Stories families/whanau tell to describe care by nurses within hospitals: a narrative analysis

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Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning

Abstract

Having a child in hospital is a stressful time for the whole family, yet existing research of this experience has predominantly focused on the perspectives of the boarding-in parent/guardian. Consistent with the theoretical approaches of working collaboratively with families, this study explores the experience from families' perspectives, seeking to understand how care is revealed in their stories.

The narrative analysis has explored the meaning of care constructed by these family/whanau as revealed within the stories they tell of their experience and contextualised with wider socio-cultural narratives. Stories of care are analysed with structural, performative, thematic and creative narrative lenses to explore the narrative processes the storytellers used. The genre narrative lens of Frank (1998a) highlighted the performative nature of the stories and the competing narratives influencing them. Participant experiences are presented as interpretive stories (McCormack, 2000a) – a representation that weaves participants' stories with the interpretive process. In this way the stories of care are shown with the influences of context clearly evident.

Nine families, whose children have been cared for by nurses in hospital, have told stories of their experiences of nursing care. The stories span diverse care contexts yet also demonstrate some similarities across families and experiences. Families perceived care when they and their child are acknowledged as unique and deserving of personal attention. Their stories reveal that physical and socio-cultural hospitalised spaces both support and undermine their sense of care. The families have told stories of wanting to trust, yet feeling the need to hold some personal agency in reserve, never entirely confident. Throughout the stories however, families remain grateful and gracious toward the nurses for the care received.

Families often expressed a lack of personal agency and bewilderment, even when they were more familiar with the environment. They seek to be effective parents in spite of unfamiliar systems and staff, and experience a lack of certainty when this is not supported. While there are many quest-type stories of resiliancy and stoicism, they are interspersed with chaos-type stories of passivity and disempowerment that challenge their understandings of nursing and care. These stories show the chaos often experienced by families and the ways that nursing care can support them through this.

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also emotional work for you as you listened to the suffering within the families' stories. Thank you.

To my colleagues in practice – I love working alongside and seeing the genuine effort you bring to delivering safe and effective care for children and their families. While we don't always 'get it right' I know there is a deep commitment to those who need our care – and that continues to fill me with hope. Thank you for being part of my ongoing journey. And I hope these stories resonate for you in some of the ways they have for me.

And my family. What can I say that in any way refunds the time and energy withdrawals I have had to make from our relationships? Sincere thanks for giving me the space to be 'in my own head' and pondering over issues that impacted on **other** families. Thank you Jo for stepping up so often and sustaining the family (despite, at times, feeling like it was on your own). Tessa, Matthew and Rebekah – you have lived through this long process and made allowances for me along the way – thank you. And for the wider whanau – I promise to try not being such a hermit.

To all the families I have had the privilege of working with, as a nurse, in the care of their children – I cannot remember all your names – but you have challenged and shaped me in so many ways – thank you. Apologies for the times I have not delivered care in a way that met your needs. Your stories also continue to teach me.

Chapter One

Introduction – Caring for Children and Families in Hospital

> I can only answer the question "What am I to do?" if I can answer the prior question "Of what story or stories do I find myself a part?" (MacIntyre, 1981/1984, p. 216)

Defining the study

This study explores the stories told by nine families about having a child nursed in hospital. Their experiences span from short episodic stays through to chronic ongoing visits, cross several cities and providers, and range from the birth of a baby to the death of a child. The families all volunteered to participate in this study to tell stories of their experiences. This chapter outlines the context for the study and introduces the methodological approach and key terms used.

Care and healthcare

Healthcare recipients are often confronted with oppressive master narratives that are common in hospitals and medicalised settings and which minimise their individual agency (Palmer, 2007). To achieve acceptance and privilege it is necessary to have "the feel of the right games" (Frank, 2002a, p. 390) – exploring their stories is one way to study the ways that families negotiate their way within the healthcare context. An example is the use of labels – when a 'child' becomes a 'patient' this inhibits some personal agency and requires complicity with the healthcare providers (Frank, 2007) – families even ask if they are allowed to leave the ward, despite there being no explicit sign inhibiting them. Stories can make these invisible "relations of rule" – the socio-cultural narratives that enforce the status quo (Stone-Mediatore, 2003, p. 183). Therefore examination of the context of the participants' stories involves the wider narrative context as well as the physical environment.

The clinical written records are the "institutionally legitimated stories" about patients and families and lay some claim to representing their reality, suppressing the legitimacy of the experience of the patient (Frank, 2006). Families are not routinely invited to participate in this documentation, and if they wish to read what is written about them, often have to make a formal request (Egerod & Christensen, 2010). This request may have to be in writing, further excluding some from access if they are not confident in letter writing. This study seeks to foreground families'

stories – acknowledging that their voices are essential to understanding care of children and their families. While the stated focus for this study is care, participants told stories in the order they wished, in the ways they wished. All stories were accepted and discussed during the interview – and brought forth in this analysis. In the prevailing narratives of care, there remains the risk that certain stories are silenced for the comfort of others (Frank, 2010b). In this study there is no censoring of stories or their presentation – while some people may prefer not to hear stories that do not match their narrative habitus or master narratives (of care), these are the stories that are told.

Why families?

The choice to focus on families/whanau was deliberate – when one member of a family is sick (and in hospital) all members of the family are affected (Wright & Bell, 1981/2004). This family approach is also congruent with the indigenous Māori conceptualisation of health where whanau (broadly family) is considered a pillar of ora (health) (Wepa, 2005). As well as Māori culture, this family focus is also aligned with Pasifika cultures where family/fono is intrinsically linked to understandings of health (Arlidge et al., 2009; Binney, 1987). This reinforces the commitment to listen to the stories of New Zealand families to gain insights into their experiences. Additionally, within the discourse of child health nursing, families of sick children are stated to be the focus of care (as family centred care) (Darbyshire, 1994).

Much of the literature exploring the experience of having a sick child in hospital has been based on reports of parents (primarily mothers) (Aitken, Mele, & Barrett, 2004; Chenery, 2007; Darbyshire, 1993; M. Foster, Whitehead, & Maybee, 2010; Gasquoine, 2005; Pai, Bhaduri, Jain, Kumar, & Sethi, 2008; Price, 1993). This is predominantly because mothers are overwhelmingly more likely to stay with the hospitalised child (Fisher & Goodley, 2007). The impact of the hospitalisation is experienced by the whole family however. Seeking to engage with the whole family allows this wider experience to be explored (Hartrick & Lindsey, 1995; Svavarsdottir, 2006). With much of the literature focussed on parental views rather than that of children and families (Limacher & Wright, 2003) this approach may uncover new stories. Narrative analysis does not seek a grand narrative with which to subsume all the stories told; instead its aim is to explore the complex lives of the participants and allow them to be heard where once they were not (Frank, 2004a).

The narratives, as they have been chosen and told, will be explored to understand the individual experience and the context in which it took place (Moen, 2006).

Families who have a sick member have to adapt not only to the physical changes and challenges, but also to disruption of their sense of identity (Harter, Japp, & Beck, 2005). A father who acts to protect his child, for example, is normally viewed positively – however if in a health facility the father acts to protect his child against a perceived threat from the staff, the same motivation is viewed negatively. The stories families tell of these experiences can give insights into the interrelationships between their subjective experience and the socio-cultural context that influences them (Harter et al., 2005). These joint interviews offer the opportunity to see the shared as well as individual experience (Liamputtong, 2007).

Children are often silent members of the family discourse (Graham & Fitzgerald, 2010). At times in healthcare the voice of their parents are taken as proxy for their own (Coyne, Hayes, Gallagher, & Regan, 2006). Much family research attempts to present data from one or more parent as a report for the entire family (Donalek, 2009). Yet children are not just passive participants of experience; they engage in their own lives and actively seek to make sense of it (Balen et al., 2006). Children are able to speak of their own perspectives (Moore, McArthur, & Noble-Carr, 2008). If children feel they are able to express themselves without having to conform to the 'right' story, they are very capable of expressing their experience in their own particular voice (Moore et al., 2008). Including this whole perspective allows the family to be conceptualised both as its parts and its collective sum, to gain insight into their experience (Eggenberger & Nelms, 2006). Focus groups (and a family group is a somewhat homogeneous focus group) are useful because participants support each other and speak for each other (Hesse-Biber & Leavy, 2007). Inviting families to contribute together displaces the locus of control from the interviewer to the collective group, complicating the interviewer-interviewee conversation – the layered and overlapping stories offer complimentary and competing perspectives that must be explored (Seaton, 2008). In this study the different participants within each family group are represented with different coloured fonts. This is to ensure each voice is visible and the collective family story does not overwhelm any story told by an individual. Individual participant's stories will be explored as individual stories when they are presented as such – and the collective story explored where the story is a jointly created narrative. The jointly created stories offer clues as to

the collectively shared values of the family, while the individual stories reinforce the individuality within the group.

In hospitalised settings, families are additionally categorised by not belonging to the dominant narrative group of healthcare professionals (Carter & Martin, 2005). While they might support each other in those times they are not routinely invited to tell their stories beyond the family group. The forum created by a family interview allows those who have had the experience of challenging circumstances to express their stories in ways that are valued (Adams, 2008).

While family/whanau is the focus of the study, the choice to participate, and identify who those participants were, remained with the family. In the current cultural discourse it remains women who are viewed as primarily responsible for children and their care (J. Lindemann Nelson, 1992; Nelson, 2006). They also continue to be the parent most likely to board in with a child in hospital (Gasquoine, 2005; Pai et al., 2008). Therefore while the invitation to participate was to families – it is mothers who are most likely participants (MacKean, Thurston, & Scott, 2005). Arlidge et al. (2009) in their study with whanau/family also found that it was mothers who predominantly spoke on behalf of the family. In order to not exclude the perspective of the person most likely to have been present (Gabb, 2010), the decision was made to include interviews irrespective of the number of family members present. This reflects the multiple forms of families – but additionally, the final stories differentiate voices of family members rather than aggregating them to one voice.

As the focus of this research is family/whanau rather than individuals, per se, analysing the way stories were told and by whom, offers further insights into the ways families create meaning around these experiences (Atkinson & Delamont, 2007). It is the *perceptions* and *experience* of the family/whanau having had a child nursed in hospital that is centre of the inquiry. The use of this qualitative methodology allows the rich engagement of the everyday experience of both researcher and participant (Yanchar, Gantt, & Clay, 2005). Narrative inquiry incorporates elements of both post-structuralism and critical theory (Armstrong, 2002). Hence the narratives of the participant whanau/families will be explored both at the 'micro' level of text analysis and at the 'macro' level of the context in which the narratives are set.

New Zealand environment

New Zealand has a primarily socialised public health system where admission to hospital for acute injury or illness is free of charge for citizens and residents (P. Davis et al., 2006). Hospitalised care of children is primarily in designated children's wards or hospitals. The Child Health Strategy (1998) has set forth government principles in relation to care of children in New Zealand. Two of the nine principles are particularly relevant for this study – that health services should be focused on the child and their family/whanau; and that these services should be culturally safe, integrating diversity into the approach (Ministry of Health [MOH], 1998). The Māori word 'whanau' is used interchangeably with the English word 'family' throughout this report. When speaking of whanau, Māori consider a broader conceptualisation of kinship that includes more than simply the immediate and nuclear family (Wepa, 2005). For this project, family/whanau is taken to mean whoever the participants considered 'family' and wished to include.

In New Zealand there are over forty thousand admissions to hospital each year for children aged up to 14 years (MOH, 2009). Many of these admissions are for unintentional injury, but the significant majority are for illness and infections (Craig, Jackson, & Han, 2007). The health of children is particularly sensitive to social determinants (Raphael, 2010), and in New Zealand many of the causes for admission relate to reduced family income and ethnicity (Craig et al., 2007). All the children in this study were admitted to hospital for at least one night and included both injury and illness. The cause for admission was not a focus of this study, however, rather their experience of care once they were admitted.

In New Zealand several studies have compared perspectives of healthcare providers and families/whanau (Ameratunga et al., 2010; Arlidge et al., 2009; Bolitho & Huntington, 2006; Chenery, 2007). The socio-cultural context of New Zealand differs from other western countries represented in the literature. Te Tiriti O Waitangi (as a foundational document establishing nationhood) underpins the place of Māori in New Zealand, and is expected to be integrated within the healthcare system (MOH, 2000). Family (or the more broad concept of whanau or kinship) is a foundation to health in Māoritanga (Wepa, 2005). This cultural approach to viewing the child within the kinship relationships is clearly paralleled with family-centred approaches to nursing and healthcare (Frost, Green, Gance-Cleveland, Kersten, & Irby, 2010). The importance of family to the wellbeing of the

hospitalised child is reflected across cultures and contexts (Garwick, Jennings, & Theisen, 2002; Svavarsdottir, 2006).

Previous experience of whanau/family is a major determinant of the ways in which Māori families engage with the health service (Bolitho & Huntington, 2006). Issues relating to poverty and reduced access seem to impact significantly for Māori families. These factors contribute to Māori children being overrepresented in hospital and ill health statistics in New Zealand (Bolitho & Huntington, 2006). For the four families interviewed in their thematic qualitative study, hospitalisation was a significant resource drain for the whanau/family. Additionally they felt vulnerable and at the mercy of the healthcare professionals – aware that their parenting skills were being judged. This study highlighted the continuing barriers that many families must overcome to access and then engage with healthcare organisations and staff. Hence there appears to be the opportunity to contribute further to the understanding of the meaning of care by undertaking research that explores care as it is experienced by whanau/family.

Since the 1950s, the culture of hospital environment has changed – and families are more able to participate in the care of their hospitalised child (Coyne, 2008). The experience of children and their parent/guardian has been explored over many years now with the goal of increasing the quality of their experience (Callery, 1997; Darbyshire, 1994; Harrison, 2010; Nuutila & Salanterä, 2006; Shields, Kristensson-Hallström, & O'Callaghan, 2003). What these studies continue to demonstrate is that nurses' perceptions of care are not always shared by families, and that there is further need to understand families' experiences (Association for the Welfare of Child Health, 2005; Avis & Reardon, 2008; M. Foster et al., 2010).

Nursing care in the midst of becoming family – neonatal environment

Some families enter the experience of having a child hospitalised at the same time they enter parenthood – with a premature baby. These families have to adapt quickly from their anticipated narrative of a 'natural' pregnancy and delivery to one that is clinically determined and 'unnatural'. There is much to absorb when first entering a specialist premature baby care unit (Lupton & Fenwick, 2001). They commonly have an open plan design to allow nurses to more easily monitor several babies at any one time. Visually, there is a high technology appearance with multiple pieces of equipment and digital displays to measure vital signs of babies –

babies who are likely to be much smaller than prospective parents have prepared themselves for. These machines also add to the aural environment – with beeps and alarms common, and adding to the intermittent sound of crying infants. These sounds can be confusing – they may indicate a problem with the baby that requires attention, or may instead be incidental, and therefore are ignored.

The babies may initially be completely enclosed in a Perspex incubator, with human contact only available through doors in the sides (only big enough to just allow access and not release all the warmth). As babies develop and become more able to adapt to the outside environment they progress to more open bassinets. They may remain connected to monitors, however, through their whole stay. Nursing staff are always present, though the personnel changes across different shifts. Medical staff are more likely to come and go throughout the day – but are likely to be consistent across a week. These staff all interact freely and often. Because of the open plan layout, there is unlikely to be much privacy - so even with the sensitive use of screens, conversations about one baby become shared with everyone in the open space. Until one becomes more comfortably familiar with the environment and people, this is simultaneously a reassuring and intimidating environment (Obeidat, Bond, & Callister, 2009).

In child healthcare nursing, it is always important to understand family (Darbyshire, 1994), but in neonatal care families themselves are often still coming to terms with suddenly being parents (Fenwick, Barclay, & Schmied, 2008), and therefore the concept of 'family' is not yet fixed. Especially if there are pressing healthcare issues for the neonate, the care is likely to be centred around the infant (Fenwick et al., 2008) with the responsibility for the care of the mother less clearly defined. So for example, if the mother has had a caesarean section to deliver the baby, but wants to be in the neonatal area with her baby, she must return to the maternity area to receive pain relief, or manage on her own. Because of the infant centred approach of staff, it can be challenging for mothers (and families) to establish themselves and their roles in the context of this care delivery environment (Lupton & Fenwick, 2001; Shields, Kristensson-Hallstrom, Kristjansdottir, & Hunter, 2003). Not being able to 'be the mother' is a source of significant distress for mothers in neonatal units (Obeidat et al., 2009), a complex issue with ideals of mothering bound up with cultural and societal expectations (Fenwick et al., 2008). Awareness of these issues in this study ensures that the intersecting narratives are included.

Nursing care as family with a hospitalised child

Beyond this time of having a neonate admitted, families tend to bring their child in to a hospital (whether for illness or injury) having exhausted their own strategies and resiliencies. They arrive expecting expertise and competence (MacKean et al., 2005), and to have their concerns treated with respect (Lewis, Kelly, Wilson, & Jones, 2007). In New Zealand hospitalised care of children is generally from birth until they turn 15, after which time they are admitted alongside adults. So the context of these stories is hospitalised care delivered by staff who work exclusively with children and families.

Hospitals are by nature very clinical environments. Machines and monitors are now relatively commonplace throughout wards and hospitals. Families may initially find these technologies unfamiliar and therefore be uncertain as to the meanings of the information they produce. Even routine assessments of children now often involve the use of monitors and digital displays. Parents often experience short interactions with nurses, centred around the recording of numbers from equipment (Shin & White-Traut, 2005). This reliance on monitors can add to a family's anxiety as they return home after hospitalisation.

The families' stories cover many clinical areas (apart from intensive care units). These areas are typically organised around medical specialties – so the reason a child presents to hospital generally determines the ward the child is placed in. When the hospital is full, or when there are multiple specialties involved, this 'allocation to a ward' is not quite so predictable. With multiple admissions, though, the families often become familiar with staff as well as the general environment.

On a typical day the families would see 2-3 nurses over the 24 hour period, multiple medical staff for 'ward rounds' (for medical review), cleaners, allied staff, and many other families. Depending on the reason the child was admitted, they may be allocated a single room, or double, or four bedded room. As the stories in this study reveal, the reasons for the allocation are not always apparent to the families. The more 'unwell' the child, the closer their room tends to be to the clinical staff hub. Conversely if they are regarded as being nearer to going home, they may be quite some distance from staff and resources. The rooms may or may not have doors, may or may not have external windows, and may or may not have hygiene facilities

in them. In other words, families have little control over their environment and who they may have to share it with.

Even the most basic needs become complicated with a child in hospital. Once a child is admitted, the hospital provides meals for the child. Some hospitals will give the boarding-in parent breakfast, and most will feed a breast-feeding mother (though often only if the baby is six months or less). Apart from this, if a parent/guardian/care giver wants to eat they must either rely on someone bringing food in for them, or leave the ward to find a shop. Families that become more familiar with the environment may develop coping strategies – for example calling on friends or extended family (when available) to share in the load. This complex interplay of influences provides rich opportunity to research and explore the ways that families experience care within this environment.

The question

The focus of this research is the stories families tell of nursing care while they have a child in hospital. The initial question aimed to remain open to the agenda/s of the participants – and what they deem important and requiring to be told:

What stories do families/whanau tell about having a child in hospital?

This guided the initial conversation with the families during the interviews. Families often began by recalling incidents from their experience where the centre of the story was the child and/or the family. However as the interviews progressed, I sought examples and stories that focused on the nature of their relationships with nurses and nursing. In this way the follow up question, and a lens through which to view the data was:

How is nursing care revealed in the stories that families/whanau tell of having a child in hospital?

Narrative approach

Stories matter. Stories are the way we learn who we are and where we fit; in families, in neighbourhoods, cities and society. Families tell stories to their young to ground them in identity – 'that is how we do things in our family'. As they grow older, children learn about pecking order and hierarchies by whose stories they are allowed to share in. Adults tell stories to each other to glue friendships and

succeed in their vocations. Organisations and countries have collective narratives that help define who its members are (e.g. 'our family' or 'best' or 'underdog'). Understanding stories helps us understand those who tell them and the social forces at work in their lives.

Stories must be considered along with their personal history and master narratives they exist within (Conle, 2000). Each of the interview transcripts were searched looking for stories that spoke of the family's experience of care. These were organised chronologically and analysed using a performative narrative framework (McCormack, 2004; Riessman, 2008) and narrative typology (Frank, 2010b) as lenses. To ensure the co-construction of meanings throughout the interviews remained apparent, these stories are presented as an 'interpretive story' (McCormack, 2000b, 2004) weaving together the contextual and personal. The goal is to begin with – and bear witness to - the significance of the personal by illuminating the wider social context (Conle, 2000).

Some authors distinguish between 'story' and 'narrative' – but there is no consistency in this (Riessman, 1993) so I have followed the practice of others and use the terms somewhat interchangeably (Bingley, Thomas, Brown, Reeve, & Payne, 2008). Where there may be a use in differentiating is in comparing an intimate or local 'story' of something specific with a conceptualisation of 'narrative' carrying broader themes and ideas (Riessman, 2008). So, for example, we might tell a story of an event that reinforces a more generally held narrative or belief about the nature of reality. This distinction is only arbitrary however and (like all language) context of its use will have to give some sense of meaning. In this study, the interviews provided hours of talk - the stories were often interspersed with other forms of speech. The analysis focused on the stories of experience within the broader narrative context.

Other qualitative approaches to narratives look for thematic, discourse and language analysis (Bingley et al., 2008). Narrative inquiry may include aspects of these, but particularly looks to the shape and content of the story as a whole (Ezzy, 2000). The urge to generalise has to be resisted to embrace a pluralistic approach that is able to hold multiple meanings and interpretations (Bochner, 2001). Much research on illness seeks to explain participant behaviours (e.g. coping, grief) as adaptations to their experience. Narrative seeks to explore the social systems the

participants' lives are embedded within (Frank, 2001). It is the role of analysis to attempt to differentiate between the voice of the dominant discourse and the voices of the participants (which are each embedded within the narratives) (Eldershaw, Mayan, & Winkler, 2007). At times this requires highlighting master narratives the storyteller is unaware they have embedded into their storying (Frank, 2002b).

Illness stories

Illness stories are one particular type of story (Frank, 2006). As a tool for making sense of events that seem to lack cohesion, storytelling is well suited to unpacking the experience of changes in health (Frank, 2004a). While it may be suggested that family stories are not 'illness stories' because it is the child who is unwell, it is in fact the family who share the experience of illness (or injury). Parents, siblings and extended family/whanau are intimately connected to their children – so anything that happens to one family member is experienced (even vicariously) by the rest of the family. In remembering the hospitalisation, the participants re-present the experience to show what they went through, and what they continue to regard as important about it (Radley & Taylor, 2003). In this way their story of illness/injury gives insights into the experience.

Stories from those who receive care have much to teach about the experience of care (Bingley, Thomas, Brown, Reeve, & Payne, 2008) as they have personal insights not available anywhere else (Parse, 2008). Illness stories are not abstract tales – they are embodied stories, told when illness and injury go beyond the ability of the storyteller to 'fix' themselves (Frank, 1998b). Illness and injury threaten the status quo, at very least physically, but also potentially existentially (Frank, 2009). Therefore they are stories of vulnerability that speak of moments of 'calling out' for care. Being receptive to the construction of narrative highlights on interactions, hegemony, perceptions of expected role, and insights into patient care (Overcash, 2003).

Healthcare professionals will often 'take' a patient's history – but the information sought is not a personal history at all (Frank, 1998b). What tends to be sought is specific, professionally identified interests or headings that relate to reducing the client' experience to a diagnosis or problem list – and only information related to these will be documented (J. Clark & Mishler, 1992). This can lead to the patient (and/or family) reducing the content and focus of their own story to that validated

by the professionals (Harter et al., 2005; Monks, 2000). Narrative inquiry seeks to reorient the focus by taking an interest in the broader told story and the aspects that the participants view as important.

To make sense of the stories that families tell, I have analysed them using several 'lenses' or viewpoints. These lenses allow particular aspects of the content, form, and performance of the stories to be considered and explored. Some of these lenses focus on the construction of language and ways the storyteller conveys their viewpoint. Other lenses consider the context the story tells of – that which is visible to the storyteller, but also that which may not be apparent to them. This raises the concept of habitus – utilised by Bourdieu to uncover the social reality of various vulnerable populations – and applied by Frank (2002a) to demonstrate the way personal and social norms influence our lives. Habitus is the unconscious cultural world view an individual holds and lives their lives from. It is not deterministic - individuals and families can change their viewpoints if they consciously choose to – but without a level of reflection, it nevertheless influences language, relationships, dreams, and therefore stories. Analysis of stories requires being mindful of own as well as other's habitus.

Performative approaches of narrative inquiry do not deliver a final conclusion based on themes derived from individual's stories (Riessman & Mattingly, 2005; B. Smith & Sparkes, 2008). The stories as they are told are personal self-reports that can only offer partial insights on the complex and nuanced experience of the storyteller (Polkinghorne, 2005). As a constructionist approach it calls for tentative understandings that reflect on the multiple interpretations possible (Wear, 1996). To assert a particular interpretation potentially limits each storyteller's agency and loses the individual differences and variation that can be disguised by categorisation (Donalek, 2009). Narrative analysis celebrates the particular – the goal of this research is to tell the stories of the participants – illuminated with critical analysis – but remaining their stories (Barone, 1995; McCormack, 2004; Riessman, 2001). Narrative analysis explores not only 'what was told' but also asks why the story was told by the storyteller in that way (Riessman, 2001). There may be commonalities between stories – these often reveal the socio-cultural context and prevailing narratives available to those telling the stories (Bourdieu, 1993c).

Although there has been research exploring care from the perspective of nurses and from family members, I am not aware of any that have used narrative analysis of families' stories in relation to their experience of care. Both qualitative and quantitative researchers have explored nursing care in hospitals and this has contributed to knowledge of care as experienced by families. The purpose of this research is the analysis of narratives shared by whanau/family in order to arrive at a multiplicity of understanding of 'care' as shaped by the experience (Polkinghorne, 1995, 2005). The narrative approach taken in this study is a hybrid - taking the illness-type stories of families, and analysing them using the structural approach of McCormack (2004) along with the appreciative narrative genre approach of Frank (2010b). It is hoped that clinicians would equally reflect on these stories and ways to improve outcomes for whanau/families in the healthcare system.

Researcher's background

My interest in this area of inquiry has been there from my time as an undergraduate nursing student. At that time children and families were cared for in a dilapidated temporary building that had been used many decades beyond its original purpose. There were holes in the floor and leaks when it rained. Despite many attempts at eradication, cockroaches continued to remain co-habitants of the building. It was old and run down – yet my experience of (learning about) nursing children and their families began a passion that continues these many years later.

While my nursing practice has been able to move to newer and more purpose built facilities, it is the interactions with children and their families that continues to both delight and disturb me. I am awed by the generosity of spirit they so often share – while they are worried about the health and wellbeing of their child, and have to engage with a procession of nurses and other healthcare professionals, they share their joys and sorrows with us – visitors in their lives for this time. I am also delighted by the commitment to excellence that many RNs continue to demonstrate. I have worked with many nurses who shared my passion for 'getting it right' and 'adding value' to their visit with us. These people continue to fuel my belief that we can be family centred.

The disturbance comes from a sense that we do not always deliver what we say we want to. I put my own hand up on this. I continue to remember a 12 hour shift where I worked doubly hard on collaboration and partnership with a new mother

(and father) and their premature baby. For 10 hours this mother was able to determine as many of the 'how' and 'when' of interventions with her baby that I could clinically facilitate. They had gone home to get some dinner and agreed that they would be back at a certain time to feed the baby again. Except that they weren't there at that time. So in my busyness, I fed the baby so I could get on with other things (and get ready to go home). The mother arrived a short time later – highly distressed that the baby had been fed and that she would not be able to have another attempt with breast feeding - really distressed; and angry. The good work of the previous 10 hours evaporated into forgotten-ness. Now I can justify what I did – premature babies require regular feeds; the mother was not there; she had some post-natal depression so her reaction may have been larger than normal. But for this mother, at this time, none of that mattered. By virtue of being on staff, I wrote in the clinical progress notes – the baby was fed, all cares given, vital signs as expected, family have been in most of the day. But her story of shattered expectation and disappointment was not recorded anywhere. I did speak to the mother several days later, and all was forgiven - in fact she apologised for her reaction (though that is another question – why apologise for an emotional response?). But I remain disturbed that many families journey through our hospitals and their perspectives are hidden – so we can only guess if 'care given' is 'care received'. These types of experiences have brought me to this study.

Overview of the thesis

This introductory chapter outlines the nature of the study and clarifies key terms used. It has given an outline of the research methodology and background to the study. Chapter two reviews literature relevant to the study around children and families in hospital. Chapter three explores the philosophical underpinnings of narrative inquiry as they relate to this study. The methods and procedures used will be explored in chapter four. Chapters five to seven contain the 'interpretive stories' from each interview. Chapter five focuses on the families whose babies were born prematurely and required nursing care. The interpretive stories of the families whose children required short term acute admissions are the focus of chapter six. Chapter seven presents the interpretive stories of families whose children require/d ongoing nursing care. The summary and discussion of the findings and implications of these stories is in the final chapter eight. The limitations of the study are also addressed there.

Chapter Two

Literature Review

> We need exemplars, accounts of efforts that not only include patients' stories in transcripts of clinical encounters - which was a big leap forward - but that engage them critically as socially positioned persons with alternative understandings of what has been happening to them (Mishler, 2005, p. 443)

This chapter explores literature related to nurses caring for children and families in hospital, particularly looking for how families' stories of care are revealed in the literature. In keeping with the methodology, the participants' stories remain central to the analysis, with the literature explored to gain deeper understanding of the personal and contextual factors made apparent from the interviews (Conle, 2000). Specific health databases Scopus™ and Ebsco™ were used to explore available literature. Key search terms included (various spellings and combinations of) 'care', 'nursing', 'family', and 'hospitalised child'. 'New Zealand' was an additional search term once the international literature had been reviewed. More specific search terms were added in the development of the interpretive stories for different contexts (such as care of premature babies), and when particular narrative threads were apparent (such as 'trust' and 'role'). The search parameter was initially limited to the last ten years; however where articles pointed to seminal authors and/or research, this was also included. The intent of this literature is to explore the existing narratives that exist and influence the care of children and families in hospital. With a focus on nursing care, the majority of literature included relates to nursing practice and relationships with children and their families.

Caring

It has been suggested that the healthcare system has forgotten that it is founded in care (Kuzel, 2008). 'Caring', while often spoken of as central to nursing practice, is not easily defined (Corbin, 2008). Henderson et al. (2007) suggest several behaviours that communicate 'care' such as informing and listening. The prevailing approach to understanding the concept of caring has been exploration from the perspective of nurses - as they perceive the delivery of care (Hudacek, 2008; Maben, Latter, & Clark, 2006; McGrath, 2008; Persky, Nelson, Watson, & Bent, 2008; Summer, 2008; Young et al., 2006b). This literature has explored the activities and attitudes that nurses retrospectively believe enact caring toward a patient/client. Maben et al. (2006) found nurses identified particular behaviours,

such as giving time, that they regarded as being caring of the patient/client. However they also identified many organisational and cultural barriers to them being able to effectively deliver care. Persky et al. (2008) also found nurses wanted to provide compassionate care but felt constrained by environmental factors. This work notes that there may be differences between nurses and patient/client expectations of care.

An underpinning value of care is that all humans are of equal worth; the presence or absence of this value will be demonstrated in a nurse's manner and practice (Nåden & Eriksson, 2004). Being a caring person does not necessarily lead to the experience of care by the client (Corbin, 2008). Wikberg and Ericksson (2008) acknowledge that care is a complicated interpersonal phenomenon that is influenced by both the nurse and the client's background and socio-cultural values. Including family in the care of the patient increases the complexity of the interrelationships (Wikberg & Eriksson, 2008). When working with children and families there are developmental and cultural viewpoints influencing the interpretation of nursing behaviours as caring or not, with both children and adults included in the interactions. While it is possible to explore behaviours that support care, it is only families who can actually determine whether care delivered is received as child/family-centric and a good 'fit' for them (Betz, 2006). This is not simple to measure, however, as patients do not routinely report this directly to staff (Austgard, 2008).

Austgard (2008) suggests that while caring may be evident by "trust, open speech, hope, and compassion" it also involves metaphysical values (p. 316). Patients can be viewed in a reductionist and objectifying way that excludes their 'personhood', or perceived in their humanity (Austgard, 2008). This is similar to the 'loving eye' that Frye (1983) argues is essential for care. Viewing the patient (in this case, the child and family) in this way ensures that they are able to express their own story instead of being forced to conform to the dominant narratives of culture and professionals (H. Lindemann Nelson, 2001). Thus ethical care involves accepting patients as they are, in spite and because of their differences from the nurse (Kärkkäinen & Eriksson, 2004). This relational positioning by the nurse of the client as unique and having their own story requires cultural awareness and commitment on the part of the nurse (Paulsen, 2011).

The technological environment of hospitalised care can be both a barrier to and enabler of patients and families experiencing care (McGrath, 2008). Even having a child 'monitored' can involve both a sense of reassurance and a notion of feeling under surveillance (Forbat, Maguire, McCann, Illingworth, & Kearney, 2009). The technology is present, however, because hospitalisation requires a body-focused intervention (for illness or injury); at the same time as an identity crisis that calls for care (Griffiths, 2008). So the experience of care is built in a relational state between the patient and the nurse that is influenced by the physical and socio-cultural context (Wikberg & Eriksson, 2008). In the child health context this is further complicated by the various family members involved and the likelihood that each of them requires slightly different interventions to perceive care as present.

Several studies have explored the experience of families receiving nursing care (Callery, 1997; Dickinson, Smythe, & Spence, 2006; Espezel & Canam, 2003; Lupton & Fenwick, 2001; Opie, 1998; Stoltz, Willman, & Uden, 2006; Young et al., 2006b). This includes research across the life span of the patient/client, from mothers of neonates (Lupton & Fenwick, 2001) through to families of older adults requiring continuing care (Opie, 1998). Significantly however, the predominant approach taken is to focus on the experience of one family member - often the mother if the patient is a child, or spouse/partner when the patient/client is older (Callery, 1997; Lupton & Fenwick, 2001; Obeidat et al., 2009; Stoltz et al., 2006). The experiences of families in the literature reveal a variety of experiences and perspectives. Some report families experiencing nursing care that they view positively and of a high quality (Heller & Solomon, 2005; Oermann, 1999). Others however, found families whose experiences were frustrating and less caring (Lupton & Fenwick, 2001; Lynn-McHale & Deatrick, 2000). Lupton and Fenwick (2001) found mothers told stories of tension with nursing staff, feeling like they were in a 'tug-of-war' over the care of their child. Other studies tell stories of tenuous trust, sometimes built up and other times broken down (Lynn-McHale & Deatrick, 2000). The research demonstrates that the experience of families with a child being cared for in hospital is complex, with some parents describing feeling watched and somewhat judged by nurses (Darbyshire, 1994; McKeever & Miller, 2004). Many parents seem to feel like the uniqueness of their particular situation is not always acknowledged by those caring for them and their child (Dickinson et al., 2006).

Children in hospital

The first children's hospitals were opened in the mid nineteenth century – primarily for the children of the poor to provide both physical restoration and religious instruction (Dudley & Carr, 2004). The nature of hospitalised care of children has changed most significantly since the 1950s (van der Horst & van der Veer, 2009). Prior to this parents were limited to visiting their hospitalised child for a few hours during weekdays – effectively excluding working class parents (Dudley & Carr, 2004). The change has been significant - now there is an expectation on parents to board in with their child (Coyne, 2008; Ygge & Arnetz, 2004). The professional language, however, does not always match this shift in relationships – for example policies of family carers being 'allowed' to stay with their child (L. Lam, Chang, & Morrissey, 2006).

'Family centred care' is the term more recently used in nursing literature to describe the nature of the care relationship with children and their families (Shields, Pratt, & Hunter, 2006). This approach calls for the focus of care to include the family and build a collaborative relationship between family and carers (Shields et al., 2006). Despite the ideals of this approach, parents and children continue to exert little influence on decisions related to treatment and psychosocial interventions (Betz, 2006). This is not just related to medical models of decision making – many nurses continue to struggle sharing decision making power with families (Harrison, 2010). Many families find their involvement limited to day-to-day parenting with the professionals acting as gate keepers to greater participation and decision making (Betz, 2006). Definitions of family also remain constrained by staff (Lupton & Fenwick, 2001; Maijala & Astedt-Kurki, 2009).

There is growing recognition that to deliver effective care involves recognition of family-as-client as well as the family member in the hospital bed (Yagil, Luria, Admi, Moshe-Eilon, & Linn, 2010). Yet while families often have clear expectations of how nurses should behave with them, they also often are hesitant to disturb nurses (Yagil et al., 2010). Darbyshire (1994) also found that families are try to avoid being a nuisance to nurses, not always sure if their needs are 'urgent' enough.

The hospital setting reinforces the hierarchy of knowledge and decision-making (Callery, 1997). Families often seem to feel that their perspectives are not sought or quickly dismissed in preference for the professional perspective. Parents'

perceptions of nurses being busy also contributes to their sense of having only a utilitarian relationship with staff (Darbyshire, 1994). Nurses are often unclear about where the locus of control and power does or ought to belong, for example, around whether the responsibility for the hospitalised child is their's or the parents' (Shields, Kristensson-Hallstrom, et al., 2003). The professionalised and institutional nature of hospitals presents a new cultural experience for families where their roles as family and parents require ongoing negotiation (Skultans, 2004). In extreme cases this can cause significant cultural and emotional distress (Lynn-McHale & Deatrick, 2000; Power & Franck, 2008; Tanner, Agius, & Darbyshire, 2004).

In their literature review of family centred care, Mikkelsen and Fredericksen (2011) found partnership between nurses and families was built on common goals and reciprocity. This reinforces the findings of Marino and Marino (2000) who found that parents and nurses sharing clear goals is vital to a collaborative working relationship. This requires nurses being able to share power and move away from medical models of practice (Mikkelsen & Frederiksen, 2011). The caring relationship is facilitated when parents are allowed to be parents and advocate for the best interests of their child (Mikkelsen & Frederiksen, 2011). Nurses who facilitate families in this may find themselves working against the dominant narrative of institutional control (Limacher & Wright, 2003). These structural influences, such as organisational culture and educational support, act as enablers or barriers to the delivery of care centred around the family (Mikkelsen & Frederiksen, 2011). Children and families will often attempt to break down the clinical nature of the environment of their bed spaces – but this relies somewhat on the understanding of the nurses involved in their care (Lewis, Kerridge, & Jorden, 2009).

Hospitalisation of a child causes a variety of challenges for families including emotional, financial and relational stresses (Aitken et al., 2004). The length of the admission does not seem to be necessarily correlated to the impact on the families (Arlidge et al., 2009), with both short and longer admissions causing difficulties for families (L. Lam et al., 2006). Families are more likely to report satisfaction with nursing care when they receive care 'in sync' with their experience and preferences (Marino & Marino, 2000). Unclear expectations of parents by nurses seems to contribute to their frustration and distress (Ygge & Arnetz, 2004). However many

families believe that they are the cause of this by not being assertive enough (Aitken et al., 2004).

Gender is another influence on the care relationship as it involves cultural understandings on the part of the nurse as well as the parent (Yagil et al., 2010). Yagil et al. (2010) found fathers are least likely to be satisfied with nursing care, in part due to the assumptions on the part of many nurses that the mother is central to the child's care. However when nurses with traditional preconceptions of 'family' see fathers in the primary caring relationship with a child, they may respond even more warmly as they see a male fulfil a nurturing role (Yagil et al., 2010). Research that includes consideration of these cultural types (such as narrative inquiry) will be helpful in exploring the impact of these influences.

Care for neonates and families

Wiebe and Young (2011) interviewed 21 parents with babies requiring intensive care. With a particular focus on culturally appropriate care, they found that socio-cultural influences intersected with interpersonal relationships to influence the experience of care (Wiebe & Young, 2011). In common with Aagaard and Hall (2008), parental vigilance of nursing staff caring for their babies was common. A trusting relationship with the nurses, however, seemed to relieve parents of the need to be so watchful, and to be much more tolerant with minor grievances. Establishing this trusting relationship was a complex activity – while they were clear about the manner of interactions they sought from nursing staff, families were reticent about verbalising concerns or questions (Wiebe & Young, 2011). A high level of trust is necessary to comfortably leave a vulnerable infant in the care of another (Fenwick et al., 2008). This is not simply in relation to nursing staff, however; families are sensitive to the rules and culture of the environment with respect to inclusion/exclusion of family participation. Nursing interactions that communicate genuine interest and commitment that are congruent with organisational structures reinforcing this message are necessary for families to build trust and perceive care (Wiebe & Young, 2011).

The experience of becoming a mother while her baby is cared for within a hospitalised setting complicates an already complex transition (Heermann, Wilson, & Wilhelm, 2005). Heermann et al. (2005) interviewed 15 mothers using a qualitative thematic approach to analysis. Similar to the study by Lupton and

Fenwick (2001) this study identified that mothers perceived power imbalances where the 'ownership' of the baby was contested and transitioned over time (Heermann et al., 2005). Many mothers waited passively for permission of nurses to touch or interact with their babies (Heermann et al., 2005). While all these babies eventually left the hospital and their mothers were required to parent their babies independently, not all mothers in the study moved beyond the role of silent observer (Heermann et al., 2005). Facilitating and empowering this transition is an integral aspect of nursing premature babies and new mothers, yet some of the mothers learned not all nurses involved in their care accept mothers in a partnership role (Heermann et al., 2005). Heermann et al. (2005) only interviewed mothers, so the experience of other family members (also transitioning in identity with the arrival of a new baby) is not evident here. They noted that mother's attempts to negotiate were frequently misunderstood by nurses (Heermann et al., 2005), further reinforcing the need for further studies that include the ways that all family members negotiate their roles.

Care for children and families requiring acute care

Families present for professional care when their own strategies are no longer adequate to meet the perceived needs of the child (A. Williams, O'Rourke, & Keogh, 2009). Parents tend to assess their child's health and often intervene prior to presentation to a hospital (A. Williams et al., 2009). Williams et al. (2009) found that parents tend to regard presentation to hospital as a last resort, having considered many other options. Nevertheless many families feel judged by staff as to their competence when they do bring their child to hospital. It is this relationship between nurses and families that determines a family's satisfaction with care – more than length of stay or severity of illness of the child (Marino & Marino, 2000). Therefore any research that explores the caring within these relationships offers insights into practice and experience.

Focus group interviews have been used to elicit the stories of parents while their children are in hospital (Teare & Smith, 2004). Teare and Smith (2004) interviewed 15 parents over four focus group interviews (though this only included two fathers). The researchers found setting up these interviews difficult as parents were not keen to leave their children in case they were away at a time they were needed (Teare & Smith, 2004). Those who did participate seemed to enjoy the opportunity to talk with other parents and tell of their experience (Teare & Smith, 2004). These

parents found it difficult to advocate on behalf of themselves or their children, wishing that the nurses would be more inclusive of their participation (Teare & Smith, 2004). The timing of these interviews may have been a limitation to this approach, however, with the immediacy of their child's illness/injury likely to be the overriding concern. Families may have felt constrained in speaking of concerns if they felt 'complaining' could impact on the care of their child. Satisfaction research taken at the time of or very close to the hospitalisation also risks the 'halo effect' where families are grateful for a positive health outcome and their experience is viewed through that relief (Battrick & Glasper, 2004). Interviews that take place after the hospitalisation would allow the families to reflect more on their experience and in this way tell stories that continue to be important for them.

Latour et al. (2011) interviewed parents (39 mothers) of 41 children admitted to intensive care. In their thematic analysis they identified several overarching themes, all of which are influenced by the relationship between the nurses and parents, and the environmental supports (Latour et al., 2011). Just over half the interviews had both parents present. This is common with much research with parents of hospitalised children. The research report did not outline reasons for this level of participation of fathers – though two interviews had only the father present. The parents in this study identified several priorities such as honesty, accessibility and accurate information, wishing this to be presented in a hopeful manner (Latour et al., 2011). The theme identified as influencing all others was emotional intensity – the depth of emotions experienced by families as a result of their child's health, influenced by relationships with staff and the environmental factors (Latour et al., 2011). While this may be particularly evident in an intensive care environment, it has similarities to the watchfulness and vigilance identified in other studies, where families interpret nursing behaviours through their own cultural viewpoints (Heller & Solomon, 2005).

Moorey (2010) has explored the influences on children and families with unplanned hospitalisation. Children, especially younger children, often adjust their emotions to that of their parents in unfamiliar environments, such as those experienced with unplanned hospital admissions (Moorey, 2010). Nursing interventions that seek to understand the family and their concerns tend to reduce their anxiety (Leahey & Svavarsdottir, 2009), therefore relieving one source of anxiety for the hospitalised child. Leahey and Svavarsdottir (2009) focused on the admission assessment at

the beginning of hospitalisation. They found families reported being more at ease due to being able to express their stories to the nurse. This can help establish a collaborative relationship with families so that the whole family feel more able to understand and be understood (Betz, 2006). The impact of these interventions ripple throughout the immediate hospitalisation, but will affect the reactions of children and families with future hospitalisations (Moorey, 2010). Therefore gaining deeper understanding of families' experiences of care will have application for nursing practice by recognising that these experiences continue to impact children and families.

Shin and White-Traut (2005) videoed eight triads of nurse, hospitalised child and mother to further understand the care relationship in the hospital setting. Despite consenting to the study, and therefore being aware of the camera, nurses in this study spent very little time with children or the mothers that was not directly related to a technical intervention (such as administration of medication) (Shin & White-Traut, 2005). Even when in the room for the purpose of assessing the child, the average time spent for that activity was only 2½ minutes (Shin & White-Traut, 2005). During these videoed interactions, very few were initiated by the families themselves, and rarely were mothers asked for their opinions or perspectives (Shin & White-Traut, 2005). The findings of this video study are useful in offering objective measurements related to the interactions between nurses and child/family, but are limited because they do not explore the families' perceptions of the interactions. A constructive approach such as narrative inquiry usefully adds the subjective factors and contextual influences not captured by a video lens.

Care for children and families with ongoing health issues

Ford and Turner (2001) explored the experience of care in hospital for children with specialised needs from the perspective of the nurses. This thematic analysis of nurses stories found that nurses believed it was possible to form synchronous relationships with families of children with chronic illnesses. The ways that the nurses evidenced these caring relationships was in remembering, reciprocity, and an acknowledgement that each family was different (Ford & Turner, 2001). Despite this potential for satisfying relationships between nurses and families, this was not always achieved, with many parents continuing to have their expertise and knowledge ignored or minimised by nurses (Ford & Turner, 2001). Many families

with children with ongoing health issues experience the subordination of their expertise in relation to professional knowledge (McKeever & Miller, 2004).

Families with children requiring ongoing care have to manage more than the chronic health issues of their child; mothers in particular also carry societal expectations of fulfilling ideal roles (McKeever & Miller, 2004). Nurses would be more adept at working with these families if they were more aware of the dominant narratives that shape the lives of these families (Garden, 2010). This cultural awareness would, for example, make more overt the narrative of professional knowledge being superior to family knowledge. Families of children with chronic illness often have significant expertise in assessing their children, and while the acuity of their presentation may not be high, the underlying chronic illness makes the management beyond that of a local doctor (A. Williams et al., 2009). These families have particular challenges as they are familiar with the health issues of their child and the hospital environments yet continue to be outsiders in the decision-making of their child's care.

Ravindran and Rempel (2011) have widened the family conception to include grandparents involved in the care of a child hospitalised with a chronic illness. Previous research has indentified the way many grandparents experience concern for their own adult children as well as the hospitalised grandchild (Hall, 2004). Ravindran and Rempel (2011) interviewed 15 grandparents of six children using a grounded theory type approach to analyse interview data. A notable finding was grandparents concern for the whole family unit, more than previously identified, to additionally ensure care for siblings throughout the illness (Ravindran & Rempel, 2011). These grandparents enacted family centred care, stepping in wherever they discerned need or opportunity (Ravindran & Rempel, 2011). Hall (2004) (who interviewed seven grandmothers) found that the nursing staff do not always support grandparents in this support role. Grandmothers experience fear and helplessness at seeing a premature baby requiring interventions, yet are often excluded from participation, or even asked to leave (Hall, 2004). While neither Ravidran and Rempel (2011) nor Hall (2004) present families' stories, their transcript excerpts give glimpses into the identity roles of the grandparents within the families. This reinforces the value of incorporating the perspectives of more than parents to understand the impact of hospitalisation of a child on families.

Jackson et al. (2007) have explored parent's perceptions of having a child hospitalised with a significant illness using questionnaires administered at various points along the families' experience. By using a survey format they are limited in the scope of responses available to families, however they have reinforced that both the environment and staff influence parental satisfaction with care (Jackson et al., 2007). While the early experiences of diagnosis and initial hospitalisation are associated with feelings of helplessness and fear, the challenges that families experience continue throughout the hospitalisations (Jackson et al., 2007). Factors that increased families' satisfaction with care included effective communication, honesty, appropriate knowledge, which helped build a sense of trust (Jackson et al., 2007). Factors that caused families to feel less satisfied with care included environmental issues such as overcrowding and lack of privacy, as well as interpersonal issues such as lack of attention and rudeness of nurses (Jackson et al., 2007). Communication between families and nurses is consistently demonstrated as a factor in perception of care from nurses (Ammentorp, Mainz, & Sabroe, 2006). Ammentorp et al. (2006) also used a questionnaire methodology to explore families perceptions of care, finding that relational factors far outweighed organisational factors. The findings of both these studies have been limited by the categories created by the researchers – to further explore the ways that these factors influence families experience of care, a more open-ended approach, such as narrative inquiry, will enable a family-centred viewpoint to emerge.

Family stories

Several articles have now been published in academic journals presenting the stories of families (Taylor, 2006; Wills & Wills, 2009). These are quest type stories (Frank, 1995), where the learned truth of their experiences are presented to professionals with a request for others to learn as well. Taylor (2006) asks for nurses to "hear what it was like" (p. 20), while Wills and Wills (2009) wish for nurses to 'know' – both offer their stories in the hope that it could be better for other families. While the stories are not formally analysed by their authors, there are narrative insights evident in the form. In the orientation to one story, the work of establishing narrative credibility is begun, by foregrounding her previous role as a physician (Wills & Wills, 2009). This mother then describes feeling like 'Alice in Wonderland' – where her narrative identity is no longer assured to herself or to those around her. The father's narrative identity as a father is so challenged he

describes feeling "impotent" (Wills & Wills, 2009, p. 320). In their reflections they are able to see the impact of both nurses and the culture of the hospital on their experience of care (Wills & Wills, 2009). Taylor (2006) offers brief stories of her experience, though suggests that speaking her story to a packed conference auditorium was easier than speaking her concerns to the nurses at the time it happened. Having a nurse care in such a way that she felt permission to speak up is presented as a powerful yet uncommon experience (Taylor, 2006). The cultural context of the hospitalised care and nurses who work within it both act as enablers and barriers to the experience of care for this family (Taylor, 2006). These stories further reinforce the value in seeking out and further analysing the influences on families in hospital with their children.

In New Zealand

Ameratunga et al. (2010) used individual and focus group interviews to explore the issues impacting on the delivery of healthcare to children and families following an unintentional injury. They found that effective care was able to help families care for their children throughout and following the hospitalisation. Clinicians reported that children (and families) admitted with more mild injuries often received less adequate care due to the busyness of the acute environment and the need for prioritisation of available resources. This was in spite of hospitalisation having a significant impact on families irrespective of how clinicians perceived the severity of the injury. Staff felt that the emotional and psychological needs of families/whanau were frequently poorly addressed in part due to the speed at which children are discharged from inpatient care. While Ameratunga et al. (2010) have focused on the perceptions of staff in their study, it provides some context for this narrative inquiry by revealing some of the contextual influences on nurses as they provide care.

The study by Arlidge et al., (2009) set out to explore the experience (of admission with an unintentional injury) from the perspectives of families/whanau. A thematic qualitative approach was taken to allow the unprompted concerns of families/whanau to be raised. Of the 23 individual/family group interviews, 21 involved parents only, highlighting the difficulty of setting up family interviews (Arlidge et al., 2009). Many families felt judged by healthcare professionals. They stated they needed to prove themselves to staff in order to challenge the stereotypes they felt they had been labelled by. The hospitalisation was stressful

irrespective of the severity of the injury to the child. Factors that did impact on how families coped included previous experiences of hospitalisation within the family, socio-economic status and ethnicity (Arlidge et al., 2009). Families with fluent social and cross-cultural skills were able to engage with staff more effectively and had better outcomes in relation to themselves and their hospitalised child (Arlidge et al., 2009). These findings demonstrate the potential for a larger study that explores in greater depth the ways that ethnicity and culture impacts on the care of children and families. However there also appears to be a gap in understanding the impact of more broad socio-cultural interactions between families and nurses around the care of a hospitalised child.

