated that a minimum of thirty participants may meet the study's ability to meet the intended comparative component.

In hindsight, whilst the ICD coding identified children who had been admitted with one of the study's five acute illnesses, this process had not managed to remove those children who also had an underlying chronic health condition. There are many ICD codes for these, consequently it is likely that the predicted potential population of 200 children admitted to this area, may have been an overestimation.

3.2.4 The telephone contact

It was important that as the researcher, I acknowledged the complex and busy nature of the lives of parents and caregivers who participated in this study. This was one of the distinct advantages in choosing the telephone-based interview approach, as this enabled the ability to complete the research at a time to suit each participant. This meant that the research interview could be completed at any time of the day or night. There were also no financial costs for the study's participants, as all telephone calls were placed by the researcher.

It was also important for this study, that this telephone interview was completed within a realistic timeframe to support the participating parents/caregivers recent recall of their needs. It is this importance of recalling recent events that is supported by Grinnell & Unrau (2005). To support this recall, this research attempted to complete the telephone interviews within the first two weeks of their child's discharge from hospital.

This usually involved two phone calls to each participant. The first phone call was to check that they still wanted to participate, and to schedule a time for the phone survey at a time to suit their needs. The second phone call involved the actual survey interview. This was designed to take approximately 10-15 minutes to complete and included introducing myself, revisiting the research, explaining what was involved in the study and discussing the possibility of audio-taping the telephone interview. It was anticipated that audio-taping would strengthen rapport building during the interview, by allowing the researcher to solely focus on listening to each participant (as opposed to also trying to take notes during the interview). It also ensured that the more detailed responses often provided, to the open-ended questions, were able to be recorded verbatim. At the completion of

each telephone survey, the audio-tape was listened to and notes transcribed onto the survey tool. Despite the advantages for the researcher, the decision around audio-taping was always determined by the participant. On occasions this option could not be offered to participants, if audio-taping facilities were not available. Audio-taping relied on the availability of facilities conducive to recording, this included access to a speaker phone as well as the privacy to allow this. This availability depended largely on the interview time chosen by the participants. Consequently the option of having their telephone interviewed for the purpose of this research was available and offered to nine of the eighteen participating parent all nine provided their verbal consent to audio-taping. For the other nine parents, their statements were transcribed onto the survey tool, during the telephone interview.

3.2.5 Data analysis

This study's survey tool (Appendix B), collected both quantitative and qualitative data, both of which were analysed. A coding system was developed for the quantitative study data, and after each telephone interview, the data was entered directly onto an excel spreadsheet. This included the baseline demographical data (child's age, admission reason, length of stay, their ethnicity, geographical location, and the parent/caregiver's ethnicity). These were presented in two frequency tables to allow a comparison with the same data for the overall children acute admitted to this unit during the study period, with the intention of providing a measure for the representative or true reflection of this study's participant population.

The participant responses to the three closed questions (questions nine A, B and C) in the survey tool were also coded. This data is presented as a simple frequency table. Responses from the rating scale (Question eight) from this study are also presented in a bar graph. To meet the comparative aim for this study, these ratings were also presented using descriptive statistics in a table form, showing mean, median, mode and range. This resulted in categorising each rating response into the following groups; rural and urban participants, ethnicity of participants and the child's age.

The qualitative data (Questions five, six and seven) involved entering each participant's responses that were documented verbatim, directly onto excel spreadsheet. At this stage, any identifiable details in their statements (such as names), were removed from the data, and pseudonyms were used to ensure the anonymity of study parents in the final report, as it was planned to provide some verbatim data to support the key themes drawn from the study findings. At the completion of the telephone surveys, the open ended questions were analysed using a content analysis approach. Key themes have been drawn from the main concerns or needs they felt when they first came home from hospital. Where regular key themes have been identified there may be some quantitative analysis provided, in terms of the number of times a key themes occurred as discussed in Wilkinson and Birmingham (2003).

Finally, in keeping with the comparative objectives of the study, again where possible key themes that emerged from the findings, have been analysed into the following groups; rural and urban participants, participant's ethnicity groups and the different age of the young child. Whilst the open questions were qualitative in nature, the comparisons have been presented in a quantitative format, and therefore, includes the number of times a key theme arose. If there were any clear differences in the themes identified between these comparative groups, then this is mentioned.

3.3 VALIDITY AND RELIABILITY

The validity of a study is defined as "the degree to which it measures what it is supposed to measure" (Pallant, 2007, p.7). As this study's instrument measure, the survey tool was pre-tested, and included input from experts in the field. Kumar (2005) suggests that validity is also about being able to justify every question in a survey tool, and ensuring they are meeting the study's objectives. This survey tool did measure the study's aim, in that it sought to describe the identified needs of parents/caregivers in supporting their young child's health care once discharged home from hospital. Although validity is not quite so straight forward when the studies are about an area of attitude, Kumar (2005) states the way around this is to "ask several questions in order to cover different aspects of it" (p.154). The survey

design met this through using both open and closed questions, as well the inclusion of a rating scale.

Reliability on the other hand is determined by the “extent to which, on repeated measures an indicator yields similar readings” (Gillis & Jackson, 2002, p.712). The survey tool (Appendix B), was found to be useful in identifying the discharge needs and concerns that parents/caregivers had when first home. The rating scale question provided a diverse range of ratings (therefore not ‘similar’), from the parents/caregivers in this study. This would be expected as it was based on individual opinion. Both Steinberg (2004) and Kumar (2005) say that reliability can also be ensured through having interview conditions that are consistent. This study ensured that there was privacy for all telephone interviews, and arranged at a time convenient to meet the participant’s needs. Maintaining privacy, and using a non-rushed approach, was used to ensure consistency in the population sample. The survey tool used a structured interview schedule (including prompts), this approach enabled the survey tool to be used with a wider population sample, and therefore, further test the reliability of this survey tool.

3.3.1 Generalisability

As a small exploratory descriptive designed study, it is very much a study based on the expressed discharge needs of parents and caregivers, in one paediatric ward and in one DHB. The overall intention was to describe the needs of a sample of the parents/caregivers from this particular population. This would then provide some local research that may inform future discharge preparation practices to ensure that we meet the needs of these parents and caregivers within this DHB. It is very much a starting point for research in this particular subject area, and as such, may encourage further local research.

Both the study setting and the context of this particular DHB are provided in this report. However, although this small study is not generalisable as such, it may provide the potential for others to consider the findings and recommendations in light of their practice areas. This could be another New Zealand DHB or in a

similar child health setting internationally, and may well provide the opportunity for some further research in this much needed area.

3.4 ETHICAL ISSUES

This study involved ethical approval from the DHB Kaumātua Kaunihera (Appendix E), and the Regional Ethics Committee (Appendices F and G). A locality agreement with the DHB was also required, as although all actual research was completed once the participant was home from hospital, the study participants were first approached about the research study (by the CNM), whilst within this DHB's clinical environment.

Ethical issues that were addressed in this study included acknowledging that participants could choose to withdraw from the study, at any stage, and that as the researcher, there were processes were in place to support this. It was important to ensure that the anonymity of participants in the study was maintained, by removing any names and identifiable information, and using pseudonyms in the final study report. Processes needed to be in place, should a participant express a concern about their child's hospitalisation or care during the telephone interviewing.

As part of my consultation with the Kaumātua Kaunihera research sub-committee at this DHB, I was required to complete a Health Equity Assessment Tool (HEAT), (MOH, 2004a). I presented my research ethics application and HEAT at their research sub-committee meeting. They approved my research, and made the suggestion at the meeting that I could include an alternative phone contact for potential participants who do not have telephone access at home, to ensure participation opportunities for all potentially interested parents/caregivers. This was subsequently added to the participant baseline information (Appendix C).

The Kaumātua Kaunihera granted their support for this study on 18th July 2007. In their approval letter (Appendix E), they also expressed a recommendation that the research findings would move towards influencing good practice and policy at this DHB. The research checklist was signed off by the General Manager of the DHB on 19th July 2007. I attended the Northern Y Regional Ethics Meeting in late July and they granted approval for this study on 9th August 2007, reference

NTY/07/07/078 (Appendix F). The final locality agreement was signed off by the General Manager of the DHB on the 16th August 2007, with the required documentation provided for the Quality & Risk Service, in accordance with this DHB's Research Policy.

Due to the extremely busy ward environment during the initial three months impacting on the study in this research setting, a further two month extension to the participant selection process was requested in writing to the Regional Ethics Committee in early October. This extension was approved on the 18th October 2007 (Appendix G).

During the telephone interviews, parents were often eager to talk further than the survey requirements. Whilst this mostly involved wanting to talk about their child and their family situation, on a few occasions particular issues were identified by the participant.

3.4.1 Addressing any ethical issues

At the initial ethical planning stages for this study, as the researcher, I ensured that processes were in place, should a participant express a concern about their child's hospitalisation or care during the telephone interviewing. This support was subsequently required on three occasions during this study. These included providing local well child provider options, supporting access to discharge information and for one parent providing the details about the complaint process.

3.5 SUMMARY

This chapter has provided both a complete overview and the rationale for the research approach for this exploratory descriptive designed study. This included discussing the telephone interview approach and a description of the survey tool developed specifically for this study. The process for gaining study participants from the local child health area, and the study criteria used, were explained. Validity and reliability appropriate for this study were then discussed. This was followed by an overview of the study's ethical requirements and the process used. Whilst this chapter addressed the limitations in the generalisability of this small

study, it highlighted that the strength of this study would be its ability to share the findings with local health professionals. As a study, it intends to provide a piece of the discharge planning picture that is not known, it is this 'piece' that may also help inform future discharge preparation practices to ensure that we meet the needs of these parents and caregivers within this DHB. It is anticipated that these study findings will provide what Lobo (2005) refers to as foundational research, as we move towards discussing these findings in the next chapter.

CHAPTER 4: THE RESULTS

This chapter presents the research results from the telephone interviews with the parents who participated in this study. It is divided into six sections. The first section provides an overview of the telephone interview process and the study outcomes. The demographic characteristics of the study's participant population are then compared with the overall population of children (who met the study criteria), who were discharged from this ward during the study period. This includes commenting on representativeness. The findings from the three open questions are presented, and common themes are identified. This is then followed by the findings from the closed questions, including the two that related to previous research findings. This includes some key statements from the interviews. In the last section, the results of the rating scale are presented to provide the final comparative aspect of the research. This shows any differences in the needs rated between rural and urban participating parents, their identified ethnicity (ies), and the age of their child.

