

The meaning of being in dilemma in
paediatric practice: A
phenomenological study.

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Attestation of authorship

I hereby declare that this submission is my work and that to the best of my knowledge and belief it contains no material previously published or written by another person nor material which to a substantial extent has been accepted for the award of any other degree or diploma or an university or other institutions of higher learning, except where due acknowledgement is made in the acknowledgements.

Tineke Water (signature)

Tineke Catherine Arohanui Water

Date: 3rd April 2008

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Abstract

This study explores the phenomenon of dilemma in paediatric practice. Using a hermeneutic phenomenological method informed by the writings of Heidegger [1889-1976] and Gadamer [1900-2002] this study provides an understanding of the meaning of 'being in dilemma' from the perspective of predominantly paediatric health care professionals but also families in New Zealand.

Study participants include four families who had a child requiring health care and fifteen health care practitioners from the disciplines of medicine, nursing, physiotherapy, play specialist and occupational therapy who work with families and children requiring health care. Participants' narratives of their experiences of 'being in dilemma' were captured via audio taped interviewing. These stories uncover the everyday realities facing health professionals and families and provide an ontological understanding for the notion of dilemma.

The findings of this study suggest that experience of dilemma for health professionals reveals a world that is uncertain and questionable where they are thrown into having to make uncomfortable choices and must live with the painful consequences of their actions. The consequences of being in such dilemma are having to find ways of living with the angst, or risk becoming too sensitive or desensitizing. For families the experience of dilemma reveals a similar phenomenon most evident in circumstances where they feel totalized by the impact of health care encounters. This study has uncovered that the perspectives that health professionals and families bring to the experience of dilemma reveal different concerns and commitments and may be hidden from each other. This thesis proposes that health professionals and families need support in living with their own personal encounters of enduring experiences of dilemma.

Chapter one

Introduction

This hermeneutic phenomenological study seeks to explore and uncover the lived experience of dilemma for health professionals and families in paediatric practice in New Zealand.

Being called to a question of dilemma

Each research study arises from a certain horizon of disclosure. Heidegger suggests that the possibility of the world showing up in such a way that true or false statements can be made about it - the possibility of it being 'intelligible' - depends on horizons of disclosure. Disclosure, says Heidegger, is always simultaneously revealing and concealing and therefore may obscure the intelligibility that would be revealed by other horizons (Young, 2003). The predominant disclosure on dilemma at present relies heavily on epistemological horizons and the question arises "what might be hidden by using only such an approach"? Is there a risk that situations that stand for dilemma become revealed only as ethical principles in an epistemological horizon? If dilemma is only revealed as standing for ethical principles what is being concealed?

Dilemma is not just a situation with attributes. In health care it usually becomes a situation because there are people at the centre of it. Removing dilemma from the context it occurs in; abstracting it out, removing oneself one step further away does not acknowledge that the world in which dilemma is encountered is one with others and carries with it consequences for each action or decision.

I am not arguing here to throw out all ethical theory and perspectives. Rather an ontological perspective may show another way of seeing dilemma and its attributed meanings and understandings. Heidegger's (1993) questions regarding technology could be linked to the questions concerning dilemma. Heidegger's concern about technology is not against technology, but rather the essence of technology. He says that nowhere can we remain free from technology, but where the risk lies is if we regard technology as neutral, which then blinds us to its essence and therefore possible consequences. I would argue that nowhere in practice do we remain free from

dilemmas that arise, but the risk is if we only ever see dilemma as an epistemological endeavour, we firstly may not recognize dilemma in a differing form of representation and secondly may not be aware of the consequences for others and ourselves. By only asking, “what *are* dilemmas?” we may only disclose one representation of dilemma.

To ask what *is* dilemma is perhaps to ask how we think about dilemma. How do we recognize dilemma prior to any attempt to make it fit in with the representations of what we know dilemma may stand for? How do health professionals and families ‘see’ and ‘think’ about dilemma when they experience it in practice?

Heidegger (1968) asks “what is called thinking?” He says if we should ask “what shall we call a child?” we are playing with the verb to call in the sense that to call is to name or be named. “To call” simply means to give something a name. But Heidegger puts forward if we were to hear the question in a sense that it asks for what it is that *directs* us to think, we are compelled to accept the verb ‘to call’ in a different sense that may no longer be familiar.

Similarly what is called dilemma has often been defined as a set of principled actions or theories, whose circumstances are already known. But if we were to ask “what calls us to dilemma?” we perhaps question “what is it that calls health professionals and families to join in a world with others where dilemma comes forth?”

What lies in the calling of this research question?

The beginnings of this study lie in my experiences as a paediatric nurse and later as an educator teaching in area of child health. My early experiences as a paediatric nurse were to be influential in calling me to this choice of question whilst latter experiences as an educator were to strengthen my belief that there was something yet to be uncovered about the notion of dilemma in paediatric practice.

Without giving the experience of dilemma an explicit name such as ‘moral’ or ‘ethical’, I had always thought about the issues and questions that arose from practice. There were the issues that stood out, such as working with a family who identified as Jehovah Witness and refused to sign consent for their child to have a blood transfusion. I had a good rapport with this family but when I returned after several

days off, the child had been made a ward of the state and the family felt betrayed and angry. Although I could rationalise that the child had a lessened risk from dying should he haemorrhage during surgery, I also worried about the trust we had broken with the family and the impact this might have on future interactions. Although the principle of best interest for this child might have been upheld from a medical viewpoint, there were very real consequences and costs of this decision that were borne by this family and by me as the nurse caught in-between.

Being interviewed by a colleague who was undertaking a post graduate ethics paper stood out in my mind as I tried to make sense between the discourse on ethical dilemma and the realities of practice. She asked me to tell her about an ethical dilemma I had experienced whilst in practice. I struggled to find a story that fitted into the discourse of rules, principles and obligation. I told a story of a young girl of three, whose condition over the course of the morning deteriorated. I was new to the intensive care unit; acutely aware of my lack of experience and trying to convey my concerns to others. I was unsure if my inexperience was contributing to being too anxious over her condition, or to not being aware of everything that might be causing too her condition. Intervention in the form of dialysis, ventilation and inotropic support hit hard and fast later that morning, and the room became jammed with health professionals jostling for space. Feeling uneasy I had called for the parents to come down from the ward. The situation became more and more acute, and each time the parents tried to enter the room they had to leave again. At midday their daughter died without them there, and without them having a chance to say goodbye.

My colleague's response to hearing this story was to ask "*yes, but what ethical principles were at stake?*" I tried to tell her about the contextual nature of the situation, how the parents had looked when they were told their little girl had died, about feeling that I should have done more, either to help save her life or to make sure that she had her parents there instead of strangers. I tried to tell her although we had done the best job that we could, I felt we had let the parents down. The value of being with child in the most intimate and devastating moment of a parent's life had been trumped by the necessity of trying to save her life. I felt I didn't have the language of 'ethics' to frame what had happened yet was still captured by the emotions of the experience.

Partly in response to this situation and wanting to be more 'ethically aware' in 2000 I took a postgraduate nursing ethics summer paper, where many of the ethical dilemmas that arose in practice were debated. I enjoyed the discussion and the ethical perspectives others brought, however I had a growing sense that there was often a predetermined nature to this. It was easy to put forward opposing views, because on reading any ethical text or paper, these positions were already clearly held.

At this time in New Zealand a very public and heated ethical debate was raging around the case of Liam William-Holloway and provided the basis for much of the classroom discussion. This case centred on a young boy, Liam, and the disagreement between medical staff and his parents about what constituted his best interest. Liam's parents rejected paediatrician's offer of a fifty percent chance of successful treatment with chemotherapy, and choose instead to seek alternative therapies for their son's cancer. This led Health Care Otago to apply to the family court for a custody order to make Liam a ward of the state. Liam and his parents went into hiding and a nation wide hunt by police began. Four months later through mediation from the Health and Disability commissioner at the time, Robyn Stent and the Office for the Commissioner for Children, the Williams-Holloway family came out of hiding.

Although Liam's case was discussed widely in the ethics class, a media ban meant there was little discussion or comment by government ministers or health professionals at the time. Those who were able to comment either supported Liam's parent's decision, such as Robyn Stent the Health and Disability commissioner at the time, or supported seeking a custody order to compel the parents to seek conventional treatment in the form of chemotherapy, such as the paediatricians involved with the family and the Paediatric Society of New Zealand. The positions that were held by each party focused on principles of best interest, the rights of children versus parents, and the legal rights of the state or medicine to intervene on behalf of the child.

Discussion in the class mirrored much of the debate around the principles of best interest and on rational objective thinking to elucidate some consensus. However at lunch time many different conversations emerged. The conversations amongst nurses did not reflect the common discourse of ethics debates or textbook scenarios. Nurses

discussed the agony for the parents in having to make such a decision and the isolation they might be experiencing as a result of some of the views put forward. My colleagues were adept in discussing the best interest debate, but this was contextualized in relation to the possible reality for this family. Those discussions were invaluable to my thinking, as other nurses discussed the complexities and issues they faced in practice.

In the following year I had discussions with Charge Nurse Educators from paediatric areas around what ethical and moral dilemmas they faced in practice. The stories they told did not match those represented in paediatric texts. Nurses described how they were not part of any ethics committees and that many of the ethical issues that did arise disappeared into the background of 'everyday' practice issues.

I began to wonder what was dilemma as experienced by nurses. Was to use the word 'ethical dilemma' too narrow in recognising the complexity and richness of practice? By already knowing what an ethical dilemma was, did this actually hide the everyday dilemmas nurses encountered in practice? This view from a nursing perspective was to broaden as the study progressed to include other health professionals working with children, and families whose child received health care.

I began reading about how dilemma was viewed. Many of the studies I read were focused on ethical decision making. But this assumed there was already some predetermined recognition of dilemma. Studies that did test health professionals sensitivity to ethical dilemma used pre given and hypothetical scenarios. Again this assumed some knowledge of what ethical dilemmas were likely to be encountered. Following on from these studies, several authors asked participants to use 'real life' examples, but were concerned with these in relation to decision making, and whether health professionals came from a justice or caring orientation. The literature on dilemma for families mirrored the assumptions associated with decision making in relation to pre-given situations. Internationally and in New Zealand there appeared to be a taken for granted assumption that what constituted a dilemma was known.

Dilemma appeared to be seen in the realm of ethics, yet it seemed to be assumed as something that was already labelled and classified. The question that began to trouble

me was not what the dilemmas *are*, but what *is* dilemma? How do paediatric health professionals and families find themselves in a world where dilemma shows itself?

Van Manen (1990) says “human science research is concerned with meaning - to be human is to be concerned with meaning, to desire meaning. Desire is not just a psychological state; it is a state of being. Desire refers to a certain attentiveness and deep interest in an aspect of life” (p. 79). The calling of this question lies in my desire to understand in a different way what dilemma is in the world of paediatric practice.

The purpose of this study

The purpose of this study is to explore the experience of dilemma for health professionals and families in paediatric practice. Given that both health professionals and families are the essential participants in the interaction that happens when a child needs health care I will examine the experience of dilemma from both perspectives.

In this study health professionals are defined as New Zealand Registered Health Professionals (with the exception of play specialist who do not have a registration) who work with children receiving health care in a wide range of settings. Families are defined as those who identify themselves as a ‘family’ and includes the interrelationships identified by them as contributing to their sense of family. Although referring to the ‘family’ as a whole, it is the perspectives of parent(s) that are examined.

I have generally used the word ‘children’ rather than listing each age group represented such as neonates, infants, children and adolescents or young people. Therefore in general discussion the term ‘children’ refers to all these groups, and elsewhere where specific examples are given, the age / developmental group of the child is referred to.

In this study the term ‘paediatric’ has predominantly been used rather than ‘child health’. In New Zealand common use of the term ‘paediatric’ has become associated with hospital care and the care of sick children, whereas ‘child health’ has become associated with the care of well children in the community. As the term ‘paediatric’ is most common in the national and international literature I have chosen to

predominantly use this term but view it as health care for children both in acute care and community settings.

The term dilemma for this study takes its reference point from being defined as a difficult problem seemingly without a satisfactory solution or a situation involving the choice between equally unattractive alternatives. 'Di' (di-lemma) comes from the Greek word for 'two', the original meaning of the word dilemma arising from the phrase 'the [two] horns of the dilemma' (Sletteboe, 1997). The word 'ethical' and 'moral' has often been used in conjunction with dilemma. In this study the way dilemma is interpreted has been kept open.

Choosing a methodology

In 1997 I took part in a research project examining the use of different research methods in relation to the same topic (humour in the workplace of education). As a novice researcher, I took part in a group which used critical social theory to look at how teachers used humour in the workplace. I learnt about power issues, dominant ideologies, false consciousness, enlightenment and empowerment in relation to how humour was used. When comparing findings with the three other research groups (discourse analysis, ethnography and phenomenology) I was amazed at the different findings and perspectives provided to what was essentially the same topic. It was the findings of the phenomenology group that resonated with me. I was drawn to the poetry of the writing, the depth and view of experience and its non-impositional view.

During this time I was influenced by the work of Benner (1984) and Bishop and Scudder (1990) in uncovering both the philosophical and practical world of nursing practice through phenomenology. The work of Darbyshire (1994) was influential in uncovering the world of families and health professionals in paediatric practice through a phenomenological approach. Darbyshire's work showed new meanings related to the taken for granted philosophy of family centred care that underpinned paediatric practice. I was also captured by hearing Max van Manen speak, as he used phenomenology to uncover layer by layer the life world of a child, intertwining philosophy, poetry and art to reveal rich and contextual meanings.

When it came time to choose a methodology for this study I knew that using a critical social theory or feminist research approach would be to come with a definite set of assumptions that would provide a certain 'lens' to what would be uncovered. It was not questions of power that I wanted to uncover; rather it was the everyday experiences of dilemma that I wanted to discover that at present seemed hidden. There is some debate when coming to a methodology whether it is appropriateness of the methodology to the question that determines the researcher's choice, or if the questions researchers ask are already determined by their philosophical orientation. In this study I am aware of already having been influenced by a particular way of viewing the world (such as phenomenology), but equally that any decision for choosing a methodology must be cogent and appropriate. Choosing hermeneutic phenomenology for this study seemed appropriate as hermeneutic phenomenology is particularly useful in allowing the researcher to uncover meanings that have become hidden or taken for granted.

I started this study as a Master's thesis and in the beginning relied on van Manen's (1990) work as a 'road map'. As I began to read more and the study progressed to become a PhD I drew on the work of Heidegger [1889-1976] and Levinas [1905-1995]. Their work provides the foundation for this study. Through the process of writing I also became aware of other philosophical ideas that would support my interpretation of the meaning of dilemma in practice. The ideas and writings of Arendt [1907-1975] and Gadamer [1900-2002] also inform this study.

Pre-understandings

Pre-understandings are seen as the researcher's prior experience of the phenomenon. van Manen (1990) suggests that in phenomenological research it is not that we know too little, but that we know too much. Often what we think we already know may blind us to seeing what is before us. Our pre-understandings can give us a certain 'lens' or 'perspective' that hides the phenomenon from our view. These pre-understandings or assumptions cannot just be put aside. As Heidegger (1962) tells us, we are already situated in a world that contributes to our understanding of it. Our situated-ness as well as the social and historical context will determine our interpretation of the world around us. Whilst some approaches to phenomenology

such as that used by Husserl advocate 'bracketing' our values and beliefs, so these do not influence the research process, a Heideggerian approach argues this is not possible. Rather than ignoring or setting aside the prior knowledge and circumstances of how we come to research, van Manen (1990) suggests making explicit our beliefs, to prevent any premature conclusions and expose any shallowness. Koch (1996) refers to this as 'reflexivity' and it is seen as the understandings of the reciprocal influence between the researcher and what is being researched.

Personal pre-understandings as a nurse, educator and mother

As a paediatric nurse I worked for three years in a paediatric ICU and paediatric ward. Prior to this I had worked in adult areas, stumbling into paediatrics by chance. Whilst completing a clinically based post graduate course, part of the requirements of the course were to work with neonates, children and young people in medical, surgical and in intensive care settings. This provided a turning point in my career, where it felt very 'right' to be working with these groups and their families. Whilst working with children and their families many issues and questions arose. Interventions that were taken for granted in adult areas took on new meanings when faced with the vulnerability and anxiety of a child. Interventions and care also seemed more complex in that not only was there the child to consider, but also their family, who were often in a distressed state and dislocated from extended family support. There was trying to reconcile my ideal view of family dynamics with the realities for some families, trying not to judge, but also being responsible for contributing judgements about whether some intervention was warranted. An increase in experimental surgery and growing increase in technology saw children who would have died the previous year, now being offered a chance of survival. This posed questions of risks and benefits to children and families. Should some children undergo this surgery in hope for a good outcome, or would it most likely to be those children that followed who would benefit from improved surgical techniques and knowledge? I felt the tension between maintaining a family's hope and being honest and realistic about what was happening. Language was used very carefully to prepare parents for the worst possible outcome, but at the same time not to suggest that this was a definite conclusion. It seemed that many children died in this area, and I struggled with making sense of this.

From these experiences I bring an understanding of dilemma as embedded in everyday practice, in the questions that we worry over. I understand dilemma as being contextual and changing as new situations present themselves. I understand dilemma as the tension between not judging but having to judge, between risk and benefit, life and death, hope and despair.

Whilst completing a postgraduate child and family diploma, the opportunity arose to teach on a child health team within the University. The following years of working with students in paediatric areas provided a different perspective, often from the outside looking in. Balancing this outsider's perspective with the acknowledgement of the reality of practice was challenging at times for me and the students. I found myself balancing my experience of practice with the sometimes more idealised view of academia. At times the stories of the students provided freshness and newness to the same issues I had grappled with as a staff nurse. Students recounted stories of having to inflict pain on children, of not being able to practice as they wanted, and their awareness of the suffering of children and families. Students would question this practice world, but also express distress over the perceived inevitability of some of the situations they found themselves in.

From these experiences I bring an understanding of dilemma as something that comes with inexperience and experience, as balancing between idealised views and the realities of practice, and as something that one cannot run away from.

My experience as a mother has provided yet another perspective of dilemma. Several years ago we took our daughter to a specialist, for what I thought was a routine visit to follow up some concerns our GP had expressed. We were told she would have to have investigations for possible spinal lesions or neurological disease. Between the times of first seeing the specialist and having tests done, our family experienced dilemma in holding on to our belief that our daughter was absolutely okay in the face of expert caution. For the specialist being cautious and 'thorough' demonstrated the due diligence and concerns for our child, yet for our family this diligence represented the possibility of a worst case scenario. After diagnosis, going to clinics presented dilemmas of being witness to less than optimal practice from a 'nursing view point' but being there as a parent. Several times I wanted to say something, but also did not

want to jeopardise the ongoing relationship with the health professionals we had to deal with. When surgery was presented as a solution, the dilemma arose of trusting expert opinion to know what was best, versus my instinct (and wide reading of international research) that this may not be the best course of action. I live with the small uncertainty of hoping we made the right decision not to proceed with surgery but a stronger certainty of knowing we have.

From this I bring with me an understanding that dilemma finds its place in doubt; that ideals may give way to pragmatic realities; and that every decision bears with it consequences that must be borne.

Dilemma also has presented itself in the different roles of being a mother or that of a health professional. As a paediatric nurse I wholly supported the practice of immunisation however as a mother this was not without some qualms. Based on all the information I had read, the statistics, the research, I made a rational 'informed' choice to immunise both of my children. Although I knew that immunising my children would promote herd immunity amongst all children, the utilitarian principle did not negate that this was *my* child I had to decide for.

I bring with me an understanding that informed choice as something that gives autonomy to parents but with corresponding responsibility for any consequences which the parent then must live with. My understanding of dilemma is that deciding for your child is not always the same as deciding for all children. I understand dilemma as particular, rather than universal. I understand that difficult decisions (in the same situation) are experienced differently by parents than for health professionals, and that for a family it is *their* child, not just *this* child for whom decisions and consequences must be weighed in the balance. I understand that equally health professionals must make decisions and promote interventions for the greater good of all.

Pre-understandings as a researcher

Prior to beginning this study I asked one of my supervisors to interview me to uncover my personal pre-understandings. Many of understandings that emerged I have shared in the above discussion. An understanding that emerged in relation to the

research question was how I felt (un-expectably) emotionally moved in the retelling of the stories. My pre-understanding about asking about the phenomenon of dilemma is that it is a very subjective experience, and that no question is neutral. I understand that reliving an experience may bring with it emotions and feelings that researcher and participant may not always have expected. I bring with me an understanding that some stories of dilemma may be those we live with.

These prior understandings and experiences have perhaps been an advantage in one sense of understanding the stories and perspectives of health professionals and families. On the other hand this may be a disadvantage as I am 'blinded' by what I already know. I am aware of the constant tension between balancing my pre-understandings whilst remaining open to the phenomenon.

The structure of this thesis

This thesis is presented in ten chapters.

Chapter one, "**Introduction**" has discussed what is called for in the question for this study, the purpose, my pre-understandings and why I selected hermeneutic phenomenology as methodology and research method.

Chapter two, "**The social and historical context of dilemma in child health in New Zealand**" places this study in the social and historical context of New Zealand from 1840 to the present day. This chapter follows how dilemma has been shaped by societal values and beliefs held at the time, and how changes in degree of choice and complexity has contributed to the phenomenon of dilemma.

Chapter three, "**Horizons of disclosure of dilemma in the literature**" explores literature specifically relating to 'dilemma' and how this has influenced what is known and perceived. This chapter describes how dilemma has been viewed from epistemological, theoretical and interpretive perspectives.

Chapter four, "**Philosophical Underpinnings**" describes the philosophical ideas that have guided and provided the foundation and guidance for this study. Drawing on the work of Heidegger [1889], Levinas [1905], Arendt [1906-1975] and Gadamer [1900-

2002] this chapter describes how the philosophical writings of these philosophers have informed this study.

Chapter five, “**Method**” clarifies the conditions by which understanding in this study has taken place. This chapter shows the congruence between the philosophical underpinnings and the steps taken to answer the research question.

The interpretive analysis of the study is presented in Chapters six to nine:

Chapter six, “**Dilemma announces itself in the mood of “not feeling at home”**” uncovers the way that dilemma is first experienced by health professionals. This chapter describes how the world of practice is put into question, where what was taken for granted is now revealed in a differing light.

Chapter seven “**Dilemma is experienced as feeling caught up in a world of practice**” illustrates how health professionals are thrown into a world of practice where they are claimed not only by the responsibility for their choices (or lack of choice) but also by the presence of another.

Chapter eight “**Living with dilemma – living with uncertainty and doubt**” describes how health professionals try to make meaning of having to live with the experience of dilemma and struggle to find a balance between not becoming too sensitive or de-sensitising.

Chapter nine “**Families’ experience of being in dilemma – a fusion of horizons**” reveals how families experience dilemma when encountering the health care environment and the meaning of these interactions to their family. This chapter also offers the perspective of both families and health professionals and how an understanding of each other’s experience could inform a different perspective.

Chapter ten “**Returning to where I started from**” brings the meanings uncovered in this study back to the whole. This chapter considers the implications of this study for practice, education and future research. Limitations are offered as a means for further

discussion and research. Recommendations are offered to ameliorate the negative impacts of the experience of dilemma.

Chapter two

The social and historical context of dilemma in child health in New Zealand

Heidegger (1962) suggests that any interpretation [of dilemma] is always against a background of human activity, against the involvements and relations that form the world. These interpretations are not just in the 'here and now' but are also handed down from the past, where understanding and meanings have been 'reworked or worked anew'. Crowe (2006) says that these inherited interpretations provide the un-discussed background for the way we think about ourselves and about the world with which we are concerned.

The purpose of this chapter is to show the context in which the phenomenon of dilemma has emerged in New Zealand and how this has been reflective of the social and historical context of the times. The attributes of dilemma mean that dilemma only occurs in a context where there is a conflict between values, beliefs, principles or obligations and having to make a choice. Whether dilemma exists or not is therefore reflective of the values, beliefs and principles an individual or society hold, and always against a background of the choices available to them. The notion of dilemma in New Zealand society is one that has been shaped by a move from limited choice and questioning, to an explosion of choice and seemingly complexity in the questions that face individuals and society. Although it appears that increased choices for health professionals and families signals the progress of knowledge and technology in the area of child health, the social and historical context of child health in New Zealand reveals many of the same concerns and issues that have prevailed throughout the decades.

Pre colonial New Zealand

New Zealand was first settled by Maori in the 13th century and as the first indigenous people of the land they are known as the 'tangata whenua' or the people of the land (King, 2003). Maori families lived in communities based on the foundations of iwi (tribe) hapu (sub tribe) and whanau (extended family) which contributed to strong economic survival (based on agriculture and use of natural resources) and a cohesive

society (Cameron & Freymond, 2006). Child rearing was seen as the responsibility of the whole community so that children were brought up by the extended family (whanau) (Cameron & Freymond, 2006; Durie, 1994). By all accounts, Maori children were brought up in an affectionate and relaxed child rearing environment which was in contrast to childrearing ethos in Europe at the time (Bryder, 1995; Cameron & Freymond, 2006; Love, 2006; Mikaere, 1994).

During this time health for Maori was not an end in itself, but rather a unity of mind, body and spirit (Lange, 1999). The distinction between religion and science was not made so that sickness was not viewed as a scientific problem but rather a moral problem (Lange, 1999). These embedded traditions of the links between spirituality and knowledge would later stand in opposition to the positivistic forms of thinking introduced by European settlers (Harvey, 2006).

Illness was viewed as having offended some aspect of the spiritual world or Tapu¹ which could affect other parts of the community if not resolved (Durie, 1994; Gluckman, 1976; Lange, 1999). People who were sick or dying were considered Tapu and removed from the community lest they affect other dwellings (Lange, 1999) with many sick and deformed children dying from exposure soon after birth (Gluckman, 1976). However pre colonization, most Maori enjoyed healthy and active lifestyles with limited exposure to disease. In part the notions of Tapu which applied to people, food, plants, animals and social relationships, contributed to what would now be considered good principles of public health (Lange, 1999). The provision of health and spiritual care was largely by a Tohunga, a learned and skilled person who acted as the medium between spirit and natural world (Harvey, 2006; Lange, 1999). The Tohunga's role was central to the daily life and thought of Maori (Lange, 1999).

The arrival of European settlers and the signing of the Treaty of Waitangi in 1840, handing over sovereignty of Aotearoa² to the British, were to have far reaching consequences to all aspects of Maori life. King (2003) has argued that since the signing of Treaty of Waitangi New Zealand life has been one of two cultures and two heritages, very often looking in two different directions. The impact of colonization

¹ *Sacred state or condition.*

² *Land of the long white cloud – the Maori name for New Zealand prior to the arrival of the settlers.*

was the decimation of Maori from introduced diseases; land confiscation which challenged the foundations of communal living (through whanau, hapu and iwi) and economic survival; policies banning the speaking of Maori in schools which saw a generation distanced from oral traditions and histories; dislocation of traditional communities during urban movement; assimilation policies linked to genocidal influences; and over representation in statistics of social inequality (Cameron & Freymond, 2006; Harvey, 2006; Love, 2006). Authors have argued that many of the dilemmas that face New Zealand Maori today are a result of social change following the colonization (Durie, 1994; Harvey, 2006; Love, 2006).

The dilemma of health for children in New Zealand

The history of New Zealand following colonization is a fairly 'young' one and finds its beginnings in the 1840's. For European settlers coming to New Zealand in the 1840's life was harsh. Many had left 'home' in search for a better life and opportunities in New Zealand, but were faced with a reality of economic hardship and starvation, with no infrastructure of charitable relief or welfare in place (Koopman-Boyden, 1978; McDonald, 1978; May, 1997). The dilemma facing early settlers was having to be self sufficient or perish. At this time self sufficiency was linked to ideas of morality, where poverty and pauperism were seen as evidence of a lack of morality because families were not working hard enough (Dow, 1991; Koopman-Boyden & Scott, 1984). In this light ill health was seen as the responsibility of the individual or family, rather than that of society or the state.

Prior to the 1900's not only was provision of health care limited due to lack of governmental responsibility for the health of its citizens, but resources and knowledge in relation to disease processes was also poor. The lack of certainty around the process of diseases, meant families and doctors often would have to take a wait and see approach to what course the infection or disease would take. Maria Atkinson writes to her mother in 1865:

Dear Ruth is convalescing from Scarlett fever...no other member of the household at present shows any sign of sickening and the whole subject of infection seems so surrounded by uncertainty that one does

not know what to expect next, nor when to reckon that we are free from danger (Porter & MacDonald, 1996, p. 395).

The dilemmas of not knowing what to expect meant that treatment was often offered as a 'chance' rather than a cure. With infectious diseases prevalent, coupled with a lack of knowledge of the infectious process, effective medicine or medical services, the mortality rate for children was high. In 1854 the Lush family recorded losing three of their six children in nine days to the Scarlett fever epidemic (Webster, 1995). Faced with little choice over the harsh reality of children dying led early settlers to describe life and death as an inevitability to be borne, rather than a dilemma of possible treatment or cure (Porter & MacDonald, 1996).

The late 1800's saw the growing body of knowledge emerge over the casual links between diseases and their mode of transmission (Hyslop, 1995). The rise of science offered more certainty in the predictability and control of health and illness, leading to more control by medicine in the health of the population. In the early 1900's the advent of greater knowledge in science and control of health coincided with societies' changing views; that poverty was not a result of poor moral character, rather it was largely due to circumstances beyond the control of the individual (Koopman-Boyden & Scott, 1984).

The dilemma that now faced New Zealand society was that poverty could affect the future health of the whole nation. There were two issues that were influential at this time in changing society's views. The first was the dilemma of falling birth rates (and therefore the perceived risk of being invaded by another country) and secondly the dilemma around the lack of young healthy men to meet the requirements of military service (McDonald, 1978; May, 1997). Children were now viewed as an investment in the future of New Zealand so the responsibility for their welfare shifted from the private concern of the family to the public concern of the state (McDonald, 1978; May, 1997).

One of the solutions to the problem of the lack of healthy young men for military service was the establishment of the Plunket Society in 1907 by Truby King. His goals were the survival of the nation "based on a new moral order people and

protected by fit Plunket reared adults” (May, 1997, p. 140). The new moral order that King referred to was that of subjects as self reliant and self regulating beings. This was to start in infancy and be achieved through strict routines and maternal distance, lest the baby should become self indulgent or spoiled (Olssen, 1981). King’s views were that mother’s instincts were not sufficient, and that motherhood should be seen along the lines of scientific principles and therefore learned; Plunket nurses being the experts (May, 1997).

The impact of these new regimes on mothers revealed the dilemma of no longer being confident in their ability and intuition to parent, and questioning whether to trust one’s self or the voice of the expert (who would also be the final arbitrator of her ability to parent and raise a ‘healthy’ child) (May, 1997; Olssen, 1981). During this time, medical dominance went largely unquestioned or challenged. This ethos was to prevail until the 1960’s when consumer advocacy groups began to challenge the expertise and dominance of the health professionals and the state when it came to the health and wellbeing of children and families.

By 1912, the large proportion of children now attending school meant that a school service was able to be implemented to survey the health of New Zealand children thereby solving the challenge of the ability to survey and intervene in the health of children. Teachers at school noted everyday issues of poverty, inadequate clothing, un-cleanliness, lice and sores (May, 1997). Medical inspectors commented on the paradox that in a country with the advantages of climate and general welfare, New Zealand children displayed unacceptable levels of physical ‘deformity’ (McDonald, 1978). This paradox was to be noted again by health professionals in the 1980’s. Dental health of children was also identified as appalling, leading to the establishment of a free school dental care system in 1921 (McDonald, 1978).

By 1938 the dilemma of high childhood mortality had been solved in part by the efforts of the Plunket service. The deaths of European babies fell from 88 per 1000 in 1907 to 32 per 1000 in 1938 (May, 1997). However in 1938 the infant mortality for Maori infants was four times higher than that for European infants. For Dr Turbott this disparity presented a dilemma of equality in a country known for the lowest European infant mortality rate. Concerns were expressed around the appropriateness

(and dilemma) of European services and policies ability to meet the needs of Maori in attaining the same standards of housing, education, and health (May, 1997). The dilemma of equality represented not only the appalling health statistics amongst Maori at the time, and their ability to attain the same standards of housing, education and health as the European population, but also that the services that were provided did not meet their social and cultural needs (Durie, 1994; Lange, 1999; May, 1997). Te Paea Herangi called for health services that were based on European scientific knowledge, but that also respected Maori tradition and Tapu (May, 1997).

Gains related to the health of children (predominately European) as contributing to the nation's wealth were disrupted in the 1930's by the Depression and World War II, and during this time many children went hungry and were visibly malnourished (McDonald, 1978). Although the 1950s and the 1960s were a period of relative stable economic growth, by the 1980's it appeared that little had changed in child health in New Zealand. In the 1960s New Zealand children had ranked 6th in the world for child health indicators, but by 1985 this had slipped to 22nd (Keene, 1987). The report by UNICEF³ stated that although the situation was bad for New Zealand children, for Maori children it was twice as bad (Keene, 1987). In the 1999 the Listener magazine headlines read "South Auckland imitates the Third World". National statistics for child health quoted in the article painted a dark picture, but in some large urban areas such as South Auckland infant mortality rates were twice that of the national average, with immunization rates of only 60 percent, one third of children iron deficient, and past killers such as TB⁴ and Rheumatic Fever re-emerging (Philp, 1999). Nettie Knetsch, the leader of child and youth services in 1999 for South Auckland, commented that when New Zealand doctors went overseas and talked about rheumatic fever, they were met with disbelief (Philp, 1999). This highlighted the dilemma of third world diseases being prevalent in a 'developed' country with supposed resources and infrastructure to ensure better health for children.

The end of the century highlighted the same concerns raised in the early part of the century around the inextricable links between the health of children, poverty and policy. Lamont, head of community services described this dilemma arising because:

³ *United Nations International Children's Emergency Fund*

⁴ *Tuberculosis*

“we’ve traditionally poured money into health...said we want you to solve this and that disease. But in fact that doesn’t work well. The infectious disease thing is more about housing policy, about education and employment” (Philp, 1999, p. 29). The dilemma facing many health professionals were that health, education, housing, unemployment and poverty were often viewed as separate issues, with money and resources allocated on the basis of individual ministerial portfolio responsible. This appeared to contribute to the fragmentation of services rather than an integrated approach. In 2007 the Innocenti Report Card by UNICEF reported 14% of New Zealand children living in poverty; only 84% of New Zealand children immunized (although there can be other contributing factors other than poverty) and that New Zealand children ranked 18% below the OECD⁵ average (UNICEF, 2007). The concerns expressed by health professionals and government representatives over the health and well being of New Zealand children remains as relevant today as the previous decade (Collins, 2007).

The dilemma of providing health care

Not only has the history of children’s health in New Zealand revealed dilemmas, but the ideologies inherent in the provision of health services by health professionals has also revealed dilemmas. The post war years brought about concern not only for the physical health of New Zealand (vis-à-vis children as the nations wealth) but also concerns around adult psychological adjustment, which was believed to be related to the quality of childhood experiences (Bowlby, 1970, 1982; May, 1997). In 1950 there was a change from the detached child rearing ethos of Truby King to a more humanistic view of the child (Darbyshire, 1994). In 1962 the Commission for Education asserted that emotional relationship in childhood was critical in leading to the establishment of child health clinics, courses in child psychology and child psychiatry (McDonald, 1978).