Chenery (2007) explored changes in the ways nurses work with families of hospitalised children since the shift towards more family participation in the 1960s. Similar to international literature, the changes in practice have been significant, but the nature of the family/nurse relationship does not always match the theory (Chenery, 2007). Chenery (2007) explored the socio-cultural narratives in New Zealand nursing and related literature from the 1960 – 1990s. This revealed an evolution in the professional literature that has not been consistently matched by parental/nursing experience (Chenery, 2007). For instance care in the context of family has been called for in nursing literature (Wright & Bell, 1981/2004) and was identified as a principle of the New Zealand Child Health Strategy (MOH, 1998). Therefore there continues to be an opportunity to explore family experience of care against a backdrop of the wider narratives (professional and societal) that surround it.

Learning from families

Learning from the experience of families, along with the actual patients, is acknowledged to be valuable in contributing to improving quality of care (Oermann, 1999). In the course of being consumers of healthcare, families often meet many nurses throughout their child's hospitalisation (Goodley & Tregaskis, 2006). Mykhalovskiy, et al. (2008) has argued that failing to listen to family experiences and perspectives will impact on the effectiveness of care. This requires creating the opportunity for whanau/families to tell their stories. Nurses are already part of an oral culture where stories are often used to make sense of their practice reality (K. Foster, McAllister, & O'Brien, 2005). As such they have many opportunities to tell the stories of how they believe they demonstrate care. These are the sanctioned

and validated versions – verbal in nursing handovers, written up in perpetuity within clinical progress notes and debriefed in professional supervision - yet the family's story is not told within the formal record of the healthcare encounter (Carter, 2002).

What are missing are the stories of care that families tell. Some of these stories do exist on the internet, often on websites of support groups (Brown, 2006; *Lara's story*, 2009). These stories tend to be focused on the aims of the organisation hosting them – so (as in these examples), they are quest and restitution type narratives to provide hope for other families in similar situations. A search of Google ™ for 'patient stories in hospital' for instance returns 89 million 'hits' – however one needs to scroll through 13 pages before finding any stories not sanctioned on a health provider website. These 'official' stories do not tend to explore the complicated 'nitty-gritty' of their experiences of care. Even the language of healthcare practice can be a mechanism that hides individuality behind an assumed homogeneity – as for example, 'family centred care'. There is no representative 'family', and to be centred requires seeking out and hearing the unique and human stories that individuals tell (Hurwitz & Greenhalgh, 2004). The interpretive stores that follow seek to be individually family-centred. Narrative inquiry is a useful methodology to hear stories based in the families' agendas as it explores both the personal and the social construction (Connelly & Clandinin, 1990), the nature of the story and the context in which it is told.

Summary

The nursing care of children in hospitals has undergone significant change and is influenced by socio-economic, socio-cultural and professional factors. Differences continue to exist between the perceptions of children and families, and nurses, about what types of behaviours constitute care. The experiences of New Zealand families seem to mirror those of families in similar countries. Many nurses appear to be hesitant in implementing power-sharing care practices with children and their families. Being sensitive to the experience from the perspective of the receivers-of-care remains an important tool in improving the care experience (Dibley, 2011).

There continues to be a need for greater involvement of children and families in the planning and critique of children's care (Battrick & Glasper, 2004). This review of literature supports the notion that it is timely and appropriate to consider families' experiences of caring for their hospitalised children.

Chapter Three

Narrative Inquiry

> Narrative analysis takes as its object of investigation the story itself... the purpose is to see how respondents in interviews impose order on the flow of experience to make sense of events and actions in their lives (Riessman, 1993, p. 2)

This chapter explores the methodological approach of narrative inquiry. This includes the philosophical underpinnings of the narrative approach as well as the differences and commonalities within the 'family' of narrative research. My personal understandings and narrative perspective are included to maintain the transparency of my impact on the interpretation process.

Narrative inquiry has come to include a broad family of approaches (Riessman, 1993). It has been used across many disciplines as a framework to understand the social world (Harter & Bochner, 2009). Denying the worth of another's story reduces that person to insignificance (Frank, 2010b) so part of the work of narrative analysis is to ensure the stories of participants are valued and heard.

Social research is not a neutral activity – it is an act of engagement with a question and with the people it concerns. The endpoint of narrative inquiry is a story – a narrative that captures the meanings as generated by the participants (Elbaz-Luwisch, 1997). As such, rather than detachment, there is a subjective relationship with the participants and their struggles (Frank, 2005).

Nature of my approach to narrative research

Research is an interpretive act (Bourdieu, 1993c; Denzin, 2004) that has the potential to surface the multiple stories that exist within the social realm (Jipson & Paley, 2007). It is an activity that seeks to understand the social world in which experience occurs (Garro & Mattingly, 2000). There continues to be some tension between narrative researchers (with differing beginning understandings) as to the relative position of participants and researchers (C. Thomas, 2010). One perspective on the continuum is explicit that the researcher takes the role of expert, analysing the stories as text (Atkinson & Delamont, 2007). Challenging this position are others who insist that knowledge is contested and understanding of experience should be centred around the participant (Bochner, 2010). Frank (2010a) notes

that storytelling is itself a social activity, and as such, requires awareness of the interrelatedness of multiple narratives in the construction of meaning. This approach rejects the claim of neutrality of researcher, instead positioning the researcher and participant in dialogue with each voice informing the other (C. Thomas, 2010). For this study I have aimed to take a dialogical stance with the participants, seeking to ensure their understandings of the experience of having a child in hospital are clearly presented. This next section clarifies my position as researcher in regard to: what can be known; the nature of narrative research design; and, what it is to 'think with stories'.

What can be known?

Knowledge is an arbitrary combination of fact and fiction (Moen, 2006) because it is always from a point-of-view (Bruner, 1991). Knowledge is "intertwined, embedded, interwoven with a great many other things besides the 'truth' which is itself a representation" (Opie, 1992, p. 58). Stories offer a way to feel the truth of the teller – subjective and situated within the cultural habitus in which it is told (Bochner, 1997). For this study, therefore, I do not seek to establish whether or not the stories happened the way they are described, but to situate them as a particular view point that represents an understanding of the experience. Any conclusions drawn are therefore tentative and open to alternative interpretation.

Nature of the research design

Stories are exceptional – not only do they convey 'happenings', but they also teach us what counts – what or who gets a story. From when we are children stories teach us about social concepts such as family and community and normal responses to different situations (Frank, 2010a). Focussing on stories enables the researcher to explore the content of the story and the social forces at work in its construction. Narrative research begins with the story and ends with a story in order to show the multiple narratives (individual and collective) that underpin our understanding of social reality and the interconnectedness of each other's stories (Frank, 2010b).

Thinking with stories

Dialogical narrative research necessarily involves relationship with participants so as to hear the raw and human voice of the teller (Bochner, 2010). Thinking with stories requires mindfulness of the particular as well as the in/visible cultural

contexts in which both the telling and the recalled events occur (Frank, 2004b). Thinking with stories requires "joining with them; allowing one's own thoughts to adopt the story's immanent logic of causality, its temporality, and its narrative tensions" (Frank, 1995, p. 158).

Research with storytellers and their stories requires taking a place in the interrelatedness that occurs each time a story is told (Frank, 2004b). The stories do not offer a clear view of the past – the retelling is an act of interpretation (Riessman, 2005). The "aim as researcher-storytellers is not to seek certainty about... phenomena but to raise significant questions about prevailing policy and practice that enrich an ongoing conversation" (Barone, 2007, p. 466). In this study therefore, the stories have been explored in relation to nursing care, both relationally and contextually, to add to the growing understanding of practice with children and families.

Narrative approach

While the reasons stories are shared and the form they take differs, they are told all over the world (Pellowski, 1990). Much seems universal – for instance 'Cinderella' type stories are told across hundreds of different cultures (Weiss, 2004). There are also cultural variations on the narrative form (Nespor & Barber, 1995). The typical form of a story in Western countries involves a primary teller ("I" rather than "we")(Riessman, 2008) and conforms to a timeline ('so what happened next') (Nespor & Barber, 1995). These forms reflect the cultural habitus (Frank, 2002b) norms of individualism rather than collectivism, and interest in causality over time. In making a distinction between paradigmatic thinking (objective and categorical) and narrative thinking (action orientated and linking) Bruner (1991) suggests that narratives are the universal way that humans make sense of the world.

Telling stories is an act of interpretation with the storyteller choosing which aspects to include and what relationships to accent (Bruner, 1991). Stories rely on a presumption that, as time passes, disparate events are able to be causally linked (Polkinghorne, 1995). The causality determined by the storyteller is their perception rather than an objective relationship, so analysis of stories must review the wider context and structures influencing why the story was told that way (Bourdieu, 1993c). We live our lives as stories, shaped by our sense of self as well as the master narratives that surround us (Hyvärinen, 2006). By being the

recipients of stories, children learn about themselves in relation to others and the world they are a part of (MacIntyre, 1981/1984). Stories "animate" human life by giving depth to the categorisations that otherwise represent people (Frank, 2010).

Interest in stories requires a conceptualisation of storytellers – a self who can narrate (Strawson, 1999). While there is some debate about whether there is a fixed identity who remains continuous over time or a self that is episodic and dyschronous (Strawson, 2004), there seems to be agreement that a storytelling self is "fundamental to human life" (Strawson, 1999, p. 102). This reinforces the approach taken in this study that each participant has a legitimate story to tell, and that their individual perspectives should not be collectivised into one amorphous story that represents them all.

Memory is also essential to storytelling. Memory is not fixed, but malleable with every re-telling (Debiec, LeDoux, & Nader, 2002). While memory is regarded as essential in the formation of identity (to form a narrative thread explaining how we got to here and now) it does not give a direct window to past experience (McCrone, 2003). Remembering saves previous experience from being consigned to oblivion (Chatman, 2009). Memory is influenced by cultural values and by particular noteworthy events (Kahneman & Riis, 2005) – so for example a friendship can be mutually beneficial, but if there is a 'falling out', it is likely the cause for the breakdown that is primarily remembered. Stories of a recalled event are necessarily an interpretation of the earlier experience from the perspective of now (J. T. Harden, 2000). Memories are therefore told as stories "to make sense of the present" (McCrone, 2003, p. 26). This is an important consideration when approaching the stories of participants in relation to chronological distance between the experience and the recollection. Some family participants augmented their stories of recent experience with stories from longer ago. Understanding the fluidity of memory ensures that all stories are viewed as reflections on the past and therefore edited accounts, irrespective of time passed.

Not only are stories a means of creating self identity – they also help form social identity. Anonymity remains possible only while the existence of a story is suppressed (Engel, Zarconi, Pethtel, & Missimi, 2008). Stories place individuals in space, time and social context, confirming or contesting the social strata they exist within (Garro & Mattingly, 2000). Stories are often told when there have been a

disconnection between what was expected or a disruption to identity (McCance, McKenna, & Boore, 2001). All storytellers therefore project a 'self' to their audience seeking legitimacy and validation to confirm their value and worth (Peterson & Langellier, 2007). This makes analysis of stories a valuable tool in exploring the understandings of the cultural context of the storyteller, often those whose stories are not otherwise well known (Hendry, 2007). There is no such thing as a uniquely personal story – all storytellers exist within an historical and social context that shape how stories are told as well as what stories are available to be told (Gubrium & Holstein, 2009). The analysis requires exploring what is told within the story, while also incorporating the impact of "the interactional, cultural, political, and organizational circumstances" that led to the story (Gubrium & Holstein, 2009, p. 52). In this way narrative analysis is more than the recording of events; it allows the stories to be viewed from various different perspectives or lenses (Bingley et al., 2008).

The turn to narrative seems to have been arrived at from many different disciplines and philosophical backgrounds (Hyvärinen, 2006). It has been used to explore social construction since the 19th century, for instance researching with poor people in the UK (Gubrium & Holstein, 2009). For many years authors (for example Dickens, Hugo, and Orwell) have used stories to capture wider societal contexts and the impact of these on individuals (Bochner, 1997). The use of stories in understanding healthcare seems to have increased markedly since the early 1990s (Frank, 2006).

Stories in healthcare have often been dismissed as opinions or anecdotes (Yiannis, 2004). For example, for many years the British Medical Journal (BMJ) published narratives – but they were typically at the end of the journal with no page number (making them not easily referenced) (Engel et al., 2008). When they are sought they are often to meet the agenda of the healthcare professional (Mishler, 2005). Even when they appear to be valued they are often relegated behind more 'objective' forms of knowing – for example Arthur Frank being asked to speak to training doctors about patient experiences, but only being given 'lunchtime' optional sessions (Frank, 1995). Yet the stories told by recipients of care by healthcare professionals have much to teach about "living… suffering and the experiences of suffering" (Bingley et al., 2008, p. 653). They offer a far broader conceptualisation

of the experience of healthcare than the narrow focus on pathology often taken by health professionals (Engel et al., 2008).

Narrative inquiry acknowledges the dynamic process that is required to recall events, formulate an understandable story and explore the content, form and context of the told narrative (S. Thomas, 2009). Narratives are a meaning making tool, using characteristics of plot and flow to demonstrate that meaning (Adams, 2008). Despite this understanding, narrative inquiry includes a diverse stable of approaches (Riessman, 2008). Narrative researchers have used approaches such as thematic, structural, interactional and performative analysis (Riessman, 2005). They all take as focus, however, the story and the storyteller.

Telling a story (of the past) is essentially a social act (Atkinson & Delamont, 2006) that requires an audience (whether that be self or other), an historical context in which the events occurred, and a cultural habitus (Frank, 2002b) of the storyteller. Habitus is the "embodied habits… dispositions that are acquired through growing up [within a cultural setting]" (Bourdieu, 1993c; Frank, 2002a, p. 17). It is the 'common sense' that colours experience and perceptions of that experience. It enables certain stories to be 'available' while other narratives are not considered. For example, I watched a medical student studying while we both waited for a train. He was intently reading a textbook on childhood diseases and syndromes, complete with accompanying photographs. As a student, the most apparent discourse (or habitus) was that these conditions can be reduced to facts and summaries. Whether this student considers an alternative view (say of normalisation or the child being loved by its mother as a child rather than a 'diagnosis') will depend on their upbringing and exposure to alternative perspectives. So narratives are told individually but they exist within a context of social and cultural conventions that shape both the teller and the listener (B. Smith, 2007).

Narrative inquiry also highlights that not only the participant, but also the researcher are social agents, sub/consciously shaped by the social world, and therefore only aware of certain available narratives (Alex & Hammarstrom, 2008). A tension therefore exists within this post-structural approach to narrative, where simply acknowledging the shaping influences (as contextual and therefore fluid), may lead to mere description of the social context (Armstrong, 2002; Atkinson & Delamont, 2007). Armstrong goes on to argue that if narrative inquiry is to have

any value to the participants and practice it needs to include critique of the ways that identity is shaped and formed over time, uncovering the social milieu of participants. Otherwise the voices of the storytellers exist merely to "echo in an otherwise empty world" (Atkinson & Delamont, 2007, p. 197).

One particular way that narrative inquiry differs from other 'experience' focussed methodologies is in the relationship between the experience and the participant. Rather than viewing the story as providing an unmediated glimpse into the recalled experience, it takes a post structural approach that recognises the influences of language, culture and context (Allen & Cloyes, 2005). This post structural focus on the particular, seeks to ensure stories that do not fit the prevailing narratives are considered, along with analysing those master narratives (Hesse-Biber & Leavy, 2007).

Analysis of narratives offers the opportunity to explore the personal as well as the political, structural, cultural and social contexts from which (and to which) they are told (B. Smith & Sparkes, 2008). Narrative posits that knowledge is socially constructed, and can therefore only be contextual and partial (Hendry, 2007). This post structural approach enables these influences to be acknowledged and surfaced where otherwise they may have remained hidden to see the complexity implicit within them -

> Post-structural narratives problematize the act of constructing the narrative itself... rather than relying on extended direct quotation of the subject's voice as a way to capture the 'truth', post-modern approaches to narrative emphasize creating a text which invites the reader into a vicarious experience. The reader should come away from such texts with a heightened sensitivity to the lives being depicted, and with some flavor of the kinds of events, characters and social circumstances which circumscribe those lives (Blumenreich, 2004, p. 79).

By letting go of the notion of an 'all knowing' subject, the post-structural nature of narrative inquiry is able to explore the multiple voices present in any story (Sundin & Fahy, 2008). Therefore, however, there can be no claim on 'truth' or an objective grasp of 'reality' (Sundin & Fahy, 2008). Acknowledging the polyphonic nature of reality – where there are multiple narratives (and storytellers) competing to be heard minimises the risk of typecasting participants or aggregating their experience in a way that limits their individual agency (Ezzy, 2000).

A recollection of an event, told as a story can therefore not be seen as objective and incontestable. Each narrative is a choice to tell one story rather than another, to include some details rather than others, and cannot include details that were not noticed – each included component is there to convey what the storyteller wants to communicate (P. Bailey & Tilley, 2002). This is a departure from other qualitative methods that focus on the experience; the focus of narrative analysis is the ways in which participants draw on their past experience, in the form of memories, and view it in the present - with insights not necessarily available during the original experience (C. Bailey, 2007). Thomas et al. (2009) suggest a metaphor of a river to describe narrative analysis. The stream of the participant's stories is likened to flow of the river. To more effectively understand the words it is necessary to step in and be impacted by the stream of data - looking to discern the narrative threads or currents. However in order to explain these storylines, the analyst must consider the sources (c.f. tributaries), the socio-cultural narratives influencing the telling (c.f. the landscape of the river), and the performative aspects (c.f. the sounds and nature of the water). These existential factors form each storyteller and the stories they tell, and therefore must be considered in the analysis (Clandinin, Pushor, & Murray Orr, 2007). In this way the stories are not seen as containing themes or concepts (which they may), but are additionally explored asking, "why this story?" "why told in this way?" and "what influences this telling?" (Harter et al., 2005).

Stories tend to include particular narrative threads which identify speech as story – "beginning with an abstract, orientation, an evaluation section embedded in the complicating action, a resolution and a coda" (Labov, 2007, p. 47). While not all stories are 'tidy' with clear resolutions or endings (Nespor & Barber, 1995), these components are useful in recognising when a story is being told, as opposed, for instance, to a position statement. Not everyone follows this subconscious structure, and not all stories contain all elements (Frank, 2010b). These elements, however, are the markers of a story – and if the audience is willing – form an effective way to communicate deep ideas. Stories of past experience do not always follow standard chronological flow (Chatman, 2009), but may draw these storytelling devices to create a plot that is adapted for the immediate audience (Vecchio, Munakata, Kobayash, Mattingly, & Good, 1994). While the meaning intended by the families remain the principle focus, awareness of these factors allows exploration of the 'how' as well as the 'what' of the story.

Narrative lenses

Within the broad family of narrative inquiry there are several different approaches to understanding the stories (see figure 1). Bruner (1991) suggests that humans organise their thinking in either paradigmatic or narrative sequences of meaning. Paradigmatic thinking largely categorises and organises ideas within logic sequences (Murray, 2002). Narrative thinking instead involves organisation of understanding around stories to create meaning (Bruner, 1991). This is an unconscious process – people reflect on life and their place in it retrospectively and create a story sequence to explain how things ended up as they did (Murray, 2002).

In narrative research these different approaches can be utilised and contrasted as analysis of narrative (paradigmatic) or narrative analysis (narrative) (Polkinghorne, 1995). These approaches exist on a continuum and are not always exclusive of each other. Analysis of narratives often involves exploring the content of a story and the language used to tell it, in order to create a general understanding of the experience. Narrative analysis, utilising narrative thinking, aims instead to consider the nature of the story as an act of meaning-making to create understanding related to the particular. This study will explore the stories of the participants with different lenses in order to gain insights from each of these approaches (see figure 1).
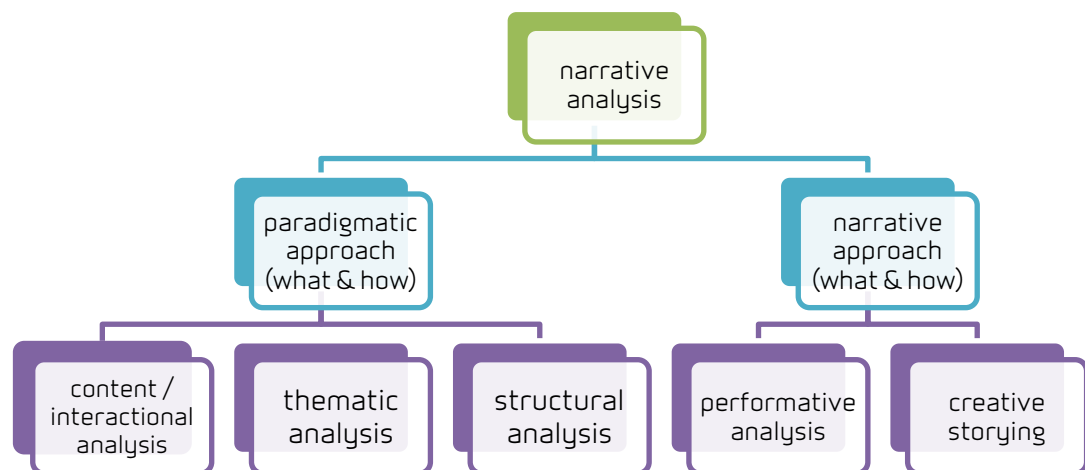
Figure 1 Narrative approaches

In her exploration of narrative analysis, Riessman (2005) identifies four particular approaches to narrative analysis: thematic, structural, interactional and performative. It is her assertion however, that this is not exclusive of other

approaches. Each approach illuminates different aspects of the story or the context, but each also have limitations.

Thematic analysis utilises the words spoken as a resource to understanding the experience under investigation. The story itself is not the focus of investigation (Riessman, 2005), rather the story is seen as a means of accessing the experience. A challenge to this approach is finding a way to include stories that do not fit the more common themes. In this study, the thematic lens is only used once all the stories have been told to explore where there are overlaps and similarities.

Structural analysis explores the "communicative work" of the language of the narrative (Riessman, 2005, p. 4). This can be useful in exploring the use of language to create meaning – but does risk ignoring the contextual and socio-cultural influences. There is a risk of reducing participants' experience into discreet episodes that disguise the complex interplay of interpretation and reflection (Jipson & Paley, 2007). This lens is incorporated into the interpretive stories by including discussion of language of participants.

Interactional analysis of narratives shifts the emphasis of the analysis to the interaction between the storyteller and the audience (Riessman, 1993). This approach views the complexities of speech and language as enhancing the words spoken, and includes recognition of the immediate context of the storytelling. In this study the interactional lens is included by foregrounding the immediate context of the storytelling (the interview) and the ways some participants seemed to be mindful of other audiences reading their stories.

Performative analysis seeks to explore the storytelling and the storyteller by emphasising the praxis of narrative – as a complex process of communication (Peterson & Langellier, 2007). A distinctive of this approach is the recognition of the "polyphonous" nature of any story (Jipson & Paley, 2007, p. 9). These multiple voices within a story are the narratives that inform the identity and context of the storyteller. Stories are presented by the storyteller with both conscious and unconscious influences – but they are a tool used by the storyteller to position themselves within the local and wider social narratives (Peterson & Langellier, 2007). This approach is mindful of the 'place' of the storyteller, and the way they cast the drama of their story (for example, the positioning of self and other, and the way the conditions of the experience are described) (Harter et al., 2005). Smith

and Sparkes (2008) suggest the important question in performative analysis is 'how is the participant constructed in this telling?' rather than 'what is the participant's story about?' The performative approach acknowledges the 'past' being told through the eyes of the 'present' and the socio-cultural influences on each (Riessman, 2005).

Creative storying posits that all recounted stories blur fact with fictionalisation (Sparkes, 2002). It involves thinking in a creative manner about the participant's story and its construction, as well as the place of the researcher as interpreter (Stanley & Temple, 2008). Creative storying reflects the unstable and constructed nature of identity within participants' narratives (Stanley & Temple, 2008). Having employed the other analytic processes described, in creative analysis the researcher presents the findings in the form of a story (Polkinghorne, 1995; B. Smith & Sparkes, 2008).

This study draws on aspects of content, thematic, structural, performative and creative lenses to more effectively explore the meanings invested within the participants' stories. A comprehensive analysis requires exploration beyond any of these structural aspects of narrative to explore the life-world of the storyteller (Frid, Ohlen, & Bergbom, 2000). Each of these different lenses or viewpoints on stories offers a perspective that explores the story, its construction, and the constructors. In the same way that the image in a kaleidoscope changes with different light and angle, so each narrative analysis perspective offers a tentative insight into the human world of experience. Illness narratives can be explored to reveal the socio-cultural discourses that shape the subjectivity of the storyteller (J. T. Harden, 2000). These types of stories bring to focus the first person account of suffering, set in the midst of the unknown outcomes and unknown and pervasive systems (Bochner, 2001). Narrative analysis seeks to explore this personal-cultural-political interface as it is exposed in the stories of those with the experience.

All interpretation involves consideration of data through particular viewpoints or lenses. Narrative inquiry takes particular lenses to view the story, the storyteller and the context in which they occur. It acknowledges the tentative nature of these viewpoints – that they are situated and partial. Viewpoints offer a type of clarity by focussing in on particular aspects but require awareness of their limitations. For example, in the figure (pictures taken through a mail slot) some details are

highlighted while others are obscured (see figure 2). Therefore in this study, to explore the stories that families tell of having a child in hospital, each different lens is applied to draw attention to various aspects of the participants' stories. Each participant family told of their experiences – and the *content* of these stories is considered in relation to the perception of care. The stories have in common 'a child in hospital' – but many also share other narrative threads – these *themes* are drawn out in the discussion. The *structural* formation of the stories are analysed to explore the socio-cultural influences on families and their experience of hospitalisation. *Performative* lenses allow the ways that families position themselves within their stories to come into focus. This also allows for exploration of the narrative genres that families frame their stories within. Finally, creative storying will synthesise the stories to bring clarity to the intended meanings within the stories (B. Smith & Sparkes, 2008).

Figure 2 Viewpoints and perspectives

Frank's genre typologies

Frank (2010a) takes a holistic approach to analysis of stories that affirms the worth of the storyteller and the story they tell. He argues for an appreciative approach to analysis that acknowledges the storyteller and the work they do in telling the story rather than reducing the stories to objective categories (Frank, 2010b). This appreciative and dialogical relationship with the storyteller certainly draws most strongly on the performative approach, but remains open to the other lenses. He argues for being mindful of the social influences that may be hidden in the telling of the story – for example, when a child is instructed to "tell the doctor what hurts"

they are being socialised to learn what counts as a valid story (Frank, 1995, p. 3). Thus analysis must be mindful of the socio-cultural influences hidden in the telling.

Frank uses various approaches as he encounters stories: at times he uses themes and typologies (Frank, 1998a); he also makes use of the structural approach to recognise stories within text (Frank, 2009); and he is mindful of the performative aspects of story, such as the use of language (and silence) (Frank, 1994). His overarching position however, is to take an appreciative approach and focus less on reduction and more on learning about human life – letting the story speak (Frank, 2010b).

Stories typically follow socially prevalent plot types, as learned from childhood through culturally reproduced story-lines (Riessman, 1993). These cultural forms are evident as similarities across stories – for example in western cultures the common usage of pronoun "I" when recounting personal experience, which privileges the individual over more collective (Riessman, 2008). While he eschews definitive method, over the years Frank remains drawn to analysis that reworks stories to explore the narrative voice (genre or typology) and seeks new understandings (Frank, 2009). He suggests illness narratives tend to fit into one of three types – restitution, quest and chaos.

Restitution stories are the culturally preferred narrative (Frank, 2010b). These stories tend to describe an episode of transitioning to a 'sick role' for a time bound period before returning to their normal role (Frank, 1994). This often involves compliance with the health system and health professionals to allow them to 'do their work' (Frank, 1998a). These are the stories that are typically endorsed and presented to the public by the healthcare system, for example on medically sanctioned and disease focussed websites. Websites that call for families to share their stories often have rules about what is able to be included. For example in New Zealand "little treasures™" site (for mothers of babies to connect with each other), there are instructions to avoid criticism of health practitioners (SCA Hygiene Australasia). This type of censoring of counter-stories, while for legitimate reasons, leaves families who have not had a straightforward restitution story without a forum to tell their story. In narrative inquiry, "the personal is political" - it listens for stories irrespective of whether they fit the expected norms, seeking to legitimise stories that might not otherwise be heard (Harter et al., 2005, p. 23). Restitution

stories must therefore be analysed looking for the prevailing socio-cultural narratives that they adhere to.

Quest type illness stories are stories that attempt to capture meaning when experience does not follow the expected linear trajectory (Fisher & Goodley, 2007), for example, in the absence of 'cure' or in the face of unexpected adversity. Quest narratives tend to emphasis ideas of perseverance rather than restitution (Frank, 1994), to capture the lessons learned as a result of the experience (Frank, 1995). Frank (1995) identifies three particular types of quest illness story: memoir, manifesto and automythology. Memoir quest stories capture experiences when the narrator's identity is disrupted; manifesto quest stories tell of "prophetic" (p. 120) learned truths where there is a demand for improvement; and automythological quest stories speak of reflection and personal learning (Frank, 1995). All these stories are attempts to draw meaning and purpose to the illness experience (Frank, 2010b). Quest stories must be analysed in relation to the restitution narratives to which they do not conform, as well as the dominant master narratives to which they may. For example in my experience as a clinician, when families complain they are often insistent that 'no one get into trouble' and that 'everyone learn from the experience'. These stories highlight what was expected to happen as well as being told by families who continue to have to negotiate relationships with the same people.

Chaos type stories are typified by a struggle to maintain the narrative coherence (and therefore integrity of self) (Frank, 2010b). Illness stories come from an attempt to create meaning and continuity to disparate events that have unfolded (Bingley et al., 2008). Chaos type stories are all that is left when that meaning and sense of continuity seems no longer available. At times this is marked by a struggle by the storyteller to tell a cohesive story, at times being unable to say anything that can capture the experience (Frank, 1994). Other markers of chaos type story are a lack of sequence – the flow from complicating factor to coda; evidence that the storyteller is struggling to reflect on self; and a sense that no one is in control, or a lack of agency (Frank, 1995). These stories challenge the prevailing expectation of 'overcoming' and resiliency – that everything that happens has a purpose (Uehara, Martha, Morelli, & Ishisaka, 2001). In narrative analysis these stories are valued as expressions of human meaning - "narrative chaos and anti-narratives are eloquent, personal expressions of such defeats" (Uehara et al., 2001, p. 57). Typically the

storyteller describes being 'stuck' in the face of immoveable challenges where the expected sequence of events does not follow (Frank, 2010b). Chaos type stories come out of experiences of vulnerability where the 'common sense' stories that are normally sustaining are suddenly inadequate and the "life narrative[s] to that point are disrupted and interrupted" (Palmer, 2007, p. 372). Chaos stories need to be analysed in relation to what happened in the story – but also by exploring the competing narratives that leave the storyteller without active agency.

Effective narrative analysis requires a caring relationship with the participants (rather than distant while claiming objectivity) that allows their story to 'get beneath the skin' and therefore remain particular rather than abstract (Bochner, 2010). The narrative genre approach ensures the diversity of stories and the intertwining of genres is considered rather than just the extreme stories – it is the day-to-day stories that are the more common and therefore part of the shared human experience (Palmer, 2007). These typologies are a lens through which to review what types of narratives the participants have available to them. This incorporates aspects of both content and performative analysis (Frank, 2002b). The aim is not to explain behaviours but to explore the socio-cultural context in which the participants' stories are embedded (Frank, 2001). Importantly, these distinctions between stories are of narrative structures and not the storytellers – the purpose of highlighting these different genres is to explore the ways that they are used by the participants (Frank, 2010b).

There are several examples of published research that have explored narrative using the Frank (Frank, 1995, 1998a) narrative approach (Bingley et al., 2008; Carter & Martin, 2005; Ezzy, 2000; Fisher & Goodley, 2007; Palmer, 2007; Uehara et al., 2001; Whitehead, 2006). Carter and Martin (2005) used this narrative approach to explore the stories of parents with children with chronic fatigue syndrome as they encountered healthcare professionals. This approach allowed for the exploration of the prevailing cultural narratives about health that these parents also had to negotiate. Fisher & Goodley (2007) explored the stories of mothers of children with a disability, using this narrative approach to explore the way these mothers challenged the socio-cultural narratives they were expected to fulfil. These other studies were with adults. Bingley et al. (2008) used Frank's typologies in their exploration of palliative care. Ezzy (2000) used these narrative types to explore the competing narratives in the lives of people with HIV. Palmer (2007) used

autobiography alongside narrative analysis of others' stories to explore how people negotiate mental illness/wellness and the narratives that accompany this. Uehara et al. (2001) took this approach to explore the stories of refugees and the multiple culturally intersecting stories in their lives. Whitehead (2006) explored the stories of families where a member experienced chronic fatigue syndrome and the way groups often constructed stories to sustain each other. These studies have demonstrated the value of narrative analysis incorporating this genre approach by adding to the existing understandings of the areas of inquiry. In this study, once the stories are identified in the transcripts, they will be explored for evidence of these narrative genres. This will facilitate the discussion of identity of the storyteller and the competing narratives influencing the type of story they tell.

Interpretive stories

In more traditional approaches to interview transcripts, excerpts from various participants are extracted from the telling and teller and grouped together in themes that span stories, people and contexts (McCormack, 2004). Interpretive stories are an alternative presentation that retains the complexity of the participants' stories, the nature of the co-construction between the participant and researcher, as well as the contextual influences (McCormack, 2004). The aim of this process is to produce a coherent and accessible 'story' for the reader from the vast amount of interview data (that was not originally presented with the reader in mind) (Dibley, 2011). It highlights the tentative nature of interpretation and knowledge by foregrounding the process of interpretation to the reader (Josselson, 2007). The interpretive story weaves the interview process with the participants' stories to ensure the construction of the performances remain visible (Allen & Cloyes, 2005).

The participant stories are identified by the presence of narrative 'markers' (McCormack, 2004). These markers – an orientation, abstract, complicating factor (what happened), evaluation and coda – are typical of most stories (Labov, 2006). The evaluation (which typically outlines the 'point' of the story) is taken as the story title (McCormack, 2000a). These are then organised chronologically as the beginning of understanding the participants' stories.

The process of developing the interpretive story from each participant involves viewing the transcript through various lenses to discover the multiple influences

and meanings within the text (McCormack, 2000a). The goal of this new story, evolved from the dialogue of an interview is to capture the characters in all the complexities of their experience (Ellis & Bochner, 2000). This involves ensuring their struggles, inconsistencies, and work is captured for the reader. This participant-centric approach is able to capture performative aspects such as how the participant framed their stories (Dibley, 2011). This approach is able to begin where the participant begins their story. Participants begin their recollections in ways that make sense to them – and in ways that may not fit the obvious agenda of the researcher – ways that inform their understandings and identity. An example of this in this study is the two mothers with premature babies – they begin at their beginning (labour and delivery). This does not clearly match the research question – and yet these experiences are foundational to the experiences that follow – this approach enables this framing to be included. These narratives are also multi-sensorial – there are non-verbal elements that could otherwise be hidden in the transcript (Sharf, 2009). An example of this is Melissa spending time flicking through a photo album to convey something that words could not – this can be acknowledged in the interpretive story.

McCormack (2000a) describes a process of moving from transcript to interpretive story. The approach as she outlines it, is not prescriptive (McCormack, 2000a). It ensures the interpretive process is transparent and does not separate the participants' words from their performative context (McCormack, 2000a). With multiple interviews over an extended period, she was able to maintain an ongoing relationship with participants, drawing them in to the decision-making process along the way, for instance in agreeing on story titles (McCormack, 2004). This member checking is not universal in the narrative approach however, particularly when only one set of interviews is undertaken (Bottorf, Radsma, Kelly, & Olliffe, 2009; Carter & Martin, 2005; Crocket et al., 2009).

Having identified the stories within the transcripts (by narrative devices orientation, abstract, complicating factor, evaluation and coda), the story 'evaluations' are listed as story titles (McCormack, 2000b). These are organised in order of temporal flow. In the McCormack (2000b) study, at this stage she had the individual participants respond to several questions in relation to the interpretive story. In this study several families insisted they did not want to revisit the stories from the interviews and another did not respond. The dialogue between me and the participants

therefore happened only within the interviews. Each interview, however, lasted a significant time, allowing for exploration and clarification together.

Another important point in creating an interpretive story from the text of the interview is to demonstrate that the researcher is more than a neutral recorder of data – they are central to the interpretation (Hardy, Gregory, & Ramjeet, 2009). Interviews themselves are social interactions that influence the storytelling (Tanggaard, 2009) – the interpretive story illustrates the nature of the production of the data. However this choice of appreciative presentation of data also ensures that the local and personal story remains central (Bochner, 2001). It does not exclude comparing and contrasting to see interconnecting themes between stories – but this lens must ensure the stories are maintained for their individuality also (Dibley, 2011). While all the stories are told from the point-of-view of the present, they also build developmentally as one experience informs the next. By re-presenting the stories from the transcript in their temporal flow, it is possible to see the changes in agency over the course of the families' experiences. This presentation also foregrounds the interpretive process, weaving the families' stories with the discussion – the personal with the public narratives threaded together to explore each.

Full circle – thinking with stories

Thinking with stories involves becoming immersed within the struggle of the storyteller to communicate their experience and understanding (Frank, 2002b). The stories reveal, not what is true, but what the narrators believe to be true (Phillips, 1994). By considering the stories in light of each other, the aim is to approach an understanding that incorporates multiple views of the experience (Polkinghorne, 2005). The interpretive stories help explore this by including descriptions of the cultural context of their production (Polkinghorne, 1995). By using narrative thinking to explore the participants' stories, "the outcome of a narrative analysis is the generation of a story" (Polkinghorne, 1995, p. 18). The final step of analysis therefore is the production of a story that synthesises the meanings expressed by the participants. This is the application of narrative thinking to support the paradigmatic thinking involved in structural analysis (Bruner, 1991). Centring on the stories of participants makes the links to the context and practice more overt (Bensimon, Polkinghorne, Bauman, & Vallejo, 2004). Polkinghorne (1995) suggests the broad contextual influences should be incorporated into the

final story in a way that brings order and meaning to the diverse elements. This creative storying, built from the extensive interview transcripts and analysis, aims to represent the participants' stories with integrity that is not always possible in snippets from the interview (Richardson, 2000; B. Smith & Sparkes, 2008).

The hybrid approach for this study incorporates each of the different approaches discussed. This allows for the analysis to respond to the stories and their tellers with different lenses rather than reducing the stories to any one viewpoint. Stories of healthcare involve the intersection of many socio-cultural narratives (Lo & Stacey, 2008). Analysis which aims to explore the unconscious habitus as well as the story must draw on different approaches. The appreciative approach of Frank and the structural approach of McCormack complement each other and overlap with Polkinghorne's approach to narrative analysis. This is congruent with Riessman (2008) who suggests that performative approaches re-present the dialogue between researcher and participant stories. It allows the reader to view the interplay between the method, findings and discussion throughout the report (Riessman, 2008). This is the approach taken for analysing the families' stories of care with a hospitalised child.

Organisation of the stories

Comparison of more than one case highlights the subtle distinctions between participants' experiences and demonstrates the inadequacies of standardisation (C. Thomas et al., 2009). In this report the families have been grouped in relation to the nature of admission due to the particular issues related to each. The first is families whose children (babies) were born requiring immediate admission and nursing care due to their prematurity. These families had anticipated being within the healthcare system when the babies were born – but not till several weeks/months later. A particular difference for these families is that they are in the process of 'becoming' family. Until the child is born the concept of 'parent' is more abstract and conceptual. Therefore having a baby prematurely born and admitted to hospital likely impacts on the identity formation of the parents, as well as making the transition to 'parent of this new baby' more public than the families had probably anticipated. While all sick children are vulnerable, the size of these babies (in this study all less than 1700g) adds to sense of vulnerability for the families at the same time they are suddenly parents.

The second grouping is families whose children required short term (acute) nursing care. Families of children requiring short term care have an unanticipated hospitalisation where they are often unfamiliar with staff and systems. For these families their preconceptions of hospitals and nursing primarily come from sources other than experience (such as TV and other forms of social media). These socially constructed narratives of healthcare interplay with the families' actual experiences in these stories.

The third group is families whose children require/d on-going nursing care. Families of children requiring ongoing admissions and care may have unanticipated hospitalisations, but they are increasingly more familiar with the staff and organisations. Their expectations and preconceptions for each episode are built on previous experience of hospitalisation. The nature of their relationships with nurses and other staff through the child's development or illness is much more clearly explicated in these families' stories.

These groupings reflect the nature of the relationships between families and nurses rather than the severity of the cause for admission. None of the families who participated had children who were imminently requiring hospitalisation.

The research proposal to AUT ethics committee stated a goal of 8-10 participant interviews. This number was to attempt a balance between manageability and breadth of respondents. While narrative research may include as few as one participant (as for example autobiographical and case study research), more normally at least two participants are required to explore difference and particular (Frank, 2010b; C. Thomas et al., 2009). This research was undertaken as part of a master's level of study. More than 10 interviews would have generated a volume of data that required longer than the available time. Nine families whose experience fitted the criteria participated in an interview and their stories are included here. There are at least two interviews within each context of experience to enable comparison and contrast within and between each grouping.

Pre-understandings

While the focus of narrative study is the story itself, just what is the story is more complex than at first it seems. Stories emerge in an immediate context – in research because a researcher asked a question. Participants tell stories, and

adapt the telling, in response to the researcher. Researcher and participant co-construct what gets told and what is deemed important (Frank, 2010b).

As the investigator it is necessary to foreground my own perspectives and understandings to make transparent the ways this has shaped the research. Telling a story that reflects on my own experience highlights my pre-existing beliefs and interest in this area of study (Kelly & Howie, 2007). In the spirit of narrative I do this by telling and unpacking my story.

What keeps it this way?

I have changed names and details to avoid characters in the story being readily identified. Not to make it less true – it is as true as I can manage without causing a new story of breached trust.

So how do good stories begin? Once upon a time? Not here. This is not a fairy tale. It is about real people. So... there was this time when... in the course of my role as a nurse teacher I went with a student to interact with a child and mother, inpatients in hospital, the child the one with the ID bracelet and chronic illness. A chronic illness that is likely one day to kill him.

The student, Mary, went in to check in on Andrew, the three year old, and his mother Jan. I did my normal introduction and tried to fade into the background while Mary got on trying to do what she perceived she 'should do' (when there is a teacher watching). And Andrew did what three year olds should do. He played - pushing himself around the room on a ride-on truck. Which is great when you are three – but challenging when you are the nursing student trying to listen with a stethoscope. Jan watched till clearly embarrassed, she spoke up, "I'm really sorry. Andrew! Behave yourself please. Let Mary do what she needs to. Andrew! You need to behave! I'm really sorry Mary."

To her credit, Mary tried to reassure Jan that everything was fine, and that she could do without auscultating Andrew's chest this time. She created some closure, and we left the small family to themselves. Mary and I discussed the interaction - what worked, what could have been done differently to get different outcomes. Things like playing with children as a means to assess them and have them participate in their own care. And I wondered with Mary, how it was that a mother would feel the need to apologise for her child being appropriate for their age. Why a parent would consider their child 'being good' and performing for staff expectations was more important than the child just 'being'.

We took the conversation back to Jan – I was keen to hear her perspective – and for Mary to hear it also. Jan suggested that it was more subconscious than conscious – that she wanted to please the staff, and have Andrew please the staff also – so that everything was easier. I added my perspective that it is fine for Andrew to just be three – and that it is up to the student (in this case) or any of the staff to come up with the

necessary skills to do what they need. And that she and Andrew were not the problem. She seemed to appreciate the support.

The interaction remains in my thinking for days later. A few weeks later I speak to a nurse I think will know the child - a colleague from 'way back' who I admire and respect. We had been talking about my research, 'I wonder what kind of story they would tell? I did not anticipate the answer, 'Oh, no. She's strange. She's got mental health issues. She would tell a different story every time. You don't want to talk to her.'

And I am left confirmed in my belief that some stories are muted and excluded. Wondering what keeps it this way.

As the storyteller I tell this story to convince the audience of my authenticity and commitment to families and their receiving good care. I sense that it demonstrates that I am committed to students learning from families as much as from textbooks. The form of a story allows my actions to be seen in relation to my values. The 'evaluation' – here reflected as the story title – is the point of the story – my motivation is to find out 'why?'

It is important to note agency of the characters in the story. The child and family provide a context through which the other characters live out their roles. Without them there is no need for anyone else. All the other characters (me included) have their behaviours and speech mediated by roles and expectations. This is evident reviewing when the characters are free to speak. As I told the story (written that day), I am able to speak up and create choices. Up to a point. There is silence in response to my peer. Because I was… silent. I did not challenge the perspective I disagreed with. In some ways this reflects my awareness of the politics within the healthcare system – Jan's words could have been mine. I went along with the situation, "so that everything is easier."

The final paragraph (or coda) offers some insight – there is reflection - and that reflection keeps this story present and available for retelling. While I did not feel I had power to bring about change in that moment, I have claimed some agency beyond it. As DasGupta (2007) suggests, "the stories of children [and families]… intertwine with [our] own stories, get into our bones, and provide us with an opportunity to learn something deeper about our work and ourselves" (p. 1390)

My story demonstrates a belief that power is fluid and not fixed – but that those who are most vulnerable are least likely to be in a position to jockey for it (Frank, 1998b). Families and children do not wear ID badges marking them as legitimately

able to walk the hospital buildings; their presence is always at the judgement of another. They are less likely to be familiar with the environment, and because they tend to have singular focus on their own child, families are less aware of the cultural habitus of the staff. Stories that do not conform to this dominant narrative tend to be excluded or stigmatised (Blommaert, 2007; Bruner, 1991). The families' perspectives and stories tend to remain verbal and therefore lack the gravitas and endurance of the written narrative of the healthcare professionals. However bearing witness to the suffering of others is important in affirming those who speak of it (Bochner, 2010). Some critics are concerned that highlighting the patient voice diminishes the voices of others in their stories (Atkinson, 2006) – however the dialogical approach taken in this study does not imply greater authenticity for these participants than those described in their stories. What this approach does seek is to ensure that the exploration of these stories contributes to greater understanding between healthcare workers and those who receive care, and the cultural scripts that inform those interactions (Bochner, 2001).

It is important to situate myself by ethnicity, class and experience to ensure consciousness of the impact of these on the research (Dodge, Ospina, & Foldy, 2005). My pre-existing beliefs and values – my cultural habitus – is built upon my own Pakeha working class family values (where service was esteemed), and now attempting to be a good parent myself. It is built on my practice as an RN (where I have both cared for and failed families), and my experience as a teacher seeking to share a passion for facilitating good outcomes for children and families. It is built on watching my mother care for a friend dying of multiple sclerosis while I was still an adolescent. It is unable to be separated and it impacts on my approach. I have taken responsibility with this by clearly differentiating the voice of families from my own. I have recognised the interviews where the wealth of data was produced as co-constructions of meaning – the stories would not have been told at this time, in this way if I had not been there and participated in the conversation.

This chapter has explored the literature underpinning the diverse family of approaches that is 'narrative research'. The approaches of Frank, McCormack and Polkinghorne have been discussed in relation to this study. The structural, thematic, performative and creative analysis lenses have been outlined showing how they are synthesised in Frank's genre lens. Chapter four will discuss how this methodological approach has been applied in this study.

Chapter Four

Methods and Procedures

> There is not any method… of narrative analysis… a prescribed set of steps that the analysis should follow (Frank, 2010b, p. 72)

Narrative inquiry is an interpretive process, from the initial question until the final full stop of the research report (Frid et al., 2000). This chapter describes these steps of interpretation – the methods and procedures of the research process. This includes the ethical approval process, the way participants were selected and protected, the transcription and analysis process, as well as the strategies to ensure trustworthiness. The purpose of this process is to answer the question:

How is nursing care revealed in the stories that whanau/family tell of having a child in hospital?

This purpose of this study has been to understand more deeply the ways in which whanau/families experience nursing care and hence view their experience of having a child in hospital. Rather than developing a model of care, the aim is to see the complexities that whanau/families experience and allow these insights to inform practice (Frank, 2004).

Ethical approval

Reflecting on possible power relations is an integral part of acting ethically (Alex & Hammarstrom, 2008). This included ensuring potential participants felt freely able to volunteer or not, and that they were clear about their rights throughout. The ethics approval process was an important process that included reflection on ways that participants might be vulnerable within an area of inquiry. Gabb (2010) suggests this step is important in that personal immersion in the questions can lead to becoming less sensitive to the possible risks.

Ethics approval was sought and gained from Auckland University of Technology Ethics Committee (AUTEC) on 9 December 2008, AUTEC Reference number 08/253 (see Appendix nine).

Vulnerable populations

Consideration was given to the focus on families as participants – this raised the possibility of the research involving legal minors. Children and/or young people were never interviewed alone. Their participation in the family group interview occurred only if the family/whanau chose to include them. In this way they were never isolated from the context of their family/whanau. They had the presence and support of their family/whanau at all times during the family group interview. All children and/or young people who participated had the consent of their parent/guardian. They also gave assent to the interview themselves with an age appropriate information sheet and assent form provided (see Appendix five).

Many Māori whanau/families are recipients of nursing care for their tamariki/children in hospital. Therefore, while it was not intended to deliberately seek out participants of any particular ethnicity or culture, participation was sought from Māori whanau/families in the hope that their narratives would be included. There is a strong case to involve Māori in this type of health research given both Māori representation as healthcare users and also their status as tangata whenua of New Zealand (Health Research Council of New Zealand, 2008). Consultation towards this began with Kate Haswell (Associate Dean (Māori Health) AUT) and Carolyn McKinney (Senior Lecturer, AUT) who confirmed the value of inclusion of Māori whanau/families in this study. They introduced me to a Māori community healthcare provider where further consultation and discussion occurred. Unfortunately, due to a restructuring of that organisation, these liaison people were no longer available. The recruitment process continued more generally after this, and while no demographic data was sought from any of the families, two of the participant families did have children who identified as Māori. However, in both these cases it was the Pakeha (New Zealand European) mothers who were the primary participants (with one interview including one of the children). Therefore while there were families of differing ethnicities who participated, none of the narratives are representative of any ethnicity. They represent the story told by that family/whanau.

Consent

All families read and discussed the consent form and were made aware of their right to withdraw any or all of their data from the study up until the writing of the analysis. Children participated only when their parent/s included them in the interview, though they each gave assent independently. When children were

present, the rights of participants were extensively discussed prior to the interview beginning, ensuring the language used was developmentally appropriate. No families chose to withdraw once they had participated despite the emotional nature of some of the interviews. Where unpleasant or distressing events were recalled, the participant families were given the offer of stopping or continuing – all chose to continue. The conversational and open approach of the interviews allowed the children to ask questions and clarify issues throughout.

Risk to participants

Stories often arise as a means to tell of difficult times (Adams, 2008). Having a child in hospital is likely to be a worrying and challenging time with health concerns for a child. Recalling a distressing time can lead to further distress and/or emotional discomfort. The information sheet highlighted this possibility, along with the continued right to withdraw from the study. This was also discussed in the email dialogue as well as in person prior to the actual recorded 'interview' taking place. All families who had indicated willingness to participate chose to continue. The emotional risk was different for different families – perhaps most marked for the mother whose daughter died – but there for all. For some families the health issues are ongoing and so the issues they experience are not constrained to the past. They were all offered follow up support at their request – none took this up.

All families and characters in their stories have been given pseudonyms. The anonymity provided by pseudonyms and changing of details likely to lead to identification (C. Davis, 2006), reduced the risk that this could lead to personal harm. The stories exist over a wide geographical context and over a broad time span, further reducing the chance for identification of the participants. Some families stated they did not feel that their anonymity was necessary, some questioning its value – however to protect both participants and the staff spoken of in their stories, identifying details are changed. The risk of this is to "depoliticize the research from the point of view of the person(s) masked" (Nespor & Barber, 1995, p. 61) as though it could happen anywhere to anyone. The interpretive stories seek to ensure that anonymity does not equal generalisability.