4.1 THE TELEPHONE INTERVIEWS

The participants were selected over a four and a half month period from the 20th August to 31st December 2007. A total of 20 parents agreed to participate, with 18 telephone interviews successfully completed. The two non-completed interviews were because one participant was unaware of the research, when contacted, and another participant agreed to participate, but was subsequently unable to be contacted.

Being able to interview parents/caregivers by telephone proved to be a very effective approach for this exploratory descriptive piece of research. As an approach, it was relatively non-invasive for participants, because it did not require actually meeting the researcher face-to-face, allowed for a certain amount of anonymity, whilst also requiring a reasonably small amount of participants' time (10-15 minutes). From the researcher perspective, the use of this study's structured survey tool enabled a consistent approach to the brief telephone interviews, whilst

this consistent approach still provided the valuable opportunity to interview parents/caregivers and to learn each of their perspectives (their expressed needs).

4.1.1 Length of time home from hospital

In order to maximise the recall of participants' initial needs when first arriving home following their child's discharge from hospital, the researcher aimed to complete the telephone interview within the first two weeks of discharge. This required a fine balance between allowing the participants enough time to settle in at home whilst also contacting them soon enough to support that ease of recall around their initial needs. Being able to set up a telephone interview within this first two weeks was dependant on being able to make the initial contact with the participant, as well as being able to schedule an interview time to suit the needs of each participant within this timeframe.

Three interviews were completed within the first week of being home. A further eleven were completed between the first and second week home, and a further four interviews were completed after more than two weeks of their child's discharge. Three of these later telephone interviews were completed between days 16 to 19 of discharge, with a further one interview completed one month after their child's discharge. This meant that 14 (78%) of the telephone interviews were completed within the intended first two weeks of arrival home from the hospital. It seemed 'easier', when interviewing parents and caregivers about their initial needs when first home from the hospital, if this was more recent. This ease was due to less need to clarify questions.

4.1.2 Time of day chosen for telephone interview

Telephone interviews were also arranged and completed at a time to suit each participant in the study. This involved an initial phone contact, to clarify any questions they may have had and to schedule a time to complete the interview, particular to each participants' needs. All the telephone interviews were completed between the hours of ten in the morning, and eight in the evening. Four o'clock in

the afternoon was the most common time selected with seven (39 %) choosing this time to complete the telephone interview.

4.1.3 Telephone interview length

Telephone interviews were initially planned to take approximately 10 to 15 minutes to complete. Overall, the telephone interviews took between 9 to 25 minutes to complete. Although one interview length was not documented, it did show however, that 14/17 calls or 82% were completed within the planned timeframe. Three of the telephone interviews lasted between 20 to 25 minutes.

The concise nature of this structured interview survey tool, meant that whilst some parents were happy just to complete the requirements of the interview survey, most seemed to relish the opportunity to talk about their experience of both having a child hospitalised and what happened for them and their child, once home. These conversations often extended far further than the survey requirements, and clearly showed that many parents were keen to talk about what it was like for them. It was through the course of these conversations that one participant shared their child's recent positive discharge experience in comparison to their earlier experience of feeling unsupported after discharge. This parent recollected what it had been like for them to return home with a sick baby and the associated uncertainties that went with this.

Given the apparent ease in which many parents wanted to talk, in addition to the confines of the survey questions, the first two introductory pages on the survey tool (Appendix B) which supported rapport building with the participating parents, proved effective.

4.1.4 Choosing a copy of the study report

Upon completion of each telephone interview, all participants (parents) were offered the choice to have a brief research report from the study sent to them at the conclusion of the study. Every parent chose to have a copy posted out. These will be posted out when the final report is completed.

4.1.5 Choosing the option of grocery voucher

At the very conclusion of the study all parents participating were thanked for their involvement, with each offered a \$5.00 grocery voucher as a small token of appreciation for their involvement in the study. This small token was accepted by 15/18 parents, and these were posted to them the next day. Three participants declined this option, as they did not feel it necessary.

4.2 THE PARTICIPANT CHARACTERISTICS

Parents and caregivers who choose to participate in the study identified their relationship to their child, during the initial part of the telephone interview. All 18 participants identified themselves as the mother of the young child. One of the two participants unable to be contacted was a father. The demographical characteristics of the parent population, which includes both the parent and their child, are provided in Table 1. These are now discussed.

4.2.1 Age of the child

Thirteen (72%) of the children whose parent participated in this study were under one year. There were no children over three years of age in the study sample.

4.2.2 The rural and urban location of the participants

Thirteen (72%) of the study parents lived in a rural location. This meant that the remaining five parents lived in an urban area, which for the purpose of this study, was defined as living within the city boundaries.

4.2.3 Ethnicity of the child

Nine (50%) of the children in the study were identified (by the parent) as Māori. Six (33%) were New Zealand European and two (11%) were identified as Pacific children. There was one (6%) child identified as being from an other ethnic group.

4.2.4 Ethnicity of the Parent

Each participating parent was asked whether they felt comfortable stating their own identified ethnicity or ethnicities. All parents answered this question, with six (33 %) identifying themselves as Māori, five (28 %) as New Zealand European, three (17%) as Pacific people. A further one parent (5%) identified themselves, as from an ‘other’ ethnicity. There were also three (17%) parents, who identified themselves from both Māori and New Zealand European ethnic groups (Table 1).

The inclusion of the parent’s ethnicity was to enable one of the comparative aspects of this study. That was to see if there were any differences in the needs expressed by the parents of different ethnicities. However, the ethnicities of the parent/caregivers of the overall child population was not known and therefore not provided in Table one.

Table 1: The demographic characteristics of the participant population compared to the overall child population admitted during the study period.

* Some figures are rounded off to simplify percentages

	<u>Study Populati on Number</u>	<u>Percent</u>
<u>Age of child</u>		
under 1 years	13	72%
1-2 years	4	22%
2-3 years	1	6%
3-4 years	0	-
4-5 years	0	-
<u>Geographical Location</u>		
Rural	13	72%
Urban	5	28%
<u>Ethnicity of child</u>		
Māori	9	50%
Pacific	2	11%
NZ European	6	33%
Other	1	6%
<u>Ethnicity of parent</u>		
Māori	6	33%
NZ European	5	28%
Māori /NZ European	3	17%
Pacific	3	17%

Other	1	5%
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4.2.5 Length of stay

Table two shows that six of the children in this study (33%) stayed more than four nights in hospital. Three each (17%) stayed either three or four nights. Four (22%) stayed two nights, and overall only two (11%) stayed one night.

4.2.6 Reason for Admission

The reasons for the child's acute admission are shown in Table two. Nine (50%) of the children were admitted with a respiratory infection. There were no children admitted in this study with either acute asthma or a skin infection. Three children (17%) were admitted with gastroenteritis and a further three (17%) were admitted with a febrile convulsion. However, this study also included three children (16%) admitted with an 'other' acute illnesses that met both the study criteria, and fitted an ASH admission-type picture (Table 2).

Table 2: The Length of stay and reason for admission

* Some figures are rounded off to simplify percentages

	<u>Study Populati on Number</u>	
1 night	2	
2 nights	4	
3 nights	3	
4 nights	3	
> 4 nights	6	
<u>Reason for admission</u>		
Respiratory Infection	9	
Acute Asthma	0	-

Gastroenteritis	3	*
Febrile Convulsion	3	*
Skin Infection	0	-
Other acute illness	3	*

4.2.7 Representativeness

In order to assess representativeness, the characteristics of the study population (n=18) were compared with the overall population (n=132) of young children discharged from the study setting during the same four and a half month period of the study (20th August to 31st December 2007), (DHB, Casemix report, December 2007). This overall population were the children who met the study criteria during this period and included the small number of children whose parent/caregiver participated in the study. Table one and two show the comparison between these two groups and support the following comments about the representativeness of the study population.

Age of the child

Table one shows that the under one group in this study, were represented at a higher rate (72%) than when compared to the overall population (59%). Although there were no children in the study group over three years of age, 11% of the children in the overall group were aged over three years old.

Rural and urban locality

The rural/urban mix in the study had the closest representativeness with the overall group. With 72% in the study group compared to 68% in the overall child group living in rural areas of this DHB (Table 1).

Ethnicity of the child

Children who were identified as Māori were evenly represented, with 50% in the study group compared to 54% overall. With two children identified as Pacific in this study, at 11% they were represented at a higher level than overall (2%). Table one also showed that New Zealand European in the study group (33%) were also representative of the overall group (29%).

Length of stay

Table two presented the length of stay for children and provided a comparison between the study and overall population groups. Whilst 33% of the study group stayed four nights or more was closely representative of the overall group (22%). Children who stayed one night (11%) were not well represented in comparison as nearly one third (30%) of overall children acutely admitted stayed just one night in hospital

Reason for admission

A comparison for the reason for the child's acute admission between the two populations was also provided in Table two. Children admitted with a respiratory admission in the study group (50%) were a little less representative compared to 62 percent overall. Gastroenteritis admissions (17%) were representative overall (20%). Although there were no children admitted in the study group with either asthma or a skin infection, these admissions actually were small overall, and respectively made 9 percent and 4 percent of the overall child admissions. Both children with a febrile convulsion (17%) and an 'other' acute illness (16%) were represented at higher rates in this study than the overall group, which had 3 percent admitted for a febrile convulsion and 2 percent for another acute illness, and therefore not representative.

4.3 THE OPEN QUESTIONS

The three open questions in the survey tool used for the telephone interviews have been analysed by revisiting the answers that each parent gave to each question. These were recorded verbatim from either the recorded telephone interviews or

documented during the telephone interviews, when audio-taping wasn't possible. These relate to questions five, six and seven on the survey tool (Appendix B).

Many parents provided quite lengthy responses to these open questions, whilst others were also keen to talk further about their experience of hospital, and aspects that were important to them. The content of their statements were grouped into themes. These are presented after each of the questions, with both the number of times each theme arose as well as the inclusion of key statements to support each theme. The common themes drawn from the participants expressed needs have been presented in order from the "most prevalent to the least prevalent themes" (Sandelowski, 2000, p.339). A few of the parents' statements have been used in more than one theme, as appropriate. Pseudonyms have been used throughout, wherever parents mentioned the name of their child in the interviews, to ensure anonymity of both them and their child in their statements.