Prior to 1956, children in New Zealand hospitals were admitted on their own with parents only being allowed to visit once a week on a Sunday (Dobbie, 1990). An exception to this was an eight bedded plastic surgery unit in Lower Hutt established by Dr H. Pickerell and Dr C. Pickerell in 1927, where mothers were encouraged to

⁵ *Organisation for Economic Cooperation and Development*

stay and participate in their child's care (Dobbie, 1990). In other paediatric wards, emotional interaction by either parents or nurses was considered unnecessary, sentimental and a disruption to the child's integrity (Palmer, 1993). Ruth McNeur, a student nurse at Waikari Hospital in Dunedin recounts:

When I first came to paediatrics as a student nurse, parents were barely tolerated disturbers of children and hospital routine. They were permitted to visit for an hour on three days of the week. We scarcely knew what sort of people they were, or their home circumstances. Parents had few acknowledged rights. When the child recovered he or she was handed back to the 'grateful' parents (Parkes, 1996, p. 56).

It was overseas studies that raised the possibility that what had been thought as the best way to care for children in a hospital system based on an ethos of asepsis, routines and separation from parents was actually detrimental to the child's psychological wellbeing (Bowlby, 1970; Khan, 1963; Spitz, 1945). The effect of raising questions around what was the best care for children was to create new dilemmas for health professionals as they were now confronted with changing practice or retaining practices that had existed for decades. It was in fact not the health professionals who responded to these findings, rather it was parents who were now given a voice to many of the concerns they had. The campaign efforts of Nancy Sutherland in 1949 and the Parents Centre for better access for families to their children in hospital was met with reluctance by health professionals (Dobbie, 1990). The dilemma for parents was trying to find ways to challenge the entrenched ideologies and practices of health professionals.

Documentary style films by Robertson in the early 1950's depicting the emotional disintegration of children following hospitalization and separation from parents were condemned by health professionals as over dramatizing the plight of children featured in the films (Darbyshire, 1994). There is evidence that not all health professionals in New Zealand felt like this, however any concerns tended not to be expressed overtly. Ruth McNeur takes up her story of her changing views to parents in 1960, following her return from overseas: "As I became more relaxed and confident, I became more and more uncomfortable about this aspect of care and overseas experience confirmed

my feelings” (Parkes, 1996, p. 56). Here Ruth’s feelings of discomfort and unease were confirmed in being exposed to alternative ways of practicing and as a consequence raised questions of how to practice. Ruth said that a small group of nurses quietly began the practice of having breast feeding mothers live-in, not wanting too overtly challenge the ideologies still prevalent. For these nurse’s, subversive action seemed to be a more likely way of ensuring that mother’s needs were met, than to confront entrenched practices and hierarchies head on.

The publication of the Platt report 1959 in the United Kingdom was influential in changing opinions in New Zealand, as well as the lobbying by consumer groups. In 1973 and 1974 the Minister of Health and the Director of Hospitals encouraged all hospital boards to make provisions for mothers to stay with their child as well as to adopt more liberal attitudes to visiting (Dobbie, 1990) overcoming to some degree parents’ dilemmas of being separated from their child. By the 1970’s most hospitals in New Zealand had instituted the policy of ‘rooming in’. The reforms of the 1970’s also paved the way for a new philosophical basis for health professionals to work with families. Health professionals rather than being considered the expert in the care of a child were encouraged to adopt the philosophy of Family Centred Care. This has led to Family Centred Care being considered the underpinning philosophy of paediatric practice in New Zealand today.

This philosophy has been described as an equal partnership between families and health professionals, which acknowledges the strengths and knowledge each brings to providing the best care for the child (Ahmann, 1994). Briefly the key elements include: viewing the family as the constant presence, exchanging complete and unbiased information, honouring the diversity of families, recognizing and respecting the different way of family coping and support, peer networking, provision of coordinated services and support, and appreciating families as families and children as children (Shelton & Stephanek, 1995). Although espoused as foundational to paediatric practice, families and health professionals in New Zealand have described the tensions and dilemmas that arise whilst trying to work within this framework (Dickinson, 2004; Gasquoine, 1996; Thomsen, 1999; Weaver, 1999).

The dilemma of children's rights

In the 1970's the rise of consumer advocacy and special interest groups, who were willing to challenge the status quo, again shifted the way that children were viewed. Rather than the child being viewed as a behavioural or psychological being, the emphasis was shifted to the rights of the child as a special interest group and citizen in society (McDonald, 1978). This approach challenged how institutions functioned in promoting the welfare and rights of the child, rather than the child just being a passive recipient of care (McDonald, 1978). A report by the steering committee on the 1990 Bill of Rights for Children in New Zealand, identified several dilemmas in light of societies changing views. Firstly the report identified that many of the child welfare practices used often perpetuated deprivation (rather than solving it) (McDonald, 1978). Secondly that remedies used were often worse than the child's previous situation and thirdly that children were discriminated against in New Zealand as they had no rights to advocacy or legal redress, other than through adults who were responsible for their care (McDonald, 1978). The passing of the Children and Young Person's Act 1974 acknowledged that children should be accorded the same rights and legal protection as adults (Koopman-Boyden & Scott, 1984; McDonald, 1978). Although consumer groups were now challenging areas of health care, and special interest groups such as women and children were now seen as having rights, the disclosure of the "Unfortunate Experiment" was to show the New Zealand public how tenuous these claims were.

The "Unfortunate Experiment"

In 1987 the exposure of a cervical cancer research project at National Women's Hospital which came to be known as the 'Unfortunate Experiment' was a milestone in New Zealand medical history. The publication of the 'Unfortunate Experiment' in the Metro magazine uncovered dilemmas related to informed consent, patients rights, issues of power between physicians and patients, issues of power in hospital hierarchies, teaching methods of medical students and processes embedded in ethics committees (Coney, 1988). The purpose of the study by Dr Green had been to study the natural history of carcinoma in situ in a group of women who had abnormal cells found on a smear test. One group was treated whilst the other was not, even though international evidence suggested treatment. The women themselves did not know that they were taking part in the study, and 22 percent of the untreated women developed

invasive cancer, compared to the 1.5 percent among women who were treated (Coney, 1993).

Two doctors within the hospital, Dr McLean and Dr McIndoe tried to stop the trial, but despite challenging Dr Green, the hospital management and ethics committee, and raising their concerns with the hospital board authorities, no action was taken. McIndoe's family talked about the effect on him as he became obsessed with trying to halt the trial, and described his moral distress at not being able to prevent the death of yet another woman who went untreated for what should have been a very treatable disease (Coney, 1988). Although other doctors and nurses may have voiced concerns, the overwhelming hierarchy and power relationships within the hospital, and the fear of retribution prevented many of them from speaking out.

A national outcry saw the establishment of the Cartwright Inquiry in June 1987. The inquiry also uncovered practices of vaginal examinations by medical students on anesthetized women without their knowledge, and the mass taking of vaginal smears on new born girls without their parent's knowledge or consent. Williams (2004) says what was shocking was this was not the middle ages, there were in fact international guidelines set out in the Nuremburg Code in 1948 and Declaration of Helsinki 1964 following the atrocities of the Nazi experiments during World War II. The Cartwright report led to establishing of the Code of Health and Disability Services Consumers Rights under the Health and Disability Commissioners Act 1994, in effect implementing a doctrine of informed consent for health care consumers. By 2004 there were 15 Health and Disability Ethics Committees established in New Zealand, chaired by a lay person and with significant non health professional representation on the committee (Pinnock & Crosthwaite, 2004).

Chest physiotherapy at National Women's

In 1995 another breach of informed consent was to take place at National Women's hospital. This time it involved chest physiotherapy on low birth weight babies with the use of a 'cup' or face mask. Although research on the use of chest physiotherapy on low birth weight infants was inconclusive, it had been implemented as a standard treatment (Coney, 1995). The chest cupping resulted in several neonates with neurological impairment. An inquiry by the Queens Counsel found that National

Women's did not have a protocol for the use of 'cupping' chest physiotherapy on low birth weight infants, and although any change to protocol (such as the use of a cup) was supposed to go through an ethics committee this had not been done. The arguments given by Dr Harding (similar to those expressed during the 'Unfortunate Experiment') were that this treatment was considered 'standard' (presumably because it was already in place) (Coney, 1995).

The inquiry found that the treatment offered by National Women's did not meet the standards of other neonatal facilities (Coney, 1999). As well as physiotherapists, nurses were also implicated. Their involvement came about due to the requirement of having to provide afterhours physiotherapy service for the neonates. This was resolved by teaching nurses to provide the cupping treatment. The inquiry found that the nurses had been taught incorrect techniques resulting in far too vigorous treatment. At the time nurses had expressed concerns that the treatment was "overly aggressive for the stage of the babies" (Coney, 1995, p. 510). The dilemma for nurses was being directed to carry out a treatment that was argued by experts to be beneficial, while being faced with professional doubt over the efficacy of the treatment. Many nurses just stopped giving the treatment.

The major findings of the inquiry highlighted the lack of consent sought from parents for the treatment of their baby (as the treatment was not standard) and parents not being aware that nurses would be providing much of this treatment (this not being considered in the scope their practice and the level of training and supervision being arguably lacking) (Coney, 1999). Again for parents (as the health consumer) dilemmas arose in having to be able to rely and trust the expert opinions of health professionals; not being given adequate information around the treatment of their child; not being able to express a choice; and having to live with the consequences these interventions had on their child, which for some resulted in neurological harm.

The "stolen hearts" at GreenLane Hospital

In 2002 a third issue of consent was to arise in the care of infants and children. This involved the retaining of hearts in what came to be known as the "stolen hearts". It was reported that more than 1,300 hearts were collected by GreenLane Hospital from the 1950's onwards ("Hearts taken without consent", 2002). Many of the hearts came

from babies or aborted fetuses. Often hearts came from other hospitals around the country. An audit carried out found that although many families had been asked by the hospital for permission to retain their children's hearts; there were also those who had not been asked ("Hearts taken without consent", 2002). The voices of health professionals and families reveal different perspectives around this issue.

For Nadia Glavish, an Auckland Hospital Health Board senior Maori advisor the dilemma was that for all the talk of cultural sensitivity; treating people as human beings had just been negated. She exclaimed "it's not just body parts...it was a person" ("Hospital returns hearts", 2002). For many Maori the concerns were that their cultural beliefs centred on the importance of the person being buried whole, and there were consequences of knowing that many of their mokopuna⁶ were buried incomplete. The effect on Maori groups and families was to feel "trampled" over and "devastated, disbelief and angered" by this knowledge ("Hospital returns hearts", 2002). For some families the conflict was that they knew that their child's heart had contributed to perhaps saving other children's lives, but that this was overshadowed by the feelings of betrayal and hurt in never being asked ("Hearts taken without consent", 2002).

Many of the GreenLane specialists were devastated by the scandal and pointed out that the collection had started at a time when a different ethos prevailed. The dilemma for them was being unwitting (and unquestioning) accomplices to a practice started years before many of them commenced working at Green Lane and that hindsight was too late to take away the grief and anger for families. Dr Kirsten Finucane apologized to all the families ("Expert urges review of procedures", 2002), but also acknowledged that the collection had contributed to huge gains in valuable knowledge by surgeons in being able to dissect and examine these hearts ("Hospital returns hearts", 2002). Specialist faced the dilemma of wishing to be sensitive and empathetic to the needs of the families, whilst also recognizing the value the collection had on developing techniques that had improved survival for children requiring cardiac surgery and would continue to have on the survival of other children ("Supporters of research speak out", 2002).

⁶ Children

The names ‘the Unfortunate Experiment’ and ‘the stolen hearts’ have gone on to represent the dilemmas that have affected the often nameless and faceless families and individuals. Equally there are also individual names of children that have gone on to be indelibly imprinted in the minds of New Zealanders as representing dilemmas of informed consent, best interest and responsibility.

Liam Williams Holloway

The case of Liam Williams Holloway, described in chapter one, has shaped the discourse of dilemma around children requiring health care in New Zealand. The voices of both the proponents and opponents of Liam’s parents’ decision to seek alternative treatment to chemotherapy (and the subsequent battle lines drawn out in the legal arena) reveal the complexity and differing perspectives of what constituted Liam’s best interests. Moore (1999) stated “there are obviously no simple answers to a question fraught with emotion and festooned with individual judgements. The rights of the child may be paramount, but they place us in a web of infinitely complex and delicate issues” (p. 4).

For Dr Sullivan, Liam’s primary paediatrician, his dilemma was not so much about whether to respect parents’ choice to seek alternative treatment but the impact that alternative treatment and the lack of conventional treatment would have on Liam. He described two other instances where children had come back for conventional treatment in dreadful conditions and said “I found it really distressing...you wouldn’t put your dog through it frankly” (Martin, 2000, p.1). The dilemma for Sullivan was that whilst he could not endorse or recommend the alternative therapy, he was convinced of the efficacy of chemotherapy. Sullivan believed that Liam had a 78 percent chance of being cured after two cycles of chemotherapy (this was later to drop to 50 percent) (Ansley, 1999). This he rationalized was “enough to warrant the kind of treatment he was getting”. Sullivan’s concerns about the claims made about the quantum booster⁷ led him to tell Liam’s parents that he would not be able to support alternative therapy alone, and would have to discuss Liam’s case with CYFS⁸ (Child

⁷ A device claimed to achieve better well being

⁸ A New Zealand government agency with legal powers in the area of child protection from abuse, neglect or problem behaviours.

Youth and Family Service) (Ansley, 1999). Sullivan says that when Liam's father asked him "are you going to bust us" he replied "no, but it's my ethical and legal duty when there is no evidence that alternative therapy would be effective" (Ansley, 1999, p.19).

The controversy over alternative treatment was further fuelled when Robyn Stent the Disability Commissioner at the time, called upon registered health professionals to provide information on alternative therapies to patients, to ensure 'informed consent' (Moore, 1999). Many paediatricians were angered by what they perceived as the double standard of providing informed consent; whilst alternative therapy practitioners were not called upon to 'prove' the efficacy of the treatments they offered (Moore, 1999). Sullivan says "alternative therapists can offer anything. But I must practice by the highest standards...here we have parents of a child with a potentially lethal condition. They are frightened, vulnerable people and they are being offered false hope. How can we accept this gross situation? Where is the information? The informed consent?" (Ansley, 1999, p. 19).

Sullivan argued that although the rights of the child were paramount and that health professionals should not come between the child / parent relationship, the dilemma facing health professionals was the question of "what if the parents got it wrong"? (Ansley, 1999, p.19). It was the belief that Liam's parents had got it wrong that led health professionals and Health Care Otago to take action in compelling Liam's parents to accept conventional treatment. To some it appeared that compelling parents to do something that was against their own judgment of what was best for their child was heavy handed. Wellington hospital oncologist Dr Peter Dady says there was a perception that Liam and his parents were being bullied by Health Care Otago but the dilemma was that "if the doctors hadn't gone to court, they could have been accused of dereliction of duty" (McLoughlin, 2000, p. 75). Anthony Howie, Otago's children's services manager says there was no choice of opting out of advocating for Liam (Ansley, 1999). For Dr Ross Corbett a paediatric oncologist, the fact that Liam could not state his wishes placed a huge burden of responsibility on his parents and health professionals as surrogate decision makers (Moore, 1999). The dilemma here was that neither could agree on what decision was best for Liam.

The expectations of being a surrogate decision maker placed Liam's parents under the spotlight as to the extent or limits to this role. The commissioner for children, Roger McClay said "we tried to be sympathetic to the parents, but we didn't agree they had the right to make decisions relating to his life or death. Parents have the right to make decisions on behalf of their children, but children are not chattels" (McLoughlin, 2000, p. 75). Corbett felt so strongly about the decision Liam's parents had made on his behalf that he remarked they had made "an amazingly illogical decision" (Ansley, 2000, p. 24). Others in the public arena did not agree with the views expressed by Corbett and McClay and replied that "that state has no business interfering in the private decisions made between parents and their children" (Ansley, 2000, p.24). An editorial in the Nelson Mail, suggested that Liam's parents had made a considered choice in deciding in Liam's best interest, and that accusations by a paediatrician that Liam died because his parents chose something else, belies the fact this will always remain unknown. The editor says that had Liam's parents chosen differently, and endured the treatment they were so anxious to avoid, he still may have died ("Little Liam's Legacy", 2000).

For David Becroft (a paediatric pathologist) Liam's case was not as clear as some positions had suggested. He said "it isn't black and white. You can't completely say that if you do this you will survive – he has a poor outlook and you do what you can" (Ansley, 1999, p.20). However Becroft argued that to not have Liam available to try further treatment was to negate any hope. Barry Taylor, the then president of the New Zealand Paediatric Society expressed similar views to that of Becroft. He suggested that many views had polarised a difficult situation where there was never going to be a positive outcome unless one group acquiesced to the strong views of the other. Taylor commented that it would have been "a disaster either way, trying to give long and difficult chemotherapy to someone whose parents didn't want it given. It is an impossible situation" (Chisholm, 2000, p. A2).

When the family of Liam finally came out of hiding, Liam's father commented that he was overjoyed to be home, but angry that health professionals failed them (by pursuing them) in their hour of need (Thomas, 1999). Professor Abbott, a paediatrician commented that "I can fully appreciate the dilemma facing them. I have seen children go through chemotherapy and other regimes which included serious

side-effects and a considerable emotional impact on the family. You can understand when they say no more treatment. You can understand the grief, anger, and frustration at losing control of the situation” (Moore, 1999, p. 4). However, Abbott believed that Liam’s parent’s had to bear the ultimate responsibility for their son’s welfare and consequences for their decisions.

Tovia Laufau

In 1999 during the Liam Williams Holloway case, another boy, 13 year old Tovia Laufau died at his home in Auckland, after not being treated for a tumour the size of a golf ball on his knee (Martin, 2001). Tovia had been diagnosed with osteosarcoma, and oncologists at Starship Hospital told his parents that with treatment Tovia had a 60-70% chance of a full recovery. The parents returned home but never came back to seek treatment (Brandon et al., 2001). One of the reasons given was that Tovia did not want the treatment. His parents supported their son’s decision not to go to hospital as he and his parents believed that God would save him (Martin, 2001). McLoughlin (2000) reported that in the wake of the negative publicity surrounding the Liam Williams-Holloway case, the doctors at Starship hospital did not seek a court order, reasoning that his parents may also go into hiding. This immediately brought a rebuke of health professionals from the commissioner for children Roger McClay, for not intervening because of the fallout from Liam’s case (McLouglin, 2000).

A survey was undertaken by Dunedin School of Medicine and Otago University, to investigate professional (medical) and public (academic) attitudes towards the two cases of Liam William Holloway and Tovia Laufau (Brandon, et al., 2001). The researchers found that seventy seven percent of participants supported medical staff in seeking a court order in the case of Liam William Holloway as it was seen as the ‘obligation and duty of care’ of the doctors. The twenty three percent of participants’ who disagreed, did so because they felt such a decision was the ‘responsibility of the parents’ and that legal intervention was so final, aggressive and instrumental in destroying the parent / doctor trust. In Tovia Laufau case, seventy percent of the participants disagreed with doctors for not seeking treatment, supporting a notion of ‘duty of care’.

However later a consultant involved in the case contacted the researchers and a more complex picture emerged of the case of Tovia (Brandon, et al., 2001). The consultant told that although the health professionals had been influenced by Liam's case, in the case of Tovia, his age and steadfastness of his opinion were taken into account. This was further influenced by the doctors finding further metastasis, which dramatically decreased Tovia's chances of survival. In this light and the contested and complex issues around compelling treatment, the consultant said doctors did not pursue the case as vigorously. Had this information been available to the participants of Brandon et al. (2001) study, their responses may have differed.

Caleb Moorhead

In 2001 another child was to die, but this time unlike the case of Liam and Tovia, Caleb Moorhead's condition and death was seen as being totally treatable. Six month old Caleb Moorhead died of bronchial pneumonia after his strictly religious parents removed him from hospital to treat his illness with herbal remedies. Contributing to the cause of Caleb's death was his severe vitamin deficiency brought on by his mother's strict vegan diet ("When children need more than blind religious faith", 2002).

Patrick Kelly, the paediatrician who first saw Caleb said he had a sense of trepidation as he knew Caleb didn't have long ("Science, religion and a dying baby", 2002). Kelly said he was so worried about Caleb's parent's apparent lack of understanding about the severity of Caleb's condition, that he called CYFS to arrange a court order for the next day to remove Caleb if necessary. Explaining what he had done and the consequences for Caleb if he did not receive treatment, Kelly left the Moorhead's to think about it. The response of the Moorhead's was to uplift Caleb and flee the hospital. Their departure was witnessed by the charge nurse of the unit who was so concerned that she followed them outside trying to explain to them that Caleb would die if they took him home. The lack of the court order prevented anyone from physically restraining the parents from taking Caleb.

Five days later the social worker managed to persuade them to return. By this time Kelly thought that Caleb's brain damage would be irreversible and told his parents that he would need a MRI under general anaesthesia to assess the consequences. The

parents distrust of conventional medicine, and frightened that Caleb would die on the operating table, led them to flee again (“Science, religion and a dying baby”, 2002). Kelly in the meantime realized that Caleb’s apparent brain damage could be cured with injections of vitamin B12. He left numerous messages on the Moorhead’s phone but these went unanswered. Caleb subsequently died at home. Kelly says he lives with the loss and knowledge that Caleb’s life could have been saved up until half an hour before his death (“Science, religion and a dying baby”, 2002) whilst the social worker spoke of feeling that she had failed, and of feeling she should have done more (“Social worker felt she failed baby and family”, 2002). The Moorhead’s spent three years in jail for the manslaughter of Caleb (“Convicted parents looking after child”, 2005).

Nia Glassie, Chris and Cru Kahui, Delcelia Witika, and James Whakaruru

These names are imprinted in the minds of health professionals who work with children, as an unspeakable reminder of the suffering and short lives for some New Zealand children. The 2003 UNICEF report showed that New Zealand ranked twenty second out of twenty seven countries for child homicide. This equated to fifty five children killed over a five year period, nineteen of those less than one year of age (Hassell, 2006). This needs to be viewed in light of New Zealand’s population of just over 4 million people in 2003. A recent case of child abuse highlighted in the media (July 2007) involved three year old Nia Glassie, who over a period of three months was beaten, swung around on a clothes line until she flew into the air, and trapped in a spinning clothes dryer. The extent of trauma that Nia sustained resulted in her being placed on life support and subsequently dying. Public reaction to Nia’s horrific experiences was overwhelming and on the 8th of August 2007 three minutes of silence was observed. Yet that very same week, the New Zealand Herald reported a further three cases of children being admitted to paediatric units with broken bones and head injuries as a result of violence at the hands of adults. The dilemma is that for every high profile case that makes the headlines, there are other children, hidden statistics, who face unhappy and violent childhoods.

Helen Clark, the Prime Minister of New Zealand commented to the media that somebody, a neighbour or relative must have known about Nia’s abuse, because she

couldn't believe that such a level of abuse could go on unnoticed. Helen Clark issued a call that all adults needed to advocate and speak up for children who may be at risk. Weeks later the headline in the New Zealand Herald read "The good neighbours dilemma" (Cuming, 2007). One of the Herald reporters retold how in the wake of the Prime Ministers' call for action, she had been visited by police because of a complaint laid by a visiting friend of a neighbour concerned about the screaming coming from her house. The children reassured the police that their mother was not beating them. This prompted a flood of replies from the public asking how neighbours can distinguish screams of agony from a tantrum and how can neighbours always be aware of what happens behind closed doors. The public questioned that even if abuse was reported would any action be taken? This highlighted the point in the public's mind that questions of whether and when to intervene are never easy. This dilemma is also one that faces health professionals working with families where there may be risks for abuse.

In 2006 the media reported the case of the three month old twins Chris and Kru Kahui who were beaten so severely that they died. Health professionals were especially targeted as to their involvement and whether the tragedy could have been avoided. There had been reports of concerns by health professionals prior to the twins being discharged, around the lack of time the parents spent with the boys in hospital but as a hospital spokesperson pointed out this did not constitute abuse ("Nurses raise concern before twin's death", 2006). A social worker involved with the family told that she also had concerns, and did raise these informally with CYFS but the dilemma was that these concerns did not reach the threshold required to constitute a formal notification. Here the dilemma for those concerned was the threshold between 'concern' and 'proof' of abuse or neglect.

The burden of 'proof' or 'concern' does not only represent a dilemma in how guidelines are to be interpreted, but also, the impact that any decision made (or lack of decision) will have on how health professionals can work with families. Health professionals who work closely with families and children in community settings (and in their homes) are often faced with the dilemma of trying to establish a relationship with the family whilst also being there to carry out surveillance of the health of the child (Wilson, 2001). Plunket nurses commented on this tension in the wake of the

recent introduction of the new family violence screening program (Collins, 2007). A Plunket nurse said that for her the hardest part was telling the mother that if she disclosed abuse then she [the nurse] would have to tell someone about it. For this nurse this presented a dilemma of potentially threatening the relationship of trust with the mother and the possibility of then no longer having access to a child who may be in a vulnerable situation. In this light, the nurse felt she had to weigh up the risk of the safety for the mother and child, with promoting the ongoing relationship with the family. Health professionals are often caught between being non judgmental and having to make judgments.

One of the solutions offered has been that of mandatory reporting, however Patrick Kelly a New Zealand paediatrician argues that such simplistic answers belies the complexity of the issues health professionals are faced with (Kelly, 2000). Kelly asks that if mandatory reporting for abuse was introduced, would there be also be mandatory resourcing? The dilemma Kelly suggests is how health professionals can support a policy that will increase notifications when the present health system is not coping with the cases it already has.

Kelly says the dilemma of mandatory reporting means that health professionals must adopt a policy that families are “guilty until proven guilty”. However the alternative would be to a policy of “innocent until proven guilty” and while health professionals wait for families to prove their guilt, would they be condemning some children to further injury and death? (Kelly, 2000) Kelly says that this burden of responsibility often means that health professionals have joined in a conspiracy of silence, feeling powerless to intervene. In the meantime “abused and neglected children and young people have often been abandoned and betrayed by those who are given the responsibility for their care” (Kelly, 2000, p.11).

Being caught in the dilemma of acting or not acting places health professionals in unenviable positions; however it is also the position of the child that many health professionals are acutely aware of. Those health professionals who speak out about being with children who have been “beaten and broken” talk not only of the burden of their legal and professional responsibilities, but also of the weight of being witness to the horror many children have endured.

A nurse commented that “it keeps happening...you’re not just dealing with the kid in the bed but the whole family...and when you run into three or four cases over a six week period it really burns you out” (du Chateau, 2007, p. B6). For a social worker what is distressing is that “you hear everything, how they’ve been beaten with broom handles and vacuum cleaner pipes...kept home from school because they’re so bruised their parents are scared they’ll be found out...[you] have to step back because it can become overwhelming” (du Chateau, 2007, p. B6). For those involved in child abuse cases the dilemma is one of how to carry on. A detective involved with child abuse cases in New Zealand told du Chateau (2007) that “when you deal with it day-in, day-out, you build some immunity, distancing yourself emotionally. If you personalized it you couldn’t do your job (p. B6).

Dr Ian Hassell, a past Commissioner for Children argues that when children are put into driers and hung out on washing lines, dehumanization has occurred as people relate to children as objects rather than as human beings (Masters, 2007). For health professionals in 2007 the dilemma was trying to retain some objectivity in light of appalling experiences for some children whilst still being able to remain present to the humanness of the child.

Running alongside the debate of child abuse in New Zealand has been the implementation of the controversial ‘anti smacking’ Bill passed by Parliament in May 2007. Opinions have been polarized with some sections of society advocating for parental rights whilst others advocating for the rights of the child (“Anti-smacking fight heats up”, 2007; Hoskings, 2006; Small, 2006). Prior to the introduction of the new bill, parents were allowed to discipline their children with ‘reasonable force’. In response to the notion of reasonable force, Roger McClay the commissioner for children in 2001 argued “is a little bit of violence okay, which is the smacking argument. Would a little bit of child rape be okay? Of course it is not. And the problem with smacking is how do you judge what is reasonable force? A court found recently that a piece of kindling wood and welts on the body of a little boy was reasonable. But if I had gone outside ...and started thumping a puppy with a piece of kindling...What I want to know is, if it is so effective why do we confine it only to children?” (Stirling, 2001, p. 20) The dilemma for many is that children do not

appear to have the same rights as other groups in society, and behaviours that would be considered abhorrent towards these groups appear to be legitimized in relation to children. McClay highlights the dilemma of where do we draw the line with reasonable force and who decides where that line is. The parent, the concerned neighbour, the health professional, the police or the judge?

For health professionals, there is a dilemma of being caught between the interpretations of the law, and faced with the real and tangible consequences for children. In one particular case Dr Desmond Wood was reported to be in contempt of court for objecting to a child being handed back to a father who had been charged with battering the child (Stirling, 2001). Although not reported, as the reader we could imagine the gravity of the concerns for this child that prompted Dr Woods to act in such a manner. Eighteen months later the father was charged with the manslaughter of the child. Woods described his disbelief and horror at being a witness to what had happened to this child and the dilemma of having known the risks for this child yet being powerless to intervene. His sense of frustration and outrage is evident as he questioned how a parent could be charged with “some namby pamby charge as ‘injuring in a way to bring about death...[when] you see children whose brains have been bashed out” (Stirling, 2001, p. 20). Being aware that for many children there is no choice of a ‘safe’ childhood led one health professional to comment: “a lot of us have held dead battered children and felt glad for them. There is nothing worse than saving a tiny child and knowing they will go back to more of the same brutality” (Max, 1990, p. 47). Here dilemma is disclosed in the questions of what sort of society we live in where it might seem preferable for a child to die, than be returned to the same miserable conditions of what should be a happy and carefree childhood. The questions that this health professional raises are not only in regard to the ideals society holds in relation to living in ‘God’s own’⁹ but the apparent lack of resources to intervene in the conditions in society that makes this abuse possible.

Throughout the history of child health in New Zealand rights to health and a safe childhood remains ones that are contested. For health professionals there seems to be

⁹ *A colloquialism for New Zealand*

a terrible repetition of the same dilemmas and issues that have prevailed from the 1900's through to 2007.

Looking towards the future

Carden (2007) writes the dilemma that faces much of New Zealand society today is not a lack of access, but rather one of choice (although I would argue that lack of access and choice remain prevalent in some areas of New Zealand society). Most people live in a society where never before have they been faced with so many choices in their everyday lives; which brand of the forty different types of toothpaste to use, or which coffee to buy at Starbucks. In the area of healthcare, if a child injured themselves in the 1957 their choices may have been limited to seeing a doctor and being prescribed pain relief. Fifty years on, the same child now has a choice of seeing a general practitioner, a specialist, a physiotherapist, a chiropractor, an acupuncturist and more. Health professionals are also faced with increased choices in what diagnostic tools and interventions could be used to treat this child's injury, set against a background of accountability for costs versus what may provide the best outcomes. The dilemma is that not only are there more choices, but that these choices come with conditions and implications that need to be taken into account.

Professor Essex in speaking to paediatricians at a conference in New Zealand highlighted that the increase in medical science which now sees technology dependent children (such as ventilation) being cared for at home, has created new dilemmas for health professionals (Essex, 2004). Essex says these technological advances have not kept up with ethical and legal guidance. One of the questions Essex asks is should health professionals offer technological support just because it is available and because parents "want everything done?" Essex suggested the dilemma for health professionals is being called to ask parents to make decisions about their child, when often this unknown future is one parents cannot yet imagine or know if they will have the personal coping mechanism or personal support systems to take on this responsibility. Essex says that doctors are caught in-between, being accused of paternalism and their duty to make some of these hard decisions without handing all the responsibility to families.

Health professionals must always weigh up the pros of advocating for a technology dependent child to be nursed by their family in the community, with the known “cons” such as the personal and financial burden to families. The dilemma is that once the use of technology is suggested or possible it is difficult to go back. The use of technology becomes taken for granted and normalized, and may hide the huge cost that must be borne by families who at the time of agreeing may not yet understand or be able to fully comprehend all the possible future consequences of such a decision.

Robinson (2002) tells the story of a young man with Cystic Fibrosis who was offered the choice of a BiPAP¹⁰ machine as new therapy at the end of his life, having decided against a transplant or ICU stay. Although his breathing did improve he was now dependent on the machine. This young man described that rather than his death being a ‘gradual loss of consciousness’ he was now faced with being responsible for his own death. He claimed “this machine has turned my death into a suicide” (p.105). The dilemma for this young man was that rather than letting life and death take its natural course, he was now faced with having to decide the moment of his death. Death, rather than being a consequence of nature, had now become a matter of difficult choice.

In Australia in 2006, guidelines were drawn up at a national conference (which included New Zealand health professionals) to provide a framework for decision making in relation to the choices that face health professional and families for the care of premature infants. In drawing up the guidelines, the committee came out with a position statement that all of the following perspectives needed to be incorporated when considering decisions regarding the care of prenatal infants. The committee stated: “Perinatal care at the borderline of viability demands a delicate balance between the parent’s wishes and autonomy, biological feasibility, clinician’s decisions and responsibilities and expectations and the prospect of an acceptable long-term outcome; coupled with a tolerable margin of uncertainty” (Lui et al., 2006, p. 495).

Dilemma is revealed in the questions of who decides what ‘biologically feasible’ is when feasibility slides further towards conception all the time? Who decides what the

¹⁰ *Bi-level Positive Airway Pressure*

‘acceptable long term consequences’ should be? The parents, the health professionals or the state who have the responsibility for some of the future financial support (or some economists would argue economic burden) for this child? What is a ‘tolerable margin of uncertainty’?

The Committee on Foetus and Newborn in a policy statement discussed the dilemma that treating high risk newborns with advanced technology often results in prolonged dying or profound neurological consequences yet not to treat would result in increased mortality where there might be hope (Kent, Casey & Lui, 2007). The hope that has been fostered by advances in technology, which have been described as modern day miracles (such as the survival of babies who can fit in the palm of one’s hand), have also contributed to society becoming hostages to technology (Muraskas et al., 1999). For health professionals and families it is difficult to decide on the future of a child when both have different expectations. For many families, deciding for their child will often be based on the hope that their child will be the one who does well. For health professionals this may be one of pragmatic reality and experience, but balanced with never quite knowing for certain what the outcome may be.

Gains in biomedical technology have been exemplified in the human genome project, heralded as the biggest advance in medical science this century. However this has brought with it increasing questions and dilemmas. There have been concerns from consumers that the information gained from genetic testing may result in discrimination by health insurance companies and employers (Fulda & Lykens, 2006; Lapham, Kozma & Weiss, 1996). Issues such as ownership of genetic material, privacy and societal protection have been expressed (Wiesenthal & Wiener, 1996) and these issues have been evident in a legal cases in the USA between patients whose DNA has been used without consent to develop commercially patented cell lines (Evans, 2006). There are dilemmas around the disclosure of information to families where there is a history of Huntington’s disease where the family member may be known to be at risk but remain an unknowing party (Hakimian, 2000). Although disclosure is the right of all, physicians are faced with the dilemma of being aware of how such information may impact on families lives when the disease itself is late onset and incurable (Hakimian, 2000). The questions that face health professionals are whether families will view living with the knowledge of the disease as a dark cloud

hanging over their future or an opportunity to live their life to the fullest before the onset of the disease?