Participants also, knowingly or not, risk their stories and experiences being misrepresented, with the possibility of different interpretations being drawn than those they already hold (T. Clark, 2010). It is possible (or even likely) that I will have

a different viewpoint of events than the participants, and therefore re-present the narrative with a different motivation than originally intended. The dialogical nature of the interviews is one way to surface the co-construction of meaning occurring (Meiers & Brauer, 2008). By clarifying and checking throughout the interviews I sought to check my understandings with the families, acknowledging that the final story is shaped by my presence there (Hardy et al., 2009). Some families asked for a copy of the stories, but no changes were requested. Other families insisted they not receive the transcript or stories from it, and this was respected. McCormack (2004) suggests that if the interview has been openly dialogic it is likely that any changes are typically grammatical and cosmetic. There is a balance required here between participants and researcher. While the approach seeks co-construction of understanding with the participants, the participants have not participated in the data analysis. Frank (2005) suggests the dialogic approach underpins research and is evident in the ways it values the participant voice/s. Representing participant stories in an interpretive story ensures the researcher's monologue is interrupted by the dialogue of the participant (Frank, 2000a). Further, Frank (2000b) suggests the relationship with the participant continues to be dialogic when their story is maintained in its integrity. The co-construction continues as a value of the research as the participants' point-of-view is appreciatively maintained (Frank, 2000a) not simply by asking whether they agree with the interpretation.

There are risks with all types of research - in qualitative interviews there is risk of emotional distress as events are recalled, and there is potential risk to reputation if anonymity is not maintained (Gabb, 2010). The same protective action of establishing a trusting and supportive rapport with participants, can also lead to them sharing with greater disclosure than they might originally have intended (Gabb, 2010). The information sheets were emailed to participants prior to the interviews to ensure they had sufficient information to decide whether or not to participate and could prepare themselves for the interview. If in the comfort of the interview any details or opinions were shared that could be misinterpreted or lead to their clear identification, this was excluded from the resulting stories. Of the family participants who wished to review the stories, no one has asked for any detail to be removed. The majority of families have not participated further in the development of the interpretive story. This differs from process outlined by McCormack (2004), where she continued to involve the participants in the analytic process. A significant difference, however, is that in her research project she had

multiple interviews with participants over an extended period of time. This allowed for the development of themes and understanding over the course of the experience under study. Dibley (2011) also utilises McCormack's lenses approach, however similarly relies on the stories gained in the interview to ensure the dialogical interplay of researcher/participant voices. Riessman (2008), when outlining her dialogic/performative research, also demonstrates the dialogue with the existing participant stories rather that returning to participants for further data. Some of the reasons families gave for not wanting to be further involved included not wanting to dwell in the recalled experiences, and busyness of the families. For any subsequent studies it may be useful to incorporate greater participation throughout to see if this changes the analytic outcomes.

All names have been changed in this report and any other obviously identifying features that could lead to identification have been disguised. This has been done whilst attempting to maintain the integrity of their story. All reasonable effort has been made to ensure their confidentiality – digital files are stored in a password protected computer.

Recruiting participants

Families were recruited by accessing community and informal networks. This included putting the invitation poster (see appendix two) in publically frequented spaces such as schools and churches or clubs. Information was also posted on Facebook™. AUTEC approval included notices in public spaces – this 'virtual' notice board was only accessible to selected 'friends', and was an invitation for them to pass on the information. I spoke about the research with several people who also asked within their networks. Recruitment was purposeful (Patton, 2002) where participants were sought out for their experience of having had a child nursed in hospital. Some snowballing occurred when initial participants found value in the interview and passed on information to others in their family networks.

All participant families were voluntarily involved. They were all either approached by a third party facilitator or heard about the research from the information sheet. Each family chose to continue contact after being sent information sheets. This was almost exclusively via email, further reducing any sense of obligation as there was no personal verbal contact until families indicated willingness to participate.

Introductions became the primary point of access – with colleagues and others in personal networks speaking to potential participants about the research. If they were interested, they emailed me and I replied with the information sheets (see appendices three & four). While the asynchronous nature of email often led to conversations occurring over some time, it also seemed to give families more power to ignore or not reply at their choice. One or two families stopped replying once they had received the information, so I did not follow up with them. All the families who read and indicated an interest, however, were asked to suggest a time and place that would be suitable for them. While the electronic communication was effective – it also solicited families from other regions. In keeping with ethical approval, as well as for time and cost reasons, the families who participated were all within the geographical constraints of Rodney and Waikato (incorporating Auckland).

The recruitment process was eventually successful with families representing different ages, reasons for hospitalisation and District Health Boards. The process did take longer than I had anticipated however. This may have been related to the target group. Families are often likely already busy without adding meeting a stranger for an interview for which they receive no particular benefit. Once I had been able to make initial contact the families were generally interested and generous in making time available. The static and impersonal approaches (such as the poster and information sheets) on their own were generally not successful. So, for example, once a principal heard about the research she was very keen to support it and advertise it in the newsletter. However this only led to one parent making contact, and they did not follow up. On the other hand, families who heard about it through other families seemed much more likely to end up as participants. The opportunity to reflect and talk about their perspectives seemed an attractive aspect to the research (T. Clark, 2010) once I could personalise it. It seemed the talking to 'someone' rather than talking 'about' that was the primary motivation. I learned about engaging with multiple networks and having key people who were able to introduce the ideas within their field of influence (Arlidge et al., 2009).

The research participants sought were whanau/family who had had a child nursed in hospital. The inclusion criteria of the study design was for the hospitalisation to have been in the previous 12 – 24 months to ensure that the recollections were relatively recent, and therefore reflect insights into the practice of caring by nurses as it is currently delivered. While all families met this criteria, some families

included stories from outside this time frame. These were included when these memories were fluent and contextualised the more current experience. Given the interpretive nature of memory and storytelling (Ellis & Bochner, 2000), the time passed seemed to make little difference if the story had been retold elsewhere and was important to the identity of the family.

Membership of the whanau/family were determined by the whanau/family themselves (Bernardes, 1993), and always included those who were whanau/family to the child at the time of their hospitalisation. The majority of storytellers were mothers, reflecting how women are often primary caregivers of children (Fisher & Goodley, 2007). This was similar to Arlidge et al. (2009) who also set out to interview Māori and Pasifika families, but ended up predominantly with mothers. This was not a cause of non-inclusion however; the voice of the woman was not excluded because of the unavailability of partners or children. At times the women were pragmatic and chose times they themselves were available for simplicity and ease. In the end the participant families included multiple forms of family: a single mother; the mother as representative storyteller; both parents together; and parents with children. All adult participants spontaneously reflected on the hospital experience for others in their family (as for example, women reflecting on partners' experience, and parents discussing impact on other children). Demographic information was not sought or collected, other than what was offered in the course of the interview and surrounding conversations. From these conversations it was apparent that the families were of various ethnicities (including Pakeha, Māori and Asian) and socio-economic levels.

The 'diagnosis' of the child was also not sought unless it emerged as part of the family's story. This was to limit the risk of categorisation (Frank, 1998b) of the child and family, and the story be read as a clinical account rather than personal exploration (Bourdieu, 1993b). The urgency and importance of the hospitalisation seemed to matter more than the name of the reason. The stories represent families' experiences from birth to death. The children involved ranged from premature babies to a 14 year old adolescent. While they did not contextualise their experiences in this way, I have chosen to group the interviews by the nature of the hospitalisation. This does not reflect similarities in those stories (they are distinct) but in the care context. The analysis chapters reflect this grouping.

The intention had been to recruit 8 - 10 families to cover a range of experiences and backgrounds, to gain a diversity of stories about experiencing care and allow the 'multivoicedness' of the narratives to be explored (Moen, 2006). While more families than this indicated their willingness to partipate, the families eventually included were those who met the inclusion criteria of having had a child admitted overnight (or longer) and within the previous two years. Participants were all English speaking - due to the complexities and nuances involved in telling stories likely being lost in language and translation (Polkinghorne, 2005).

The participants all represented "families who have had a child in hospital". Each of them are unique and have particular interests and emphases in their stories. To avoid assimilating each of them simply as a category (family), aspects of their individuality and identity that they shared have been captured with a brief introduction of each family (see Appendix one).

Interviewing

> Storytellers want to focus, among other experiences, on stories that have been shrouded in secrecy - hidden stories, unacknowledged tales that may shame us into acknowledging truths we haven't dared to tell. Instead of talking about, storytellers want to talk to and talk with (Bochner, 2010, p. 664)

A semi-structured approach is useful as it allows participants to raise issues that they feel are important in their own words (Arlidge et al., 2009). The intention to invite whole family/whanau was to ensure as many issues as exist for the family were able to be raised. This included children impacted by the hospitalisation as they are social agents in their own right with stories to be told (Balen et al., 2006). Interviews are necessarily a verbal interaction. Families however, do not have to be able to articulate polished narratives (Booth & Booth, 1996) – though all were effective communicators in the context of the interview. Seeking out this broader participation is one way of attempting to hear from those within the experience whose stories might otherwise not be heard (Curtis, Roberts, Copperman, Downie, & Liabo, 2004). So while I prompted the participants for examples and stories it was not the work of participants to present tidy stories. At times participants spent long periods of time theorising and describing rather than recounting experience stories. The group interviews often involved others correcting and reshaping the shared narratives, demonstrating the complex nature of storytelling (Seaton, 2008). So at times there were shared stories, while at others the family members' stories

seemed to exist in parallel to each other. In the development of the interpretive stories, these were represented as either a common storyline (with various voices included) or as distinct stories told by an individual within the group interview. My role in the interview was to elicit stories of experience; once transcribed the analysis involved identifying and 'thinking with' the stories within the transcript.

Interviews are not simply about listening and reporting; the interview is a co-creation where the conversation is shaped by each person participating (Alex & Hammarstrom, 2008). The meanings that evolve out of any interview necessarily include tentative understandings of 'self' of the storytellers and those interviewing (Armstrong, 2002). It was important, therefore, throughout the interview, to be alert to ideas of identity as well as narrative form. The interview is also part of the representation of the family – the content and form, as well as the performance of the story was a means of making sense of what happened in relation to who they believe they are. Family groups were interviewed whenever possible – group interviews allow group members to support each other while also demonstrating their shared values toward each other (Seaton, 2008). Sitting in a circle around a table or lounge at the choice of the participants also helped the setting seem more relaxed and inclusive of all present. While the intention had been to prompt for the perspectives of family members not present, in each interview these were raised by the family members there in the interview.

The interviews all took place in the families' homes, with one exception where we met at the University. They were all at times indicated by the family. As well as going over the information sheet, the preamble to the interview included social talk to 'get to know' each other as much as possible in a short time. Where there was only one family member present the conversation was obviously limited to the two of us. Where there were more people present the intent was to include everyone. This offered a rich opportunity for multiple levels of interaction and viewpoints – the family speaking collectively as well as individually (Donalek, 2009) and prompted conversations that might not have otherwise happened (Liamputtong, 2007). I had anticipated some challenges in gaining full participation within a group interview given pre-existing family dynamics; however everyone present in each interview seemed to participate to their level of comfort. Hyde, Howlett, Brady, and Drennen (2005) suggest group interviews allow for checking of details, and in these conversations the family members often challenged each other's memory of details

and clarified the stories. Where this happened in this study, the interactions were included in the interpretive story.

To ensure the family understood I was there as a researcher genuinely interested in their experience I planned for the interviews to be conversational and interactive. While I participated in the discussions, it was the families who spoke the most by far. Turning up on time and following the lead of those whose home I was in also went some way to ensuring the family did not feel I was asserting myself over them (Alex & Hammarstrom, 2008). I tended to ask questions hesitantly, indicating a lack of calculation in my approach to indicate an openness and genuine desire to hear from the families (Frank, 2008). What was challenging was the dual task of being genuinely present for the participants while simultaneously seeking "good" data for analysis. As I did more interviews, I tended to be more comfortable in this, though leaned more towards the listening – trusting the process to deliver rich data.

The children who participated were all of school age and freely chose to participate. In those interviews I deliberately spent longer explaining and checking understanding prior to beginning the interview (Docherty & Sandelowski, 1999). If there were children in the interview, it was reinforced that there were no 'right' answers. Children are able to convey their understanding if they are not limited by the adults present (Balen et al., 2006). In these interviews parents, as well as me, would seek to include the children. If there were children present I began the interview by talking to them. This seemed to help them feel more comfortable contributing throughout the interviews. Having had some success with this, it seems that interviewing children, along with parents, is a useful way to explore the family's perspective.

The interviews were conversational and open. I would preface each interview with a summary of the interview purpose and the participants' rights. After this, they tended to flow easily, most taking about an hour – but up to two hours in duration. The families were often consciously aware of my agenda, asking, "is that the kind of thing you wanted" [Barb]. It is not clear how much this influenced the talk however, as this question only emerged once the recorder was turned off. I had a list of indicative questions (see Appendix six) – these were prompts if the participants were finding it difficult to talk. This was not a problem in any of the interviews. All the participants seemed ready to talk – 'where shall I start' being more of a

challenge. This was not surprising given that these families had self identified as participants and had personal experience of the topic of discussion.

There were silences in interviews – but these were natural pauses and reflections on what had just been talked about. At times I would ask a participant to return to something they had mentioned earlier, otherwise the families tended to direct the pace and much of the direction of the conversation. In one case, a participant (a child) chose not to expand on that experience – which was respected and the conversation moved on. Where a topic seemed to be particularly emotional, I asked the participant if they wished to continue, reiterating the initial information. Whenever this happened the participants indicated a desire to continue.

Notes were made after each interview which, along with listening to the recordings, formed the beginning of the analysis. The first interviews were learning for me. My interview skills as a clinician were useful in initiating and maintaining an effective interaction. My supervisors were helpful and read through the initial transcripts and discussed with me ways to fine tune this and become more effective as an interviewer. Aware that the digital recorder captures only the audible aspects of the interview, I also kept some note of other performative features which contribute to the telling of the stories (Peterson & Langellier, 2007) to include in the interpretive stories.

Introducing the context of the interviews

Most of the interviews took place in the families' homes. This was always at the preference of the participants. As with Williams (2000), my interest was not in the clinical case, but in hearing as they talked about their lives at the time of the children being in hospital. The home environment seemed to aid this. Power and hegemony is not simply removed by situating the interview in the home of the participant – power is fluid and complex and influences the dialogue in unseen ways (Frank, 1998b). Being on time and following the lead of the family is one way that I sought to empower the participants. They were all aware, however, that I work for a University and am undertaking this research as a health professional. In the case of these families, this did not seem to be viewed as a hierarchal position. And while I was transparent about my being a nurse, through the course of the interviews, this did not seem to inhibit their storytelling, with positive and less positive stories emerging in the dialogue. The red light on the digital recorder also

did not seem to limit the talk – though I was aware of it, knowing that our utterances were being captured for review.

Transcript

The step of converting the 'spoken text' to 'written text' was the first step of analysis. McCormack (2004) suggests "active listening" (p. 222) is the first step in turning the hours of interview into the final analysed form. Active listening involved listening several times over, noting the emphases evident from this listening that may not have been evident during the interview itself (Doucet & Mauthner, 2008). This accessibility helped me remain familiar with the interviews (and participants) throughout the process.

I began transcribing the interviews myself, however found that the time required for this was far in excess of what I had anticipated. In consultation with my supervisors, this aspect was passed on to someone who had extensive experience transcribing interviews. My intention had been to immerse myself in the stories at every step, aware that the act of transcribing is interpretive (Riessman, 1993). The change in medium from oral to written introduces translation "infidelities" (Bourdieu, 1993c). Evidence of this became apparent when I began initial readings of the transcribed interviews. Many of the performative markers had been excluded – repetitions, pauses, space fillers such as 'uhm'. These speech functions are functions of communication (McCormack, 2004). So while the 'content' of the interview was accurately captured, some of its presentation had been lost. In the process of checking the accuracy of the transcript I added these components back in.

Where there was only one family member present, the transcription was relatively straight forward. With the group interviews however, there were more frequent speech overlaps and rapid changes in speakers. These were captured as accurately as possible by re-listening to the recordings, and by identifying various speakers with font colour changes. There were similar family values evident from the speech within families, however there were also differences which it is important to surface to avoid suggestions of homogeneity (Gubrium & Holstein, 2009). An example of this was parents accentuating different aspects of the same event.

Once I was confident the transcripts accurately captured the interviews, I looked for the temporal ordering of the events and reconstructed the transcripts to reflect this (McCormack, 2000a). Stories are told to convey a meaning and frequently are not bound to chronological ordering (Hurwitz, 2004). Re-ordering the stories allowed the narrative timeline to become more evident, and the impact of previous experience to be seen. Often very little change was required – especially if the hospitalisation/s had been for more acute episodes. For other families, the order of the stories seemed less predictable with one memory triggering another. Stories with beginnings and ends are typical of Western narrative structure (Riessman, 2008) so this temporal ordering helped me understand the total experience of the families more effectively.

Analysis

> The people who come to us bring us their stories. They hope they tell them well enough so that we understand the truth of their lives. They hope we know how to interpret their stories correctly. We have to remember that what we hear is their story (Coles, 1989, cited in Bochner, 2001, p. 132).

Many authors have written about narrative and its underpinning philosophies (Barone, 1989; Connelly & Clandinin, 1990; Frank, 1995; Gubrium & Holstein, 1998; Polkinghorne, 1995) however for new researchers there are few who write about how to approach this large amount of data (McCormack, 2004; Riessman, 2008).

The analysis in this study was underpinned by the approach developed by Frank (1995) where stories are viewed as extraordinary human social tools that offer insights into fellow human beings and their environment (Frank, 2010a). This interpretation involves dialogue with the families as they explore their experience; as "an engaged witness whose recognition people seek as confirmation that their struggles are moral, at least in intent" (Frank, 2005, p. 972). Their stories give a human view of experience (Eldershaw, Mayan, & Winkler, 2007) that allows for the exploration of their social realities (Draucker & Hessmiller, 2002). This is an appreciative approach that recognises the storyteller having something important to say (Frank, 2010a).

The work of McCormack (McCormack, 2000a) also supported the analysis. This approach is to analyse the transcript using different views or lenses until a final "interpretive story" (McCormack, 2004, p. 220) is able to be told that represents

the co-construction of meaning from working with the participant. This work mapped out the process of analysis by naming some of the lenses necessary to explore the transcript. Each transcript was scanned for 'markers' of stories (orientation, abstract, what happened, evaluation, coda). This structure became the first step in developing an interpretive story and involved ensuring that the participant's narrative thread was predominant. An important step in this was active listening (McCormack, 2004) to reflect on assumptions and the performance of the story. This listening involved multiple re-hearings of the audio recording and re-readings of the textual transcript. The goal of this was to enter in to the emotion and details as defined by the storyteller. Dwelling for a time in the participants' stories was one way to 'think with stories' as opposed to rushing past, and filling in the blurry details with my own professional and cultural assumptions (see figure 3).

Figure 3 Taking time to listen

Once the 'stories' were identified, narrative lenses (McCormack, 2004) were used to explore each story for meaning and context (narrative processes; language; context; genre).

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Narrative processes are tools storytellers use to enhance their story and give meaning to their life story (McCormack, 2000a). *Theorising* is when the teller reflects on what is happening and wonders 'why', or tries to draw some meaning from it. *Augmentation* is the process of adding information – details that the storyteller thinks will add weight to their story. *Argumentation* is when the primary story reminds the teller of other situations that reinforce the meaning of the story. *Descriptive* elements are details the storyteller brings that do not add to the narrative flow, but fill in details. This process involved literally 'cut and paste' from the transcript to the narrative lenses table (see Appendix seven) so that these individual stories could then be explored with the next lens.

The lens of language involved close review of the talk of the families – what is said, how it is said, what is unsaid (McCormack, 2004). Language is the mode of communication and fundamental to the construction of the stories. Exploring 'what is said' initially involved looking for words that indicated the storyteller's relationship with others and their environment. Note was made of words that made an assumption of shared understanding (e.g. 'you know'), words that created space for thinking (e.g. 'uhm'), and use of jargon. Repetition was noted as a point of emphasis or when complex layered meanings were intended (Seaton, 2008). How the storytellers made use of pronouns (e.g. "I" or "we"), metaphors, and active or passive voice were markers looked for in exploring 'how it was said'. 'What was unsaid' (but flagged within the interview) involved listening to the recordings and reviewing the transcripts for points of heightened emotion and silences. These silences and omissions are important within stories – 'what does not happen can be equally worthy of interpretation" (Frank, 2010, p. 107). Spoken stories are often not constructed in the constructed and edited form that the written presentation allows for narratives to take (Harter et al., 2005). Translating the "bits and pieces" to a written form that "makes sense" and captures the sense of the conversation can disguise the disjointed manner most interviews take (Harter et al., 2005, p. 19).

Exploration of the context involved reflecting on the context of the interview, and therefore the way it was shaped by my presence, as well as the context that the story took place in. Viewing the stories offered by participants along with knowledge of the context allows new insights of the hospital settings, "places which bring together people who have nothing in common" (Bourdieu, 1993a, p. 3). Considering the context involved reflecting on the power relationships with people

to understanding the relationships between healthcare providers and those who receive such care (Frank, 2002a). This included the wider discourse they exist within, the social and institutional (grand) narratives that "are inevitably woven into our personal stories of lived experience with the institution" (Riessman, 2002, p. 37).

Analysis allows the individualised narrative to be seen in a social context, enabling the diversity of narratives which differ from the hypothetical 'norm' to be seen and heard (Armstrong, 2002). This analysis is what takes narrative from being simply collection of folklore and research of social activity (Atkinson, 2006; Atkinson & Delamont, 2007). For example, the experience of having a baby cared for in hospital must be considered within the context of societal expectations of parents. Narrative inquiry is not simply review of stories using a template approach – it involves both intellectual analysis and an artist view to creatively represent the inter-subjectivities implicit in human life (Conle, 2000).

Frank (1995) makes a case for thinking *with* stories rather than *of* them. This is a work of immersion into the intent of the storyteller, "allowing one's own thoughts to adopt the story's immanent logic of causality, its temporality, and its narrative tensions" (Frank, p. 158). Stories from recipients of nursing care may not be tidy (in the way that healthcare workers learn to tell the medicalised story), but they do often fit genre types (Frank, 1998a). So part of the analysis is to look at the ways the stories are crafted and create meaning of experience. Restitution, chaos, and quest stories are devices used (and resisted) by storytellers as they recall experience (Adams, 2008).

Restitution type narratives follow the culturally preferred master narrative where illness is followed by 'restitution' to the previously held state (Frank, 1998a). These are the narratives often presented to families as the norm – for example a photo-board of babies who have gone home from a neonatal unit. This (visual) narrative leaves little room, for example, for families of babies who died as a result of complications of prematurity. While restitution stories may capture the complete trajectory of a child's hospitalisation, exploring the families' stories can uncover whether this is a consistent narrative thread.

Quest type narratives are stories told of change as the result of an illness experience (Frank, 1998a). An example of a well known quest narrative is Mitch

Albom's 'Tuesdays with Morrie' where Morrie shared with his previous student the life lessons he felt he had gained through the experience of dying of a neuromuscular disease (Vroman, Warner, & Chamberlaine, 2009).

Chaos type narratives seem to be one response to a lack of personal agency (Vroman et al., 2009). This agency can be reduced unconsciously (where the available narratives are limited by the master narratives or institutional narratives) (Palmer, 2007). For example a mother may regard self sacrifice as the norm as she conforms to socially mandated constructs of women (McKeever & Miller, 2004), or other family may feel their participation is limited when they are referred to as visitors. When the previously held narratives and 'sign posts' no longer work, the told narrative becomes disjointed and confused (Palmer, 2007). Frank's approach is a useful way to approach stories by reflecting on the ways they are told to understand the experience of those who suffer (Thomas-MacLean, 2004). These typologies are of the stories – not the storytellers – they allow exploration of the wider narratives at play (Frank, 2010). People learn narrative templates (plotlines and genres) from childhood and these become the models through which experience is interpreted (Frank, 2010).

This part of analysis is not to compartmentalise the story or the storyteller – most stories contain aspects of more than one type – but to allow the exploration of the meaning-making by the participants (Andrews, Sclater, Squire, & Tamboukou, 2004). So once the stories within the transcripts are identified, they will be reviewed for plot, actors and agency (Riessman, 1993). The stories must be explored for more than what they are about (Frank, 2006). Being alert to which types of stories are told, and how, offers insights into the narratives available to the storyteller. The potential richness of narrative analysis is found by moving beyond viewing just the structure and plot of the story – additionally to explore the agency of the characters and their place in the story-told world (Gubrium & Holstein, 2009).

Content of interviews, while important, must be considered alongside form (or performance) – who tells what stories, and why (Atkinson & Delamont, 2007). Social conventions and various positions of narrative authority allow some stories to be told, while reserving others in silence. This was important to review internally in relation to the way the families shared speech time, but also in relation to whether these stories had had other opportunities to be heard. Integration of this wider

analysis with the story lifts narrative inquiry from becoming positivist case study with sample size n=1 (Stauffer & Barrett, 2009). However this is also a position of some paradox within narrative analysis; on one hand, meaning is co-created within the dialogic texts of participants (Frank, 2004a), but on the other, participants are only able to see and use culturally available discourses - it is not apparent who is able to 'see' what is really happening. Atkinson and Delamont (2007) suggest that participants are unable to see what is not apparent to them (influenced by culture, society, convention, power relationships), and that it is the role of the researcher to uncover these contexts in the analysis. This dilemma is addressed by foregrounding the development of meaning within the interview and later in the interpretive story as conditional understanding. This affirms the decision to not include 'member checking' with participants as part of the method of analysing these intensely personal accounts. Member checking has been suggested as an important tool in qualitative research to achieve rigour (Jones, 2002). However, as shown, the prevailing hegemony may make the researcher's findings unrecognisable to the participants (B. Grant & Giddings, 2002). Jones (2002) does suggest writing to participants at the end of the study to outline what was learned from them (individually and collectively). The intention is to finish the project with such a letter.

Interpretive story format

Once the transcripts were reviewed for accuracy, stories identified and chronologically ordered and then reviewed through these narrative lenses, the final step was the re-presentation of the data as an interpretive story (McCormack, 2004). Each family's interpretive story begins with an 'orientation' – to allow the reader to see the immediate context of the interview and story production (Dibley, 2011). The evaluation (the point of the story) forms the heading for each of the stories (McCormack, 2000b). The words for each story are the words of the participants – though the details may have been rearranged to capture the sense of meaning evident from the interview. For example if there was a long stretch of theorising within a story, only the story elements were included to ensure readability and cohesion. The analysis and discussion weaves around these stories to form the larger interpretive story demonstrating the analysis process. The analysis is supported initially by text within the interview – the stories were enhanced in the interview with narrative processes; description, augmentation, argumentation and

theorising. Where these narrative devices would have made the primary story less clear they are included in the associated discussion. This participant speech is indicated with quotation marks and the speaker identified. The discussion is also augmented by use of literature (part of the wider professional narratives). This re-presentation ensures the process is transparent and visible to the reader (Dibley, 2011).

Narrative inquiry begins as the study of an individual's story – but continues as the exploration of context and social construction (Frank, 2005) recognising the multiplicity of meaning available. It is the story as told by participants of their experiences over time, but not understood as chronology, rather "time whose significance is given by the meaning assigned to events within its compass" (Bruner, 1991, p. 6). Telling stories is a way we ascribe meaning to the things that happen to us - it is the way we make sense of our world and our place in it (Bruner, 1987/2004). Therefore the interpretive stories allow insights into the participants' world construction and their understanding of their place in it.

Interpretation and analysis in this study is focused on nursing and care – which, while important to the participants, is but one of several motivations that shaped the choice and nature of the stories told. Allen and Cloyes (2005) demonstrate how interviews are complex social interactions that involve overt as well as hidden agendas. While a story is told, the teller is rarely consciously aware of all the influences on the story they are telling (Andrews et al., 2004). Member checking asks the participants if the researcher has "got it right" on the presumption that the participants are able to see the incontestable facts of the experience (Allen & Cloyes, 2005, p. 99). The analysis approach taken here seeks to move beyond the narrator's original intentions and link these stories to other narratives and discourses (Frid et al., 2000). The represented interpretive stories remain faithful to the stories by presenting them as wholes (rather than selected phrases). However the analysis and interpretation may not necessarily be shared by the participants. This potential difference is not a weakness of the approach - the conclusions remain centred within the participants' stories, but are connected to wider narratives and the socio-cultural context they exist within – connections the participants may or may not be consciously aware of (Borland, 2004).

Trustworthiness

To attain trustworthiness, a study must build in strategies to ensure rigour throughout the process (Morse, Barrett, Mayan, Olsen, & Spiers, 2002). It is not an afterthought to be ticked off at the end but a transparency of method and intent at every step (Moss, 2004) where the reader is able to judge the integrity of the method and appropriateness of each interpretive step.

Ensuring rigour in narrative research does not necessarily lead to the research being able to be replicated by another researcher in another context with the same findings (D. Davies & Dodd, 2002). However the research process must be reproducible for the results to be credible and believable. Whittemore, Chase and Mandle (2001) have synthesised several assessments for considering validity and rigour in qualitative studies.

Credibility

A study can be said to demonstrate credibility if the results are believable and accurately reflect the context as well as the experience of the participants (Whittemore et al., 2001). To credibly capture the experience of participants, long stretches of the participants own words have been re-produced in the report rather than as a selection of short excerpts. This ensures the context for the words remains evident. The integrity of participants' stories is maintained by presenting them within a temporal flow and also by demonstrating the interview context they were shared in. The interpretive story and findings all come from dialogue with the participants and therefore the claim is that the findings reflect a shared understanding of the experience. The template for identifying stories, reviewing them through narrative lenses, and developing the interpretive story was followed with all interviews (for an example of the analysis process see Appendix eight).

Authenticity

This aspect of rigour is demonstrated with the emic perspective represented showing an awareness of the subtle differences between the voices of all participants (Whittemore et al., 2001). To ensure the emic and distinctive are maintained, the words of the participants are used to tell their own stories – their understandings are presented clearly alongside my own etic perspectives. Where

there are differences in perspectives, they are expressed openly but tentatively. Borland (2004) suggests that differences are not uncommon as researchers bring their own 'concern for', experience of and 'insights about' the experience being explored. The basis of interpretation remains the participants' stories. My aim "in pointing out certain features, or in making connections between the narrative and larger cultural formations, may at times differ from the original narrator's intentions" (Borland, 2004, p. 523). Highlighting differences in interpretation between participants and researcher is a way to authentically ensure the collaborative nature of the interview does not become a colonisation of their story (Savin-Baden & Van Niekerk, 2007). In the same way, different perspectives within families are also identified in an attempt to showcase the complimentary/independent nature of narratives told within a family interview (Donalek, 2009).

Criticality

To demonstrate this aspect of rigour a study must show evidence of critical appraisal (Whittemore et al., 2001). The whole journey of this research has been one of critical appraisal, both internally and externally. Consulting with Māori healthcare providers and other clinicians early in the process ensured that the approach was sensitive to the research question and relevant to this area of practice. My research supervisors reviewed the first interview transcripts offering timely feedback to ensure further development of interviewing ability and consistency with the methodology. I have read widely around the use of narrative (particularly) in health research to ensure consistency with the underlying philosophy of narrative inquiry. The use of multiple narrative lenses is consistent with the narrative approach and allows for the co-existence of multiple interpretations. I continuously reviewed relevant literature throughout the analysis process to ensure these interpretations are plausible amongst the multiple possible meanings (Feldman, Skőldberg, Brown, & Horner, 2004).

Integrity

The criteria for showing integrity within the research asks whether there are recursive and "repetitive checks of validity as well as a humble presentation of findings" (Whittemore et al., 2001, p. 534). To maintain integrity of approach to data, all the interviews were explored using the same process – synthesising the approaches outlined by McCormack (2000a) and underpinned philosophically by

Frank (2010b). This included ensuring the transcripts accurately captured the nature of the interview; multiple reviews of the transcripts and listening to the audio recordings; review of the transcripts to identify stories related to experience of (nursing) care; consideration of the stories using various narrative 'lenses'; and development of interpretive story to highlight the analysis process. Reviewing the relevant literature throughout the analysis process was an important step in checking the validity of the interpretations as they were considered.

Additional criteria

'Explicitness' is an important characteristic, where the methodological decisions have been addressed along with the interpretive pathway (Whittemore et al., 2001). My pre-understandings have been clearly outlined. The impact of my biases has been checked throughout the development of the interpretive stories, and also within the interviews as the dialogue worked for a shared understanding.

'Vividness' in qualitative research asks whether "thick and faithful descriptions been portrayed with artfulness and clarity?" (Whittemore et al., 2001, p. 534). To achieve this there are a mixture of ordinary and somewhat mundane stories, as well as more 'powerful' and shocking stories. I have presented these with all their inconsistencies and grittiness to capture the reality as it was told (Gabb, 2010).

Imaginative ways of analysing and presenting data demonstrate the criteria of 'creativity' (Whittemore et al., 2001). In this report of the study a variety of presentation methods have been utilised to capture the intensity of the stories as they were told. Use of different fonts and colours has been used to foreground the multiple participants who contributed to the final stories.

The criteria of 'thoroughness' questions whether the findings address the research question convincingly (Whittemore et al., 2001). This study has explored both the notion of how families experience care, and the stories they tell to describe it. Stories been explored across several practice contexts and from families with diverse backgrounds and experiences. These have all been included – not to demonstrate saturation (not a focus of narrative approach) (Riessman, 2008) – but to demonstrate differences and similarities of experience.

To demonstrate 'congruency', the processes must align with the findings. Using a narrative approach this has been challenging as the methodology covers multiple

viewpoints. However, the tentative presentation of interpretation and findings is consistent with the narrative methodology (Riessman, 2005). The focus has been less on the 'truths' of the accounts and more on the meanings the families themselves create to make sense of their experience.

'Sensitivity' to the participants and their cultural and social contexts is essential to an ethical approach to the relationship with participants (Whittemore et al., 2001). While I have interpreted and explored these stories, it has been with an attitude of gratefulness toward the participants "to turn the tables of power and to learn at the feet of those one would teach, to listen to the voices and silences of the children and adults for whom we care, and, in doing so, to approach a more-mindful [practice]" (DasGupta, 2007, p. 1391). Any difference in perspective between me and the participants was either clarified within the interview, or is expressed here in the report tentatively and transparently.

Summary

This chapter has discussed the methods and procedures followed from research design to presentation of study findings. This has been underpinned by a synthesis of the narrative approaches of Frank (1995) and McCormack (2000a). Nine families agreed to tell their stories, with the numbers of family members present ranging from 1 – 4, although no extended family members were present in any of the interviews.

Each of the transcripts has been represented as an interpretive story in the following chapters five to seven. They have been grouped in relation to the contextual factors they have in common. Chapter five includes the stories of two families with premature babies hospitalised immediately following their delivery. These are stories of nursing care in the midst of becoming a new family. Chapter six includes the stories of four families whose children have been hospitalised with acute episode/s of illness or injury. These are stories of nursing care in the midst of an unfamiliar environment. The final set of three stories form chapter seven. These three families have had ongoing and long-term experiences of hospitalisation of a child. These are stories of nursing care in the midst of ongoing relationships with healthcare providers.

Chapter Five

Nursing Care in the Midst of Becoming a New Family

> Hindsight and distance do not allow us to see more of the past. They provide a different view of this (Bishop & Shepherd, 2011 in press, p. 8).

Introducing the context of their stories

Becoming a parent is a strongly culturally defined transition in identity (McKeever & Miller, 2004). Both the families (see Appendix one) whose stories are included in this chapter had babies born prematurely and therefore required specialised neonatal care at the same time they were making that transition. Their experiences span four different wards and occur in different cities in New Zealand. For these families there was not only the newness of the hospital context, there was also the suddenness of becoming parents – weeks and months earlier than expected. Identity is fundamental to all stories – stories are told from the perspective of the storyteller and their perception of themselves. These important identity (mother/father) roles are in the process of being established at the time the stories speak of – and is evident in their stories.

Ideals of parenting – particularly women's roles of 'mother' are culturally determined (Koniak-Griffen, Logsdon, Hines-Martin, & Turner, 2006; Nelson, 2006). Western narrative discourses of family position responsibility for children primarily with the immediate family rather than the community (H. Lindemann Nelson & Lindemann Nelson, 2008). This is exacerbated with the increasing urbanisation of society and the distances between extended family and community. Much of the expectation of parents, and especially mothers, is rooted in middle class historical patterns, and has not always adapted to increasing pace of change in society (Koniak-Griffen et al., 2006). Parents are often judged by their willingness to sacrifice for their children, with little regard to the environmental support available to those parents as they seek the well-being of the child (H. Lindemann Nelson & Lindemann Nelson, 2008; Lupton & Fenwick, 2001). For new parents there is often little opportunity to critique these prevailing narratives prior to suddenly and (in a hospital setting) publically being expected to live up to them (Andrews, 2002).

Neonatal care is organised as a particular practice specialty delivered in a very clinical environment with particular protocols and mores (Lupton & Fenwick, 2001). This was a completely new context for all the families. The only exception to this was for Kelly, who had worked as a nurse in this type of setting before – however she had not worked in the unit where Chris and Mitchell were cared for, so was also unfamiliar with the specifics of that unit.

Adita's story

Temporal flow
She was born in a very dramatic way just 31-3!
It kept my sanity for that night because that night she was on one side of town... and I was here
She was just down the corridor
And she said, 'sorry, you have to go.'
But even knowing this didn't make it any easier
...and you know, she's out of duty
That was quite confusing, especially to someone who's struggling with it
... it was a good thing that she did what she did
And it calmed her down. I'm glad he listened
They made him feel a part of it
And that's how you feel

Titles (vertical label on left side)

Orientation

Adita, Kapil: Nidhi

I have found Adita's house – not a part of the city I am used to – and I am glad I am not late. We have been communicating via email for several weeks now. She heard about the research from a mutual contact – "she's got a really interesting story!" The first appointment had to be changed when Nidhi was going in for her immunisations – Adita had been apologetic about this – I just appreciate that someone is willing to participate. So it is on.

This is my first interview. Not sure why I feel apprehensive, though. I talk to people most days – and many days they are families of children in hospital. But that is when I am familiar with the environment and rules – now I am in someone's home – and I want something from them, rather than the other way around. It is me who is tentative – knocking gently – hoping it is the right house, not knowing if the person who opens the door is the person I have been emailing. This is a new position for me.

Adita welcomes me in – Nidhi is there – I end up cuddling her for a time, till she falls asleep. We chat for a short time, then Adita gets into the business of telling her story:

> ### She was born in a very dramatic way just 31-3!
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> She was born in a very dramatic way for me. It was on Good Friday - I had come from Mass, and was very conscious of the fact that the whole day I'd not felt her move much.
>
> I didn't tell Kapil (my husband) during the day because I didn't want to alarm him.   So we called up our midwife and she said, 'come to the hospital.' We went to the hospital. The midwife steps out and the hospital gynaecologist, Doctor Alice, she happened to be walking in for no particular reason. So Sam (the midwife), asked her whether she'd take a look at me. She just stared at the monitor and then after five minutes she said, 'That's a sick baby. We've gotta have the baby now. She's not gonna make it. You're not gonna make it unless we have the baby now.' Then the Doppler went silent.
>
> They pressed code red. And they actually ran with my bed… and this nurse came running towards me saying, 'are you the one they pressed code red for?' And I was like, I didn't know - what's code red? The guy pushing the bed says, 'yeah, she's the one. She's the one.'   And she said, 'ok honey, just relax.'   She pulled my dressing gown aside. And started swabbing me as we were running. They were putting me under general anaesthesia even before putting me onto the operating table. Then they practically yanked her out.
>
> Nidhi was nearly two months early – she was only 31-3!

These stories flow rapidly. Adita seems at ease as she tells me, a stranger, this story while I cuddle her baby to sleep – she only interrupts the flow to explain how Nidhi loves to be held. These initial stories tell of Adita's own experience of care, rather than of Nidhi – yet she begins with these stories deliberately. There are several health professions involved in this story – midwives, doctors and nurses. The situation clearly became critical – with emergency procedures initiated. At the time Adita could not have known what any of these procedures meant – she laughed as she recalled being asked about the 'code red' – there is irony in the professional asking her, the focus of the emergency call, what was going on. Yet as she tells the story she is focused on the outcome – what is happening to me and my baby? For Adita everything is contextualised around this dyad.

Nidhi enters the world – and the story at this point. Yet she remains abstract at this point. All Adita has had is a glimpse of her baby through her post anaesthetic perspective. The midwives are cast heroically – they stood up for her and Nidhi –

this is a marker of commitment to them - that they would advocate on behalf of this new family irrespective of consequences to themselves.

It kept my sanity for that night because that night she was on one side of town… and I was here

The team from the specialist place came to pick her up, because she was too little to be kept where we were. So the first night we were separated.

But the midwives put their foot down saying, 'You don't take her till the mother has seen her.' So they woke me up and said, 'Look – that's your baby girl.' And I saw her, two months prem, with that chock full of hair. Which I think was amazing 'cause it kept my sanity for that night because that night she was on one side of town… and I was here. The midwives also took a photo of her. I kept it by my bedside.

But that first night we were separated

These stories are separated by a breath - it is not clear where one story finishes and the next begins. While the clock continues – the narrative time (for Adita) is centred around her baby – everything is measured in relation to Nidhi.

She was just down the corridor

The next morning… within 14 hours of her c-section I was standing on my own feet having a shower because I just had to get over to see her.

And the next day, in the afternoon they transferred me over to where she was. She was just down the corridor. I think they were also really sweet to me because I had a baby in the special unit

We are now ten minutes or so into the interview. Adita is articulate in her description of the events around the birth of her daughter – but she has only just gotten to the part of the story where Nidhi and Adita are together again. I wonder, how much I should coax and direct? How do I allow this to be Adita and her family's story, and yet get it to be a story about having a child nursed in hospital? This brief story offers a glimpse of the relationship with the nurses – they are "sweet" – but Adita recognises the tenuousness of this situation – their sweetness clearly felt conditional.

I try to trust the process – Adita has read the information sheet and we have discussed my area of interest – she is telling the story she wants to tell, and I am here to listen. As the conversation continues, Adita repeats the idea that this experience was 'difficult'. This is her word. I impose myself into the thread of the conversation – "you've said several times now that it was a difficult time – can you tell me more about that?"

And she said, 'sorry, you have to go.'

I was very upset the day we were sent to another hospital across town. I was expressing milk. The nurse called me up and said, 'Right, could you just come?' Of course I panicked. She said, 'Don't worry, your baby's fine. But you're from a different DHB and you now need to go to that hospital. These are the rules. The ambulance will be here in two hours.'

It just blew my mind, I was like - this is insane; how could they do this to us?

I begged them, 'Why can't you keep her here, the whole place is almost empty. Can't you just keep her here till we get a bed closer to my home? My husband had just started a new job. It's the height of the recession. I've had a caesarean; I can't drive for six weeks. . Don't you know if something happens it's gonna take me half an hour to 40 minutes to get there. It's just not good enough!'

But she came back and she said, 'sorry, you have to go.' And they just transferred us to this other hospital.

And I didn't realise the fact that she was doing well enough for us to leave. And while there is a leaflet in the pack you get, which does state you might have to be moved, you aren't gonna read leaflets and stuff that you can be sent away... that quickly. Your basic focus is just getting her to breathe.

It was very abrupt, like, 'Ok pack your bags, you're going'... so, that was it. I cried all the way in the ambulance.

Adita works at making sense of this situation – now several months later – but cannot, "while the rational part of me understood it I was angry... there was space there." There are aspects of chaos here with repetition of feelings of helplessness. Adita does recall names of staff in some of her other stories – but here it is expressed as "I" and impersonal pronouns "they" and "she". Chaos stories express powerlessness in the face of insurmountable obstacles – here Adita points out she was doing the 'right thing' – "I was actually expressing milk", but even that was not sufficient to stop this transfer she still cannot understand.

As the recall of this story closes, Adita reminds me that Nidhi was premature. She recalls hearing in the news about hospitals sending mothers of new born babies out within hours of the birth. Here though, something that previously had horrified her becomes the story that she could not have – "you just get to walk out!" So the journey she had anticipated becomes a path through the unknown and unprepared for.

But even knowing this didn't make it any easier
You know,
even looking back now,
the most difficult part,

I think,
was leaving Nidhi in the hospital,
and us coming home.

I know I didn't have any choice,
I had to stay sane,
and strong…
and healthy.
But that was the most difficult thing I have had to do.

I did spend all day with her – I used to get there by 730 in the morning and used to come back at 9 o'clock in the night. That was immaterial.

But it wasn't easy,
you know…
it's not just like come home,
sleep and go back.
You have to express milk,
and take the previous day's things,
and…
all that jazz.

And to get there then, we had to leave early enough to drive the 40 minutes across town, drop me off, and then Kapil go on to work.

I was thankful for the time there – Nidhi's she's my only child so I had the luxury of spending the whole day with her - more than twelve hours each day.

And I used to watch the nurses,
with other babies,
whose parents weren't there.
And I saw that they handled them
with just as much love and care as Nidhi…
you know, they didn't ill treat them…
though they were left there defenceless.
And I saw them handling each child
according to their case histories,
each child different from the other.

But even knowing this
didn't make it any easier –
each night I left without her
felt like I was abandoning my baby.

Here Adita alternates between narratives of quest and chaos. The story threads through the events – and the physical outcome is the anticipated one – Nidhi is fine. This is complicated, however, by the loss of control and uncertainty about whether what she did was right. Adita's language seems tentative as she tries to validate her actions – "I can't help it… I had a c-section myself… I couldn't stay… I

would crash." Despite these being more than reasonable reasons to self-care, it feels as though she is trying to convince me (the audience) that she did the right thing.

This narrative weaves the dominant cultural discourse of children as helpless and vulnerable (Berman, 2003) with cultural expectations of mothers and parents (Lindemann & Lindemann Nelson, 2008). Adita highlighted the sacrifice she and Kapil had to make to drive across town to see their baby "more than twelve hours a day." The babies are pictured as defenceless and vulnerable to abandonment. The parents are vigilant, they watched the nurses and judged their competence before they would go home. This 'checking out' of nurses' competence and manner is common in premature care units (Obeidat, Bond, & Callister, 2009). This story is augmented when Adita describes her mother phoning from India and checking that the nursing staff were 'good enough' to be caring for her grandchild – even needing to know the name of the nurse working each night. The societal expectation of families to be protectors of their infants is played out within the hospitalised setting. This is clearly a tension for parents who, in most other contexts, would determine who had any interaction with their baby. Here there is no choice about which nurse cares for Nidhi – or even where that care is delivered. Establishment and maintenance of trust between families and nurses is fundamental – yet always a work in progress (Dickinson et al., 2006). Adita's response is vigilance and oversight, though it is not apparent what would happen if they had not been satisfied. She compares the care of the three places Nidhi was moved between and differentiates the approach of each facility. She describes nurses who come in and watch the monitor and those whose approach is much more matter of fact and baby-centred. The irony is that while staff monitor the interactions between neonates and mothers, this mother is similarly monitoring them.

Adita gives an example of an interaction she has in the tea room with another mother. This mother is frustrated at the staff for hovering and telling her what to do, "I know how to do this. I don't need them standing over my shoulder." Adita's solidarity is with this other mother – speaking in the first person for her, while acknowledging the vast difference in mothers' needs, "I knew zilch about babies." Adita accentuates the need for personalised approach, where 'normal' is different for each parent (Water, 2008). I ask her to expand on what it looks like when it works.

…and you know, she's out of duty

There were lots of nurses; and you get to know lots of them when you spend so long there… lots of them really skilled and loving working there – it showed, you know. There was me, I had been to one antenatal class. She was two months early and I knew zilch about babies. And the nurses would come with lots of things to teach… I enjoyed that. But it was more than that – there was kindness – and love.

I remember one of them… I was looking out for woollens for Nidhi… and remember, I was in a hospital on the other side of town … I didn't know that part of town at all.

The nurse tried to explain where this wool shop was, but she got kind of confused about it and wasn't sure. Apparently, after her shift, not on duty any more, she drove out of her way to go and see. Then she calls up the unit, and asks for me to tell me, "I went to see where that shop was and it's there and they're having a sale so you might like to pop in when you can." That was so nice.

I guess there were a few, say the 10%, who… I won't say they were stroppy. I mean, they have looked after so many mothers, so many babies… You know, I think nurses who work with babies need to love what they do, and need to want to be there. I really appreciated that.

This was narrative thinking at work – in order to make sense of the nurses she had seen and worked with, Adita tells a story "there was this nurse…" Adita is clearly taken aback by this level of interest in her and her family, "and you know, she's out of duty" or in other words not being paid to care. This is reinforced by repetition "and she went out of her way… over and above the call of duty" highlighting the significance of this moment – care is evident when the nurse does more than 'just their job'. This seems to shift the relationship to one between two human beings rather than an objectified patient/nurse dichotomy. But then immediately this story is contrasted with the next.

That was quite confusing, especially to someone who's struggling with it

I had read as much as I could find about premature babies. So it was such a big step when I started to breastfeed Nidhi. I really wanted her to be breastfed. Plus it was the biggest step towards getting her able to get home.

I wanted her to enjoy it. My mum never forced me and my sister to do anything - We were never told, 'you must!' She always encouraged us towards things. I grew up like this. So I didn't want Nidhi to get traumatised by forcing it and then have her hate it. I was not keen on putting her on the bottle. But I didn't think she was quite ready – I mean, I would put her to the breast and she would be completely disinterested, like, 'right, now what?'

> I found the nurses quite confusing, especially to someone who's struggling with it. Some were like, 'she is 34 weeks gestation – she can breast feed.' One made me feel a real failure, 'no. You need to do it this way.' Another nurse came on duty and said, 'oh she's 34 weeks gestation, she's too little.' So some said the sucking switch in the brain comes on at 33 weeks, others 34 weeks. And I'm like, she's too little.
>
> I know they were doing their jobs... pushing me... when they felt that they needed to, and perhaps I was a little bit frustrated, but the confusion made it hard when I had to depend on them

This story accentuates the 'doing the job' – needing to makes sense of the confusion by justifying the confusion. Adita's speech through this story is full of pauses, "I was starting to breast feed her... and... I thought that she was just not ready, because she was very little... and... just that urge to suck was just not there." The pauses create spaces to think and reflect – that even from this vantage point of her own living room, there are aspects that do not make sense to her – as though 'could no one see what I could see?' Adita even uses language she will have heard from the nurses, such as "switches" not turning on yet. Adita's story acknowledges the professional role of the nurses "doing their job" – yet the effect of this approach left her feeling "I was boxed in a corner."

The narrative device of argumentation (Adita's own experience of growing up with her mother) is included to justify her understanding of being a mother. Her cultural beliefs are that to be an effective parent is to work with a child. This value is challenged by the approach taken by staff, causing her distress. Darbyshire (1994) found that parenting in hospital presents particular challenges. In this context, Adita is still establishing her parenting practices, yet finds little room to do this with the professional approach taking precedent.

Adita acknowledges the challenges of working with all the different approaches of the different nurses "it depends on each nurse. If someone had the brisk persona... I would hesitate to talking to that person" Adita also, however, asserts herself in there "get your facts right ladies!" – but this position of strength seems only available now – and were not her words at the time.

I ask whether the care was important. Adita insists it is the axis on which all else depends – that it was what made the experience copable.

> ### *... it was a good thing that she did what she did*
>
> It mattered how the nurses spoke to me - some nurses are firm with me and... I'm glad they were, at certain occasions. I think it's also difficult for a

nurse because it's quite tricky – sometimes you do things that are good for the baby, and the mother might not always see it.

There was this time, about four days before she's about to be discharged. She was on just the apnoea mattress… and I was sitting in front of her and reading… and suddenly the apnoea mattress alarm goes off. And I went into such a, you know, I just lost it. And there was this nurse who was actually feeding a baby in the next cot… she left the syringe and she came to me… she didn't touch her… she switched off… the beeper, cause I was just… I was going, 'what's happening, what's happening?'… And she said [firmly], 'look at your baby! You need to stop looking at this monitor… and you need to start looking at your baby. Look at her… not blue around her mouth, she's breathing, and she's got colour in her cheeks… and she's fine… and you need to look at that. You need to stop that!'

Adita's performance of this story is dramatic – the nurse's exclamation is loud and abrupt. I ask "So how was it being spoken to like this?"

And I needed it, at that point in time… and… it was a good thing that she did what she did. It's like one of those times you go into a frenzy and need someone to slap you. But then I… I actually stopped and… I looked at… the baby.