4.3.1 Main concerns/needs when first home from the hospital

The first question asked the participants to reflect back to the time when they arrived home from the hospital. They were asked about what their immediate main concerns or needs were, as they cared for their young child as they recuperated, when first home from the hospital, with five common themes drawn, as follows:

Needing reassurance and advice

The most predominant theme was around the need for reassurance and/or an opportunity for accessing follow-up advice. This was described by eight of the 18 parents. They were concerned about the need to know that their child was recovering or that they were providing the right care for their child. Although only small in number, further analysis showed that five out of these eight parents (63%) lived in areas defined as rural. Their statements included:

“First thing I thought, I should have stayed in hospital. I didn’t have the support at home, even though I didn’t need the support in hospital – at least I knew they were there... When I got home I worried”. *Participant 10*

“That I was doing everything for Elana to make her well”. *Participant 6*

“It was just waiting for that follow-up. I was worried about his airways, how he grunted really, I just wanted reassurance Harry was ok” *Participant 9*

“I stayed with relatives for the first week, as we live a significant distance from hospital” *Participant 4*

“Her breathing and chest rising (it looked like it was a bit swollen) and the need to make her better” *Participant 13*

“Someone to call, the weather wasn’t very nice- for advice and reassurance that the rash and vomiting was due to this...” *Participant 10*

“My midwife came around and checked on us and he was doing fine.
(I contacted my midwife and she automatically came around)”

Participant 7

“When I got home from hospital, I don’t have any relatives here, I’m the only one to look after my child. My first child, I have never looked after a child. I had to make sure to do the right things when I got home from hospital.

Participant 5

Along with the expressed need for reassurance and advice by some of the parents in this study, there was also a shared worry about their young child getting sick again.

Worried about their child getting sick again

Seven of the eighteen parents expressed that they worried their child would get sick again. However, this time three of the seven (43%) were urban parents, although three parents represent a small number, it is important to recognise that there were only a total of five urban parents in this study. A few of their key statements relating to their worries are presented below.

“Suppose the biggest thing, Bruce would go back to where he was because he wasn’t fully recovered, I felt antibiotics would help, scary”

Participant 2

“Worried about Carol getting it again as they said she could easily get it again, it was really windy and freezing when we left hospital”

Participant 4

“My only concern was having it good for her to breathe I’m afraid that Georgina might get the flu again”

Participant 8

“Just that she’d get better and that she would not get sick again and (later) I never want Elana to have that seizure thing again”

Participant 6

“Making sure that everything was okay at home, clean and warm, so Anaru wouldn’t get sick again”

Participant 1

“I was hoping no going low again (blood sugars)”

participant 19

“The main thing I was worried about was like my child’s coughing would get better. I wasn’t worried about Darren’s asthma or skin, because I knew they’d get better. But his coughing, I can’t handle it, he’s too young as well”.

Participant 5

Along with worrying that their child could get sick again, there were other initial worries expressed by parents through the course of the interviews, these are now presented.

Other identified worries

Although, their expressed worries were varied and could not be grouped as such, this did show however, that there were other concerns that the study participants identified when first home from hospital. Examples are presented below.

“That when I put him in the cot, to stop the cot death and that heaps of things were playing on my mind”

Participant 7

“Mainly Nigel’s condition, I had never heard of it” *Participant 16*

“Also about the side effects of the medicine, like hair growth. I’m hoping not any others that they don’t know about” *Participant 19*

“The main thing I was worried about was like my child’s coughing would get better...” *Participant 5*

“Making sure the other children were careful around him, the Doctors felt Marcus would get better faster at home” *Participant 15*

Home environment concerns

Along with the theme of worrying that their child did not get sick again, a few parents expressed similar statements around wanting their home environment to be ‘right’ to help care for their recuperating young child, these statements included:

“Making sure that everything was okay at home, so he wouldn’t get it again, clean and warm” *Participant 1*

“Having the environment clean, having a different temperature and the quietness” (and later) “My only concern was having it good for her to breathe in, making it dust free, bit of a problem” (and later) “I can’t keep the house at one temperature” *Participant 8*

“Well his breathing was one and his temperature, the weather is so muggy and Piripi feels the heat, we want to make sure we don’t overheat him” *Participant 18*

One further theme was expressed by a small number of parents in this study, this related to their child’s general nutritional status.

Their child’s nutritional status

Four parents expressed that they were initially concerned on whether their child was eating and drinking enough. A further two made reference to their child’s feeding when first home from hospital.

“Just trying to keep Kerrin’s hydration up, he was...so..he wasn’t drinking or eating well, so just his nutritional things, would have been my biggest concerns”

Participant 12

“Just really to get Jordan’s fluids going. Nothing really because I knew what he had and that I knew he was going to get better, so I wasn’t really worried about anything- other than just getting him to eat and drink”

Participant 11

“How much Oslo was eating really he wasn’t eating much at all”

Participant 17

“That Suzette still gets enough fluids, I kind of knew that her loose motions will be there for a while. My concerns were that she kept hydrated. Before (going to hospital) with her high temperatures, it was really hard to get the fluids in”

Participant 20

“His feeding”

Participant 18

“Making sure that Eruera was fed and that he was sleeping alright”

Participant 7

4.3.2 Anything they needed that would have made it better

One half of the participating parents (nine) when asked this question, expressed that there was not anything else that they felt they needed that would have made it better. Whilst many of these parents just answered no, other parents made statements, as follow:

“No not really they wouldn’t have discharged my child if she wasn’t well enough to leave. They gave me brochures and stuff and I was confident enough to care for her once home anyway”

Participant 4

“No, because I have already had a child before and my midwife came around and checked on us and he was doing fine. (I contacted my midwife and she automatically came around)”

Participant 7

“No I can’t think of anything not really, they explained it as much as they could. The doctors and nurses made it clear”

Participant 19

“No not really, because the doctors were really good, I was getting really worried before I went to hospital. I took her twice to the doctor, I wanted to go to the hospital”

Participant 20

“In our situation no, I pretty much knew everything I needed to know to make him recover”

Participant 11

The few that made suggestions specific to their needs, although their responses did not allow for any familiar themes, their feedback is presented in the following examples.

“I think them explaining to me instead of a whole lot of different people saying the same thing. It would have helped because they all used these fancy words- just spoken in an easier language, I guess”

Participant 9

“Having a new house- probably I could say my house- I do the best to make the environment good for (my child) to breathe in”

Participant 8

“They gave me a discharge sheet , but I also felt they could also have written ‘this is what to do’ to ensure that Elana gets better i.e. keep inside, not play with others, sleep, when to go to play group etc... I didn’t get to talk to the doctors as they had already discharged her when I arrived”

Participant 6

Having an older child and first time Mum’s

Two parents specifically made reference in their interview about having another child, in their response to the question about any needs they may have had around caring for their recuperating child at home.

“I have an older child who had this, so I knew when Bruce was sick”

Participant 2

“No because I had already had a child before....”

Participant 7

A further two parents made reference to being first time Mums, in their responses to questions about their needs in the interview, these were:

“Because since I got home from hospital, I don’t have any relatives here, I’m the only one to look after my child. My first child, I have never looked after a child..... I had to make sure to do the right things when I got home from hospital”

Participant 5

“I was too busy worrying....I’m a first time Mum.”

Participant 10

4.3.3 Any other needs, thoughts or ideas expressed

Again as in the previous question, this final, open question resulted in the majority of parents 11/18 stating that they could not think of any further needs, or ideas that they wished they had known more about. Although some didn’t have anything specifically to say, there were additional needs expressed by a few parents to this question, this included information such as:

“They could include just some healthy brochures, fun ideas for toddlers, healthy dinners, what clothing to wear for immunity my child had got a bit low on immunity”

Participant 6

“We wanted to know anything we could do at home to make Marcus better- what might trigger things”

Participant 15

“CPR information, to refresh my mind, would have been handy. I have done first aid at high school, a long time ago” (and later) “there was another one, I thought of something to help him clear the mucus for him. I asked the nurses about this, they said if he coughs it up that’s good”

Participant 18

4.3.4 Additional comments

At the completion of each telephone survey, parents were asked if they wanted to ask me (as the researcher) anything about the research study, or if there were any additional comments that they may have wished to make. Whilst the majority of parents did not wish to make any further comments, there were comments about 'going home' from hospital in this section, one parent commented that:

"One thing that stuck in my mind was the big relief to go home, a lot of parents have been in there a long time"

Participant 4

It was in response to the opportunity to make any further comments that one parent told her story about the negative experience of her child's much earlier discharge following an acute admission with a young baby, in comparison to their recent discharge experience.

"When we went home we felt absolutely stranded/isolated we didn't know what we were looking for- we felt like we didn't have anywhere to go." (*And this time around? – the researcher*) "Totally different - we were sent home with an exact diagnosis" *Recalling the first admission again.* "Paediatric appointment in one month ended up two months later, the letter took two months to get the GP. It was a really stressful and unknowing time- when people go home with that sort of stuff a real lack, we should have had a lot more contact, if we had any worries."

Participant 12

Another two parents made similar statements here about how they actively asked staff questions about their child's care, whilst in hospital and how this impacted on their needs.

"I think the best thing is to ask questions before you leave, even anything trivial, just so you know you've covered all your bases, communicating and asking questions"

Participant 4

"No not really they practically told me everything. They often would tell me things like 'that's a good normal temperature', I'd ask what this was"

Participant 8

Some parents asked further about the research study and three in particular wanted to know how the research would help other parents. It seems appropriate to end with two of their comments made at the conclusion of their telephone interviews with parents in their survey.

"Does it help with other communities?"

Participant 5

"I just want to do anything to help others"

Participant 18

At the conclusion of the open questions, parents were then asked the closed questions, this provided an understanding of the type of discharge support provided to the participant. This helped provide some context to the needs and concerns they expressed in the previous section of the survey tool.

4.4 THE CLOSED QUESTIONS

There were three closed questions asked after the open questions in the telephone interview. These related specifically to written discharge information, the provision of a contact number for advice and any follow up referral received. In a deliberate attempt to avoid predetermining any identified needs of the study participants, these closed questions were asked after the open questions in the telephone interview.

Each of these questions initially asked participants to answer 'yes' or 'no', as appropriate. Further detail was then sought from participants who responded affirmatively to any of the three closed questions during the telephone interview.

4.4.1 Written discharge information

The first question asked the participating parents if they received any written information about their child's discharge care to take home. Every participant answered this question. Although one participant was initially unsure, they were subsequently able to recall the information they had received. The majority of parents, 16 of the 18 (89 %) had received some form of written discharge information (Table 3), with some having received more than one type of format. This was most likely to have been a copy of their child's General practitioner's (GP) discharge summary, as this was identified by 13 of the 16 parents.