Other authors have argued that gene mapping and therapy has the potential to deconstruct and reconstruct both our physical and social identities (de Witte & Welie, 1997; Geetter, 2002). The risk of eugenics has been raised as a consequence, where societies' demand for a healthy population may give way to screening programs to eliminate diseases or disability (Geetter, 2002; Nelkin & Tancredi, 1994; Paul, 1994). 'Routine' antenatal screening now offers nuchal thickening, CVS and amniocentesis tests to predict the risk of having a baby with congenital or chromosomal abnormalities. The risk of miscarrying from some of these tests is similar to the risk of having a baby with some 'abnormality' (for a mother under a certain age group). Which risk does the mother opt for? There are also risks of false positives or false negatives. In the USA health professionals may be sued for 'wrongful birth' related to the loss of opportunity to prevent conception or live birth of a child born with congenital or chromosomal abnormalities (Klein & Mahoney, 2007). Inherent in these dilemmas are questions of how society values children born with disabilities or disease. In the future could funding agencies (private or governmental) demand that if parents have knowledge that their child may be a burden on financial or economic resources, that they terminate the pregnancy or support the child themselves? A profoundly deaf person writes that they would say 'no' to genetic screening for deafness, as it discriminates against disabled individuals, however equally they would not expect society to pay for people who have the duty to know about their own genetic makeup (Chadwick & Levitt, 1998). This raises a whole spectre of dilemmas in relation to responsibilities or consequences of one's own genetic makeup.

Some families are now choosing to screen for inherited genetic diseases such as Cystic Fibrosis and choosing to select those embryos without the inherited trait. Other parents in response to having one child with types of childhood cancer are choosing to have another child to be a match for the donation of blood or tissue. The responsibility of one sibling for the other siblings survival is powerfully portrayed in the novel 'My sister's keeper' by Jodi Picoult (2004). A report by the Human Genome Research Project at Otago University New Zealand recommended that all newborn babies and

some embryos be tested in order to be able to harvest ‘saviour siblings’ for sick children (Nicholas, 2007).

No longer are health professionals just battling against death and disease where science lit the way about what is truth and good. Rather the space that health and health care inhabits has become one of contested realities, often on the borderline of what is and what is not possible. Hodgkin (1996) comments that what seemed to be so certain in what health professionals know and do is no longer the case. This however is not just the case for health professionals but society at large as the “unquestioned biological givens are disintegrating around us: the stability of the climate, the immutability of species, a life span of three score year and ten, the unchangeable genetic make up of one’s unborn children. ‘The facts of life’ have melted away, and our collective sense of bewilderment and wide eyed possibility rises” (Hodgkin, 1996, p.1569). No longer is the world a place where undisputable facts can be known. Increasing advances in science and knowledge and ways in which we understand the physical world also bring with it increasing quandaries. Not only are there now more possibilities in what we know about the world, but also more choice in what is possible. These choices however present not only an opportunity, but corresponding questions of whether and how we should use these. Fundamental to these debates are the questions of the worth and dignity of human life.

Conclusion

The literature on the social and historical context in which the phenomenon of dilemma in New Zealand has emerged reveals how many of the understandings of the past have been ‘reworked’. Although there is a plethora of questions that face society with the rapid gain in technology and knowledge, many of the questions around the dignity of human life remain the same. Changing values and ideas in society on the rights of children (to things such as health, education, family, love and safety) have been ‘worked anew’ and are reflected in changing legislation and practices of institutions, yet many of the questions and issues in attaining these remain the same. Underlying the dilemmas identified, and the contexts they arise in, are people’s experiences of uncertainty, questioning and distress.

Chapter three

Horizons of disclosure of dilemma in the literature

Chapter two has described the social and historical horizon of disclosure in which the phenomenon of dilemma has been revealed in the New Zealand context. This provides one way of understanding how past understandings may influence our present understandings and interpretations of dilemma in paediatric practice today. Other horizons of disclosure also exist such as non fiction literature, literature, art, poetry and film, which may reveal yet other understandings of how the phenomenon of dilemma is disclosed. Heidegger suggests that these are all ways of illuminating or providing a 'clearing' in which understandings may be revealed or concealed. For Heidegger and Gadamer any understanding is influenced by our prejudices or preunderstandings therefore what is revealed or concealed is influenced by what we already know, what we already have read, and what has already been written.

For Gadamer (1989) much of what we know [of dilemma] is influenced by the 'traditionary texts'. The traditionary texts provide a body of writing that inform those historical, epistemological and ontological understandings that have been handed down to us. Kavanagh (2005) argues that as we are so 'language dependent', ways of thinking, patterns of writing become ways in which phenomenon is represented and in turn influence the connections between previous and present understandings.

The purpose of this chapter is to review the literature and explore the various horizons of disclosure related to the phenomenon of dilemma. These horizons include the languaging of dilemma; theorising on moral orientation towards dilemma; the experience of dilemma as moral sensitivity, moral distress and burnout; and how dilemma is depicted in fiction. The purpose of this review is to uncover what is already known about dilemma and provide a basis for connections with new understandings that may emerge as a result of this study.

Languaging dilemma

One of the ways in which horizons of disclosure are mediated is through the use of language. The phenomenon of dilemma is very often discussed *as* an ethical or a moral dilemma. The use of ‘as’ enables the phenomenon of dilemma to be represented in language as something graspable and accessible; as something that may be ordered, defined and understood explicitly. Dilemma defined *as* an ‘ethical dilemma’ is associated with having theoretical knowledge pertaining to which principles, duties or obligations should be taken into account when making a choice or decision between the competing choices presented within a particular ethical dilemma (Johnstone, 1994; Lutzen, Dahlqvist, Erikson & Norberg, 2006; Thompson, Melia & Boyd, 1994). Dilemma *as* a ‘moral dilemma’ is also defined as concerned with having to decide between competing principles, duties and obligations but moves to include a persons moral agency in enacting these decisions and is often focused on whether this agency is enacted through a justice or caring approach (Johnstone, 1994; Lutzen et al., 2006; Thompson et al., 1994).

Woods (2002) argues that language provides ways of thinking, seeing and being from which we take up a certain attitude. Using words such as ‘justice’, ‘rights’ and ‘good’ in relation to an ethical dilemma becomes a way of calculating responsibility, rather than opening thinking to the meaning of ethos as a way of dwelling (Woods, 2002). For Gadamer, ethics belongs to the “logos of justification” insofar as it is concerned with explanation and legitimizing ethical decisions (Gadamer, 1999, p. xii). He argues however that ethics can not be separated from ethos, which is a kind of being, “but not as an object of consciousness” (Gadamer, 1999, p. vii). Therefore the way language and words are used may disclose dilemma as something that is transformed into an object by the cerebral cortex, rather than revealing the world as significant involvements and understandings that belong to the experience of being-in-dilemma (Diekelmann, 2005).

In order to further refine what an ethical or moral dilemma is or is not, authors have sought to differentiate between the meanings attributed to the word ‘dilemma’, ‘problems’ and ‘quandaries’. It is these definitions that reveal more about what it may mean to be in the world where one encounters dilemma, rather than offering

theoretical explanations. A ‘problem’ is defined as being thrown towards something that comes from life or experiences itself and leaves a person feeling uncomfortable or perplexed (Thompson et al., 1994) and ‘dilemma’ (prior to being ethical or moral) is defined as a feeling of being stuck (Johnstone, 1994). A ‘quandary’ is seen as a state of being perplexed or uncertain (Thompson et al., 1994). These definitions give us more insight into the subjective meanings that may be evoked by the experience of dilemma in contrast to what might be objectively known about theories on dilemma.

For Heidegger the basis for understanding is through language, as there is no separation between naming (a thing) and the thing itself. The task of phenomenology, of hermeneutics, is to let something be seen in the play of time and space that goes beyond some Archimedean point in a foreclosed present (Diekelmann, 2005). For Heidegger, hermeneutics becomes a play of what comes into view through language and what is beyond our view; and that which we become possessed by but cannot possess (Diekelmann, 2005). This suggests that we may possess knowledge of dilemma as moral or ethical, but the experience of dilemma is not something that can be possessed, rather we are claimed by the experience itself. In this study the use of the word ‘dilemma’ has been deliberately left open, so not to foreclose on meanings that may be attributed to the phenomenon of dilemma.

Representing dilemma

Not only has language been used to construct dilemma as a form of theoretical knowledge, but it has also been used to represent dilemma *as* a particular situation. In this way dilemma has come to stand as a particular situation, leading readers to associate dilemma *as* the dilemma of euthanasia, abortion, do not resuscitate etc. In such a horizon of disclosure, dilemma has come to be represented and associated with particular situations and may blind people to other contexts in which dilemma may be experienced. Heidegger would argue that such direct vision on a particular event such as dilemma hides that every moment is an event which is never fully visible or definable (Harman, 2007). Such an approach risks “stilling the stream of human life, by fixing it in some conceptual framework” and hides that dilemma is also embedded in the everyday (Crowe, 2006, p.213).

In the field of pediatrics much has been written on 'ethical dilemmas' in the area of neonates and intensive care, and focuses on what Johnstone (1994) refers to as the big issues (such as 'do not resuscitate'). In reviewing the major pediatric ethics texts and case studies for health professionals, these describe hypothetical cases that represent dilemmas and are analysed from a bioethical position (Bandman & Bandman, 1985; Brykczynska, 1989; Ellis, 1992; Nelson et al., 1995; Richardson & Weber, 1995; Street, Ashcroft, Henderson & Campbell, 2000). Others have described ethical dilemmas such as paediatric organ transplants and removal (Robertson, 1999; Rucker, 2002; Spital, 1997), decision making and consent (Bourdreaux & Tilden, 2002; Burns & Troug, 1997; Friedman Ross, 2002; Lather, 2003; Woods, 2001) neonatal care (Campbell & Heischman, 2001; Doran, Veness-Meehan, Margolis, Holoman & Stiles, 1998; Harms & Giordano, 1990; Skansky, 2001) and paediatric care (Bagwell & Goodwin, 1992; Hamblet Berlandi, 1997; Todres, 1992). Representing dilemma as a particular situation does not contribute to an understanding of what it is to experience dilemma, or the situated world in which pediatric health professionals encounter dilemma. For Heidegger, understanding of what is a meaningful human life comes *before* theory and *before* categories (Crowe, 2006). Representing dilemma as a particular situation can only inform us of the attributes and theoretical perspectives on this situation, and less about the significance of the phenomenon of dilemma.

Drawing on the literature of dilemmas faced by families, dilemma is often constructed as the dilemma of technology, withdrawing life support or decision making on behalf of a child (Brinchman, Forde & Nortvedt, 2002; Fryer, 2000; Kirschbaum, 1996; McHaffie, Laing, Parker & McMillan, 2001; Striener, Saigal, Burrows, Stoskopf & Rosenbaum, 2001). There is a body of writing in paediatrics that although not explicitly looking at the experience of dilemma, has uncovered issues that could be seen as potential dilemmas by parents (Alderson, 1991; Darbyshire, 1994; Dickinson, 2004; Gasquoine, 1996). The experiences of parents would suggest that their experience of dilemma is around issues such as sharing of information, role negotiation, trust and parenting in a public forum. Alderson (1991) identified 'informed consent' as an ethical issue for parents and concluded that removing ethical dilemmas from the context they occur in (i.e. via ethics committees) denied the questions of significance, power, and dependence for parents. Alderson concluded that it was often the 'trivial' details of everyday life that constituted the dilemma. Alderson's

study is significant in that it removes the focus from the big issues to acknowledge the everyday world in which giving consent becomes problematic.

The phenomenon of dilemma has not only been languaged, represented as a particular situation, but has also been theorised about. These theories strive to account for the development of moral orientation (to dilemma) through measurement and comparison of different orientations (justice / care) and gender.

Theorising dilemma

Early literature on dilemma is focused on the development of theories to account for moral awareness and moral development. Kohlberg, one of the early founders of moral development theory, studied 821 boys over 20 years to develop a theory of universal stages of moral development (Kohlberg & Kramer, 1969). Six stages of moral development identified by Kohlberg described individuals as moving from a narrow self serving perspective to a multiplistic perspective with a strong notion of justice. These universal stages were identified through giving hypothetical scenarios of a dilemma to the boys to gauge their moral awareness. Criticism by Carol Gilligan that his work included only males (Gilligan, 1977) led to Kohlberg including women and girls in his study. Female subjects never reached Kohlbergs higher stages of moral development, leading to a conclusion that women were not as mature in their moral reasoning as their male counterparts.

Gilligan critiqued Kohlberg's findings in relation to women's moral development, arguing that women responded to dilemmas in a different way or in a 'different voice' as it came to be known (Gilligan, 1993). Gilligan's concerns that Kohlberg's theory was blind to the particularities of voice (in particular women's voices) led her to undertake a study of women's moral orientation, which showed that women's moral development arose from conflicting responsibilities, rather than competing rights. Since then both Kohlberg's and Gilligan's theories of moral development have seen support and critique, and significantly have polarised views of moral orientation towards dilemma into a debate of gendered responses to a justice versus care orientation.

A justice orientation

The literature from the 1980s (particularly nursing) reflects strong support for Kohlberg's theory of moral development with a justice orientation. Crisham (1981), de Casterle, Crypdonck, and Griep (1992), Ketefian and Ormond (1988), Corley and Selig (1992) supported an interest in a justice perspective and used quantitative tools to measure ethical reasoning in nursing students and nurses. These studies were characterised by the use of hypothetical case studies of ethical dilemmas and then measuring nurses ethical response (and therefore level of development and reasoning) via the administration of the Rests Defining Issues Test (DIT), and Ketefian's Judgement About Nursing Decision Test (JAND). These studies focused on the epistemology of reasoning and what decisions were made.

The use of hypothetical case studies means that 'the' dilemmas had already been identified and presented to the participants who were asked to decide what to do. Being prompted to respond to a particular dilemma and focusing on 'doing' or 'deciding' does not give any indication of why this issue may have been perceived as a dilemma for the participants in the first instance. Johnstone (1994) and Sletteboe (1997) in a concept analysis of dilemma suggest that firstly the person must have knowledge of the phenomenon, and have an awareness of the alternatives to see the situation as a dilemma. If the person lacks knowledge of differing alternatives the dilemma may not be recognised. The use of hypothetical case studies does not show why situations are perceived as a dilemma other than the theoretical perspectives already attributed to it. Several authors have suggested that a situation may not be perceived or recognised as ethical unless a sense of dilemma is involved and the person is involved in the situation itself (Allmark, 1992a; Sletteboe, 1997; Wygant, 1997). Being called to think on hypothetical situations focuses on what is already assumed to be known, rather than what called a person to thinking about the phenomenon of dilemma (of recognising, or perceiving dilemma).

Hypothetical case studies tend to reinforce the epistemology of dilemma, which is described by Johnstone (1994) and Sletteboe (1997) as the second attribute of dilemma, which involves having to make a decision around what to do. Focusing only

on epistemology (not only in hypothetical situations) has been criticised as giving an illusion that there is some 'right answer' to the situation. Blum (1991) argues that:

Moral philosophy's customary focus on action-guiding rules and principles, on choice and decision, on universality and impartiality, and on obligation and right action has masked the importance of moral perception...for unless [a person] perceives moral situations as moral situations...moral principles and skill at deliberation will be for nought and may even lead them astray (p. 701).

Being aware of a situation as a dilemma is not the same as being aware of a particular principle. There may be a gap between the intellectual grasp of a principle and recognising it in real life (Blum, 1991).

Hypothetical dilemmas do not engage the person in the final attribute identified by Johnstone (1994) and Sletteboe (1997), which is that the choice is difficult as the real consequences may be unknown, unwanted and unavoidable. Bearing the consequences of an abstract decision (where consequences are only abstract possibilities) is not the same as having to bear the consequences of an embedded concrete situation that a person is involved in. Removing dilemma (via hypothetical case studies) from the reality of practice, although contributing to theorising on ethical decision making, may not contribute to an understanding of the impact of the decision on the people involved in the dilemma (Davis, 1991; Woods, 1997). For Heidegger human life is not visible from the outside looking in and always exceeds any properties that may be ascribed to it; rather human life can only be understood in how it is enacted in its own reality (Harman, 2007). We may ascribe properties to dilemma or decision making, but to understand what it means to experience dilemma, we need to go back to the life world itself.

Walker (1989) in a longitudinal study of moral development found that orientation was affected by the life world in which dilemma was encountered. Hypothetical case studies were more likely to elicit a normative and fairness orientation (focusing on liberty, equity and equality) whereas asking participants to recall a dilemma from their own experience elicited a care response (emphasising the consequences of moral

actions on self and others). Walker (1989) concluded that regardless of gender, a dilemma that involved an interpersonal dimension elicited a higher care response than an impersonal dilemma.

These findings are supported by Hepburn (1993) who argues that hypothetical case studies lead participants to making objective decisions which excludes personal context or experience. Such approaches reduce human existence to abstraction by generalisation (ascribing properties to things in a linear manner) and formalisation (ascribing properties of things as discrete) (Harman, 2007). Both these approaches are rejected by Heidegger as objectifying things by 'de-living' them and 'cutting them off at the knees'; removing the phenomenon from the richness of life, which is always situated, multifaceted and mysterious (Harman, 2007). Heidegger argues that phenomenology must come from life itself, not some limited abstract of life. He suggests that understanding of what it means to be 'I' (experiencing dilemma) is not through theoretical reflection but through enacting the 'am' (of dilemma) (Crowe, 2006).

In health care, bioethics has been an approach that has been particularly used to explore ethical and moral issues and decision making (de Vries, 2007; Engelhardt & Tristram, 1996; Harris, 2001; Kuhse & Singer, 2006; Moreno, 2005; Seedhouse, 1988). Bioethics has predominantly been aligned with normative approaches such as utilitarianism, deontology and universality of set principles. Recently this position has changed to include a call for qualitative, experiential, and narrative approaches to decision making (Charon & Montello, 2002; Walter & Klein, 2003).

A caring orientation

An alternative perspective to a justice orientation has focused on a care orientation to decision making. This view has particularly been taken up by educational theorists, nurse theorists and ethicists to support an ethic of care (Benner & Wrubel, 1989; Bottorff, 1991; Fry, 1989; Gadow, 1989; Leininger, 1981; Noddings, 2003; Watson, 1979). Caring as a concept has been linked to the attributes of being female (Noddings, 2003). Whereas Gilligan (1993) and Belenky et al. (1997) claim this has given women a voice that provides an alternative explanation to the moral concerns and agency of women, others have critiqued linking caring as a female attribute as

reinforcing passive female stereotypes such as caring and nurturing (Friedman, 1993; Harding, 1987; Hoagland, 1990; Sherwin, 1989). Others such as Allmark (1992b), Paley (2002) and Stockdale and Warelow (2000) have critiqued caring as not being able to support a virtue ethics approach or acknowledging the hierarchies and social conditions health professionals work in. Kuhse (1993) says that whilst caring embodies a certain attitude to others, it cannot provide an adequate basis for justifying actions or decisions.

Taking up the idea that justice is linked with being male, and caring linked to being female, researchers have endeavoured to try and prove a causal relationship between gender and decision making (Amdo-Grunstein, 1992; Ford & Lowery, 1986; Norberg & Uden, 1995). Pratt, Golding and Hunter (1984) found there was little support for gender differences between a justice orientation and a care orientation in Kohlberg's model of moral orientation. Harding (1987) and Walker (1989) found it was not gender that impacted on the decision making, rather it was how one experienced oneself in the world (embedded and contextual or abstract and removed). This finding was supported by Amado-Grunstien (1992, 1993) and Soderberg, Norberg and Gilje (1996) who using a qualitative approach found that decision making by nurses and doctors was affected by the context in which dilemma arose rather than gender.

It appears that there may be a discrepancy between perception and action. Liaschenko (1997) and Soderberg et al. (1996) used phenomenology to analyse nurses' narratives of being in difficult ethical situations. The authors found that although nurses were able to analyse dilemmas from a bioethical perspective, they responded to the situation emotionally and were concerned with the relational aspects of the nurse – client relationship. This is supported by Oberle and Hughes (2001) who found that nurses and doctors perceived dilemma from a caring perspective but the different expectations of the respective professions and the context in which the decision had to be made impacted on whether a justice or caring orientation to decision making was utilised. It appears that gender or profession does not so much influence the perception of a dilemma, rather it is the obligations and the responsibility of different professions that may influence decision making following this perception. Perception and the following need for action may not be synonymous with either a care or justice perspective, as previously argued.

Justice or care

Focusing on either a care or justice perspective, which has been linked to gender, sets up a dichotomy which perhaps hides that both care and justice are modes of dilemma, one that shows what concerns us, what may attune us to dilemma, the other a mode of decision making which follows. Kavanagh (2005) argues that we live in a world where things are “systematically and discretely (even concretely) dichotomized into *either-or* ...a world in which it seems anomalous to think of phenomena as continuous (both good and evil...light and dark)” (p. 61). It is the task of phenomenology to find the continuities and the in-between-ness (Kavanagh, 2005). Rather than focusing on ‘either / or’, attention should be given to the ‘and’ of moral perception and action.

Although a justice orientation has been critiqued as being blind to the particular and concrete life world, it should be acknowledged that it may also provide of mode for action when a care orientation may be lacking. Kohlberg’s theory was developed “in response to the Holocaust” (Kohlberg, 1981, p.470) and Gilligan herself acknowledges such a demand for action is necessary in preventing events when ethical dilemmas may not be perceived due to culturally relative values (Gilligan, 1993). Equally a caring orientation has been critiqued as focusing too narrowly on those close to oneself, and where the basis for moral action is related only to those whom a person has a relationship with, therefore the perception of dilemma and the need for action is not experienced outside this relationship (Card, 1990; Myhrvold, 2003; Paley, 2002). Both Curzer (1993) and Paley (2002) have raised concerns that this close relationship is based on who one likes, rather than who one should act in a caring manner towards.

Drawing on the work of Kierkegaard, Ferreira (2001) argues that when we are involved in a close interpersonal relationship with others, this may lead to a situation where ‘love is blind’. The closeness of this relationship means that the two identities become one, and the individual is no longer seen. Kierkegaard’s answer to this is a non preferential love of all others as we would a neighbour. Ferreira (2001) argues that such an impartiality where another is abstract or universal is as much a risk of blindness to the concrete particular self and the other as the same as self. Such arguments draw our attention to the danger of privileging one orientation over the other. Heidegger suggests that we never arise above our lives as if untainted by it, to

pass some sort of judgement over it, rather all we can do is liberate the hidden assumptions by making them visible (Harman, 2007).

Narrative approaches

Rather than focusing on one orientation over another, a narrative approach to ethics has been championed as a way of explicating ethical / moral concerns and dilemmas that arise from practice. This approach is argued to provide a fuller picture of the contextual and often contested nature of dilemmas and tensions that arise. Those who use narrative to uncover stories of ethical / moral concerns include Benner (1991, 2000), Brody (1987), Carter and Robinson (2001), Frank (1995, 1997b, 2000), Gadow (1999), Hudson Jones (1999), Hauerwas and Burrell (1989), Hunsaker Hawkins (1994), Liaschenko (1999), Robinson (2002) Spreen-Parker (1990) and Tauber (1999). These authors argue that narrative perspectives on health care provide a fuller account of human life and suffering and the ethical and existential questions embedded in the life world (as opposed to theoretical). Davis (1991) and Carnevale (2005) say that narrative approaches are more ‘full bodied’ that involve both the storyteller and the audience to understand ‘thick descriptions’ of morality and what it means to be human, rather than ‘thin’ descriptions of universal principles. These perspectives move closer to revealing dilemma in the context in which it arises, and what attunes people to dilemma prior to theorising about it.

Moral sensitivity

In the literature, health professionals’ attunement to dilemma has been described as moral ‘sensitivity’. The word sensitivity arises from the Latin word ‘sensus’ meaning to ‘feel perceive’ which implies it may be aligned with an embodied response to dilemma. Early approaches to moral sensitivity however focused on measuring these ‘responses’ using data collection instruments such as the Ethical Issues in Nursing (EIN) test, and the Moral Sensitivity Questionnaire (MSQ) to measure the degree of ethical sensitivity towards dilemmas (Berger, Sverson & Chvantal, 1991; Lutzen et al., 2006; Lutzen, Everston & Nordin, 1997; Oddi, 1995; Redman, 2002; Rest, 1979). The instruments used were developed from ethical issues identified in the literature and participants’ responses were measured on a Lickert scale. The responses by participants can only be interpreted as a response to the particular situations already defined by the researchers, and the response itself may be more reflective of a

cognitive response rather than an embodied response to a situated dilemma from the participants own practice. This was found in the study by Lutzen et al., (1997) who uncovered a discrepancy in the use of a theoretical framework based on previous interviews with nurses, and responses by psychiatrists.

A qualitative study by Oberle and Hughes (2001) highlighted the problems of focusing on sensitivity to specific issues. The authors found that although doctors and nurses identified different issues, perhaps relating to each groups differing professional roles and responsibilities, both groups responded because of the suffering of others and the 'felt' obligation to respond. The researchers say the findings suggest that the perception of moral issues in practice is not reached through cognitive reasoning, rather it is a felt moral obligation to respond to another's suffering that is the catalyst.

More recently moral sensitivity has been explored in the literature as a subjective experience, rather than something that can be measured. Moral sensitivity has been described as a genuine concern for another (Jaeger, 2001; Lutzen et al., 2006); of recognising the vulnerability and suffering of another (Glasberg, 2007; Lutzen et al., 2006); that understands and respects the complexity and meaning of human life (Jaeger, 2001); as an affectivity of an embodied response, like a gut feeling (Hardingham, 2004; Sherwin, 2001, Weaver & Morse, 2006); and as a preconscious understanding prior to reasoning that prompts one's moral responsibility to another (Glasberg, 2007; Lutzen, Johansson & Nordstorm, 2000; Weaver & Morse, 2006).

Along with the attention given to moral sensitivity, authors have also explored the notion of moral insensitivity. May (1992) says that a morally insensitive person may fail to notice the suffering and distress of another and be unaware of the impact of their actions on others. May suggests another reason for moral insensitivity may be that the values are 'good' but they have become stereotypical or part of what is familiar which leads to certain assumptions of a situation. Arendt (1978) describes these as "clichés, stock phrases, adherence to convention, and standardised codes of expression and conduct that have the socially recognised function of protecting us against reality, that is, against the claim on our thinking attention" (p.4). Being exposed to the similar situation repeatedly over a period of time and accepting the status quo may lead to a person becoming 'desensitised' (Sherwin, 2001).

People may also choose to desensitise as a way of coping with empathetic distress. Being faced with overwhelming suffering of another may lead a person to look away from the victim or think distracting thoughts in order to reduce the distress to themselves (Hoffman, 1984). May (1992) argues that the consequences of being desensitised means our peripheral vision or even our ability to see (sense) another may be impaired. The metaphor of 'seeing' has been used in the literature to describe this phenomenon. The use of the word 'see' is not taken as a literal meaning, but rather fits with the notions of moral sensitivity as being aware of another person and their suffering. Another way in which moral in-sensitivity has been described is as a 'moral blindness' (Johnstone, 1994).

The result of moral blindness on the person who is not seen (as a person) has been described as reducing a person to demographic statistic in health rationing (Jaeger, 2001); as an object of health care and their care constructed as a technical issue (Johnstone, 1994); or as a collection of symptoms and diagnosis independent of their life history (Brody, 1987; Frank, 1995). Others have explored relationships from a humanistic perspective to highlight those behaviours and actions that may dehumanise another (Buber, 1970; Patterson & Zderad, 1988). Mekechuk (2006) argues that the rapid increase in modern technology is contributing to a type of moral blindness, as it outstrips human ability to recognise or comprehend the consequences.

Conscience

Closely linked to the notion of moral sensitivity (or insensitivity) is that of conscience. Whereas moral sensitivity has been described as an awareness or 'seeing' the suffering of another, conscience is described as 'what troubles' a person about what is perceived (Glasberg, 2007; Lutzen et al., 2006). Conscience has been constructed either as a voice from outside the person, or a voice from within.

In a traditional sense conscience has been constructed as an impersonal voice outside a person, such as the voice of God, that forbids certain actions and places values on what is right or wrong (McGurie, 1963; Olson, 1959; Thompson et al., 1994). Coming from the Latin word 'cum' (with) and 'scientia (knowledge) this view suggests that a persons conscience is based on theoretical and practical knowledge that enables a

person to take a circumspect view of things before taking action (Thompson et al., 1994).

Others have interpreted conscience as a personal voice from within (Childress, 1979; Jenkins, 1955; Heidegger, 1962). For Heidegger, conscience does not tell me what to do or not, but calls me to think about my self, my own actions and choices in relation to others and to bear the responsibility for it (Inwood, 1997). Heidegger argues that conscience is the voice from oneself that makes one more aware of what has been hidden by the everydayness. Jenkins (1955) describes conscience as that what solicits our attention and hold us to account. Jenkins says that conscience shows the existential nature of man and what has befallen him. Conscience is viewed as a call to one's integrity, but in doing so may also disrupt it (Brown, 1996; Childress, 1979; Jenkins, 1955). The feelings evoked by our conscience such as remorse, fear, and anxiety may make us feel that "we have lost our balance, or that we cannot regain our true course" (Jenkins, 1955, p. 264).

Dahlqvist et al. (2007) in an effort to identify various perceptions of conscience amongst health care professionals, found that a troubled conscience was not dependent on the situation (such as a dilemma represented in a particular situation), but on the person's values and beliefs (the experience of dilemma). They found six factors that related to the understanding of conscience. They concluded that conscience is 1) perceived as an authority to protect ourselves and others from harm; 2) in order to do so health professionals must be sensitive to their conscience and be willing to stop and listen; 3) although conscience can be an asset 4) it could also be a burden; 5) silencing our conscience may be the only way to escape the demands it places on us; 6) and that conscience is dependent on the social context and our outlook on life.

Dahlqvist et al. (2007) study shows that conscience is both an awareness of a (external) responsibility to uphold certain behaviours and equally a personal feeling of discomfort when this does not happen (being held to account). Brown (1996) reinforces the idea that conscience is not just a personal phenomenon but is socially embedded with others, as it involves the sharing of values and concerns (of the profession) and honouring these. A study by Mildred et al. (2005) of doctors and nurses working in a paediatric ICU, found that over half (fifty four percent) reported

acting against their conscience while providing care for a child. The authors did not explore the reasons for why or what contributed to a troubled conscience but it is significant as a troubled conscience has been linked to feelings of a loss of integrity.

The loss of integrity evoked by a troubled conscience is closely linked with feelings of guilt (Childress, 1979). This is particularly pertinent to an ontological perspective on dilemma where “dilemmas by their nature cannot be solved, they must simply be faced” (Bishop & Scudder, 1990, p.122). Greenspan (1983) says the dilemmas are ‘real’ and one must choose between two incompatible actions; the person is ‘guilty’ no matter what they do. Greenspan says this residue of guilt that is left after the event is not only for what the person did, but what they were not able to do. Greenspan suggests while examining the ‘facts’ could convince the person of the necessity of their choice, this does not account for is the ontological, the felt guilt, that cannot be explained away.

Miceli and Castelfranchi (1998) say that feeling guilty and being guilty are quite different. Being guilty is a fact that may be judged as true or false, whereas feeling guilty is usually linked to feeling responsible for having let someone, or a closely held belief down. One of the consequences of feeling guilty is a lowering of ones moral self esteem associated with the feeling of having failed another, or oneself. The authors say that people, who experience feelings of guilt, often suffer *with* the other and suffer *for* the pain they have caused them.

Moral distress

Miceli and Castelfranchi (1998) views on guilt suggests that a person’s moral sensitivity is not only linked with being aware of another’s suffering, but also that they may also suffer as a consequence. This suffering has been described as moral distress. Moral distress has been described as a type of suffering that undermines ones sense of self (Rushton, 2006; Wilkinson, 1987-88); affects physical health (Wilkinson, 1987-88); feelings of pain during troubled times (Nathaniel, 2006), or feelings of anxiety, anguish, sorrow and worry that alerts one to a state of danger (Austin, Bergum & Goldberg, 2003) and may impact adversely on patient care (Mekechuk, 2006; Peter & Liaschenko, 2004; Wilkinson, 1987-88).

In a seminal definition, Jameton (1993) defines moral distress as a negative feeling associated with a person not being able to act (morally) as they wished. Barriers which result in feelings of moral distress because of not being able to act how one would wish have been described as institutional (Jameton, 1984; Yarling & McElmurry, 1986; Woods, 1999); external (Austin et al., 2003; Corley, Minick, Elswick & Jacobs, 2005; Kelly, 1998; Wilkinson, 1987-88); internal (Wilkinson, 1987-88); situational (Volbrecht, 2002); hierarchical for nurses (Erlen & Frost, 1991) and hierarchical for doctors (Oberle & Hughes, 2001) .

There are contradictory views on personal characteristics linked to likelihood of developing moral distress, some researchers suggesting that moral distress increases with age (Schwenzer & Wang, 2006) whereas others have suggested it decreases with age and experience (Corley et al., 2005). Reasons for this have not been stated by the authors (having been noted as a variable) however Soderberg and Norberg (1993) in a qualitative study found that more experienced female physicians' displayed less moral distress than their more inexperienced colleagues'. This was attributed to the more experienced female physicians accepting what couldn't be changed, whereas their more junior colleagues' were focused on using principles that they had learnt in order to solve dilemmas' they encountered in practice.

Tiedje (2000) suggests that people who are highly morally sensitive (although how this is gauged is unclear) are more at risk for experiencing moral distress. For health professionals this is particularly pertinent when working so closely with vulnerable people. Penson, Dignam, Canellos, Piccard and Lynch (2000) argue that in today's health care system, health professionals are seeing more and more patients, yet there is also a professional demand that they still try to connect with patients on a personal level. It has been suggested that being morally sensitive enhances one's awareness and response to the suffering of others, yet being morally sensitive is also about making oneself vulnerable. The process of being vulnerable to another's suffering may result in what Henri Nouwen describes as "the wounded healer" (Penson et al., 2000).

Several researchers have endeavoured to measure moral distress using a Moral Distress Scale (MDS) (Corley, Elswick, Gorman & Clor, 2001; Corley et al., 2005; Zuzelo, 2007). In testing for content validity of the MDS Corley et al. (2001) found

that the issues identified had to be contextual and match the ‘lived world’ of the respondents in order to elicit a valid response from the participants. The issue that elicited the highest score for moral distress was inadequate staffing. Why this caused such high distress was not explored, but a phenomenological study by Austin et al. (2003) on moral distress found it was the consequences of lack of staffing that caused the distress amongst mental health nurses. For these nurses moral distress was linked to not being able to respond to the call of the patients (literally and morally). The inability to respond to the call of patients meant that nurses felt they no longer were engaged in the relationship with the patients, which was perceived as an underlying moral value of practice. This disconnection from patients caused them feel ‘less human’, ‘like a machine’ or an object.

Austin et al. (2005) say it is the nature of the moral commitment made by nurses, as a profession, to maintain a fiduciary relationship with those in their care that led to moral distress when they are unable to uphold this. This view is supported by Peter and Liaschenko (2004) who suggest that although moral distress may be experienced because of organisational constraints, moral distress occurs in a social space because morality is essentially interpersonal and intrinsic to the way social practices are organised. Peter and Liaschenko (2004) argue that the proximity (both moral and geographical) is important as it is easier to make difficult choices (and not experience moral distress) when one is removed from the implications, or able to view people as just statistics or numbers. Moral distress is more likely to be experienced when a person is engaged with the people and the situation. This was borne out in mental health nurses as they described the screams of patients in mental anguish, knowing there was no one to respond (Austin et al., 2005). Nurses working in paediatric ICU experienced moral distress because of their concerns with the cost of saving a child’s life (Mekechuk, 2006). Nurses did not talk about the financial cost or constraints, but rather the impact and long term consequences a certain course of action would have on the child or family (for example a child needing a high fore limb amputation because of bacterial meningococemia).