It was just that she had wriggled down the cot and the apnoea pad wasn't picking her up

Adita reflects further on the interaction and being spoken to so abruptly. She justifies it by comparing it to extremes, "… I mean, she didn't tell me, shut up! Why are you screaming?" She also recognises the expertise of the nurse in seeing things that were not apparent to her. The interaction was situated in relation to Nidhi – because the net effect was to her baby's benefit, the manner of the delivery seemed less important. This story demonstrates the ways that families appreciate care that is child-centric – that their child is important – and that is all that counts.

Of some importance however, this story occurred just days before being able to go home, yet Nidhi continued to be monitored using technology not likely to be used at home. There are therefore competing narratives at play here which add to Adita's insecurity. One narrative is of normalisation and home; the other is of vulnerability and requiring technological surveillance. Having watched staff behaviour over the months of this hospitalisation, Adita has been enculturated to trust the technology over her own assessment of her baby. With only a few days before being sent home this seems a source of some anxiety for a mother who is already terrified at the thought of leaving behind institutionalised care.

Adita continues by moving on to a clear restitution story – with a tidier outcome.

And it calmed her down. I'm glad he listened

In each of the places we were, and I don't know whether all nurses get this training, but lots of them kept telling me that I was her advocate; that they were on shifts, but I'm the constant. Some seemed to be like, 'ok, I'm here for the job, so let's get this done' –they were more like a labourer in a garden – and the others were like the loving gardeners.

Like there's this one day she was screaming for no good reason, and I... I knew that something was just... wrong, you know... and then I looked into her chart and see that they replaced her NG tube... so I asked this nurse, who's on duty; the one who replaced it was on night shift. I said, 'look, she's just crying, there's no aggravation so can you just... have a look and see whether the tube is in the right place?'... and he said, 'uh... I don't think it's in the wrong place', because he... took an aspirate, and it was the stomach contents. I was like, 'ok, I agree it's in the right place, in the stomach, but it might be just... up a little, you know, where the flap is, it's not gone down a bit, and that can be irritating her'... so he said, 'alright'... and he... replaced the tube... you know... and he said, 'look, you know better, I've just come on a shift, so... if you think, that is what, let's just do it, and let's see whether it calms her down'

And it calmed her down. I'm glad he listened. He didn't argue. It's that love that made that plastic box a bed for Nidhi... otherwise it's just... a box

This story demonstrates some change in Adita's positioning of herself. Unlike the previous one, in this story Adita describes herself as having more agency and power. She looks into the documentation and is able to read when the "NG" tube was last changed. This documentation is kept at the cot space so Adita is readily able to read it. What is different is that she seems increasingly empowered to advocate on behalf of Nidhi. This confidence remains tentative and less than assertive, "can you, just...ok, I agree... you know... it might..." Adita seems to have learned that it is better to suggest and prompt than to come out and demand for change.

The response of the nurse is held out as an example of care – it is an acknowledgement of her assessment skills as a mother. The notion of family as expert is implicit in family centred care theory (Shields, Pratt, & Hunter, 2006), but in a neonatal unit the expertise of the family is often still developing (Aaraard & Hall, 2008). While it seems the nurse was certain the tube was fine, by following Adita's lead, the nurse demonstrated a level of partnership and power sharing in the decision making of care.

Adita makes use of several metaphors here, trying to capture what it was that made some nurses effective in caring for her and Nidhi. Metaphors never capture the whole, but Adita spends some time comparing the loving gardener to the labourer

"who hates weeds… He's not going to be bothered about, oh there's a small plant there that's not a weed, I shouldn't hack it, I should go around it, you know, he's just gonna take it and go whoosh." This is not gentle language – there is an unstated implication that some nurses are not as gentle as she believes is appropriate. And yet the care from nurses who approach their role as artisans rather than technicians seems to take on almost magical qualities, "she is there because she has to be there… and to me… it's that love that made that plastic box a bed for her." Clearly Adita had also experienced care that made the high technology environment less intrusive and but a tool to provide love to her daughter.

The talk of home prompts me to ask about the rest of the family. Kapil was not able to be there for the interview – so I ask Adita how it was for him and for the rest of their families.

They made him feel a part of it

Kapil had to go back to work. He found that hard… he found that very, very… painful. He was so involved in her care. He changed her nappy before me; he fed her first before me; he did a lot of things before me and the nurses encouraged him to do it.

We were impressed with the nurses there and the care they took - they are a whole different breed. And he knew I was there during the day. He still came every evening… to… he spent time with her. The nurses were like would always say, 'oh dad! Dad's come!'

But he needed to know who were going to be looking after her. He needed to know who was there when we weren't. That's why we would wait until the last shift switch had taken place… and we met her night nurse… we would never leave without meeting her night nurse. We just needed to know if Rachel is there, or it's Natalie, you know, or it's whoever looking after her tonight. Kapil made that extra effort to get to know each of them.

And actually Kapil is the one who showed me how to change her nappy, and not the nurse.

Adita tells of Kapil as intimately involved with the care of his baby – and highlights the nurses who notice this and include him. In these types of units there are typically many more women than men – something Adita would have noticed. Kapil was not in the interview to tell his own story – but here Adita recalls the way that vigilance over staff was not exclusively the position taken by the mother. The nurses who stand out for them have names – even months later Adita is able to name nurses whose care meant they were able to go home confident. This speaks of a significance of relationship where the care delivered met the family's expectation and hope.

The family unit is also accentuated here by Adita – she highlights that it was Kapil that taught her about nappies. Their identity as a family is beginning to be more established as they become more confident in the tasks associated with the role.

I sense Adita is coming to the end of her story of this time, so ask her how she might sum up the experience. She immediately theorises and paraphrases Nietzsche...

And that's how you feel

The whole experience was such a traumatic period. But I think overall I would say, what doesn't kill you makes you stronger? Scary... very frightening, very, very frightening...

There's a story... it's Indian. There was this ruler, a maharaja, this was the time the British were invading India... and he was the last of the kings to fight the British. There was this fort, and they called, and the fort used to close at 7, they used to close the doors of the fort at 7 every evening... and the fort was high up on this hill. So every day this milk woman from the village would come, she would bring milk, and go into the fort... and the guard on the night duty... saw her go in, but didn't saw her leave... and next morning... when he opened the gates again, there she was... so he said, 'look, I didn't see you leave... so, how come, I assumed you were spending the night,' And she said, 'no, I climbed down the hill.' He said, 'from the fort? Impossible.' And she said, 'no, I did.' He said, 'no, you have learned to get out of the fort in some way, so you have to be a traitor.' And they started to persecute her. When Shivaji, the maharaja heard of it, and he said, 'bring her to me.' So he asked her, 'can you show me how you did it?' So she went down to that hill, to that section where she climbed down from... and he said, 'ok, so climb down again.' And she started shivering, and she said, 'no I can't.' He said, 'but you did it that night.' And she said, 'yes, because my baby I'm feeding was crying in the village for her feed... and that was the only thing I could hear... and I did it, but now it's daylight, and I can see this, and I can't hear my baby cry, and I can't do it again, I will die if I do it... it's just like that.' At that point in time, you will climb anything, and everything, but if you look at it in the cold day of light, later on... you feel, how did I do it, and you don't think you can do it again. He actually rewarded her very well, and that part, that part was raised higher up, and that's how that story went about, how the fort was modified. So... that's the story of the milk lady. And that's how you feel.

It's nothing like when you get a full term baby, you take it home, and your main fear is, 'o god, I don't get any sleep!' No. Here you're like, 'o god please just let her breathe'

The story is not of her own experience – but is another metaphor for her experience. Adita seems to identify with the 'milk lady' – who will do anything for her baby – even though it feels like it is against almost insurmountable odds. In the story the environment which is meant to protect actually becomes an obstacle between mother and baby. Adita recognises the need for the hospitalised care – she wants

her baby to keep breathing – but is also pointing out that some of the interventions feel like barriers to the connection between mother and baby.

The interview was over an hour and a half, with the conversation only ending when Adita demonstrated she was clearly 'finished' with, "so... yeah..." There had been long periods of theorising and description. On reviewing the transcript to look for the stories, many seemed not focussed on experiencing nursing care. This was not for want of prompting – "can you think of an example... can you think of a time when this happened..." However they seem to be doing the work of stories – making sense of what happened – the storyteller's agenda.

There are clearly the 'shock and awe' stories (Carter, 2008) – Adita begins with a story of seeing no movement in her uterus on the ultrasound, being 'rescued' by a riding jacket and boot wearing specialist who 'finally gets it', and having Nidhi literally 'yanked out.' Knowing that the baby only scores 3 on the Apgar scale, taking ten minutes to get to the full score of 10, only adds to the sense of drama and stress in this account. Then at the other end, Adita concludes with another dramatic story – this time not her own, but a story from her own cultural heritage. This is a story of quest (Frank, 1998a) that seems to be positioned as a metaphor for Adita's own experience of discovering strengths and resiliencies that she did not hitherto recognise within herself. With these two stories, Adita provides 'bookends' to the stories of having a child nursed in hospital. The orientating preface demonstrates that the stories that follow represent but one brief episode of this family's life; while the concluding story provides the 'moral' or meaning within which the stories should be heard.

The thread changes once Adita begins talking about being there in the hospital with her baby, now as a new parent. The talk through this section of the transcript is full of pauses and incomplete sentences – "the height of recession... so... Kapil took a week off the week she was born, but after that he had to go to work... and I... I mean, even if I was driving, I was under caesarean, so for six weeks I couldn't drive... so... I was just shattered when they transferred... I was so upset, oh, I was... and the fact that, as I said it was so difficult to leave her in the night." 'Difficult' is the recurring idea through this section – but there is no clear narrative of what that difficulty looked like. The talk is descriptive, augmenting the snippets of stories – offering more impressions than stories. This lack of clear narrative flow provides

some evidence that the quest narratives that bookend this interview were not adequate to describe all her experiences; that there continues to be a sense of chaos and disempowerment as she reflects on that time. Adita's own sense of agency seems tentative and faltering as she is unwilling or unable to challenge the expertise of the nurses. Even when she does assert herself, it is with questions. She spoke of interactions with other mothers – with the tea room being the space to speak candidly of concerns and frustrations rather than directing them to the nursing staff.

It was important to Adita that their individuality was noticed. Even as she told the story to me, Adita highlighted the 'specialness' of her baby. So for example, she described how Nidhi's feeds slowly increased a few millilitres at a time – not like "full-term babies". Nurses who responded to them as unique and particular where named and remembered – while the others became "they". This is a significant memory for Adita – she disclosed that they are unlikely to have any other children – so this experience is formative in her development as a mother.

The spaces of care were also important to Adita – in her experience they were shifted several times to different sites across the city. This influenced their perception of care as the ways that the message was delivered added to Adita's sense of isolation and vulnerability.

Kelly and David's story

Titles	**Temporal flow**
	We did both decide and it felt better 'cause it was us making the decision
	I think I changed their first nappy
	I was actually… likewise felt a bit pissed off… if you can make something a little less challenging for… we're talking little boys
	It was fine, but it was just that, it was that awful moment, and I'll never forget it

Orientation

Kelly, David: Taylor; Mitchell; Chris

This is the second interview. I am a little concerned as this is another family who have had premature baby nursed until able to head home. It was not the scenario I had had in mind when thinking about the research – but it is the families who have generously volunteered to tell their stories. One significant change is this time there are both parents here – what I had hoped for – interviews involving more than just the primary care giver, to get a feel of the impact and experience of families. We have chatted for a while – and I got to read a story with Taylor, the twins' three year old big sister while they were prepared and put to bed. Then it is Taylor's turn to head to bed, mostly happily, as the adults turn our attention to the agenda (and digital audio recorder) I bring. It has been a warm welcome and lovely to be able to help with the evening routine with the children. Everyone seems comfortable with each other and the fact the conversation is about to be recorded.

We did both decide and it felt better 'cause it was us making the decision

The main thing we had to do at that time was make a decision as to whether… we were gonna let them come of their own free volition or… give them steroid to, to get their lungs developed and all that, cause they were nine… nine weeks prem… yeah, so, so lungs weren't quite there

The decision was, let's get this over and done with or let's give them a better opportunity

Next morning… I actually started having pains… and they took me through to delivery suite… when they realised I was 4cm dilated at that point… they… uhm, did scans of the boys, made sure they were all fine… I remember that, making the decision about whether we go ahead… and just wait, or whether we stop the contractions with drugs and uhm… wait for the 31 weeks which was still 48 hours away.

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> I seem to remember I was feeling a bit... like I needed to make that decision right now...and they were just kind of standing there waiting... and I think you said to give them, to give us a few minutes to talk about it.

Yeah, while they were drawing up the drug

> Things slowed down a little bit... took all day... to get it under control

I am drawn into some dilemma with this story – Kelly and David have read the information sheet, so they know I am interested in the experience of having a child nursed in hospital. Yet the story that emerges and is further augmented and described is the journey of delivery of the twins, Mitchell and Chris. Storytellers start their stories where they believe the beginning is. This story forms a bookend for the stories that follow - it is important for them to start here because this is part of the boys' story. Kelly and David have conceptualised their family as including the twins, even before the twins were actually delivered – "these were my babies... I needed to know it wasn't going to have an impact on the boys." Family, with all the associated responsibilities and roles, clearly existed prior to the birth of the babies.

The story was augmented with comparisons to the birth of their first child, Taylor. This theorising, or trying to make sense of the situation made it difficult to pick out a particular narrative thread – there were many stories intertwining: a subplot of a niece trying to advocate on behalf of her auntie; some people listening while others appeared not to; and the thread of Kelly trying to affirm her knowledge and experience. This could have been chaotic – yet there was a constant interplay between Kelly and David, each picking up from and 'correcting' the other.

This story of the twins being born seems to be about wanting to be heard and acknowledged. Kelly and David each portray themselves as seeking to gain agency and voice, yet having that attempt rebuffed or diminished. Similarly to Adita's story, there seem to be competing discourses – that of the professionals (and experts?) and that of the mother and family – and whose will be heard.

In real time I wonder how I will be able to make use of this story, but want to remain focused so am happy to reflect that it is still the story of parents and their child in hospital. I vacillate between thinking I should be more directive and trusting the process. I trust the story. Time will tell. The boys are born – and present in ways that make them more apparent to the rest of us and perhaps now able to participate in the narrative...

I think I changed their first nappy

Mitchell had CPAP for about four hours... ... just gave him a bit of air just to help him breath. It was mainly Mitchell. Chris had it for a very brief period of time and that was... his lot...

From that point onwards I was involved, you know... I was like, you want me to change this kid's nappy? I mean, you know, there was nothing to him, you know, that was... the smallest nappy they had was too big for the little bugger... you know.... and how, how do you do it, you know, they just said, you know... do it like you normally would, and they got me involved with the feeding straight away. The kangaroo cuddle was... was huge... they just chucked a blanket over me, you know, just so he wasn't too warm and I was comfortable and that sort of thing

You pretty much did everything first with the boys

David is keen to tell of his part in his boys' early life. And there is a change – David tells of being included and empowered to participate. Fathers often focus primarily on the physical needs of the baby and mother and take the lead of the staff in their involvement with a premature baby (Lundqvist, Westas, & Hallström, 2007). Kelly spoke of her fears for David in this high technology environment, but David, having been shown around prior to the boys delivery, seems quite at home:

You very quickly got used to the environment, it's sort of reminded me of an old school lab, or something like that... but you know... they... they told you the rules, they let you know that you had to wash your hands and all that sort of thing... and... you just mucked in... and again, you know, it was about your boys... getting them, well giving them, well, the sense of family that they required

Even with situations that might otherwise have been uncomfortable, such as taking your shirt off for a skin-to-skin kangaroo cuddle, David tells of being made to feel comfortable – and interestingly "it's not the sort of thing you expect to do in a hospital." The narrative though is of nurses as "they" almost as bit players to the story David asserts – me and my boys. Clearly being able to BE a parent is the important aspect here. So while they are not clearly spoken of, the nurses have ensured that the space the family find themselves in is conducive to their participation in the twins care. Fathers also tend to be sensitive to the behaviour of nurses toward their babies (Lundqvist et al., 2007). By providing care focused on the boys they have become less visible in the story, yet enabled David to also focus on what is working.

Kelly continues the conversation with description of what happened and theorising around it. She found that the nurses coped with her being a nurse and allowed her to be a mother first, not presuming shared understandings - "so I am not sure how you did things where you worked, Kelly, but this is how we do things here". She

gives the example of administering sucrose syrup to the neonates prior to unpleasant interventions. However this sparks David's memory of an occasion when this was not done:

> *I was actually… likewise felt a bit pissed off… if you can make something a little less challenging for… we're talking little boys*
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> You know, I really wanted them to have sucrose, before their blood tests, cause that was important for me because of the knowledge I had about how it worked with pain relief, and they would say, yes they have, and, I had seen the way we had done things, and I wanted to see how they did it
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> There was the one time though that they took a blood test and they didn't actually offer it… one of the ladies did, and we were a bit miffed about that
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> This lady had done a heel prick thing… and hadn't offered anything… and I remember Kelly getting a wee bit… oh why didn't you ask, why didn't you think to offer, why didn't you, you know… which I felt was fair enough… They were very, very fragile, particularly when, you know, when they came out… initially, it was like… holy shit… what are we supposed to do with this

Kelly did not initially recall this – but for David, "when you were talking about pain relief… I remember a time when…" This is one of the benefits of group interviews (Eggenberger & Nelms, 2006; Hyde, Howlett, Brady, & Drennan, 2005) where the conversation can trigger memories that might not otherwise have emerged.

The story is about providing comfort during a painful procedure. The parents have positioned themselves as advocates for and protectors of the twins. David described how small the boys were and how worried he had been for them, which seemed to call on him to be vigilant on their behalf. There is often tension with nurses as family/nurses make sense of each other's roles (Koniak-Griffen et al., 2006; Young et al., 2006b). The nurse ("this lady") would have undertaken a blood test as an intervention for the good of the baby – yet it was experienced as a violation of trust because she did not do it as the family wished. Lupton and Fenwick (Lupton & Fenwick, 2001) found that nurses and mothers often disagreed as to who was best able to care and protect the neonate. Here David is 'a bit miffed' – but continues to recall the incident nearly two years later.

This lack of clarity around roles and purpose seemed to prompt the final story. Kelly kept asserting throughout the interview that "most of the nurses were really good…" but as the conversation lulled to signal we were heading to the end, another story emerged…

It was fine, but it was just that, it was that awful moment, and I'll never forget it

> When we were up in the nursery...and, uhm... they were fine... I knew they were progressing quite well
>
> I had actually said to them... uhm... I was in no way gonna keep asking when the boys could come home
>
> And then, they had said to me, Oh, we can get them home, was it tomorrow or the day after, I think they gave me 48 hours notice... and I actually said to them, 'will you need me to stay... beforehand?' They were like, 'no, no', it was fine. And I was making, three trips a day, at that stage
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> Then at the last minute they said to me, oh, well you can go home tomorrow, but you'll have to room in tonight.
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> And I was by the front door... on my own with a single bed, two cots beside me jammed up against the basin and me, and I was to spend the night there alone with the boys, on my own and feed them, and there was no space... basically was left to it, just go for it, and no help.
>
> Packed all my bags as I should the next morning, and was all ready; ferried them back down to the nursery, cause I didn't know what else, no one had explained to me what to do, so I assumed that's what I had to do.
>
> When the doctors came around to do their round, and I was standing there, they turned around in front of the doctor and me and said, 'oh this is the pushy mum, she wants to know if she can go home.' I was actually in tears
>
> Found out later, it was probably a bit of a joke... did not take it as a joke... was not taken as a joke

Kelly is a little upset as she tells this story – it seems to undermine the previous positive experiences. As she tells the story she has little agency or influence in what happens. She had believed she had a positive relationship with the nurses – yet this incident caused her to doubt that. For Kelly it is as though her expertise did not count for anything. She acknowledges that she has 'played the game' of not being pushy or demanding, anticipating that this will gain her the goodwill of the nurses. Then at the final stage she feels like it was withdrawn. She describes the space as "no space" – both physically and in regard to the attention she received at that time. While the story is told and what happened is communicated, the performance marks it as a chaos type story – it is a story of passivity and disempowerment with no outcome of note and no lesson learnt. It is framed by attempts at making sense of it – but ends with doubt that this was in any way a joke.

The interview was much longer than appears from these stories. There are long stretches of theorising and description – but not with clear markers of a 'story'. This could be evidence of chaos type narratives – where the storyteller/s struggle to

find meaning within the recollection of what happened. And there is evidence of this, with stretches of rapid fire broken patterns of speech:

> I can't remember... but basically they put them together, and I tell you what... that feeling of knowing, it's crazy but the feeling I knew... when they were together when I left, made such a difference... and it was the fact that they had each other when I wasn't there, cause it's the hardest thing to leave them there, knowing that I... [long pause] and still it was hard... I still feel awful... but to see them together...

This reflection came as Kelly described how important it was to have the twins regarded as important both individually and as twins. She cannot give words to the feeling of seeing them together in a large cot "but to see them together..." pausing to check if she had communicated the intensity of this moment. The next sentence, however, is of returning the next morning to find them separated again. Kelly seems to accept this – but there is hesitation in that acceptance, even now – "it would have been nice to have seen them... together more, but... maybe that would have been...[pause]" The contradiction in expectation and experience seems to be glossed over, recognised, but too difficult to reflect on in depth.

This seems in contrast with David's experience. Once he was confident in their ability he was able to feel more confident in the space - "For me, 'cause I'd have a joke with them, I'd give them shit all the time". Fathers often seem to be more at ease trusting the health professionals (Obeidat et al., 2009). This gender difference is viewed retrospectively however – and is filtered through expectations of masculinity (Bottorf et al., 2009). So did David engage differently with staff due to wishing to be viewed in a particular way (for example friendly and 'chummy') or did staff engage differently because he is male? He may also have exhibited this type of humour as a deflection from his anxiety. It is impossible to extricate the environment and habitus (Frank, 2002b; Lo & Stacey, 2008) of the all those involved (Riessman, 2002). Needing to be liked so that your child is well cared for is another well documented factor (Fenwick et al., 2008).

The flow of Kelly and David's story is quest-like – they had a significant and unexpected challenge and became a stronger family through it all. But there is also pain evident here – nearly two years later, the story that Kelly chooses to punctuate the interview with, is a story of being misunderstood and devalued by those she had worked so hard to form an alliance with. The telling of this story is a way of trying to make sense of that chaotic and 'difficult to make sense of' episode (Frank, 2004b).

Each of the stories told, Adita, David, and Kelly's, all conform overall to the socially expected unfolding of healthy baby following pregnancy. However having a premature baby was unexpected and therefore somewhat unprepared for – requiring new stories and meaning making (Palmer, 2007). Both families undertook this by seeking alliances with staff and fitting in. For example Adita spent often over 12 hours a day in the unit, even immediately post c-section – presence being one of the key behaviours nurses note as evidence of being a good mother (Fenwick et al., 2008). Kelly positioned herself as "not one of those demanding mothers", playing down her own expertise and experience of working with premature babies. This dissonance between the person the mothers believe themselves to be, and the person they sought to project must undermine genuine relationships and care. It was when there was synergy that the families noted caring. A nurse phoning off shift to pass on information about a baby knitwear sale is more akin to sisters sharing local knowledge than professional/client. But this counter-story – one of intimacy over detachment – is what is held up as care of note.

The families all affirmed their place as parents – they all strove to establish their identity as 'good parents' based on their own values and cultural beliefs. Some of the tension evident in the stories is where this identity construction was in constrained by the environment and nurses interactions. Each of the families tried to realign their experience to the 'normal' families - "because, it's your healthy baby, you know, you're healthy, and you're baby's healthy, you don't know what a miracle it is by itself, you know, you just get to walk out... whereas we didn't get to just walk out" (Adita). Wanting to be the mother – and do the mothering – is the role mothers work towards (Lupton & Fenwick, 2001; Obeidat et al., 2009) – the story they want to live. For these women, the chaos stories seem to emerge when others stand between them and this role.

Care was clearly evident, however. When David trusted the competence of the staff, he felt at ease in the environment and able to relax from hyper-vigilance. Adita spent many hours in multiple units and was able to compare them – she expressed care in stories of nurses listening to her perspective. Kelly had the additional challenge of another child to care for, but felt care when she watched David included and acknowledged – that their family was respected for who they were.

Illness and hospitalisation interrupts personal identity and the narrative that supports this (Frank, 1998a). These stories have demonstrated the ways that mothers, fathers and grandparents seek to regain their agency within uncertainty, and the ways that this is facilitated by nursing care. Chapter six explores the stories of families who have children admitted to hospital acutely unwell or injured. Families continue to evolve in their identity along with the growth and development of the children (H. Lindemann Nelson & Lindemann Nelson, 2008), so while in this chapter, these parents were 'becoming', in the next chapters the families are 'evolving' in their identity as parents and family. This is the context for their experience as they enter the world of professionalised healthcare with a hospitalised child.

Chapter Six

Nursing Care when a Child is Acutely Unwell/Injured

> "At first stories simplify complexity for humans living in a world that can overwhelm us with perceptual possibilities, but then stories turn around and complicate reality. Translating reality into a story underscores reality's openness to multiple interpretations and its inherent morality" (Frank, 2010b, p. 160).

Introducing the context of their stories

These stories range across several cities and hospitals/healthcare providers. Primarily they occur in public hospitals. New Zealand has a socialised public healthcare system – whereby if someone is acutely injured or unwell there is a public hospital somewhere nearby. Some of the stories occur in private facilities – but these were visits for interventions that had been subcontracted there from the public system. All the visits were unexpected (acute) except for one that was an elective procedure following an injury. They were all episodic; that is, with no particular expectation of ongoing hospitalisation required. For this reason these stories were grouped together.

The ages of children in the stories range from babies through to adolescents. This wide range is part of the range for admission to paediatric services – normally up until a child's 15th birthday.

Because the visits were unexpected, the routines and environments were unfamiliar to all the families – though for some families this changed quickly after several admissions. In one family the mother continues to work as a Registered Nurse, so the environment was familiar to her more so than the children and other family members.

Barb's story

Temporal flow	
Titles	*So yeah, completely caught between a rock and a hard place with no where really to move*
	Every single time, it catches me out when I'm putting my signature on the consent form
	Those moments between them saying to me, "Jed needs to be here." And him actually being here. They were like the longest minutes of my life
	Then I was just a little bit anxious but not like… I mean, I slept. I trusted them
	The family routines are totally disrupted. Like everything revolves around hospital…everything

Orientation

Barb, Jed: Lynda; Ruth; Richard; Judy

As with many of the interviews, finding a time that worked was challenging – in the end it was Barb who called it, "why don't you just come 'round on [this particular] afternoon – I'm not sure who will be there, but let's just do it." I was aware I was adding more to their busyness – but was pleased that they had taken control of the time and place. I arrived at their home hoping I had transcribed the house number correctly. I had. Jed was not there at this time, Barb apologised, as he had had some work come up. I feel bad that there is a sense that an apology is even necessary, but assure her that I just appreciate the opportunity. We re-cover the information sheet over coffee and chocolate biscuits, the biscuits enough to bring Judy and Richard in to the conversation, for a short time at least, before they disappear off to much more interesting things. We adults make a start on the topic at hand.

> **So yeah, completely caught between a rock and a hard place with no where really to move.**
>
> Lynda had 3 days in hospital, out of town, completely as surprise. The very down side of being in hospital away from our home town was that I was breast feeding Richard and they wouldn't let him stay with me.
>
> Lynda contracted a very severe kidney infection while we were camping, while we were tramping. While we were driving back to the nearest city before our drive home we got a phone call that she needed….they had already booked her into the hospital and we had to go there as soon as we

arrived. She didn't want Jed, but I was fully breastfeeding Richard – he wasn't on any solids.

Lynda actually had a really good time. Like the next day, once the antibiotics had really kicked in she was actually fine and she was pretty fine and thinking the nurses were wonderful. So no, she has some really good memories of that like jelly and ice-cream and the nurses were wonderful to her

Barb starts the recorded talk by framing all that follows, "We've had all the children in hospital." Even in this there is a sense of shared experience. It is not, "the children have all been in hospital" – which would leave the ownership of the experience with the kids themselves. It is "we" - family and "us" is evident from the beginning. Barb conceptualises their experiences around their identity as family.

This first story is from several years ago. As I listen I know that it is beyond the time indicated in my research proposal. I also know that that time frame had been somewhat arbitrary – and from wondering how long ago it might be reasonable to expect a family to remember. This thinking was also from a time early in my understanding of narrative – when I was still imagining that memory gave an 'accurate' reflection of the experience – a window giving view of the episode. My understanding has moved. Anyone recalling an experience is a storyteller. They are not the same person as the person who had the experience – they are now an evaluative and remembering self (Kahneman & Riis, 2005). All experience stories are about the past, and not the past itself, irrespective of time (Ellis & Bochner, 2000), and therefore time is less important than the meaning being conveyed. So rather than interrupt and redirect, I listen.

Barb's recall is fluent.   She remembers the family holiday they were on – and the track where they were tramping. The details that are important to the family are still available for telling, "…so the very next day we walked out and took her to a doctor close by, who treated us as if we were complete morons and said there was nothing wrong." This complicates the more obvious restitution story of Lynda being sick and getting well. In chaos type stories the timeline is not straightforward, and one event does not naturally lead to the next (Frank, 2010b). In the interview, Barb's story jumps around the chronological ordering of the events and between attempts at making sense of what happened -"I kind of get why you couldn't have a baby stay with you in the ward... it was just this hopeless situation... we couldn't resolve it; they couldn't resolve it for us... I don't know how they justified it. It was not

possible. It was dreadful." Even with the benefit of hindsight Barb cannot make sense of what happened – it is too 'dreadful' to be tidied up and justified.

There are multiple layers evident here. Barb almost blames herself for the situation. The family had made the practical decision to keep this 10 month old fully breast fed (happily) so they did not have to carry formula and baby food on their tramping trip. With the hospitalisation, however, she feels internal and external judgement over this decision.

> "If this kid had been weaned, if this kid was on solids there would not be an issue. You've created this issue." Oh yeah I felt all of those things, like I'd made this worse by insisting that this boy.......You know. While at the same time having a sick daughter... and she was really sick. This wasn't a little bit sick. She was actually ... [pause]... yeah.

Barb seems to feel guilty for Jed having to drive around the city trying to settle Richard, who has obviously gulped down the milk from his bottle as well as a quantity of air. Society expects mothers to be 'ideal mothers' at all times (Andrews, 2002) – but it is of note that even with hindsight Barb does not resist the expectations. She does not question why Jed did not 'wind' the baby, or feed the baby more slowly (this perhaps being a new experience for them both). She does not fully understand the imposition of rules by the nurses on the ward, but rather than blaming the environment for the predicament, she accepts responsibility. Barb seems to accept the grand narrative of women being able to mother in adversity (H. Lindemann Nelson & Lindemann Nelson, 2008) – despite being in hospital at the time with an acutely unwell daughter. So this story about having Lynda in hospital is dominated by Barb's sense of not being adequate in the situation. She seems to have felt without choice, but carrying the responsibilities, "So yeah, completely caught between a rock and a hard place with no where really to move".

Barb's story seems to contrast with Lynda's experience – it is as though they are almost unrelated. Lynda receives the antibiotics and the next day is eating ice cream with the nurses. These two concurrent narrative threads concern the same child but depend on the frame of reference. From an organisational perspective, this is a successful (restitution) story of a child treated and discharged – and even having fun with the nurses. However from Barb's perspective, in relation to their experience as a family, the story is much more chaotic and convoluted. Even several years late, this story is readily able to be told and continues to contribute to

their identity as a family. And the restitution thread is clouded with the chaos of identity questioned.

And then with a short pause, the next episode in their experience follows. "Next there was Richard when he broke his arm" – but this didn't require any invasive interventions, so "not a great emergency." Not requiring an operation seems to be the trigger for the next memory - "Ruth did go to theatre though".

> ### Every single time, it catches me out when I'm putting my signature on the consent form
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> We were only there for the day but she had to go in to theatre and have a general anaesthetic
>
> She split her head open running into the edge of the couch and her head popped open like a watermelon
>
> I can remember... I got very distraught having to sign away the papers. Having to consent for the general anaesthetic... being quite tearful and quite emotional in the hour or so she was under the GA, waiting for her to come out of recovery.
>
> She didn't stay the night, she just got the stitches in her head and we were out again. But that was huge!

There seems to be a pattern to the stories – the obvious and measureable external events counterpointed with the emotional journeys. This time it is Ruth's turn. Her contribution to the story is limited however: "she split her head open... she had to have a general anaesthetic... she got stitches in her head and we were out again". The impact of the experience is again carried by the mother. This is a less-than-24-hour stay, "but that was huge". What stops this being straight forward for Barb is having to sign the consent form. Clearly this is partly about the anaesthetic, "I know people who have died under GAs. So yeah, I think that's always in the back of my mind." But as Barb adds to the meaning of the story by theorising around it, it seems that this is more about the position she found herself in. She describes the moral dilemma she feels forced into, "If something happened to her it kind of made me responsible because the hospital do the 'all care no responsibility' thing, but I've signed it." In the language she uses, there is no personalisation of the staff– it is "I" and "they" – one mother alone facing an impersonal system – "I think... for them... this is just the procedure. Sign. For me it wasn't like that at all." Families (and mothers in particular) are expected to carry the full emotional load (H. Lindemann Nelson & Lindemann Nelson, 2008). This is further evident in the lack

of description in this story – there are few details of the space or people – it seems stripped down to the only what is essential to convey Barb's emotional journey.

While Ruth receives the necessary interventions, Barb's story seems devoid of care. She does not contextualise the environment or the people – there is no differentiation between nurses and others. The sense of isolation is clear – it is Barb who waits for her daughter to emerge from the anaesthetic – the other characters in the story would all have something to do. She just has to wait. This may have been routine for the nursing staff, but it remains deeply distressing for Barb.

There seems no evidence of a quest narrative – where an illness experience has contributed somehow to the participants' lives (Frank, 1995). Barb augments this story by recalling her own experience of requiring a general anaesthetic for a broken leg. A chaos typology is more evident in these narratives, "exactly that same thing crossed my mind as I signed the papers [for myself]." The system seems not to have changed or adapted to her concerns, and she continues to position herself as somewhat powerless and with limited choice, "but you know that you've got to get your blinkin ankle fixed so there's no other way to do it other than to sign that piece of paper." It may be that in fact there is little choice about the procedures, but this story shows a perception of a rigid system that patients and families must conform to and accept responsibility whether they feel equipped for it or not.

Barb picks up the thread again.

> ***Those moments between them saying to me, "Jed needs to be here." And him actually being here. They were like the longest minutes of my life***
>
> The biggest one though, the scariest, the most significant one was when Judy had a massive epileptic seizure. It was so huge they couldn't stop it. We hadn't been able to control the seizure at home... we called an ambulance
>
> Ambulance took me and Judy, because it was an ambulance we went straight through and they started giving her all these drugs and what not, and nothing was happening, she wasn't coming out of it. They tell me the only way to stop this child from seizing is to put her on full life support. "Right, probably Jed should be here, shouldn't here?" They just looked at me very honestly and said, "Yes, he should." So they let me use the phone straight away and I rang him. They were like the longest minutes of my life.
>
> So they stopped the seizure... she went into Intensive Care

The experiences with Judy in hospital are the most recent and, by Barb's description, the most traumatic. The recounting of the experience from the arrival at the hospital and in to intensive care blur and overlap into one unfolding story. I separate them here to differentiate the spaces and to see the development of the experience.

Unlike the previous stories there is very little theorising here. The events unfold. Things happen. But this time there is evidence of kindness in the midst of the chaos, "they looked at me honestly...they let me use the phone." Barb's story is augmented with further details – she describes her sense of loneliness – despite being surrounded by people,

> Absolutely 100 percent alone. Watching them deal with my daughter. Standing there watching, having pretty much no idea. Them not actually talking to me because they're busy... I was standing at the end of the cubicle that they were in with her and there were three doctors. It was no small thing. Yeah, there were three doctors. I can remember thinking that was very significant that there were 3. It wasn't like there was one. They were really dealing with this girl

This isolation was physical – "Jed is home with the kids and I'm in here" was a phrase repeated several times. This repetition of phrase seems to indicate its underlying importance. It influences Barb's interpretation of events – she is hyper-vigilant over the staff involved in Judy's care – not just who, but how many. While having three doctors intervening could have been reassuring, as in 'my child is getting the appropriate attention', it was also interpreted as a cause of concern – evidence of the severity of Judy's health status. Families left without explanations need to make sense of what is happening on their own, based on their previous experiences.

However, Barb begins to resist the passive role she has described herself taking with the previous admissions, "in the end I forced a commentary out of them by asking questions. I needed to initiate it. 'Can you explain to me why?' 'Can you please explain to me what you are...'" There is no evidence from the story why this has changed. This and the previous story share a fear about a child dying, but in this episode Barb reports more active agency. It may be that Barb feels being the mother of a child with a 'disability' requires more assertion to ensure they are heard (Goodley & Tregaskis, 2006). Whatever the cause for the change, it is a significant shift – challenging healthcare professionals (even gently questioning them) is not

without its risks (Carter & Martin, 2005). Her experience is positive – "there wasn't ever an issue", and the response of staff seems to allow her to relax and be herself.

Again, however, Barb does not differentiate between nurses and other staff. She notes that having several doctors involved is significant, but the other interactions involve anonymous pronouns. This silence about nursing care could be that in the crisis, the only thing that mattered was that care happened rather than who delivered it. Or it could be that there was little interaction with nurses at that time. Barb is reassured by physical presence – having people with her daughter demonstrated their focus on her. There would have been nurses in and out of the space checking Judy's vital signs and undertaking other nursing cares, but these are not apparent in Barb's recall of what happened. It is also Barb who initiates the family focus – she asks if Jed needs to be there. This situation was clearly very busy as the staff sought to manage Judy's seizure, so the focus was on the child rather than the family – yet this mother tells of feeling 100% alone and needing the support of her family.

> ***Then I was just a little bit anxious but not like… I mean, I slept. I trusted them.***
>
> She went into Intensive Care… when I saw the level of support that intensive care provided, it's like all that worry just actually disappeared.
>
> I was just amazed at how many nurses there were and the fact that she was just being monitored around the clock, all the time. They sent us home with the Emergency Number. They said 'you are to ring us if you are worried; you are to ring us if you are anxious.' It was brilliant. I think there was the option to stay, but we just all agreed that we weren't going to make a blind bit of difference being there, sleeping badly in an unfamiliar place and we would be better to come home and be in our own bed and get some sleep. Yeah, so we did.
>
> Then we went in and she'd only just started coming around

This is clearly a significant memory. Barb had kept the piece of paper with the phone number of the area "the other day I was doing a big clean out and there it was. This little card. In my bed side draw… we didn't use it." This experience with Judy was no less significant than with the other children "this was quite scary because it was out of control" but it is told differently. Even the pacing is different. Barb acknowledges that it all could have gone wrong – but then highlights what she notices the nurses doing - constantly watching her child. She trusted because she saw that nothing would happen "without anybody noticing things going wrong." Unlike when Ruth went to theatre, and Barb felt she carried the responsibility for

what happened despite not being able to be present, in this time, she seems to feel that the responsibility is shared – and therefore that she can go home. So although there are still no names, the staff are recalled interacting personally and offering choices and agency.

The nurses speak to Barb's concerns – and make themselves available. This space of care is not necessarily physical – the nurses create a 'trust space' that allows Barb to go home. She is not clear how they have achieved this – but she has seen them in action, seen the way they watch and touch her daughter. And this gives her confidence to leave the building. The intensive care environment allows a nurse to focus exclusively on one child, and this helps the family believe that the care is real and sustained.

This 'emergency' passes and Judy is transferred to a ward.

> ***The family routines are totally disrupted. Like everything revolves around hospital. Everything***
>
> Then really quickly we were back on the ward... A really big problem was she's not really super sick. She's not needing around the clock nursing care and nurses left us pretty much to our own devices. Apart from the times that they came and took her observations
>
> She had 5 days, 4 days, on the ward as they then tried to ascertain why...
>
> I couldn't leave. I couldn't have done it because I couldn't guarantee that she would be safe. So Jed and I for those 4 or 5 days, were ships that passed in the night. He would come up with the children. They would see Judy and then I would take them home. And then he would stay the night and then in the morning I would get up and about 8 o'clock or 9 o'clock, we would then pass. I would bring the children and then he would come home. So we never actually got any time when the two of us could actually sit and talk properly about what was happening... and this was almost straight after this hugely traumatic experience.
>
> It's really good that we haven't had to go through that much lately

With the change of environment, the storytelling changes again. Unlike the account of Judy's admission and emergency management, Barb here feels the need to reflect and theorise some possible meaning for what happened next. From her account, nothing in particular happens: they are on the ward for several days, they learn about some of the medications, and they go home. But it does not meet Barb's expectation of nursing care. She remarks, "nursing seems to have changed". This relates to Barb's expectation of what care the nurses would give Judy while she was there. Perception of nurses and nursing influences expectations

of parents (Avis & Reardon, 2008). Indeed Barb points out that they have not had any "ER" type situations, referring to the television programme, as one source of information about the healthcare system. She seems to balance not wanting to criticise, "definitely not faulting the nursing care" with her actual experience of feeling left to do all the care themselves. Barb describes a hunch that the nursing staff were absent because she was present, "I don't know what would have happened if we had not been able to be there."

In Barb's story there is little care evident – it is as though they provide the nursing care. She identifies that Judy not being "really super sick" means that her care is not a priority. Yet this family had just lived through an emergency situation where they did not know if Judy would survive. The contrast between the emergency and this level of care is marked. Where there were several staff all focused on their daughter, now there seems to be no one – apart from coming in to check her 'observations'. The coda reinforces Barb's relationship with the experience, "It's really good we haven't had to go through that much lately." This part of the experience is what leads Barb to theorise and reflect – not the acute stage where the immediate concern was Judy's survival – but the waiting in limbo, suspended from time and their normal narrative lives.

For this family, however, there was no choice – their shared narrative is of a family who stick together and are there for each other, "You know we'd just leave our jobs or stop whatever we were doing." Barb positions herself and Jed as central to Judy, committed to her well being. The descriptive details that she adds are of time dragging slowly, "It was just hard work. Excruciating. Yeah it really is hard work... we don't complain." There is no doubt that parenting a sick child in hospital while also parenting other children is significant work (Aitken et al., 2004). With this story however, Barb positions herself as a stoic and committed mother who sacrifices for the benefit of her child, accepting the socially normative role (Vallido, Wilkes, Carter, & Jackson, 2010). By taking this role she was less able to challenge the situation that, in hindsight, she now questions. Now she wonders, "So what I can't work out in my mind is are they taking advantage of parents who can be there to do that job or is that the expectation that you will just be there", something that she did not voice at the time.

What is evident in Barb's recounting of this part of Judy's hospitalisation is a seeming lack of purpose. Whereas the more acute episodes had clarity and meaning ascribed to them, this point in the narrative becomes clouded in chaos. Time just passed. There seem to be no effective connections with nursing staff – to the contrary, they are completely absent. The language Barb uses positions staff all aggregated into "nursing". This lack of personalisation adds to the sense of chaos within the narrative structure. Even the sentences have a staccato quality to them. For example Barb augments the story with more detail, "And just having no choice… not really… I couldn't leave. I couldn't have done it because… I couldn't guarantee that she would be safe. No there was no choice… you couldn't do it… you could maybe nip to the toilet but that's all." The sense of powerlessness continues as Barb, even now, struggles to understand the way she sees the system treats families. She asks, "I don't know it just seems like hospital wins all the way and families actually don't. I don't know. I haven't actually thought or articulated this out loud before." This is another clue to the sense of chaos within the story – the fact that it is not able to be freely told. Stories that confirm our world view and make sense are easily told (Frank, 2006). This episode might have been reflected on since it happened – but its lack of clear narrative structure is in part due to its dissonance with Barb's world view and understanding of care – it does not get often told because it is too difficult to tell – or even to think about. This is a challenge to practice.

Across these various recollections there is a sense of thankfulness that the children all recovered from the things that brought them to the hospital – a blend of quest and restitution, but most also are intertwined with a sense of chaos and purposelessness. Where expectation and identity were affirmed, the experience seems more straightforward. Where Barb's identity as a mother or their identity as a family is challenged, the narratives become much more reflective and disjointed by attempts at theorising.

Emma and Hera's story

Temporal flow
But then when you are there as a parent, you're on the other side
The nurses were sort of, 'do what they had to do' and off
So I stayed with him, and at no time did anybody make me feel like I was in the way
I was treated pretty much the same as I was when it was my own children
There wasn't a lot said but the "Oh!" really said a lot
So then we ended up back in ED the following day
I had to be thinking ahead as well as being for him there and then

Titles (left vertical label spanning the table rows)

Orientation

Emma, Wiremu: Hera; Aiden; James; Ryan

The interview had taken some organising – the challenges of meeting with a busy family – Emma holding down two jobs as a nurse, Wiremu working long hours with his job, and each parenting their four children. And on top of that they frequently took in foster children to be nurtured in their home. So in the end it was Emma and Hera who could be there for the interview. We chatted for some time before putting on the recorder – but as soon as we 'started' (signified by the red 'record' light on the digital recorder), Emma began alternating between theorising and storytelling, as if trying to make sense of her varied experiences.

Emma had multiple stories, emerging almost rapid fire, one sparking the next. It is not always apparent whether stories are distinct or part of one another (Frank, 2010b). This was less apparent during the conversation than afterwards and trying to identify story beginnings and ends. At the time Emma wove the stories together in conversation with Hera and me. There were almost functional stories told within the longer story narratives – e.g. Ryan went into hospital with a pin in his lung (orientation); He inhaled a notice board pin into his right bronchus (abstract); Had antibiotics (what happened then); He was sick for quite a long time (evaluation); Got better (coda). These simple stories were enhanced with theorising and augmentation as Emma unpacked the memories of those experiences (as in 'So I stayed with him, and at no time did anybody make me feel like I was in the way')

So on invitation to tell their story(s) Emma started with theorising - "I think my perspective is slightly different because I am part of the system" but immediately flowed on by demonstrating with a story:

> **But then when you are there as a parent, you're on the other side.**
>
> Hera came into the ED with a really high temperature. It was at a time when there was a norovirus outbreak – so there were truckloads of kids in there with this vomiting and diarrhoea thing.
>
> I explained to everyone that when Hera has a really high temperature she vomits – and she did vomit a couple of times. But there was something slightly different with Hera... that didn't really fit with norovirus. So I said, "can she have a chest x-ray – I know she hasn't got the same as everyone else has got?" They just assumed that she had the same thing as everyone else, "Oh no, no. We know what we are talking about."
>
> So we ended up having a six day stay in hospital – and finally on day five she had a chest x-ray... and she had pneumonia.
>
> I wonder if my perspective is different because I am part of the system... but it's actually quite different being there as a mother and having no control. Experiences like this have changed my practice.

The context of hospitalised care presents challenges for healthcare professionals and parents to establish roles and relationships. The voice of the 'expert' often becomes the primary and dominant discourse, while the voice of 'experience' is relegated (Yiannis, 2004). So in this story Emma recalls "it was assumed that she had the same thing, where as I knew it wasn't... so as a parent – not in control." This seems a common parental experience where their role (or even purpose) during the hospital experience is unclear (Young et al., 2006b) and where their 'expertise' is stated as important but not acted on (Callery, 1997). Care would have been evident if nurses had recognised Emma's skills and focused on this unique child.

With this and with most of Emma and Hera's stories there are attributes of quest type narratives with reflection and acceptance (Frank, 1995). For instance in this story, Emma reflects on how this has changed her, "I have changed some of the things I do from being on the other side." Hera reflects on how these experiences define them as a family, "I think it might be different for mum because she knows what we need if we're sick better than other parents might know." In other words, these experiences are woven into their individual and family identity narratives – helping them make sense of what happened as well as confirming how they see themselves. Emma's use of language gives insights into this – there are very few

other characters in the story – the family and sick child remain central, with all others cast in roles surrounding them.

This story blends into the next, as the emergency department visit turns into a longer admission:

The nurses were sort of, 'do what they had to do' and off

So when we got up on the ward... I wonder if the resources were a bit stretched... there were lots of kids there with diarrhoea and vomiting, and it was really busy.

Hera's wristband fell off on day one! I think it might be different for mum because she knows what we need if we're sick better than other parents might know. Now I suppose being a nurse, you know how important that wristband is. So I asked for a new one but it never arrived – and we were there six days! So I'm sitting there watching the nurses give Hera the antibiotic, without the name bracelet, but... you see... you have to be really careful. You can't alienate the people caring for you. You don't just say it – 'cause you know that if you put someone's back up at the beginning of the shift it could impact on your child. So I just ask the right questions to make sure it is safe, "Oh... what is that?" So that I can see the chart and check for myself it is all right.

We did have students – they were the best nurses that looked after her. They would say, "My name is, whoever, and I'm here to do Hera's temperature. Is that ok?" They used your name – and that made you feel more comfortable knowing it's not some stranger poking you with a needle or something. But the other nurses were sort of 'do what they had to do' and off.

The conversation is an interplay between the three of us – story – question – clarification - comment. The story of 'nurses not checking the medication against the bracelet' gives the 'nurse teacher' in me some concern – but my focus is how care is experienced in this situation. I ask for clarification to ensure I had pictured the story accurately. As a nurse, Emma would know the 'theory' – what should have happened. But even so, she is tentative in the way she positions herself and the nurses, "I think so.... I think so... you know..." The "you know" is a narrative device to signify a shared understanding (McCormack, 2000a). Emma uses it here to check that I understand what she means by needing to, "not put someone's back up at the beginning of their shift." Emma knows I am a nurse, so there is an assumed shared understanding that this risk (of alienating the nurse and paying the consequences) is a well known phenomenon. This goes to the heart of my interest – the experience of care from nurses – there is dissonance between the expected behaviour of nurses and what happens. This type of inconsistency causes uncertainty and concern for families (Yagil et al., 2010). Emma is required to

remain hyper-vigilant to ensure Hera's safety. She cannot relax and trust the care provided because one of the fundamental aspects of safety that she was aware of, was not maintained.

Emma adds a coda to the story of this experience: "the students pretty much took care of us... the outcome was fine... but it was all cool". The difference here seems to be in the attention to detail. Although the students similarly did not replace the ID bracelet, their approach made it feel different - they checked in with Emma as a natural part of their routine. This demonstrates a finding of Wiebe and Young (2011) that parents will forgive a range of grievances if the nurse has established a trusting caring relationship. This creates dilemma for families, however, because they expect nurses to be competent (MacKean et al., 2005). It is possible that Emma had lower expectations of competence of students than the nurses. Also because the students spent more time with Emma, getting to know each other, the students were personalised for Emma (and likely, Emma for the students). Parents consistently report wanting more support (MacKean et al., 2005), which Emma seems to receive in this caring approach taken by students.

Emma almost immediately moves on to the next account.

> ### So I stayed with him, and at no time did anybody make me feel like I was in the way
>
> The next one was when Ryan ended up in hospital. And you wouldn't let me go with you. No. Because I just didn't know what was going on I didn't want to have to think about anyone else besides Ryan. He was unwell, non specifically unwell. So we went into hospital via ambulance. He was sick. He wasn't responding very well. He was febrile, yeah, so they tried to put in an IV line, couldn't get one in... it was rushed and...scary... but they were very good. Very good and very quick. Within maybe half an hour of being in ED it was.....Bloods were done, x-ray was done, white count of 26. Through that whole process everyone explained what they were doing. Although it was really quick people did explain what they were doing, like the emla cream. We'll put this on him before he goes to X-ray because we will put a line in when he gets back. The x-ray showed he had inhaled a notice board pin into his right bronchus. Then In theatre it was, "You come with us, hold him, we'll put him to sleep. We'll take him away. Would you like a cup of tea while you're waiting?"
>
> And then it was up to the ward, IV antibiotics for a day or two... yeah.

Emma fluently recounts these clinical details evidence of her familiarity with them and their meanings. But despite having this expertise, it is the inclusion as a parent that she notes in her story. This is repeated several times through the story. In the

emergency area she recalls the pace of events and their impact, "They did the X-ray first which was really good because next on the list was a lumber puncture... so it was cool... it was rushed and...scary... but it was ok... as long as I could be there." Families who feel that the care of their child is under some 'control' tend to feel less need for vigilance over every staff member and detail (Heller & Solomon, 2005). The anonymity of the staff in this story seems to indicate a level of trust – they are aggregated together rather than singled out for scrutiny. Building trust between nurses and parents is complex, but often takes time (Dickinson et al., 2006), which is not always available in acute settings. With no time to get to know the nurses, Emma interprets the behaviours, "very good and very quick." Perhaps because she is also a nurse, Emma notes efficiencies – putting the local anaesthetic cream on Ryan rather than waiting showed the nurse's foresight and planning. Families often feel like they are their child's strongest and most necessary advocate (MacKean et al., 2005) so for Emma to be able to share that role seems to be experienced as reassuring.