From my personal knowledge of working in this area, this will have been either a duplicate handwritten version, or a copy, of the recent and more extensive electronic version of the discharge summary. Either way the intended audience is the general practitioner and thus not really written with the parent or caregiver in mind. Although three parents mentioned getting a copy of a letter to their GP, these are not usually ready at discharge. So again this is likely to be a copy of their GP discharge summary. Some of the confusion may have been as this discharge summary is addressed to their GP, and therefore considered as a 'letter'. Pamphlets about their child's health condition and care at home, were received by four parents (4/16), with a copy of the letter to their GP received by three (3/16) parents.

Two parents didn't receive any form of written information on discharge. They both made statements about their needs in their interviews. One parent had wanted to know anything that could have been doing at home to help their child 'get better'. The second parent made the comment when rating how their needs were met, that they had received "answers for some things and not others".

4.4.2 A contact number for advice or support

The second question asked if they were given a suggested contact phone number for advice after discharge. Although four parents participating were a little unsure when asked, they were unable to recall the actual point of contact for advice. However, only five of the overall eighteen parents (28%), stated that they had received a phone number to call for advice after discharge (Table 3). Some of these parents were provided with more than one point of contact. The ward was the most likely contact, with four out of these five parents identifying this as their advisory point of contact. Two parents identified that their GP phone number was given, with one being given the after hours medical centre and another parent also received the contact phone number of their lactation consultant.

4.4.3 A follow up referral

A third and final question asked the participating parents if they had received a referral to any health professional for their child, after discharge (Table 3). Again a

few of these parents received more than one referral. Of the ten parents out of the eighteen (56%) who had, the most common referral for five of these ten, was to primary care. These included four referrals were to the GP and one to the practice nurse. A further four of these ten parents identified follow-up with a Paediatric outpatient appointment. The three other follow-ups included two parents identifying a referral for further medical tests and one parent identifying a prescheduled time to revisit the children's ward, for a check-up.

Table 3: Discharge information, contact for advice and follow-up referrals received

* Some parent participants had received more than one option in response to the three questions above.

Therefore the number of responses for each question will be different from the denominator

Question 9 (a) Of the 16 participants who received written discharge information. <i>The type of information received included:</i>	
Copy of GP Discharge Summary	13 /16
Pamphlets (about their child's health condition)	5 /16
Copy of GP letter	3 /16
Question 9 (b) Of the 5 participants who were given a contact number for advice after discharge. <i>These were for:</i>	
The ward	4/5
Their general practitioner	2/5
Other	2/5
Question 9 (c) Of the ten participants who received a follow-up referral for their child. <i>These were for:</i>	
GP/Practice Nurse	5/10
Paediatric outpatient clinic	4/10
Other	3/10

4.5 RATING HOW THEIR NEEDS WERE MET

One rating scale question was included in the telephone interview survey tool (Appendix B). This was asked at the completion of the three open questions. This question asked them to recall when they first arrived home from the hospital, how they felt their needs as the parent/caregiver had been met, in order to help care for their young child's recovery at home.

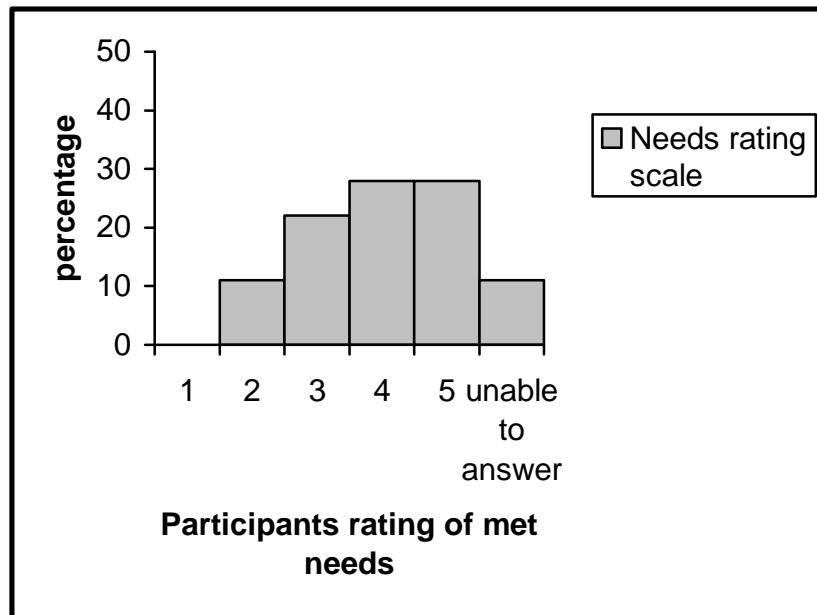
The rating ranged from one to five, with 16 of the 18 parents (89%) answering this question. Despite further clarification two parents felt they still could not answer this question. One parent said that they hadn't actually thought about their own needs, and the other parent commented that she had to continue working while her child was in hospital, and as such had not been able to 'prepare' for discharge. Figure one, shows the percentage of each rate as chosen by the participating

parents. The scale rating of one meant that their needs as a parent were not met at all (no study parents chose this), three meant that some of their needs to care for their child's recovery after discharge were met. The scale rating of five meant that they considered that all their needs as a parent were completely met. Of the 16 parents who answered this question, two parents rated their initial met needs were at a two, four parents felt that some of their needs to care for their recuperating child were met, by rating at a three. Five parents chose a rating of four, and a further five (29 %) rated that their needs were completely met, by selecting a five.

The five parent participants, who rated that their needs had been completely met, were more likely to have had a child under the age of one (4/5). Two of the five parents had received written discharge information, a contact number for advice and a referral for a health professional for their child. Whilst four of the five had not expressed any particular concerns or needs in the open questions. One of these high rating parents had expressed concerns about needing reassurance and the need for clearer verbal explanations. All five of the parents who rated their needs were totally met were also rurally based participants. Although only small in number, these parents were also more likely to have had a child with either gastroenteritis or another acute illness (3/5), rather than a respiratory infection.

Only two of the eighteen parents in this study, rated this question at a two therefore, rating their met needs after discharge between not met at all to some of their needs were met. Although very small in number, both parents were Māori, and had a child under one. Neither parent had been given a contact number for support/advice, and both lived rurally. Both had made comments about worries at home and about not having their own needs met.

Figure 1: Rating of met needs by participants after discharge



4.6 A COMPARISON OF THEIR NEEDS

The small size of this exploratory survey precluded the use of any comparative statistical analysis. However, since the issues related specifically to rurality, ethnicity and age of the child are of particular interest to this study, the results have been described according to these variables (Table 4). Sixteen parent participants responded to this question. The mean, median, mode and range have been used to show the overall results for these 16 parents. Care needs to be taken due to the population size of this study, and the very small number of parent participants in some of these groups. However, some differences between these groups may well be indicative of issues that may need to be addressed particularly in further research.

Overall the 16 parents had a mean needs rating level of 3.6, with a median of four and mode of five. This showed that overall as a group, they rated their met needs to care for their recuperating young child, when first home from hospital, as tending between mostly to completely met.

This was then analysed by comparing differences in the rated needs between rural and urban parents, between the Māori, Pacific and 'other' ethnic groups, and

finally the comparison between those with a child under one year old and those with an over one year old.

Rural/Urban differences

Whilst the urban group only had four parent participants, and was therefore, substantially smaller than the rural group who had 12 participants, there are some slight differences in how these two groups rated overall. Urban parents tended to rate their met needs at a slightly lower level than the rural parents, with a mean and median of 3.5 compared to a mean of 3.9 and median of 4 for the rural group.

Differences between Ethnic Groups

Care also needs to be taken with the different ethnicity group comparisons, although there were eight Māori parent participants, there were only three Pacific parents and five in the other ethnicities group. However, as the smallest group, the Pacific group rated their level of met needs after discharge at a lower mean (3.3), median (3) and mode (3) than the both the Māori and other ethnic group, who were quite similar in their rated level of met needs. With the Māori parent group having a mean 3.9, median 4 and mode 4.5 and other ethnicities participant group mean, median and mode of 4.

Age group difference

Finally, whilst again there were different sizes between the under one age group with 12 parent participants, compared to the over ones (4), there were some differences in how they rated their needs had been met. The over one year old group had tended to rate their met needs higher (mean 4.25 and a median of 4) than those parents with an under one year old (mean 3.7 and a median of 3.5).

To summarise the overall rating of met needs for this rating scale question, there are three particular areas that this question highlighted. These were in relation to the lower rating for the urban parents, Pacific parents and those with a child under one. These issues will be explored further in the next chapter.

Table 4: Comparative needs rated by participants

- Only sixteen respondents answered the rating scale question

	All Participants	Rural participants	Urban participants	Maori participants	Pacific participants	Other participants	child under 1 year old group	child over 1 year old group
Number of participants	16	12	4	8	3	5	12	4
Mean	3.6	3.9	3.5	3.9	3.3	4	3.7	4.25
Median	4	4	3.5	4	3	4	3.5	4
Mode	4.5	5	3.5	4.5	3	4	4	4
Range	2-5	2-5	3-4	2-5	3-4	3-5	2-5	4-5

4.8 SUMMARY

This chapter has provided the results, from describing the telephone interview process, providing an overview of both the child and study participant populations, through to the analysis of the questions asked in the telephone interview survey tool. The open, closed and rating scale questions have been presented in using both a descriptive statistical and content analysis approach. Key statements from the interviews have been used to support the themes that unfolded from the participating parents' expressed needs. This study has produced some useful findings that will now be discussed in the next chapter.

CHAPTER 5: DISCUSSION

This small exploratory descriptive study sought to provide some much needed research around the needs of parents/caregivers as they cared for their recuperating child at home. The telephone interviews with the eighteen parents, in this study proved valuable and enabled an insight into their needs and concerns after discharge from their perspective. Although it included less than the thirty parent/caregiver participants initially hoped for, this study has provided some useful findings that helped to inform the development of the recommendations. These are discussed in this chapter. The first section looks at the main concerns that the parents identified in relation to their child's discharge. This is then followed by a discussion about some of the issues relating to their expressed needs. In the next section the differences in the demographics of the study population are discussed. A reflection on the research is then provided. This is followed by a look at this DHB in relation to the research findings. Final recommendations for both practice and further research are then presented, followed by the conclusion to this research.

5.1 A LACK OF DISCHARGE SUPPORT

There were several themes identified through the telephone interviews with parents. Two themes in particular expressed by these parents, were the need for reassurance and advice, and also that they worried about their child getting sick again. These two areas (or themes), are so closely interrelated, it may be plausible to assume that if their individual needs for reassurance and advice were met, that this could also address some of their worries about their child getting sick again.