Nathaniel (2006) developed a grounded theory of moral reckoning to describe how nurses moved through a process or ‘critical junctures’ of moral distress. Nathaniel described the first stage of moral reckoning as ‘ease’, as nurses new to the profession

assimilate the core values such as personal, professional and institutional values in 'becoming' a nurse. What followed was that nurses were exposed to 'situational binds' characterised by conflicts with any of the core values, the nurse had developed. The impact of the 'situational bind' constituted a crisis of 'intolerable internal conflict, and was characterised by feelings and emotions of moral distress. In the second stage of 'resolution', Nathaniel says the nurse had two options, to make a stand or give up. Having made a choice, nurses moved to the final stage of reflection. The attributes of reflection involved remembering, telling a story, examining conflicts and living with consequences.

The act of remembering and having to live with the consequences of moral distress highlights the temporal nature of this experience. Corley et al. (2005) found that nurses continued to experience moral distress long after the event occurred. For others, moral distress did not always happen when the event occurred but later with hindsight (Mekechuk, 2006). This supports findings of 'moral residue' which is the impact each episode of moral distress leaves (Hardingham, 2004; Nathaniel, 2006; Webster & Bayliss, 2000). Nathaniel (2006) says remembering events associated with moral distress evoked strong feelings and emotions, even years later. Nurses could tell in detail the sights, sounds and incidental detail (Nathaniel, 2006). Nathaniel says these images were 'seared' into their minds. Gunther and Thomas (2006) uses the term 'unforgettable events' to describe how sometimes years later, nurses would still struggle to make meaning of an event and at times absolve themselves from blame.

Rashotte (2005) refers to moral residue as the 'stories that haunt us'. Rashotte suggests that the stories that haunt us are not only episodes of reflective story telling, but also affirm and reconnect the meaning of another's existence and our own humanity. This has implications for the way we uncover experiences of moral distress, as story telling itself has the function of resituating people in a situated life world and allowing reinterpretations to emerge of what it means to be moral (rather than focusing on moral actions, focusing on the situated, contextual and moral nature of all human living and interaction). The sharing of stories was found by Rashotte (2005) and Gunther and Thomas (2006) to be a way of breaking down the social isolation often felt in association with moral distress.

The consequences of moral distress have been described in the literature as a disruption to a person's integrity (Gunther & Thomas, 2006; Hardingham, 2004; Nathaniel, 2006; Tiedje, 2000; Webster & Bayliss, 2000) which an individual must cope with by adaptive or maladaptive strategies. Tiedje (2000) suggests that adaptive strategies to cope with moral distress caused by external constraints are individual action such as whistle blowing, or group action to change protocols or values of the organisation. Adaptive strategies to deal with inner constraints and moving to inner strength are suggested as looking for role models, discussing the issues with others through storytelling, owning ones marginalization (for example finding a way to find positive aspects to this position) and finally acquiring a coach (Tiedje, 2000).

Taylor (2002) differentiates moral distress from moral fatigue. Taylor describes moral fatigue as the loss of sensitivity that produces a weariness of the whole person. Whereas moral distress may lead to action, moral fatigue is more likely to lead to withdrawal or apathy (Taylor, 2002). Apathy leads to nurses only doing what is required (carrying out care) without showing a caring attitude to the patient or family (Taylor, 2002).

Maladaptive strategies have been described as the use of black humour (Felton, 1998; Mekechuk, 2006), over rationalising (Mekechuk, 2006) and avoiding situations (and patients) that cause moral distress (Mekechuk, 2006; Tiedje, 2000). The most severe consequence of moral distress has been linked to no longer being able to provide adequate patient care, and burnout (Taylor, 2002; Tiedje, 2000).

Burnout

Felton (1998) says that burnout is most often found in those working in human services professions. In identifying the reasons why health professionals may be more at risk for burnout, Felton says those attracted to health care tend to be idealists who want to help others. Felton suggests that hope and optimism are some of the attributes that health professionals bring with them when entering the profession. When health professionals are not able to affect the outcomes they hoped for, and are exposed to repetitive illness, dying and death, feelings of hope and optimism are replaced with feelings of frustration, despondency, and futility. It could be argued that the long term

stress of not being able to practice how one would choose too (moral distress), and the consequences this has on self identity leads to burnout.

Burnout has been described as a physical and emotional exhaustion, depersonalisation (of patients and self) and feelings of low personal accomplishment or self esteem (Felton, 1998; Freudenberg, 1974; Penson et al., 2000). Burnout is not something that happens abruptly (although there may be a water shed event that precipitates the process); rather it can be insidious, creeping up on health professionals in the unrelenting suffering they are exposed to, and the vicarious loss that they carry (Felton, 1998; Penson, et al., 2000).

A study by Watson and Feld (1996) found that one of major sources for burnout and stress for paediatric nurses in a major general hospital in New Zealand was feeling inadequately prepared to deal with the emotional needs of children and their families, and dealing with making meaning of a child dying. Subscales of these two themes included; nurses feeling that they did not have enough time to provide emotional support to children and families; feeling distressed at having to perform procedures that children found painful; and watching children and families suffer. Paediatric nurses in this study said that regular team meetings or debriefing would be helpful in reducing emotional distress experienced. Paradoxically, although the nurse, child and family were identified as a source of stress, this relationship was also a source of satisfaction and validation that the nurse was doing a good job.

Earlier studies suggested that those who are more morally sensitive to another's suffering are more likely to experience moral distress. Contrary to the belief that 'getting too close' to patients puts a person at higher risk for burning out, researchers found connecting with patients is one of the most important ameliorating factors against moral distress and burnout (Penson, et al., 2000; Watson & Feld, 1996). Researchers found that the nurse – client relationship gave most meaning to practice (Bishop & Scudder, 1990) and that palliative care nurses had lowest rates of burnout which was assumed to be a result of the close relationship with patients (although death scored highly on the MDS for other groups of health professionals) (Mallette et al., 1991).

Burnout is linked to high rates of alcohol abuse, drug addiction and suicide (Penson et al., 2000). In reviewing the literature on the personal risk factors for physicians to burnout Penson et al. (2000) found that burnout results from an: imbalance between the demands of a job and the ability to cope (Ulrich & Fitzgerald, 1990); by the emotional baggage physicians brought to practice (Creagan, 1993); through childhood experience and personality traits (Payne & Firth-Cozens, 1992); being younger and single (Ramirez, Graham & Richards, 1995; Whippen & Canellos, 1991) and being able to make meaning in the face of suffering (Creagan, 1993). Hale and Hudson (1992) also found that burnout resulted in negative defence mechanisms in junior staff, such as denial and intellectualism.

Given the negative consequences of burnout on health professionals it is alarming that a high proportion of health professionals have reported feeling burnout. A study by Maslach and Jackson (1986) using the Maslach Burnout Inventory (MBI) found that from a sample of one thousand, one hundred and four physicians and nurses, twenty two percent had experienced emotional exhaustion, seven percent had experienced feelings of depersonalizing patients, and thirty percent has experienced feelings of lack of personal accomplishment. In New Zealand, Green and Walkey (1988) found that burnout amongst general nurses resulted in feelings of emotional exhaustion, low feelings of personal accomplishment, and contributed to feelings of distress and somatic symptoms. Fields et al. (1995) found that thirty six percent of physicians working in paediatric critical medicine were classified as at risk for burnout, and fourteen percent were classified as burned out. High levels of emotional exhaustion were reported, with the main reasons given for perceived burnout as not feeling valued in their work, and lack of autonomy (Fields, et al., 1995). In a Canadian hospital based child protection program thirty four percent of health professionals were found to be experiencing burnout due to the cumulative effects of vicarious exposure to trauma and high work demands (Bennett, Plint & Clifford, 2005).

Burnout is also implicated in high numbers who leave the specific specialty area or choose to leave the profession altogether. In the United States thirty to fifty percent of physicians surveyed reported they would not choose to go to medical school if re-choosing a career (Lambert, 1993 cited in Felton, 1998). Milette (1994) found that half of the twenty four nurses in her study left nursing or changed their practice focus due

to moral distress around the care they wished to provide, and the reality of the care they could provide and Corley et al. (2005) found that fifteen percent of the respondents indicated they had left a previous position because of moral distress.

The results of the studies on burnout suggest that the lived experience of moral distress (and dilemma) in practice may have more far reaching consequences on the health professional than is uncovered by focusing exclusively on moral / ethical orientation and decision making.

Dilemma in fiction

Sophie's choice

The notion of dilemma has also been written about in fiction literature and provides an ontological basis for understanding the experience of dilemma. Van Manen (1990) says that phenomenological research takes its point of departure from within the situation (the life world), to follow human beings and the fascinating stories they have to tell of their world. It is the evocative descriptions in the narratives (both factual and fictional) that give the reader an insight into the 'world' of dilemma. William Styron's (1976) book "Sophie's Choice" is a story most often cited from fictional literature to represent the notion of dilemma. Styron's story centres on Sophie, a mother of two children, who upon arriving at the concentration camp of Auschwitz, encounters an SS doctor who forces her to make a decision.

...The doctor said, "You may keep one of your children."

"*Bitte?*" said Sophie.

"You may keep one of your children," he repeated. "The other one will have to go. Which one will you keep?"

"You mean I have to choose?"

"You're a Polack, not a Yid, that gives you a privilege- a choice."

Her thought processes dwindled, ceased. Then she felt her legs crumple. "I can't choose! I can't choose!" She began to scream. Oh, how she recalled her own screams! Tormented angels never screeched so loudly above hell's own pandemonium. "*Ich kann nicht wahlen!*"

she screamed. The doctor was aware of unwanted attention. “Shut up!” he ordered. “Hurry now and choose. Choose, god dam it, or I’ll send both over there. Quick!”

She could not believe any of this. She could not believe that she was now kneeling on the hurtful, abrading concrete, drawing her children toward her so smothering tight that she felt that their flesh might be engrafted to hers even through layers of clothes. Her disbelief was total, deranged. It was disbelief reflected in the eyes of the gaunt, waxy-skinned young Rottenfuhrer, the doctor’s aide, to whom she inexplicably found herself looking upward in supplication. He appeared stunned, and he returned her gaze with a wide-eyed baffled expression, as if to say: I can’t understand this either.

“Don’t make me choose,” she heard herself plead in a whisper, “I can’t choose.” “Send them both over there, then,” the doctor said to the aide, “*nach links.*”

“Mama!” She heard Eva’s thin but soaring cry at the instant that she thrust the child away from her and rose from the concrete with a clumsy stumbling motion. “Take the baby!” she called out. “Take my little girl!”

At this point the aide- with a careful gentleness that Sophie would try without success to forget- tugged at Eva’s hand and led her way into the legion of the damned. She would never forget a dim impression that the child continued to look back, beseeching. But because she was now almost completely blinded by salty, thick copious tears she was spared whatever expression Eva wore, and she was always grateful for that. For in the bleakest honesty of her heart she knew that she would never have been able to tolerate it, driven mad as she was by her last glimpse of that vanishing small form.

Students, studying “Sophie’s Choice” are asked to reflect on her actions and what *should* she or *could* she have done. Comparisons in literature on medical ethics are made between Sophie and a doctor having to save patient A or patient B if there is limited time or resources. Other perspectives focus the responsibility of Sophie in what might be interpreted as an act of evil (sending one child to die in order to save another or self) or whether Sophie should bear the responsibility of the evil perpetrated by others at the time, which included the mass genocide of men, women and children.

The question that is missed in such rational approaches is what would it mean for Sophie to be in such a situation? There is no running away from what is happening; Sophie must make a choice. This is no choice of free will or rational thought. As a reader we cannot but be aware of the horror of the situation in having to choose between children. The horror is evident in the anguish of having to make such a choice when so much of a mother’s embodied relationship with a child is to protect them from harm and evil. Sophie’s choice in a sense violates the trust between mother and child, and as the reader we begin to wonder how Sophie (or ourselves) would be able to live with the knowledge of this choice. Indeed, bearing the burden of the consequences becomes too heavy for Sophie, and later in the story Sophie commits suicide. What Sophie’s story points to, at least ontologically, is that every experience of dilemma has its basis in the lived world, and as such decisions about what one *should do* does not account for how one feels, and that consequences are not just a result of some rational decision, rather they are something that often must be borne, or lived with.

Beauty Mark

In another work of fiction, the poem “Beauty Mark” by Pereira (2004) gives the reader an insight into what it may be like for a doctor who experiences dilemma when he is asked to carry out a cosmetic procedure on a child.

The grandmother wants me to excise
a little freckle like a teardrop
just below her granddaughter’s left eye.

Too much sadness, she says, suggesting
through the interpreter that if I do not
she will cut it out herself –
It's our culture belief.

I tell her: In my culture
we call this a beauty mark -
to remove it, purely cosmetic,
uncalled for with a child.

But the grandmother persists, herself
a survivor of Pol Pot's camps.
Several visits we argue back and forth. My
Usual compasses: First Do No Harm,
Autonomy Trumps Beneficence,
Lose the Battle of Initiative –
all fail me. I begin to weaken.

What is my duty to protect a child?
And what exactly am I
protecting her from? (surely, finger-pricks
and immunisations carry as much risk
as a simple mole removal).

I agree to do a shave-excision,
Hoping to leave the tiniest scar.
Weeks later, the grandmother shows me
her granddaughter's unblemished cheek, claps her palms
together to thank me. Years later, I still wonder
if what we did was right.
(Pereira, 2007, p. 31).

Here dilemma is experienced in the clash of culture and values. The paediatrician's sensitivity to the grandmother makes him question his own moral values and beliefs

in relation to hers. Had he accepted without question this grandmother's request, it would have been unlikely that he experienced this as dilemma. The questions he asks highlights the dilemma of should he or shouldn't he excise this mole and whose interests or beliefs should take precedence? The questioning and uncertainty point to the ontological experience of dilemma in that he has no way of knowing what the right thing to do was or of being sure about the choice he has made. Pereira (2007) highlights that what is experienced as a dilemma for one person will differ for another.

Although the above story (Sophie's choice) and poem (The beauty mark) offer fictional accounts of the experience of dilemma, they also fit with the understandings uncovered in the "traditionary texts". These fictional accounts take us beyond the epistemology of dilemma to a place where the reader may come closer to understanding what the experience of dilemma may be like.

Conclusion

The traditionary text has uncovered how dilemma has been represented through language as a way of calculating responsibility or the logos of justification; it has been theorised as either justice / care, female /male; and measured as moral sensitivity or moral distress and associated with the notion of burnout. Different aspects of dilemma have been studied such as moral perception, moral decision making and to a lesser degree moral consequences of the decision made. Qualitative accounts of moral distress and burnout and fiction literature move closer to providing an ontological basis for understanding the phenomenon of dilemma. It is the ontological perspective that is the question of this research.

Chapter four

Philosophical underpinnings

Carrying out a phenomenological study is inextricably underpinned by the philosophy of phenomenology itself. As a philosophical stance and lens, it informs and influences the questions one asks and the interpretations and understandings that are revealed. There is no discrete philosophy, methodology or method; rather the philosophical underpinnings are embedded within the research inquiry process. Understanding the interpretations the inquiry process has revealed is also to understand the foundations from which these arose. As with many other researchers (Caelli, 2001; Dickinson, 2004; Koch, 1996; Smythe, 1998) the process of coming to understand the philosophical notions of phenomenology has often been a daunting one. The alchemy of understanding the philosophy of phenomenology has been like life itself; the more I read and the more I experienced the ‘doing’ of phenomenology, the deeper my understandings have become. This chapter describes and introduces the philosophical notions that guide and underpin this study.

What are the historical beginnings of Heideggerian hermeneutic-phenomenology?

Phenomenology as a philosophical movement has been associated with philosophers such as Hegel [1770-1831] and Brentano [1838-1917], but it is the work of Husserl that has been influential in the development of phenomenology as we know it today (Speigelberg, 1994). Husserl was concerned with Cartesian dualism which reduced all thinking to logical or objective meanings, especially when dealing with subjective experiences (Moran, 2000). For Husserl the task of phenomenology was to describe things as they appeared in consciousness as a way of uniting the subject and object (Moran, 2000). To do this, he proposed that researchers should suspend their everyday beliefs (social, cultural and political) and use phenomenological reduction to prevent distortion and allow essential features of the phenomenon to be isolated (Moran, 2000). This would allow the researcher to understand how things appear in consciousness (how objects appear as same objects in perception) and uncover how the conscious or transcendental ego intentionally constructed knowledge of and

toward something (Moran, 2000; Thompson, 1990). Husserl claimed that “the wonder of all wonder is the pure ego and pure consciousness” (Speigelberg, 1994, p. 347).

As a student of Husserl, Heidegger was taken by his ideas, but disagreed with Husserl’s approach to uncovering ‘the things themselves’. Whilst Husserl’s approach advocated for bracketing out the world, Heidegger (1962) argued that human beings could not stand outside the world, rather they understood because they were already in the world. For Heidegger reducing things to phenomenon hid the fact that they were ‘my’ experiences (Harman, 2007). He argued that life was to be understood by experiencing the world, not by theorizing about it. Heidegger (1962) suggested that if the researcher stood back and only viewed the world through theoretical reflection, the world would go dead and things would lose their meaningfulness. Inwood (1997) gives the example that when we look at the stars at night, under the full moon and calm breeze, we do not experience this by naming and categorizing the constellations, rather we are aware of the brightness of the stars, the stillness of the night and the person we are with. For Heidegger the wonder was not one of ego but the wonder of being, leading him to say in contrast to Husserl that “man alone of all existing things...experiences wonder of all wonders: that there is being” (Speigelberg, 1994, p. 347). For Heidegger the task of phenomenology was to uncover the meaning of Being¹¹ as a-priori before theoretical constructions.

Choosing Heideggerian phenomenology seems appropriate for this study as I agree with Heidegger that I can not ‘bracket’ out my own understandings of what it means to be in a world of paediatric practice. Every step from the question to possible interpretations is already embedded by my understandings of being in this world. I am not looking for a ‘theoretical’ understanding of the notion of dilemma; rather I seek an understanding of what it means to be human and experience dilemma.

What is hermeneutic phenomenology?

Phenomenology has its roots in the Greek words ‘phenomenon’ and ‘logos’; phenomenon from the verb ‘to show itself’ and logos meaning speech, therefore letting something be seen through ‘what is talked about’ (Heidegger, 1993). The

¹¹ Heidegger used ‘being’ to signal existence, and *Being* to signal *existentiale* (ontological existence)

activity of phenomenology is to bring a phenomenon into the light of day, so that it “shows itself in itself” (Heidegger, 1993, p. 73). Heidegger cautions however that a phenomenon may not always show ‘itself as itself’. The phenomenon may appear as “semblance”, where something shows itself as “something it is not”, or it can “only look like it” (Heidegger, 1993, p. 74). Phenomenon may also ‘appear’ through “indications, presentations, symptoms, and symbols [which] have the designated formal, fundamental structure of appearing” (Heidegger, 1993, p. 74). In this manner the phenomenon is “making itself known through something that shows itself” (but not the essence of the phenomenon) (Heidegger, 1993, p. 75). What Heidegger points to here is to keep our questioning open and not be deceived by what may at first appear to be the phenomenon of dilemma. The goal of phenomenology is to open up a space to reveal new possibilities and to be aware of the place that habitual understandings have had in concealing phenomenon.

The phenomenon under investigation in this study is the experience of dilemma for health professionals and families when a child receives health care. Heidegger’s notions of how phenomenon may be revealed but also covered up challenges me to look beyond what may first appear in the taken for granted assumptions of what dilemma may be. I must stay open to the possibilities of how dilemma is revealed and may yet be concealed in the participants’ narratives and my preunderstandings.

The way in which the phenomenon is brought into the light of day is through language (logos). The term hermeneutics originates in the Greek word ‘Herme’ and means to bring understanding through language. For Heidegger the “logos of phenomenology...has the character of hermeneuein, through which the proper meaning of Being and the basic structures of the very Being of Dasein are made known” (Heidegger, 1993, p. 84). He suggests that it is through language that the meaning of Being can be uncovered and the world is made intelligible. Language is not just used to express what we see, but also when we speak, others see what we mean (Heidegger, 1982). We are embedded in language, so even when we are asleep we ‘speak’ in our dreams (Heidegger, 1971). For Heidegger we are always speaking “even when we do not utter a single word aloud, but merely listen or read...Only speech enables man to be the living being he is as man” (Heidegger, 1971, p. 189). What Heidegger suggests here is that speaking is a way in which we already are

interpreting or understanding our world. However it is not just speech that enables us and others to see meaning. It is also what is not said and remains hidden in which meaning may be revealed.

For Gadamer (1989) language is also a shared activity where the meaning of being comes into understanding through dialogue. This dialogue or ‘hermeneutic conversation’ is an interplay between the speaker and the interpreter (Gadamer, 1989). We understand each other through the medium of language and because of our own background of prior understandings of what language means. Our understanding of what is said is always informed by this background of understanding, and will influence how we interpret what is said.

In this study I am aware that my understanding of the experience of dilemma for health professionals and families will be mediated through language. I must be aware of what is said, what has not been said, and the interplay between my interpretation of the participants stories and their interpretation.

What is Being?

Heidegger (1962) uses the term ‘Dasein’ to describe the situatedness of being human. Da-sein literally means Being-there, as ‘Being’ [sein] is the infinitive of ‘ich bin’ [I am] and ‘there’ [da] in the world. For Heidegger Being-there is never just as a physical or biological fact (such as an entity with properties) rather it is to exist in an ontological sense, in that one is already embedded and immersed in a tangible day-to-day world (Steiner, 1991). According to Heidegger (1962) human existence and the world are inseparable and he refers to this as ‘Being-in-the-world’. Being-in-the-world stands for an unitary phenomenon which is the basis for the experience of existing, as well as an essential state for how we are ‘in-the-world’ (Heidegger, 1962). Heidegger (1962, 2005) cautions us that Being ‘in’ should not be thought about as some spatial relationship, such as water in a glass, or two objects related to one another, rather it signifies ‘to be familiar with’ and to ‘dwell’ in the world in a manner of taking care of it.

This notion reminds me to take care not to separate participants’ experiences into objective facts or theoretical perspectives; rather I need to show how the experience

of dilemma arises from being-in a world of practice. I need to show what it means to 'be' and 'dwell' in a world of practice with all its ambiguities and paradoxes.

Being-in-the-world through care (in our everyday involvements)

Being-in-the-world means that we not only find ourselves somewhere, but also that we are always dealing with something, or being concerned with something. For Heidegger 'dealing with' refers not only to the world around us, but also to the 'self world' and the 'with world'. Heidegger (1962) says that the basic structure of our involvement with the world is care, as we are never there as just disinterested bystanders. He argues that as we are in the world we cannot but be involved and concerned with everyday activities (such as what should I eat, when should I sleep, should I give this child paracetamol). For Heidegger, what it means *to be* is to care.

For the most part the notion of care may be seen in our involvement in the everyday ready-to-hand world around us. Heidegger describes this mode of concern as having to do something, making use of something, giving something up and letting go, undertaking, accomplishing, evincing, interrogating, considering, discussing and determining (Heidegger, 1962). In everyday terms we understand ourselves and our existence by way of the activities we pursue and the things we take care of (Heidegger, 1962).

Here I am made aware that the meaning of dilemma is situated in the interests and concerns that health professionals and families pursue. What is it that they care about, what are their everyday involvements and what do they take care of? How might this reveal the experience of dilemma for health professionals and families?

Being in the everyday world that is ready-to-hand

As we are 'in' the world, our relationship with other entities is usually that of familiarity. For example our ability to assess a sick child, use a stethoscope, understand medical terminology is usually something we don't have to think about. Heidegger calls this type of being-in-world as 'ready-to-hand'. It is the everyday living that we go about that we do not think theoretically about. It is the 'doing' of everyday living that is 'circumspective'. In being ready-to-hand things often withdraw from view or become taken for granted. It is not until something goes

wrong that these become 'conspicuous'. For instance if a child breaks their leg so that it becomes unusable (conspicuous) we may begin to reflect on the all the taken for granted assumptions (circumspection) of being able to do things that their leg previously made possible (getting to school, going to the toilet, climbing in the playground). Heidegger (1962) says that "when our circumspection comes up against emptiness [we] now see for the first time what the missing article was ready-to-hand with, and what it was ready-to-hand for. The environment announces itself afresh" (p. 105). Heidegger (1962) describes this mode where the world shows itself as 'unready-to-hand'.

This reminds me to be aware of what may be taken for granted and covered up. Have I accepted meanings as self evident? What is yet to be revealed in what is hidden in the everyday? What is 'ready-to-hand' and circumspective? How is dilemma revealed in the conspicuous?

Being in the world that shows itself as present-at-hand

When things come more explicitly into view from the background of the everyday use and understanding they become 'present-at-hand'. In this mode, people stand back from the every day activities and view things from a theoretical perspective (Plager, 1994). Although this reveals the taken-for-granted assumptions that had been previously attributed to this thing or situation, Heidegger (1962) cautions us that this way of viewing the world can detach things from their referential meanings and concernful relations with Dasein.

I am reminded here that my role is not to theorize, and to make sure that I remain grounded in the everyday experiences of families and practice. I am reminded that the moment I hold something explicitly in view, the risk is for the background of meaning to disappear from view.

Being thrown into the world of facticity and possibility

How do we come into Being-in-the-world? Steiner (1991) suggests that other than the physiological facts of birth and death, how we will come into 'Being' between these events is largely unknown. Being is always a mixture of possibility and actuality. Heidegger describes this as being "thrown" into the world. "This characteristic of

Dasein's Being, this 'that it is'...we call 'thrownness' of this entity into its 'there'" (Heidegger, 1962, p. 174). Being thrown is to be 'delivered over' to the condition of human existence (Steiner, 1991). Steiner (1991) describes thrownness as being delivered over is to "an actuality, to a 'there', to a complete, enveloping presentness. Dasein must take up this presentness; it must assume its own existence. It cannot do otherwise and continue to be" (p.88). Heidegger describes this as facticity, in that Dasein is not a free floating self projection but determined by thrownness as a fact (Heidegger, 1962). He says "as something thrown, Dasein is thrown into existence. It exists as an entity which has to be as it is and as it can be" (p. 231).

Although Heidegger (1962) claims that Being is "constantly more than it factually is" (p. 185) in that we are always projecting ourselves toward future possibilities, this none the less is constrained by actuality. Heidegger says this is the 'facticity' of our existence. Gadamer (1994) describes facticity as running up against the boundaries of existence despite how much control and certainty Dasein thinks it has over its own existence. He says that "Dasein may well choose it's Being...but in truth, with this choice Dasein only overcomes it's own existence into which it has already been 'thrown'"(Gadamer, 1994, p.p. 55-56). Being-in-the world then is one of possibilities but these are not endless, and not all possibilities we wish for will be attainable, as we are also constrained by the circumstances we find ourselves in.

I understand here that no 'world' is perfect and ideal and that to understand the others experiences I need to be aware of realities and the possibilities of the world health professionals and families describe.

Being-in-the-world-with -others – "mitsein"

Being-in-the-world means we also share this world with other human beings. Heidegger (1962) says that as long as Dasein exists, it is always with others. Even when we are alone, we are aware of others because of their absence. Virtually everything Dasein does is involved with others, such as providing and receiving health care; those who provide the necessities for life (such as food, electricity, and clothing) and those who purchase them. Dasein's world is essentially a public world, accessible to others as well as itself (Inwood, 1997). By being with others, Heidegger (1962) says we do not mean everyone else but me. We do not distinguish ourselves

from others, we are already amongst them. Being-with-others is conditioned through care and concern in our involvement with everyday undertakings in the world around us. He says through these everyday undertakings others are not objects of concern; rather our relationship with them is one of solicitude (Heidegger, 1962). Heidegger describes solicitude as 'Fursorge' – a factual social arrangement (Heidegger, 1962). He suggests that solicitude has two extreme possibilities.

One extreme is where one takes care away from the other by 'leaping in', and where the other is taken over, disburdened or becomes dominated and dependent. The other extreme possibility is 'leaping ahead' where the others potentiality for Being is made transparent to them and frees them to become authentic. What does Heidegger mean by being 'disburdened' or being 'authentic'?

Disburdened or being authentic

Heidegger (1962) describes the everyday 'who' of others or Dasein as 'they' or 'das man' where Being-with-one-another dissolves one's own Dasein completely into the others. We laugh because they laugh, we find something shocking because they find it shocking, and we go along with what everyone says and does because it is what 'they' say and do (Heidegger, 1962). In going along with everyone else we have become disburdened into having to think or decide for ourselves (Heidegger, 1962). Heidegger says it is our close proximity to others that paradoxically our own self (Dasein) recedes into the distance. Therefore the everyday 'self' of everyday Dasein has been dispersed or subsumed into 'they' (Heidegger, 1962). Heidegger describes this absorption into what 'they' say and do as 'fallen'. In falling Dasein is lost in the publicness of the 'they' and lost its authentic potential for deciding for oneself (Heidegger, 1962). Heidegger describes this as the everyday mode of being-in-the-world as the 'haziness' of life. Gadamer (1994) argues that this is a basic condition of life, rather than living one's life as if it was informed by "principles of clear and distinct perceptio of the ego cogito" (p. 63).

For Heidegger (1962), bringing Dasein back from the fallen-ness of 'they' is through having to face one's own death, which makes Dasein see that all possibilities end with death, so that Dasein must take responsibility for its own life until that moment. The fact that no one (or 'they') can die for Dasein brings Dasein back into deciding how to

choose to live one's own life. Heidegger (1962) says that death makes us have to think about our own possibilities for being, and that these possibilities are not endless, rather they are grounded in fact there is only so much time (finitude). In doing this we have taken authentic responsibility for our own existence. For Heidegger (1962) "human Dasein is neither a free self projection nor a self realization of an intellect, but rather a Being-toward-death...and that means that it is essentially finite" (p. 57). In this sense Heidegger recognized the "restriction of the use of understanding to the realm of possible experience" (Gadamer, 1994, p.57).

The questions I ask myself are how health professionals and families find themselves in a world with others? What is the everyday busyness of life that health professionals and families get swept up in? Are there times when health professionals and families go along with what is said and done, and other times when they see how this may take away their thinking or choices? What are the everyday conditions in which health professionals and families are disburdened or authentic?

How do we come to understand being-in-the-world?

Knowing for Heidegger is already grounded in Being-in-the-world. He says we do not just stare at something as if it is something present-at-hand, rather it is because we are already in the world and fascinated by the things that concern us that we understand (Heidegger, 1962). Heidegger (1962) suggests that when we direct our attention to something to understand it, we do not step outside of our inner sphere, nor when we have grasped it bring it back to some inner 'cabinet' of consciousness. If we hear a child crying we do not theorize why they are crying, rather we understand immediately that crying signals their distress because of pain, hunger, loneliness, fright or tiredness.

For Heidegger interpretation is based on the assumptions of shared understandings as being part of being-in-the-world. Heidegger (1962) describes interpretation as being based on three fore structures of understanding. These fore structures include 'fore having' which is the understandings we already have in advance, 'foresight' which is the view from which we approach the phenomenon, and 'fore-conception' which is how our understandings have led us to question and our expectations of what will be found. Our fore having is that we know that crying signals distress; our fore sight is

whether we encounter the crying as a parent or health professional, friend or stranger; and our fore conception is that if we understand crying as distress we will also expect that there will be some cause for it. For Heidegger the structures of fore having, fore sight and fore conception are the “upon which” that things become intelligible as something (Heidegger, 1962, p. 193).

Heidegger suggests that these fore structures of understanding also point to the temporality of knowledge and understanding. He says that “people still hold the view that what is handed down to us by tradition is what in reality lies behind us – while in fact it comes towards us because we are its captives and destined to it. The purely historical view of tradition and the course of history is one of those vast self deceptions in which we must remain entangled as long as we are still not really thinking” (Heidegger 1968, p.76). For Heidegger what we know does not just stay behind us, rather it informs the decisions and the perspectives that we bring to present and future decisions. In this way he claims that our past always meets us in the present and follows us into our future. These fore structures form the basis of the hermeneutic circle.

The questions I ask myself are what are my preunderstandings? How do the fore structures of understanding affect both my own interpretation and those of the participants? How does history inform our interpretations?

The hermeneutic circle

Being ‘there’ means that all understanding is already understood as the whole of being-in-the-world. All interpretation is based on what we already know (fore-structure) and some understanding of what is to be interpreted (Heidegger, 1962). Therefore the answers we expect to hear depend on our way of posing the question, which in turn is a result of our presumptions (otherwise how could we ask the question?) (Moran, 2000). There are no questions that arise from pure ignorance, rather the answers to questions we receive force us to revise the assumptions we started with (Moran, 2000). Heidegger (1962) describes this as the hermeneutic circle which is the interplay and ‘to and fro’ of what we already know and what we seek to understand. Gadamer (1989) describes this as moving between the ‘parts’ and the ‘whole’.

Gadamer (1989) describes what we already know as ‘prejudices’ which may enhance or distort how we see the phenomenon. For Gadamer understanding requires shedding light on the prejudices that ‘hide behind our backs’ (Moran, 2000). Our prejudices form the ‘horizon of disclosure’ which is the platform or vantage point from which we view the phenomenon. Gadamer (1989) says that our own horizon of disclosure also merges with others interpretations and understandings to form a ‘fusion of horizons’.

Gadamer (1994) suggests that our understanding is never just regaining what someone else has said, rather we move in a free space around what is said to come to our own understanding and reply to what has been spoken about. Gadamer sees this as necessary for the interpreter if “instead of parroting ...truly wants to understand” (Gadamer, 1994, p. 42). In this way understanding is always on the way and what comes into language “is not merely a collection of opinions...rather [the] experience of the world itself is given” (Gadamer, 1994, p. 43). Arendt (1978) suggests that understanding is ever changing, and unlike objects of contemplation “meaning, which can be said and spoken about, is slippery; if a philosopher wants to see and grasp it, it ‘slips away’” (p.122). Being underway with understanding is to recognize how meaning may never be explicitly ‘this’, rather it is something we grasp before it moves and conceals itself again.

Within the hermeneutic circle lies hidden the possibility of the most primordial kind of knowing, and the task of thinking in this way is not to let our fore-having, foresight, and fore-conception cover these up (Heidegger, 1962). Rather the task of the hermeneutic circle is to open up new possibilities and to try and stay as close to the things themselves (Heidegger, 1962). What may cover things up is when we make assertions that ‘it is’ and the phenomenon becomes present-at-hand or a semblance, a representation. Gadamer (1989) argues that we need to look at the ‘in-between’ of spaces to see what is still being concealed. When the phenomenon is uncovered the researcher has the sense of already knowing what was already there. I am reminded here to be aware of the in-between spaces and to be open to what may yet be revealed.

What is truth?

Heidegger (1993) warns of staying clear of an idea of truth as a correspondence to a category of true or false. Rather, truth for Heidegger is when something is seen closer to what it is, having been brought out of concealment and into the open. Heidegger (1993) describes this openness as 'region' or 'clearing'. He suggests that rather than translating 'aletheia' as 'truth', we should see it as an 'unconcealment'. He says "this translation is not only more literal; it contains the directive to rethink the ordinary concept of truth in the sense of correctness of statements and to think it back to that still uncomprehended disclosedness and disclosure of beings" (Heidegger, 1993, p. 125). Arendt (1978) says that truth has often been linked with the faculty to judge; that "this is wrong" or "this is beautiful" (p.122). She argues that judging is not the same as thinking. For Arendt, thinking deals with what is invisible and the uncovering of what is still absent. I am challenged here that there is no 'truth' about dilemma; rather truth is in the thinking towards things that lie waiting to be uncovered.