This story begins in an emergency room, as did Emma's opening story. Families have often assessed and even begun treating their unwell child well before presenting to these departments (A. Williams et al., 2009). As a mother (and a nurse), Emma had done this each time, recognising her child's deterioration. Yet the stories are quite different. In this story Emma describes being included, as for example holding Ryan while he was anaesthetised. In the first story her expertise and knowledge is sidelined and dismissed. There are many contextual factors that could lead to this – but for the family, these are peripheral to the child at the centre of the story. Emma does not theorise in this story – it seems her expectations of what should happen was matched by the experience. So this story is more augmented with description and clinical details – it seems these are able to emerge when Emma's narrative integrity is maintained by nurses allowing her to participate as mother.

When describing the theatre experience Emma seems more focused and anxious. I ask her, "Do you think they knew you were anxious?" I am not sure if she is communicating her anxiety from the perspective of hindsight, or whether she was demonstrating it at the time. The response is definitive, "Absolutely." Emma notes though, that she would have been unknown to these as it as an area she had not worked. So she was treated as might any other parent. She explained the source

of her anxiety, "the time that I think I was really anxious was when he was in theatre... when I couldn't see what was going on. But I was fine as long as I was right there. If I got asked to go away it would have been... [sustained pause]... They didn't, though..." What is silent here is a sense of Emma's agency – of her taking some control of the situation. Instead she positions herself as passively going along every step of the way – she wanted to be present for Ryan, she got to be there for some parts – but not because she negotiated, more because that was just what happened next. Despite her expertise she took a subordinate role in the relationship, again perhaps to not get anyone's "back up." Emma's expectations were also influenced by her own practice, "you know, I'm used to working with adults where family aren't allowed to go to theatre. It's just – 'you sit on the ward and we'll bring them back when we're ready for you'." So how Emma anticipated the process unfolding was shaped by her familiarity with a similar system (adults as opposed to children) and by her awareness of the politics involved. Any involvement was therefore appreciated, but of note, not advocated for.

Hera interjected into the story, "you wouldn't let me go with you." This was accompanied with facial expressions seeming to indicate not understanding. Emma's response indicates her beliefs around her role as a mother – she was having to juggle the physical needs of an unwell child with the emotional needs of a sibling. In the end she acted to protect them both. This 'work' of a parent would not have been evident once she arrived at the hospital – they would only see a mother and child. This background activity is often invisible to nurses and healthcare professionals, yet impacts on the family's ability to manage. As the oldest sister, Hera has seen several of her siblings in hospital and in nursing care. She adds argumentation – an additional story triggered by the current story, "I remember being there on Christmas Day one year. I think the coolest thing was that they gave everyone a little present, and all the staff, although they were working Christmas Day, they were really nice. I thought they would all be grumpy that they were not having Christmas Day with their family but they were really lovely." Hera enjoyed the generous staff on that 'special' day – but the way this picture is offered seems to highlight its difference from more normal days. It is not clear what 'really nice' looks like – but like the nurse in theatre offering Emma a cup of tea, it seems to include spontaneous responding-in-the-moment.

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Emma's stories flow quickly one on to the next, each an extension of the family's ongoing narrative:

I was treated pretty much the same as I was when it was my own children

Ira was probably the next one. He was one of our foster kids. Overnight stay for a bronchoscopy. Laryngomalacia.

I think the difficulty with the foster kids is that we were care givers and not guardians. I had to reinforce to the staff that actually I'm not able to sign anything which was funny, cause the nurses did call me 'mum', bearing in mind that he was Samoan and I'm not.

Ira was in a cot and I was on a mattress, on the floor, underneath the hand basin in the room… so my bed was under the basin… it wasn't that relaxing because… I just felt in the way

But he had the anaesthetic.

These are functional stories – seemingly shaped by Emma's understanding of my interest. I have to ask specific questions to clarify and get any picture of the nursing care. Some of this narrative efficiency is possible because Emma knows/assumes that I will understand the context and terminology. So "overnight stay for bronchoscopy. Laryngomaliacia" is all that is necessary to convey the complex medical needs this child would have. The absence of other details seems shaped by the family's busyness. Having a child in hospital is an interruption to an already hectic schedule – so these stories accentuate the progress (or its lack) rather than dwelling on any particular points.

I ask about the relationship with nurses, given that she is there as a foster parent rather than 'kin'. This question brings up the broader contextual information. Emma felt that she was compartmentalised as "mum" despite the evidence to the contrary. Emma said she did not mind this. Emma augmented this story with further details. The family had provided foster care for Ira since he had left neonatal intensive care unit. They had worked hard to help this child make loving human connections, "He had lots of issues because he had been in hospital for months and not attached to anyone." Of note, though, Emma reports that it was she who had to keep reminding staff about the nature of the relationship. Despite the push for family involvement being several decades old now (L. Lam et al., 2006), many nurses still seem uncertain about how to enact this effectively (Ygge & Arnetz, 2004). Once nurses understood the relationship, Emma felt they became something of a novelty, "I did get a couple of sort of sideways looks; there were lots

of 'Oh's' and 'why is he in care?' I was having to explain who I was and I why I had this child". She also had to take on a maternal protective role in the face of what she felt was inappropriate curiosity, "You know, I think although he was only a baby, everyone doesn't need to know his business. So it was 'he is in our care while his family is sorting out their stuff.'" It was Emma who anticipated the needs of Ira's birth family and was mindful of the likely ongoing relationship they would have with these healthcare professionals. She clearly felt she had to manage the situation and acted according to this. It is uncertain whether any of the staff would have been aware of Emma's agenda around this.

The story is evaluated with a sense of being judged, "I did get a couple of sort of sideways looks." Those in the "dominant culture" often stop seeing difference and variation, with an assumption of generalisability of their own experience (Stone-Mediatore, 2003, p. 183). A baby with 'brown skin' accompanied by a Pakeha mother seemed outside the realm of 'normal' for some of the staff she encountered. Despite increasing awareness of the diversity within family units, traditional stereotypes continue to influence the way that families are assessed (Corlett & Twycross, 2006; Harris, 2008). Parents of ethnic minorities often feel judged and stereotyped by nursing staff (Arlidge et al., 2009). Culturally held beliefs, such as 'what is family' are often invisible and long held (Frank, 2010a). Emma's discomfort in this interaction seems to be as result of a clash between social norms of family (Andrews, 2002) and this family's counter narrative (of family being those they determine are included).

Emma does not dwell on this, however. Feeling looked down upon slips down the hierarchy of human needs when physical needs have to be attended to, "my bed was under the basin... it wasn't that relaxing because... I just felt in the way." Emma notes that the staff probably had little choice – but the impact of feeling like she did not belong in the space (provided) left little energy to assert herself with less pragmatic issues. This passing statement alludes to the impact of environment on the experience of care. Sleeping on the floor physically positions the boarding parent beneath everyone else. Having that limited space further compromised by being 'in the way' only adds to the vulnerability. Families often feel like they have little control over what happens in hospital (Corlett & Twycross, 2006). Being physically positioned with no actual space of her own, Emma remains on edge and unable to relax. It is likely difficult to be assertive when nurses and doctors stand

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over a mattress on the floor. This makes the *evaluation* of the story somewhat ironic – Emma feels that she was treated the same with Ira as she was when her own children were hospitalised. She intends this as a positive reflection - yet in this story it is juxtaposed by an image of Emma on the floor and in the way while nurses wash their hands. Families' gratefulness for treatment of their child often masks their dissatisfaction with other factors (Battrick & Glasper, 2004). In this story there is no evidence that Emma was able to speak up – it is only in the storytelling that she gives voice to her frustration. Yet pragmatically she moves on – "he got the anaesthetic" – as though as long as the child gets what it needs, everything else is secondary.

Consistent with the rapid flow of stories, and functional approach, Emma notes, "...nearly there..." and moves on to talk about James' hospitalisation.

So then we ended up back in ED the following day

James had his knee surgery farmed out to Osmond Surgical Co-op; so it was under the hospital but it was farmed out to them. The other patients that were there that afternoon weren't children. But we had problems with pain management

It was a Friday and the Surgical Co-op was closing at 6 and he got into recovery at 3.30, 4 o'clock. They gave him IV something, Morphine? Pethidine? An IV narcotic which helped with his pain briefly, but then he needed it again. So I was thinking how am I going to manage this at home? But in the end what happened? "Give you some IV Morphine; we'll whip your line out. We'll stick you in a chair, off you go."

James – He's pretty good but, he's not a complete wimp, he is pretty good, but I could see that he was in a lot of pain and any sort of movement.

I was thinking, that's fine he's lying on the bed but how am I going to get him from the bed to the toilet being a ten year old who doesn't want his mother helping him to get to the toilet. Any sort of twisting of his knee caused quite severe pain. I was thinking through all the sort of logistics of how we were going to manage. I had already worked out in my head that I wasn't going to get any more help from the staff there... because he was the last case of the day. So it was almost as if "Let's stick him in a wheelchair." We'll get him out to the car for you and "see you later"

He was crying. I just remember he was crying a lot

While this visit did not involve an overnight stay, James required hospitalisation the next day as a result of the issues Emma raises in this story. The efficiency and haste that Emma normally values is problematic in this experience. Emma views the efficiency from a different perspective than the staff apparently did. Her experience and familiarity with the context is evident in the way she 'speaks' the

presumed thoughts of the staff. She has no way of knowing, apart from interpreting what they do say – and what they do. Emma interprets in the light of her personal experience.

Emma repeats several times, "I was thinking…" These thoughts did not seem to be verbalised at the time. The environment seems to have inhibited her agency. She reports being very aware of the time and the shrinking timeframe before the Co-op closed. She seems aware of the behaviour of the staff as they cleaned up in anticipation of 'home time.' It is only as they are being guided to the door that Emma seems able to speak up in response to all her internally held concerns. Emma augments the story with more details, "I said, 'I want him to have some oral pain medication before we leave.' Which they were, 'Oh alright then.'" They were responsive to her request – however they did not seem to anticipate James' or the family's needs. Almost ironically Emma suggests, "I'm very good at asking for what I need" – a viewpoint that stands in conflict with her actions as she recalls them. She seems to simultaneously offer a reason for her silent resolve, "James was in pain and he was a bit scared, so he needed me to appear calm and in control otherwise he would have freaked out. He needed me to be that person." As a parent, Emma was having to manage the expectations of the staff, scrutinise their practice, anticipate her child's needs (not just in the immediate but through until other support might be available again), and project a resilient exterior to all. Apparently without letting anyone else know she was juggling all these competing tasks.

Emma wondered about the skill set of the staff, "and I think it is different… perhaps they were quite used to looking after adults, perhaps not so used to looking after kids." While the adult patients may or may not have spoken up about their pain, eliciting an understanding of children's pain experience requires particular skills (Carter, 2004). The presence of adult patients may also have impacted on James' behaviour – children often try to manage their responses in relation to those offering care (Garden, 2010). Nothing in Emma's story indicates the staff attempting to seek a deeper understanding of James' experience. It is only once they are out of the professional gaze that Hera sees her brother's behaviour matching his experience, "I just remember he was crying a lot".

I had to be thinking ahead as well as being for him there and then

So the following day it was just us two that went into hospital because it was an easier thing to do. And taking a day off work.

But it's just what you have to do.

And this time instead of waiting in the waiting room, James was put into a treatment space with a bed and he was given some Panadol as soon as we got there, but we had to wait obviously for something stronger to be prescribed

We went to the kid's ward and it was, "We'll give him some Panadol, we'll give him some Severadol and then it was, "We'll come back in half an hour and see what his pain is like." He was, "I'm sore, can you just tell them?" I said, "Well actually you have to tell them, otherwise they can't do anything."

He did have difficulty explaining how bad his pain was. You know – the little smiley face thing…. he got confused with the 1 – 10 thing, so they did the smiley face thing… They would say, "What's your pain, 0 is none and 10 is…… What is it?" They could see this confused look on his face so they went away and got something else.

So I had to be thinking ahead as well as being for him there and then.

Because the other thing is that he could potentially have ongoing problems. You don't want a ten year old to be frightened of hospitals

And now he's going back in March to have surgery again

These stories overlap for James. The separation of them is arbitrary and reflects merely a change in location. For James there is his story of pain. Adults wanted to reduce it to a measureable quantity and document this finding (Carter, 2002) – something that only seemed to confuse James. If James had been present in the interview, this could have been explored. Instead this is Emma's story of what happened.

Emma repeats through these stories the need to be thinking ahead. Her experience seems to indicate that this anticipating aspect of care was not present. Emma tells of sitting beside James – in both locations – with no sense that the care offered was mindful of the considerations she was grappling with. Care in this situation might have been demonstrated by asking Emma about her concerns. Instead the focus seems to have been on the immediate tasks. This leaves Emma to have to manage this responsibility as well.

The multi-tasking remains evident – Emma foregrounds that this additional visit represents a financial cost to the family as she has to call in 'sick'. The family's values are evident in the abstract – "it's just what you have to do" – the implication that family/whanau take precedence. Wiremu has not been mentioned often in the

hospitalised stories – though Emma points out, "Wiremu is a lovely dad, and he's at home with all the other kids". It is overwhelmingly mothers who accompany children in hospital (Fisher & Goodley, 2007). However Wiremu's absence here is not an abdication of parenting – his contribution to family/whanau precedence is by caring for the other children and maintaining the family routines. This is their values at work. Emma is also having to anticipate James' future needs at the same time staff are responding to his immediate requirements. So even though this is a different facility, it is the mother, rather than the nurses, who are planning ahead for the child's care.

Emma remains sensitive to process and progress – she notices that they do not remain in the waiting room, but are moved to an area for monitoring. As a nurse she recognises this way that staff prioritise and manage clients and their care. After being admitted, Emma tells the story as the nurses determining the goals and plan, "their goal was to get his pain sorted and managed within the day." Undoubtedly managing the pain was also the family's goal – that was why they had brought him in to the hospital – but this use of language highlights the clinician driven care. When they left they were given a prescription that included oral morphine, a synthetic opioid, as well as paracetamol – evidence that the staff trusted the family to manage James' pain at home and make decisions with James about timing of medications. While they were in hospital however, the staff determined this, "We'll give him some panadol; we'll give him some severadol." Families are often expected to contribute to care, but their role in negotiating care is less clear (Ygge & Arnetz, 2004). Emma had to 'translate' the clinical language of the nurses for James, but it is not apparent that they were able to influence the timing or choice of medications.

It is not clear why the nurses did not pick up on James' confusion in their assessment of him – this thread did not seem important in Emma's story – in part because James' pain did reduce. Emma's coaching of James means that the challenge of James communicating his pain experience remained invisible to the nurses. For a parent this is not viewed as a problem because the goal was achieved. The possibility that this occurs more often than nurses are aware of is worthy of further consideration. Working more closely with whole families rather than just a child-centric approach would go some way to enhancing effectiveness of nursing care (Frost et al., 2010).

The stories finished there. Emma had quickly and 'efficiently' summarised the family's experience of having many children in hospital. The stories appeared to be influenced by her narrative identity of mother/nurse as much as by what happened. Emma was aware of the culture and practice in hospitalised settings, and was therefore able to navigate the experiences without getting 'off side' with the nurses or other staff. Yet to do this she also had to 'be quiet' when she had legitimate concerns or issues. This constraining of agency in order to ensure the child's needs were met is worthy of consideration – do families need to know how to 'play the game' in order to feel they are cared for?

Mike and Audrey's story

Temporal flow
They said, "Oh strike, she is sick." Then it all started happening quickly after that
After the first few days it wasn't an adventure
Of course I didn't know that that was like the emergency bell
When she went in it was a big emotional thing. I think it did hit home how serious it was
I thought it was so gross… I just thought that they would think it was gross too

(The left side of the table is labelled vertically: **Titles** *)*

Orientation

Mike, Marcia: Audrey; Oliver

We had traded emails to set up the interview – the downside to trying to have family interviews is trying to coordinate multiple schedules. This was an evening interview – so after dinner I headed out to meet the family. On arrival Mike met me at the door to let me in, "Sorry, Marcia is not here – she has had to take Oliver to the doctor. Is that going to be a problem?" I assured Mike and Audrey that as long as they were happy to proceed, I was more than happy – and that perhaps the others would make it later. I brought out the chocolate biscuits and we chatted a while till the jug boiled, clarifying the point of the interview and going over the information and consent. Once everyone was comfortable I pressed 'record' to mark the beginning of the interview.

They said, "Oh strike, she is sick." Then it all started happening quickly after that

Well it started off on the 28th February. Audrey, she'd been sick for a few days vomiting… pain……

Went to the doctor… thought she had gastroenteritis… that wasn't getting any better… she said well it's probably urinary tract infection… it still wasn't getting better… "Well you're not sick enough to go… through the public system, so we'll send you for a private scan." Doctor took one look at the scans, gave her an admittal to the hospital. Went there. We told whoever it was that saw her first. She said, "Oh it can't be that she's not sick enough." You know, they did the test and stuff – she's not in enough pain. She should be sicker than this. They kept asking what her pain level was like and she was, "It's not that bad." "You should be sicker than this. You should be in more pain than this."

Then they looked at the scan stuff…"Oh strike, she is sick." Then it all started happening quickly after that.

We waited in the A and E for about 4 hours

I am struck by the attention to detail – Mike names the day it all began and recalls the events as though very recent, despite this taking place a couple of years earlier. This story – of having Audrey in hospital - seems to be important to them. It is full of description and theorising, some evidence of reflection on these events. The conversation is also banter between Mike and Audrey, "at that stage I had a line put in….Cause she hadn't eaten much…Yeah cause I had to be nil by mouth for the scan or something. Just fluids." I don't have to say much at all – this was clearly a shared experience and the retelling of it is similarly shared between them.

Mike offers an aside (using the narrative device of argumentation to reinforce the primary story), "I don't know if I should tell you this, but parents have a sort of code…" He recounts how he was informed about where and how to park, not by staff, but by other parents – those who had been there longer. He then fulfilled his part in the chain and passed this information over to newer families. This clear identification with 'each other' is almost tribal, with rites of initiation (admission for longer than a day or two), shared language (meeting together in the parent kitchen to compare notes) and cultural norms (going off to get coffee together). Aitken, Mele and Barrett (2004) found that parents in hospital value sharing their stories with others in similar situations. This seems to have helped Mike manage what is otherwise a challenging situation - he even describes it as an adventure.

After the first few days it wasn't an adventure

I was in there for 14 or so days, or something like that. I had an operation to put a drain in to drain the fluid

I just told them at work. Family comes first… my main focus was Audrey…

There were rituals like she had to go to the toilet in a container. I had to measure it every time and …… Carry it all the way down to the sluice room… and I had a book I had to write in and so I had to examine it. I had to go in with her when she went to the toilet and take the little container out and empty it. She had to drink Ribena and they get you to do a certain amount of stuff. I had to go and make up so much Ribena every hour. And then… Audrey was on this drip thing all the time and in the middle of the night the thing would run out… start beeping… And the idea was that you'd push the button because it would start beeping. But you learnt very quickly what to do to shut it off; otherwise it was just beeping

You got to know the system quite well, how everything worked. After the first few days it wasn't an adventure… So you just support each other

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I have to check my own response here – my immediate response to hearing this account is to wonder where the nurses are. Mike does not say whether or not this arrangement was negotiated – though in the course of the conversation it appears not to have been. Mike notes several times that according to staff, Audrey "didn't look sick enough." Lack of negotiation between nurses and families can be a source of significant conflict (Power & Franck, 2008). But this family talk about 'getting on with it' – and in this telling of it describe family pulling together for each other. This cultural value, where "family comes first", seems to form part of their identity, and perhaps explains why they were not questioning, 'why is it like this?' For instance, during this interview Audrey apologies to her father for 'making' him have to look at and measure what she passed in the toilet - as though it was her fault. Mike recounts standing outside the female toilet waiting for his adolescent daughter to finish, acknowledges that "it was a little weird", but does not here question the appropriateness of it. Perhaps they did not feel there was any choice, "because at night time there was hardly anyone around. Hardly any staff." The family still position themselves as working within the system, "and you got to know the system quite well... how everything worked." There is little evidence of resisting or challenging what happened – even when it seemed unjust:

Of course I didn't know that that was like the emergency bell

I remember one time, I think mum might have been at work and dad had gone to move the vehicle or something... I don't know. It was a little bit scary

The IV pump started beeping and I didn't know what buttons to push.

We learnt that the first night, didn't we? From the lady in the same room as us, "You just push the button and it's quiet, then you push the button for the nurse."

So I pushed the button and no one came and I got really fed up after a while of pushing it and no one was coming, so I pushed it three times... of course I didn't know that that was like the emergency bell

All these people came running and I got so told off for causing a big shock when there was no need

It was great to have Audrey there as part of the interview – she gave an immediacy to the interview by checking and augmenting the recollections of her parents. Yet strictly speaking this story is of her experience rather than the families. Audrey recounts an episode of requiring help, yet when the help arrived it was punitive rather than nurturing. She was admonished for behaviour she could not possibly know was 'against the rules'. Yet she has already depersonalised the interaction –

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she does not report being told off by any particular person – she is positioned against "all these people." This follows earlier description of being woken up in the mornings – "So I had to be kind of be awake for that. I remember a couple of times just a room full of people. It was really kind of overwhelming a couple of times because I'd just woken up and feeling weird anyway, but all these people just looking at me was a bit daunting I think." Perhaps by virtue of feeling ill at ease, Audrey seems to identify with the students in that situation, "some of the [medical] students, they just seemed kind of almost anxious as well. Maybe they were new at it as well, I don't know." What is absent in this story is any sense of being able to challenge or assert herself in the situation. For example Audrey's language use demonstrates limited personal agency, "I had to... you just..." – these being passive responses to the situations she described.

With regard to the family experience, Mike's response to the story of this episode is notable. Rather than coming to her defence, Mike almost justifies the behaviours of the staff by theorising an explanation – "But your emotions were all up the wop too." It is as though fitting in and playing along are most important. Rowe (2003) calls this "the structure of the situation" (p. 40), where social expectations and hierarchies are unconsciously maintained by all participants. Parents seem to accept responsibility for maintaining the status quo whether or not it meets their needs (Aitken et al., 2004). The possibility that the nurses responded inappropriately is not entertained by Mike. The conversation moves quickly on to more acceptable familial conflict, "Marcia would come in – she was at work and everything and then she'd want to know what was going on and ask Audrey all these questions... I remember being really angry at mum... Mum was the one that copped it." So in their combined story, Mike and Audrey work together to deflect the attention away from the story of calling three bells. What began as a counter-story – a story that challenged the dominant narrative of caring nurses – was reined in and made to conform.

From this point there are large stretches of description and theorising – marked by "I think..." and "I thought". In terms of narrative typology, this seems to combine aspects of restitution – there was an expected outcome of Audrey getting well; quest – where there are gains achieved through this uncalled for experience, "I think because I was there we developed a really close bond and we still have it now I think because of it"; but also chaos, where some of what happened still does not

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make sense to the family. The chaos is evident in some of the things not talked about. For instance I asked about going to theatre – Mike acknowledged "When she went in [to theatre] it was a big emotional thing. I think it did hit home how serious it was" and described that Marcia went in with Audrey for the anaesthetic induction. However immediately they moved on to a long description of how "gross" the drain was post operatively.

> **I thought it was so gross… I just thought that they would think it was gross too**
>
> When they put the drain in and she came in with this little bottle thing
>
> It was disgusting, it stunk. I was so embarrassed
>
> It used to fill up and they used to come and swap it over… I was saying to the nurses, "Can't you smell that?" They'd say, "No, no, it's nothing." I said to dad, "Can't you smell that?" He said, "No."
>
> I thought it was so gross… most of the nurses were really reassuring and like you could tell that they cared. I don't know if it was a thing where, "We have to make the patients think that we care".
>
> One of the doctors said, "This is nothing compared to some of the smells when you open people up." I think that kind of put me at rest.

The story of an adolescent girl waking up with a tube from her abdomen - collecting pus and exudate in a bottle - became a story of not wanting to offend staff or others. The characters all seem to move around each other without fully engaging with each other. Audrey does not want to be unpleasant for the staff; she wonders whether the staff are being pleasant as part of their role; and even Mike and Marcia taking their part in accepting the apologies. Audrey kept apologising all the time, "Sorry. Sorry for this". Everybody seems polite and content with this surface interaction. Audrey points out that most of the nurses were reassuring to her – and she seems to have been comforted by this – only later reflecting on the motivation. She does not identify how the nurses conveyed the reassurance – Audrey gives the example of the doctor placing the problem into a wider context.

Marcia arrives at this point – having brought Oliver back from emergency clinic. Oliver is not feeling well, so chooses not to participate in the discussion. Marcia joins in, and much of what has already been covered is enhanced with her perspective – having to figure out who is available to be there for the child in hospital; juggling family responsibilities and family demands; managing relationships despite only seeing each other for short periods – in busy spaces. Great insights into what it is to be a family with a child in hospital – but, for me, not

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much about the experience of care from nurses. Marcia did have a clearer sense of quest though, "We're very fortunate to have a health service that is so accessible. Lots of people ill in the world don't have this kind of healthcare…Yes there was awful stuff that needed to happen and was very undignified and it was hard seeing Audrey suffering through all the pain and stuff but the ultimate aim was to get her better. Yeah, got there in the end."

The family continue the conversation. They describe the environment and some of the people they met in it. Again, however there is a reluctance to critically explore what happened. Audrey briefly describes a nurse trying to administer medication via an IV luer. After watching her struggle for a time, Audrey describes explaining to the nurse how to do it. But this is quickly countered with Mike commenting that most of the nurses were "really nice", and that there was really only one who was a bit "hard to get on with".

We finish once it is apparent the family have come to the end of what they want to say. The conversation continues out to the footpath – the family clearly at ease telling their story and feeling safe to tell it to me.

The stories this family shared both demonstrated and helped form their family identity. Family identity was demonstrated in the way they positioned themselves as a unit, being there for each other. The stories confirm and shape their identity in the way the story was adapted when it did not fit their expectations – as for example the story of Audrey being told off became a story of 'misreading' the situation. Many of the accounts are shaped to fulfil restitution narratives – they had a strong trust in and appreciation of the healthcare system so somewhat passively accepted what happened along the way. There were also quest type aspects in their recall – though these tended to be about overcoming more peripheral challenges (as for example conspiring with other families to solve parking challenges). Mike and Marcia expected to receive care, so even in the times it was not so apparent, found ways to excuse why it was not there for them. In terms of implications for practice, it is important that this level of hopefulness and goodwill is not taken advantage of.

Cathy and Marty's story

Temporal flow
So they said... 'he will need to go up to surgery'
So we just shot out and brought him home
He wasn't anywhere near as bad as the second op
So we brought him home for the day
... I found leaving hard
What does that mean? These are all the questions that you don't process at the time

(Label on left side: **Titles**)

Orientation

Cathy, Marty: Nancy; Dan; Violet

"You'll be really interested in this story" was the call from the email. "I am interested in any story" was my response. "I feel privileged if you will let me listen" was the message I was trying to convey – but my curiosity was certainly aroused. What makes a story noteworthy? Would it be an atypical story (Carter, 2008) - though in narrative where it is the particular and individual that matters (Cushing, 2007), there are no typical stories? I arrive mid evening as planned, and am invited in to Cathy and Marty's home. Their kids' ages are not dissimilar to mine, so we spend some time swapping notes on adolescents and adolescence. Dan is called out to show off his moonboot (an orthopaedic ankle splint) – this is now obviously a recent and somewhat ongoing story. Somewhat bored by the adults' conversation, Dan retreats, while I discuss the philosophical underpinnings of narrative with his father. Marty then introduces their story, "Without having been there - so just anecdotally... and you've got the story, so it's close to the truth... perception... as I heard it."

> **So they said... 'He will need to go up to surgery'**
>
> Dan jumped out, chopped down the branch, and on his very last stroke clearing the branch the axe slipped through, so with a right handed full sized axe stroke, he parked it in his foot... So we arrived at the hospital... they put him into one of the beds at A and E and we pretty much waited, as you do

It had been a good 2 or 3 hours by the time somebody actually did come and have a look at it.... the surgeon came along and took the bandages off, grabbed his foot and just opened it up... to have a good look

The nurse came and said, "Can I have a look." Because she was there and she was just so interested

She was actually an extremely good nurse. She really built a good rapport

They said, 'he will need to go up to surgery' and that would be the next day. Then they started on the need to find a bed in the hospital

The story flows quickly and easily – the narrative structure is full of 'the complicating action' – lots of things were happening (Labov, 2006). Cathy focuses in on the purpose of the story, "They probably need to know what happened". I am not sure who the "they" refers to – but it does show the family's insight into the fact that the story is told initially to me, but for another audience. Audience shapes the performance of storytelling – the choice of what is told and how (Langellier, 1999). So immediately there is awareness that this is (as all storytelling) a show. Cathy and Marty will craft their stories, aware of our previous conversation as to the purpose of the research, for me, for nurses who might read about it, but also for themselves. I am sitting in front of them – with a digital recorder – so my presence must influence the nature of their responses (Riessman, 2005). The unseen audience, those they know will see and hear their responses, are present because they are known recipients (Garro & Mattingly, 2000). It is not possible to quantify the ways in which this impacts the presentation – but Cathy's statement shows insight into the dynamic. However, they also speak to themselves and each other. Especially as this is an ongoing episode, the stories they un/consciously tell are part of developing and confirming self identity (Peterson & Langellier, 2007).

This story sets the scene – our healthy strong son, while socialising with his friends, inadvertently swung an axe into his foot – but he was brave! It was his friends that struggled to cope with the situation, "everybody did their little panic... and I understand he had to pull them together." Everyone has a sense of themselves that they use stories to reinforce and communicate (Engel et al., 2008). Here the unspoken idea seems to be that "we cope – even when others might not." Family values can be evident in the way they talk of themselves (J. Lindemann Nelson, 1992). This sensitivity to coping is apparent as they talk about the journey to the hospital, "he never really got too intense about the pain or complained much about it. The pain scale was only 6 – 7 was only... as high as he ever got, which they were quite pleased about... that he coped." This is likely to be a value that pervades the

stories that follow. It seems to impact on their responses in the situation – a doctor came along and unwrapped the bandage to take a look, "Daniel was perturbed by the fact that they didn't actually ask him." No sense of being in a position to challenge this – just acquiescence to the scrutiny. This is contrasted by identifying the nurse as "really good." It does not come with any description – other than briefly of what she did – she asked, and she was interested.

They describe waiting and eventually having to cross the road, in the rain, to get some food – but in line with the family value of resilience, they are able to laugh at themselves in this situation. They were clearly unprepared for the visit, running across the road in jandals, "It was just a comedy show. It was. Then we were laughing and cracking up at the same time, thinking if he went A over K and Dan is in a wheel chair it could be quite interesting!" There is no theorising at this point – the narrative structure is of restitution – everyone has a part to play in getting Daniel better.

So we just shot out and brought him home

We got back to the hospital, mucked around for a while then they finally came and said… 'No beds!'

So we said again, "Can we take him home?" They went away and checked and eventually they came and said… "Yes… you can"

"You've got to be back super early in the morning"

And then we were just going out the doors… and they gave us a wheelchair to take him to the door… just going out the door… and one of the nurses stopped us and said, "Has the wound been cleaned?" And we went, "well… No probably not, because isn't that the purpose of going into surgery tomorrow and hasn't he been in hospital for a number hours?"

And she said "is there grass in the wound?"

And we said, "We believe so, it hasn't been cleaned and he cut it with a farm axe… in the bush, so… probably." She said, "You can't go."

She goes and finds the Registrar, they start having a conversation and it begins to get a little bit heated and the Registrar says, "I think we should talk about this in the office."

Leaving us standing in the corridor, waiting… but they came back and said "That's fine; we're not cleaning the wound tonight because it needs to be done in the Operating Theatre." I'm going, "then surely if you knew all of that, this has been a red herring. We should just go." And they went, "Yes I think you probably should go before it becomes a problem again."

And Dan thought it was good because he was just, "I don't want to stay in hospital. This is really annoying." So we got back to our own beds, and I think he appreciated that

The narrative is shared – Cathy and Marty each adding to the other as they build the picture of what happened. The structure of the story begins to change however, as the expected outcome does not eventuate. The expected story of clinicians as experts, with parents passively accepting their knowledge (Callery, 1997), no longer seems to fit. Marty acknowledges his uncertainty, "one of the experiences that you have when you go to the hospital is that we don't know the severity of it and even when they sort of tell you, you really don't… you don't really have any experience to put this into… it's actually quite hard because you just can't get that information." Then while feeling unsettled by the unknown, they describe a situation where it appears the staff were not as sure about what to do as they had hoped. This may have been a tense interaction – the irony is clear as the conversation is retold in the interview. They have brought their child to a place where they hope people will know what is happening and what to do. This tension is evident as the certainties of who has the knowledge and expertise become less apparent. The idea of families-as-experts is normally subservient to health professional expertise (Carter & Martin, 2005; Stone-Mediatore, 2003). Yet in this recounting, Marty describes tentatively challenging the staff. Navigating the complex relationship between families and healthcare professionals is not without risk, the dominant narrative being that the patient/family will play 'good' (Garden, 2010, p. 127). During this episode, they seem to be aware of the risk – it is not an open challenge – but their frustration does seem to have empowered them to point out the deficits that they perceive. In recounting this episode, Marty seems to be reinforcing his role as an active and involved parent – despite the risks encountered. This casting themselves as advocates for their child is a device to underpin their credibility as storytellers (Fredriksson & Eriksson, 2001). Retelling it allows the family to reassert their position in the power relations – to a new audience (Peterson & Langellier, 2007).

This tension seems to be underpinned by the family no longer having confidence in the outcome, "What does ok mean… [pause]… does it mean, "Okay does he still have a foot?" [Cathy]. The risk of infection has been shared with them, as well as the institutional limitations of having to wait till the next day to have the wound washed out. As parents they do not share this fear with their son however - this is their private thoughts. With Dan they maintain the stoicism of the family, "We were trying to jolly him on… We were trying to make him laugh - you can impress the girls saying, 'Do you want to see my scar?'" [Cathy]. So there are a number of competing

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discourses at play here – being a 'good' patient, trusting the experts, being a 'good' parent (just the 'right' amount of interested and involved), and self determination. All while the family are having to cope with the unknown sequealae.

He wasn't anywhere near as bad as the second op

So anyway we got him back there in the morning…. And yeah, not eating… that was the hardest thing of all, just distracting him from not eating food

The nurse brought in a DVD, watched the DVD and then did a few wheelies in the wheelchair… when the nurse wasn't looking. Then she brought in a Playstation. Then he got in at about quarter to 1, I think… So we went down to the pre-op area

They said I could go in with him to theatre so I asked Dan and he said he was fine. And, so… they said you can go off and do something. So I just waited and then got the text back that he'd come through

This first one wasn't too bad

This brief story is almost glossed over. There is no theorising, little description or augmentation. To all appearance it played out as expected. Yet that is what seems to happen when there is synergy between what is experienced and what was anticipated. This allows Cathy to add details of the impact on the rest of the family – "I talked to her on the cell phone that morning and she was very upset. "What's wrong with Dan? Is he going to be okay? I just want you to come home mum" and all that sort of thing" [Cathy]. The family roles become evident as the Nancy seems to feel responsibility of being an older sister – and being brave – for Violet. These roles seem clearly defined within the family – Cathy and Marty use the terms "mum" and "dad" when talking about each other. Dan is reported as expressing guilt for his injury and its impact on the family, "it all dawned on him… that this has caused us to delay the holiday" [Marty]. This becomes a challenge to which they are each expected to rise. It is the absence of theorising, and the absence of a need for theorising, that is apparent here. The story went as planned and the expected restitution plot.

So we brought him home for the day

We got sent to the ward then… he stayed over that night… then they allowed him to come home….

We got them to give permission……We asked could he go home for day leave. One of the nurses said he's on 8 hour antibiotics so you could ask… if you can go home on leave. So we were told if he does he'll need a moon boot, da da da. All sorts of stuff to get organised, but you'll have to wait for the… rounds to occur and for the doctor or the surgeon to approve, whoever does the rounds…. Anyway they came around and had no issue.

> Couldn't see what the problem would be. They said it's entirely up to the nursing staff. Not worried about that. So we go back to the nursing staff and… he had said, or someone had said something about the moon boot… so anyway, we asked about the moon boot and the nurse just went, "Oh… if you need a moon boot that's a whole different department and that will take a day to organise." And we said, "No, there was nothing about a moon boot! We were just wondering about a moon boot. " She went "Good, good, okay I'll just get his paper work then."
>
> So we brought him home… without a moon boot… just crutches

The sequence of events seems to unfold simply as Marty and Cathy tell them. There are further reflections on the system – and some awareness of the power dynamics. Marty highlights an example of this with the discharge from the ward, "therefore because the physio had been around and taught him how to use crutches, which are very complicated things to use, we do appreciate, and without having full instructions on them you could cause yourself some major damage… I understand the system… so because we had permission there was no trouble there." Marty uses irony to demonstrate their insight into the rules they were aware existed that determined their outcome – in the interview it was very apparent that 'crutches are not actually that complicated at all'. And they also recognised that it is necessary to manage the information flow – it is still not apparent whether there was an intended plan for a moon boot. So the story continues without particular need for theorising – it is loosely following an expected trajectory.

What they do not reflect on though, is the position they seem to unconsciously assume. One of the things narratives can do is allow us to see the context and cultural presumptions (Garro & Mattingly, 2000). The family seem to comfortably report taking a somewhat subservient position to the staff – not passive, but certainly at the will of the staff. "We got them to give permission… they allowed him… we got sent… we asked" are positions of some vulnerability to the goodwill of the staff who were asked. Having talked with the family for some time prior to the interview, these are not behaviours that they might normally take in their social worlds – there is something in the context that reinforces where the power is located. This context of the narrative provides some insight into the culturally dominant hegemony at play in hospitalised settings (B. Davies & Harré, 1990; Young et al., 2006b). The negotiation here seems to come from the parents rather than the theoretical models of nurses negotiating with families (Frost et al., 2010; Lewis et al., 2007)

... I found leaving hard

The next day was the day he had the second surgery; that was probably the worst day

He had a good sleep that night

That was the day they said he was first on the list

Yes and I can't even remember how long we waited

I'm sure it was again to the afternoon; yeah it was a long time

And when I went down to the post op area he was just really....the nurse just looked at me and said, "He has had so many drugs. He's going to be really out of it." I managed to hold him off only for about half an hour. He was on a mission; he would just not give up.

When he came out that was the first thing...... 'What is there to eat?' The thing was, as soon as he'd eaten... Power chucked... Power chucked right across to the entrance of the room. So we had big chunks of vomit through his bed

We didn't have any preparation, so we're sort of dithering around going" Don't panic." We'll just get some towels. "Okay, where the heck are the towels?" So we went down to the nurse's station and said, "My son's just vomited, made quite a mess - what should we do." She said, "I'll ring for a cleaner." The cleaner didn't come probably for about 3 hours and we were all walking in and out of the room over this vomit. The vomiting got worse and he got two lots of medication. Finally... he stopped vomiting

He didn't want to be on his own and he kept saying, "How much more time have you got? Do you have to go home yet?" Nancy and I were saying, "We're in no rush, we'll just stay."

Yeah, so it's still Nancy and me, and I was beginning to think 'flip, when is he going to stop vomiting because I don't really want to go until I know he's a bit more settled and he's stopped vomiting.' So fortunately... I went to the nurse's station and told her 'could we have some more medication.' She tried the next lot and that seemed to settle him and it was probably about 9.30 or something

I said "Look we'll text you when we get home and see how you're feeling"

I think... everything and all the length of wait, I was exhausted. So as soon as we left his room I just got around the corner and just... had a good bawl and Nancy's going "It's alright mum. It's alright."

The main storyteller changes here from Marty to Cathy – no other reason than she was there – but there is a difference in style. Gender is one context that influences narrative (Bottorf et al., 2009). Here, whereas Marty has been quite confident in his recollections, Cathy seems more tentative around timing. There are shorter speech segments and more pauses. She checks – for example, "I'm not sure... yeah... you know?" Where she is much more confident is in describing the relationships and interactions. Kalbian (2005) suggests that women carry cultural stereotypes of femininity and womanhood within their stories. Her concern is for her son – that he

gets to eat – and she is having to try and manage this with her knowledge of what Dan likes and dislikes. This story is augmented with a description of the meal tray arriving with pork roast rather than chicken nuggets. "He hates pork roast!" This maternal knowledge is not enough to empower her to advocate however, "And I looked into it and it was the pork roast that he hates. And I put the lid back on it. Okay right... I'm just gonna have to tell him. So I sat on that that for a while." The picture of putting the lid back on the tray mirrors what Cathy does in this situation – she has to "sit" with the knowledge that the tray is covering food Dan will not eat. Yet she does not tell the staff – she knows she needs to tell Dan. When the woman returns to tell them they have some spare trays – with chicken nuggets (!) – Cathy is relieved of the responsibility, "Honestly I could have hugged her. You are the best person in the world right now."

For Cathy, in this moment, receiving care was best expressed in being able to feed her son. Having someone seem to go out of their way to find appropriate food demonstrated a personal interest in his well being.

Ironically, having managed to get him food she knew he would eat – Dan immediately vomited it all up – Marty adds the visual picture, pointing how far the vomit had spread – while Cathy focuses on the emesis within the bed, and her feelings of powerlessness in fixing it. She recognises this, admonishing herself, "don't panic" while describing herself "dithering" uncertain how best to proceed. More than likely this would have been dealt with easily at home. In this new context, however, the task of a mother cleaning up after a sick child is made difficult "what should I do?" The environment does not seem conducive to delivery of care, with the nurses appearing to be in one space, while this played out in another. Cathy has the challenge of trying to enact her role as mother, in an unfamiliar environment, while at the same time being constrained by the 'institutional rules'. "I will ring for a cleaner" is the response for a mother who wants to get in and 'be the mother'. She recalls how the family attempted to diffuse the awkwardness with jokes – "the funniest thing was that because the doors were open... a sparrow flew in and started to eat the vomit. Nancy's going, "That's just disgusting. That's disgusting." Marty's making jokes about, "Knock yourself out mate." However this seems a deflection from the stress that builds for Cathy until she eventually leaves – and, away from the view of the nurses, "has a good bawl."

The account is given further context as it seems to remind the family of Dan being in hospital as a baby. At that time he had a viral illness, "a lumber puncture… he had so many blood tests and everything." The thing they point out about this earlier experience is a nurse not giving the medications as charted, "Marty would have to make sure that happened or [it] just wasn't going to happen". Cathy reflects on the experience "this is not the way I envisaged my 14 year old enjoying his holiday" as though she carried some maternal responsibility. In both situations, however, it is Marty who takes the assertive role. Cathy is left feeling guilty – reflecting on the situation and seeing other children in the ward, "and I think… yeah, you just realise how lucky you are." She has many roles and responsibilities she seems to attempt carrying – and draws strength seeing their family values at work, with Nancy caring for her little brother.

They finish with an account of their visit to an outpatient appointment.

> ***What does that mean? These are all the questions that you don't process at the time***
>
> When we walked in with the appointment there was people everywhere, people sitting along the corridor and everywhere and we thought it's going to be a long wait… but they were really, really efficient. In and out
>
> When I got out I thought, "Oh… didn't ask the doctor that, didn't ask the doctor that."
>
> The doctor was pretty much, "Oh yeah that's looking good and da de da da". As he was walking out he was turning round and we were still asking his questions as he was walking out the door
>
> Then we got through to the other room and they were fitting the moon boot. The lady just came along and started pulling on the sock thing that goes on before the moon boot and I'm thinking, "So are we going to clean it or…."
>
> So I said, "What happens with showering and stuff? Is it okay for him to put his foot inside the shower?"
>
> She said, "Mmm okay, no. Um, just get him to make sure it's not sopping."
>
> I tried to clarify that and I said, "Okay so he doesn't need to put his foot out." And she goes "No." I said to her do we need to put anything on it? And she said, "No, no, no, no, just you know. Just wet it with water."
>
> There are questions…
>
> I don't know. I actually don't know

Again it is Cathy who has the storytelling role here as it was her who that afternoon had been with Dan for follow-up. The closeness of the event means the questions are real – they genuinely are still uncertain what is happening. Cathy acknowledges that she feels ill-equipped to take a more assertive role, "you don't want to be one

of those precious parents who are always driving them nuts and telling them how to do their job." I ask if this is important. Without using the term, she shows how her cultural values impact on her behaviour in these situations, "I think it probably is for me... you know. Well, me being me, that's my personality anyway." She admits that even phoning back with questions could be challenging, "I'd get Marty to do it... I start off apologising and go, "I'm really really sorry to ring you and to bother you and I know you're a really busy person but can you just answer this question?"" For the other characters in this story, this turmoil is invisible – they have done the technical aspects of their roles, and Cathy and Dan have left. They are unaware that the family have unanswered questions and carry their concerns home again. Marty adds here that it is not always easy, even if you are assertive. The novelty of the situation leaves parents on the back foot, "I think as you process stuff... when it's happening... but they're doing it, they're busy... they're rushing... they're not thinking 'now what are the consequences of... that I need to think about... that I should ask about.' Are they important? They didn't tell us... so therefore you have to assume they are not important."

So the stories end with a "So there you go", indicating that they have given something of themselves to me – hoping I have received. I recognise the gift and similarly hope I have received it well. They cannot yet tell a restitution story because they have too many unanswered questions, many of which have not been given forum to be voiced. There are clearly aspects of quest evident as they have reflected on the experience and ways that their family values have sustained them throughout. And there is evidence of chaos, times when the story they expected to unfold played out differently and without apparent cause. And it will continue for them.

These four stories span several years and occur in several different places. They are each distinct and highlight both care received as well as times when families perceived that care was not present.

These families experienced care when the acute needs of their children were attended to – but additionally when they were treated as an individual rather than just as a diagnosis. For example when Dan is recovering from an anaesthetic, there is an expectation of routine interventions – but it is in attending to his adolescent food preferences that his mother notes care happened.

As in nearly every case the child's health was restored, many of these stories take on the expected restitution narrative form. Within that broad narrative trajectory, however, are examples of chaos. These tended to occur when parents felt uninformed or excluded from their child's care, or when the care they expected failed to arrive. All the families, even with those most familiar with the healthcare system seemed to have experienced a mismatch between what they expected and what actually occurred with staff and nurses. There are recurring threads of "I don't know" that indicate aspects on incomprehensibility in their experience – making the task of finding meaning all the more difficult.

There were also examples of staff supporting and understanding them as families – though even when this didn't occur, the families seemed very resilient and sought out support from other sources, often other families.

The stories of these two chapters have come from families who have had hospitalisations that were likely to be self-contained. Chapter seven focuses on the stories of families whose experience of hospitalisation of a child was part of an ongoing/chronic illness. For these families the development of relationships with nurses continues on over several months or years – whether they are mutually appreciative or not.

Chapter Seven

Nursing Care for a Child Requiring On-going Care

"All stories are part happening and part imagination. What is important about them is how people use them to make sense of their world... I may ask, 'what if this is true? What then?'... what are the multiple ways this story could be seen and constructed? What are the shared meanings we can take from it?" (C. Davis, 2006, p. 1234).

While there are overlaps and similarities in some of these stories, it is from their different perspectives that it is possible to gain understanding of the social worlds they emerge from (Bourdieu, 1993a). By listening to the illness narratives of recipients of care, mindful of the socio-cultural forces that shape them, healthcare providers can better meet the needs of those we serve (Garden, 2010).

Introducing the context of their stories

Each of these families had multiple admissions to hospital for ongoing health issues with their children. Their experiences span several different areas of practice over several years. While the first admission for each child was novel and likely distressing, these families have had multiple and long term admissions to hospital with a child. These families have had to negotiate the hospital system over an extended time frame and view each experience from the perspective of previous experiences.

The ongoing nature of the relationships between nurses and families of children with complex health issues causes challenges for both (Avis & Reardon, 2008). Avis and Reardon (2008) found that parents view each hospitalisation as part of their developing narrative, whereas any one nurse may not be aware of the continuity of their story (Cushing, 2007). Parents are keen to have their expertise acknowledged and incorporated into the plan of care (Betz, 2006) – expertise that has developed over a sustained period of time and becomes part of the family narrative identity.

Families of children with complex and ongoing health issues must grapple with experiences that do not conform to the culturally preferred restitution narrative (Fisher & Goodley, 2007). Listening to the politicised and culturally shaped stories these families tell offers insights into the structures that influence their experiences as individuals and as a group (B. Smith & Sparkes, 2008). Parents, but particularly

mothers, have to manage their children's health while also negotiating societal expectations of their behaviour (McKeever & Miller, 2004). McKeever and Miller (2004) suggest mothers of children with complex health needs negotiate a challenging balance of advocating for the child or deferring to the dominant habitus of healthcare professionals. Being mindful of the competing narratives within their stories allows these personal dilemmas to be seen in the social context of their making.

Sontag (1978/1990) suggests those with chronic illness must negotiate both the world of the well and the world of illness. The stories they tell show how it is possible to straddle these different contexts (Frank, 2006). In the context of families the health issues of the child impact more widely than just the child (Carter, 2002). Hearing and reflecting on families' stories of chronic illness and suffering provides insight into their experience in the hope of becoming better equipped to meeting their needs (Chesla, 2005).

As with the previous interpretive stories – the accounts of these three families are re-presented to capture the understandings as they developed in conversation together:

> Turn towards rather than away from families' suffering... refuse to reduce family experience to a problem to be solved. Examine everyday life in families via their knowing that and their know-how. In articulating family experience, take risks in presenting the poetry and reality of families' lives. Demonstrate your part in constructing the story, your input in interpreting the story, and your responses to what you've learned (Chesla, 2005, p. 385).

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Carina's story

	Temporal flow
Titles	*And it was basic nursing...*
	And he listened...
	She had to stay in hospital
	You really need people to be kind
	It was a really miserable evening. I felt unwelcome... and I was glad to be sent home
	I was possibly in a low at the time
	But you know, they could have done it when we brought her in at 10 o'clock at night and saved us all a huge frigging drama

Orientation

Carina, Glynn: Elise; Nadine; (Teresa)

Carina heard about my research through a colleague putting the word out. Emails had been exchanged. And after some negotiation, we arranged a time that suited her. Carina had agreed to meet me at my work. "It's just as easy for me," she said. So I booked a room out of the way that hopefully wouldn't be too noisy. It wasn't going to be a family interview – but as well as having had her own children in hospital, Carina had also been significantly involved in the hospital care of her friend Melissa's daughter Teresa. She was therefore going to be talking representing two families.

I had to apologise for the coffee – it was a step up on instant... but to Carina's standards, not much of a step. "Good company then?" we joked. We chatted for a while – I asked about her family and we compared school parent stories. Both appearing clearly at ease, I pressed record.

And it was basic nursing...

There was one night with Teresa, we were coming home from dinner with my parents, it was about ten o'clock at night and Melissa phoned. She was crying, and Teresa had a fungal infection that had grown out the back of her leg. She was in a hip spica. It had gone up the back of her leg and into her bottom and everything... It was unbelievably itchy and unbelievably painful... no room for her on her normal ward.

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> Melissa [my friend and Teresa's mum] was crying and Glynn [my husband] dropped me at the hospital and went home and I went up and... Teresa had been there all day.
>
> Melissa kept saying you just need to just give her something for the itch and they didn't want to give her something because they weren't sure it was going to clash with the chemotherapy and all that, so they ended up doing nothing
>
> And nobody was doing anything and what happened was Teresa needed to go to the toilet, it was too painful to go to the toilet... we tried to put her in one of those... wheelchairs with the loo in and sit in... and I left the room and stood outside and Teresa was... screaming... like a feral animal. It's disgusting to hear.... I stood outside. Helpless.
>
> And somebody must have put a call in because the guy came from the other ward and... he instantly said "why haven't you put her up on an IVF drip for antihistamine for the itching, for this, this, this,"
>
> It was just basic stuff and he was furiously, swearing at them and everyone was scattering and running... but you know... she put up with it all day

There is an intensity here draws us both in. Carina talks fast – but there is much to pack in to her story. I struggle at first to keep up. These people are so significant to Carina and the experience so close to her that there is almost an assumption that I can picture it as well. This is a deeply intimate story – Carina has leapt straight to interpretation – what happened almost seems incidental to the overriding sense that an injustice occurred. But for Carina this was deeply personal. She and Melissa had been friends for many years, and now had shared some difficult moments together, "I was there when the surgeon came out of the operation and sat [Melissa] down and said "Your daughter has got cancer." So while Carina was not 'kin' to Teresa, they were family. The families had previously discussed Carina being guardian for Teresa should anything happen to Melissa.