5.1.1 Needing reassurance and worrying

It was through the telephone interviews with parents that this study found that eight of the parents clearly expressed the need for reassurance and advice once home from hospital. This unmet need is consistent with the findings from all four existing research studies in this area (Darbyshire, 2003; Snowden & Kane, 1995; Smith & Daughtrey, 2000; Suderman et al., 2000).

The parents need for reassurance centred around needing to know that they were doing the right 'things' to care for their child, and the need to have some form of reassurance or support about this once discharged. One of the parent statements from Smith & Daughtrey's (2000) study, was very similar to statements expressed by parents in this study, and simply highlighted the stress and isolation, many families can feel when first home from the hospital "I needed to talk to somebody, just for them to say, 'Yes, you're doing the right thing'" (Smith & Daughtrey, 2000, p.817). It is this same 'need' for reassurance that was very similar to some of the expressed statements made by parents during the telephone interviews. Extracts from their statements included, "I just wanted reassurance", "I had to make sure to do the right thing" and "someone to call...for advice and reassurance".

Two parents in this study also made particular reference to being the only one to look after their child's health care once home, "I'm the only one to look after my child" and "I didn't have support at home". These statements link to the well supported concept in the literature, in terms of parents returning home to being the sole care of their child (Darbyshire, 2003; Snowden & Kane, 1995; Smith & Daughtrey, 2000).

The needing advice in Smith & Daughtrey's (2002) study related to parents wanting more details about their child's readjustment to being at home, their nutrition and when to return to school. Again there were similarities with this study's findings with parents, as there were needs expressed relating to nutrition for their child by six parents and one parent mentioned that it would have been helpful to know when their child should return to preschool.

Eight parents in this study specifically expressed that they were worried or concerned that their child would get sick again. Smith & Daughtrey (2000) found that whilst "most parents worried about their ill child ... there was an overwhelming feeling of being left to cope on their own with no-one to whom to refer" (p.817). Although both Smith & Daughtrey (2000) and Darbyshire (2003) said that worrying about a child is a normal part of parenting, these authors also acknowledged that there was a need for better support for families after discharge.

Both research papers said that the parental need for advice and reassurance is most needed in the first 48 hours after their child's discharge.

Seven of the parents in this study also expressed other concerns about their child. Whilst as the literature says, it may not be possible to alleviate all parental worrying, this study found that nearly 40% of parents (7/18) had received no form of support at all after discharge (neither a contact number for advice or a referral to any health professional). This may lead to some parents feeling as Smith & Daughtrey (2000) found, that same sense of being left to 'cope on one's own'.

However, one important point to take from the findings in this study was that the parents who expressed a need for reassurance and support were not necessarily the same parents who expressed worries about their child. What it did show was that two thirds of the parents (12/18) in this study expressed either the need for reassurance, and/or that they worried about their child getting sick again after discharge. Whilst this is cause for concern with these findings, it adds strength to the opportunity to address the support that could be offered to these families after discharge.

5.1.2 Discharge information provided

This study found that although sixteen parents had received written discharge information, this was predominantly a copy of their child's discharge summary, which is written to their GP. Parents and caregivers are not the intended audience of this clinically-focused information. It is therefore questionable, as to whether this actually meets any of their needs as parents. Snowden & Kane (1995) challenge health professionals to consider "whether parents received discharge instructions based on staff's perceptions of what information was needed, rather than parents' perceptions of their needs" (p.427). Whilst a few parents in this study identified that they had received pamphlets about their child's condition/care, these are neither individualised nor considered a discharge plan. It was concerning that although sixteen of the parents in this study had received a copy of their child's discharge summary for their GP, not one had received an individualised discharge

plan. However, perhaps most alarming was fact that two of the parents were given nothing in writing about their child's care after discharge.

Although the need for reassurance and advice came through quite strongly in this study, very few parents overall (5/18) had actually been given a contact number to call for advice or support after discharge. With only four of the parents being given the ward as the contact number, this is incredibly small. Providing parents with a contact number after discharge, particularly in the first 48 hours (Darbyshire, 2003; Smith & Daughtrey, 2000), could possibly have met the need for reassurance expressed by many of these parents. It may be that, even if the telephone contact isn't utilised by the parent, the mere knowledge that they have it available, may have helped to alleviate some of their concerns and worries about their child.

Darbyshire's (2003) study also recommended that "parents would appreciate a follow-up phone call from the hospital inquiring as to how the child is doing" (p.307). This links really well with the experience of talking to parents in the telephone interviews. These parents seemed to really appreciate, actually being asked how their child was 'now', with many relishing the opportunity to just talk. Given that all the parents in this small study had a telephone (mobile and/or landline), it would seem that providing parents with a contact number for any further advice or support required, as well as offering a follow-up phone call after discharge would have been both feasible and warranted for many of these parents/caregivers.

5.1.3 ASH admission opportunities

Little more than half of the parents (10/18) in this study had received any follow-up referral for their child. Four of these parents' children received follow-up with the paediatric outpatient clinic at the hospital. However, only five of the parents overall (28%) had received any referral to return to their primary care provider. These are all children who were admitted with an ambulatory sensitive condition, which the MOH (2004) view as potentially preventable in the first place, through early access to primary care. Yet for the majority of these children and their parents there seemed a lack of attempt to make the connection back to primary care.

During the data comparison stage for this study, it also became apparent that some children in the overall child population group (Table 1) had more than one acute admission within the four and a half month study period. In fact one of the parents in this study mentioned that their child had been readmitted to hospital again within days of being home. “They gave me a Bronchiolitis pamphlet the first time, he went back to hospital only about three to four days later, I was doing everything...”

These readmissions have an obvious financial impact on the health system. More importantly a child’s readmission places another burden on the already worried parent, and having another acute illness episode also places further risks on the young child’s health and wellbeing. Any child being readmitted with an ASH (and so quickly) reinforces the need, and the enormous potential, to ensure that we improve the support for all families at every admission.

These missed opportunities to link with a range of primary care providers leaves a gap in the continuum of care and a risk for these children and their families. Every young child’s admission needs to be seen as those ‘windows of opportunity’ (MOH, 2004). The fact is that these children are all under five years of age, and therefore, there are enormous opportunities for health gain. We need to widen the focus and see these admissions not just as an ‘illness event’ but also as the opportunity for improving the health and wellbeing of children and tamariki.

The numbers of children actually enrolled with a primary health organisation (PHO) show some disparities. Although approximately 90 to 95 percent of children overall are enrolled, there has been recent concern expressed about the under one age group. Craig et al. (2007a) stated that “in the last quarter of 2007, children aged under one year had the lowest PHO enrolment rate (75%)” (p.118). This is extremely concerning, given that this study highlighted the large numbers of ASH admissions in particular for this age group (Table 1).

These ASH admissions provide an important opportunity for health professionals to incorporate the standard practice of asking all parents/caregivers about the primary care links for their child. This needs to be seen as a positive opportunity to provide further support as required to make those linkages, whilst the child is in hospital.

This could be as simple as checking that they are actually enrolled with a PHO and that they have a Well Child or Tamariki Ora provider for their child, and that parents and caregivers are aware of, and able to access the range of child health and wellbeing services that they are entitled to. These include well child checks, immunisations, oral health care, vision and hearing screening and the range of other support services. The glaring inequalities in the ASH admission rates for Māori and Pacific children and for those with socioeconomic need indicate the need to strengthen this continuum of care for these children and their families and whānau.

It is through accessing good primary health care, that the Craig et al. (2007a) report states “is associated with better health outcomes, improved preventative care, and reduction in hospitalisation” (p.124). It needs to be standard practice that every child admitted with an ASH, leaves hospital with a referral back to their primary care provider. There is a real need to refocus on the links between primary and secondary care for these young children and to strengthen that continuum of care. This is more extensive than merely sharing a copy of the GP discharge summary. Incorporating these long term practices for these children and tamariki directly supports the best practice intentions towards reducing health inequalities (MOH, 2002).

5.1.4 Individualised discharge planning

The notion of an individualised approach to discharge planning with families is not a new concept (Bristow, Stickney & Thompson, 1976), and is well supported in the literature on this topic (Darbyshire, 2003; Smith & Daughtrey, 2000; Snowden & Kane, 1995; Suderman et al., 2000). Whilst this study showed that some parents felt very confident about managing their child’s care at home, “I pretty much knew everything I needed to know to make him recover”, others weren’t so comfortable “I was too busy worrying” and the parent who didn’t have support at home and wished they had stayed in hospital “even though I didn’t need the support in hospital, at least I knew they were there”.

It is this no ‘one size fits all’ concept with regards to discharge planning that is supported by Sarajärvi et al. (2006) as they said “each family’s experience of their

child's illness is unique" (p.205). Individualised discharge planning potentially encourages engagement opportunities between nurses and the parent/caregiver (Griffin & Abraham, 2006). Darbyshire (2003) also found that parents wanted flexibility and the ability to make choices with discharge planning. It is this active involvement in their child's discharge plan that also reduces the stress and anxiety for the parent/caregiver (Smith & Daughtrey, 2000; Snowden & Kane, 1995).

Sarajärvi, et al. (2006) reinforced the need to look further than the hospital setting, as nurses "will not be able to provide individual support unless they are aware of the families' life situation and resources" (p.206). This opportunity for engagement, and looking further afield, was evident in this study. Two of the parents made particular statements about being first time mothers, and how that impacted on their worries, and the sense of isolation that they felt. One parent mentioned that she had no extended family available to 'learn' from and yet another talked about housing concerns and inability to keep the temperature right for her young baby after a respiratory infection admission. These few examples reinforce the need to develop discharge plans with parents based around their particular needs.

The different learning styles that parents have about their child's health care, as identified by Suderman et al. (2000), seemed evident in some of the statements made by the parents in this study. Two parents expressed that they felt confident asking staff questions to enhance their learning about their child's healthcare. A further two made statements about having experiences with other children so felt comfortable in their knowledge. While that takes care of the 'proactive' and 'experienced' parent learning styles that Suderman et al. (2000) referred to as the 'diversity of learners' concept. It was the third learner style that they referred to as the 'silent' parent that one cannot make assumptions about. It is unknown whether this parental learning style existed within this study's group of parents, but the stressful nature of the hospital environment also needs to be taken into account with regard to parental learning needs. However, given the common concerns and needs identified in this study it was clear that many parents had not had their discharge needs met.

It is feasible to propose that through using an individual approach to discharge preparation, and involving the parents and caregivers right from the early stages, that these parent's needs may have been met. This would build on the well supported theme of a family-focused approach to children's health and wellbeing (MOH, 1998a; MOH, 1998b; MOH, 2002; MOH, 2004; Ministry of Social Development, 2002; PSNZ, 2002; Standards New Zealand, 2004; DHB, 2004). Through using a comprehensive discharge approach with parents we may, as Snowden & Kane (1995) stated, "indirectly assist families to move towards a higher level of well-being" (p.428).