For Heidegger seeing truth as "correspondence to the matter of knowledge" and therefore something "able to be measured as correct or not" so that is "immediately evident to everyone" is a way of reinforcing knowledge as 'obvious' or 'common sense' (Heidegger, 1993, p.p. 118-119). Heidegger (1968) describes this common sense as a way of 'blinking' where things are set up in a "glittering deception which is then agreed upon as true and valid" (p.74) and on the basis of mutual understanding not to question the setup. Being false then is to cover something up; deceiving the person by showing itself as something it is not. Just as logos or language may reveal (aletheia) phenomenon, certain types of language may contribute to concealment (lethe) of the phenomenon. Heidegger describes this talk as 'gerede' where assertions are made and others accept this and pass this on because 'they' have said it. Heidegger (1968) says a consequence of common sense is that "language plays with us...it likes our speech to drift away into the more obvious meanings of word" (Heidegger, 1968, p. 118).

In undertaking this study I am aware I must be alert to the common sense meanings or signs that have already been attributed to what dilemma may be. I need to be cautious that my thinking of dilemma does not drift into more obvious meanings that have

come to represent dilemma. I am aware of keeping thinking open to what still lies hidden and waiting to be revealed.

Reading Heidegger

Heidegger has been critiqued for his use of language that at first glance can seem incomprehensible. His rhetorical arguments and the use of hyphens to join words together can be distracting to a beginning reader of Heidegger. Coming to Heidegger's written language was more a process of 'immersion' than reading. I would read, reread and read again. What I found however was that with each subsequent reading it became clearer how Heidegger invited me as the reader to think. He called me to think, not by laying out a clearly mapped path of ideas; rather by inviting me to join in the dialogue (hermeneutic circle) with his ideas which with each turn, spiral and question brought me closer and further away from the original idea he posed. When reading Heidegger I was reminded by Gadamer (1994) that the main body of Heidegger's published works came from lectures he gave, so that in their original format they would have been oratory works which showed Heidegger's skill as a teacher in engaging his audience in his thinking.

While for a beginning reader of Heidegger it was easy to get frustrated with his terminology such as forgetfulness-of-Being, withdrawal-of-Being, Gadamer suggests we need to visualize what Heidegger 'sees' in reference to word. He says "there are words that function merely as signals, and then there are other words, and this is not confined to poetry, that bear witness themselves to what they communicate. These words are so to speak, proximate to something that it is: that discloses itself in its own act of speaking" (Gadamer, 1994, p.24). Heidegger's use of hyphens in 'Being-in-the-world' then suggests that there is no separate 'being' or 'world' rather he asks us to see it as an unitary phenomenon. Heidegger's use of language in such a way suggests the interrelated and embedded nature of words and their meaning. Although it was tempting to translate these terms into more 'simple' representations, what Heidegger intended by these terms could have been lost.

I have also used some of the original German words as used by Heidegger. This is because throughout my reading of Heidegger these words have resonated with me

(as a speaker of the Dutch language) and captured the embodied meaning more than some of the English translations. I could 'see' what they meant.

Heidegger's political involvement with National Socialism

Any student using Heideggerian phenomenology cannot but be aware of his involvement with the Nationalist Socialist (Nazi) party during the Second World War. As the legacy of the Nazi era was the mass murder of Jewish people (as well as gypsies and those with disabilities) it becomes an important question to ask to what extent or if any were Heidegger writings implicated in the ideology of National Socialism. The other question is whether we judge Heidegger as the man or the philosopher? There are many books written on this topic such as Farias (1989), Wolin (1993), Lang (1996), Young (1997) and Safranski (1999) arguing both for and against the man and his philosophy.

In trying to understand Heidegger's involvement with National Socialism (albeit from a distant vantage point in history) I looked back at the social and historical context of the time. In Germany, the aftermath of World War I brought with it economic decline, massive unemployment and challenges to social and state institutions of the Weimar republic from groups such as Bolshevik's and empowered women (Feldman, 2005). The rise of fascism was an attempt to rescue Germany from the threat of modernity, chaos, decadence and cultural decay and coincided with the collapse of the Weimar republic in 1929 (Feldman, 2005). Fascists and intellectuals alike saw themselves as the guardians of values in society and in an ideal position to enact change (Feldman, 2005). Gadamer (1994) says to understand how events unfolded one also has to understand the mood of the time:

To grasp this one must visualize the catastrophe of World War I and what the outbreak meant to the cultural consciousness of European humanity. The bourgeois society, spoiled by the long period of peace, had developed a belief in progress and a cultural optimism that came to characterize the liberal age. All of this collapsed in the storm of war...it is obvious that the profound cultural crisis that came over the whole European culture at that time would have to express itself philosophically, and it was just as obvious that this

would be especially pronounced in Germany, whose radical transformation and collapse was the most visible and catastrophic expression of general absurdity (p.p. 3-4).

Heidegger's response to the perceived dangers of consumerism, individualism and hedonism was to attempt to re-establish the German identity and national pride through asserting its own cultural-ness or Innerlichkeit (Young, 1997). For Heidegger and others, this difference from other nations was based on the idea of Innerlichkeit, (the overthrow of metaphysics to assert a new spiritual and cultural awakening) whereas for the National Socialists this difference was seen as racial, the supremacy of the German people based on race and biology (Young, 1997). For the intellectuals and the National Socialist the hope for uniting the German people rested on rejecting individualism in favour of a greater community (Young, 1997). It was hoped that one leader would lead, and make decisions for the greater good of all. It was in this climate that Heidegger's ideas related to the re-awakening of people (as volk) and universities took place.

Steiner (1991) poses two questions. Firstly was there anything in Being and Time (Heidegger, 1962) that could have related to Nazism, and secondly why did Heidegger remain silent after 1945, not only about his own involvement with National Socialism but also the holocaust and the atrocities of the Nazi era? In relation to Steiner's first question, Young (1997) and Wolin (1993) say there is nothing in Being and Time (Heidegger, 1962) that could be read as supporting the National Socialist aims of ideology based on biology or race, or that supports anti-Semitic ideals.

For Lang (1996) the second question of Heidegger's silence is the most perplexing. He asks was there any presence behind the absence of speech? Lang (1996) suggests that Heidegger was anti-Semitic but only in so far as he privileged the ideals of the German volk and was opposed to any thing that might have undermined this (such as technology and communism). Lang (1996) argues that for Heidegger the 'Jewish question' was never one based on race or biology, so therefore to address in retrospect a question he denied earlier would have seemed inauthentic. In the famous Der Spiegel interview with Heidegger in 1966 "Only a God can save us" published posthumously following his death in 1976, Heidegger was asked about his ideas of a

revolutionary new way of thinking. Although the question asked by the interviewer did not relate to his silence in regard to the Jewish question, his reply perhaps gives some insight to why he would not have spoken out. The interviewer said to him "...silence is denied to us. We politicians...citizens...constantly have to make decisions of one kind or another. We must adapt to the system we live in, we must attempt to change it...we expect help from the philosopher" (Wolin, 1993, p. 110). Heidegger replied: "I cannot, because the questions are so difficult that it would be contrary to the meaning of the task of thought to step up publicly, as it were, to preach and to impose a moral judgment" (Wolin, 1993, p. 110). It could be speculated that to speak out would have gone against Heidegger's philosophy on what the task of thinking is.

The letters of Heidegger's past Jewish students such as Arendt, Jaspers and Levinas paint a picture of a man who as a philosopher and teacher provoked wonder but as a who in the end was all too human (Safranski, 1999). In reconciling the use of Heidegger's philosophy for this study I firstly believe that to untangle these historical events from such a distance is not to be able to fully understand the multiplicities of opinion, arguments or perspectives that go beyond the scope of this study. It is difficult to judge Heidegger the man; however because of the availability of his writing we can judge Heidegger's philosophy. In taking a stand to use Heidegger's philosophy I believe I must be attentive to any aspects of his work that could be interpreted as anti-Semitic and therefore implicate the findings of this study. Including the philosophy and ideas of two of Heidegger's most ardent admirers and vehement critics, Emmanuel Levinas and Hannah Arendt, provides a counter balance, an alternative perspective and challenge to the philosophical tradition Heidegger offers.

Following Heidegger

Just as Heidegger challenged and shaped the school of phenomenology handed down by Husserl, so too did students of Heidegger challenge and shape the ideas handed down by him. Hannah Arendt and Emmanuel Levinas join in the hermeneutic circle in interpretive phenomenology from their own horizon of disclosure.

For Hannah Arendt her horizon of disclosure includes being a former student and lover of Heidegger's. With the advent of war in Germany, Arendt as a Jewish woman

had to escape living first in Paris and then in America (Moran, 2000). Much of her thinking and writing dealt with issues arising from her experiences during the war and directly thereafter. Although she lost contact with Heidegger for a period of years, he was to remain a pivotal point and connection in her later life (Safranski, 1999). In regard to Heidegger's involvement with National Socialism she described him as a highly intellectual man who was politically inept (Safranski, 1999).

Levinas was also a student of Heidegger, whose fascination with the man and his philosophy turned to disbelief and disillusionment when Heidegger's involvement with National Socialism became public (Strasser, 1994). Levinas was also Jewish, his wife and daughter escaping death by being hidden by friends, the rest of his family being wiped out in the Holocaust (Strasser, 1994). Levinas himself was imprisoned in a POW camp rather than in a concentration camp, because of his status as an officer in the French army (Levinas, 1989). Both Levinas and Arendts' experiences have shaped their philosophical ideas and provide an echo; a different voice to the ideas set forward by Heidegger. In this study I found their ideas have revealed differing perspectives to some of my unanswered questions

Emmanuel Levinas

Levinas's philosophy has been described as an act of commemoration of the horror and totalizing effects of culture, society and the gas chambers of the Nazi reign and as a challenge to western philosophy to acknowledge societies' responsibility to their fellow men (Moran, 2000). He claimed that ethics precedes metaphysics (questions of being) and that ethics should be a first philosophy. Although Levinas talked of 'ethics', he was clear that this was to describe and find the meaning in ethical relations, rather than constructing a theory of ethics (Levinas, 1998).

Levinas draws on the notion of "totalizing" to describe how people are dehumanized if they are assigned to categories or constructs of absolute knowledge (Moran, 2000). He describes this as when everything and everyone is the same and everybody exists in a homogenous continuum (Levinas, 1969). Totalizing can occur when people are assigned to categories such as race, class or occupation and the individual is no longer visible as a unique presence (Strasser, 1994). Levinas claimed that "life and work are

nothing more than masks” so that no one is themselves anymore because everyone is reduced to what they achieve in anonymous ways (Levinas, 1969, p. 178).

This is where Levinas breaks with Heidegger’s notion of being-in-the-world. For Levinas (1998) Heidegger’s being-in-the-world maintains a privilege and priority of mineness [Eigentlichkeit] in relation to the other person. Although this is still a care for a person, for Levinas this is “in terms of occupations and works in the world, without encountering faces, with [out] the death of the other signifying being-there” (p. 215). For Levinas being-with-others is not a matter of authentic ‘mine’ or faceless ‘they’, but an ‘I’ who is with human beings and who matters as such. Levinas (1998) suggests that it is not being aware of our own death that makes us authentic; rather it is the metaphorical death of another where we recognize the limits of human suffering and when the other is disclosed as significant that authenticity is possible. What breaks the anonymity of ‘they’, what disrupts our mineness (interiority) is the face of the other (Levinas, 1998).

Levinas’s use of the word ‘face’ should not be interpreted as a ‘literal’ face, rather it is a primordial signifier (Critchley & Bernasconi, 2002). The etymological origins of the word face in French and German is ‘visage’ and ‘gesicht’ which refer also to seeing and to be seen (Critchley & Bernasconi, 2002). In this sense the face signifies ‘seeing another’ not only in the literal sense, but also metaphorically in what it means to be seen. Levinas says the face is not something that is seen, observed, deciphered or understood; rather it is somebody responded to (Critchley & Bernasconi, 2002).

Not relegating the face as literal means that the other’s face remains ambiguous, or a borderline phenomenon between visible and invisible. Levinas refers to the face of the other as ‘alterity’ in that we can never understand the other as the same (Levinas, 1998). For Levinas this is an important distinction, as if our empathy is based on the sameness of human beings, then it is easy to lose this moral imperative if others are judged not the same. If we can rationalize that others are not the same, such as children or those with mental illness, it is easy for them to lose their identity and become faceless (totalized) (Levinas, 1998). Levinas may have been thinking here of the wide spread genocide of the Jewish people, who were described as no longer human, but rather categorized as ‘sticks of wood’ (Hatley, 2000).

Levinas suggests that because the other can never be understood as the same (alterity) this means they maintain a relation to us that is outside (exteriority) our sense of self (interiority) (Levinas, 1999). What breaks totality is when the other's presence (face) breaks into our sense of self (interiority) and we are compelled to respond (held hostage). Levinas describes this interruption of our self as the trace of the other. By trace Levinas says the person does not appear (as a theme or a concept) they do not become a phenomenon, rather it is the disturbance or the doubts that are evoked by the demand of their presence or absence that leaves a trace (Levinas, 1999). This way the trace of the other remains ambiguous, and something non-reducible (Levinas, 1999).

Levinas also overturns Heidegger's notion of death as pointing to the finiteness of our lives (and having to be authentic for what is mine). He asks what if contrary to Heidegger's analysis of authenticity in death that "all relationships to the other person were not undone?" (Levinas, 1998, p. 215). Levinas suggests that because we have a sense of responsibility to the other (as plural not definitive), this obligation does not die with death, rather it reaffirms the humanity of the other and all the others that follow. For Levinas ethics as a first responsibility for all others means this is not just a care for this generation but also for the next. Death then becomes a metaphor for the love between a father and son, mother and daughter in whom the death of another preoccupies one before thinking of one's own death, therefore revealing the responsibility for the other. Levinas (1998) says "the future of death in the presence of love is probably one of the original secrets of temporality itself and beyond all metaphor" (p. 217). For Levinas death discloses the significance of the other.

For Heidegger (1962) being aware of the finiteness of one's own possibilities (because of being toward death) reveals a mood of anxiety, of uncanniness and reveals the world as 'is gibt' (there is nothing). Heidegger sees this uncanniness, the nothingness, as a world stripped of 'das man' and therefore the possibility of being authentic. For Levinas (1987) it is this very mineness that gives rise to 'il y a' (there is) which is experienced as an endless sequence of monotonous 'there is' and a growing mode of horror. It is only relating to another that can break this solitary emptiness and bring one back to an authentic mode of being. Il y a is the unbearable

indifference – the horror of an unceasing monotony deprived of meaning and others (Levinas, 1987). Whereas for Heidegger anxiety is about ‘nothingness’ for Levinas anxiety is because ‘there is’, and it is this that calls us to leave our self preoccupation to be occupied with the other. For Levinas this is what calls us to take into account those that pass before us.

Hannah Arendt

Hannah Arendt, although agreeing with Heidegger’s notion of breaking free from the publicness of ‘they’, re-interpreted this to include what it means to be a human being in the midst of the world. For her the world in which people live and encounter each other is always more than the sum total of an individual (Safranski, 1999). For Arendt the world is shaped by plurality and she criticized Heidegger’s Dasein as an “atomized self, capable only of mechanical reconciliation with others in an ‘over self’” (Moran, 2000, p.301). She argued that we are not only in-the-world but also ‘of’ the world and with this responsibilities of love and belonging also exist (Moran, 2000). For Arendt, authenticity is not revealed in the openness of self, rather authenticity is revealed in an openness of acting together with others (Safranski, 1999).

In response to Heidegger’s concept of truth as unconcealment between man and things, Arendt argues that truth as unconcealment takes place between human beings (Safranski, 1999). For Arendt, truth plays out in the social arena of the world, in the tragedies and comedies of life. What conceals ‘truths’ for her is the alienation and impact of isolation of modern humanity through totalitarianism. As Levinas, Arendt is concerned with the impact of totalitarianism which she argues occurs when everything in society, including reality is managed and people become displaced and manipulated (Moran, 2000). For Arendt authenticity is not obtained through one’s own death, but rather through the notion of ‘natality’ which she describes as “the miracle that takes the world, the realm of human affairs, from its normal natural ruin” (Arendt, 1958, p. 247). For Arendt natality presents the possibility of bringing something new into the world therefore the birth of each person is the possibility of a new beginning.

Conclusion

In this chapter I have discussed the philosophical notions that will guide this study. Whilst Heidegger and Gadamer provide the philosophical basis for approaching this study, the writings of Levinas and Arendt provide another philosophical perspective to analyzing participant's experiences of dilemma. Although it could be argued that the ideas of Heidegger and Levinas differ, I believe they provide an echo and counterpoint to each other, and ensure that more than one interpretation may be present. In the following chapter I will describe how the philosophical underpinnings provide a basis for developing my own process of inquiry.

Chapter five

Methods

The ‘thinking’ and the ‘doing’ of this study

For Gadamer (1989) the task of hermeneutic phenomenology is not to develop a procedure of understanding; rather its task is to clarify the conditions in which understanding takes place. Rather than a method, phenomenology has been described as a thoughtful attentiveness to what it means to live this life and be human (Heidegger, 1962; van Manen, 1990). This thoughtfulness stems from a tradition of thinkers and writers whose work has contributed to a body of knowledge and insights (Gadamer, 1989; van Manen, 1990). Gadamer (1989) suggests that the researcher stands in a ‘tradition’, a particular orientation and thoughtfulness to the phenomenon under study as a mode of understanding. If there is any method to be found, it must be one that shows congruence with the philosophical underpinnings and steps taken to have best answered the questions: ‘How has the understanding of Being been uncovered in relation to the experience of dilemma in this study?’ and ‘What has called for ‘thinking’ in the ‘doing’ of this study’? This chapter lays open the doing and thinking of this study.

Already understanding

Gadamer (1989) says that the question the researcher asks is because they already have an understanding of being-in-the-world of what is being studied. Gadamer argues otherwise how could questions arise about what we see? The research question for this study has already revealed some of the interests and concerns I have in relation to the phenomenon of dilemma. In chapter one I have disclosed my pre-understandings (prejudices) or horizon of disclosure which has contributed to the vantage point from which I view the topic of dilemma. In chapter two and three I have explicated the New Zealand context and broader literature which has contributed to a historical consciousness of the notion of dilemma. These fore structures of understanding go with me, in the decisions and choices made regarding carrying out this study.

Consultation

Prior to commencing the study in 2002, I consulted with professional groups such as the Nurses for Children and Young People of Aotearoa (NYCP), Nurse Educators and Charge Nurses. I wanted to gauge the appropriateness of the question at a time when there were other research questions that could be asked, and to uncover any potential issues in relation to carrying out this study. Colleagues' endorsed the need of carrying out research in this area. I was also aware that New Zealand is a multi-cultural society, and that potential participants may identify with these cultural groups. In keeping with the spirit of the Treaty of Waitangi I consulted formally with Maori groups and informally with Pacific Island groups for support and cultural advice. I received a letter from the Kauwhakaruruhau committee offering support and a commitment to act as cultural advisors should the need arise. In this study none of the participants identified with these cultural groups, and no cultural issues arose.

Gaining ethical approval

In May 2002, the Auckland University of Technology Ethics Committee (AUTEC) granted ethical approval for a master's study exploring nurses' experience of dilemma in paediatric practice. In 2004 approval was given by AUT doctoral committee to extend this study. I chose to interview a wider range of health professionals thereby promoting the ideals of a multidisciplinary approach to paediatric practice and to give voice to the perspectives that seemed to be missing from health professionals (other than nurses) who worked with children and families. A decision was made to also interview families, as paediatric practice is based on the philosophy of family centred care, thereby also giving voice to those in the relationship with health professionals. In April 2004 approval was granted by AUTEC and the Northern Regional Ethics committee for a doctoral study exploring health professional and families' experience of dilemma in paediatric practice.

Although ethics committees are part of the ethics process in carrying out a study, I was aware my own ethical orientation to the study. This centred on respect for the participants at all times, valuing their trust in 'handing over' their stories and experiences and being aware of the impact that being in this study might have on them. Ethics in research is not just about a set of rules or abstract principles, rather ethics exists in our ways of doing and practicing research, it embodies our

attentiveness to issues and potential problems each research situation brings (Davies & Dodd, 2002).

Accessing participants

Leonard (1994) suggests that to understand what it means to be a person we have to study the experiences of people in the context in which their values and what they find significant shows up. In order to understand what it meant to be a person who experienced dilemma when a child received health care was to turn the world of practice. This hermeneutic phenomenological study therefore sought stories from those health professionals and families who had experienced dilemma in paediatric practice. The inclusion criterion for health professionals was very broad including any health professional who had experienced dilemma in paediatric practice. In seeking family groups, I was looking for families who had experienced dilemma when their child received health care. I did not specify what sort of health care, or depth and duration of health care provided.

My own background in child health meant that many of the professional networks were already established, and I was known to many of the health professional participants. I had also worked with students in some of paediatric areas. I was aware that this could either contribute to a willingness to be involved with the study, or a risk of feeling coerced to participate. Prior to recruiting participants and during the interviewing with particularly the nurses, I choose not to work in any of the paediatric areas, thereby minimizing any risk of coercion or blurring of roles.

Health professional participants were primarily recruited through professional organizations. I attended a number of professional meetings and introduced the study to the potential participants. After having verbally discussed the study, I gave out an information sheet (Appendix 1), which reinforced the verbal information given. Contact details were included on the information sheet for interested people to contact me via email. Later some participants were also recruited as a result of my having presented early findings from my master's study at professional and educational conferences. Several people came up after the presentations and began telling stories of their own experiences. Of these, some asked if they could be included in the study. I explained the study to them and gave them information sheets saying I would

contact them a week later to see if they were still interested in participating. I was conscious of not coercing potential participants in any way at any time.

Family participants were recruited through social networks via snowballing technique. Friends often knew of families who had experienced dilemma when their child had required health care. They would approach the family, giving them the information sheet (Appendix 2) and gauging their willingness to participate. Those families expressing an interest to participate either emailed or phoned me. Families participating were not involved with any health care provider at the time, and were not recruited via hospital networks. Recruiting families this way influenced the cultural and demographic groups I had access to.

Once participants agreed to participate, an interview time and venue was arranged. On the information sheet, I offered to meet participants at a location of their choice to eliminate the possibility for health professionals or colleagues being aware of their participation in the study. Participants chose to be interviewed at work and at home.

The study participants

As New Zealand has a small number of health professionals who work in paediatrics, I have chosen to describe participants very generally, so as to protect their anonymity. Health professional participants included seven nurses, three paediatricians, three play specialists, one physiotherapist, and one occupational therapist. These groups represented both men and women, working in community and acute areas. Their ages spanned from 25 years of age to 55 years of age and all identified as European / Pakeha. Participants had from 5 years to 35 years experience in paediatric practice. The time spent in the area of paediatrics combined with further education all participants had undertaken, meant they were seen as experienced and in some cases expert practitioners. There was never any intention of seeking out this group in particular, but this became an interesting feature of the study. I had a sense that these participants had stories they wanted to share.

One issue that arose during the study, was that four health professional participants left the area of paediatric practice either just prior to or not long after being interviewed, either to work in a different specialty or to leave the profession

altogether. This raised the question of what role being part of the study may have had. On clarifying this with the participants it became apparent that the decision to leave was not influenced by being in the study, but rather their decision for wanting to be in the study was influenced by feeling they had to leave paediatric practice because of their experiences of dilemma. It is possible that sharing their experiences acted as an 'exit' interview, a safe and anonymous place to share their feelings and experiences. These participants' experiences fit with the understandings uncovered in chapter eight, and also the literature on moral distress and burnout discussed in chapter three.

Family participants included five families with children who either were chronically ill, had a life threatening illness resulting in the child's death, or suffered an acute episode of illness. I have used the word 'family' although in four of the interviews it was the mothers that were interviewed. When I was approached by a participant willing to be part of this study, the invitation was given to interview any adults in the family who wished to tell their story. In the first interview I interviewed a mother and father together. Their living room was large and I had brought a microphone in order to pick up sound. Unfortunately the microphone failed and the back up audio tape was too indistinct to be intelligible. This couple was happy to be interviewed again, but the busyness of their lives made trying to reschedule a subsequent interview difficult. I felt I could not intrude any further on their busy lives, and they already felt relieved by the telling of their story. Their stories are therefore not included in the data.

Subsequent interviews included two mothers who were parenting alone following the break up of their marriages. Two other mothers, after consulting with their partners chose to be interviewed alone. This brought up the issue of whether I was interviewing 'families' or 'mothers'. On reflection I considered that although the voices in the stories belong to mothers, it did not preclude them from being part of a family or being-with-others.

Literature on family interviewing (Dickinson, 2004; Hogan, Etz & Tudge, 1991; Holaday, 1989; Whall & Fawcett, 1991) has critiqued the term 'family' being used when often participants are more representative of one group than another (predominately mothers). Although these critiques provide a timely reminder of the multiple voices and perspective within a family, I was mindful of what it may mean to

break families into a representation of ‘equal’ parts, rather than acknowledging what it means to be embodied as family.

In this study the word family has been used to acknowledge how mothers identify themselves as in a world-with-others, rather than having interviewed a wide representation of participants from a ‘family’. The voices are the mothers interpretation of what happened to ‘their’ family.

Were there sufficient participants? Sandelowski (1995) suggests that in qualitative research it is not only the number of participants that determines sample size but also the depth and quality of the data. There came a point in the research process when I believed I had enough data, there was a sense of hearing a similar resonance in the stories participants told.

Phenomenological interviewing

As hermeneutic phenomenology is essentially a linguistic project, the use of dialogue to uncover the experience of those embedded in the life world under investigation is essential. The researcher must establish a conversational relation with the participants to uncover rich descriptions of the experience (Benner, 1994; van Manen, 1990). Although some authors have suggested that art, poetry and fiction literature may contribute to understandings of the phenomenon, in this study I returned to those who had experienced dilemma in a world of paediatric practice as a means to uncover experience of the phenomenon.

Prior to each interview I reminded participants about their rights in choosing to withdraw, and to not answer any questions they did not wish to. Consent was signed prior to each interview (Appendix 3). I always brought food with me to the interview and this served as an ‘ice breaker’ and also provided opportunities during the interview to stop, eat and reflect.

In interviewing health professional participants I started each interview with the question “*could you describe to me a dilemma you have experienced whilst caring for a child and their family*”. Gadamer (1989) says that in questioning we need to keep open to new possibilities, so that we move beyond the semblance of the thing. One of

the issues was the assumption made that the question was about 'ethical' dilemma. Many participants began telling stories about 'ethical' dilemmas initially during the early part of the interview. This only uncovered the 'semblance' of what the experience of dilemma may be. Later they would move from the perception of 'ethical' dilemma, to times that had posed a dilemma for them, but not necessarily seen as 'ethical' by predominant discourse.

When planning this study I had been aware of not using the word 'ethical' in conjunction with dilemma as this could result in preconceived ideas as to the nature of dilemma. Although I did not use the word ethical in questioning, health professionals appeared to see the two as inextricably linked. Four of the participants asked me to define 'ethical' for them and I discussed with them how this study was looking at the everyday dilemma they encountered in practice. This perception of dilemma as only seen as 'ethical' perhaps reflects the predominant discourse of 'ethical' viewed in a certain context and certain meanings attached.

To overcome this perception I began to follow my initial question with further prompts such as: "*Could you tell me about an incident that created a sense of tension for you while you cared for a child and their family?*" or "*can you describe to me a situation from practice where you were left feeling uncomfortable about either decision that could have been made?*" Despite some of the initial perceptions of dilemma, health professionals were articulate in talking of their experiences. Many of their stories could have been 'fitted' into an ethical framework, but primarily the participants shared the experience of living with dilemma. The stories were rich in anecdotes and examples from practice. Once I had asked the initial questions, participants needed little or no prompting in sharing their stories. Further lines of inquiry were then taken to clarify or identify additional aspects. Probes were used such as "*How did that make you feel?*"; "*who said what?*"; "*what happened then?*" and "*can you give me an example?*" to help clarify how events had unfolded and how participants had felt throughout them. This also had the function of orientating participants to a specific place and time rather than just general descriptions.

Families did not ask me about what dilemma meant. They appeared to already have a clear understanding of those specific situations that had been experienced as dilemma

by them. After asking the initial question, families needed little prompting to share their stories.

As I listened to the participants' stories, I tried to remain open to further questions that would reveal more about participants' understandings around the phenomenon of dilemma. This also highlighted an issue of what the researcher expects to hear and what they are told. There was a dialectical tension between trying to stay close and open to the experience of dilemma, and equally wondering why a particular story may have had significance for the participant. I would question whether I had not yet seen some aspect of the phenomenon or whether this was a story that just needed to be told. I listened to participants' stories, recognizing that the retelling of experience rarely takes a neat and linear form, and that what may appear as incidental detail or wanderings off the topic contributes to the whole in the end. This was particularly evident in the interviews with families, whose stories took on the shape of the history of the family, often starting with "*shall I tell you when he/she was born?*"

Interviews with the participants were between one to one and a half hours long. The length of the interview depended on the participant and when they felt they had told their stories. Towards the end of the interview and after having thanked participants for their time and stories, I would leave the tape running for any last minute words. Often this was the time when participants would add significant observations or anecdotes that they did not share in the telling of the stories. The twenty interviews with participants gave such a breath and depth of stories that I did not return for a second interview. There was also the sense that 'once the story is told, it is told' (Smythe, 1998). To return to the story again would be to change it in the retelling.

Interviews were audio taped, which allowed me to concentrate on the conversation and non-verbal gestures. Participants agreed to and appeared comfortable with the use of the tape recorder. Audio taping interviews allowed for a more reflective attitude, as talking is easier than writing and allowed me to stay closer to the experience. The first ten audio tapes were transcribed by myself which although time consuming, allowed me to re-immense myself in the verbal conversation and revisit the emotion and tone of interviews, which often can become lost when written. This experience contributed to an embodied knowing through transcription. The effect of this was also at times

personal. When health professionals shared stories of children dying I was taken back to my own experiences of having nursed children who died. When a mother told the story of her son dying it also drew my attention to my own children, one who was the same age at the time. During this time I would make sure that I celebrated life with my children, with a walk along the beach or going to the playground. Once the participants' stories were written down in black and white, I was able to read them more objectively.

The next ten interviews were transcribed by a typist (who had signed a confidentiality agreement Appendix 4) and made possible through a scholarship from the New Zealand Nurses Organisation (NZNO) Nurse Education and Research Fund (NERF). An unanticipated issue was to arise here. On returning the transcribed interviews the typist disclosed her distress at a story one participant had told over the death of a child. In further conversation it emerged her sibling had died in similar circumstances. We talked more and I referred her to a counsellor. This highlighted the embodied and also vicarious experience transcription may be, and impact this may have on a person. The potential vulnerability of a transcriber / typist was not addressed in my ethics application; however the moral obligation to respond was no less than if she had been a participant. This incident highlighted to me assumptions I had made about the typists role being to objectively record words onto a page, yet this belied the fact that she was equally being-in-the-world as the participants or researcher.

After each interview field notes were taken to document significant points such as the content of the interview, the time and setting and any interruptions. A journal was also kept to record my thoughts about the interview, issues that arose and any decisions that were made. Notes were also made to remind myself of what had worked well, and any additional lines of questioning for subsequent interviews.

Incidents occurring during interviewing

Several times whilst interviewing participants, they became tearful relating a particular incident that had significance. These were incidents that happened at least three years ago, in some instances over 15 years ago. Often participants' stories were very moving and I cried along side of them. I would then sit quietly with them until they felt ready to carry on with their story.

My role as a researcher was highlighted here. Several times the participant's stories telling moved from being in the 'moment' to a more analytical or hermeneutic / self interpreting stance. At these times I did not always probe with deeper questions. The stories participants shared were often very personal and still very close to what had happened years ago. Often there was an unresolved feeling about them, so to dwell on these stories was to bring back conflicting thoughts and the mood of the experience. To ask questions that took participants beyond their comfort zone seemed too unethical. On other occasions, although being aware it was the participants' experiences and not mine, I would disclose similar experiences and empathize. To be a distanced observer standing outside their experience felt wrong.

Another issue arose over disclosure, and the role of the researcher responding. Several health professionals shared stories (for the first time) of experiences that had happened years ago, and their uncertainty and grief over whether they had done the right thing. Although there was no answers to the dilemmas they had faced I felt I had to reassure them that they were a remarkable person who had acted to the best of their ability in the circumstances. This again raised to me the issue of being 'non-judgmental' yet ethically such disclosure needed some sort of affirmation of the difficult position some participants had found themselves in.

Davies and Dodd (2002) highlight this tension saying that interviewing in phenomenological research is a social interaction and as such is a "shared communication, not just a one-way traffic of information from respondent to researcher" (p. 283). Concerns have been raised about over identifying with participants, yet the very success of a phenomenological interview rests in establishing a rapport based on empathy and understanding so that participants feel safe and comfortable in telling what are at times very personal stories (Davis & Dodd, 2002). Empathy has also been critiqued as perhaps leading the participant's answers, yet the very act of interviewing is already framed by the context and research topic (Davis & Dodd, 2002). I was aware in the interviewing for this study that the relationship between researcher and participants was not objective, rather I shared in their social world of paediatric practice and that of being a parent. I was also mindful

of the question I asked, the significance of the memories and stories that may be uncovered and being respectful and ‘careful’ for both the participant and their story.

Phenomenological research is to return to the experience itself, so as such the researcher must be prepared for the participant to ‘relive’ the moments. I was concerned in that reliving the moments participants might be left with feelings of distress. When this occurred I would always follow the interview up with a phone call the following day. The response from the participants whom I phoned was that they felt unburdened by the sharing of the story. Crying appeared to be a sign of the emotion attached to the event and significance of this event had for the participant. There was a sense of honouring the significance of the event.

Strategies to ensure confidentiality and anonymity

I was aware that despite editing and name changes, paediatric areas in New Zealand are distinct and people might still recognize participants. In order to maintain confidentiality and anonymity for the participants and also children and families at the centre of participants’ stories, diagnosis and details such as age, sex, culture and location were often changed. In one instance the story involved a high profile case that had been in the media. I chose to not use this story, as it would have been too identifiable of the child and their family.

Participants’ names were changed to a pseudonym to protect their anonymity. Four participants chose their own pseudonym whilst the other sixteen asked for one to be chosen for them. The tapes from the interviews have been destroyed, and transcripts from the interviews held in a locked filing cabinet, and all computer files were password protected.

Further involvement with participants

Transcripts of the first draft of the crafted stories were returned to the participants to check that this was an accurate portrayal of what they had told. The decision to return a first draft of crafted stories rather than a verbatim transcript was taken as it seemed this was a way of showing participants ‘their’ stories. I had already made the decision not to return the analysis to the participants for confirmation, as Smythe (2003) argues this always is the researcher’s interpretation of the participant’s interpretation or

telling of the story. By returning the first draft of the story however, participants were able to view their narrative as a whole, with the intent or 'wholeness' of the story apparent. This first draft was very close to the verbatim transcript, but with some minor changes to the sequence and structure to aid coherence. I loosely identified stories in the narratives and labelled these with a name that best described what was happening. The crafted stories were sent back to participants. At this time participants were able to remove any detail or part of the transcript / story they did not want used. Only one of the participants requested a change to the details of a story.

Caelli (2001) discusses that the crafting of narrative or stories is not well described for the novice researcher. Her experience of returning verbatim transcripts to participants suggests that participants did not connect with this version of the conversation and felt unconnected with the research process. Caelli found that when she returned the 'stories' to the participants they viewed the process differently and viewed their experience through the researchers crafting of the story. This enabled the participants to become engaged with the 'story' and this seemed to validate the experience in the story for them.