Carina reflects and theorises simultaneously as she tries to make sense of what happened. There are tense changes and interruptions to the flow. These are typical of chaos type stories where the line between the present and the described story are not clear (Uehara et al., 2001) There is also a lack of agency apparent – all she could do was stand outside the room, worried she was going to throw up herself – powerless to a child's suffering. It is a powerful moment within the interview as we both picture the events she describes. I ask, "Why?" Carina has thought about this, "because they were scared and no one was in charge." This seems to directly reflect Carina's own predicament. Everyone involved seems powerless in the face of this tragic situation. And while Carina has a response to my question – it is not as certain as it seems, "I think... I don't know... I don't know... I

think" – there is only grasping for reasons that remain elusive. This is clearly chaos narrative where the situation seems "devoid of effective action... vision of how awful life can get" (Frank, 1998a, p. 202). Carina adds her attempts to make sense of what happened, possible explanations – but cannot find an acceptable rationale, "it was sort of shocking to me how much they seemed to not care about this little child."

There are some master narratives (H. Lindemann Nelson, 2001, p. 6) that are challenged here. Nurses are supposed to care. Children are not supposed to suffer. Relief is meant to come quickly. The system is supposed to work. Perhaps Carina has no conscious choice but to tell a chaotic story when so many common truths are being challenged. The account may cause a "but is it true?" That question immediately calls into doubt the veracity of the storyteller – perhaps they got it wrong (H. Lindemann Nelson). Carina offers the account of one who was there (told as filtered from here and now). Truth is not the goal of narrative inquiry – it is myth that objective truth is possible on retelling (Yiannis, 2004). However, as an aside, Melissa (unprompted) tells of the same episode in an interview months later – the verisimilitude of the account seems assured. Carina continues with the account.

> ### And he listened...
>
> Well, the next morning. On Oncology, the rounds were at 7 in the morning, so I'd sort of catch the ferry at 6 and be over there because sometimes Melissa was trying to keep her job going at the same time... and I would go in the morning and do the morning rounds... Melissa would go off to work
>
> That particular morning I said to the doctor what had happened the day before... because they were talking about hydrating her and getting her ready for her next chemo. 24 hours of hydration and she can't go to the toilet because it's unbelievably painful. I said, "What are you doing, talking about?" And I'm saying "you can't be talking about hydrating for the next 24 hours when she is too frightened to even wee because it's so bloody painful and it's obscene the amount of pain she was in last night. She was scratching and biting Melissa and screaming like an animal. She is a child and you can't expect her to deal with that level of pain. It's disgusting and you know you have to get her pain under control before you do anything else with her. It's wrong."
>
> And he listened... they instantly then stopped treating the cancer and focused on getting the fungus cleared up

This must be what Frank (1995) is talking about when he suggests hearing chaos stories can be like being sucked into a vortex. We were both drawn into the story. Hearing that someone responded to the suffering feels like being able breathe

again. This is like two sides to the same story – in the first half Carina casts herself as powerless to act – while the next morning she is advocate and champion for Teresa. "And he listened." Before there was "nobody" and "what was happening" as the agents of the story - here Carina speaks of "I" and "he" as active participants to what happened. There is no cure – just listening. But it changes the telling of the story. In this story there is no theorising – it makes sense on its own. The behaviours of these identified individuals seem to lift the story out of chaos – listening; telling the truth; not looking away when it is tough. This seems to be the face of care – that the narrative of this child was believed and responded to.

Carina orients her story by legitimising her place in it – she supported Melissa by sharing the emotional journey of being family for a young child with cancer. It seems she is reinforcing that despite not being officially family, being family – where there is an intimate sharing of important interests (J. Lindemann Nelson, 1992) – is demonstrable. This is not a position held by all nurses however (Hall, 2004), which is perhaps why Carina feels the need to reinforce her role here. Yet having claimed that position, she is drawn in to this experience of vulnerability and confusion, where previously held expectations no longer seem adequate (Palmer, 2007). Palmer (2007) suggests that counter-stories told in response to oppressive institutional narratives of hospitals are rarely adequate to restore hope and integrity. In this story, Carina holds up the example of the doctor coming in, listening and acting – yet nothing can take away the suffering that has already been experienced.

Carina continues reflecting and trying to make sense of what happened by telling more stories.

She had to stay in hospital

Another time Teresa was coming out of an operation and had a… urinary line in and they were taking it out… She couldn't control the bladder because she hadn't gone to the toilet for a week

So she'd wet the bed… enormously and I'm calling for a nurse and they're sitting at the station… and they're looking at me and they're saying, "Your nurse is coming." Teresa was sitting in the bed full of her urine… Melissa just wanted to get out of hospital. And the nurses were sitting at their desk. Couldn't get off their arses and come around. And the cast was soaked in urine; we had to take it off. And no one said sorry, and I yelled at them for being so incompetent to do this to Teresa

So she had to stay

And Teresa cried... she thought it was her fault

The injustice of the situation is apparent to us both. Carina tells the story without requiring prompting – all I do is clarify, occasionally asking for more details to help me understand. The narrative thread is intertwined with reflection and theorising, "I'm still the adult there, I should have spoken up or... I don't know, grabbed hundreds of blankets... you know... I didn't know." It is as though the irrationality of the situation has removed the possibility of active agency (C. Davis, 2006). The points of reference that help make sense of life outside the hospital seemed useless here (Palmer, 2007). This story is given another backdrop – it seemed to drive a wedge within the family – Carina reports that Melissa did not speak to her for days after this – that she felt let down by Carina, "she'd said to me, 'Make sure they'd done this.' She knew what needed to be done." So even though it was an issue of the technical skills of the nurse involved, the consequences were borne by Teresa and her family. The most vulnerable in the situation made further vulnerable. Carina attempts to make sense of it - suggesting that it may be as a result of being on different wards, or individual nurse competence or language ability – but it seems inadequate to her. The idea of nurses not caring is raised again, "Oh, I don't know if they are just so surrounded by anxious parents that they... have a mechanism where their empathy level just... doesn't kick in anymore." This story runs counter to the prevailing narrative that nurses care – and that seems to overwhelm the story of a small child calling for care.

You really need people to be kind

But this one particular nurse, she really didn't like Melissa and Melissa hated her... this nurse was sort of quite nasty... and I remember wondering what the fuck she was doing nursing, and she did things like... Melissa was in the room everyone hated... she had got up and turned the light off in the linen cupboard, or the meds cupboard which was directly across the corridor from this room with the big glass doors, and she'd turned it off. It was like 2 in the morning and this nurse comes back and turns the light on then goes back and sits in her station. So then Melissa has to get up and find tape and tapes paper up over the windows and the nurse comes in at 6 in the morning and slams the door open, whacks it into the bed, you know, kicks people around. You know just... nasty... But she was like the one; most of them... were kind to you

This sense of meaningless events continues – there is a lack of purpose in the stories. But chaos stories need to be heard (Palmer, 2007). This account is counter to the expected story of warmth and affection toward children and their families – it is uncomfortable. But as uncomfortable as it is to hear, this is how the

experience is told, "you really need people to be kind to you." In this story the space becomes another actor in the script – she describes the room, the windows and lights because this is the space that contributed to the experience. "You need people to be kind" because the space was not well designed; because it is hard to sleep when light streams in; because nurses cannot even come in to the room without banging the bed and waking you up. "You need people to be kind" because you are coping with the anxieties that surround mortality and pain. Carina's story juxtaposes "most of them were kind" against a story of the absence of kindness. The environment is an important factor – but it is the people who act within it that lead to the presence or absence of care.

Interestingly, while this is Carina's story, it is not Carina's actual experience. Carina tells it as thought she is present – yet it must be a story relayed to her by Melissa. Nevertheless it is presented by Carina as representative – an example of practice. This is not of narrative concern – as family, they would have shared stories and compared experiences at the time, as well as subsequently. It has become their story so it has narrative truth (Seaton, 2008). So while she was not present, the story is full of descriptive details (some excluded as they include potentially identifying characteristics). This further reinforces the likelihood that this story has been told several times before until it has become almost a metaphor for the absence of nursing care. Metaphors are useful pictures to capture invested meaning (Frank, 2008). In this picture, the absence of care is evident when the nurse does not look, speak or act according to the expectations of a caring nurse. This representative nurse seems to consciously act 'against' Melissa, putting her in the 'worst' room, and ensuring that the experience was unpleasant. The converse perhaps offers a glimpse of what care might be – personalisation, accommodation, kindness, and sharing of resources.

In the discussion surrounding this story, Carina describes a tentative trust in terms of relationships with nurses. She described how parents stick together and tell each other each others' stories to compare notes and experiences. It seems this is safer than complaining to nurses at the time – "But you don't say it… no… because you don't want them to take it out on your child… no, lots of bitching in the linen cupboard… between parents… oh god, yeah." This reinforces the vulnerability that parents seem to feel in relation to nurses and the care of their children (Avis & Reardon, 2008). This seems to remind Carina of other positive things. She

augments the story with other narrative threads – for example, a side story of a nurse who "had your back and had your child's back", an important consideration for families (Heller & Solomon, 2005). While not giving examples of what behaviours demonstrated this, Carina did describe that nurse as, "like a really good girl friend" – which when there are weeks in hospital away from real friends must be of some comfort.

I ask Carina, "so kindness matters?" "Yes" – and this prompts her to describe the opposite of this metaphor – nurses who were kind to them. She describes a nurse as 'a rule breaker' who gives Teresa some pain relief before all the protocols have been followed, "he's just, 'Fucking put it in her. I'll deal with it later. She's dying.'" This seems about both parent and nurse being centred around the needs of the child. Carina can see it – and is relieved when the nurse responds to the humanity over the system, "I mean they could have let her carry on suffering and not seen the bigger picture. Fortunately it wasn't going to kill her, she's dying." And more than this. Nurses who shared their lives, who "built friendships with us... made you feel that your child was a little bit special" – these were the nurses who made the unbearable bearable.

A development evident as the stories progress is the change to Carina and Melissa's identity. They are no longer the 'newbies' – Carina notices the new wave of admissions of children as they come in – "they've got hair! And the parents still decorate their bedrooms." The unspoken corollary to this is that Teresa does not, and that her cancer is not cured. This context cannot be removed from the stories. They have gained insights and skills in navigating their way through the system, "we were constantly studying the nurses, tone, look, turn of an eye, body language... you're reading signals the whole time to try and get the full picture." But these skills are inadequate to change the now inevitable. Not long afterward, Teresa dies. But it is not the end for Carina and her family's stories.

> **It was a really miserable evening. I felt unwelcome... and I was glad to be sent home**
>
> Not long after Teresa died, Nadine was hospitalised. It was ten o'clock at night, and we'd gone up to Osmond St Clinic and... they'd taken one look at her and said to me, "Go straight to hospital." It was horrible actually, and really stressful... because Glynn was overseas
>
> Nadine had been sick and then... had gotten all sort of floppy and feverish. They were waiting for us when we arrived. I walked in with Nadine and they were like, "Are you Carina?" Put us straight through... and instantly sort of

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> opened up her shirt and started circling all little spots on her body. She was just completely out of it. She'd passed out. They took blood samples and stuff.
>
> It was just ugly... really. Just sitting there, because the nurses and that, had all looked at me when I said she's not immunised. And it was like, oh fuck... because they thought they were dealing with meningitis...
>
> Totally attitude... and I was sort of left lying on this chair and I said to them "are we going to be let out because I've parked out in the car park." They said, "Oh no you're in for the night." I said, "Oh okay." Then they said, "If you look in another booth there may be a chair that you can sit on."
>
> That was it. Then they told me I had to go and move the car.... so I was wandering the hospital in the dead of night like I used to looking after Teresa... I was glad to be sent home
>
> So that was pretty... miserable and she was fine and they sent us home

These final stories relate, not to Teresa, but to Carina and Glynn's own children. They are the continuation of Carina and her family's experience of hospitalised care. Carina acknowledges that the experience with Teresa and Melissa has influenced this (and all subsequent experiences). This is not to the detriment of the story – all experience is filtered and reflected on in light of previous experience (Yiannis, 2004) – every story is coloured by other events – even by being asked to recall it at this time. In this story "I was glad to be sent home" Glynn was overseas at the time. Despite this he sends an SMS text to support Carina and acknowledge the significance of this visit so soon after Teresa's death. So in this story she is alone. She does not have anyone to come and relieve and support her. This perhaps makes the response she gets from the nurses feel more pointed.

Being back in the same building seems to have brought back the memories of Teresa's hospitalisations – she augments the story with more details:

> you sit there and you see your child lying in hospital and all the stuff we'd done with Teresa the previous year... where you fix their little bed sheets and you tuck them up around them and you make them cosy and comfy, and you do all that mothering where you think you are saving them... and it gives you comfort as a mother and here I am... with the same bed sheets and it's all so familiar and the orange paeds' sticker on the IVF stand and it's all so familiar. Yet I know that actually, it's not saving her. There's no safety in any of it. There's no comfort in any of it

Carina acknowledges that it is the unease that this familiarity brings that contributes to her feelings of powerlessness. Her role of mother is called into question – doing the 'motherly' caring actions that she had done with Teresa had not saved Teresa – and here it might not be sufficient to meet Nadine's health

needs. She cannot comfort her daughter, and she does not receive comfort, "they were just mean..."

Carina affirms her stance by demonstrating her health literacy and awareness of issues related to children. She recalls a child who was disfigured as the result of meningococcal disease whose case was extensively covered in the media. She discusses the merits of immunisation and the behaviours of pharmaceutical companies – in the interview she is clearly trying to demonstrate that her stance was not without reflection or thought. I do not engage in the issue, but do acknowledge the challenge of getting it 'right' as a parent.

The story is intertwined with reflection – attempts to make sense of what happened. Carina tells of the perceived change in attitude towards her when the nurses hear that her child was not immunised, as though she had her rights withdrawn from her. "I didn't feel like I had the right to even ask for a chair" leaves her physically without a 'space' to belong in – should she sit on the bed? Where does she belong? It is even more perplexing to Carina because the decision to not immunise had not been made lightly. Her parenting skills were on show to the healthcare professionals (Darbyshire, 1994; White, 2002) and found to be wanting. The blockages in information are cast as punishment for her deficits as a mother. But even in this position, Carina offers explanation, "you look back on it and you think... you don't know what's gone on with them that day, you don't know that they haven't had to deal with some...dumb parents doing stupid things to their children all day long.. and, you know, I was the last straw, but it was unnecessary.... again it's just kind of mean." It is important for Carina to demonstrate that she is not one of those "dumb parents" – to me in the interview, and to the nurses in the middle of the night – to anyone who will listen.

I was possibly in a low at the time

Then she was hospitalised again a few months later. The doctor kept saying, "Just keep an eye on her." I let it go on for about 6 weeks and... she was just losing weight and losing weight

We went into hospital and that time it was a much better experience

The staff were friendly and they got me a chair and I got to drink disgusting coffee... then they admitted her and she was there for about a week.

They sent a psych into me; they said, "Would you like to see somebody?" And I said, "No, really I'm fine." So they did send a Psych lady in, who was horribly embarrassed, and kind of forcing her way in on me and insisting that she see me, and it was just really funny.

I was absolutely fine.

Carina seems aware that there is a struggle evident in these stories, so offers this one to counterbalance the chaos. It is still clearly important to Carina how she is perceived by the staff – that she is seen as a good mother, for instance here where she brings Nadine to the doctor, but it is the doctor who kept saying to wait and see. This shifts the accountability for what happens to the health workers rather than her as a mother, the implication being, 'see – I did the right thing!' While the staff's concern was reassuring, Carina is at pains to project togetherness, "they could see I wasn't stupid... maybe they felt I couldn't ask for help and they were just pushing it to give me the opportunity." Even in the interview Carina suggests she feels a bit embarrassed about the whole episode; that perhaps the admission was to care for her rather than Nadine. She goes on to describe the stay.

> ***In the week that I was there…. I didn't develop a relationship with anybody***
>
> We had a little room all to ourselves and that always makes you feel a bit special
>
> They didn't know what was wrong with Nadine, so they put us in infectious diseases... They just left us alone and they got on with just trying to find out what was wrong with Nadine and... kept me up to date with everything... didn't pretend that they absolutely knew what they were doing... because they really couldn't tell... it took them ages to stop the vomiting too. It took a couple of days
>
> We were pretty much opposite the nurse desk and you got sort of the two doors that you can close there... and we were left alone. The nurses were always at the nurse desk. I'd sail past in the morning and say that I was popping out to get coffee... 'Nadine is sleeping or Nadine is watching TV," and they'd say, "Okay." And that was it.
>
> They must have come in to do blood pressure and things like that... they were doing their best

This story adds to the gap between Carina's beliefs about nursing and their experience. There is little by way of narrative action – nothing in particular happened – what is present is descriptive details and argumentation of additional stories. This prompts a memory of a cold night – and having to find extra blankets for Nadine and herself, by herself. The implication is that even basic human needs were not attended to. Carina takes an active role in response to this, showing herself to be resilient and able to meet her child's needs. Though she does not say when this happened, the fact it is cold may indicate it is winter, a time when children's wards are particularly busy with sick babies. This is not a reason for failing to engage with Nadine and Carina, but may be the context in which the

recalled episode occurred. Families often report that nurses are busy, and do not like to add to their busyness (Avis & Reardon, 2008; Darbyshire, 1994; Price, 1993). Carina here contrasts the fact that the staff were worried for her, yet it is she who must meet the fundamental needs of her child. The lack of relationship is as evident in her evaluation of the story "I didn't develop a relationship with anyone" as it is in the description of the nurses, passive, sitting, with the only word they are remembered as offering is "okay." The contrast here is with the relationships the families developed with the nurse while caring for Teresa.

The narrative lacks restitution qualities – no one knows why Nadine is sick, and while she gets better, the chaos is evident in the meaninglessness. She is there with her sick child, but "I didn't have to ask for much, but I also made sure that I didn't either." Carina takes the active role here, actively managing their relationship with the nurses. This is the work of families, on top of caring for their sick child (Wright & Bell, 1981/2004). Even from the vantage point of the interview it does not make sense for Carina, "I didn't want to be that lame arse mother that's making everyone's life difficult… And yet you're there with your sick child and you're really vulnerable, yeah."

The interview continues – but there are no particular stories of nurses and nursing care. There is description – details added to the events already described; and further theorising – pulling at possible meanings to explain her sense of care missing the mark. This lack of narrative structure is further evidence of the unconscious falling into chaos storytelling – "you know what… I think a lot of it is…. I think that with nurses… I think that…" There is grasping for purpose and sense.

And then suddenly the end. "Anyway… [pause]… an experience." Life changing and formative interactions with the healthcare system and the people working in it, relegated to… 'an experience'. The interview closes and we both feel wrung out – even the retelling has been an experience. Carina emails later and admits this was hard work – harder than she anticipated. The recollection of experience that even now feels chaotic, continues to sap and drain her. The stories take on the character of chaos narratives when the situation they describe fails to resonate with 'self-story' – the sense of identity of the storyteller. So here Carina believes she is, and has demonstrated herself to be, a good mother – yet the actors within the experiences she describes question this. When Carina's world view and cultural

habitus (Frank, 2010b) is challenged, a dissonance is created that perhaps leaves her without her normally trustworthy points of reference. The healthcare setting is a particularly challenging environment where diversity of culture (individual and institutional) will frequently co-exist uncomfortably with the habitus of healthcare users (Lo & Stacey, 2008). The environment of the interview provides a forum to unpack and retell what happened, in an attempt to convince the listener that the storyteller's perspective is in fact correct. But even being heard cannot undo the sense of injustice and disappointment in these stories – it is cathartic to tell; it is hopeful to be heard – Carina now has to trust those who hear her story.

Beth, Peter, Karl, Sian and Isaac's story

Temporal flow
But eventually I got used to it.
When they put that monitor on him I get that real, I feel like I'm going to be judged
He really took it onboard
She actually taught me how to look after him in the hospital
So same building different experience… hugely. Hugely, different
But it just feels like being caged in…
And he still stresses about getting it taped to his face
I quite like that sort of…. being in control, in a sense

(row label: **Titles**)

Orientation

Beth, Peter: Karl; Sian; Isaac

Daylight savings is great when you have to find an address in an unfamiliar part of the city. As is Google Earth™ - I recognise the fence and the house as I come around the corner. I check in the mirror – impressions matter – and collect all I need. Beth greets me at the door, "yes it is still ok… I hope what we have will be ok… Zac is in bed already as he is not feeling the best – will that still be ok?" I feel warmly welcomed. We sit together at the kitchen table, "Come in Karl. That man is here who wants to talk to us." Karl and Sian sit very politely and wait to see if I will open the chocolate biscuits. I open them – but to my embarrassment and their delight, the heat of the car has melted the stacks of biscuits together. "I've only got one!" But it has broken the ice. The kids and I spend quite some time talking together – I am aware that Beth and Peter are listening and participating quietly, but I want Sian and Karl to feel comfortable and willing to contribute. Family interviews bring everyone together, but not necessarily the children's voices (Bennett, 2008). The effort seems to have worked, though. When I push 'record' Karl is quick to speak.

> **But eventually I got used to it.**
>
> I just started school, and when I was still in my first room and the teacher said, "Okay write down your news from the weekend."

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> I wrote 'my brother went into hospital. So I went and stayed with my grandparents. We played on the bikes and went in the pool. It was fun.'
> Eventually I got used to it …yeah and I'm quite used to the hospital

Karl seems comfortable participating. I am pleased, as having family interviews was one of the aspects I was keen to have distinctive in my approach. I had read about some of the challenges and strategies to enable this (Curtis et al., 2004; Docherty & Sandelowski, 1999; Moore et al., 2008). I knew that literature demonstrating children's views around families and hospital care were scarce (Dickinson et al., 2006), despite their being cognitively capable of giving helpful contributions (Irwin & Johnson, 2005). So I felt privileged to have this young boy sharing so willingly.

Beth added that they have had more than 35 admissions – so it has been a regular part of their lives through primary school. The underlying causes for Isaac's ill health do not seem to be known – "he is a bit of a mystery case." For me the label is not important – I am here to listen to the family's experience. The lack of a name for the diagnosis here helpfully inhibits a reductionist view of the family being grouped with all others who share the label (Frank, 1998b). The focus is the family.

Karl admitted that his 'being used to it' has taken some time, "I was a little bit nervous, a little bit scared, I was never keen on hospitals". He also mentions a personal experience, "because I had a bad experience. Something that happened to me. So it was a bit scary". This story never emerges, however. It was mentioned here, early on in the interview. I tentatively prompted for anything more – but Karl had moved on. His account of being five and having his brother in hospital is straight forward – and shows how having a sick sibling becomes part of the family narrative identity. This is a story that has been told before, and is now part of the family identity. He positions himself within the experience – none of the 'clinical' information seems necessary – he is five and he got to spend time with his grandparents doing normal developmental fun play. Karl has been hospitalised himself – but this story seems not to be about that – having a sick brother/child is their story. Beth fills in the details.

When they put that monitor on him I get that real, I feel like I'm going to be judged

He got sick and then he started keeping on getting sick… and I struggled, I really struggled and I still struggle with the whole hospital. Of when to take him in and quite often he's …….you know…

And depending on who you've struck, they'd either be really condescending like "You're over reacting and you have to go home" or you'd be away for the night

I feel like I'm going to be judged, Like "Oh 'over-reactive mother' – she's back again." I've heard...

Both Beth and Peter contribute to the story – this is a mother's experience – but Peter has been there with her and stands beside her (in the telling as well as at the time). This simple account is supported by lots of talking around what happened. They theorise: "he did really well and then he just didn't and I think I was just completely distracted" trying to make sense of what happened. Peter is much more pragmatic, instead focussing on the systems and people who ask the same questions over and over each of the 30+ visits, "You just feel like shaking them and saying this should be on your computer, you should be able to pull that up, gets this kid's history, read it, then come and see me and see what his current status is... but you know?" This calling on common sense is a clue that their understanding was not reinforced in their experience – and a call to me as the story listener to position myself. There is no need or time – the chaos of this situation leaves little silence as Beth and Peter's recollections spark new comments and thoughts.

The situation is augmented with other occasions, "I remember going through outpatients and the specialist saying, "What are you doing here, you need to be in A and E with this kid." Beth is clearly still uncertain about what it is that health professionals expect from her as a mother to judge the wellness of her child, "It took me years and even now I don't feel confident that I can judge that with him. It's really hard to judge."   It is this feeling of their judgment being judged that seems to have triggered the story, and its multiple permutations, "some reactions have been less than complimentary." The narrative structure is chaotic with different incidents blurring with each other – the particular clearly less important than the meaning of this telling – "how can they act like that?" (Frank, 2002a). They seem trapped by people and systems. Beth describes one person they seem to keep meeting who, she feels, undermines her as a mother, "They said to me, 'we think he might have reflux, we might have this' and I said, "I thought that's what it might be" and as he walked out he said, "I love these mothers who think they are such internet doctors."" The tension between the expertise of parents and healthcare professionals is common (Le Fanu, 2004). But this puts the family in the unenviable position of being judged for their involvement – whether it is being too interested, or not enough. Peter expands on this as he describes their

advocating for Isaac, ""Okay we'll get him taken for an X-ray," and we're like, "No you are not going to take him for another X-ray, he's had too many X-rays." "Okay, we'll give him some asthma medicine." We go "No don't give him asthma medicine, we've tried that and it doesn't work."" Peter cannot understand how the system can be so inefficient and unable to cope with a child who is so frequently admitted. This conflict between the habitus, or dominant story, of the institution and that of the family goes to the deeply held positions of each (Frank, 2002a). Health professionals-as-expert seems to sit uncomfortably with parent-as-expert (Yiannis, 2004). Yet the parents dare not renege on their vigilance over their son – for instance, they carry knowledge about certain tapes reacting with their son's skin, yet have experienced staff not wanting to hear it, and unwilling to look it up because his file is too big. Beth reports carrying tape with her now, but if "I haven't got it in my purse… I'm the one to blame." The way they tell the story they seem powerless to change anything. They have picked up the language of the clinical area, but even this does not help them be believed, "in there it's busy and he's just sitting on 94… and I know he's going to drop, so we don't want him at 94… so I'm like… I'll go home and come back… we know if we come home at that stage we'll be back within 6 hours or less." Despite understanding peripheral oxygen saturations and being able to assess their son – recognising change and deterioration – they do not feel their perspective will necessarily be heard. Lay knowledge is overridden by that of the 'expert' who has control of the procedures (J. Harden, 2005).

Karl has been quietly listening. Digesting more than chocolate biscuits. "Who was that 'he' you keep talking about?" The parents know their concerns are real – but own them for themselves. They know that with their ongoing relationship with the healthcare system the children need to be comfortable with the healthcare providers. As part of their role as parents, they try to protect Karl by minimising the issue, "I don't know… just a doctor…" and move on quickly.

I didn't know how to… like there was stuff that I was scared to touch and do stuff

He got rotavirus one time, he was really sick. He was really sick… and he was still a baby… and he was on oxygen… and he was on a drip. He was attached to everything.

He was vomiting and vomiting. Isaac vomited all over the floor and then got diarrhoea while I was trying to figure out all the things and a nurse came in and she wouldn't clean it up because that was the cleaner's job and the cleaner didn't come in until the morning, and she wouldn't sort of help me. So I ended up trying to bathe him and I didn't really understand any of the

equipment, trying to change the bed with all that stuff… if they want me to nurse – which is fine, I'm happy to do that… they need to acknowledge that I'm there doing that stuff and that I don't often see anyone for hours at end. It's really weird

I don't know…..Well I don't know…. I coped

Beth tells of having a sick baby – away from the known and familiar environment of their own home – capable of mothering her child, yet having to cope with a system that does not support her in that role. She speaks of herself in the singular pronoun "I", accentuating her sense of isolation. She speaks of her actions as uncertain, tentative, "I was trying… I ended up trying… I didn't really understand… I don't know." The irony here is that in a ward she will be surrounded by other families and by staff – yet Beth describes herself alone.

This triggers a reflection between Peter and Beth as they try to understand, the story unable to capture what they feel. Peter acknowledges that once Isaac is stabilised he is not the sickest child on the ward. The lack of a diagnosis returns:

> He's not a neurological complaint. He's not a urological complaint. He doesn't have a nice compartment where you put him and say "Right you can go on that ward"… So he's just this mystery. We just blow in the wind… So no one has really taken ownership. Except us! People get annoyed with us for owning it, they don't want us to own it… none of them were taking possession of that and said right; we're going to deal with this…What they're always trying to do was trying to get him off which I completely understand. They want to get rid of him

The sense of isolation seems to have become part of their experience – they have been in hospital all these times, yet it feels like they belong nowhere. In a system that codes admissions and discharges into categories of diagnoses (Diagnostic Related Group), and allocates rooms dependent on what medical team 'owns' that problem, to have no diagnosis is to have a vulnerable story (White, 2002).

This is not a clear narrative stream – it is chaotic, theorising mixed with fragments of experience, each overlapping the next. Beth describes sometimes knowing Isaac is not well, but feeling like she does not have permission to be scared for him, "I sometimes have this thing where I know that he's not feeling cool. I know, but I sometimes get this feeling that I'm not allowed to be scared, I'm not allowed to feel that." Even driving in to the hospital can be part of this – having a child in the back seat who has gone floppy and unresponsive – but feeling like the security 'guy' will tell you off for stopping in the wrong place. Needing a kind response somewhere.

From anyone. "I just want someone to go 'you're allowed to be a bit frazzled' but I always get that 'Oh God, just calm yourself down'."

Karl has clearly been intensely listening, "I didn't know the hospital was so bad back then." Beth reassures him, "these are just my frustrations." She worries, "I sound like nothing goes right – lots does. I'm not complaining… I'm just…" We talk about this being a discussion, and unpacking the experiences – that no one is thinking of it as complaining. Almost to demonstrate this they discuss what would make it more tolerable. Beth uses the analogy of a bridge to describe someone who would work with the family,

> It would be nice just to have a bit of a bridge. Almost like, "Alright ok, what are you worried about?" It's like parking - what do I do. "You know what… we'll get someone." Just instead of thinking "Oh shit, now what do I do?' Them saying, "This is what you are going to do. We're going to do this for you"… because it's all logical when you've been there 35 times, but not on the first few times.

She also identifies the ways the environment isolates them. She speaks of being stuck in a room down the corridor, afraid to push the button on the wall to get help, instead nervously putting her head out with an "excuse me. Excuse me." Once again this idea of parental expertise sitting uncomfortably is raised, "Honestly, I can't tell you how many times in the night we had the alarms beeping. I'd just reset it. I checked his oxygen, I put his oxygen up. Sure he's not going to die, that's fine but it's sort of strange. Just the whole thing is… strange." The aspect I note is not a parent 'touching the equipment' – but a parent feeling the need to. From the original story, the role of the family seems as unclear to me as a listener as it seems to Beth in her telling of it. She is able to openly participate in the physical cares of the child, bathing Isaac after he has vomited and had diarrhoea. Yet in feeling isolated and 'out of view', reinforced by the structural layout of the ward, and a sense that it is the paper work that is most important, the family also feel obliged to manage the technical cares of their child. What seems missing from this is the sense of negotiation of roles (Young et al., 2006b). Yet this is juxtaposed with another picture – Beth gives a fragment of an experience on another visit that feels less chaotic, "if I took him to the bath or the shower, I came back and they'd changed the bed for me." The scene still lacks personalisation ("they") but Beth hints at how personal it feels, "… for me." The difference between the two scenes seems to be how Beth portrays her sense of being visible to the nurses. In the first,

she feels that she carries the full care of her child, hidden away from view – while in the hinted episode, nurses did something kind, unsolicited, for her.

Beth seems uncertain how to move forward. "It has been really bad… but no… I shouldn't slag them." Patients and families are often aware of their vulnerability to the system and therefore hesitant to complain (J. Grant, Luxford, & Darbyshire, 2005). In this case, however, I did not think I represented the system – we had talked about me being a nurse, so the family knew I work/ed within the hospital context. But it is impossible to know what impact my social positions had on the way the stories emerged (Bishop & Shepherd, 2011 in press). I did not feel powerful in the immediate context – this was their home, these were their stories, at their pace – so I affirmed that I did not feel anyone was being 'slagged' and we talked about just unpacking the ideas. Telling stories is so intrinsic to our existence (De Benedetto, de Castro, de Carvalho, Sanogo, & Blasco, 2007) – Beth expresses her position, then almost automatically has to give an example – to tell a story to demonstrate what she means, "These were my frustrations… at that time we had a nurse…"

> ***He really took it onboard***
> That time
> we had a nurse
> she put a really bad
> inflexible tape
> on him
> I said 'he can't blink. You…
> … you need to take that off'
> but he started
> kicking up
> and she said,
> "I'll tie your hands down
> if you do that"
> he still repeats it to this day… several visits later to the hospital, he would still ask
> "they are not going to
> tie me up
> are they mum (or dad)?"

This story brings the whole family in. Even Sian, who has hardly spoken to this point, speaks up, "the hospital isn't really a fun place…" This simple incident has become so much larger for them as they have had to manage the impact on Isaac. Beth offers some explanation, "I… think it was a joke." Peter is not convinced however, "They're lucky I wasn't there. It really brought my heckles up." This is a physical as well as verbal response – Peter broadens his shoulders as he suggests

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this. Roles within the family are made clear in the way they retell their stories (Harter et al., 2005). Here Peter positions himself as protector – but unable to fulfil the role, "I wasn't there." Vigilance over their child is a role many parents will take, with negative experiences increasing their perceived need to be watchful (Heller & Solomon, 2005). The family position themselves as observers of what happened – there is no talk of negotiation or clarification. By noting the ongoing consequences of this episode, they flag that they remain responsible for a situation they did not create – which for a child requiring multiple admissions, is a significant stress.

Because of these multiple admissions, this family is in a position to critique the normally held cultural stories around children and healthcare. The ideas that everyone who works with children is special, or that the family will be centre of care, which they may have had or held initially, have been slowly critiqued and modified. Peter reflects on the place of nursing now, "That's my general impression of the nursing as it now stands... it appears to me that they take obs, they enter them in a computer, they hand out meals.... Pills..." It is perhaps because they have lowered their expectations of the nurses they work with that the above story is not more chaotic and angry than it might otherwise be. Ygge & Arnetz (2004) suggest that families who have frequent hospitalisations may be more critical than others. Peter and Beth patchwork fragments of experiences to try to make sense of their experience. If there is criticism, it is implicit (and perhaps unconscious) in their choice of stories rather than an explicit focus. They add further snapshots – adolescents on the ward at the same time who do not seem to be receiving any hygiene cares; having no hot water or heating in the room; babies not being cuddled. But against that they also give examples of staff who listen, who remember, who treat them as individuals.

She actually taught me how to look after him in the hospital

Like there was an older nurse I used to see sometimes and she was great, because Isaac was a real handful around any procedures and I really struggled to manage him

It's like there's all these unknown rules...and things... she would just say, "Isaac I've got 20 other kids on this ward; they can't listen to this carry on. Stop. And your nose is disgusting and you need a wash. Mum you need to do this." She taught me how to wash his nose and she was great. She took 40 minutes out of whatever else she was doing and she did it with me and you know...

Now when I see her, she'll go, 'I know that boy' and march down. "I told you not to make that noise."

I have to curb my intuitive emotional response to hearing this. I want to say, "but that does not seem age appropriate care; it does not seem you have been respected as an individual with your expertise." Beth senses my response anyway – "No… it's good… I don't think she was the warmest person in the world but she was great." Beth has just suggested that it is important to feel like you are not just taking up a bed space, to be validated as a parent. This is her narrative habitus. Here she tells of the nurse using Isaac's name, who recognises what is working and what is not, and who clarifies the role that Beth can take as mother. And that in this she felt she was the focus of the care for a time. This story is of a nurse who has made an individual connection with the child and the family – who recognises his cry even without seeing him. It is as though to be remembered is to count (Chatman, 2009). Even if it is only to be told to be quiet. The converse seems to leave the family uncertain where they belong, "Like we won't come and show you around the ward…because you've been here so many times, but when you are walking up past the desk we never… we'll just pretend we don't know you. So yeah, you know, you feel like you're skulking around…."

This story also gives clues into their experience of parenting a sick child in hospital. Parenting skills and norms are on show for the scrutiny of staff, who may or may not share their values (Darbyshire, 1994). This has been part of Beth's experience, "They comment a lot about… I've heard lots of comments, like 'She's alright, she can stay.' I've heard lots of comments about you as a parent." Yet the illness of the child adds complexity to the parenting. Mothers often take responsibility for how their children are perceived (J. Harden, 2005). Yet as Beth tells it, it is hard to know how to manage both the child's behaviour and the judgement of the staff,

> What do they want you as a parent to be? Are you disinterested if you go, "Come on Isaac, get it together?" Is that you being hard? Like what is it? Like there is that thing like, what do people in hospital do with their hysterical non compliant child? What's the right thing to do? Are you meant to be there soothing them or are you meant to be helping the thing go through or what the heck?   And what are they wanting from you? And… I don't know

Isaac's behaviour has been challenging (to?) at times – "he's throwing a tray or whatever it was… I remember a doctor entering the room and him just going, 'Fuck off.' When he was like 3, 'fuck off.'" And the family find themselves unable to support Isaac as they have to manage staff perceptions, "I stay there for that and it's really embarrassing because I think they think he is just really naughty." Isaac is

absent from this conversation, but he is also silent (apart from his effective protestations) in the series of stories. The culturally dominant view of children is that their views are secondary and that they are passive in response to adults (Berman, 2003). The family are in a precarious position where they feel they have to enable procedures to occur, but also realise they are personal advocates for Isaac. The family stay with him once the procedure is finished and the staff leave. The family carry the consequences. So Beth's story of a nurse who spent time with Isaac and gave some teaching about what she, as a mother, can do, seems to offer meaning amongst the chaos they find themselves in.

> ***So same building different experience… hugely… hugely different***
>
> There's lots and lots of good experiences too. Like for Karl… the last 2 visits he's been sick so he's just come up
>
> The last two times were very nice, very relaxing. We had our own room, they brought an Xbox for the boys. If they could give us a dinner they did.
>
> And I just sit there and watch

The family keep asserting, "this is not about slagging the system – we are really grateful… we've had some amazingly good, you know… stuff happen to us…. I cannot believe how generous the whole system is… incredibly generous and the spirit of it is really, really amazing." I am confident that complaining is not the family's agenda – they are aware of the mechanisms available for this. Notable events within an experience do, however, tend to colour the nature of the recollection (Kahneman & Riis, 2005). Memory is not an objective record of everything that happened; it is always selections told to an audience to make sense of 'then' from the perspective of 'now' (McCrone, 2003). So the stories that surface to consciousness on being asked to recall events are the threads of recollection that capture what the storyteller wants to communicate. There are positive experiences – but it is the chaotic ones that spring to mind because they most capture how the family feel.

So this short simple story – with no particular complicating factor is told. It is about family. Karl is sick as well as Isaac – and he is included in the care package (unofficially as he is not 'admitted'). "We" had space to be 'family' – and 'they' responded to the boys as boys – letting them play together. This 'rule-breaking' is a sign to the family that they are important. Potentially they could have been asked to take Karl home – it would be justifiable according to strict processes. The family could have had to feed themselves – it is likely not strictly ward policy to feed

anyone other than the patient. So someone taking a spare meal and letting the family have it is about someone possibly seeing that a parent with two sick children is going to find it very difficult to go out and get food. It is having their plight visible to someone else and the load shared that makes this a comforting intervention. Especially because 'they' are probably not supposed to.

This example of a positive experience becomes a trigger for other memories. The juxtaposition of the argumentation is a narrative device to convey something meaningful – that the family seem to feel they live in extremes. The contrasting pictures are of feeling objectified and judged as being less than she is, "even now, like I'd get back [from a shower – Isaac being asleep when I slipped out] and he'd be like 'Arrrrrrrrr' from the cot. Shaking the cot… and the cleaner looking at me like, 'For god's sake.'" She feels vulnerable from judgement from all staff, "and it's awful if all the doctors arrive and you're still in your jammies and they're like 'slovenly mother' and I'm like, 'No-o-o. I've been up all hours, I just can't leave the room.'" The experience of having staff 'break the rules' for her - and acknowledge their family – is a figurative opposite to the feeling that everyone within the hospital hierarchy is judging her inadequacies as a mother.

And then Beth adds, "he's had a few nurses he connected with… a few… yeah… usually it was young, new nurses who babied him… and he loved it… and I loved it and I loved them". This is a simple story fragment – the 'what happened' is a handful of nurses engaged with her son in a caring, nurturing manner. The 'coda' is reciprocity – the care and nurture is returned and multiplied. This brief insight feels like an eddy, a calm spot, in the middle of the chaos. This intimate moment is almost lost in the dissonance between expectation and experience. The family feel like guests in their son's care, "we are visitors." They feel like the environment actively works against them being able to be the parents they want (and are expected) to be. For example, "we'd have times we'd have a 2 year old in a four bedded room… in with teenagers, they're up till 10 o'clock at night with half the family sitting there eating buckets of KFC and we're trying to get a 2 year old to sleep because he's sick." This is clearly a cultural interface of expectations between families – the family and social needs of adolescents are equally important with the family and physical needs of a pre-school child. Peter is pointing out the environmental challenge where the institutional needs (to fill beds) can impact on a family's ability to care.

I have included Sian at various points, asking her what it was like for her, what she thought. She has spoken about the challenge to the family – about coming home from school and wondering, "where's mum? Where's Zac? Oh, probably at the hospital." She has described mornings where her dad gets everyone else up and ready for school, and him not being as comfortable with the task as her mum. Sian has noticed that it is mostly Beth who "stays up there" with Isaac. Throughout this recent part of the conversation she has been quiet – so we all take notice when she suddenly interjects.

> ***But it just feels like being caged in…***
>
> You know what I hate about hospital?
>
> The children feel so caged up… Like, I come in and go, "Hey Zac, want to go to the playground?" He goes, "I can't. The doctor says I have to stay in bed on oxygen."
>
> But it just feels like being caged in…
>
> Yeah

The adults add context- "It's that oxygen isn't it? And often he's got… another illness as well… so he can be contagious". The adult (logical?) rationale seems to end the story. This is one risk of the group interview where children's voices can be overwhelmed by adult discourse (Eggenberger & Nelms, 2006). So it is included here. Sian's focus on a sense of justice and rules seems typical of her middle childhood stage (Cincotta, 2002). So her story is of having to be compliant to the rules – without having been given any particular rationale that makes sense to her. Sian's story also illuminates her sense of sharing her brother's illness experience – the impact is not just on the sick child (Hopia, Tomlinson, Paavilainen, & Astedt-Kurki, 2005). Sian's metaphor of a cage captures her sense of the space in which care is delivered – a cage limits movement both in and out of the space. Cages also represent vigilance – where those on the outside gaze on the objects of interest. This is a de-humanising image – the environment stops them doing what is most natural for children – play. There is silence in regard to any interactions or explanations – though Sian's brief story here was quickly superseded by the adult explanations. Children actively work to make sense of the social contexts in which they find themselves (Berman, 2003). As she reports the conversation between her brother and herself, the 'learning' seems to be 'do what the doctor says'.   That this story suddenly, and without prompting, emerged is a clue that these adult explanations are inadequate to the understanding of a seven year old.

Beth and Peter augment Sian's story with further details. The sense of being 'caged' is Sian's metaphor – but the family describe other ways that they are 'trapped'. They have had several experiences of having a short oxygen tube, and having to argue for a metaphorical 'longer leash', "when we arrive on the ward and I say, 'can we just have a longer oxygen tube?' It's always a drama so they expect this kid… to sit on a thing like this [indicates with hands]… Get a long one, yeah… I just don't understand why it always ends up being such a hassle". Beth sounds exasperated with the final comment – it is a genuine grasping for understanding – why does my seeking to be a good mother for my son have to turn into a challenge?

With this issue of ensuring Isaac receives the oxygen effectively, Beth moves on to reflect on the relationships with the nurses. The oxygen administration is the vehicle for the story about the family's interactions with nurses. They begin by acknowledging that Isaac resists having the nasal cannulae taped on. Sian adds weight to this, "he hates it." So there is some sense of sympathy for the nurses who see conflict avoidance as the way forward – and suggest an oxygen mask instead. With multiple admissions to their experience, the family believe this will be ineffective – but their opinion of this does not seem to be enough.

I quite like that sort of…. being in control, in a sense

This is another thing with this older nurse [mentioned earlier]. She just wouldn't have any trouble with it. She'd just be like, "No, this is what's happening." Always, where I'm saying "the mask doesn't work". They're like, "I'll give it a go." "No. Don't give it a go… because I'm the one that's up all night." So the mask goes on… and it's always a failure. So **we** have 3 or 4 nights of not sleeping and it comes on and it comes off and eventually we have to put the tube on anyway. I like that older nurse because she's just like, "Isaac, you need oxygen, this is how we are going to do it." He's like, "Waaaaa." 'Whatever. It's still going to happen.'

There are a few that I see and I think, 'You, we're a good team." And they sort of know what I know. But I do often… wonder…

This story is surrounded with theorising and reflection – it is reassuring to have one nurse who they know will 'do what needs to be done' and who, more importantly, shares their understanding. But the family find it overwhelmingly unsettling to feel like many other staff will not listen or understand them. Beth is not sure if she is at fault, "I need to say to the nurse… and I truly try and sort of say to her… So I need to somehow figure it. I don't know…" The context for this turmoil is over thirty admissions to hospital – and yet Beth still does not feel like she knows how to express herself to the nurses. She has insight into the risks inherent in negotiating

with staff, "I mean, there's a couple of nurses I feel like we go well together, but I think it's very, very easy to get backs up. Really easy. And you know it…" This is not just Beth's issue – Peter acknowledges, "You get a vibe." This is a shared story – the two of them interact in the telling. Beth gives an example,

> I say you need to put this tape and then you need to put this under-tape on and that can get people really pissed off. I'll say, "No, that's not the tape." They go raaaaa. And I don't know what it's called, I can describe it and they'll go and get some and I'll go, "No, that's not the tape." Then that begins the end of a beautiful relationship.

The irony is evident – there is a limited relationship, and little beauty to it. But that is further dilemma for the family, "knowing that really I won't actually see them again so… really, I don't really care. But then that sort of annoys me too, that I won't actually see them again." She seems to be aware of the need to be working in partnership – but that insight just serves to further deepen the frustration of the situation.

The sense of chaos in the narrative involves the family, "I don't really like the nurses who get real angry at everything and stuff, about the tape… I'd love to see what's written in our file – 'This bloody family.'   But that's amazing as well, because sometimes they seem to know nothing about us at all." Nothing that each of them look to as a support seems to deliver care. Families rarely ask to view their clinical records – it is as if they know that they are written out of the record (Egerod & Christensen, 2010). For Karl, nurses should care anyway; for Peter, systems should work for the patient; and for Beth, their individuality should frame their care. These were the stories they expected - but reality has not lived up to this – hence the sense of meaningless evident here. Beth seems to see this, "maybe the public, people like me, actually don't know what nursing is and maybe our expectation of it is what's actually wrong. Because I think I went into hospital expecting something quite different." This is chaos in the sense of nothing seeming to be in control (Frank, 1995) where expectations have to be constantly lowered to avoid disappointment (Avis & Reardon, 2008).

The family's uncertainty about the how to navigate through the healthcare system even after so many visits is clear. They have some wonderings, but these seem to be tentative,

What exactly is their job, I don't actually really know, and what the boundaries of their role is. I always feel guilty if I get back and they've cleaned something up. What do they do all day? Yeah you need a pamphlet as you arrive, like – This is what your nurse will do for you… Yeah you do because you think they'll see you, then when you've been in there 6 hours you actually think, "Oh God they've forgotten I'm here, now what am I going to do?"

There is a pause in the conversation. It feels like this part of the conversation is coming to an end. Once again, though, Karl has been quietly absorbing the conversation and asks a profound question, "So how come you guys just don't tell them this?" This stumps everyone – because the question cuts through to the heart of identity and culture of everyone in the stories (as well as us sitting around the table).

After a brief silence, Beth simply suggests, "Because they're the staff… [pause]… I need them on our side".

Nothing more seemed needing to be said. So we finished – we had talked well past the kids' bedtimes. So off they went. In fact, all we had done was finish that part – the recorder was off. The reflection and dialogue continued over another coffee as we attempted to solve the world's ills. The conversation flowed freely – it was as though feeling heard, Beth and Peter felt comfortable being themselves and just expressing themselves. It was a privilege to share an evening and their stories.

Melissa's story

Titles	Temporal flow
	It's fucking endless hideous stuff
	She did her own stuff
	She did it herself
	The look on her face. The panic, it's awful and I knew damned well she had to have it
	She made a monumental cock up. I didn't get mad at her
	So, "You're having a crack at me for smoking… please? Join a queue"
	I didn't care… you become a mother just being there
	Louise was a very nice nurse. Teresa had really attached to her
	And she treated me like… an intelligent parent, not someone who had to be spoken at. Maybe that was it
	I knew that I'd done my dash there
	That's what I mean… they just did nice things

Orientation

Melissa: (Teresa)

This was an interview that 'snowballed' from the earlier one with Carina. Carina had been 'like' family to Melissa and Teresa before and during their experience of Teresa's illness. Carina had told her story – then at her own initiative had talked to Melissa about the experience of the interview, to see if she would consider participating as well. I felt the need to check with my supervisors – I did not want to take advantage of the family's vulnerability. The possibility of hearing Melissa's story/s as another piece of the picture alongside Carina's did fascinate me. This was the broad view of family as I had originally conceptualised – not just a stereotypical nuclear family (D. Smith, 1993). But having heard Carina's version of the story, I needed to be sure my intellectual curiosity was not obscuring any ethical issues involved in following up with Melissa. I discussed this with my supervisors, who felt as long as Melissa was given every opportunity to decline, that it was up to her. In the end, with a couple of months passed, Melissa assured me that she was willing to participate. Normally that might be "happy to" or "comfortable with"

participating – but neither of these fitted. Melissa was not only going to talk about Teresa being cared for in hospital. Teresa died. Any talk of Teresa meant Melissa would have to speak of Teresa in the past. We were both mindful of this when I arrived as arranged at her home. And it was Melissa's home, too. Continuing living in the same house as where Teresa died had been too painful; another loss for Melissa to carry. One of the first things Melissa did this evening, though, was bring out a photo album of Tess for us to look through. And it stayed there on the coffee table between us – so that in many ways, Teresa was as present through the conversation as we were.

We spent some time talking before I turned on the digital recorder. It was particularly important to me, and especially in this context, that Melissa knew my interest was genuinely in her – and not a 'snatch and grab' of her story as one might solicit an opinion for a poll (G. Williams, 2000). So we took our time as we shared stories. Very quickly narrative ideas of identity (Rimmon-Kenan, 2002) emerged and the turmoil of un-negotiated change to identity:

> It doesn't go away, no. How can it… your future gets wiped out. One day I was a mother… and now… I'm not a mother… I mean I baked, I cooked, I had school, I had Brownies, we had netball, we had… [pause]… Then the next day nothing… Planning for schools and planning trips, talking about our future and what we wanted to do together. Then the next day nothing… Just all gone.

Melissa continues to have to grapple with meaning and purpose – her identity had been shaped by her relationship with Teresa – still unsure of what role and who she is supposed to be now. The fixed social norms of family (Andrews, 2002) no longer seemed to fit, leaving Melissa struggling to find a new story in which to position herself. This uncomfortable positioning of herself formed one bookend, the context in which she began to recall her experiences of Teresa and hospital. The severity of the loss is reflected in the severity of the story.

> ### It's fucking endless hideous stuff
>
> Endless rounds of Morphine, temazapam… all those "pam" drugs… Constipation… the side effects!
>
> In the end the only time Teresa would shit would be when she stood up and I would have to catch it in my hand. She wouldn't even sit on the toilet. It was too painful.
>
> It's those things people don't realise, you get cancer and you just lose your hair.

This was the first story. It's graphicness begs the questions – why tell this story; why here (Frank, 2010a)? The picture it paints seems deliberately counter to several culturally sanctioned narratives (B. Smith & Sparkes, 2008). The medications Melissa lists are analgesia – pain 'relief' – agents of 'comfort' – but here they are shown to be the cause of her daughter's pain and misery. Melissa challenges the image of children with cancer, losing their hair, a cosmetic change, as inadequate to capture the multiple layers of suffering. Even one of the most (socially) private bodily functions is challenged – elimination is no longer intimate and individual – it is fearful and humiliating. And a mother who stopped changing her daughter's nappies many years ago is pictured with her hands cupped as her daughter defecates.