5.2 EXPRESSED NEEDS

Parents in this study were clearly able to express their needs and concerns after discharge. However, when asked about what they felt would have made their child's discharge better from their perspective, very few parents provided any actual suggestions or ideas. This is despite the fact that the majority of parents subsequently answered the rating question about how they felt their initial discharge needs as parents as having had been met (Figure 1). Although parents rated their met needs on a range between two (this was the midway point between considering their needs had not met at all and some of their needs had been met) and five (where their needs were completely met), as an overall group, their collective rating showed that they rated their met needs at a four. This clearly showed that whilst some parents felt all their discharge needs were met others clearly had not.

Very few of these parents (4/18), had actually expressed specific ideas or thoughts about what could have made their child's discharge better and there may be several possible reasons for this. One possibility is that this particular question may have suited a more in-depth interview approach in that, a less structured interview, may have allowed for more exploration with parents who expressed particular concerns. Another possibility is these parents may have felt that they had already expressed their 'needs' in their responses to the previous questions. Equally so, it could be

that they simply just hadn't considered how their needs and concerns might be actually have been met in practical terms.

Overall, it seemed that whilst many parents (12/18) had talked about their need for reassurance and worrying after discharge, it seemed more difficult to articulate their actual needs from a discharge planning point of view. It would seem unlikely that these parents would have explicitly stated that they needed 'an individualised discharge approach'. Only four parents could identified something that they felt would have helped them after discharge, there were no themes as such. Their suggestions included learning CPR information, two had ideas for written discharge information they needed, and one parent wanted some healthy brochures. Whilst small in number, it is perhaps the diversity of these responses that simply again reinforces the need to use an individualised approach, to meet these parents differing needs.

However, their expressed concerns after discharge certainly provided an insight from their perspective. There is clearly a need for health professionals to consider the discharge needs of parents of children admitted with an ASH. This small study found that current discharge practices did not meet the needs of all the parents. Much has been written about the difference about the between what staff think, or *perceive*, are parents discharge needs and what parents consider, or *express*, as their actual needs (Darbyshire, 2003; Robinson & Miller, 1996; Sarajärvi et al., 2006; Shield et al., 2004; Snowden & Kane, 2000, Suderman et al., 2000). There are some definite findings from this small exploratory study that will be useful to share at a practice level. However, there is also clearly an opportunity to continue to look at the discharge needs of the parents and caregivers of children admitted with an ambulatory sensitive illness. This will ensure that any changes in discharge practices are also informed by the expressed needs of parents and caregivers (Suderman et al., 2000).

5.3 DEMOGRAPHIC DIFFERENCES

The small size of this study limited the ability to determine if there were any differences between parents expressed needs in the comparative aspect of this study

(see Table 4). What it did do however, was serve to highlight some potential areas for further exploration.

There were more rural parent participants in this study (13/18), and this was directly representative of the overall admissions to the area during the same period (see Table 1). It was concerning that whilst many lived a substantial distance from the hospital (mean 74 kilometres), these families received no notable difference in either their discharge care or referral to their primary care provider than the urban based parents. Although the discharge concerns were expressed by both rural and urban parents, it appeared that rural parents rated that their discharge needs were slightly better met than urban parents (Table 4). Extreme caution needs to be taken however, as the numbers in this study were too small to be able to be at all conclusive. But it does suggest that this is an area that could be further investigated, given the geographical nature of this DHB.

There are two particular further aspects that need to be explored. This study had a greater representation of children who stayed four nights or more in hospital (50% compared to the 37% in the overall population). This is important as the longer length of stay for many of the children in this study indicates that they were likely to have been very unwell at the time of their admission. As ASH are seen as preventable through early access to primary care (MOH, 2004), the knowledge of the participants' existing links with a primary care provider was unknown, but important. Research in this area could help to further inform discharge planning opportunities. A question about their existing primary care links this could easily be included in this telephone survey tool.

Socioeconomic determinants also play a role in ASH rates (Craig et al., 2007a). However, this telephone survey was seen as an inappropriate approach to gather this information. An understanding of the links between socioeconomic need and discharge needs is important at a local DHB level. The socioeconomic context for families and whānau would require perhaps a more personalised research approach and would be useful for extending further research in the area of needs after discharge.

Although a higher number of under one year olds was to be expected, parents of these young children seemed to rate their needs less met than the small group of over ones. Given the higher rates of admissions, especially for respiratory infections for this age group, further research in this area is also needed.

The inequalities in ASH admission rates for Māori and Pacific children were also reflected in this study. Half of the children in this study were identified as Māori. This was representative of the general admission population. There was a slightly higher representation of Pacific children for this small study size. Although the numbers were very small in the comparative component, these suggested that Māori parents rated their met needs equal to parents in the other ethnic group. Pacific parents however, appeared to rate their discharge needs were less met than other ethnic groups in this study. These differences would need far more extensive research and reinforces the particular need to focus on reducing these inequalities for tamariki Māori and Pacific children. However, rather than await further research in this area, adopting an individualised approach to discharge planning for all parents/caregivers of young children admitted with an ASH, could ensure we are better meeting their discharge needs now.

As a small exploratory study, this research was based at one paediatric ward at one hospital in one New Zealand DHB, its generalisability therefore is limited. It has however, provided some much needed local research in a very much understudied area. It has identified large gaps in discharge support and care planning for these particular parents at a local level. Given the concern for ASH admissions in this age group and the inequalities in these admissions, the findings from this study are concerning, however, this can be seen in a positive light, as there are so many real ‘windows of opportunity’ for these young children (MOH, 2004), and a way forward with family-focused discharge planning.

5.4 REFLECTION ON THE RESEARCH

This small exploratory descriptive study provided a good insight into the discharge needs and concerns of these 18 parents. The telephone interview proved a very effective approach, with many of these parents keen to talk further about their child

and their own experience as the parent. The structured survey tool developed specifically for this study clearly identified the common worries and concerns that these parents expressed during the interviews. Rapport building was also easily achieved through use of the prompts and introductory pages developed as part of the survey tool. Whilst using a structured survey tool for the telephone interview did not elicit specific need, it did clearly identify that worry and concern were of central importance. The reason for this lack of specificity is not quite so clear, but it is possible that using a less structured format and face-to face interviewing approach may have been more successful in enabling the participants to articulate their particular discharge needs.

Although, with eighteen parents, this study was smaller than the thirty initially hoped for, these parents were definitely keen to be involved. According to the CNM, when potential participants were approached about this study, their interest and subsequent agreement to be involved was not an issue. In terms of participant selection, there were several unanticipated factors involved. These included that the study ran during the busiest period of the year, and although this meant there were many acute admissions, the reality was that as the only staff member involved in approaching potential participants, the CNM was often simply too busy with her clinical workload to be able to commit additional time for recruiting into this study. In early November, this ward also reduced, from 24 beds down to 20, as is usual for the summer period. The arrival of the warmer weather as the seasons changed during the study meant a drop-off in acute admission numbers, further compounding recruitment difficulties. Further research in this area, would require a more proactive approach to participant recruitment in order to maximise sample size. In hindsight, having more than one person involved to approach participants about the study, would have enabled more participants and taken pressure off the staff involved.

Predicting the overall possible population sample proved complex, with the difficult task associated with ICD (International Classification of Diseases) coding. To further look at the potential overall population, I originally estimated, through the use of coding data, that approximately 200 children over the initial three month

study period could potentially be participants. However, this figure had not excluded those children, who also had an underlying chronic health condition, and therefore, outside this study's focus. The somewhat impossible task of knowing all the ICD codes to exclude, was also exacerbated by the need to rely on the accuracy of multiple codes having been entered at the time of the child's acute admission. This is where the CNM played a crucial role at the participant level, as her knowledge of a child's underlying chronic health condition, simply meant that these parents were not approached about the study. Given the difficulties associated with the ICD codes and unknown underlying conditions, it is more than likely that the 132 overall potential participants for the study period (see Table one), may still be an inflated figure.

Initial planning for this study involved reviewing the overall population of acute admissions, at this setting during the same period in 2006. This provided a predicted demographic 'picture' to ensure that this study's participants were as representative as possible. This showed that the study sample should reflect a higher proportion of parent participants with children who were under one year of age who identified as Māori; and who lived rurally. These children were more likely to have been admitted with a respiratory infection. This study matched the demographics on all four fronts.

5.5 THE RESEARCH AND THIS DHB

This small exploratory descriptive study has highlighted some real gaps in discharge practices for this particular study group of parents. It provides some distinct opportunities for the DHB, both in terms of using a more individualised approach to discharge planning, and strengthening the continuum of care for these young children and their families following an ASH admission. However, neither of these are new concepts, as they were highlighted by stakeholders during the development of this DHB's model of care for children and adolescents (2004). Perhaps it is the parent voice that is the strongest and may impact change at a local practice level.

This research study focused on the one paediatric ward at the one hospital. As the only paediatric specialty medical inpatient unit for this DHB, it caters for children from across this broad geographical area. The small number of participants came from throughout the DHB area. Their issues and concerns were remarkably similar regardless of whether they lived in rural or urban areas. The local inequalities in these ASH admissions overall (Table 1), show the need to particularly focus on meeting the needs for tamariki Māori, Pacific children, the under one age group, children with a respiratory admission, and rural families.

The findings from this study are a useful starting point when planning to address the discharge needs for parents and caregivers of young children (particularly the under one age group) admitted to this unit with an ASH. It is hoped that this study's findings may provide an insight for nurses working in this study setting. Through having a small glimpse into these parents expressed need after discharge, it may result in some positive opportunities for these families. However, it is always important to recognise that any changes in discharge practice needs to be evaluated, to ensure that discharge practices are effective for parents and caregivers, and that practices and/or resources aren't developed that don't meet the needs of those who use them

5.6 RECOMMENDATIONS

This study has facilitated the development of recommendations both for practice and for further research. These recommendations have been supported by the findings from this study in light of the literature available in this area.