Working with the data

The first level of reflection and reading of texts was to formulate narratives into stories and as Diekelmann (1991) describes 'getting the story right'. The first draft of the crafted stories was almost verbatim from the participant's words. Some sections were organized in a more coherent and chronological manner, where the participant may have wandered away from the story, and then later come back to the particular story. Grammar was changed in some instances to aid to the flow of the story. Participants' pauses were indicated by '...' to reflect the hesitations and silences. This became important as the emotion of the story at times became lost in the reductionist nature of the written word.

Some stories were deleted at this point as not being relevant to the phenomena. This process of letting go some of the stories was at times difficult, as I was unsure if I might be letting go of something I may not have recognized as relevant to the question of dilemma.

Having crafted these large stories from the transcript I then began to explore the notion of dilemma inherent in the dialogue. I tried different ways of questioning the data. In some sections I questioned each sentence and paragraph in relation to the question of dilemma and would write in response. In other sections I wrote in response to the whole story. Responding to paragraphs in the participants stories led to more individual stories, or stories within the story. Writing in response to the whole story the participant had told tended to elicit a more overarching view of the whole, but with less detail.

This type of analysis is close to van Manen's (1990) description of identifying themes in the data. Van Manen suggests the following approach:

1. The holistic reading approach – a sententious phrase which captures the meaning of the text as a whole.
2. The selective reading in which certain phrases seem to reveal the phenomenon.
3. The detailed reading of each sentence or paragraph to reveal meaning of the phenomenon (1990, p. 93).

I tried to keep the question of 'what is the meaning of dilemma here' in the foreground which led to questioning, re-questioning and new lines of inquiry. Questions I asked of the data included: What does this say about dilemma? What phrases and language reveals its ontological nature? What is the mood that is being uncovered? What is the individual meaning and the whole? What does dilemma say about 'being'? During this time reading the writings of Heidegger, Arendt, and Levinas drew my attention to further lines of inquiry. This reflection, reading and writing helped in weaving the notion of dilemma with questioning the data and questioning these philosophical works.

Once this first level of analysis was done, themes began to emerge. These themes emerged as a result of certain phrases that participants had used, but also in the intent of the stories. The trap here was to focus on the content of the story, for example 'of when a child dies'. Gadamer (1989) says that to understand we need to question what lies beyond what is being said. Going back to my question and response to the stories helped to move this interpretation from the 'what are' (the dilemmas) to 'what is' the notion of dilemma. The second layer of analysis involved 'gathering' the themes and

beginning to explore this in more depth. I wrote an overview of the themes at this point to bring some framework to my writing, aware that this would change. The themes were explored in more depth such as the dilemma of caring when having to do ‘uncaring’ procedures. Again this involved writing questions and responses to the data, always keeping the notion of dilemma in front of my thinking. At times it felt I had more questions than I knew what to do with!

As I moved away from specific examples, themes were interpreted in light of the original phenomenological question. van Manen (1984) describes this as a reflective grasping of what gives the experiences their significance. I kept questioning what was essential to the phenomenon here? Would the phenomenon be the same without this? Do these understandings reveal what was concealed before? Have these understandings increased thoughtfulness? Gadamer describes this process as part of the hermeneutic circle, where there is a dialectical movement between the parts and the whole. For Gadamer the whole needs to be understood in terms of its parts and the parts in terms of the whole. Smythe (1998) describes the hermeneutic circle as interplay...a restless toing and froing to gain deeper understanding of the phenomenon. When a deeper understanding was gained there was a sense of already having known. For Heidegger (2005) this is the process of undertaking phenomenology, as understanding does not become different, rather it becomes itself.

In interpreting the data I was aware that interpretation belonged to three different groups. Firstly the interpretation belonged to the participant in the telling of the story. Questions I asked myself were ‘how did their telling of the story disclose dilemma’? ‘Why was this story a dilemma for them’? Secondly, as a method of inquiry the interpretation of the stories belonged to the researcher. Questions I asked myself were: ‘How do I show that the interpretation is mine and have I shown how I have come to this’? ‘Have I been true to the experiences of the participants’? ‘How has my own historical consciousness influenced this interpretation’? Thirdly, interpretation belongs to the reader. Questions I think about are: ‘How does my interpretation resonate with the reader’? ‘Does the reader recognize their experiences in that of the participants’? ‘Is there a sense of coherence and plausibility’? ‘How does the readers’ horizon of disclosure meet with that of the researchers’ interpretation of the participants’ stories’? Gadamer (1989) tells us that “all understanding is always more

than a mere recreation of someone else's meaning" (p.338). Each of us brings our own understandings to the interpretation of dilemma. The researcher cannot show the reader some 'truth' about dilemma, rather they can only attune the reader to an understanding of dilemma. Gadamer (1989) describes this as always bringing other people's understanding back to our own. For Gadamer (1989) this means that the "discovery of true meaning is never finished, it is an infinite process" (p. 265).

Phenomenological writing

For van Manen (1990) writing is the creative attempt to somehow capture the phenomenon of life through linguistic description. Gadamer (1989), Heidegger (1962) and van Manen (1990) describe the role of hermeneutic phenomenology as essentially a linguistic project, whereby some aspect of lived experience is brought into understanding. Although writing is a creative attempt it was also at times one that presented challenges. Trying to gather 'themes' together with stories from the data allowed for further reflection, but trying to 'fix' this on paper seemed reductionist. Van Manen (1990) captures this tension well as he describes how writing may distance us, de-contextualize thought and abstract us from our experience of the world. Paradoxically Van Manen (1990) says writing may also offer a way to draw us closer, return thought to praxis and concretize our understanding of the world.

One of the ways suggested by authors to bring understanding closer to the reader is the use of anecdotes. Van Manen (1990) suggests that powerful anecdotes and thick description allow us to see deeper and more 'transparently' into the lived experience. Anecdotes helped to show the themes, and ensure these were grounded in the data. Benner (1994) suggests the researcher find exemplars and paradigm cases that will show the everyday meanings embodied in everyday practices. She cautions the researcher that these need to be shown in a way that does not destroy, distort, decontextualised or trivialise their originary meaning. The tension in writing is to remain true to the stories and provide an evocative account, without sentimentalising it, and writing into the account what is not there.

This brought up a further issue of 'voice'. Van Manen (1990) suggests that the researcher should provide an account that 'draws' the reader in, so that they can see more deeply the meanings of the lived experience under study. The use of 'we' is

more inclusive, suggesting shared meanings and dialogue between the writer and reader. The tension with using 'we' however is assuming that the reader may already share these views or interpretations. Using the term 'one' suggests that the writer does not assume to understand the reader's viewpoint or position, however this also distances the reader from being included in a shared dialogue. This tension was not easily resolved so that in places I used 'we' and in other's the term 'one'.

At a point when it came time to write the data chapters I tried to weave the stories of health professionals and families together, as Dickinson (2004) and Smythe (1998) had done. I realised however the context in which dilemma arose for families was often so different that I felt as if I was forcing something to 'fit'. A decision was made to write the families experiences of dilemma as a separate chapter, one which would alert and inform health professionals to the realities and experiences faced by families. This changed the flavour of the thesis where the predominant voice now belonged to that of the health professional.

Are my interpretations warranted?

During the course of this study I have the opportunity to present 'parts' of the findings to colleagues at both national and international conferences; at professional forums within clinical settings; academic forums at the university and teaching across the faculty. Many times I was aware of the phenomenological nod – a silence across the room and a nodding in agreement. These were the times I knew that I had captured the mood of the findings. Following conferences or presentations people would often come up and want to tell me their story of similar experiences.

Whilst working with students in clinical areas I became aware of hearing similar stories to those the participants had told. This was affirming that the narratives shared through the research process were also those told in other settings. At times it was a particular narrative that resonated with a particular group. Early in the study whilst collecting data from paediatric nurses I became aware of the reoccurring 'death of a child' narrative. When I shared this with colleagues in the tearoom many of them spontaneously shared their stories of the first time they nursed a child that died and the emotion and feelings that accompanied this event. Again this reaffirmed that there was something 'warranted' in the interpretations emerging.

A framework for trustworthiness

In undertaking this hermeneutic phenomenological study one of the questions I needed to ask myself was whether what I was doing was trustworthy. There has been much debate in the literature on how the trustworthiness of a qualitative study should be judged (Cohen & Omery, 1994; Crotty, 1996; Darbyshire, Diekelmann & Diekelmann, 1999; Emden & Sandelowski; 1998; Emden & Sandelowski; 1999; Paley, 1998; Ray, 1994; Sandelowski, 1986; Sandelowski, 1993) but there is agreement that the framework used should reflect the underpinning methodology and be an expression of that, rather than a generic ‘one fits all’ qualitative criteria of rigor (deWitt & Ploeg, 2006; Koch, 1996; Leonard, 1994; Plager, 1994, van Manen, 1997).

Koch (1996) proposes the following criteria for evaluating a phenomenological study: credibility, dependability, reflexivity and transferability. To this I have added the synthesis of trustworthiness offered by de Witt and Ploeg (2006) and expressions of trustworthiness offered by van Manen (1990).

Credibility

Koch (1996) says that credibility is when the reader or participants recognize the interpretations of the experience that are offered. Van Manen (1997) and de Witt and Ploeg (2006) describe this as ‘lived throughness’ (or concreteness) where the interpretations resonate with the readers understandings of an embedded ‘lived world’. Frank (1995) describes this as recognizing how it affects “one’s own life and to find in that a certain truth of one’s life” (p. 23). For Heidegger (1962) this ‘truthfulness’ brings the researcher, reader and participant closer to seeing things as they are. This seeing is not just a cognitive understanding of the phenomenon but also an embodied understanding. Hillman (1981) portrays this as a ‘gasp’, a ‘breathing in’ as a primary aesthetic response. Others such as van Manen (1990) and de Witt and Ploeg (2006) describe this understanding as a resonance or the ‘phenomenological nod’. In carrying out this study I needed to consider if my findings would prompt familiar feelings and thoughts. Would the findings resonate with the reader? Would the interpretations seem reasonable? Do they adequately capture various aspects of the lived experience of dilemma? Presentations of findings to health professionals during this study (described previously) would suggest there has been resonance with the findings as they emerged and developed.

I was aware that in order to bring the reader closer to the experience of dilemma, by engaging the senses and bringing it more vividly into presence, I needed to use ‘evocation’ (van Manen, 1997). I asked myself whether the language I used was evocative enough to capture the phenomenon without ‘sentimentalizing’ it. How would I ‘intensify’ the language and meaning to evoke further understanding rather than falling back on conceptual definitions? (van Manen, 1997). Had I ensured my interpretations were grounded in the data and shown adequately how the interpretations emerged? De Witt and Ploeg (2006) add a criterion of ‘balanced integration’. Had I shown congruence between the philosophical concepts that underpin this study and the interpretations that emerged?

Finally van Manen’s (1990) writing cautioned me that there is a tension in trying to establish credibility; to ‘capture’ some understanding of the life world whilst being aware it is an attempt “to accomplish the impossible: to construct a full interpretive description of some aspect of the life world, and yet remain aware that lived life is always more complex, than any explication of meaning can reveal...full or final descriptions are unattainable (van Manen, 1990, p. 18). I am aware of certain ‘truthfulness’, ‘resonance’ and ‘lived throughness’ that my interpretations may bring but equally that life is more complex than any one interpretation and that understanding of what it means to be human is always on the way.

Dependability

Koch (1996) describes dependability as the transparency of the theoretical, methodological and analytic choices through this study. Another term used to describe dependability is the audit trail. I was aware I needed to show what I did and why I did it. Previous chapters have described decisions related to methodology and appropriateness to the research question; underpinning methodology; and decisions related to ethics, accessing participants, interviewing, data analysis and phenomenological writing. I have kept a journal throughout this research journey in which field notes, observations, contextual factors, issues that arose, and decisions that were made have been recorded. Keeping a journal not only aided as a record of research processes (and part of the audit trail), but also became a record of insights that emerged and the development of my thinking. Koch (1996) describes this as

'reflexivity'. De Witt and Ploeg (2006) add to dependability the notion of 'openness'. They describe this as a consistent orientation and attunement to the phenomenon that is sustained throughout the research process.

Reflexivity

Davies and Dodd (2002) say that reflexivity is a critical self examination of the researchers own ideas and research experiences that render visible those issues that arose during the research process. Koch (1998) and Leonard (1994) expand on this notion to include the researchers understanding of the connection between historical understandings (including events throughout the research process) and the topic under study and how well the interpretations help to understand the original question. Leonard (1994) argues that interpretations should never just be a descriptive account but be concerned with the 'break down' in human affairs and how this opens up the possibility of understanding. In this report I am aware of showing the interplay of my preunderstandings, my developing understandings and the social and historical context these have arisen within that inform my understandings of what it means to be in dilemma in paediatric practice. I am aware that 'reflexivity' is an integral part of the hermeneutic circle that informs this research process.

Journaling (as described previously) has been one way of maintaining reflexivity as I examined assumptions and judgments I made in relation interpretations of being in dilemma. This enabled me to become aware of times I 'jumped' to conclusion and other times where early insights (that were to become key) had been forgotten. Conversations with my research supervisors were also ways of confirming, challenging and being attentive to multiple perspectives on the phenomenon.

Transferability

Koch (1998) describes transferability as a similarity between contexts. In phenomenological research there is no intent to generalize findings to the wider population. Rather there may be transferability to different contexts if the reader has had similar experiences or even if they have not had the experience they recognize certain aspects that may make them more alert to it (Munhall, 1994). There is no intent in this report to generalize these findings to all paediatric health professionals or families who have a child who experienced health care. However returning to the

earlier criteria of credibility if there is a resonance, or recognition of the interpretations offered of being in dilemma, there is some degree of transferability. In discussing transferability in a phenomenological study it is phenomenon of dilemma that may be transferable, rather than the specific context that gives rise to dilemma.

Actualization

Although not discussed as criteria by Koch (1996) there is an implicit understanding that any understandings that are uncovered are those that will influence the way that we think about ourselves and others. As the aim of phenomenology is to become more fully human (or aware of our humanness); how do the findings inform this? (Munhall, 1994). I tentatively offer the findings of this report as one way of being aware of what it means to be human and to experience dilemma. Thorne (1997) argues that research has a moral obligation to be applied to practice thereby actualizing the findings. I am aware that not only do the interpretations of this study arise from an embedded world, but that the findings must also return to this world. The implications of the findings from this study must return to the world of paediatric practice in order for the research itself to be a 'useful' product (Annells, 1999). De Witt and Ploeg (2006) add to the notion of actualization suggesting that interpretation does not end at the completion of the study, and researchers need to be aware of how their findings may be interpreted in the future. This reinforces the need to show how the findings of this study are historical and socially embedded (chapters two and three) so that any new interpretations will be seen in the light of past, present and future possible understandings.

Conclusion

This chapter has discussed the 'thinking' and 'doing' of this study. Throughout the discussion in this chapter I have endeavoured to show the congruence between the philosophical underpinnings and the steps taken to answer the question of 'what is the meaning of dilemma in paediatric practice'. Although I have offered criteria of trustworthiness at the end of this chapter, notions of trustworthiness are implicit throughout this chapter and the 'thinking and doing' throughout this research report.

Chapters one to five have laid the foundations for the undertaking of this study and chapter's six to nine will explore the phenomenon of dilemma that has been

uncovered in the participant's narratives. Health professionals' perspectives are offered in chapter's six to eight, whilst chapter nine explores the experiences of families.

Chapter six

Dilemma announces itself in the mood of “not feeling at home”

This chapter begins the journey of exploring the interpretations that have arisen from health professionals' narratives. It explores how dilemma is announced and what calls health professionals to become immersed in the thinking of dilemma. I will argue here that dilemma is announced in a mood of 'not feeling at home'.

Drawing on Heidegger, knowledge of dilemmas as 'ethical' or 'moral' suggests something explicit or theoretical and may not contribute to our understanding of 'being-in' dilemma (Inwood, 1997). Rather, Heidegger first turns to moods as a way to understand how one finds oneself (Befindlichkeit) in the world where dilemma may be encountered. Heidegger does not view moods as a mental state; rather to be in a mood is to view the world in a certain way (Inwood, 1997). Moods are seen by Heidegger as beyond our control, so rather than directed at specific entities they are directed at the world (Inwood, 1997). Another word that Heidegger uses is 'stimmung' which means to tune a musical instrument. To be in a mood is to be tuned or attuned to a world in which dilemma is encountered.

For health professionals and families mood is an important way in which we are engaged and aware of those around us. Heidegger tells us we are never “without mood”. He says “Dasein is always brought before itself, and has always found itself, not in the sense of across itself by perceiving itself, but in the sense of finding itself in the mood that it has” (Heidegger, 1962, p. 174). What Heidegger suggests here is that we do not take a reflexive or cognitive stand toward ourselves or the world. We understand the world because we are 'in-the-world' in our everyday concern. Mood discloses the 'how' of how we find ourselves in the world.

For health professionals and families, dilemma is announced in a mood of ‘not feeling¹² at home’. When we feel at home somewhere, it is associated with a sense of familiarity; a known and trusted part of our world. Being at home may be a particular place, but it also signals things that we feel most comfortable with. There is a sense of effortlessness with feeling at home. Home is not just a physical abode, but also refers to ‘dwelling’, which Heidegger uses as another way to signal ‘Being’. Therefore feeling at home is the ‘dwelling’ or ‘Being’ of familiarity and ease in the world.

Feeling ‘not at home’ is feeling uncertain, or feeling uneasy as the world seems different or ‘not right’. When we feel ‘not at home’ the world appears as no longer known or trusted; doubt is introduced. Feeling ‘not at home’ is for the world to appear not as familiar as how it previously did. When a mood of ‘not feeling at home’ overtakes health professionals the world in which they encounter others is put into question. Harman (2007) says it is this “strangeness that makes us more alert to the everydayness” (p. 35).

Feeling ‘not at home’

For Brooke it is the strangeness of not feeling at home that announces the experience of dilemma.

On my second day on the ward I worked with a girl who was dying. And she was the first child that I’d ever come across who was dying. She had asked her mother to tell her when she was going to die and her mother had chosen not to tell her. For me that was a dilemma. Trying to be honest with the child, yet it wasn’t my role to say anything. I guess I was quite anxious as to whether this child would say anything to me or not [Brooke: play specialist].

¹² Mood is not a feeling or inner state, it is how we find our selves or ‘Befindlichkeit’ and discloses how the world matters. Moods are “the ‘presupposition’ for, and ‘medium of, thinking and acting” (FCM, 68). We have feelings but we are in moods (Hatab, 2002). I have used the word ‘feeling’ to describe how participants find themselves in a particular mood. To ‘feel’ is the verb that in English embodies us in the mood. We ‘feel’ not-at-home but this is not directed at something, rather it is something that overtakes us, which we are claimed by.

Brooke experiences dilemma as uncertainty. She is caught between wanting to be honest, and not feeling that she can. For Brooke part of her everyday practice is being honest with children. Yet here she is, unable to say anything, constrained by the wishes of the mother and yet knowing this young girl wants to know. Dilemma is experienced as anxiety, as Brooke is uncertain if this child will say something that will force her to either to be truthful and therefore step beyond her role, or to say nothing and feel that she hasn't been honest. There is a chance that this child may not say anything to Brooke, therefore letting her 'off the hook' so that she will not have to either be dishonest with the child, or go against her mother's wishes. However Brooke still experiences dilemma in the moment, worrying about what might happen and anxiety over what the right thing to do is. Dilemma is experienced in the anticipation, the anxious moments of what is yet to come, not being certain which way this situation might play out.

In contrast to Brooke, Anne says she knows what the right thing to do is. For Anne dilemma is experienced as the uncertainty and anxiety over consequences that doing the right thing will have on a family.

There was this young child who was in the hallway and he was kicking and screaming and carrying on. I walked out to intervene and as I did I noticed marks on his legs and I thought "I'm dammed sure those are cigarette burns!" And it was a family already in crisis - real heavy and I knew that. And for just a brief moment I thought it would be just easier all round if I didn't start another racket out here. Then I thought "no this is wrong, this is a child. I'm an adult, whatever the consequences first of all I have to see this child is safe" [Anne: play specialist].

Dilemma is announced here in a moment of certainty "I'm dammed sure those are cigarette burns" and the uncertainty of 'what will happen if I act on this?' For Anne there is a brief moment where she wavers, thinking about what will happen if she acts. Dilemma is experienced in the moment of worry and question of 'what will happen?' Anne knows this family is already in a very distressed situation and her disclosure will add to the 'heavy' situation they are in.

Here dilemma is announced in the certainty that to act or not to act will have consequences for the family and for the child. If Anne doesn't act, this child may be at risk for further abuse. Anne believes the right decision is to ensure the safety of the child, however she also worries that this family is already under stress. Could this abuse be a result of a family under stress, and coping mechanisms stretched to the limit? How will her actions impact on this family's already stretched resources? Anne worries about how this family will manage if she goes ahead and discloses this abuse to other health professionals.

Dilemma is experienced as knowing the right thing to do is not always an easy thing to do. Anne knows cognitively that this is the right thing to do, but this does not stop her from experiencing anxiety or worry or 'not feeling at home' with this course of action. For Anne and Brooke, dilemma is revealed in the tension and uncertainty of what to do and the anticipation and not knowing what may happen as a result. Dilemma is revealed in the dissonance between 'knowing' and 'having to do'. Dilemma is disclosed in the anticipation of how one should act and consequences of acting.

In the next narrative Karen has acted, made a choice toward a certain course of action, but even after the event Karen cannot be sure it was the right thing to do.

I was a brand new 'useless' paediatric staff nurse and we had this child die in the middle of the night. This child was about two, developmentally delayed and didn't have a lot of visitors. And I had to ring in the middle of the night to the next of kin to say this little child had died. And there had been nobody there with the child when he died. And it's really hideous when you think about that.

And so I lied. I told the parents he had got really sick and they needed to come to the hospital straight away. Because I couldn't say, "your little child has died". I didn't know how to. I thought about if I got a phone call in the middle of the night. I still don't know if it was the right thing to do. And of course when they got there I said, "Well he's just gone and I was with him". Which was a lie! I worry about that, but I think I probably did the right thing because I'd like to think that nobody dies alone [Karen: nurse].

Karen believes so strongly that children should not die alone that when she has to ring the parents she lies and does not tell them their son has already died. For Karen to think about a child dying alone; to think about being a parent who gets that phone call in the middle of the night would just be 'hideous'. 'Hideous' discloses a world that takes on a mood of not at home. Hideous is the opposite of a world 'at home' in which children would not die, where children would not be left 'alone' and where parents would not get phone calls in the middle of the night that would change their lives forever.

Karen tells us she was a 'brand new staff nurse'. For Karen dilemma is experienced in feeling unprepared, uncertain and the enormity of having to say, "Your little child has died" and not knowing how to. Here a mood of feeling 'not at home' has so overtaken Karen that she is left without words that would enable her to tell the parents what has really happened. For Karen feeling 'not at home' is to feel vulnerable and exposed, not feeling prepared to deal with a situation that feels so unfamiliar and unknown.

For those of us standing outside this situation, dilemma is revealed in not knowing whether prior experience or education could have made a difference to Karen. Could this have given Karen the words that she needed? Or would Karen's strong beliefs that children should not die alone mean that she would still want to create this illusion for the parents?

For Karen this illusion is based on how she would feel, as she has no way of knowing how these parents would want to remember their child's death. Dilemma is experienced here as being unsure, in the dark as to how important this may be to the parents. Even when Karen has created this illusion that their child was not alone, she has no way of perceiving if this was a comfort to the parents and she worries about having told a lie. Karen must live with the tension of 'was it the right thing to do?' Karen has no way of knowing, and the uncertainty of whether this was the right thing to do will stay with her.

For health professionals dilemma is experienced in the uncertainty and tension of knowing ‘what is the right thing to do’, ‘what might the consequences be’, and ‘was it the right thing to do’? The mood of ‘not being at home’, the unfamiliarity that the world now takes on does not abate once one has acted. The tension stays with people, wondering ‘is this’ or ‘was this’ the right thing to do? The mood of ‘not being at home’ discloses dilemma in *how* we find ourselves; in the uncertainty of not knowing, never quite knowing, and an uncertainty that lingers.

In the most part we are ontologically ‘in-the-world’ where our everyday living is familiar, ‘at home’ or as Heidegger describes this ‘ready-to-hand’. It is not until the familiar or the ‘ready-to-hand’ becomes unfamiliar, and uncertainty is introduced, that the world is now experienced as ‘not at home’ or ‘present-at-hand’. When we experience the world in a mood of ‘not at home,’ the everyday nature of the world is taken from a background of understanding and pushed into the foreground. Feeling not at home is to bring the everyday world into thought and raise questions as alternative possibilities are put before us. For Heidegger the break with the everyday means we no longer truly know; knowledge is no longer simply perceiving the given, rather the give-ness of everything has come into question (Polt, 2006).

Feeling not at home is to put the everyday world into question

For Karen uncertainty is introduced when she begins thinking later that there is a possibility that the environment she works in may be ‘harmful’ to children. Karen works in an intensive care unit where the focus of care is often on saving lives. She notices children looking around the unit which she says can only be described as a ‘scene from hell’. At the time, Karen does not think too much about this as she says “you have to use your common sense and keep children alive”. It is not until later, that Karen thinks about her everyday ‘at home’ world, and begins thinking in a way that now discloses it differently.

Children used to come back from intensive care shocked to the core. And I remember one little one who was blind, deaf and couldn't move. We thought he was absolutely stuffed. I remember standing at the end of his bed and saying “it would have been better if he had gone to heaven”. And he wasn't. It was just the extent of the trauma.

He actually walked out of the ward. His mother wrote back a year later and said he was running around like a normal toddler. And I thought about that heaps. How could he recover from being blind and deaf from just absolute fright? [Karen: nurse].

Karen begins to think – how could a child be blind and deaf from fright? Karen's earlier assessment, that this child was 'stuffed', and it would be better if he had gone to heaven, is now also open to reinterpretation. The possibilities that she now considers is that if it was from trauma, what sort of environment does she work in that this could happen? Part of Karen's everyday world is that care is directed toward making a difference to the health outcome of a child, often even saving a life. Yet here is a possibility that a child is traumatized from the very care they have received. For Karen dilemma is disclosed in not being able to reconcile the certainty of the care that she gives, with the possibility that this care may also cause harm.

For most, it is taken for granted that in society children will be nurtured, protected and cared for as part of a family and wider society. The possibility that children are hurt, harmed or injured by another's actions is not one that we like to entertain readily. In the following narrative of child abuse this assumption is challenged as Sharon must think about not only does it happen, but what should she do.

A huge dilemma is when you have got sort of persistent, relatively mild abuse where if you try to do something about it and try to remove the child from that situation, is that actually going to be the best outcome for the child? So is a bad parent better than no parent? That's what the question basically boils down to. Is this parent who is continually shouting, smacking and abusing in a way that is inappropriate, and the only way to stop that is to remove the child; then are you actually going to help the child by removing them from the situation? When you've got the real severe abuser then it's clear that you have to remove the child for a certain period of time. But the smacking, beating and verbal abuse? Is some parent better than no parent? [Sharon: paediatrician].

We live in a world where child abuse is considered such an unthinkable act, that legislation exists to prohibit any actions of abuse, and to protect children against the actions of others. The thought of child abuse is so untenable that it appears there is

only one course of action. But for Sharon, the possibility is raised in her thinking, that perhaps the view that children should not be harmed, and the legal position that children will not be harmed, does not address the complexity of the situation. Dilemma is revealed in the tension of the question “is some parent better than no parent”?

In this world there is a possibility that children love their parents and separation from them may lead to isolation, and the child feeling a victim all over again. There is a possibility that parents may love their child but do not have the coping strategies of parenting skills that society assumes each parent is competent in. There is a possibility that rules and legislation do not always address the individual needs of the child. There is also a possibility that these rules and legislation do have the function and role of protecting the child. Not to follow them could put a child at greater risk.

In light of these possibilities Sharon must decide “how much harm is okay”? How can she know what is severe and what may be tolerable? How can she know the consequences of acting or not acting for the child? For Sharon dilemma is revealed in the thinking of possibilities that would not even be considered in a world that is certain, safe and where children would never be abused.

Arendt (1978) says that “thinking is always out of order, interrupts all ordinary activities and is interrupted by them” (p. 187). Dilemma is revealed here in the sort of thinking that brings the ready-to-hand into present-at-hand. It is the sort of thinking that sees beyond assumptions, what is taken for granted and what seems certain. This is the thinking that opens up possibilities that are unwanted and unpalatable. There are no easy answers. The dilemma for health professionals is that this sort of thinking is so uncomfortable, and so uncertain that often they long for the sort of thinking that feels at home.

The type of thinking that feels at home is that of certainty, answers and in its ‘ready-to-hand’ state is embedded in practice. In order to promote health, to ‘fix something’ health professionals must follow a path of assessment and diagnosis, which based on facts, allows them to predict outcomes and plan interventions. This type of thinking contributes to the world being experienced as ‘at home’. There is certainty in facts,

being able to predict and to come to some sort of conclusion. Andrea describes how she feels at home with this type of thinking, and when she must think differently misses the certainty that it offers.

Sometimes I felt I couldn't do enough. So different from the whole medical side where you can give drugs and such or ask them to come in for an inpatient stay and we'll sort this out. The whole field of what I was doing wasn't like that. It was much greyer. A lot of it is subjective and wishy-washy. It's funny because that is probably why I turned back to more muscoskeletal¹³. I felt it was more black and white. There were things we could diagnose and there would an outcome [Andrea: physiotherapist].

Andrea sees thinking that offers certainty, which is able to predict and offer good outcomes, as 'black and white'. Heidegger (1968) describes this as calculative thinking, the sort of thinking we use whenever we plan, research or organize something. Calculative thinking is measured in outcomes, so that when Andrea works in an area that she describes as 'wishy-washy', she experiences dilemma as not being able to be certain; how can she know she has done enough? In black and white thinking Andrea knows when she has done enough, she can measure it. But when something is gray how can she know? How does she know when she has done enough, or not enough, or too much? Andrea doesn't feel at home in this world, and her decision to return to the specialty of 'muscoskeletal' is linked to her desire for more certainty. Peter, a paediatrician, also alludes to the certainty that calculative thinking offers. When thinking falls outside of this, Peter suggests it raises questions that are an antithesis to Doctors 'curey' way of thinking and doing.

Without a doubt the biggest difficulty, that is such a big contradiction to what it seems to be, is what we think we are supposed to do, that is cure people or something like that. That sounds very much like the core nature of what nurses and doctors do. We are 'curey' people and we like to interfere in other peoples lives and make them better. So when that process doesn't work its adding insult to pain. So that is a bit of

¹³ 'Muscoskeletal' refers to the area of physiotherapy which focuses on muscle and the skeletal system of the body.

a dilemma...if you're a 'thinky' sort of person, which by and large doctors are!
[Peter: paediatrician].

For Peter there is certainty in being able to 'cure'. In fact it is the 'core nature' of what doctors and nurses do. That Peter links this to health professionals' nature, suggests this is a way of thinking and doing which has become so embedded, it is now 'second nature' to them. But when things don't go to plan, when the process of calculative thinking and curing is not enough, it introduces uncertainty, and dilemma as the world is put to question. The uncertainty that this thinking engenders lingers. The mood of not feeling at home opens up the world for questioning that moves between the past, present and future.

This movement points to the temporal nature of dilemma. Dilemma announced in a mood of 'not at home' is not always disclosed in the moment. Dilemma may be experienced in the moment with 'insight', but also as looking back with 'hindsight', or looking toward the future with 'foresight'.

Feeling not at home is disclosed in time

Insight

Heidegger (1962) suggests that seeing the world in the moment, as a sudden insight or revelation, may be described as an 'augenblick'. An 'augenblick' is a moment in time, when the eye perceives what is happening around it. Jane narrates how dilemma is experienced in a 'flash', an augenblick, whilst doing chest compressions on a young boy.

The auntie and the mother started to beat him and wail. It was an experience that I hadn't been part of before. For a western person it was so out of control! They were beating his body and thrashing him and wailing in really high pitched very loud excruciating sound. And I was doing CPR. He was so toxic I was slipping off his chest; I couldn't get a grip on him. He had a temp of 40 + and he really wasn't a well boy. The person who was leading the resuscitation who was in fact the

anaesthetist said to the family to get out. That was it, “get out!” And I thought this could be the last time this family sees their child alive [Jane: nurse].

There is no time to ponder as Jane is caught up in a situation where every effort is being made to ‘save’ this young boy. This situation seems chaotic as Jane tries to get a ‘grip’ on this young man’s slippery chest amidst the wailing and thrashing of limbs by the family. Then in the midst of the life saving measures, the noise and chaos, time stands still for a moment and in an ‘augenblick’ or insight Jane realizes that this family may not see their son again. It is in this ‘augenblick’ that the world is revealed as no longer at home. Although all efforts need to be focused on saving this young boy, should he not survive then his family may not have had the opportunity to say goodbye and be with him.

Heidegger (1962) suggests we experience these ‘augenblick’ or moments of vision, as an authentic presence, where we see beyond the semblance of the present situation to understand how we have arrived there. For Jane, she sees the urgency in her colleagues to resuscitate this young man but also for the family, their grief and the real threat of loss of a child. Jane sees that the consequence of an unsuccessful resuscitation for the family would mean being deprived of the last moments with their son. She also sees her colleagues desperately resuscitating this young man so that he may have future moments with his family. Heidegger would suggest this is an authentic present, as Jane understands in an instant a different view of time and the consequences of actions. Here dilemma is revealed in the tension and urgency to save a life, or to spend the ‘last’ time with a son.

Foresight

Time is not just experienced in the moment. For health professionals time is also something to worry about. As we cannot predict what the future may hold, or the consequences of our actions, the future is the unknown. In the following narrative Peter worries about the consequences of his actions into the future. His concern is that ‘knowing’ the facts doesn’t help to ‘know’ what the consequences might be for the future. Feeling not at home is disclosed in uncertainty of the future. For health professionals there is often no way to anticipate the known or unknown consequences of their actions.

So it's difficult doing things consciously that you know are going to create havoc for the family. And of course assuming what you are going to do is going to have some benefit. You're going to take a child away from his family and how much of that is going to be beneficial? They might get the odd broken leg in that family but to be taken away from that family and shoved out into the community for attachment after attachment to be broken, broken, broken! And they end up psychopaths, which I know is the extreme. So you can say 'well maybe they are better off being able to form an attachment and to deal with the occasional broken leg'. I don't know [Peter: paediatrician].

Here Peter grapples with the question 'is some abuse better than no family?' He must weigh up two terrible consequences - physical harm and emotional harm. Peter knows he has to act yet the consequences of either decision holds grave implications for the future of this child. Here the future is disclosed as unknown and something to be viewed with anxiety. Health professionals often have a body of knowledge and experience that contributes to them being able to predicate outcomes, yet it is this very knowing that also contributes to experiencing dilemma. For Peter knowing what the consequences of his actions might be does not help to decide what action to choose.

Hindsight

Dilemma may be revealed in the moment, in an augenblick, or in the unknown future that lies before us. Our past however, is assumed to be already known. But at times it is the reinterpretation of the past that dilemma is revealed in. For health professionals and families this is a dilemma. How can they know everything they need in that moment of time? At times they don't have the knowledge that they may gain later. What happens when their understanding of a situation happens with hindsight?

Situations that have happened in the past, and not experienced as a dilemma at the time, are now with hindsight reinterpreted as dilemma. Karen relates how with growing knowledge she suddenly realizes what she always held to be the best practice is no longer true:

When you are giving a baby an antibiotic we just used to put them through a leur. I used to find it was much easier to do it when they were breast-feeding, or drinking. So you'd shoot it through and they would cry in pain because it would hurt. "I thought well this is good because comfort is close to hand". Then I learnt in my studies and realized that they would come to associate feeding and perhaps the smell of breast with this huge jolt of pain. It kind of hit me then it was a terribly wrong thing to do [Karen: nurse].