Stories are devices that uncover identity construction (B. Smith & Sparkes, 2008). Melissa has begun by positioning herself as a mother who goes way beyond normal expectations, and who has watched her daughter suffer physically and emotionally, powerless to comfort. It seems to shout out to anyone who can hear – 'I am mother!' – a counterpoint to the struggle for identity in Teresa's physical absence. Stories also shape and are shaped by families and their values (Moules & Streitberger, 1997). Melissa talked of Teresa and herself being 'tight' – very close to each other; this story shows that intimacy in some extreme. By telling me this story, Melissa brings me in to the scene to witness her suffering – an experience that seems to have challenged many of her prior held beliefs about life. By listening – and retelling it I bear witness to the pain and affirm its reality (Frank, 2004c). We pause and dwell in the moment. It is me who breaks the silence, to ask "I wonder how we can be better at walking with families?"

She did her own stuff

I can remember one nurse who was a bit of a bitch and I didn't like getting her but most of them – the nurses I actually found the best... were the younger nurses because they sort of related to Teresa's level... I'm so grateful for the nurses who did it, who let her take control of some of her own procedures... and they were so good at it. They taught her about the monitors and how to read them. They let her take her own temperatures. I would just walk out of the room. I'd come back and she'd have the thing on her finger, just all that sort of stuff. She was determined

In the shadow of her opening story of profound helplessness, Melissa here recounts moments where 'help' was indeed present. There is an apparent anonymity to the nurses, "they", but Melissa apologises many times about this, "I can't remember all

their names now... I should..." To counter this, Melissa augments this account by recalling how some of the nurses were acknowledged, "those were the ones that... teddies got named after. Teddies got named after the really... the ones... that there was a connection, that she felt connected to them and I felt connected to them." This story offers an insight into how the connection was established – in an out-of-control situation, these nurses offered power and control back to Teresa and Melissa. Melissa punctuates this by pointing some out in the photo album – so though they have no names, they have faces and are remembered.

While letting Teresa 'read' her monitors did nothing to control what was happening to her body, it was a small way to take some control of what happened to her body and environment. This is mirrored by Melissa feeling comfortable leaving the room. The description of walking out of the room seems to convey trust in the people and the environment, trust that here was shown to be well placed. Stories uncover more than what happened, though, they also can give insight into the social context (Littlewood, 2003). Here Melissa seems to unconsciously speak of a hierarchy of control, as the nurses "let" Teresa "take" her own temperature. Institutional care often involves a sacrifice of narrative control (Harter et al., 2005) as the medical discourse takes the dominant position. To speak of being 'allowed' to check her own temperature blurs the ownership of her body between the healthcare professionals and the child herself. Teresa had the final say on this however, as Melissa remembered,

> In fact the day after her funeral, I went home and because we'd been living in the lounge and everyone had been living in.......I decided to vacuum and I pulled out the couch and I heard this 'click, click' and she'd been posting them behind the bed where I couldn't see them. You know... and I laughed and I cried and thought, gosh, she was determined she wasn't going to shit. It was painful and she didn't want to do it.

This argumentation story (a seemingly unrelated story that is told to reinforce the primary story) demonstrates Teresa claiming agency and self-determination. It is set against the primary story of the nurses "letting" Teresa participate in her own care. When nurses' talk is of *permission* they may subconsciously limit the empowerment they were seeking for the child. For instance these same monitoring activities (checking temperature, etc.) are frequently and expertly undertaken by parents and children themselves in the community, yet here Melissa mirrors nurses' language of 'allowing'. This is an example of the way nurses and other health

professionals shape the language and story of the ill (Frank, 2007). Though a subtle difference, nurses' teaching *about* a procedure positions Teresa more in control of her own body – control she was claiming back anyway - in whatever measure she could - in spite of everyone around her telling her what she should do. The permission giving approach of some staff triggered Melissa to remember it's opposite.

She did it herself.

She had the luer in and she had to give her own GSE [?] or whatever it is - the easiest way for me to get around that was she did it herself. So she learnt to do it herself. I taught her how to do it.

She felt in control of it, because then she'd pretend she hadn't done it and she'd fill it up with water and she'd call me in and we'd do this whole ritual of, "Oh Teresa you've got to do it." Then she'd squeeze it out and go, "It's done, ha ha ha." We had one nurse who just fair shit herself because Teresa was putting the needle into her own thing and… I said, "Just leave it." Even Teresa told her to go away. She said she couldn't do it. "She can't do that. You cannot do that. Give it to me. You cannot do that yourself." Physically wanted to take it away. Teresa threw a tantrum and I said, "No, you need to leave it." "But……" "No you need to leave it." And Teresa got shitier and shitier and she left the room.

She did it herself

After a while I would give it to her when she was lying in bed or wherever and I'd say, "I'll be back, make sure you do it." She did do it; of course

This quest story (Frank, 2010b) flows seamlessly from the chaos before it. In the interview there is barely a breath between them – but in style and meaning they are poles apart. Where before there was passivity and action in response to the direction of others, here Melissa speaks of agency and empowerment – for herself as well as for Teresa. In the course of her chemotherapy treatment, Teresa would require periods of hydration to facilitate the excretion of those medications. Of note here, not only does Melissa speak of Teresa being in control of this – so much so that she jokes around with it – Melissa speaks of her own role in this, "I taught her how to do it." This speaks of a mother able to be the parent she envisages – she manages the problem, "the easiest way for me to get around that" by actively leading the process. Undoubtedly there would have been medication administration sheets, fluid balance charts, signatures of the health professionals involved in the delivery; Melissa augments that official record with a story that offers "meaning, context, and perspective [from] the patient's predicament" (Watson, 2007, p. 1285). The abstract, or point to this story is "she learnt to do it herself. I taught her how to do it" – an intimate picture of mother and daughter. Into this story

comes a metaphorical 'dragon'. In standing up to the 'monster' Melissa creates "a piece of magic inside myself, magic to use against the meanness in the world" (Allison, 1995, p. 68), and wrestles control back to the locus of the family, "she did it herself."

Healthcare professionals and family members are likely to view events from quite different cultural viewpoints (Engel et al., 2008). For Melissa this scene is viewed in the context of Teresa's life (and death), while for the unnamed nurse, it was likely one task within her busy day, one guided by rules and regulations as well as other patients' needs. If the nurse were to tell of this interaction, it might be a story of feeling perplexed that a 'routine' event suddenly became anything but routine; or intimidated by a family when she was only trying to do her 'job'. More likely, it is forgotten (Cushing, 2007). Yet for Melissa, to forget is to accept that there is no meaning in what happened – the photo album sitting between us is a sign that what happened, mattered. Telling the story and naming its players is a way to ensure they are not lost to labels and generalisations (Tierney, 2000). So Melissa tells this story of her daughter asserting herself, "Teresa was furious. She was furious and I nearly interfered and then I thought, no actually I'm not going to. To the point I said, 'Seriously you just have to let her do it, she can do it. Leave her to do it.' I don't know… I mean I can understand that they were nervous but for me it was like, 'For god's sake.'"

This is about agency however, not just being assertive and determined. Melissa adds to this the way that Teresa took on a 'champion' role with newer patients,

> And she became the person who would sit with new people who had to have a NG tube and she'd say, "You need a number ten, don't bother with the one or two because they come up much quicker when you vomit. The ten will stay down a whole lot better. I'll come and sit by you." She sat by one girl when she had her first NG tube put down and in a way… she was helping her but also I reckon in hind sight, you are less inclined if you've got a peer sitting there to look like you're going to…..But yeah, she'd go, "You need a number ten, don't let them do a small one. Cause it will just vomit up."

By doing this Melissa seems to be adding context to the primary story of standing up to a nurse – the "don't let them" was about standing up for self and others. This became more clearly a family value as the interview continued – the people who are valued are those who 'stand with' the vulnerable and 'stand against' the strong. So no one in this account was likely intentionally challenging – it is a story of

competing stories where each person's story (and agenda) seemed more important in that moment than the other's (Frank, 2002a). This told story – the only one available – is of needing recognition and trust, and feeling the need to fight for it when it is not forthcoming. But as Melissa now shows, there is a finite amount of 'fight' left.

> ### *The look on her face. The panic, it's awful and I knew damned well she had to have it*
>
> But it was having the NG tube put down – that was the one thing I couldn't watch, the look on her face. I couldn't watch, I had to go out of the room. Everything else I could cope with... just the NG tubes, the NG tube... I couldn't stay.
>
> I was outside the room just rocking
>
> We got kind of lucky - I'd only leave her if the nurses she was with I really liked

This brief little story is told straight after that of Teresa helping the newer children negotiate their way through having a naso-gastric tube inserted. It seems that the stories almost alternate between quest and chaos, from agency to passivity. The hospital experience seems to be a journey of endurance (Gasquoine, 2005). Melissa seems to embody her dilemma at feeling unable to be an 'ideal' mother (Vallido et al., 2010), "just rocking" unable to be physically present for her daughter. She quickly counters this, however, with ways that she was able to protect Teresa, "I'd only leave her if the nurses she was with I really liked... and then it doesn't bother me... but if it was people I knew or felt hadn't shown love and kindness before... then I wouldn't have left."

One way of maintaining the parenting responsibility is to be vigilant over those involved in the child's care (Heller & Solomon, 2005). Melissa was able to assess and judge the nurses on their ability to connect with Teresa and treat her as a unique child, "they understood how much Teresa could do, then they understood what she liked and what she didn't like. They knew her personality. They had jokes with her. They played with her." These two pictures are juxtaposed uncomfortably against each other – a mother rocking outside her daughter's room, unable to be with her; staff playing games and 'popping' in to create games. One seems inhumane (to all participants) while the other is completely humanising. Melissa tells that they can somehow co-exist with each other. She alludes to how frustrating the feeling of anonymity is, "to have to go through and explain who you are to another nurse... Fuck me... Just irritating..." The relationship with Teresa was the

only thing that seemed to matter, "possibly even if they didn't connect with me... but they connected with her, then I might not have minded so much. We could have gone outside and had a... whatever, yeah... it's the love of your child that..." By implication here, the adults could sort out their differences, but if the nurse connected with Teresa, more than that, loved Teresa, other things were forgiven.

She made a monumental cock up. I didn't get mad at her

We had some nurses that made monumental cock ups... We had one that forgot Teresa had had her operation

They put the cast on, a brand new cast, ready to go home, decided to pull the catheter out. When she was ready to take her catheter out, forgot to let her go to the toilet, and as soon as that sensation of pulling... out it all came. All through the cast. Completely soaked it. Fuckin' end of story. And of course that was after chemo and it drained all the way into her cast. Had to have the cast cut off on a Friday. I was in tears actually, because it meant 2 extra days in hospital waiting till Monday, till we could have a cast reset

She was just horrified and it was actually fine because she was actually a kind nurse. It mattered because it cost us two full days. Two weekend days. Fuckin' stuck in the hospital, that was a hard, hard ask, but I don't know... in the end it didn't matter

This story is also told by Carina. In her telling the nurses were not as helpful, and had insisted on removing the catheter 'their way', and contrary to the wishes of the family. This telling does not negate that – it is a different story, told by different person for a different reason (Hesse-Biber & Leavy, 2007). Melissa is telling a story of love in the midst of chaos.

In this context, even Teresa's urine is problematic. Because she has recently had a course of chemotherapy, the urine is potentially toxic with the by-products of the medications. This was not just about having a smelly cast – the urine soaked cast was a potential threat to Teresa and those caring for her. After nearly three weeks in hospital and major surgery, they were desperate to get home – yet the action that was meant to facilitate this, the removal of the urinary catheter, became the mechanism that blocked this. Melissa has downplayed the impact of the two days, "I think you become a bit institutionalised. You go, 'Oh well, it's just another 2 days. Stuck here.'" But this was huge – everything they had been looking forward to dissolving like the plaster in the cast, "we were so ready to leave... even packed up ready to go... she just cocked it up... she fucked up big time; she was so apologetic... maybe that's the difference." While the nurse is not given a name, she is "she" rather than "they" – and she does have descriptive elements added, "she

was kind hearted… and apologetic… maybe if she'd been different I might have really squawked hard." Kindness seemed to make a shattered dream (of getting home) less overwhelming. Reinforcing this interpretation is the way the details of the story twist and change in the interview – initially this began as a story of getting a cast on; then off. Stories offer 'narrative truth' rather than some objective verifiable truth (Polkinghorne, 2007). The order or detail of what happened is not the point here – Melissa has chosen to tell this story, in this way, to show the depths and ongoing nature of the suffering they had to endure, despite the good intentions of those involved. She acknowledges that the nurse made a genuine human mistake – but shows that the cost was borne by Teresa and Melissa.

Melissa then tells of how she managed in the hospital. This involved a lot of description of what it was like, "The food is crap… lack of room… like where you slept under the fucking sink… if you were last in you were under the sink - you try that for 7 days, and I had to work as well. I had to keep an income coming in." She paints a conflicting picture of how she responded to that, "and I'm not an unlikeable parent, so I was as accommodating to them, you know. I didn't stomp around the ward demanding… though I mean we got a room more than… some, mainly because… I bitch like you wouldn't believe." This contradiction did not seem apparent to Melissa – they were pragmatic responses to situations as they found them. So walking around the ward to see what rooms were full or empty became one way that she was able to claw back some control when little else was going to plan. She also acknowledges her own agency by pointing out many other families who were not as assertive, "the ones that were less assertive and less aware and less willing to just sit there and wait – Pacific Island people. You know, I just felt for them, because I felt they weren't getting… as much as perhaps… possibly I would have got because I voiced what I needed… and you know they'd say, "We're just waiting, just waiting for the doctor to come." And I'm thinking, "Fuck, why are you waiting? Get up! Fuck, go get them!"" This is the strong Melissa: the Melissa who is able to judge that she trusts the nurses working at this time, and go home to feed the cat; the Melissa who is able to assert herself and take some control of the environment.

So, "You're having a crack at me for smoking… please? Join a queue"
I did keep smoking… needed it. Used to go downstairs where it says no smoking… All of us… We all smoked downstairs where it says 'no smoking' and you know this is at 12 o'clock at night. You've had a horrendous day,

> you need somewhere to sit and talk to... and mothers, especially cancer mothers...

> You could see the security guards coming over and it was sort of like, "Come over here, bring it on, bring it on. You will just get nailed" You'd see them come around, "Fuck that." And off they'd go.

> I've actually given up so many times. I'm on herbal cigarettes now

When there is little joy in her life – hanging out with other mothers represented an oasis – a space they created to challenge the hostile environment (Gasquoine, 2005). This is a counter story (H. Lindemann Nelson, 2001) that challenges the official story of resilient families who follow the treatment plans that are often told by health professionals to new families as they enter treatment (Hartman, 2004). In Melissa's story, the mothers are resilient – but not compliant – they smoke underneath the 'no-smoking' sign – in the face of authority – and dare anyone to challenge them. The parents supported each other through their suffering, "as it was there were only like two that lived in the whole sort of intake."

But then, as if aware that she had challenged the ideal parent role, Melissa reinforced her worth as a mother, described the lengths she had to go to.

I didn't care... you become a mother just being there

> Most of the time... you've seen kids. It's classic, they're all fine and bubbly, and they're not unhappy about going in, then the chemo hits their veins and it's just like... they just stop. They just lie there in this comatose state.

> She didn't eat hospital food once. I had to leave the ward to do washing, had to leave the ward to do the cooking... it was all home cooking. Took all Teresa's food... my own food. I'd do mince with rice, mince with spaghetti, mince with tacos, tomato and onion and I'd grate in courgettes. She wouldn't know that they were in there. I didn't care... you become a mother just being there... it was great that you could get that down her

In the months that they were in hospital, being able to participate in the care became one of Melissa's coping strategies, "I think too because you are there all the time, if you don't have something to do you'd go vaguely insane." And yet holding up this story as an example that explains Melissa's behaviour obscures the social context in which the story occurred (Frank, 2001). Melissa cooked Teresa's food, after being at work, having not slept in her own bed for weeks, changed the bed 2-3 times in a day when Teresa was vomiting or incontinent, cleaned the ward – because at some level she felt she had to. For Melissa, to be a good mother was to provide comfort to her daughter in her time of need. This is a strong socially constructed model that women are obliged to follow (Kalbian, 2005). Once a child

is admitted to hospital it is not always clear who carries responsibility for the care and protection of the child (Shields, Kristensson-Hallstrom, et al., 2003). Melissa notes the uncertainty, "and, you know it's funny… when I went into the hospital, I thought… they would do all that but then… it didn't even cross my mind… I just did it." She had to cook because there was no suitable food provided; she had to change the sheets because she could not sit back while her daughter lay in her own body fluids; she had to clean because she saw a risk to her daughter. The drive of the behaviour was both intrinsic - Melissa chose to act in this way; and extrinsic - in that the environment and cultural context left little her choice. Nurses, as part of the context, add their expectations of how good parents should act (Young et al., 2006a), often with little negotiation over how this is enacted (Young et al., 2006b). This all seems to add to the sense of uncertainty, and the seeking of control evident in Melissa's stories. Nurses who enabled control became noteworthy.

> ### Louise was a very nice nurse. Teresa had really attached to her
>
> When she lost her hair and we shaved it off. We made a big ceremony. The nurses were great about that. We made a big ceremony about the head shaving off.
>
> Kara who'd lost her hair, the older 18 year old, she said it was easier when it was shaved off because it's uncomfortable when it comes off, so I said to Teresa how about it? We'd both cut our hair short but Teresa had to go the next step and I wasn't ready for that. So I said, "How about it, we take your hair off?" So we got Kara and one of the nurses Louise, who was great, Louise said 'I'm the expert hair cutter' and they didn't have a hair cutter so I had to go get some. I got my work to donate some hair shears, and we made a big thing of it. It was a marked occasion. Louise came in, we had people standing around, we watched all the hair come off. We got photos. It was just nice.
>
> We gave Louise a toy because she was going on a holiday and she took the toy all the way around on her road trip. She took the whole toy – Teresa chose a little kiwi we gave her and took pictures of where the kiwi went on the road trip

Teresa's hair started falling out as a result of the treatment she was receiving. This is an external sign of the internal changes to her body – shaving seems to demonstrate a point of no return, and taking on the outward appearance of 'child-with-cancer'. Melissa speaks of the "look", almost unable to stop staring, while many other people were drawn in with pity. But in this story a nurse walks through the transition with them. It is a story of community – Kara, Louise, and the others were witnesses to this rite of passage. They became like family – those who were present there went on to be marked with gifts and further photos – evidence of a

relationship transcending time. Melissa reflected on the nature of the relationship with some of the nurses, "you know, some people might say it's not professional? You know, well lots of the nurses brought us presents if they'd been away. And it was fine... and we gave them presents when they left."

It is the personal touch that is evident in this story. It reminds Melissa of others who sensitively joined them through other transitions. There was an older woman who, when it was apparent Teresa was dying, "then in the end when there was no point to it, she just disappeared. She just melted away. She had the right touch; she just melted away when it wasn't appropriate, you know. Just faded away. 'I don't need to be part of this and she doesn't need this.' Just lovely... really lovely." For Melissa these are people who responded to them as they were, sensitive to their individual needs rather than as 'the patient'. The whole concept of friend and family becomes blurred, "We knew about [the nurses' lives]... they shared their lives; they knew everything about our lives. Our lives were laid bare... open. No secrets... the comings and goings. They knew all of that and it was quite nice too..." With the extended stay/s and ongoing relationships, the recollection includes talk of weddings and babies; of presents and overseas trips - intimate and personal relationships, "we chose a book that had been Teresa's favourite to give to them to give to the baby." This intimacy must have been so 'normal' that when I ask Melissa about this depth of sharing in each other's lives, it is the question that makes it more apparent, "Yeah. It didn't cross my mind; it's only now that you ask me. But yeah it was quite strong for us."

The story is surrounded by Melissa theorising – 'wondering' about what has brought her through the experience,

> Not everybody but quite a few we shared quite a bit of special time with. If you'd line them up now I could point out each and every one of them that... that just cared. They treated us with great care actually. There's always a little bit extra you can give or a little bit extra you can make happen for the people that you like the best. All those people made that happen. It was always little bits that they did that were a little bit extra for us... and, but they didn't do that straight away of course, but it was just, I don't know. Just straight away I knew if I was going to get on with that person or not

The Louise who helped them mark Teresa's entry into the 'no-hair' stage is an example of the nurses who "did that little bit extra for us." They became important enough to each other that they have entered each other's stories (Frank, 2002a). But for Melissa, they cared enough to value her story – those that did not were not

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welcome, "I had to protect her from some people, most definitely... there was no crying. If you want to cry, fuck off. Don't come into me crying and when she was... not feeling well." It is as though 'normality' was the story she wanted to live in whatever measure possible. Melissa tells this in the midst of her daughter no longer having eye brows, and other children they were admitted with dying along the way. In the middle of this, the people who put aside the labels and titles and "just cared" and shared their lives were the ones who made the chaos more bearable.

> **And she treated me like... an intelligent parent, not someone who had to be spoken at. Maybe that was it.**
>
> I remember I didn't know anything about Ewing Sarcoma, of course I knew a bit about osteo infection, and of course I knew about cancer but Ewing's was brand new to me, so of course I started looking it up on the internet. I remember that I wanted to know.
>
> I was talking to the doctor and said I'd been looking it up on the internet and it says blah blah blah. He said, 'don't look it up on the internet, don't look it up. Let us talk to you.' And when they left, because Nurse Tracy came on the rounds, she said, "Good on you. You need to look it up. They're not God." And I thought you and me gonna get on girl.
>
> She treated me like... an intelligent parent and she greeted Teresa with this sense of, just lots of love pouring out

This is triggered by us thumbing through the photo album together, Melissa wanting to show those who cared, and to share the memory of Teresa, "I'm trying to acknowledge all the people that were really good." These were the staff who challenged the dominance of expert knowledge (J. Harden, 2005; Redding, 2008), who facilitated Melissa to be the mother she needed to be. "Of course I started looking it up" represents her habitus – it is her common sense that a mother would want to know. Outside of this particular context the action of a mother looking up things related to their child's health and wellbeing would be regarded as a sign of engaged parenting. In a context where expert knowledge is hegemonic and dismissive of alternatives (Le Fanu, 2004) this same action is viewed negatively. So Nurse Tracy coming alongside her and almost subversively praising her becomes an affirmation of her as a mother, not simply as someone of intelligence. This story reinforces a grand narrative of nurses being more accessible and friendly than medical staff (Weitz, 1999). What it does not question, though, is why the nurse came back in private and did not speak the words of affirmation in public. This clearly helped Tracy's relationship with Melissa – she is described with almost saint-like qualities, "just lots of love pouring out." The family require a working relationship with the whole team, however; this secretive interaction only cements a

relationship between this individual nurse and the family. When any member of the healthcare team believe their narratives represent the best way, the family have to thread their way through the interpersonal politics (C. Davis, 2008) as Melissa is almost obliged to take sides. So while this relationship, and others described, were sustaining to the family, these institutionalised behaviours impact on the experience, and therefore, the stories available to the family (Rowe, 2003).

It is also Melissa's habitus that Teresa was central – the nurses who stood out were those who also had Teresa as focus, "showed she was important to them… so they gave her some power and then they'd have jokes and Teresa loved to play jokes. Or they'd be stupid with her… as you should be with an 8-year-old. Just that little bit stupid… you know." Melissa's examples here are of cleaning the luer plug before medication was injected, or putting a heart monitor on. These are not usually the play of well eight year olds, who might normally be outside playing complex games with age peers (Cincotta, 2002). Instead Teresa's new normal seems to be playing repetitive games with adults many times her age, often focused around her medical interventions. The environment seems to have masked the 'abnormal' nature of the interactions.

Remembering all these people brought a smile to Melissa's face as she recalled them in Teresa's life. But the narrative flow continued – the story had to be told to its conclusion, so the next thing that happened has to follow.

I knew that I'd done my dash there

Her head started to hurt and I knew that didn't… that wasn't good. You don't get sore at the top of your head, even my limited knowledge of Ewing's Sarcoma… …I knew

I pushed really hard for another bone scan. They said, "Oh well, she's due it." So I refused to go home that night, so we went down to one of the wards… got a room of our own… and they pushed forward the bone scan.

Anyway we went down for the bone scan and we get there and Teresa said, "I have to go to the toilet." Now going to the toilet with a hip spica is not easy…

[whispers] "Gotta go, got to go, **got** to go **now**." So I lifted her straight off the bed, I raced around the corner and I went in to – God forbid, the staff toilet. Fucking hell. I know. And this woman, I hadn't quite shut the door and she said, "You can't go here. You've got to go down there." Teresa's on the toilet trying to go and I've got the woman… and said, "Fucking sue me!" I slammed the door in her face. I was furious.

I heard them in there flushing it and flushing it because they're worried that whatever she has drunk will splash up in her urine.

I stood there watching the scan and I knew damn well... it wasn't right

This story is two stories within one – the over-riding story of discovering Teresa's cancer was terminal, and within it, the story of an interaction with staff. One is of control being finally wrested away from her, while the other is of attempting to maintain some control. Melissa positions herself in the story as a mother who is capable – she was capable of recognising the 'signs' of deterioration in Teresa; she was capable of asserting herself within the system, having learned the system works; and she was physically capable of carrying and caring for her daughter. Against this is cast the inevitability of the disease process, an impersonal system and a lack of support in a moment of need. The only intimacy in this point of their narrative is an awkward one, as Melissa is alone,

> I turned to the guy that was reading it and he said, "There's a few worrying spots there." I said, "Are they Ewing Sarcoma worrying?" And he looked at me and I said, "You need to tell me." Cause he was gonna wait till... and he turned to me. And I said, "You need to tell me now." He goes, "Yep." And I knew then, and I knew. And I kept it together to get up to the ward and they must have already told them and... we were put in a room and then I went into a separate room... (pause)... and just went into a treatment room on the side

This finding out occurred with a stranger who she had to coerce for the truth – and then when the only space where Melissa could go was across the corridor in a treatment room – a clinical space where invasive procedures are undertaken on children. Alone knowing her child was dying. Knowing that her maternal instincts had been right, but wishing they were not.

Within that story, however, was another. A story of having to fight against people within the system at the same time she was learning of her daughter's death sentence. Melissa is angry even as she retells of the incident. She tells of being alone with a child in a chest-to-toe cast who "was shocking, she'd leave it till the last moment." This maternal knowledge only added to the crisis. But she breaks the 'rules' by going into the staff toilet. This contrasts with her ability to 'work the rules' and insist on a bone scan by refusing to go home till it was done. The demarcation of "staff" versus 'other' seems hollow given the level of input she was obliged to give in caring for Teresa. Even for a family who have been in and out throughout the nine preceding months, it seems that it is impossible to do enough to be considered an insider. Melissa paints the conflict as interpersonal – but she also insightfully acknowledges the environmental influence, "why is the toilet there

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to start with? Why was that the staff toilet?" The conflict seems to be over whose story of what is important would be dominant. This mother had already lived through a urine soaked cast and its implications, and she was harbouring suspicions as to what this test would show – so for Melissa, the immediate was paramount. For staff who seek to maintain control and distinction between themselves and 'other', rules and enforcement remained paramount. Melissa has to straddle between different worlds. In one they buy baby and engagement presents for staff, and staff who return from OE buy gifts for them – and the distinction between 'professional' and 'family' is blurred. In another they are relegated to the toilets most far away and reminded of their place in the hierarchy. But there are no obvious sign posts marking when one moves from one land (with its set of rules) to another (Sontag, 1978/1990). Families are just meant to negotiate the language and associated narratives of the different parts of the same system (Gesler, 1999).

Again we do not know what story this anonymous woman might tell. She may have stayed late to help out; she may have just finished cleaning graffiti off the walls of the toilet; or she may have family crises of her own to manage. Yet there are expectations for nurses and other staff are to deliver highly professional care despite increasing complex influences on practice (Rankin & Campbell, 2009). Melissa does not have to carry any of that as she tells her story. Melissa tells a story that is true as it explains her experience – she experienced profound inhumanity in the midst of a degrading and deteriorating moment. Other stories will exist that accentuate other aspects and different context (Gudmundsdottir, 1996). The staff can debrief to each and document their stories for the record. Melissa tells this story because I asked. It is the story that gets told here because otherwise it would pass unnoticed (Charon, 2007b) and because it is the more vulnerable story (Mishler & Steinitz, 2001).

From here the story quickly turns to the final days of Teresa's life.

That's what I mean… they just did nice things.

We were home for 6 weeks, but had a bit of a lapse in medication… couldn't get on top of her pain… obviously needed bigger doses… had to come in and get that balanced and sorted. That visit… they let an extra person stay in the room, my niece – Teresa's cousin, she let… so we had two people in the room which you're not supposed to have. Just quietly - they broke the rules. And she was only two years older than Teresa. But screw the rules, they just didn't care, they just let her sleep. I'd pushed my

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bed right next to Teresa's hospital bed and there was that funny little day beds in one of the rooms, because it was a two person room used for one person. So they let her sleep there. So they let Leini stay in a bed.

It felt we got special... like we were special

This idea of breaking the rules as an acknowledgment of uniqueness is raised again, this time in relation to family. Melissa wonders if it made a difference that she was a single parent, "maybe because there wasn't a father or husband or partner or anything... they let my friends fill in. It was really awesome, actually. I hadn't thought about that until you mentioned it, because for me it's just.....my normal, yeah." Family became to mean more than just 'kin' but a broader conception (Temple, 2001) and included Melissa's sister, as well as Carina, and others irreverently referred to as the 'Pall Bearers Club.' At times Melissa seemed to use friend and family interchangeably, as though the distinction was less important than the care they offered. This particular episode stood out for Melissa because it actually was not for Teresa at all, "but wasn't really... it was for her cousin... yeah." By this point Teresa was highly medicated with analgesia, and was therefore not always aware of all the things going on around her. The rules apparently suggest that only 16 year olds are allowed to stay – but the staff turned a blind eye to that and actually facilitated a family-care intervention. This allowed Melissa to have her sister's child present to participate in the care of her cousin.

This rule breaking reminded her of another story.

Christ, I don't know how you do it

Your doctors come and go but a good nurse, on a bad day... made all the difference

And they understand... there was one time that we were in this ward and this... kid came in, this kid came in and she'd fallen off a horse... badly. She'd knocked herself out and the parents thought she was dead. We were in a two people room and, honest to God, she was just like a princess... and we had three days of her. She was this complete princess of a girl and her parents were "ahhhhh." "What's wrong with your kid?" "She's got cancer." "Oh well mines got la la la la la." "Okay fine, yours will get up and walk again." I remember going up to the nurse and saying, "Christ that woman is driving me insane." "Oh yeah sorry about that." You know they kind of... they sided with you, they dropped that sort of professional attitude all of the time, they knew she was a right bitch, her kid was a fucking princess and I'm stuck with her. And they sort of said, "I'm so sorry for that, she's going to be leaving in a day so hang in there." So, okay sweet, you know... rather than that "well, you can't always choose who you're with." That sort of pompous attitude. Yeah and sort of just dropping

> that bit of professionalism. "Yeah she is, sorry about that." "Oh okay I'll put
> up with it."
>
> I would have smacked half of them

We laugh together about this. Melissa clearly has no intention of 'smacking' anyone, but the story provides some relief. There was shared humour in the experience. The humour is in the irony (that is only apparent to Melissa and the staff). The story seems to demonstrate to Melissa that she was "in" with the staff – that they included her in their humour. Families are often expected just to "get on with" whoever staff choose to put them with – though the only thing they may have in common is a child admitted at the same time. Yet here Melissa's solidarity is with staff rather than other parents. Where earlier she spoke of other mothers 'ganging' together as they smoked outside in a cohesive group, in this account the natural affinity has changed to nurses and staff. What is not spoken of in the story is whether Melissa is conscious of this – whether it is a deliberate strategy to be liked by staff so that things go more easily for her and Teresa. More likely is that this is an unconscious action driven by insight into the gate keeping capacity of nurses (Darbyshire, 1994; Fenwick et al., 2008) – it is easier to work with than against. It provides another lens to the story of Leini being allowed to sleep over – would the nurses have been so accommodating if they had not 'liked' the family. Melissa has already acknowledged that some families are not as good at 'playing the game' as others – and that they do not always get their needs met. Her insight into this shows an awareness of the politics it is necessary to navigate to be accepted. Melissa knew that some staff would give her the 'official' line – so she joked with nurses she had worked out had a similar perspective to her own. And by joking about dealing with half of the families, Melissa seems to indicate that many families are not fluent in their dealings with nurses.

From this point Melissa reflects and remembers. Remembering is a link to another time. It is also full circle – this is the idea that Melissa began with – everything that has been recounted is held by these bookends of questioning identity.

> I tend not to think about that time. Little things, after the shock of losing
> somebody you can only think of the death part and I can remember saying
> to somebody, my sister, was I a mother before cancer? Tell me, tell me,
> remind me, was I a mother before that, I can't remember. I can't
> remember anything but cancer. You forget all the little things that happen.
> It's only talking about it now, I remember all the special sort of stuff...
> Netball and the girl who wasn't nice to her on the playground...I call it my

> broken toaster days, when a broken toaster would have pissed me off for the day you know

There is pain in remembering – but without remembering, Melissa has to ask "who am I?" So she recalls people, doctors, nurses, physiotherapists, teachers who have imprinted themselves into Teresa's story. Friends and family who have walked with her. Humour – "if you don't laugh…" – the alternative unspeakable.

There is a lack of narrative structure – the enormity of having to bury her daughter before she turned 9 is too heavy a weight for a cohesive narrative thread. Melissa is ultimately passive, in that nothing she does is enough to change the eventual outcome. She demonstrated agency where it was possible, and endured the rest. She is grateful for many of the nurses and staff who made it better – she repeats this many times. Without kindness and care this depth of chaos would consume her more than it already has. Injustice is heaped upon injustice – her house is burgled – mementos associated with Teresa are stolen – and the jar containing her ashes is overturned on her bed. Melissa tells of having to vacuum these remains. The suffering has not ended.

Melissa 'admitted' that after Teresa died, and at her request, Carina had slipped back on to the ward to take down any photos of Teresa on the walls. Melissa had not wanted to consider that her daughter's image might fade away when there was no one remaining who continued to remember her. By telling the story, Melissa ensures that there is remembrance.

Though the experiences are different – even Melissa and Carina bring different views to their shared experience with Teresa – there are common threads. Despite being familiar with the environment and many of the staff, they remained vulnerable to those relationships. All these families tell of moments of agency – quickly replaced with stories of passivity and resignation. Whole families are affected – with chronicity, this support of families becomes even more important – yet extended families have had experiences ranging from feeling included through to feeling like 'visitors' to their own child. Even with all their experience – these families continue to struggle to clarify the roles and expectations both for themselves and for the nurses. At times the families find meaning and purpose in their experiences – quest stories of relationships made and insights gained. But they all tell chaos stories – there is little room for restitution with chronic and palliative illness – stories where they are the passive recipients of 'what happens' – and where their expectations of staff are not matched by their experience.

Relationships matter – this would go some way to 'bridge' the dissonance gap between the habitus of the families and that of the nurses. "A bridge" – this is the metaphor Beth used to describe the way out of chaos she was clearly feeling.

Chapter Eight

Discussion – Thinking with Stories

> Storytellers that do this kind of narrative analysis work from an orientation that blends the practices and emphases of social science with the aesthetic sensibility and expressive forms of art. The goal... is to practice an artful, poetic, evocative, empathetic, multi-voiced social science in with meanings stay open and writers and readers know not just the 'facts' in their heads, but can keep in their minds and feel in their bodies the complexities of culture, society and concrete moments of lived experience (Smith & Sparkes, 2008, p.24)

The stories told by the families who participated in this study span from prenatal experience and the moment of new life entering this world, to adolescents old enough to ride motorbikes and swing axes, to the death and dying of a child. There are deeply intimate and disturbing experiences; and there are mundane realities. Some of the stories could be regarded as not particularly exciting. Yet for the analysis to have integrity, stories have been presented whether they are captivating to an audience or not - because something happened that mattered enough to the family to tell a story of it. The process of developing interpretive stories means that there are not tidy demarcations between data and findings (McCormack, 2000a). Creative representations such as this highlight the process and ensure the relationship with the data is tentative rather than authoritative (Richardson, 2006). In this way the process and the findings are intertwined with the goal being to cohesively represent each (Richardson, 2000). This chapter extends the discussion from the interpretive stories of chapters 5-7. The narrative processes and lenses used throughout are maintained here –though here in relation to the interrelationships of the stories rather than individually with each storyteller, beginning with the wider narratives in the literature.

Stories and literature

The families' stories confirm the findings of many of the previously published studies of parents' experience of having a child in hospital. Corlett and Twycross (2006), for instance, suggest that while parents are involved in the care of their children, the negotiation process seems somewhat ad hoc. Uncertainty and frustration about the level of participation was evident in many stories. Cathy in her story "...I found leaving hard" described wanting to be able to care for Dan after he had vomited, but being unable to get the resources she needed to do this. Barb described her frustration at the unspoken expectation she felt was placed on her

and Jed in her story "The family routines are totally disrupted." The absence of effective negotiation appears to continue to be a challenge even for families who had many admissions. Much of what underlined Beth and Peter's stories related to frustration at not knowing who was responsible for different aspects of Isaac's care. In contrast, however, care was experienced by families when there was even a small amount of negotiation and clarification of expectations. So in Beth's story of, "she actually taught me..." is a sense of relief at not having to guess who was doing what. With this clarity, the family relaxed and pointed out that particular nurse as one who helped them make sense of their experience.

Lam, Spence and Halliday (2007) identified that parents in hospital settings strive to demonstrate and develop their competence and identity as parents. In the stories from this study, parents often constituted themselves (within their narratives) as having some expertise and attempting to maintain some control. For example in Marty's story "so we just shot out and brought him home", while negotiating for Dan to get home for the night, he presents himself as a knowledgeable and assertive parent (and therefore trustworthy). Kelly describes wanting to be perceived by the nurses as 'not a complaining mother' in her story "it was fine, but...." Similarly, Emma tried to assert herself as a competent mother when she brought Hera to the hospital acutely, however, in that story her competence and knowledge was not recognised. Within several of the stories the system (both people and environment) seemed to highlight the families' perceived deficiencies rather than strengths. This seems to run counterpoint to the families' attempts at autonomy and agency reinforcing Ford and Turner (2001) finding that family expertise is frequently devalued.

Foster, Whitehead and Maybee (2010) suggest that there is a complex power matrix between families of hospitalised children and nurses. Despite families effectively managing the health and wellbeing of children outside of hospital, they frequently perceive they are sidelined in decisions of care (J. Smith, Cheater, Chatwin, & Bekker, 2009). While 'partnership' is part of the narrative of family centred care (Nuutila & Salanterä, 2006), this relies on the nurses initiating power sharing within the relationship. Adita described her wishes for Nidhi being acted on by the nurse in "I'm glad he listened." In that story it is Adita who initiates the negotiation, and while the nurse could have negated this mother's opinion, chooses to act on it – to the benefit of everybody involved. In contrast, Carina's story "it was a really

miserable evening" describes the nurses withholding nurture when they disagreed with Carina's decisions as a mother.

Socio-cultural factors influence both families and nurses (Garden, 2010). Even when they look similar, health professionals and families hold different cultural belief and value systems (Frank, 2002b). Healthcare professionals need to understand the children and families they work with as different from themselves (J. Grant et al., 2005). In this study, Melissa describes two different world views in "I'd done my dash there." For Melissa, being a mother to Teresa was her primary motivator, while for the staff in this story, it seemed that the rules and mores of the unit were what they saw as important. In the end, each misunderstood the other. This seems to contrast with Adita's experience in "it kept my sanity…" Here the midwives recognised the cultural values associated with being a mother – and ensured mother and baby were united and photographed prior the inevitable separation. This demonstrates ability to integrate the social dimensions of the mother's narrative into the professional narrative of 'delivering physical care to the baby,' So while culturally safe care is possible, when nurses and other healthcare professionals presume they understand 'the patient' they risk not being able to see the "most valuable nuances and particularities" that distinguish each child and family (DasGupta, 2008, p. 981).

Families themselves are reluctant to complain – therefore it is up to nurses to be sensitive to their needs (J. Grant et al., 2005). One way we can do this is by affirming children's and families' stories as valid and as a way of hearing what matters to them (Frank, 2002b). Emma's story "so we ended up back at ED the following day" demonstrates a competent and articulate mother being silent, while her inner monologue suggests frustration and concern. Mike's response to Audrey's story of "I didn't know it was the emergency bell" demonstrates how families reconstruct stories to confirm their values – in this case that nurses are kind. So Audrey's telling off is retold as a story of 'emotional teenager' – and then there is nothing to complain about. In Kelly's story "it was fine, but…" the family were so keen to leave, and disillusioned by the experience that they had no energy left to alert the nurses to their actual experience. Unless nurses seek out families' stories they are likely to remain unaware of the inner journey each family is on. All this requires are "a few simple questions and the patient humility to listen as their patients struggle to respond, because how to respond to these questions may not

be so simple" (Frank, 2008, p. 325). This is a necessary power sharing stance –
whoever determines the dominant narrative controls the nature of the experience
(C. Davis, 2008).

Narrative Processes

While all the participants were fluent in English and able to communicate what
happened, there are diverse storytelling processes evident. The representation of
interpretive stories emerging from the interviews has included consideration of
narrative lenses of language, context and genre in relation to each storyteller. While
each of the stories remains unique and personal, drawing out interconnecting
themes and language structures gives clues as to shared and significant issues
(Dibley, 2011).

Language

Language reveals meaning and relational understanding (Doucet & Mauthner,
2008). Identity and power relations frame narratives – the "I" of the story
demonstrates the sense of agency available to the storyteller (Doucet & Mauthner,
2008; McCormack, 2004). What is said, and at times, what remains unsaid, are
important considerations, along with the ways the stories are told (McCormack,
2000a).

In this study, some participants began very focused on the events. For example
Emma's first stories are very functional – little description or theorising; just 'this is
what happened'. Once underway, however, Emma's stories became less controlled
and conscious – for example when she told the story of Ryan after surgery, she
reflects on her inner monologue – exposing what she did not do at the time. This
reflects a lack of agency present in the moment that she was acutely aware of at
the time. Other participants had long stretches of theorising and description during
their interviews – with little storytelling. This exposes the storyteller's grasping for
understanding, even from the perspective of the present. Kelly and David's
interview is an example of this – though there are only four 'stories' that emerge
from the transcript, the interview was much longer. Much of that talk was reflection
rather than recall, with Kelly viewing the experience through her own expectation as
a child health nurse.

Many of the families included clinical jargon and language in their stories. This may have been as a result of their knowledge of my background as a nurse, or a skill the families have gained to help them navigate their way through the clinical experiences. It is evident in these families' stories, that while jargon can be a significant barrier for families (Tanner et al., 2004), they have learned the meanings of the clinical terminology so that they are able to understand. Melissa, for example, would look up unfamiliar words in order to be able to stay abreast of what was happening to her daughter. In this way, the jargon became part of the shared language rather than accentuating difference. From this study it is not clear how easy this process would be for families less able to adapt – nor how these families picked up on these words. In my own practice I frequently write down key terms for families so that they are de-mystified and understandable.

An important consideration through the lens of language is the way the storytellers speak of themselves – before their stories are taken up into the context of the researcher's story (McCormack, 2000a). When participants were confident in their position they spoke differently. For example, Barb was tentative and hesitant as she told of managing both a sick child and breastfeeding baby. In contrast, in Beth's stories where she was confident she was right, the performance was much more forceful and determined. These differences may be more apparent because the stories are presented complete with their form rather than quotes of phrases from the transcript.

Context

Narrative analysis can bring awareness of the prevailing socio-cultural and organisational narratives that influence storytellers and their stories (Ellis et al., 2008). There are several master narratives evident in the families' stories. Socio-cultural expectations of mothers were particularly evident as the dominant maternal discourses influenced both their behaviour in the story and the reflection on the experience. Narratives of the precedence of professional knowledge over 'lay' knowledge were also evident in many stories. For example, Cathy talked about wanting to find out about Dan's care, but being inhibited by the utilitarian interactions with professionals. Nurses need to be more conscious of their own cultural habitus to ensure their interactions with patients are not an imposition of professional hegemony (Frank, 2002a).

Each of the stories are embedded within the socio-cultural habitus of the storytellers. The narrative identity of individuals and families were evident in the way they recounted experiences and positioned themselves within the stories. Organisational and professional narratives were also evident in the families' stories – for instance, ideas of ownership of the child and power to 'give permission' came through in many of the stories – at times invisible to the families. This highlights the value of narrative inquiry as a tool to explore social context that stories exist in and the prevailing narratives which influence experience.

The context of culture highlights the 'taken for granted' understandings that are part of social interactions (McCormack, 2000a). In this study this included the sense that families were visitors to the hospital (as in Beth and Peter's stories). This was evident in several accounts of asking permission to leave. This had become so 'normal' that it was not challenged by any of the families until they were backed into a corner (as for example Melissa in "I'd done my dash there"). This position does not recognise the contribution families make to the care of the hospitalised child or the burden the hospitalisation adds to the family.

Genre

The lens of genre suggested by Frank (1995) develops awareness of the influence of culture with individual experience. Some families were very committed to restitution type stories. Mike and Audrey, for example, adapted their stories to fit the 'taken for granted' narrative of caring nurses, even when they were left to their own devices. The more common narrative genre evident in these stories is quest-type stories. This may be a reflection of the sample group – people often volunteer to participate in qualitative research because they have something to say (T. Clark, 2010). Clark (2010) suggests that participants are often motivated to voice their frustration for the purpose of effecting improvement in services for others. In many ways this matches the description by Frank (1995) of manifesto quest narratives being reflections of acceptance where the personal lessons are told in the hope of change. This was evident in much of the preamble to the recorded interviews, and continued in the post-interview conversations that inevitably followed.

Despite the learning and healing that occurred – many of the stories also included aspects of chaos narratives. These were evident in the stories where there was a lack of agency, disrupted narrative identity and passivity (Frank, 1995). This

seemed more apparent in the stories of families requiring ongoing care, perhaps reflective of not conforming to the cultural norm of moving from 'sick' to 'well' (Frank, 1995). However having difficulty in capturing the story (another sign of a chaos story) was also evident in Kelly's account of being discharged from the hospital with her twins. This lens demonstrates the fragility of families' stories as they encounter illness or injury. Nurses need to be receptive to any sign that families are unable to align the experience with their narrative identity. An example of this was Barb feeling torn whether to be with her breastfed baby or her sick child – this disrupted her sense of what it meant to be a good mother and caused significant distress.

Stories emerging

The stories as told by the participants are able to stand for themselves. The families were all competent at telling stories – creating narratives that expressed their experiences. This may represent a limitation of the study – only those who felt able to tell their story volunteered. It may be that families of a particular background feel ready and comfortable to do this with a researcher. This is not my experience however – nearly every family I have met in practice and with students has been capable of telling what it is like for them - to anyone who will listen. The stories are embedded, however, within the longer context of the interview. The common themes or ideas between the stories could be extricated as brief quotes from spoken text – however in line with narrative thinking (Bruner, 1991), they are represented here in story form. Polkinghorne (1995) argues that the end of the narrative analysis is a story. The stories below are syntheses of the participants' stories, representing the themes shared across many stories. They are composites in the same way that participants' stories are composites of different aspects (Blumenfeld-Jones & Barone, 2007). For the most part they are the participant's words – though not always from the same participant. This gathering and representing of the data into a story captures agency, context and individuality to communicate the shared ideas (Polkinghorne, 1995). These stories underscore the multiple interpretations that are inherent in exploration of life experience (Frank, 2010). The headings represent the themes that seem to be shared across several of the families' stories.

Trust/mistrust

Kelly, David

I want to trust... but you know....

You know I think it was hardest at the beginning... you know, before we really found our feet there. So I would be there all day... yeah, and I had to go back to work nearly straight away cause we had been kind of gearing up for leave in a couple of months... yeah, and you would come in after work, whenever you could, and I think that was really cool, cause they got to know you as well... [pause]... but going home at the end of the day and leaving the boys... that was the hardest... it was like 'I'm a bad mother... abandoning them.' But I had Taylor as well, and I knew they were watching us every time I brought her in as well. I don't know what we would have done if we didn't have your family to help look after her... And yeah, we would wait till one of the night feeds, cause by then you would know who was on for the night... yeah, the nurse... and you would sort of check them out, like how did they talk to the boys and stuff. And some of them were really good... what was her name? ... Becky? Yeah, she was great... really good... she would come in and go straight to the boys and go, 'Hi Chris, hi Mitchell, have you been good? I think you are growing!' And she would talk to them like they were real – which, I mean, they are, but... and then she would talk to me like a human being and not just a milk machine, which I know is really important, but.... But yeah, those nights we would go home and just kind of relax... but if you weren't sure, you would get home and ring in to the unit, and check, 'cause they're looking after your boys, you know?

Trust is a deeply personal and interpersonal experience (Lynn-McHale & Deatrick, 2000). Trust between nurses and clients is a constantly negotiated relatedness that remains vulnerable at all times to being undermined (Dickinson et al., 2006). Families with a hospitalised child have their roles as provider/nurturer disrupted as they have to call on expert help to provide for their child. This leaves them needing to presume that the staff will be technically competent – yet that trust is shattered when their expectations around that care are not met (Lynn-McHale & Deatrick, 2000). There are calls for nurses to nurture trusting relationships with families (Verwey, Jooste, & Arries, 2008), however the "how to" remains less clear. Reciprocity seems important, where the nurse demonstrates trust toward the family (Nuutila & Salanterä, 2006).

In the participants' stories, and synthesised as a story here, an important behaviour that nurtures trust is acting/speaking in a way that demonstrates a belief that the child is unique and important. The families continue to be committed to their child, and seem reassured when someone else shares their commitment. Adita spoke of her mother phoning from India - uncertain whether the nurses could be trusted –

yet reassured once Kapil and Adita had 'checked them out' and given them their approval. Similarly in this story, the parents are watchful over the interactions of nurses with their child, judging which nurses could be trusted to act with care in the absence of their vigilance. Identity as 'mother' or 'father' or 'parent' remains important (Aagaard & Hall, 2008), so interactions that affirm those roles are important in the maintenance of trust within the care relationship. Trust normally requires evidence of 'trustworthiness' – which is difficult in the hospital setting where relationships are transitory (Dickinson et al., 2006). Peter and Beth reinforced this when they expressed their frustration when continuity of nurses across days was not maintained. Having to "start again" involved significant work on the part of the family that undermined the co-commitment required for a trusting relationship. Being the family of a sick child is emotional and physical work even before having to be watchful over the competence and attitudes of the nurses who are assigned to them.

Know us – know you

Beth, Peter: Karl

I don't think we are bad people

And do you know what's really hard? I mean we have been in and out, I don't know, more than thirty times, I guess, and I still struggle to know when is the right time to take Isaac in. Yeah cause sometimes when we get there with Zac, it's like, 'We'll just watch him for a while' and you know they're gonna send us home. And they kind of go, 'Well we're not doing anything you can't do at home...' And I'm going, that's all very well but I know we'll be back later in the night – I've stopped arguing with them. Yeah and then at 2 o'clock in the morning this time, we bundle him up in the car and back we go. And this time it's different staff and you get the 'why did you wait so long!' There is this one nurse on the ward – I can't remember her name; she's a bit older and she just tells it as it is – not too many niceties – but she remembers Isaac. It's like she's one of the few who does – but she hears Isaac crying and stuff and she marches in, 'Isaac I know that cry! What are you doing here? Now come on Beth – let's get this sorted out!' She sort of scares me a bit. I think she scares me a bit too – but at least we don't have to start at the beginning all the time with her – that drives me nuts! And she has kind of mellowed a bit the last few times too – the last time we were in she was telling me about her mother being unwell and not knowing what to do about it – and I talked about my parents as well – yeah, so it was kind of different seeing another side to her.

Objectification of the child or the family seems to undermine any sense of care. Challenging the family's centrality in the care of a child also undermines the relationship between a nurse and family (Aagaard & Hall, 2008). Several families

spoke of care as 'love'. This is not a term usually associated with the role of objective professional. Frye (1983) argues that this objective (and reductionist) view of a client is arrogant, where the client is organised around the needs of the professional. In this perspective if there is a problem it is likely to be blamed on the client. This is contrasted with what she calls "the loving eye"(Frye, 1983, p. 74). The 'loving eye' speaks of one who perceives the 'other' as independent and distinct from the professional, and makes no presumptions that the needs of the client will be the same as their own. It is this 'loving' gaze that families perceived when, for example Melissa was back amongst staff who knew Teresa and her; in contrast it is the 'arrogant' eye that Carina perceived when she felt judged by nurses for not immunising her child (with no attempt at understanding the decision). DasGupta (2008) describes this individualising approach as "narrative humility" (p. 747). It is a mindfulness of the structural forces at play in all our lives that does not assume they are all experienced in the same way (Lo & Stacey, 2008).