5.6.1 Recommendations for practice

This study focused on the needs of parents/caregivers caring for their recuperating young child (under five years of age), following an acute illness admission. There are four recommendations for practice for this particular group that have come out of this study, these are:

- Preparing an individualised written discharge plan in partnership with the parent/caregiver and based around their discharge needs. This should involve asking parents/caregivers what they think they need before going home, making an assessment of the home situation, and planning any additional referrals or support that may be required.
- Formalising a point of contact (a phone number) for all parents/caregivers should advice, or reassurance, be required after discharge.
- Offering all parents/caregivers the choice of a follow-up phone call within the first 48 hours of their discharge.
- Strengthening the continuum of care for all children by making it standard practice that every child has a referral for follow-up with their primary care provider(s). This includes supporting opportunities to ensure families also have access to child health services. These include well child, immunisations, oral health, vision, hearing and other support services that may be required.

5.6.2 Recommendations for further research

The findings from this small exploratory descriptive study at the paediatric medical ward at one hospital in a New Zealand District Health Board have highlighted the need for further research in this area. This study involved telephone-based interviews with 18 parents of children under five years of age, who had been admitted to hospital with one of five specific ambulatory sensitive conditions. The recommendations for further research that have been developed from the findings from these interviews with these parents are now discussed.

- There is an opportunity to build on this exploratory descriptive research using the survey tool with a much larger population sample of parents and caregivers, to see if similar findings exist within a national population sample. Whilst the telephone-based interview was very effective, there may need to be a more personal interview approach required to encourage participants, who identify unmet discharge needs, to articulate how they consider their needs might have been better met. In line with ASH's and access to primary care, any future use of this survey tool needs to include the addition of a question about the child's existing primary care provider links. This would provide a really useful knowledge base for these ASH admissions, and inform any local gaps that could be addressed collaboratively with primary care.
- The links between ASH rates and families with socio-economic need are important aspects that were not explored in this study. These issues cannot be met through a telephone based survey, and requires further consideration.
- Whilst the small size of this study meant that the comparative aspect of this research could not be considered at all conclusive, the initial findings did indicate some areas that require further exploration. This included the need to expand the research with a wider population sample, to see if there are any differences in the discharge needs, between rural and urban parents. Also there is a need to compare results between parents who identify as Māori, Pacific and other ethnicities and between parents with the under ones and those in the over one age groups.
- Although not specifically targeted, the nature of this small study meant that the participants were all mothers. In a future study it would be useful to include exploring the discharge needs of fathers, and other primary caregivers of these young children.
- Finally, as it is always important to ensure that any change in discharge practice is evaluated to see whether any changes meet the needs of parents and caregivers, and have an impact on child health and wellbeing. This

could involve incorporating the four measures proposed in the above practice recommendations. It could be possible to undertake a randomised controlled trial to assess effectiveness of discharge planning practices. Although this would be a substantial piece of research, the study findings would be extremely valuable to this area of limited research, and very relevant to the New Zealand context given the ASH issues that impact upon this age group.

5.7 CONCLUSION

This exploratory descriptive piece of research, sought to provide some much needed evidence around the discharge needs of parents after their young child's ambulatory sensitive admission. Its exploratory nature intended to meet the apparent gap in the New Zealand based research in this particular area. This study sample was overrepresented by participating parents with a child under one year of age, and those admitted with a respiratory infection. However, this directly reflects the areas of particular concern for ambulatory sensitive hospital admissions for young children in New Zealand.

This study provided a different way to look at these ambulatory sensitive hospitalisations. Whilst the MOH focus tends to be on preventing these ASH admissions in the first place (MOH, 2007a; MOH 2007b), this research effectively provided the chance to 'follow them home' after their child's discharge. As an exploratory piece of research, it provided a glimpse into these parents needs. It has highlighted the need to look further at the support provided to these parents and caregivers following their child's ambulatory sensitive hospital admissions.

These are children who are often seen fleetingly in hospital, and as this study showed these families may often not have any further contact with a health professional, in relation to their ASH, once they have left the hospital. Health professionals in the ward environment will not usually know what 'happens' for these children once they have been discharged. It was anticipated that this study would provide a chance to share the findings from this research with health professionals at a local level. Whilst this study showed that there were some

glaring gaps in discharge planning and in the continuum of care for many of these families, it provides some clear ways to move forward both in terms of practice and further research.

The beauty of this small exploratory descriptive designed study was that whilst it used a structured format to the telephone interview questions, it also provided the ability to ask the open questions. This allowed the participants to express their own needs from their perspective. As the researcher, I absolutely enjoyed the telephone interviewing with the parents in this research. The fact that many just ‘wanted to talk’ was simply wonderful. The experiences that they shared were often humbling and yet inspiring at the same time. Humbling, as some of them expressed their unmet needs for reassurance and advice, shared their worries and often had a sense of ‘coping alone’. Inspirational, because as the research progressed the potential opportunities to better meet those needs started to become clearer. The findings helped get a good sense of their concerns and needs.

Finally, there is so much to be gained by all health professionals turning our gaze towards these young children’s admissions. The long-term view that “healthy children grow into healthy adults” (MOH, 2004, p.ix), should reinforce the need to engage with parents and caregivers to ensure that discharge plans meet their needs, whilst also seizing every opportunity to strengthen the continuum of care for these children.

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APPENDICES:

APPENDIX:A

PARTICIPANT INFORMATION SHEET

Dear Parent or Caregiver

My name is Andrea Mockford. I am a registered nurse who works as the Nurse Co-ordinator for Child & Youth Health for the *(Named)* District Health Board. I am undertaking a research study as part of my Nursing studies through the Graduate School of Nursing, Midwifery and Health at Victoria University of Wellington.

I would like to invite you as a parent or caregiver of a young child recently admitted to *(Named)* ward at *(Named)* Hospital to participate in this study.

Please note that your participation in this study is entirely voluntary and your decision to participate (or not) will in no way affect you or your child's health care at *(Named)* District Health Board.

The purpose of this study is to gain a greater understanding of the needs of parents or caregivers once they are home from hospital and caring for their young child. It involves a short (10-15 minute) telephone survey with the parent or caregiver who has cared for the child whilst in hospital and once they are home.

Although this is a small study, it will provide the valuable chance to hear the parent or caregiver's perspective of their needs.

You have been provided with this information sheet about the study as your young child meets this study's focus. As the researcher I will be in contact with you by telephone in the first two weeks after your child's discharge from hospital to see if you would like to be a part of this telephone-based study, and to answer any questions you may have.

If you agree to participate in this study, I will arrange a time to phone you later for the telephone survey at a time that will suit you. During that call I will be writing notes and I also ask your permission to audiotape the telephone conversation, to assist ensuring my notes are accurate. BUT you can choose to not have it taped. This will be discussed with you and your verbal permission sought, before any audio taping commences.

Confidentiality

No names or addresses or any details that could directly link any information you provide either about yourself or your child will be in the final report. Any contact details I have, audiotapes or information that you provide for this study will be kept in

a locked cabinet in my office, until the research study has been completed. After which time, all personal details will be disposed of.

At the end of this study the overall feedback from parents/caregivers will be used in a final research report as a part of my thesis.

If you choose not to participate in this study, I will shred and dispose of any contact details that I have been given for you and your child. There will be no further contact by myself.

This project has received ethical approval from the Northern Y Regional Ethics Committee and the (*Named*) District Health Board Kaumātua Kaunihera Research sub-committee.

If you would like to discuss any of this further please feel free to contact me.

Andrea Mockford

(Contact details)

If you have any concerns about this research please feel free to contact my research supervisor

Dr Joan Skinner
Graduate School of Nursing, Midwifery & Health
Victoria University of Wellington

(Contact details)

Alternatively if you have any complaints you can also contact

The Health & Disability Commission
P.O. Box 1791
AUCKLAND
National Free phone 0800 11 22 33
Email: hdc@hdc.org.nz

APPENDIX:B

TELEPHONE INTERVIEW SURVEY TOOL

<u>Preliminary contact details:</u>	
	Participant Number _____
(Relationship to child):	_____
Rural / urban	_____
Admission reason:	_____
Documented ethnicity of child:	_____
Child's DOB:	/ /
Discharge Date:	/ /

Details highlighted: The additional information above will be provided by the Clinical Nurse Manager to enable the researcher to ensure that the participants both meet the study's inclusion criteria and are reflective of the study setting admission rates i.e. rural/urban, age and ethnicity of children/tamariki.

* Pencil in the following details only to assist at the time of the telephone survey (these are then erased and then the participant is only identified by the participant number at the top of the form.

* USE PENCIL ONLY	
Parent/caregiver name:	_____
Child's first name:	_____
Contact Phone number:	_____

Date first phone contact: / / Time: _____ am/pm

- ☐ Introduce self and revisit the information sheet details about the proposed study
- ☐ Initial phonecall only to discuss the study and to set up a suitable time date/time for the phone survey with parents/caregivers who consent to be involved in the phone survey.
- ☐ Rationale for this research:
- ☐ Rationale for audio taping:
- ☐ What involved: 10-15 minute phone survey

Verbal consent to phone survey: Yes / No

Phone survey time arranged to suit parent/caregiver

Date: / / Time: _____ am/pm

Any additional notes:

Phone Survey: (Attach page one)

Date: / /

Time started:

Time finished:

I hope this is still an okay time for you to talk to me? (Check? need to reschedule)

– The survey will take about 10-15 minutes

FIRST OFF: VERBAL CONSENT REQUIRED TO AUDIOTAPE TELEPHONE SURVEY

I just need to check before we start the phone survey today if you consent (agree) to my taping of our phone conversation for this survey.

What I've found is that I really want to be able to listen to parents during the survey.

Please know that **I HAVE NOT** turned the tape on as yet as I wanted to check if this is okay or not okay with you.

It is important that you know that I listen to the tape, I then type up notes from the taped conversation to notes up of the feedback, however, my research supervisor may also hear your taped phone survey **BUT** only to check my research style and ensure that my phone survey approach is appropriate and accurate. At the conclusion of the research the tape is discarded. **NO ONE ELSE** will hear your tape.

If you are not happy with this, I can write notes as we go (it will just take a bit longer) which is fine.

Do you agree with my taping our phone conversation today? **YES / NO**

Any Comments:

IMPORTANT: If parent / caregiver have agreed to audio taping.

STEP ONE:

☐ **TAPED TURNED ON**

☐ **OR PREPARE TO TAKE NOTES (VERBATIM)**

Introduction to survey

- Okay well thanks for agreeing to be a part of this study. I am really keen to talk with parents/caregivers of young children who have recently been in hospital.
- How are things going for you now that you are home from hospital?
- What happens is: I will ask you set questions and later (with the tape) I write down all your comments.
- But your details (name/your child's name and address are all confidential) these are NOT linked to you at all in the final report. Any names that you mention will be changed to protect your privacy.

- If you are unsure about any of the questions I ask- just say so, and I will explain further.
- Also if there are any questions that you don't want to answer that's okay to say so.
- Are you ready/shall we start?