Here the past rushes to meet Karen as she realizes that what she thought was right, was a “*terribly wrong thing to do*”. Hindsight affects her perception of previous practices and experiences of giving antibiotics to babies whilst they are breast-feeding. The dilemma for Karen is that she cannot undo the past, but now must live with what she now sees as a ‘wrong’ way to practice. Even though at the time, Karen didn’t have this knowledge and acted with the best intentions, she now experiences dilemma in that her actions may have been harmful to a breast feeding infant.

Heidegger (1962) says our past always comes to meet us in the present and affects our future. Here the past collides with the present, as now Karen experiences dilemma about past actions. Karen has no way of changing what has happened, so the feelings of ‘wrongness’ and new knowledge she has around giving IV medication whilst infants are breast feeding follows her into the future.

Both families and health professionals are put in situations where they act with the best possible intentions at the time. It is later reflection or hindsight that they reinterpret these situations with a sense of loss for how they could have acted differently. Jane says this later knowledge and hindsight gives a new perspective but therefore she also experiences dilemma in worrying of what she may have missed.

And the thing is I still wonder now is how many other things have I missed or how many other people have been devastated by the lack of awareness. Things that I haven't known about, that I completely missed [Jane: nurse].

For Jane there is no way of knowing if her lack of knowledge or awareness of a situation will go on to affect the future. Here for Jane it is not only the unknown

future she worries about, but also the unknown present. Jane describes this as ‘missed moments’.

But I wonder how many moments have been lost without being aware? The thing about nursing is you never know what is going on behind those faces, what has gone on, days before, and weeks before and years before, and that’s what people bring in with them, their history. And where they currently are [Jane: nurse].

Jane experiences dilemma in that one can never know what past events families have brought with them into this situation, so that the past, present and future are intertwined. This not knowing, contributes to her sense of ‘lost moments’. These lost moments impact on health professionals, children and families possibilities and future interactions not only in the future, but also how they remember the past. The experience of dilemma reaches across known and unknown time.

Rather than dilemmas occurring ‘in’ time, the experience of dilemma is announced ‘through time’ in the mood of ‘not feeling at home’. Heidegger (1962) suggests that when we try to measure something in a traditional concept of time then only the ‘present moment exists now, the past no longer exists, and the future does not exist yet’. It would be easy to pin point a dilemma in a particular time, ‘this happened then’. But this would not capture the worry and uncertainty of being in dilemma where our past, present and future are affected.

Heidegger (1962) says that Being is not confined to its awareness of the present moment. He sees Being as “ahead-of-itself-Being-already-in -the-world” (Heidegger, 1962, p. 237). Being ‘ahead-of-ourselves’ means we are always thinking ahead, and wondering what to do next. ‘Being-already-in-the-world’ signals that we are always in a specific situation that determines the possibilities available to us. It is the mood or state of mind that reveals how we find ourselves and how our past will be constructed. For participants the mood that reveals how they find themselves in dilemma is that of not feeling at home, and is not restricted to the present, but flows into the past and future.

Any experience then is understood as temporal.

Heidegger (1962) describes this as an ecstatic unity of time, which means 'standing out'. In this 'standing out', any moment is a crossing point for the past and future, therefore the present bears with it the past and future. For health professionals the experience of dilemma as feeling not at home is experienced in the crossing of the past, present and future.

Conclusion

It is the mood of 'feeling not at home' that announces dilemma to health professionals. There is uncanniness, strangeness and uncertainty where what was taken for granted and ready-to-hand is now open for question. The questions that arise are not comfortable; there is no black or white answers rather there is a discomfort and tension of what to do. Feeling not at home reveals that dilemma is not just confined to the present, but is temporal as health professionals look with insight at their present circumstances, with uncertainty and trepidation to the future and see the past in a new light. Health professionals' experience of not feeling at home reveals the world as present-at-hand and shows the tangible and embedded world they are thrown into.

Feeling not at home is one of the moods in which the experience of dilemma is revealed. In the next chapter, the health professionals narratives reveal that world experienced as not at home also uncovers how they feel 'caught' and 'thrown' by being in a world of paediatric practice. Not only do health professionals become aware of their own mode of being in this practice world, but also the meaning of being in this world of paediatric practice with others is disclosed.

Chapter seven

Dilemma experienced as thrown into a world of practice and feeling caught

“Attunement itself constantly delivers man over to the beings in the midst of which he finds himself. In his thrownness, man falls captive to his “world”; he is enthralled and bemused by the things that are; he is pressed in upon and hemmed in by them” (King, 1964, p. 81).

The mood of feeling not at home revealed in the previous chapter has showed not only how dilemma brings the world into question, but also how it uncovers the concrete and embedded world of paediatrics that health professionals inhabit. This chapter explores how health professionals’ experience of dilemma takes place in a paediatric practice world with others and how dilemma is experienced as feeling ‘caught’ and ‘thrown’.

Heidegger (1962) tells us that any experience (such as dilemma) cannot be understood from the view point of a neutral observer, as we are always and already embedded, involved and caught up in a world that is meaningful to us. For Heidegger (1962) ‘one is what one does’, so that health professionals’ experience of dilemma arises because they are *in* a world of paediatric practice.

Dasein as ‘Being-there’ means that health professionals’ always find themselves in a particular somewhere, and are always dealing with, concerned with or interested in something (Heidegger, 1962). Heidegger describes ‘Being-there’ as not just the ‘here and now’ of how and where we find ourselves but also futural as we are always thinking ahead to the possibilities before us. For Heidegger possibilities are not endless ones, as there is always the interplay of choosing those possibilities before us and being constrained by those circumstances we cannot change (facticity) (Heidegger, 1962). Heidegger describes this as ‘thrownness’, as a way we are delivered over to the world or circumstances beyond our control. Being-in-the-world therefore means finding ourselves ‘there’ in-the-world in a particular way.

For health professionals being-there is often a tension between what they would like to do (possibilities) and what they have to do (actualities) contributing to the concrete and embedded world of paediatric practice they find themselves in (facticity). For health professionals, dilemma is experienced in a mood of feeling ‘caught’ or ‘hemmed in and pressed upon’ by being thrown into this world.

Being in a world of paediatric practice is always to be ‘caught up’ in something. In an everyday world that is ‘ready-to-hand’, being caught up is to be absorbed in what is required, not having to think too deeply about each action or consequence of the ‘there’ we find ourselves in. Heidegger refers to this as ‘circumspection’. Rather than *feeling caught*, one is absorbed or *caught up* in the everyday business of life. Arendt (1978) suggests that this is a normal state of affairs as “the very urgency of human affairs demands provisional judgments and the reliance on custom and habit” (p. 71).

However, when a mood of feeling caught takes over, it discloses the world as present-at-hand and a ‘there’ that is uncomfortable. When health professionals feel caught it is experienced as a constrained mode of being, a feeling of dissonance and discomfort. Feeling caught is to feel hemmed in by circumstances beyond their control, where possibilities may be in view but not within grasp. For health professionals feeling caught highlights the dilemma between what is possible and what is actual (facticity) and the ‘how’ of the practice world they work in.

Dilemma experienced as the mood of feeling caught reveals not only a ‘world of’ paediatric practice and a ‘self world’, but also a ‘with world’ of being with others. The world of paediatric practice is always *with* children and their families and it is their suffering that calls health professionals from a world that is ready-to-hand, to one where health professionals feel responsible for another. Feeling caught is to feel hemmed in by circumstances and the call of another.

Feeling ‘caught’ – the dissonance between ‘wanting to’ and ‘having to’

To be ‘thrown’ into the world is to not have any choice about the state we find ourselves in. For Heidegger there is no escaping our current situation “no matter how

glorious or miserable it may be; our current life is already there before us, as the hand we are forced to play. The most we can do is try to work with the situation as we find it” (Harman, 2007, p. 28). In the following narrative Rosemary shares how being thrown reveals ‘the hand she is forced to play’ and how she feels ‘caught’ by the situation she finds herself in.

You’ve got this little three year old that you’re putting IV lines into and he’s crying “don’t, don’t, don’t”. And it’s hard because you actually don’t want to be there. I would just feel like weeping. And all I could do was pat his little hand and say “you’re doing really well” and try to distract him, help him blow bubbles or whatever [Rosemary: nurse].

Although part of Rosemary’s everyday practice world is inserting IV’s into children she is not oblivious to this three year olds’ pain and his entreaties of “don’t, don’t, don’t”. This little boy’s cries wrench at Rosemary so that she feels caught up in seeing his distress and not being able to ignore it. As a consequence she feels like weeping with him. Dilemma is experienced here as feeling caught between a child’s distress and having been party to causing it. For Rosemary being thrown and having to work with the situation means *having* to carry on and do her job *despite* feeling she would rather be somewhere else. Dilemma is experienced here as feeling ‘hemmed in’ by not being able to turn away from the child or the task.

For Rosemary being thrown is not only into a particular circumstance (there), but dilemma is experienced as feeling ‘thrown’. Here to feel thrown is to feel unnerved, troubled and thrown off centre. The possibilities that face Rosemary are not those she would have chosen or wished for. Feeling hemmed in and pressed upon is experienced as a question of ‘who would willingly want to be here, in this time and place, inflicting pain on a child whilst listening to their entreaties to stop?’ For Karen feeling caught is to feel ‘trapped’ by the way that she sees herself and the child as a consequence of what she does:

Children would have a look of sheer terror. You’d be leaning over them, really holding them because they would be struggling. They’d be sweaty and they would give up because they are only little. I hated it. It’s like hitting a child, because a big

person is able to hit a child. You're sort of saying, "Well I'm bigger than you are". It's awful, it's the trapped rabbit feeling [Karen: nurse].

Karen is thrown into circumstances where she must insert a naso-gastric tube into a child; however she feels thrown because this feels like an act of violence. Karen sees the child as someone 'vulnerable' struggling and sweaty and herself as someone who is able to overpower a child because she is bigger and more powerful. Dilemma is evoked here by the images of what health professionals are thought to be (caring) and the images that Karen holds of herself as a consequence of having to carry out this procedure. Even though it could be argued that what Karen does is legitimized in this context, Karen herself experiences it as having violated and broken a trust with the child and her own sense of being a caring person. Dilemma is revealed in the question of who would willingly carry out actions that makes them feel as an 'oppressor' and see the other as a vulnerable victim of their actions.

For Peter it is not only how he views himself but how others view his professional role that contributes to the feeling of being caught.

I performed a lumbar puncture on a child who was crying. And when the procedure was over the nurse picked up the child and comforted them by saying "what has that cruel doctor done to you". Which in a sense may have sounded quite soothing to the child, but it was extremely difficult for me to handle and also sent messages to the child that didn't feel constructive to me. Because I do have anxieties about being cruel to children! Because it is the nurse's role to comfort the child, I mean I can't. A child is not going to be comforted by me after having just stabbed them in the back! [Peter: paediatrician].

Although part of Peter's everyday safe competent practice (of thirty years) is based on diagnosis and interventions that may cause discomfort, Peter still experiences anxiety, disquiet, and worrying about the distress this may cause the child. Here dilemma is revealed in the roles health professionals may have claimed for themselves where Peter has been cast in the role of 'perpetrator', and the nurse in that of the 'comforter'. The role this nurse has assigned Peter reflects the claims often made that nurse's 'care' and therefore by default doctors 'cure', implying a different engagement with

others. For Peter dilemma is experienced as the dissonance between caring deeply about the pain and distress he caused this child (and other children), the accusations of being 'cruel', but having to carry out this care as part of his everyday occupation. Dilemma here is revealed in that the stereotypes of what health professionals 'do' may not reflect the 'who' of whom one is. When Heidegger (1962) says that 'one is what one does' he does not mean just our occupations, but rather the care and concerns we have in (and towards) carrying out these roles. For Peter although what he does is prescribed professionally, this does not stop him for caring for the impact of these actions on a child.

Peter not only feels anxious by what he must do but also feels caught by being categorized into a stereotype which bears no relation to how he feels. The experience of feeling caught reveals the difficulty of challenging the public and professional perceptions of what and who he is. Dilemma is revealed in the questions of whether Peter could have picked up the child to comfort him even if he hadn't just caused them pain. As a paediatrician would his profession consider it appropriate to pick up and comfort a child? Would they see this as part of his role? Peter may want to comfort a child, to show the child the other side of him that is caring and not 'cruel' yet he is also hemmed in by expectations of the profession and the likely reaction of the child. Would the child accept his comfort?

For Heidegger, being thrown into being-there are all possible ways to be and our identity is tied into a given set of features such as occupations and interests. He says that for us to truly become ourselves we need to let go of the semblance of self that is distanced through a given set of properties (such as caring, nurse, doctor etc) and the semblance of a self that believes in the pretence of absolute autonomy and independence (Polt, 2006). He argues that it is only when our self becomes an issue for us that we truly become ourselves. "Being-there, then, is not *what* we are; it is a condition we must enter in order to wrestle with *who* we are. We can *be* only by asking, 'Who are we?'"(Polt, 2006, p. 172). The experience of dilemma shows here that 'cure' and 'care' are not dichotomous roles where a health professional may be only one or the other. Rather the experience of dilemma reveals 'being-there' is to care and to be anxious about who one is and who one *is able to be* when thrown into a world of paediatric practice. Heidegger (1962) would argue that when health

professionals experience anxiety because who they are becomes an issue for them, they are then moving from an everyday 'at-home' way of being to one that is more authentic. For Heidegger it is anxiety that renders things naked, exposes the taken for granted, and is a mark of authenticity (Steiner, 1991). When health professionals' experience anxiety and 'who' and 'how' they are becomes an issue for them, it exposes the semblance of 'absolute autonomy and independence' for them.

Feeling caught up in circumstances beyond one's control

One way the pretence of absolute autonomy and independence is shown is when statements are made such as, "I would never do that"... "Thou shall not..." or judgments are made about a situation as if it were as clear as black and white, right or wrong. The chaotic and thrown nature of the world itself means that circumstances beyond our control can overtake us and there is tension between what we always proclaimed we would do and the reality before us. In the following narrative Brooke describes being thrown into a situation where events spiral out of control and what she always said she would never do becomes seemingly impossible.

I went into the treatment room and thought I would just be there to comfort and support her. I took some distraction activities in, but she was absolutely terrified and fighting. She wouldn't let anyone touch her and was lashing out. I was standing there thinking, "I don't think distraction techniques are going to work". In the end there were about six people in there, holding her down. And I ended up being one of those people. It was really difficult for me because I was standing right by her head and she was just looking at me and screaming. She was so upset she ended up with a bloody nose. And it was hard for me afterwards because I'd always been adamant that I would never do that sort of thing [Brooke: play specialist].

Here Brooke experiences dilemma as being caught up in events beyond her control and where her role changes from that of 'distracter' and 'comforter' to one whose actions contribute to this young girl's distress. Although Brooke always swore that she would never do this, she must now stand by this young girl, acutely aware of her distress, her screams, and her young eyes accusing Brooke of her complicity. Brooke stands there feeling accused of something she never agreed to, yet also feeling caught

in having to now carry on. Here dilemma shows being thrown is to feel swept along by events regardless of a prior thought or decision.

Being in-a-world of practice is revealed as something that health professionals cannot always stand back from and take a cognitive stand on. Life is not black or white in this practice world, rather it is messy, chaotic and fast moving and health professionals must constantly play the hand that they are given. Dilemma is revealed in the assumptions that we can control the circumstances we find ourselves in and that we can 'step out' of this. Could Brooke have said no and left the room, or did events unfold so quickly that there was no time to think, to make a stand, and voice a decision? For Brooke being-there is to be 'exposed and abandoned' to things that she cannot control (Overgaard, 2004).

Hannah Arendt (1978) says that often the very urgency of human affairs means that we get swept up along in circumstances. The dilemma is that sometimes there is no time to think, or that despite all of our thinking or good intentions we have to carry on with the situation we find ourselves in. Dilemma is revealed in the thinking that life is something tangible that we can step away from prior to any involvements in it. Heidegger claims that freedom and selfhood do not come from acts of will, rather from being open to how one is thrown (which is not of ones own making) (Polt, 2006). This perspective of freedom highlights the fallacy of choice (especially in regard to the experience of dilemma).

Feeling caught reveals the fallacy of choice

The western conception of freedom is often around the idea of choice; however Rosemary, Peter, Karen, and Brooke's narratives reveal the paradox around this notion. Dilemma is not about *the* choice (as so often analyzed in epistemological accounts of dilemma), but about the contested space of being thrown into the circumstances where one *has* to make the choice (not wished for) and where one *has* to act. Even not acting is a form of action and makes a statement of how health professionals find themselves thrown into a world of practice. The experience of dilemma reveals the fallacy of choice in that 'to choose' implicates that there is some free will in the choosing. Having to choose between two unpalatable outcomes is

perhaps not a choice at all, rather is a choice foisted on one. Having *a* choice is different than having *to* choose.

It could be argued that health professionals could choose not to work in the field of paediatrics if they find aspects of it disturbing. But health professionals choose to work in this area for many other compelling reasons, such as a commitment to improving the health outcomes for children and their families. Just because they choose to work in this specialty does not signify that they can readily accept all possibilities within this. No one would choose for a child to die, yet it remains the facticity of practice. Doing procedures to children remains a facticity of practice yet no health professional would willingly inflict pain on a child. If a health professional could choose not to insert an IV on a distressed child who else would be left with this task? Are health professionals' truly free to decide what 'care' or what 'competencies' they will or will not undertake? Are health professionals free to choose who they will or will not care for? Professionally they are obligated to provide a 'service' or 'care' to those requiring it so that any choice is already within this frame of reference. Arendt (1978) says that "Heidegger shows that every action, by actualizing a single possibility, at one stroke kills all the others among which it has to choose. Every commitment entails a number of defaults" (p.184). For health professionals being thrown into a world of paediatric practice is to default to a 'there' where not all possibilities may be realized or all actualities would be wished for.

'Being there' does not just reveal how health professionals are thrown into current choices or predicaments, but also the temporality of past and future choices. Being thrown is not just determined by the past and present possibilities but also futural possibilities.

Feeling caught reveals the hopes and regrets of a possible future

Health professionals' experience of being thrown has so far revealed that they are never thrown into a world of free projecting possibilities. They must always act and make decisions within the constraints of what is possible (facticity). For health professionals part of being thrown into the facticity of paediatric practice is also to be running up against the limits of knowledge, technology and cost. The certainty however of what these limits are (especially in regard to knowledge and technology)

is nebulous, where rapid and ever changing knowledge gains mean what was not possible yesterday may be possible tomorrow. Feeling thrown is not only into present circumstances but also the knowledge of future possibilities. Sharon narrates the following story:

There was a baby who was 24 weeks gestation and I was instructed (I was a junior registrar at the time) by my senior consultant to go to the delivery to make sure that the dates were right. Essentially, if the baby was 24 weeks I was to do nothing. But obviously the dates might have been wrong and the baby might have been 28 weeks, in which case we would have resuscitated the baby. When I went in the dates were completely right, and a twenty four weeker came out. I felt that quite hard trying to explain to the parents who saw this baby come out and gasp! And it was a boy, and Dad was going 'look it's a boy' quite excited, and I'm trying to explain it's a little boy who is only going to live for a few hours and then die. I've often thought at that point in my career how fragile life was that you could be in the right place at the right time and in the wrong place at the wrong time. Because if she'd been somewhere else when she had gone into labour things could have gone differently. And that's one dilemma that sticks really well in my mind. It's made more poignant because I know now for a fact that I wouldn't hesitate but to resuscitate [Sharon: paediatrician].

Sharon is thrown into circumstances where in this time and place there is no intensive care unit, only a special care unit where the technology is not available to look after babies under 28 weeks. Had this birth happened at a different unit the decision may have been very different, and this baby may have lived. Here Sharon feels caught by being in the wrong place at the wrong time. There is no choice about where they are, but the possibility is there as a reminder – if only they had been at another centre this baby may have had a chance. For health professionals and for this family it is not a situation that they willingly enter into. Rather it is a situation that they find themselves in, with no way of escaping. This baby cannot be resuscitated, Sharon must tell the family, and the family must endure the pain and grief of their baby's imminent death.

For Sharon dilemma is experienced because she knows that somewhere help for this baby was possible, so close yet not quite within grasp. Dilemma is revealed in the

question if ‘help’ was absolutely impossible (not even a *thought* of possibility) would this be easier to live with? If Sharon had no knowledge of an alternative would this situation have been easier to bear? Would Sharon have named this as an experience of dilemma? It is often only when things go wrong that we think about circumstances as ‘the right place’ or ‘the wrong time’.

For Heidegger time can be the right or wrong time as it is not just “a string of instants but a gathering of opportunities, juncture and moments, both trivial and momentous” (Polt, 2006, p. 39). In the juncture of present and future opportunities Sharon understands the momentous significance of being thrown so that time feels ‘wrong’. Because Sharon understands that in the future the possibility of saving this neonate would have been likely she also views the past as a bitter reminder of what might have been.

Heidegger (1962) says that Dasein is “constantly more than it factually is” as Dasein understands itself by its projection on its possibilities (p. 185). Here there is no free projection into the possibility of saving the life of this neonate, rather Sharon now understands her projection into possibilities as not always possible and as a consequence sees how she is constrained by facticity. Polt (2006) argues that because all possibilities are shadowed by knowledge these are not endless or always feasible; this gives weight to our choices (Polt, 2006). The choice in not resuscitating this baby is made heavier here by the knowledge that not all possibilities can always be realized. This ‘weight’ reveals the ‘fragility’ of life. Harman (2007) says that life is always a “profound tension between what is given to us and how we confront it...life is a kind of unrest, forever torn between poles of reality” (p. 29). For Sharon dilemma is experienced in the unrest of being torn between what happened and wondering if things could have been different.

Feeling caught reveals being authentic and the call of conscience

For Heidegger existence is a way of being where “one’s own being is implicitly or explicitly a problem” (Polt, 2006, p. 39). There are two possibilities; either to evade its responsibility (in-authenticity) or to own up to this responsibility (authenticity). Heidegger argues that recognizing the finiteness of possibilities (as being towards death) is a mode of being authentic. When health professionals experience dilemma as

feeling disrupted from the everyday world (as feeling anxious, caught and constrained), they become aware of the limits of their own existence and possibilities. Heidegger (1962) argues that when we become disrupted in this way it calls Dasein back into being authentic, in having to choose or be aware of one's self. He says that what calls Dasein back from being lost in the everyday 'they' is the call of conscience.

Heidegger sees conscience as something that belongs to an individual or to 'me'. He critiques conscience as being interpreted as some kind of universal ideal or voice that relies on manipulable rules or public norms (Heidegger, 1962). Conscience is not something that comes from outside one's self, rather it is an appeal to the self that is lost in the 'they self' so that 'they' collapses and one is summoned to their own potentiality for being (Heidegger, 1962). For health professionals it is the feeling of disquiet, of dissonance and anxiety that reveals the call of conscience as they are no longer caught up in a world that is ready-to-hand. Conscience in this manner calls them to "think about myself, my actions and choices in relation to others and to bear the responsibility for it" (Heidegger, 1962, p. 282). For health professionals being authentic does not imply a 'right way' or 'wrong way' of acting (such as the traditional view of conscience) rather it is an awareness of the responsibility they have for the decisions or actions they undertake. For health professionals being thrown and feeling caught reveals a disrupted mode of being that individualises them into being authentic.

Feeling caught reveals the call of the other

For health professionals, dilemma is not only experienced because they are thrown into a world of practice and a constrained mode of being, but because they are in a practice world with others. Heidegger (1962) says we are always with others in the world (mitsein), and even when others are not present we are aware of them by their absence. For the most part being-with-others for Heidegger is through solicitude and being lost in the everyday 'they' of being-in-the-world. Being authentic is to break from 'they' and take responsibility for oneself. However for health professionals being with others in a world of paediatric practice is not only about being authentic in taking responsibility for oneself, but also about the felt responsibility for the child and their family; the claim that the child's 'face' makes on them.

For Levinas (1998) being-with-others is not only a matter of an authentic 'mine' or a faceless 'they', but an 'I' who is with other human beings and who matter as such. Levinas argues that it is not only being aware of our own death that calls us into being authentic; rather it is the metaphorical death of another, as we recognize the limits of human suffering, which discloses the significance of another who disrupts us. What breaks the anonymity of 'they', what disrupts our interiority, is the face of the Other (Levinas, 1998). Levinas (1998) says that our relation to another exceeds the confines of understanding. "Besides curiosity, knowledge of the other also demands sympathy or love, ways of being that are different from impassive contemplation, but also because, in our relation to the other, the latter does not affect us by means of a concept. The other is a being and counts as such" (p. 5).

Levinas (1998) says that the 'face' of the other must not be taken as a literal representation of the physical face, rather it is an awareness of the proximity of another and the demand they make upon us. Levinas says that when we truly 'see' someone we are also open to the ethical demand they make on us to bear witness to their suffering and humanity. For Lisa caring for a young girl admitted with non accidental injuries calls her to see and be open to the demand made on her.

There was this beautiful little girl with massive injuries. As is often the case the immediate family were not the perpetrators, but initially everyone gets blamed. The parents weren't looking after the child when the injuries happened, so you were supporting them in the realization of what had happened. Her parents were young and relied on support from other family members. You try to provide them with support, allow them to have their own support networks. But you're also thinking 'what's safe for this child'? She was intubated for a while, but quite conscious. When certain members of the extended family came in she physically tried to shrink back in the bed. She was terrified with big wide-open eyes. And the parents were happy that these visitors were coming! They weren't aware of the reactions of this child. Oh it's awful! I mean it's really hard. You're trying not to be judge and jury...you're not, you can't. You certainly record down objectively what was happening. But it was very hard to stand there and see this happening [Lisa: nurse].

Dilemma is experienced here that to 'see' is an awful seeing. Here seeing is not just to note objectively what is happening, but to see this young girl as terrified, traumatized and still vulnerable to her abusers. The face of this child calls Lisa as she realizes what her terrified wide eyes signal. Arendt (1978) tells us that in the Greek language the word 'to know' is a derivative of the word to 'to see'. She says "to see is *idein*, to know is *eidenai*, that is to have seen. First you have to see, then you know" (p. 87). Here seeing calls into the instant a gathering of thought of how the young girl looks and what this signifies; what terrible experiences have caused her to look like this; the naïve trust of her parents in those who have caused the terrible injuries; and havoc and pain that will be unleashed when they realize. Here to see is not just too objectively register what is happening, but to know with dread, and trepidation what this means.

Whilst Lisa sees these young parents need family support she also knows that this support is likely to be torn apart very soon. Lisa is caught in the moment of waiting for the parents to realize how these injuries occurred, not being able to say anything, whilst also trying to protect the child. For Lisa dilemma is experienced in trying not to judge the family, to stay objective yet also being responsible for making judgments that will keep this child safe from further harm (physical or emotional).

Being called to witness

For Lisa to see here is to know, and to feel responsible for the suffering of this young girl. Hatley (2000) says that to see another, to understand their suffering, is to take one's place as a witness:

Burdened by another's suffering we are called upon not only to understand...but also and in the first instance to witness it. By witness is meant a mode of responding to another's plight that exceeds an epistemological determination...one is summoned to attentiveness...a heartfelt concern for and acknowledgement of the gravity of violence directed towards particular others. In this attentiveness, the wounding of the other is registered in the first place not as an objective fact, but as a subjective blow, a persecution, a trauma (p. 3).

Lisa's role here has become one of observing, noticing and taking note. Yet Lisa is not just an eye witness. To see is to behold, which originates in the old English meaning 'to hold in view', or 'to give regard to'. To be *beholden* arises from the notion of being indebted. For Lisa to see or to behold this young girl is also to become beholden to her. To be beholden here is to be disrupted by the child, so that Lisa becomes a witness to her pain and suffering and personhood. Levinas (2003) argues that to be beholden in such a way is to be held hostage. Lisa is held hostage by the presence of this young girl's suffering and how this has claimed her thinking and felt responsibility to her. Here being witness to this young girl is not just an objective fact, but also a subjective blow that claims something from Lisa. Dilemma is experienced in the dissonance between the expectations of health professionals to be objective witnesses when another's presence also claims their subjectivity.

A witness is someone who gives attestation to a fact and gives testimony. Our words stand as a testimony to the suffering around us. But what words could Lisa use? What words could describe what she has seen? For Lisa dilemma is experienced in the recording of objective data and case notes which cannot capture the subjective experiences of either the child or Lisa in her role as a witness. This child is not just an objective fact, where Lisa can maintain her status as a neutral party who has no feeling over the situation. Here the role of being a silent witness (neither judge nor jury) is experienced as dilemma because in other circumstances Lisa may have acted. Bearing witness is to try to maintain some objectivity in the face of an overwhelming claim on her subjectivity. Levinas says that the face of another is not "a thought about ...a representation...but at once a thought for, a non indifference towards the other which upsets the equilibrium of the calm and impassive soul of pure knowledge" (Critchley, 1992, p. 66). Here bearing witness is to not be indifferent to another's suffering.

Being called to "say here I am" (hineni)

Sharon too is claimed by the face of a young girl:

There was a ten year old who was brought in for me to examine because she had been beaten repeatedly. She came in with her head down, she didn't want to talk to anybody, she didn't want to see anybody, and she didn't want to be examined. And

then there was the invasive procedure of examining [her], however sensitive you try to be. And trying to establish a rapport – because realistically a ten year old that has been beaten you're not going to fix it. You can try; you can give them some hope, that at least there is someone there to listen to them, that does care about them. But it's tough because you can't really fix them [Sharon: paediatrician].

To have a 'face' (in a physical and metaphorical sense) is to be exposed to a world where others can see you. To have a face is to be open to the world in some sense. Yet here the face of this young girl has turned away from the world, trying to be invisible, trying not to be seen. This could perhaps be to avoid any presence that may act as provocation to adults who have inflicted these injuries on her; if one is faceless, invisible then one can also not be seen. A child's face is such an open exposure to the world around them, that to be wounded both physically and emotionally is to want to hide one's face from the world. However although physically this young girl attempts to be without a 'face', her presence demands something from Sharon.

As with Lisa, for Sharon being claimed by the face of a child highlights her role as a silent witness, where one is aware of the others suffering but may not be able to act to take away the cause. Treat (1989) says the dilemma in medicine is that it can only counter illness, not history. The history that someone brings to the health care encounter is the gathering of the past, present and possible future. For Sharon dilemma is experienced in not being able to treat this history, only the symptoms that manifest as a result. As a consequence her efforts feel like a drop in the ocean in trying to counteract a history of pain and suffering. Dilemma is experienced in knowing there is nothing she can do to 'fix' what has happened to this young girl. There is something in this child that has been 'broken' that physical healing may never repair. Sharon cannot undo or repair history.

Levinas says the face of the other not only challenges one's power, but paralyses it (Strasser, 1994). For Sharon dilemma is experienced in being a witness to this child's suffering, but knowing that nothing can take away the pain of what has happened. All Sharon can do is acknowledge this young girl, and show her that she does care, that she will listen, that she has witnessed the significance of what has happened. Levinas (1985) would suggest that all Sharon can say is 'here I am' (hineni). Levinas argues

this is the ethical obligation where one allows them-self to be disrupted by the other, and in essence stand there in witness to the other. Levinas suggests that *saying* 'here I am' is an exposure to another, an inability to resist their demand upon me. For Sharon saying "here I am" is a passive act as it offers no solutions or 'cures' rather it is an acknowledgment of this young girl's suffering, and Sharon's willingness to let this demand be made. Here saying 'here I am' also allows Sharon to 'leap ahead' where she not only acknowledges authentically what she can or cannot do, but also makes transparent to this young girl her readiness to stand there for her, and offer hope in the possibility that there are people who do care. Saying 'here I am' offers this young girl a way of recovering her facelessness, of acknowledging that she does count, and that her suffering has not gone unnoticed.

Being called is to acknowledge the significance of the other

Levinas (1998) says being authentic is not only when we realize how we are caught up in the everyday but also when we see how others can be totalized by the everyday, where they have become faceless or anonymous. Being authentic for Levinas is when we see the face of the other, and it is this that breaks our own existence and theirs from the anonymity of the everyday. For health professionals seeing, being claimed, is a way of being authentic and acknowledging the significance of another's experience. Although Levinas argues it is the metaphorical death of another that claims us into being authentic it is the literal death of a child where this was also illustrated. Both Peter and Rosemary recount the importance of acknowledging the death of a child in order to show they understand the significance and meaning the child had for that family.

I know that staff got a lot of comfort out of attending funerals and headstone unveilings. So any particular child's funeral I would go to if I could. It meant a lot to me personally, and to the family I think. I never met a family who didn't like to see that we cared for them, that it mattered. They don't like it when it doesn't seem to matter [Peter: paediatrician].

I remember Sam being a perfect boy, still and content. Those are the things I wrote to his mother. It's really hard... But I think it's really important for them to know that

someone cares about them and they weren't just somebody that you forget, because that's what I think it's really about for them. [Rosemary: nurse].

Here Peter and Rosemary suggest the importance of saying 'here I am' or 'hineni' shows families how they were disrupted by the presence of the child and acknowledges the significance of that child's life for the family. Peter and Rosemary recognize the trace that another leaves. Levinas (1989) describes this trace as what is significant without appearing as anything concrete. The person who leaves a trace "does not appear, is not present, does not become a phenomenon...it is not that they did not exist at all...rather it is absence that is noticed" (Strasser, 1994). For health professionals acknowledging the trace that another leaves is as significant as seeing and responding to the face of another. Donne (1930) wrote that "all mankind is of one author, and is one volume...no man is an island, entire to itself...any man's death diminishes me, because I am involved in mankind" (p. 537). When health professionals are claimed by the face or suffering of another it reveals a mode of being in the world with others. Being in the world with others is not just to be involved with interests but also to be involved with humankind.

To be involved with mankind however is in the most part to be caught up in the everyday. Heidegger (1962) describes this as the basic ontological condition for living ('fallen' into the everyday). Health professionals are caught up in the tasks at hand and the urgency of human affairs where it becomes difficult at times to think or see. Dilemma is revealed in the question 'can health professional's respond to each and every person they encounter without becoming exhausted and overcome'? For a health professional dilemma is experienced in how he or she can remain open to the humanity of another without being overcome; to carry on caring when at times this is experienced as so uncaring. How do health professionals live with the doubt and dissonance that the experience of dilemma engenders? How do health professionals find ways of living with dilemma?

Lifton (1968) describes a witness or someone who has lived through an experience as an 'exposed one' (cited in Lindee, 1994). Lifton suggests there is a fine line between witness and those being witnessed – both are there. Those 'witnessing' become "changed by the experience itself, by the pain they endured...the horrors they

witness...their status as a witness that shaped how others understood and interpreted them” (cited in Lindee, 1994, p. 4). For health professionals, living with the experiences of dilemma is to be an ‘exposed one’ and the goal becomes trying to find ways to make meaning of this. Living with dilemma is trying to find ways to overcome doubt and live with uncertainty.

Conclusion

The experience of being in dilemma reveals that health professionals are thrown into a world where possibilities are not endless. Feeling caught, anxious and uncertain reveals the call of conscience and being authentic. For health professionals the experience of being in dilemma not only disrupts the everyday world where they are called to be authentic, but also a mode of being where they are called by the face of the other. Being called by the face of the other is to be called to witness. This witnessing however is not easy; often all health professionals can do or say is ‘here I am’. The risks to health professionals are that they may become ‘exposed ones’.