In this story, synthesised from the data, the family feel welcomed and cared for when a nurse stops what she is doing to single them out for attention. These themes overlap with each other – again reciprocity is important. Families identified care within human-human relationships. Melissa spoke of mutual gift giving, not as a way of 'buying' care, but as a reflection of the interconnectedness they felt. Feeling also seems important – at other times Beth describes feeling unwelcomed on a ward, existing within a vacuum where there was no one who she could connect with. Nurture first seems to be demonstrated by 'knowing' the child – then the family and nurse have something in common. This enables the possibility for a deeper relationship between the adults – and for many parents boarding in, having an adult to interact with is a welcome reprieve from the constancy of the interactions with the unwell child.

What is evident in this synthesised story is that the nurse's manner seems less important than communicating genuine commitment and interest. Clinical and relational competence is evident to the family as well as recognition of the family's individuality. This becomes the foundation for mutual trust (Lynn-McHale & Deatrick, 2000). Mutual trust then enables understanding of each other's perspectives and care to be experienced (Meiers & Brauer, 2008). The experience

of care seems unlikely where the patient is objectified and reduced to a category – so this relational stance is vital for care.

Grace and forgiveness

Carina

If you can see that they care, then…

I don't know what it is about nurses – it doesn't seem like some of them want to be there. I mean if you don't like kids and families, what the hell are you doing there? I've had Elise in hospital back in the UK and at least there the nurses would stop and talk to you. So anyway then just when we were getting ready to finally get out of there, and the nurse had to take the catheter out, and Melissa had told me to make sure they did it properly, and I told her, and she was like a bit snippy and did it her way and of course, as soon as it was out Teresa couldn't control it and just gushed everywhere! And I was running around like a headless chook looking for towels and everything. And I was so angry cause the cast got soaked – and it was a Friday and we ended up having to have the cast cut off and Tess on bed rest all weekend till they could put a new cast on. So I'm not talking just little stuff, we had the bags packed and everything and were ready to walk out the door… and just incompetence really… and Melissa was pissed off at me, we didn't talk to each other for a day or two, cause she had told me to make sure… but, you know, though it was fucking incompetence, it wasn't on purpose, or malicious or anything. She didn't go, 'I know – lets screw this up for them' she just didn't listen and thought she knew better; but she kept apologising, and I was like, hey it's done now – but all weekend she kept coming in and 'I'm so sorry' and it's kinda funny now, but at the time… [pause] I wouldn't have been so forgiving if it was one of the doctors…

Forgiving the (almost) unforgiveable is something that cannot be demanded or sought out (Berlinger, 2003) – yet many of the stories in this study contain a sense of families seeing past disappointment in nurses. Mike responds to Audrey's recount of being told off by nurses for something she could not have known was wrong by moving on to another story. Franck and Callery (2004) also identified this graciousness of families in excusing inadequate care where they perceive good intent or environmental challenges.

It is important that this grace is not a systemic constraint on the family where their genuine reaction is restrained in order to keep the peace (Frank, 2007). Many families work to appear grateful so as to avoid being labelled as complaining (Jackson et al., 2007), or create explanations for nursing inadequacies (Price, 1993). In the above story, however, the response seems genuine and freely given. This nurse seems to stand out from others 'who don't talk to you' – and this

personal relationship allows for reciprocity to occur – give and take on both sides, even if it is the family who does most of the giving.

The goodwill toward nurses does have limits. Barb told a story of being separated from her breast fed baby by nurses and their rules. Though she accepted some of the 'blame' for the situation, even several years later the narrative is broken and chaotic – she continues to feel distressed by the episode. Carina also told of her anger at nurses who judged her as a mother. Beth and Peter spoke after the interview of a time they had 'complained' – yet even that time they were not looking for punishment – just a way forward for everyone. Families recognise that complaining comes with interpersonal risk to themselves and their child (J. Grant et al., 2005). In the above story it is the family who bear the greatest cost – it even fractures the family relationship for a time – yet when they perceive genuineness from the nurse, they 'let it go'. Nurses must be vigilant to this dynamic to ensure they do not take unnecessary advantage of families.

Playing the game

Emma: Hera

You have to think about not upsetting them

So next would have been Ryan. He had inhaled a drawing pin and no one knew. Weren't we at church when it happened and you wouldn't let me come with you. No... when I saw him I thought there was going to be enough to worry about without having any others of you kids there. So we took him to the clinic and they took one look at him and called an ambulance. I handed him over to the ambo guy and he was like a dead weight. And the emergency people were all good and they explained what was going on and they did an x-ray first. Which was good. Cause the next thing would have been a lumber puncture. So as soon as they saw the pin it was like, we need to get him on antibiotics and prep him for theatre. And the nurse got him the antibiotic and it took ages to get IV access cause he was already in peripheral shutdown, but she gave him the antibiotic, and I didn't tell anyone I was a nurse, cause, you know, you don't want to do anything to muck it up for your child. And we got up to the ward afterwards and his ID bracelet must have fallen off after theatre, and, you know, the whole four days we were there he got the antibiotic and no one replaced the bracelet. But you're a nurse, mum, why didn't you say anything? Well you don't, do you. I mean, I did sort of mention it once, but you just get this kind of attitude, like, who do you think you are... so I made sure I was there whenever he had meds due, and made sure I checked for myself before it was given. So you can sort of see how mistakes can happen, but...

Dominant socio-cultural narratives have normalised relations of "domination and subordination rather than equality and independence" (Kincheloe & McLaren, 2000, p. 281). McKeever and Miller (2004) suggest that mothers 'play the necessary game' to get the care they want for their child and to avoid any punitive responses. This idea of playing along seems conscious at some times, while unaware at others. In this story, Emma weighs up the risk/benefit relationship to challenging staff – and chooses to remain quiet. In other stories however, families ask 'permission' to leave the ward, or sit back silently while their limited spaces are entered at will by nurses and other staff. Even being labelled a patient is a culturally determined role with certain complicit behaviours expected to follow (Frank, 1998b). Carina spoke in her interview of walking alongside Melissa – keeping the peace with nurses if they were unsure of Melissa's approach. In that situation, Melissa was too preoccupied with what was happening for Teresa to be mindful of the politics – Carina maintained a sense of the rules of the game and negotiated this for her. Ironically, when Carina brings one of her own children to hospital, she finds 'playing the game' very difficult, and struggles to engage effectively with the nurses.

In this story Emma has the additional responsibility of insight – as a nurse she is aware of the organisational policies around medication administration. However she also has insight into the practices of some of her colleagues and their ability to set (or change) the rules of the game (McKeever & Miller, 2004). Hera does not have experience of the dominant habitus of professionals – hence her question is to her mother rather than the system which created the behaviour.

The spaces of caring

> Melissa
>
> *And we have to live there*
>
> There was this time when we had to come in – it was quite early in the picture – and we had to go to a different ward. And you go, how is it that in the same building it can be so different? Cause they were really standoff-ish… I s'pose I didn't do myself any favours, but I didn't have any energy left over for being nice… but there wasn't even an acknowledgement that we were, you know, regulars; it was just, 'here's your room' – no, are the others in the room a risk to Tess? Just, 'the shift is changing over soon and someone will be in later… Oh and by the way, your mattress goes on the floor there under the sink'. I mean for fuck's sake… they can't even look you in the eye when they tell you – they just scuttle back to their nest and sit on the computers… anyway, I don't want to talk about them –

cause a little later Lou walked in… it was so good to see a familiar face – I think we nearly cried when we saw her. She had been shifted to this ward for the night, which she wasn't too happy about – but it became like us and them. I was like, "Lou, you gotta get us out of this room; I can't sleep another fuckin' night on the floor, not with…" and nothing against those other people, but they were coming and going, and we were there for the long haul, and… and I don't know what she did, she must have pissed them off, breaking all their 'rules', but she got us into a single room. And I didn't have to apologise all night for being in their way.   I mean… I don't know… it's just… yeah, Lou, she made a difference for us that night.

Families experience care (or its absence) in physical and cultural places. There is increasing awareness that the current model of care delivery presents challenges for both care providers and families (MacKean et al., 2005). Several mothers, for example, spoke of the environment and its impact on their perception of care. Adita spoke of the corridor representing the distance between herself and her baby. On one hand the corridor is a means of connection, but for this mother it simultaneously separated her from her baby, Nidhi. Beth similarly described the corridors – though rather than between herself and Isaac, for her they represented the distance between 'help' and her child. Melissa and Emma both spoke of being 'given' a space that was not their own at all – by being under a sink they found themselves in the way of staff at the same time as being where they were told. Frye (1983) suggests that those who are less powerful struggle with complicity in these type of situations. If they acquiesce then they become invisible and they actually have no space at all; yet if they respond with anything other than thankfulness they risk being perceived as "mean, bitter, angry… difficult" (Frye, 1983, p. 2). Several families noted their awareness of needing to not be perceived as difficult – in order to protect the needs of their child. These spaces of care are therefore both physical and conceptual.

In this story Melissa struggles to create a space that can be her and Teresa's. Families have little control over where they are put – so for Melissa, having an ally suddenly makes the space feel different. The relationship with Lou enables a new way for Melissa to consider the space – she now knows that the decision of where she must be has become personal – and that offers hope. Like other families, Melissa is conscious of where the nurses situate themselves in relation to the children. This is not always physical distance however. Carina spoke of being in a room opposite the nurses 'station for several days, yet not connecting relationally with any of them. Having a bed space on the floor positions Melissa at the feet of

all who enter the room. Being under the sink is not only unsanitary – at risk of splashing every time someone washes their hands – but it is constantly 'in the way'. Families are often grateful for anything – especially while they are acutely concerned for the health of their child – but, as in this story, they need their humanity maintained. Here the nurse cannot look Melissa in the eye as she allocates her the space. This further reinforces the objectifying that this story represents. The nurse becomes another 'thing' in the environment that limits Melissa's agency and power in the moment. If principles of partnership and collaboration are to be realised, the space (physical and relational) must be congruent with the intent.

Returning to the question

These various narrative lenses of language, context and genre have helped explore the stories shared by families. Their stories have revealed the complexities influencing the experience of having a child in hospital, with nursing care evident at times throughout. So,

How is nursing care revealed in the stories that family/whanau tell of having a child in hospital?

Care is revealed in these stories when the nurse is receptive to the suffering and struggles of the family. Care is apparent when the families are able to relax from their responsibility and vigilance of their child – and mutual trust between nurse and family is established. When families believe that the nurse recognises them and their child as unique and deserving of special consideration, then they are likely to perceive care. Care is evident when reciprocity and genuineness is sustained between nurse and family – this can become a tolerant and flexible relationship where grace and care is returned to the nurse. Care is revealed when nurses relieve families of the need to 'play by the rules of the professionals' and the family's socio-cultural values are integrated into the child's treatment plan. Families are more likely to experience care when there is synergy between the rhetoric of care and the total approach toward them (environment and systems).

The converse is possible to each of these themes. Families have little choice but to trust in the technical competence of those they hand their child over to – but they need to have the clinical and relational competence confirmed regularly. Families will likely feel devalued and ignored if they are not affirmed for the expertise and

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nurture that they contribute to the care of the child. When families feel like they are having to work at maintaining a relationship with the nurse and it is not reciprocated, their tolerance of even minor grievances is likely to reduce as they take on the full responsibility of care for the child. Not all families are aware of the expectations many nurses have of 'good' families – but they are likely highly sensitive to any evidence of being judged or stigmatised. Families have to carry significant emotional, financial, relational and vocational burdens while managing a child in hospital – when they perceive the system contributes an even greater burden they are unlikely to see other offers of care.

Care is evident when families are able to articulate their stories – when there is synergy between their expectations and what they experience. Disruptions to their narrative identity are likely to break down relationships with professional staff. So care is evident when nurses listen carefully to families and are mindful of the wider socio-cultural narratives that are evident in the story. Care is evident when family is allowed to be family and work collaboratively in a shared power relationship with nurses each focused on the wellbeing of the child.

Implications for practice

The stories within this study demonstrate a commitment on the part of families to work toward a caring and reciprocal relationship with nurses, caring together for their children. It is nurses who hold the key to this being achieved. A powerful means of demonstrating this commitment is by inviting and listening to the stories families tell. Hearing their unique voices begins to make the environment more personal and relational. This does not require additional equipment, just commitment. This commitment needs to be institutional as well as personal however, to ensure that nurses are not expected to deliver more without support (Franck & Callery, 2004). Families are already expected to self disclose as part of the admission process, and nurses fill in forms with selected parts of the information shared. Sensitivity to the narratives expressed in those interactions, built on over the period of the child's admission would reduce the risk of objectifying and labelling families. It also demonstrates value to the family – they have a story deserving to be heard (Frank, 2002a).

Dickinson et al. (2006) use the metaphor of a "companion on the journey" to describe a deeper way of working with families (p. 321). In this study, Beth

captured aspects of this relationship in her metaphor of a bridge – a bridge makes the journey easier having identified the common obstacles and guiding journeyers over them. Many hospital spaces have brochures and folders intended to fulfil this role – yet as Adita described, parents do not (or cannot) always read these. Recognising that the experience of having a child hospitalised is a journey into the unknown is a beginning. Creating a culture of enabling rather than obstructing would also go some way toward this – for example, both Mike and Marty talked about having to find out about how to reduce the onerous burden of parking by themselves (or from other parents). Frank suggests that stories are a bridging activity that links humans together (Eldershaw et al., 2007). Being receptive to the stories of children and families is essential if nurses intend to regard the patient as a deserving 'other' (J. Grant et al., 2005).

The stories in this study point to the need for developing assessment tools that challenge the tendency to reducing patients and families to types and labels. Narrative thinking ensures that the generalisations patients are often aggregated into are seen as inadequate (Lindsay, 2008). However many of the forms and tools used to collect information from children and families rely on simplifications. For instance, asking a family about immunisations without seeking to understand the context for their health beliefs and behaviours can lead to misunderstandings and judgement. Many of the assessment forms used in practice are centred on the illness/injury of the child with little or no prompting for exploring the family's understanding and narrative identity. In this way the family's voice is interpreted into the framework of the nurse, often excluding the aspects that are important to the family (Good & Good, 2000; Sakalys, 2003). To work collaboratively with families, better understanding is required – understanding that could be enhanced by helping nurses ask better questions. This may help nurses become more family-*centred*.

Listening to the stories of those we work with is vital if we are to develop and have any sense of effectiveness. Yet hearing other's stories requires both a commitment to value the story and storyteller – but also the capacity to understand the layers of meaning invested within it. Awareness of the complexities of narrative is a beginning of this capacity. Therefore it seems that teaching nursing students to recognise and think with stories is a powerful way to help them engage with the clients they work with. These skills would help them understand the interpersonal

and socio-cultural influences on them and the children/families they interact with. As a result of undertaking this study, I have already shared some of the narrative literature with several students who have used it to explore the complexities that families encounter. For instance a student recognised the story a mother told her as a chaos type narrative and therefore spent more time with her to support her through a challenging situation.

Nursing education in New Zealand has embraced cultural safety as an essential component of practice (Wepa, 2005). Cultural humility is essential to this approach, where the clinician's narrative does not engulf that of the patient (Tervalon & Murray-Garcia, 1998). One tool for enhancing this approach is narrative – underpinned by narrative humility (DasGupta, 2008). Frank (2002b) argues that this type of humility is essential to gain an understanding of the interrelationships between individual suffering and socio-political influences on the individual. Learning about and to work with patient narratives can help students remain open to the diverse worlds of families, and therefore better equipped to walk with them (DasGupta, 2008). The stories told by the families in this study demonstrate the desire on the part of families to work with nurses. Giving students further tools to create dialogue with children and families could go some way to supporting this.

Facilitating students to use narrative methods in their nursing practice will help them recognised the diverse stories between and within families (Bennett, 2008). Carter (2009) has identified the importance of being attuned to both child and family experience to more effectively meet their needs. Learning to think with stories can help students more readily recognise that there are competing viewpoints within human encounters (Charon, 2007a). Charon (2007b) suggests that this can help healthcare providers *join* with the patient in a way that affirms the humanity of each. Unless a nurse is willing to suspend their own cultural hegemony and share the story of the client "it is impossible to achieve much of the understanding upon which compassion depends" (Scott, 1998, p. 152).

Limitations

The participants in this study were all recruited through informal networks. While there are families from many different backgrounds, the diversity of the stories also creates a breadth of stories that are not easily synthesised. It may be useful in the

future to deliberately focus on some smaller population groups to see if their stories are different. Also while two of the family groups had children who identified as Māori, their stories did not include wider whanau. Given that Māori children and whanau/families are highly represented in hospital statistics, it may be useful to focus particularly on their experiences within a westernised healthcare system.

The original aim of this research was the perspective of families. This was to build on current literature, much of which does not include broader conceptions of family (Gillis & Davis, 1992). Gillis and Davis (1992) point out that interchanging *family* for *parent* or *mother* can cause lead to misunderstanding the experiences of each. For optimal care of the hospitalised child, the family-as-a-unit remains the important focus of care (Rennick, 1995). In this study, while the advertising and information documents identified families as the focus, many of the interviews ended up not including all of the immediate family let alone extended family/whanau members. At times this was a pragmatic decision on the part of families – who was available and when. In other cases the parents were the only family members older than 5-6 years available in the town/city. By using different font colours I have tried to demonstrate where stories were shared, and where they were more individual. The interviews that included parent/s and child/ren were able to include all those present in the conversation, demonstrating that where possible, this is a useful approach. It therefore remains a useful goal to seek out wider family participation in future studies of *family* experience to avoid concealing internal difference and similarity (Gillis & Davis, 1992).

Final reflection

While the story of this research and stories of participant families have been intertwined to create something more, these are not my stories. Not *my* in the sense of ownership. Each of the participants has generously shared their stories with me – so that if I would listen carefully enough –they would become a part of me. The hope is that new readers and hearers might also listen carefully, and continue this chain of sharing an understanding of what it is to be human in these vulnerable spaces.

Karl, still at primary school but highly thoughtful, having reflected on all he had heard in his family's interview, asked, "why don't you just tell them [how it is for

you]?" For nurses who are committed to delivering child and family centric care this question additionally asks, "How do I invite families 'to tell me'?

> The people who come to us bring us their stories… they hope they tell them well enough so that we understand the truth of their lives. They hope we know how to interpret their stories correctly. We have to remember that what we hear is their story (Coles, 1989, cited in Bochner, 2001, p. 132)

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Appendices

Appendix 1 – introducing the family participants

While many studies preface their findings with demographic information related to the 'subjects', qualitative research, and particularly narrative, is focused on meaning rather than quantifiable measures of participants (Holloway & Biley, 2011 article in press). So here I will introduce the families who participated in this study in their particularity rather than generalisability – the 'who' rather than 'what' are the tellers of these stories. The stories here do not have diagnoses or health issues in common. The experience they share is having a child unexpectedly admitted to hospital. By introducing the participants in this way I aim to reduce the risk of categorisation and blurring the distinctive by highlighting their individuality (Hurwitz & Greenhalgh, 2004). Narrative inquiry seeks to draw attention away from disease or injury to focus on the unique experiences and meanings drawn by the participants (Frid et al., 2000). It also ensures the political voice of the families is maintained rather than abstracted to disconnected anonymous representations (Nespor & Barber, 1995). So these are the families who have told me their stories.

These vignettes of the families have been developed from information shared by each of the families. Identifying features have been changed to avoid identification.

Adita Kapil; Nidhi

Adita and Kapil have made Newtown and New Zealand their home. Adita's parents are still back over in India, but they remain close. Adita phones her mum most nights to talk about family news and what each person is up to. Recently the calls have been to reassure a maternal grandmother that the healthcare in a tiny South Pacific country is good enough for her granddaughter, especially in comparison to the highly expert care available in her country. This is a special connection for Adita – as is calling her sister in the UK to hear about her baby, new cousins on opposite sides of the world. Adita is presently full time caring for her baby at home, having had to stop

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working months earlier than expected when Nidhi was born nine weeks premature.

Kapil works full time in a new job – one he is thankful to have in the current economic climate. He had only been working for one week in his current role when he had to take time off for Nidhi's unexpected sudden arrival. Kapil's parents also live in Newtown, and quite nearby. They are relatively elderly now, and are not as actively involved as once they might have been. However they are all deeply in love with the latest and smallest addition to the family – Nidhi – whose name means 'treasure'. And having been born so small and premature with the uncertainty that comes with that, Nidhi is indeed treasured by her family.

Due to personal factors, Nidhi will be Adita and Kapil's only child. So this nuclear family of three, isolated from their wider family by distance and changing circumstances, have had to be somewhat self sufficient and resilient throughout this experience of becoming parents and having a baby nursed in hospital.

Kelly David; Taylor, Mitchell, Chris

Kelly and David have discovered new depths of tiredness. Having three children under the age of two has stretched them – they would say, at times, to breaking point. Yet they have persevered and, with the support of family and friends, find joy and satisfaction in the family they are continuing to become.

David is trying to be the father that he feels he missed out on. Working from home has given him more opportunities to participate and play with the children. As a guitarist himself, he is highly sensitive to behaviours in the kids that might mark the next generation of musicians in the family. Rhythm and flow are important to him – and he loves sharing these as he teaches these skills to children in the community who others have already written off.

Kelly sets herself high standards. By her own admission, learning to let go (more) has been one of the harder lessons. Kelly was (and is) a child health nurse – so has many years of experience of working with other families'

children. This has clearly influenced her parenting – for instance her dogged commitment to breast feeding the twins, in spite of setbacks and tiredness, to ensure they received every advantage she could offer. She has had to cope without the proximity of her mother and sister who are on the other side of the world – visitors whenever they are able.

Taylor is three ("and a half!") and finds ways to remain special – no longer the only child, and having to share her parents. She loves books and reading and will gratefully accept any offers to read together. Whether by story repetition or not, her ability to recognise deviations from the text is uncanny given her age. She has some strong competition from her twin brothers, Mitchell and Chris. They know how to claim the spaces, and use their mobility to full advantage. Though twins, differences are evident as well as similarities - Mitchell is perhaps slightly quieter than the more assertive Chris. They share. Sometimes. And learn to be part of a family together.

Barb Jed; Lynda, Ruth, Richard, Judy

Somehow, Barb finds time to fit post graduate study into her schedule. It takes some cooperation from the rest of the family, which with four children entering or in adolescence, is not as predictable as she might wish. But she has a research project and a commitment to see it through. It is not this that defines her, however. She very definitely defines herself as 'mother', and is committed (in partnership with Jed) to doing the best by her children. She worries whether she has 'got it right' all the time, so can be hard on herself if she thinks about it too much. Her children remain her priority, a task that remains a challenge even as they get older. While each of the children are special, it is Judy's care currently takes the most energy. Other people have offered labels such as 'developmental delay' and 'learning disabilities' – though they prefer the simple "Judy." Learning to coordinate teacher aides and developmental therapists was a skill set Judy never anticipated – and while she willingly steps up to do this for Judy – it is a role from which there is little rest.

Jed shares Barb's commitment to the children. He has chosen to step away from his high pressure job to enable him to participate more fully in the

children's lives. That is what they do. He takes an active interest in each of the children – volunteering his time to help with their hobbies and social groups. For both of them their faith system is important, and informs their values and beliefs.

Each of the children are unique and individual – yet share in the family values – they stick together for each other. They are each sensitive to Judy being picked on or stigmatised – they naturally include her in their activities and are fiercely loyal to her. Judy loves being around people, and play, and making things. She has a sort of sense in picking out the people who will be kind rather than dismissive to her. And she loves school – she is one of the lucky ones who gets someone to sit with her and help her make sense of what the teacher is saying.

Emma Wiremu: Hera; Aiden; James; Ryan

Emma and Wiremu drive 'people movers' – they need to in order to transport the children and their friends between all the things they are involved in. Their place seems to be the 'hang-out' venue for the local kids – some of the attraction Emma and Wiremu's laid-back approach to life. Family/whanau is most important to them.

Emma works as a nurse – but this has primarily been with adults, so children's wards are a less familiar environment to her. She is passionate about delivering best patient care – she cannot understand the way many of the standards she ascribes to seem to be fading away around her. She has clear ideas about what should happen – and sets out to make sure the patients she works with get the best possible care. The same attitude as a mother – when she wears that hat – it is the best she can do for the kids. Marrying into a Māori family, Emma has embodied many aspects of whanaungatanga, caring for and sharing with the wider whanau.

Wiremu seems constantly helping people – first within his immediate family and whanau, but also neighbours and colleagues, and friends from their church. His job requires long hours – but he would sacrifice sleep to be there for the children.

The children care for each other – and know how to wind each other up. Hera is often having to play 'big sister' and keep the peace or arbitrate in disputes, as they defer to her opinion (mostly). They are intelligent and curious – they all love school in different ways, but excel at what they put their hands to. And they each have a genuine social conscience, engendered within their family – each with an eye for the under-dog and a sense of justice.

Mike Marcia: Audrey; Oliver

Parents of two adolescents Marcia and Mike love being involved with their children (young people!) and supporting them in their development. They do things together because "that is what families are for." Mike often ends up driving Oliver to various corners of the city for sport. He has to juggle this with his work – which does not seem to have boundaries. One of his primary values is looking out for and helping other people, something he has shared with his children.

Marcia is busy with family and work – her work in community services fitting her comfortably. She shares with Mike a commitment to helping other people, and despite some knocks along the way, is solidly optimistic about life.

Audrey was seriously unwell nearly two years ago – but seemingly having inherited her mother's optimism, sees much that was positive in the experience. She loves learning and wants to find a role one day that allows her to help other people.

Oliver is a "chip off the block" – though being regarded as 'like your father' is likely only to be viewed as a compliment in a few years time. He has found his niche in sport and loves helping others get better at what they do.

Cathy Marty: Dan; Nancy; Violet

Cathy and Marty have come from quite different backgrounds, but they are committed to each other and their children. They have moved location to ensure their children get good opportunities educationally and socially. This

has required some sacrifices along the way – sacrifices they willingly make. Their values also lead them to look for opportunities to participate in their local community and being 'good neighbours.' With them both working (Marty full time), they look forwards to evenings to share time together – kitting out the basement as a games/family space.

The children share their parent's commitment to looking out for other people. And a humorous adolescent embarrassment with their father – when Marty suggested he jump the fence to find out what the noise was in the adjacent park, they were mortified and wondered what he thought he might in fact do. They enjoy the fun of being together – and are a tight loyal group for each other.

Carina Glynn: Elise; Nadine; (Teresa)

Carina believes in being fully involved as a parent – she is on the school 'parent-teacher association' committee taking a vital interest in the school as part of her local committee. She takes this parenting seriously – the decisions involving her children are important to her, and she spends lots of time researching to find out what is best. So before the children were enrolled in school, Carina had met the local principals and talked to other parents – to make sure there was a good fit between the girls and the school. And once there is a connection – she is loyal and committed.

She loves her children and delights in watching their distinct personalities take greater form. And she invests in them to help them develop into good community citizens – so when a elderly neighbour dies, the girls are involved – handing out sausage rolls at the funeral – learning about life and service and people. Their physical health obviously matters to Carina. So when it is time for health checks or immunisations, she has looked up everything she can find to ensure she makes the best decision for her girls. Being a good mother matters.

But she is also an artist in her own right. She paints and takes photos – now on the side, but earlier for an income. Looking at the world and capturing just

how it was – this is what Carina does. Whether she is taking photos or not, she absorbs the world around her so that she can represent it later.

Glynn works hard with his job – at times having to travel and leave the parenting temporarily to Carina. He loves what he does – but misses the family at those times. He is thankful for the modern technology – even when he is overseas he can be in touch with the girls and with Carina. It may be that he just knows better than trying to stop her, but he solidly supports Carina in the roles she takes on. So when their best friend's daughter was sick (and then terminally ill), there was no question about where Carina would be – at her friend's side, walking the journey with her – and Glynn making sure that the family was sustained through it all.

Elise and Nadine love school (and lunch time and play time). They fight with each other sometimes – but you cannot be passionate and caring without rubbing against each other sometimes. They loved the responsibility they were given when their neighbour died. They had heard about the way burglars watch the funeral notices for convenient times to steal from the vulnerable – so were happy to watch the house – and then help with the afternoon tea, even though they did not really know any of the people there. Thinking about their friend Teresa makes them sad. They miss her. She could be challenging at times – Teresa did not have a sister like they do to force the lessons in turn-taking and sharing. But she was their friend. The last memory they have of Teresa is her looking grey and skinny in a hospital bed in (Aunty) Melissa's lounge. No one else in their class has had a friend die like that – but it does not feel special – just sad.

Beth Peter: Karl; Sian; Isaac

Beth and Peter run a busy house – busy enough with three children under 9 – but chaotic at times with the two boys having ongoing health issues. For Beth, there are some days that feel like there is only 'plan b' (or 'f') - 'plan a' fell apart just after breakfast. Beth is the primary caregiver for the children – she coordinates and delivers, checks and manages, rescues and supports. And she does it well – case in point the days when she is up at the hospital (most often

with Isaac), and Peter has to fill in the role – it happens… just not as fluently as with "mum".

Beth would call herself something of an expert when it comes to children and hospitals – though would quickly retract that idea and suggest she does not feel very expert at all. She as slept on many mattresses on the floor, or 'lazy-boys' in the thirty-something times one or other of the boys have been admitted. She accepts this position rather than claims it – it is a pragmatic decision for the family as Peter has to be at work each morning. Karl suggests that Peter is "quite reluctant" to sleep over in hospital – which is something of a joke within the family as both parents step up and do whatever is needed. Beth would quite like to go back to work – but has found it too difficult not knowing when Isaac would get sick again – some winters they have been in and out ten or more times. She finds it difficult to juggle being a good employee and a good mother.

Peter spends as much time as he can with the children – they have invested in a swimming pool so they can have friends over and play together. And on weekends, it is often Peter who does the 'sport parent' role, standing in the cold watching seven year olds chase a ball around a muddy pitch.

Karl assumes the older brother role comfortably. He looks out for his younger siblings at school having 'been there before'. He is remarkably self assured for a nine year old – he articulates his thoughts reflectively and with awareness of those around him. He has assimilated the values of his family – in the middle of the interview he asks for my permission to go and get something warmer to put on, not wanting to appear disrespectful. He has had his own health issues, but not to the extent of his little brother Isaac. Consistent with his age, Karl would rather be outside running around than inside talking about it – but is content to do what is asked of him by his family.

Sian is the middle child– but being the only sister gives her something distinctive to thwart being lost in the middle. She also loves school – well likes her teacher and loves hanging out with her friends. She does enjoy playing in the pool, but wishes her mother would relent and buy them a Playstation™ like so many of their friends. She does not mind going up to visit Isaac if he is in

hospital – but finds it all rather tedious – only the evenings have any potential when she can join in with the Radio Lollipop™ volunteers.

Isaac – Zac – is the baby of the family – and his health issues have accentuated this with his slight stature. He wishes he did not get sick – it is really scary when you struggle to get a breath – but even scarier when you know that adults will hold you down and so 'stuff' to you. Even though it does help. He remembers some fun times in the hospital – but actually way more fun times away from it. School is ok – it's just hard when he spends times away and misses out on everything his mates are up to.

The family believe in sticking together and care for each other deeply – being able to joke about each other evidence of the warmth they share. Beth and Peter work hard to support the family even if it sometimes feels like they are forever trying and barely making headway. And they do not really understand why it feels such hard work to be a parent of a child in hospital.

Melissa: Teresa

Melissa had not been sure she was going to be a parent – she felt that when you get past some 'certain age' that opportunity was past. And then Teresa happened. Obviously there was a father – but he has been off the scene for so long now it is almost as though there never was. And for Melissa, that was ok. There was the two of them. Especially once Teresa got to around school age – then the two of them could chat and dream and plan together. They would make hot chocolate and get out maps of New Zealand and decide where they wanted to go for their next holiday.

Teresa was not always sure about having Melissa on the sidelines at netball – exuberant and enthusiastic mothers do not always help one up the social ladder. Some of the kids were a bit mean – they either picked on her for not having a father, or else for having a father who was Maori. Some days it is hard to win. And maybe it was that she had inherited her mother's focus and clarity. She knew what she liked – and was not sure why she should have to put up

with anything else. But her mum knew what she wanted – they had a special connection – and that was comfort to both of them through to the end.

Melissa works hard. If something is worth doing – it is worth doing properly – the first time. So her boss loves having her work for him. Even when Teresa was up at the hospital, Melissa would either take a laptop and do work there – or would come in to the office and pack in to a short time what might take others all day.

By her own admission, Melissa finds it hard to 'suffer fools gladly.' It is not that she is not tolerant – more that she sets herself, and those around her, high standards. So those who are on the inner circle are 'tight' – the friends and family who are part of Melissa's support network all understand each other and share expectations. Having a sick child sorted through some of her friends – if they could not keep up with the pace of expectation, they were left behind. What this left was a small group of special friends who became like family and who journeyed through Teresa's illness (and beyond) together. Humour was one of their bonds – dark ironic humour that is deep enough to be of use in the face of suffering. They became the 'Pall Bearers Club' – their special moniker for the links they shared.

Appendix two - Poster

Appendix three – Information sheet

Participant Information Sheet

AUT
UNIVERSITY

Date Information Sheet Produced:

2 December 2008

Project Title

Stories whanau/families tell to describe care by nurses within hospitals: a narrative analysis.

An Invitation

My name is Shayne Rasmussen and this is an invitation for families/whanau who have had a child nursed in hospital in the last two years to take part in an interview that explores that experience.

This study is the thesis component of my Masters of Health Science Degree at Auckland University of Technology

Participation in this research is voluntary. You are able to withdraw at any time without any adverse consequences (up until the interview information is being analysed).

What is the purpose of this research?

The purpose of this research is to explore the experience of whanau/families who have had a child nursed in hospital. The findings will be written up as a thesis, and also for journal article(s) for health professionals to read and learn more about the experience of families.

How was I chosen for this invitation?

You may have seen a poster and indicated an interest or someone in your community may have suggested that you may be interested. If you have had a child nursed in hospital within the last two years you are able to participate in this research. This information sheet is for any whanau/families who hear about this research and make contact with me for more information.

What will happen in this research?

This research involves meeting together with me to talk about your experience as the family/whanau of a child who has been nursed in hospital. This interview will take place at a location of your choice and is likely to take up to an hour and a half. The discussion will be recorded so that the conversation can be recalled and transcribed afterwards. It is hoped that as many of your family/whanau who were affected by this experience will be able to participate in this discussion. If there are children or young people less than 16 years of age, they are very welcome to participate along with the rest of the whanau/family, but will need the permission of their parent/guardian(s). Children (or anyone else) who do not feel comfortable to participate verbally may chose to draw pictures to represent their experience. You will also review a transcript of the interview prior to the interviews being analysed. At this time you can ask for things to be left out if you wish.

What are the discomforts and risks?

The experience of having a child nursed in hospital is significant, and therefore it is possible that the recollection of this time in your lives may trigger emotional memories.

How will these discomforts and risks be alleviated?

If you or anyone in your family/whanau experience any form of discomfort, you are able to withdraw from the interview and/or the research. The research is completely voluntary. You

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will have the rest of your family/whanau present at all times so that you are able to support each other. You will be asked to choose a pseudonym (made-up names) so that no one will be able to identify you or your family in any of the research reports. If a child in your family/whanau requires hospitalisation over the time of the interview, we can defer or cancel the interview at you and your whanau/family's discretion.

If further support is required, you may contact qualified personnel at the AUT Health and Counselling Centre at either the City Campus (09 921 9992) or the Akoranga Campus (09 921 9998).

What are the benefits?

Some research has been already been done with parents of children nursed in hospital. However, there has been little research undertaken in New Zealand exploring the experience with whanau/families. Therefore this research would add to what knowledge already exists about the experience of whanau/families who have a child nursed in hospital. Your participation will also give the opportunity for other health professionals to hear the stories of the experience of you and your whanau/family.

How will my privacy be protected?

Everyone will chose a pseudonym (made-up name) for themselves as part of the interview discussion. In the final research report, all information that could possibly lead to identification of you or your family/whanau will be altered to ensure that no one could be individually identified.

What are the costs of participating in this research?

It is estimated that the interview discussion will take up to 90 minutes (responsive to and depending on the whanau/family). You will be given a transcript (a typed up record of the interview) to review after the interview. This will take time to read and may require you to contact me again to let me know if there is any information you are no longer happy to have included.

What opportunity do I have to consider this invitation?

This research is entirely voluntary and there is no obligation to participate in it.

Interviews with whanau/families who have had a child in hospital in the last two years will take place from late 2009 –2010. Therefore you have time this time to consider participating in this research.

How do I agree to participate in this research?

If you agree to participate in this research you will need to complete a consent form. You can indicate your consent as a family/whanau or individually. Children or young people less than 16 years old will need the consent of their parent/guardian(s), but can show they are willing to participate by filling in an assent form.

Will I receive feedback on the results of this research?

After the interview discussion, the talking will be typed up as a transcript. This will be posted out to you.

If you wish to receive a summary of research report, you can indicate this on the consent form and it will be posted or emailed out to you.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Annette Dickinson, ADickins@aut.ac.nz, 921 9999 ext 7337.

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTEC, Madeline Banda, madeline.banda@aut.ac.nz, 921 9999 ext 8044.

Whom do I contact for further information about this research?

Researcher Contact Details:

Shayne Rasmussen
p 921 9999 ext 7118
e srasmuss@aut.ac.nz
t 021 0405182

Project Supervisor Contact Details:

Annette Dickinson
p 921 9999 ext 7337
e ADickins@aut.ac.nz

Approved by the Auckland University of Technology Ethics Committee on 9 December 2008, AUTEC Reference 08/253.

Appendix four – Child information sheet

Thank you for completing this form – will you ask your parent/caregiver to sign here

-- (signature)

-- (Date)

if they feel that you understand what the project is about.

Researcher Name: Shayne Rasmussen

STORIES WHANAU/FAMILIES TELL TO DESCRIBE CARE BY NURSES WITHIN HOSPITALS: A NARRATIVE ANALYSIS

INFORMATION SHEET AND ASSENT FORM FOR CHILDREN
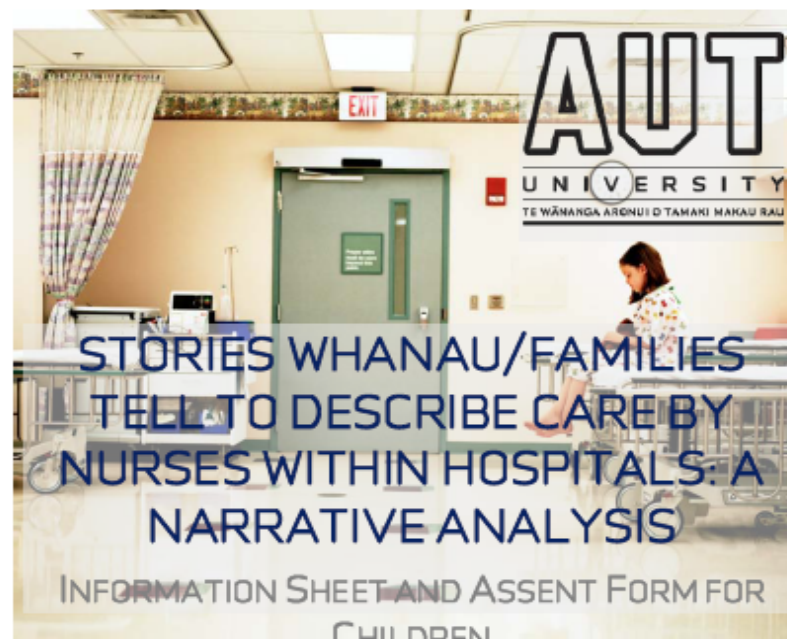
(Parent/caregivers please read to children)

This form will be kept for a period of 6 years

Hello – my name is Shayne Rasmussen. I am finding out about what it is like to have someone in your whanau or family nursed in hospital. This form tells you about what will happen if you want to help.

I will interview your whanau/family. This means I will ask you some questions about the time when you or someone from your family was in hospital. Then I will listen to you and your family talking. Your parent/guardian(s) are willing to be a part of this talking. I would love you to join in too. This is because I am interested in how it was for your whole whanau/family.

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When we meet together I will ask some questions. You and your whanau/family will have the chance to talk. Your whanau/family will be there the whole time. You can ask me about my work whenever you want to. If something does not make sense to you, you can just ask me or your whanau/family to explain. I will be recording your voice on tape. This helps me listen to all the stories you and your family tell me. Let me know how you feel about this by colouring in one of these words -

HAPPY FINE NOT SURE WORRIED

You can talk to your parent/guardian(s) if you are not sure or worried.

I will ask you to tell me what it was like for you when you or someone in your whanau/family was in hospital. You can talk about the things you remember from that time. You can draw pictures about it as well if you want to.

Please circle **YES** if you would like to take part in talking to me with your whanau/family

Please circle **NO** if you do not want to do this

Please circle **MAYBE** if you are not sure. It is fine if you cannot decide because you can still come along with your whanau/family and decide at the time whether or not to join in with the talking. And your parent/guardian will be there to support you all the time.

This is my photo:

I hope we can do this together. It will be great to meet you and hear what you want to say. You will know who I am because of my photograph. I will also wear a badge with my name, Shayne, on it.

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Appendix five – Consent/Assent forms

Whanau/Family Consent Form

Project title: Stories whanau/families tell to describe care by nurses within hospitals: a narrative analysis

Project Supervisor: ***Dr Annette Dickinson***

Researcher: Shayne Rasmussen

❍   We have read and understood the information provided about this research project in the Information Sheet dated 2 December 2008.

❍   We have had an opportunity to ask questions and to have them answered.

❍   We understand that the interview will be audio-taped and notes taken, and that this will be written up as a transcript that we will be given a copy of to read and delete any information that we no longer wish to be included.

❍   We understand that any of us may withdraw ourselves or any information that we have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.

❍   If we or any of us withdraw, we understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.

❍   We agree to take part in this research.

❍   We wish to receive a summary of research report.

Participant's name(s):	Participant's signature(s): (age if less than 16 and co-signed by parent/guardian)

Whanau/family contact details (if appropriate):

....

....

....

Date:

Approved by the Auckland University of Technology Ethics Committee 9 December 2008 AUTEC Reference number 08/253

Note: The whanau/family should retain a copy of this form.

Individual Consent Form

Project title: Stories whanau/families tell to describe care by nurses within hospitals: a narrative analysis

Project Supervisor: *Dr Annette Dickinson*

Researcher: Shayne Rasmussen

○ I have read and understood the information provided about this research project in the Information Sheet dated 2 December 2008.

○ I have had an opportunity to ask questions and to have them answered.

○ I understand that the interview will be audio-taped and notes taken, and that this will be written up as a transcript that I will be given a copy of to read and delete any information that I no longer wish to be included.

○ I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.

○ If I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.

○ I agree to take part in this research.

○ I wish to receive a summary of research report.

Participant's signature:

....

Participant's name:

....

Participant's Contact Details (if appropriate):

....

....

....

Date:

Approved by the Auckland University of Technology Ethics Committee 9 December 2008 AUTEC Reference number 08/253

Note: The Participant should retain a copy of this form.

Parent/Guardian Consent Form

Project title: Stories whanau/families tell to describe care by nurses within hospitals: a narrative analysis

Project Supervisor: **Dr Annette Dickinson**

Researcher: Shayne Rasmussen

❍   I have read and understood the information provided about this research project in the Information Sheet dated 2 December 2008.

❍   I have had an opportunity to ask questions and to have them answered.

❍   I understand that the interview will be audio-taped and notes taken, and that this will be written up as a transcript that we will be given a copy of to read and delete any information that we no longer wish to be included.

❍   I understand that I may withdraw my child/children and/or myself or any information that we have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.

❍   If my child/children and/or I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.

❍   I agree to my child/children taking part in this research.

❍   I wish to receive a summary of research report.

Child/children's name/s : ....

....

Parent/Guardian's signature:

....

Parent/Guardian's name:

....

Parent/Guardian's Contact Details (if appropriate):

....

....

....

Date:

Approved by the Auckland University of Technology Ethics Committee 9 December 2008 AUTEC Reference number 08/253

Note: The parent/guardian(s) should retain a copy of this form.

Assent Form

For completion by legal minors (people aged under 16 years). This must be accompanied by a Parent/Guardian Consent Form

Project title: Stories whanau/families tell to describe care by nurses within hospitals: a narrative analysis

Project Supervisor: ***Dr Annette Dickinson***

Researcher: Shayne Rasmussen

○   I have read and understood the sheet telling me what will happen in this study and why it is important.

○   I have been able to ask questions and to have them answered.

○   I understand that the interview will be audio-taped and notes taken, and that this will be typed so that I can read and take out anything I no longer wish to be included.

○   I understand that while the information is being collected, I can stop being part of this study whenever I want and that it is perfectly ok for me to do this.

○   If I stop being part of the study, I understand that all information about me, including the recordings or any part of them that include me, will be destroyed.

❍   I want to be part in this research.

❍   I want to get a summary of research report

Participant's signature:

....

Participant's name:

....

Participant Contact Details (if appropriate):

....

....

....

Date:

Approved by the Auckland University of Technology Ethics Committee 9 December 2008 AUTEC Reference number 08/253

Note: The parent/guardian(s) should retain a copy of this form.

Appendix six Interview Outline – Indicative Questions

◇ Ice-breaking conversation/questions

◇ Explore when it was. What it was like

◇ Interested in examples, stories from that time…

◇ When you remember that time of having a child/sibling in hospital, what is the first/most significant memory that comes to mind?

◇ It can be really challenging having a child/sibling in hospital – can you think of an example of a time when you felt cared for by a nurse from that time?

◇ Can you think of an example of a time when you didn't feel cared for?

◇ What kind of things worked for you? Can you think of a time someone did that for you?

◇ What kind of things didn't help you? Can you think of a time when someone did that?

◇ (Look for participation from all attending interview – as they feel comfortable. Consider drawings from younger children if they more comfortable presenting their experience in that way – then ask questions to clarify)

Appendix seven – Table of used to organise narrative lenses

orientation	
abstract	
what happened	The transcript text was searched for these 'markers' that a story was being told
evaluation	
coda	The 'evaluation' of the story became the story title
theorising	
augmentation	
argumentation	The surrounding transcript text was reviewed for additional narrative devices that supported the primary story
description	
language	
context	The language (what was said; what was unsaid; how it was said) used by the narrator was noted and reflected upon
genre	
Story...	

Physical and socio-cultural context of the interview and the story were each considered in relation to the story being told

McCormack (2000a) includes a lens she calls 'moments' here (epiphanies or significant insights gained). Later (McCormack, 2004) she folds this into the 'context' lens. The genre lens described by Frank (1995) seems to capture aspects of both so has been included here to provide insights into experience and agency. The content and performative factors of the story were considered to see whether the story took on Frank (1998) particular narrative types

Appendix eight – Example of narrative lenses table

orientation abstract what happened evaluation coda	To me the most difficult, you know the most… maybe even today if I look back on it, the most difficult in the six weeks was… leaving her in the night leaving her alone in the night… and coming home… was the most difficult Since she's my only child… I had the luxury of spending the whole day with her… I used to go at 730 in the morning… and used to come back at 9 o'clock in the night. I used to spend more than twelve hours with her… And I watched the nurses with babies whose parents were not there… And I saw that they handled them with just as much love and care and… you know, they didn't ill treat them… because they were left there… defenceless But… even knowing this didn't make it any easier Leaving her in the night was just… you feel like you are abandoning your child
theorising	"I had to stay sane and strong… and healthy… so, yeah… I had to come home every night." – this
augmentation	"I used to spend the whole day with her. That was immaterial "– this is in tension with the coda – the idea of abandoning your child is held in balance with 'but look how much I did do' – as a mother having to manage expectations of self and others. T
argumentation	Personal details of own story come through – "I had a c-section myself, so… I couldn't be spending 24 hours in a chair next to her bed." Other details emerge as Adita tells of getting there each day (with Kapil having to drop her off then go on to work, only to return in the evening to pick up again).
description	Description of busy routine that has to happen at home "we come home together. But the mornings, it's just too much for us… because i have to express milk, and you know, it's not just come home, sleep and go back, you have to express milk, and then take the previous day's things, and… all that jazz"
language	Even now, months later, Adita keeps asking 'you know' – as if seeking assurance that this was alright. Clearly positions self as 'watcher' of staff (vigilance) – noting examples of nurses interactions – "each baby very different from the other… and… they were like handling each child… differently, I think because they had case histories… you know there was this one baby who was there for five months… uhm, he was not doing too well… so the way they handled him was very different from the way they handled her". Adita also differentiates between different levels of care provided at different sites. But also positions self as able to recognise the different needs of the babies (and not just the professionals). Issues of trust inherent here (Dickinson) Infant also positioned as vulnerable - 'defenseless'
context	Families do not determine which nurses are allocated to the care of their baby – so as parents need to determine whether or not they 'trust' that arrangement. This is a tension in parenting role where normally parents might pick and choose who is involved with their children – who 'owns' the child. Here the nurses determine who provides care, but Adita maintains oversight
genre	This is not clear – while there is a sense of restitution – nothing unexpected happened – the baby was fine each morning; this is mixed with chaos of not actually being able to make sense of the emotional dilemma. Even now, months later, Adita keeps asking 'you know' – as if seeking assurance that this was alright. However, despite being less powerful, she maintained position as judge of care,
But even knowing this didn't make it any easier You know, even looking back now, the most difficult part, I think, was leaving Nidhi in the hospital, and us coming home.	

I know I didn't have any choice,
I had to stay sane,
and strong…
and healthy.
But that was the most difficult thing I have had to do.

I did spend all day with her – I used to get there by 730 in the morning and used to come back at 9 o'clock in the night. That was immaterial.

But it wasn't easy,
you know.
It's not just like come home,
sleep and go back.
You have to express milk,
and take the previous day's things,
and… all that jazz.

And to get there then, we had to leave early enough to drive the 40 minutes across town, drop me off, and then Kapil go on to work.

I was thankful for the time there – Nidhi's she's my only child so I had the luxury of spending the whole day with her - more than twelve hours each day.

And I used to watch the nurses,
with other babies,
whose parents weren't there.
And I saw that they handled them
with just as much love and care as Nidhi…
you know, they didn't ill treat them…
 though they were left there defenceless.
And I saw them handling each child
according to their case histories,
each child different from the other.

But even knowing this
didn't make it any easier –
each night I left without her
felt like I was abandoning my baby.

Appendix nine AUT Ethics Committee Approval

M E M O R A N D U M
Auckland University of Technology Ethics Committee (AUTEC)

To: Annette Dickinson
From: **Madeline Banda** Executive Secretary, AUTEC
Date: 9 December 2008
Subject: Ethics Application Number 08/253 **Stories whanau/families tell to describe care by nurses within hospitals: a narrative analysis.**

Dear Annette

Thank you for providing written evidence as requested. I am pleased to advise that it satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC) at their meeting on 10 November 2008 and that I have approved your ethics application. This delegated approval is made in accordance with section 5.3.2.3 of AUTEC's *Applying for Ethics Approval: Guidelines and Procedures* and is subject to endorsement at AUTEC's meeting on 19 January 2009.

Your ethics application is approved for a period of three years until 9 December 2011.

I advise that as part of the ethics approval process, you are required to submit the following to AUTEC:

- A brief annual progress report using form EA2, which is available online through http://www.aut.ac.nz/about/ethics. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 9 December 2011;
- A brief report on the status of the project using form EA3, which is available online through http://www.aut.ac.nz/about/ethics. This report is to be submitted either when the approval expires on 9 December 2011 or on completion of the project, whichever comes sooner;

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are reminded that, as applicant, you are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

Please note that AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to make the arrangements necessary to obtain this.

When communicating with us about this application, we ask that you use the application number and study title to enable us to provide you with prompt service. Should you have any further enquiries regarding this matter, you are welcome to contact Charles Grinter, Ethics Coordinator, by email at charles.grinter@aut.ac.nz or by telephone on 921 9999 at extension 8860.

On behalf of the AUTEC and myself, I wish you success with your research and look forward to reading about it in your reports.

Yours sincerely

Madeline Banda
Executive Secretary
Auckland University of Technology Ethics Committee
Cc: Shane Rasmussen srasmus@aut.ac.nz