Initial Demographic information needed:

I will start out by asking you a few questions specifically about your child to help me to look at providing an overview for the study.

1. HOW OLD IS YOUR CHILD? _____
Age in years and months

<input type="checkbox"/> Under 1 st birthday <input type="checkbox"/> >1 year – 2 nd Birthday <input type="checkbox"/> > 2 years- 3 rd Birthday <input type="checkbox"/> >3 years – 4 th Birthday <input type="checkbox"/> > 4 years – 5 th Birthday <input type="checkbox"/> 5 years age	<i>Andrea's use</i>
---	---------------------

2. REASON FOR THEIR RECENT ADMISSION? *What was the reason (health) that your child was recently in hospital?*

<input type="checkbox"/> Acute Asthma <input type="checkbox"/> Gastroenteritis <input type="checkbox"/> Respiratory Infection <input type="checkbox"/> Skin Infection <input type="checkbox"/> Febrile Convulsion <input type="checkbox"/> Other	<i>Andrea's use</i>
---	---------------------

3. LENGTH OF STAY? *(How many nights or hours did they stay in hospital?)*

<input type="checkbox"/> 24 hours <input type="checkbox"/> 24 hours-48 hours <input type="checkbox"/> 2 nights -3 nights <input type="checkbox"/> 3nights – 4 nights <input type="checkbox"/> Other _____	<i>Andrea's use</i>
---	---------------------

4. HOW LONG HAVE YOU BEEN HOME FROM HOSPITAL NOW?
Date of discharge known?

/ / or days/weeks

*I'll now ask a couple of questions about your needs after your child's discharge
you're your perspective*

**5. WHEN YOU THINK BACK TO WHEN YOU FIRST CAME HOME FROM
HOSPITAL WHAT WERE YOUR MAIN CONCERNS?**

Prompts: in caring for your child as they recovered? What worried you most? needed?

**6. WAS THERE ANYTHING THAT YOU NEEDED THAT WOULD HAVE
MADE IT BETTER?** *Prompts: Anything that you didn't get that might have helped you and
your family/whānau? Or any ideas?*

7 ANY OTHER NEEDS/THOUGHTS OR IDEAS THAT YOU HAVE?

*Prompts: You may have some other ideas or comments you wish to make
Or things that you wished you had known more about?*

8. ON THE FOLLOWING SCALE

**On a scale of one to five, how do you think *your* needs as a parent or caregiver
were met to help you care for your child's recovery after discharge? (When first
home from hospital)**

Your needs as a parent were not met at all		Some of your needs as a parent were met		Your needs as a parent were completely met
1	2	3	4	5

(Andrea circle)

The next question asks you some short answer questions about the some of the information provided at your child's discharge.

9. A) DID YOU RECEIVE ANY WRITTEN INFORMATION ABOUT YOUR CHILD'S DISCHARGE CARE FOR HOME?

YES / NO

If yes can you explain? _____

B) i). WERE YOU GIVEN A SUGGESTED CONTACT PHONE NUMBER FOR ADVICE AFTER DISCHARGE?

YES / NO

ii). IF YES WHERE WAS THIS FOR? _____

<i>Andrea's use</i>	
Hospital ward	<input type="checkbox"/>
General Practice (Dr)	<input type="checkbox"/>
After hours Medical Centre	<input type="checkbox"/>
Other (please state) _____	

C) i). DID YOU HAVE ANY FOLLOW-UP REFERRAL(S) TO ANY HEALTH PROFESSIONAL AFTER DISCHARGE, FOR YOUR CHILD?

YES / NO

ii). IF YES- WHERE WAS THIS FOR

FINAL DEMOGRAPHICS *the last two questions will help my research study to see if there may be different needs for parents/caregivers after their child leaves hospital*

10. CAN YOU TELL ME THE ETHNICITY GROUP(S) THAT YOU IDENTIFY WITH/ BELONG TO?

Can use prompts or can leave open as to how the parent identifies

Andrea's use

- | |
|--|
| <input type="checkbox"/> NZ Māori |
| <input type="checkbox"/> Pacific |
| <input type="checkbox"/> NZ European/ Pākeha |

☐ Other

11. FINALLY WHERE DO YOU LIVE? WHICH SUBURB? *(To assist if rural/urban based using the DHB definition)*

Andrea's use

☐ Rural
☐ Urban

*Is there anything that you want to ask me about this research?
Or any comments that you wish to make perhaps?*

THANK YOU ☺

Well I'm all finished thank you very much for the opportunity for your involvement with my study and to be able to hear your valuable thoughts and input. ☺ Although this is a small study towards my Nursing thesis, there is very little written in this area, and I am very keen to share the completed overview report with other health professionals who work with young children and their families/whānau about the needs of parents/caregivers after young children are discharged from hospital.

COPY OF BRIEF REPORT?

I am also more than happy to send you a brief report on the findings of this survey from parents and caregivers. This will be at the conclusion of the study, would you like to be sent a copy? (Approximately 1 page)

Yes / No

If you do I will need your name and address to post this to

USE PENCIL _____

Thank you voucher

As a small token to thank you for your input, I would like to be able to send you a \$5.00 grocery voucher. If you would like to take this opportunity I can post one out to you. Your name and address will then be removed from all details of the study i.e. your feedback is anonymous – not linked to you directly.

Yes / No

*If yes which supermarket voucher would be most useful to you?
(i.e. New World/Pak n save/countdown)?*

*Check if need name and address to post out
(i.e. for those who chose not to access a copy of report)*

USE PENCIL _____

Thanks again ☺

TAPE OFF ☐

Andrea's use

Date Survey completed: / /	Survey completed by:
Audiotape consent: Yes / No	Survey notes finished: Yes / No
Chose to have copy of findings report? Yes / No	If yes Date posted: / /
\$5.00 Grocery Voucher chosen by survey participant Yes / No	Type: _____
Voucher posted to participant Yes / No	Date posted: / /

APPENDIX: C

PARTICIPANT BASELINE INFORMATION

Participant Details Required

1. Complete this section with parent/caregiver

Parent/Caregivers Name: _____

Parent/Caregiver Contact Phone Number(s): _____ ♥

Mobile: _____

♥ *If they have no phone, is there a friend, neighbour, relative's phone that they can be contacted on?* **Phone number:** _____

Name of person whom I speak to at this number: _____

2. May need to return to child's medical records for some of the following detail

Child's Name: _____

Child's DOB: / /

Reason for Child's acute admission:

Address: _____

Documented ethnicity(s) of child: _____

Child's Discharge date: / /

3. Please ensure this form is stored in the locked research file when completed 😊

Research study

In progress

This Study has been extended until 31 December

This study with some parents and caregivers of young children after discharge. This flyer is about the (initial 3 month) research study in progress which started in August 2007 involving a small number of parents/caregivers with a child, who has been discharged from Ward 53.

Please note: That this flyer is only to notify you of this research, there is absolutely no involvement of you and your colleagues for this research.

My objective of this flyer is purely to raise staff awareness that the research project exists and who I am, as the lead researcher. Your basic awareness may be useful if a parent or caregiver mentions the study to you.

No actual research is undertaken whilst parents/caregivers are in the ward.

If you have any concerns my contact details are below.

My name is Andrea Mockford. I am a registered nurse who works as the Nurse Co-ordinator for Child & Youth Health for the Waikato District Health Board. I am undertaking this research study as part of MA Applied (Nursing) studies through the Victoria University of Wellington.

The purpose of this small study is to gain a greater understanding of the needs of parents or caregivers once they are home from hospital and caring for their young child.

It involves a short (10-15 minute) telephone survey with the parent or caregiver who has cared for the child whilst in hospital and once they are home.

This study focuses on children and tamariki under 5 years of age following an admission for an acute illness.

Although this is a small study, it will provide the valuable chance to hear the parent or caregiver's perspective of their needs.

Andrea Mockford
Nurse Co-ordinator – Child & Youth Health
Rural Health Services
Waikato DHB
Extension: 2112
Ph: 021 359 580 mockfora@waikatodhb.govt.nz

APPENDIX: E:

ETHICAL APPROVAL (NAMED) DHB KAUMĀTUA KAUNIHERA

(Named) DHB Māori Health Service
(Contact details)

Andrea Mockford
(Contact details)

18 July 2007

Tena Koe Andrea

Re: Needs of parents after their young child is discharged from Hospital following an admission with an acute illness.

Thank you for submitting research material to the Kaumātua Kaunihera Ethics sub-committee for comment. The sub-committee have read through and discussed your research proposal and provide their support pending the following amendments:

1. **F3.5:** The *(Named)* DHB's Kaumātua Kaunihera Ethics sub-committee will receive a copy of the results at the completion of your study, and
2. The results of your study must move towards influencing good practice and policy at the *(Named)* DHB.

Thank you for submitting your research to the subcommittee and should you have any further queries please contact me.

Noho ora mai

(Named) Manager

9 August 2007

Ms Andrea Mockford

Dear Andrea

"Eyes over the top" A descriptive study of the needs of parents after their young child is discharged from hospital following an admission with an acute illness: a study from one New Zealand DHB.

Investigators: Andrea Mockford.

Ethics ref: NTY/07/07/078

Locations:

The above study has been given ethical approval by the **Northern Y Regional Ethics Committee**.

Approved Documents

Telephone Survey Form for Parent/Caregiver July 2007.

Information sheet received 26 July 2007.

Research Flyer July 2007.

Accreditation

The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

Final Report

The study is approved until **28 February 2008**. A final report is required at the end of the study and a form to assist with this is available from the Administrator. If the study will not be completed as advised, please forward a progress report and an application for extension of ethical approval one month before the above date. Report forms are available from the administrator.

Amendments

It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study is altered in any way, including all documentation eg advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Yours sincerely

Amrita Kuruvilla

Northern Y Ethics Committee Administrator

Email: amrita_kuruvilla@moh.govt.nz

18 October 2007

Ms Andrea Mockford

Dear Andrea

"Eyes over the top" A descriptive study of the needs of parents after their young child is discharged from hospital following an admission with an acute illness: a study from one New Zealand DHB.

Investigators: Andrea Mockford.

Ethics ref: NTY/07/07/078

Locations:

Thank you for your letter dated 9th October 2007 to the Northern Y Regional Ethics Committee requesting extension of ethical approval for the above study.

The request was noted by the Chairperson under delegated authority and ethical approval for the study has now been extended until 31 December 2007.

Please contact me in case of any queries.

Yours sincerely

Amrita Kuruvilla

Northern Y Ethics Committee Administrator