Chapter eight

Living with dilemma – living with uncertainty and doubt

“To undergo an experience with something - be it a thing, a person, or a god - means this something befalls us, strikes us, comes over us, overwhelms and transforms us. When we talk of “undergoing” an experience... [It] means that we endure it, suffer it, receive it as it strikes us and we submit to it” (Heidegger, 1982, p. 57).

The previous chapters have revealed how the experience of dilemma announces itself in the mood of feeling not at home; as feeling caught and being called by another; and by being in a tangible and embedded world that health professionals are thrown into. This chapter explores how health professionals endure, suffer and undergo experiences of dilemma, and try to find ways to live with it.

The experience of being thrown into a world of practice reveals that health professionals are caught up in having to act and having to make decisions that even though are arguably ‘right’ can feel wrong or incongruent to the person having to act. The dissonance or uncertainty this engenders contributes to dilemma experienced as doubt about oneself in what one must do and be. For Heidegger, questioning our own existence or way of being in the world through being authentic is never to make things easier, only more difficult (Steiner, 1991).

For health professionals it is not only acting or deciding that gives rise to doubt, but also what they are witness to that contributes to the world feeling ‘not at home’. Whereas for Heidegger (1962) it is anxiety that reveals the world as not-at-home and provides opportunity to be authentic, for Levinas (2003) it is nausea that reveals the impossibility of seizing upon our possibilities. Levinas (2003) describes nausea as:

The impossibility of being what one is – we are at the same time riveted to ourselves, enclosed in a tight circle that smothers. We are there, and there is nothing more to be done, or anything to add to this fact that we have been entirely delivered up (p.p. 66-67).

Nausea is not reducible to a cause; rather it reveals the passive and obligatory nature of being there and not being able to take charge of one's life (Rolland, 2003). Rolland (2003) says that "feeling nauseous is like a sea sickness, the feeling of having lost one's footing in some way...we feel shore less...we are disorientated" (p. 19). For health professionals to live with doubt is to feel uncertain, to have reservations and worry about the rhetorical questions for which there are no answers. The experience of doubt is like feeling seasick, no longer being sure of which direction to turn. The experience of living with doubt for health professionals is to feel fallible, imperfect and not in control of the world they are thrown into. Living with dilemma for health professionals becomes one of trying to find ways to overcome doubt and making meaning of how they find themselves in the practice world.

Rationalizations to overcome doubt - 'that's what I tell myself'

For Levinas (2003) ideals (such as caring, autonomy and truth) not only ignore reality but also "scorn the concrete and poignant demands of human beings prey to their problems" (p. 72). Health professionals are thrown into a world of practice where they have to carry on despite the feeling of dissonance and unease and this reveals the 'obligatory presence' of being there (Levinas, 2003). Equally though, health professionals strive to find ways in which to navigate back to the security of some safe shore. Heidegger (1962) says that for Dasein there is always a deep longing towards security, of trying to find something to hold onto (Crowe, 2006). Because of this he says we tend to gravitate to entrenched ways of thinking such as rational explanations (Crowe, 2006). For health professionals' 'rationalizing' is one way of trying to overcome uncertainty. For Sharon dilemma experienced as doubt is overcome if she can be sure of what she is doing.

Doing procedures to children can be a kind of dilemma in that you are inflicting pain but usually I know why I am doing it. And I am confident that this procedure needs to be done. Having convinced myself that this procedure needs to be done, I've kind of taken into account the painfulness of reaching that decision [Sharon: paediatrician].

In health care there is little room for doubt. Sharon's practice is based on being able to give substantiated reasons for what she does from both a legal and professional perspective. She must be able to provide a professional rationale to account for her

practice yet she experiences this accountability as ‘painful’. Providing a rationale for what she must do however does help Sharon to navigate her way through doubt and uncertainty to a safer shore of being confident of what needs to be done. Convincing one-self is often ‘what I tell myself’. In the following narrative Lisa tosses in her mind the alternatives, trying to weigh in the balance what she must do:

It only lasts for two seconds and then it's gone. And in the day-to-day we aim to have a level of sedation, so that they're not too distressed by what we're doing to them. But you want them to be aware of the parents at the bedside, so again it is balancing, minimizing the noxious stimuli, but it would still be fairly noxious. The kind of drugs we're using they won't remember any of it afterwards, and those are the sorts of things you keep telling yourself [Lisa: nurse].

Lisa's practice is about weighing what she must do and the consequences of this. What Lisa ‘tells herself’ is an ongoing dialogue presenting the pros and the cons, trying to reach some neutral shore so that what she does will be seen in the balance of the good intentions behind this. Here dilemma is experienced because explanations do not always ease the difficulty of what health professionals have to do. The consideredness, the painfulness of having to balance these actions does not abate each time Sharon or Lisa are faced with a similar situation. For Lisa ‘telling herself’ is an ongoing justification of how she is thrown.

Justifying, rationalizing and ‘what I tell myself’ are ways health professionals use to try and overcome the impossibility of being there and having to act. Rationalizing becomes a way of balancing the books, of taking into account all the factors of having to make what is at times a painful decision. In reckoning up the books or circumstances health professionals are able to substantiate their course of action with the unintended consequences.

Rationalizing ‘if my heart is not in it’

For health professionals what they ‘tell themselves’ becomes an important part in helping them to believe in what they must do. However if health professionals don't believe ‘whole heartedly’ anymore then this opens the door for dilemma to be experienced as doubt:

We had a child whose parents wanted absolute full resuscitation, and the child was severely handicapped and I didn't feel that their quality of life was particularly good. But the parents were clinging to the child almost as if they hadn't had the chance to grieve for the child they hadn't had. My medical ethics told me I had to go with what they wanted but it was really uncomfortable. I was lucky I was never put to the test. But I always told myself that is what they wanted and that is what I would have to do even though my heart wouldn't be in it. And what I would have to live with is did I do it properly because my heart wasn't in it. Not really believing in it. If he'd failed to respond I think I would have felt that maybe I should have done more. I don't know [Sharon: paediatrician].

Dilemma is revealed here in tension that if health professionals don't really believe in what they are doing then this opens the door for questioning and second guessing themselves. For Sharon dilemma is revealed in the question that even if she did her best professionally, would she feel personally she had done her best because her heart wasn't in it? Would she always be left wondering if her doubts and lack of conviction could have potentially contributed to a poorer outcome for the child? Would she feel more responsible if the outcome wasn't what the parents hoped for? Here dilemma is experienced in the contradiction between what Sharon believes is important and what her medical ethics tell her and the tension between beliefs that are felt and those handed down as valid and true. Levinas (2001) says that institutions such as medical ethics are necessary because of their concern for universal justice for all. However he argues there is always a tension between universal general laws and humanities concern for the individual. Sharon experiences dilemma because she must suspend her own individual beliefs in favour of those of the family and her medical ethics.

Rationalizations provide comfort

For health professionals, rationalizing is a way to comfort their self; to overcome doubt every time they have to do something they don't want to do, or when their heart is not really in it. 'What I tell myself' becomes an assurance so that health professionals can carry on; that what they do is for a reason and this reason justifies and entitles them to act. For Peter rationalizations are a way of justifying that what he does is okay:

The job requires that body fluids be tested for various things, particularly blood, marrow or spinal fluid. So most of those more or less are going to take discomfort or frank pain. There is certainly a fair amount of dissatisfaction on the part of the client. And it is quite hard to do that and carry out minor procedures, when they need to be done quickly and you don't have a whole lot of time to focus on being nice to them. It's quite hard to face up to that. I don't know what other people do but I have my own personal set of rationalizations that's an okay thing to do. Overall I get comfort from those sorts of rationalizations so I can go to bed at night and not get too wound up [Peter: paediatrician].

'What I tell myself' helps Peter sleep at night and gives him some comfort. These rationalizations are not like policies or guidelines as prescribed by his profession (such as if this happens, the next step is...) rather they are personal, something that Peter uses to convince himself that what he is doing is okay. Here rationalizations provide a way for Peter to validate that he is justified in his action, but paradoxically also distances him from the situation. This distancing makes it easier to 'face up' to a situation. For Peter to 'face up' to what he has to do is not only to have to encounter the face of the child and the demand this makes on him, but also having to face up to himself in how he struggles to overcome any doubt about what he must do. Justification and rationalization become a way of trying to balance the claim made by the face of the other and the competing claims of his profession to carry out care.

When rationalization cannot provide comfort

For Peter, rationalizations prevent him from worrying too much, from not getting 'to wound up'. However for Janet dilemma is experienced when there are no longer rational explanations left to explain what she witnesses. Not being able to explain means there is no comfort, no sleeping well at night.

I remember a little boy. The first absolutely gorgeous little boy I worked with. He had witnessed the most horrible things and I remember him saying to me "do you have a husband?" "You make sure he's good to you because sometimes Dad and people who love you do bad things". It was a really interesting time. I never slept. I had the worst

sleep of my whole life while I worked in that service because I just couldn't believe that people would do that stuff to children [Janet: occupational therapist].

For Janet the experience of dilemma is not something that she leaves at work. It is not something rational or cognitive that she is able to distance herself from. The experience of dilemma is something she carries with her as she lies awake at night and worries over “how could people do that stuff to children?” “How could people who love this child, who are supposed to care for this child do these terrible things?” Of course there are rationalizations that could provide answers to those worries or concerns, such as the mental health status of the parent or adult at the time. But knowing the reasons why adults may hurt children does not take away the pain of being witness to such trauma. Here there are no rationalizations that can help her sleep better at night. The enormity of what this young boy has endured resonates in a way that defies some rational explanation. Although Heidegger suggests metaphorically that it is the call of conscience that keeps us awake to the world around us (Crowe, 2006), for many health professionals it is the angst and disquiet over the world children find themselves in that literally keeps them awake at night.

The dilemma is that in health care there are often situations health professionals are exposed to where there is no explanation for the pain and suffering that they witness. How do you rationalize an adult inflicting cigarette burns all over a four year child's legs? How do you rationalize a child left with severe head injuries as a result of being hit around the head with a blunt object? How do you justify children being spun in clothes dryers? How can you not be moved yet also try not to be overwhelmed?

Not thinking about it too much

Rationalizations may help to provide some distance, some way of not getting too close, but the risk is if health professionals can find nothing to say, nothing that can explain what they witness then how do they stop themselves from worrying too much, not being able to sleep at night? Lisa suggests that one way is sometimes not to think about it too much. Lisa says that if she thought too much, she might not be able to do her job:

Your immediate reaction is talking to them and soothing it away. I mean you want to soothe it away; you want to take away the hurt. You know that you're causing noxious

stimuli and you want to take it away but you have to rationalize it. Otherwise you'd never go back and do it again. If you perceived yourself as such a big bad person, if all you did was harm babies! There are quite a few issues of...and it's kind of like we almost don't think about it. I don't think we think about it too deeply or you might not do what you do. And you've got to believe that what you are doing is for the patient's best interest [Lisa: nurse].

For Lisa being able to rationalize is trying to maintain some sense of who she is in light of what she has to do. If she can't rationalize what she doing, if what she does seems such an antithesis of what and who she is, how could she go back? How could she keep doing what she is doing? If she can only construct what she does as 'harming babies' and as a consequence embody herself as a 'bad person' how can she go on? Health professionals need some explanation to why they will keep going back and doing these things to children.

Health professionals have been taught not to self doubt as their practice is based on having to have a sound rationale for what they do. Rationale for practice however is often based on physiological explanations and may not account for the hurt and pain that both the health professionals and child can suffer. In the face of this, is it easier not to think and to carry on with the business of health care that continues on regardless? If health professionals can no longer think of an explanation, therefore stop trying to find one, does the world become ready-to-hand where things are no longer questioned? Does this enable practices to be legitimized that do not support the integrity of the child and their family?

Qualifiers

For health professionals some of the ways in which they tried to rationalize what they must do took the form of 'qualifiers'. A qualifier became like a belief or statement used to explain their actions. Here a qualifier became like a rider, a provision or clause that would make something acceptable that normally may not be.

There's not enough time...

Sometimes things need to be done quickly and you don't have a whole lot of time to focus on being nice to them [Peter: paediatrician].

One of the rationalizations used in many instances in health care is '*there is not enough time.*' Dilemma is experienced in the question when time is always in short supply, but in high demand is it easier to justify to yourself that 'this' just has to be done now? '*Not enough time*' reveals the often busy and frantic practice world that health professionals are thrown into, but equally once the term is used it can be used as a justification to hurry, and perhaps not take the care, one usually would. The dilemma is that once '*never enough time*' becomes an accepted fact of a busy practice world, practices that follow may also become accepted and every day.

So long as...

Sometimes to support a child to do the hard stuff is to be there and let them cry. To be able to express their displeasure, their pain, and their unhappiness and knowing it's okay. So long as it is not inappropriate pain that comes from not understanding what is happening or being under medicated [Stacey: play specialist].

'*So long as*' is a qualifier that puts conditions on what may be acceptable or not. For Stacy it may be okay for children to cry with pain, *so long as* it is not inappropriate pain. Dilemma is revealed here that *so long as* may change with individual interpretation. Who decides what is acceptable and appropriate or not? The child may (and probably would) argue that no pain is acceptable. Who of us would willingly undergo such unhappiness or discomfort? Who decides '*so long as*'?

Trying your best...

We've got some right and some wrong. But not for lack of trying is one way of rationalizing dilemmas. You try your best, and hope its good enough, and at least you can't say you didn't try [Peter: paediatrician].

Does the adage “it is better to *try* and not succeed at first than to never have tried at all?” really answer the questions of doubt? Is *trying* enough for health professionals striving for certainty of outcomes? If they try hard, have tried their best, can they feel better about the outcome, whether it be optimal or less than optimal? Can saying “oh well *I tried my best...*” be an excuse for acting in a way that perhaps wasn’t the best? Is *trying hard* a good intention or a false sense of having done one’s best so that one can feel better about oneself?

It’s just got to be done...

In the chronic care setting you have time to sit and talk, whereas in the acute setting it can be extremely difficult and you just have to do it. For example, sometimes you don’t have time to worry about anaesthetics, or getting consent or anything like that. It’s just got to be done and it’s just too bad. But in a sense that’s also easier and the alternatives are serious problems or loss of life. So you try to justify to yourself what is going on, right or wrong [Peter: paediatrician].

‘*It just has to be done*’ is a great justification because there is no angst or worry about what choice to make – it just has to be done. There is no question mark; no uncertainty about whether or not this is the course of action to be followed because the alternative is loss of life. *It has to be done* is a foregone conclusion that stops questioning; there is an urgency in this assertion that makes hesitation difficult.

‘*It’s just too bad*’ means having to carry on despite feeling it is not the optimal course of action. It signals that something will be *bad*, but this is not what was intended. ‘*It’s too bad*’ is a signal that something will happen despite protestations; it is a rationalization of the inevitability of what will occur. As there is no knowing at times what the outcome might be, having to act means committing to a course of action whether it is *right or wrong*.

Doing it for their own good...

Things like siting IV’s I have always found traumatic, and even more so probably now that I have children. It’s so invasive to their little persons and their chubby little wrists.

In my view some of these things do have to occur. But they don't occur with out altering the child's space and integrity. And they become powerless. And I'd hate for people to think of me as 'doing it for their own good' type of person but in some ways that is the truth of it [Jane: nurse].

Here dilemma is revealed in the question whether '*doing it for their own good*' is a genuine concern for another or a paternalistic attitude. Here '*doing it for their own good*' becomes a mode of leaping in instead of leaping ahead, in which health professionals impose their good judgment and actions on another. The dilemma is that health professionals are professionally responsible to maintain the good of another. How far do the ends of '*for their own good*' justify the means to attain this? Does *doing it for someone's good* move our actions beyond question or reproach? Who decides what this ultimate good is?

Qualifiers

Qualifiers are ways in which health professionals (and others) are able to justify their actions. The dilemma is revealed in the question of *why* they are needed in the first instance. If there is no doubt about a course of action or if you are able to believe totally in the 'rightness' of what you do would you need to qualify this? A qualifier is revealed here as a way to legitimate something where there may be a question mark over whether this is the right thing to do. A qualifier is a signal that opens thinking to having to provide justification for one's actions.

The experience of dilemma shows that there is a tension in 'not thinking too much' and equally 'rationalizing' to the extent where one could convince him/her-self of anything. The history of mankind is littered with rationalizations for all manner of acts. The risk is that 'not thinking too much' and rationalizations may make us blind, close our eyes to what is before us, and inoculate us against the suffering of others. Dilemma experienced as doubt keeps the reason for rationalizations in play and reveals that these are contested and questionable. Doubt is a way of remaining open to the complexities and ambiguities of life. Doubt is a way of trying to balance being authentic with the realities of the practice world one is thrown into.

For Heidegger being authentic is never just a matter of individual history, it also involves a community of people (Steiner, 1991). Health professional's heritage brings with it the language, culture and practices of being a health professional (Young, 2003). Being resolute (letting one's self be summoned by one's conscience) does not cut health professionals off from their social responsibilities. Rationalizing is a way of trying to balance the call of one's conscience (anxiety and doubt) with the necessity of already being committed to a particular heritage. Heidegger says that although one's fate (thrownness) is individual, one's destiny (future) must always be collective (Steiner, 1991). Being authentic is to never be wholly free to choose, as health professionals are always on the way to themselves and never totally the master of their own destiny (Crowe, 2006). Crowe (2006) describes this as a restless 'to and fro' that compels our quest for security. For health professionals rationalization provides some measure of security in the face of anxiety and doubt. Being free is never something like a privilege or a right; rather it is being open to the conditions of facticity and the complex ambiguities of life (Hatab, 2000). Levinas argues that freedom is not the ability to be spontaneous; rather it begins with the knowledge of one's own subjectivity (Strasser, 1994).

Feeling overwhelmed – the risk in becoming too sensitive

Crowe (2006) says the tragedy of human life is to have to endure having chosen one possibility over another. Heidegger argues that freedom is being able to tolerate this choice (Crowe, 2006). For health professionals dilemma is experienced when they are no longer able to tolerate these choices and rational explanations and justifications fail. The consequences of no longer being able to cognitively distance themselves from the 'face' of the other, is to risk becoming overwhelmed. Levinas (1989) says that responding to another is not one of pure rest which strengthens our selfhood. Rather Levinas sees it provides a challenge to our selfhood and challenges the notion of being truly free to ever decide or be. For health professionals this struggle with their selfhood means either being overwhelmed (and in some cases leaving the profession) or finding alternative ways to make meaning.

Sometimes when I go into the treatment room I have to absolutely focus on one thing. I can't even think about how that parent is feeling because I don't want to be another

person who bursts into tears. So you really hold yourself back emotionally and just try to get this over and done with whilst trying to be calm and reassuring. Every now and again it really hits me. So I might be in the treatment room and there is so much emotion that I can't talk. Seeing someone in that situation where there is so much fear or pain triggers it. But I still get out different activities and try to pull myself together and then I'm okay. I tend to just sort of hold back and then afterwards I'll go right off the ward, go and have a cup of tea and just physically get away [Brooke: play specialist].

For health professionals every now and again the experience of being witness to so much fear and pain hits them and cognitive rationalization of why they are there and why the child is there fails. Instead the overwhelming presence of someone in so much suffering makes itself known in such a way that it becomes difficult to be present to this. For Brooke dilemma is experienced as her overwhelming empathy and thought for the child, which paradoxically means that she risks becoming ineffective in the room. Dilemma here is experienced in the felt closeness to the child and their suffering which therefore requires a certain distancing. For health professionals dilemma raises the question of how can they balance and protect themselves from not being overwhelmed, whilst remaining sensitive to the situation? How do they maintain seeing the face of another without the risk of losing their own? How do health professionals stop the 'leaking' of personal feelings into the professional domain?

At times rationalizations act as protection against becoming overwhelmed and not being able to function in a professional capacity. Rationalization allows health professionals to focus on the task at hand, what has to be done and as Brooke says 'pull ourselves' together. Although for Brooke being witness to pain and suffering and feeling overcome hits her 'every now and again' for Karen there was a defining moment that marked becoming overwhelmed.

I used to help with lots and lots of lumbar punctures. And I'd have to curve the child around and they'd be really strong and they were absolutely terrified. And I just couldn't do it any more after this particular one. This little girl who was about four, turned to her Mum and said "Mummy make her stop". And after that one I couldn't do it anymore. So I used to be busy doing something else. I couldn't work in the

admissions unit anymore so I went and worked on the ward. Towards the end of my time there I would supervise the young ones. I was really cunning. I would say “have you done this before?” [nasogastric insertion] and they would say “no”. And I would say “well would you like to help?” I would just think “I can’t, I can’t put a tube in”. I know it’s no big deal but I just couldn’t do it” [Karen: nurse].

Here it is one child, one moment (an *augenblick*) that defines the rest [or the end] of Karen’s career in paediatrics. The child’s beseeching eyes and pleas to make her stop affect Karen to the extent that she is no longer able to participate in any procedures on children. For a while Karen is able to avoid these situations but in the end she leaves the field of paediatrics altogether. She is able to rationalize that it is ‘no big deal’ to put in nasogastric tubes, or help with lumbar punctures, but deep inside she can no longer participate in these activities. It is not only the suffering of children that has overwhelmed Karen but it is her own suffering that makes it impossible to continue. Levinas says the suffering of the other may exacerbate our own existential suffering. What Levinas means by this is that although responding to the suffering of another engenders a sense of responsibility and ‘good’ conscience, this equally holds us to account, takes us hostage and makes us feel ‘guilty’ if this responsibility cannot be realized (Hutchens, 2004). Whereas for Heidegger being guilty is for ‘nullity’ or not taking up our own lives (being authentic), for Levinas being guilty is to bear the responsibility for another’s suffering. For Karen it is feeling responsible for another’s suffering (not just her actions but her knowledge of their suffering) that engenders a sense of guilt and through this Karen also suffers. Russell (2007) writes that to be present to another’s suffering is to also suffer one’s self. He writes:

Echoes of cries of pain reverberate in my heart...the whole world of loneliness; poverty and pain make a mockery of what human life should be. I long to alleviate the evil but I cannot, and I too suffer (p. 554).

For health professionals dilemma is experienced because they want to be there to counter and alleviate the effects of the suffering of others, yet in so many instances this seems no longer possible. The suffering of others makes a mockery of the ideals of what it means to be human. For Levinas (2003) it is not just suffering which risks

overwhelming us, but also the impossibility of interrupting it and being held fast by it. He says that suffering confronts us with the impossibility of “getting out of the game” and we lose our innocence to the notion of seriousness (Levinas, 2003, p. 52). For Levinas the suffering of others and our own is a burden – there is no turning away (Woods, 2002). When the suffering of others becomes intolerable health professionals must decide whether to risk the burden of carrying on or to leave.

I've had a lot of times where colleagues in adult branches have said to me 'I don't know how you do it. I couldn't tolerate the pain, the difficulty'. At the end of the day the biggest problem of all is being able to carry on despite those dilemmas. I think there would be very few people who would admit to it. I think partly because there is such a huge commitment in time training to become a doctor. You don't just do that unless you are really committed and want to do it. There are a few that have gone tangentially and in most cases have maintained a connection with health. I can't speak for others only for myself but it just got too hard for me. For my own sanity I had to cut down on the amount of clinical involvement I had [Peter: paediatrician].

Deciding to carry on or to leave because of one's sanity is never an easy decision and in fact Peter suggests that few people would admit to it. Health professionals work within institutions where often the operational costs are focused on, rather than the cost to health professionals or families and children. Within this ethos there is often an unspoken ethic of 'coping' and 'soldiering on'. How do health professionals admit they are finding it too hard? Not only is there an unspoken ethos about being able to cope but also there is the reality of the huge time and commitment that has gone into reaching this point in one's career that becomes an issue. How easy is it to turn your back on the investment you have made for the future? There is an added dilemma that 'coping' may be a semblance of 'not coping'. Even if health professionals are able to carry on with the job at hand this may hide the 'sickness of heart in the depths of ones self' that nausea and the feeling of the impossibility of being brings (Rolland, 2003). Here the suffering of others is also a recognition of health professionals own vulnerability, dependence and mortality and the “recognition of the limits of autonomous selfhood” (Woods, 2002, p. 29).

The dilemma is that this ‘sickness of heart’, the impossibility of being oneself is something that is not talked about readily. Health professionals own suffering for the suffering of others becomes hidden and covered over. Dilemma is revealed in the question that even if health professionals did want to talk would there be anyone there to listen?

For Andrea the impossibility of being is revealed in the death of a child and her colleagues’ refusal to acknowledge her grief and ‘sickness of heart’. During the funeral Andrea is able to turn to the nurses at the hospital who knew the child, and share her stories which reflect the significance of this young girl’s life. However over time and feeling unsupported and adrift, Andrea thinks that perhaps she is not suitable to work with children.

It took me a while to get over her...and I guess some people cope better than others. I don’t know if I can cope with this on my job. I couldn’t go through that too many times. And it’s the realization about whether maybe you’re suitable to work with children. Children sort have that little extra bit of innocence that looks at you... [Andrea: physiotherapist].

As with Peter there is a suggestion that working in the field of paediatrics makes one more vulnerable. The child’s “*innocence that looks at you*” is both difficult to turn away from or distance oneself. Levinas (1999) describes alterity as something indefinable, something that claims us yet we do not fully understand. For health professionals it is the alterity of the child that is not reducible to understanding of what it means to be an adult. What a child embodies is such a different way of being in the world. For health professional’s dilemma is revealed in the innocence that a child embodies and this being non-reducible to rational explanations for the reason of their suffering. The dilemma for health professionals is what is the right way to be? Is it better to be open to a child and the claim they make on one’s subjectivity or is it better to be able to distance one’s self therefore protecting oneself objectively? These questions trouble health professionals as they try to navigate the fine line between being present to the child and their family and distancing themselves. For Heidegger authenticity is not based on comfort or reassurance, rather it is in the turbulence of life where one comprehends oneself without illusion (Crowe, 2006).

Becoming overwhelmed – worrying about desensitizing

Although health professionals worry about being too sensitive, equally they worry about desensitizing.

I believe if you don't show some compassion then what are you doing, why are you in this profession? The day I stop getting upset I am going to stop working or at least take a break. Because that would mean I would be desensitized, I wouldn't be good for anybody [Sharon: paediatrician].

Health professionals believe that they need to have some compassion otherwise they may no longer respond to the pain and suffering of others. Dilemma is experienced in the paradox that the very thing that makes you human and perhaps an effective practitioner is also that which makes you vulnerable to the burden of the suffering of others. For Lisa not to care would be like a 'blank slate'.

In the day to day you can't get too emotionally involved but you can't care for somebody if there is not something there. You'd have to be a pretty blank slate if you did not have any emotions. I'm not saying that we should become like the parents for these children but there needs to be some sort of emotion to care for them while they are here [Lisa: nurse].

Lisa implies that the work of being a health professional is more than the competencies required; it is an attitude and orientation to being with others. How can health professionals balance the burden of caring with the sort of care children require? Brown (1995) in the poem entitled "The good physician" writes:

If I care too much,
Yours and all the others' pain will drain, weaken and kill me.
My love must be shallow enough
For both of us to survive
(p. 59).

Dilemma is experienced by health professionals as a balancing act of having to rationalize what they do, but not becoming so convinced by these arguments that they become blind to the pain and suffering of others. Dilemma is experienced as having to maintain a precarious balance between managing doubt – not becoming inured to it, or succumbing to it.

Living with uncertainty

Living with doubt, uncertainty and unresolved ness can become a huge burden to carry for health professionals. Peter suggests there are risks with carrying such a burden.

One of the things we get paid for is to be able to live with that. At the end of the day we have to be able to carry unresolved dilemmas. And you take great risks with the mind, because you have a large amount of responsibility. And at the end of the day the biggest problem of all is being able to carry on despite those dilemmas [Peter: paediatrician].

Living with dilemma can be a risky burden as health professionals question whether the weight and responsibility will overcome them. How do they carry on carrying such a heavy load? For Anne part of this burden is living with the ‘what ifs’.

I have seen people who have had post natal depression and nobody helped them and the next thing they have killed their child and it's like maybe...and you have to live with that...maybe, maybe, maybe [Anne; play specialist].

For Anne the experience of living with dilemma is the uncertainty of ‘maybe, maybe, maybe’. What if someone had picked up this mother who was at risk? Would their child still have been alive? How could health professionals have predicted this? Whose responsibility was it to intervene? Maybe if someone...Maybe if I...Maybe if this had happened...

Although it is difficult to know with any certainty after the event if any intervention by health professionals may have made a difference, it is this uncertainty that preys on Anne’s mind. The uncertainty of ‘maybe’ leaves a door open to envisage an alternative

future where this mother would not have harmed her child. The notion of ‘maybe’ signals the responsibility that health professionals feel toward having a part to play in this situation. The dilemma is that no matter how responsible health professionals feel toward a situation there is no way to predict the consequences or being able to intervene in each case. Sharon suggests that sometimes you have to live with the uncertainty and accept that you will not always be able to intervene or save every child.

Children who have died in the middle of a resuscitation you sort of feel that they shouldn't have died. I question what could we have done differently that they might have survived? But again there is always the 'what ifs'. And I've learnt from past bitter experience that there is no point in going there. Children do die. And I guess it is kind of accepting that. Not often but they do [Sharon: paediatrician].

The dilemma in health care is that so often health professionals and families hope for the best possible outcome but there is no way of knowing for certain what intervention may be successful. Dilemma is experienced as not knowing whether there was something that could have been done differently to change the outcome. For Sharon the ‘what ifs’ leave a bitter taste in her mouth, and she suggests it is better not to go there because there are no answers to the rhetorical question of ‘what if’. Sharon suggests that sometimes the only way to live with dilemma, the questions, is to accept the uncertainty.

Accepting uncertainty

For William living with uncertainty is a helpful notion that helps him to live with the burden of doubt.

Living with uncertainty, that sort of concept has been helpful to me. But I can't project that to all patients or families. There are some that can and others it's a very concrete world [William: paediatrician].

For William there is no need to have explanations for everything, sometimes what is just is. Living with uncertainty is a notion where health professionals accept being

thrown into the totality of life, despite their best intentions. It is being willing to let go and accept that uncertainty is part of being human and who one is. William suggests however that being able to accept living with dilemma (or even life itself) is individual as for some certainty is important.

For Brooke living with uncertainty is to try to look at the situation from different perspectives, trying not to foreclose on any opinion that this may be 'right' or 'wrong'.

I guess I just accept that some people have really strong beliefs and I don't know whether those are right or not. But if they can live with themselves and live with the reality of what they believe then that's okay. If that boy felt that he would rather die and he wasn't afraid of death then maybe that was an okay thing. Maybe he would have gone through a month or however long of radiotherapy and been really terribly uncomfortable, very sick and died anyway. I have often thought that things happen for the best. Sometimes I don't know. But sometimes I think every day is precious and it doesn't matter whether you live till you're six or sixty. As long as I've been able to provide a little bit of fun or something that is positive then that's better than withdrawing from that situation and not having any involvement [Brooke: play specialist].

Here Brooke suggests that accepting uncertainty is to be able to be in the moment with another, making the most of each day, not living in a past with regrets or a future of what ifs. For Brooke this is an authentic way of being as it allows her to be fully in the present with another without racing ahead or lingering behind. Accepting for Brooke is a way of being that allows her to incorporate all the complexities and contradictions of being human. Here believing that '*things turn out for the best*' allows her to accept the outcome no matter what it is. Levinas says that suffering is the patience of life, where we have to carry on with what is painful and troubling without regard for its 'why' (Strasser, 1994). There are times when life just is. Dilemma however is also revealed in the question whether accepting *fait accompli* may negate personal choice or determination and be viewed as an abdication from having to carry out difficult actions.

Forgiveness as a way to overcoming uncertainty

For health professionals being forgiven is a way of overcoming guilt and accepting themselves as fallible human beings. Forgiveness was not actively sought out but offered health professionals a way of re establishing their integrity of who they are.

It doesn't feel good to do something to a child that you know is not very pleasant, even though we can rationalize it to ourselves as for their best. They're looking at you with these big hurt eyes saying 'you're hurting me'. And two months later they come up to you and give you a big hug and you think 'oh yeah I've been forgiven!' [Sarah: nurse].

The notion of forgiveness rests on having done something which one feels is 'wrong' and therefore seeking forgiveness for. Health professionals feel it is 'wrong' to cause a child distress even if they can rationalize it is the 'right' thing to do. For health professionals the notion of forgiveness rests on the dissonance of what they have to do not being a reflection on the person they are. Blanchot (1980) writes that suffering causes wounds to our subjectivity as we feel blamed, accused and responsible for those deeds which are of concern for us. To be wounded is to also feel guilt (Levinas, 2003). Being forgiven here is to be absolved from the guilt of having caused distress and pain to a child and contributes to a feeling of absolution for both the deed and the person.

They remember voices and people but they don't remember getting horrible things done to them. It's like phew...you know...you can like yourself. And it's nice when they come back because you think that was a lot of hard work but it was worth it. They come walking in the door and smile at you [Lisa: nurse].

Lisa suggests that being forgiven is to also to be able to forgive her self. Despite the awful things she has to do, the hard work, if children are willing to forget or forgive, then she can believe that the end justified the means.

Although authors such as Noddings (2003) and Buber (1970) suggest that there is reciprocity in the encounter with another, Levinas argues that this is not the case. For Levinas (1999) there is an asymmetry in the ethical relationship because the other is also alterity. The other can never be understood as the same. Forgiveness then is not

based on any notions such as being liked, public opinion, or the ‘goodness’ of a health professional or family, rather it is an acknowledgment of the difficulty in acting in ways that go against one’s conscience.

For William it is not just the forgiveness or understanding from a child that is important but the affirmation from his colleagues.

After a while you get to know people well enough, to know what is safe to talk about. Those sort of debriefs have an element of factual information, but there is a collegial support and I think a mutual forgiveness that goes to help. You know that despite being fallible it is sometimes a question of emphasis [William: paediatrician].

The experience of dilemma here reveals the burden of the expectations that health professionals are infallible, that they will always get it right. For William, affirmation from his colleagues signals that he is fallible and although he tries his best they also accept that he will not always get it right. William suggests however that there is an element of risk attached to exposing ones fallibility; that there must be mutual trust in order for forgiveness to be enabled. The dilemma for health professionals is that if they expose their fallibility do they make themselves vulnerable if they are not supported? There are both personal and legal risks to being fallible that may make it difficult to admit ones own fallibility.

Bauer et al. (1992) suggests that self forgiveness arises out of an increasing awareness that something is wrong with one’s life, and there is a feeling of estrangement or brokenness, a split within oneself that doesn’t fit one’s self image; where one plays the situation over in one’s mind wracked with confusion and anxiety; where one’s faults and fallibilities can no longer be denied. Self recrimination for health professionals in this study took the form of second guessing oneself, getting lost in the ‘what ifs’, taking the form of ‘beating oneself up’. Bauer says that the process of self forgiveness is a reaffirming of who we are and an acceptance of “our human limitations about what we can and cannot control, can and cannot know” (p. 156). For health professionals in this study, self forgiveness is not just understanding or being able to rationalize what they did and why, rather it is a letting go and accepting that life is not always bad or

good. It is being thrown into a world where dilemma does arise and where one is only human.

The experience of dilemma for health professionals reveals the temporality of being in dilemma. There are no easy, if any answers, to the rhetorical questions the experience of being in dilemma raises. Health professionals are left with doubt, with the ‘what ifs’ which means the experience of dilemma is not one that is resolved. Instead the uneasiness and unanswered questions of how to act and who to be are left open. The experience of dilemma becomes something that must be lived with, endured and follows participants into the future. The experience of dilemma is one that leaves imprints on health professionals.

Imprints – the memory and resonance of being in dilemma

“I often have to remind myself that we’re working in an environment that’s just not natural and those things aren’t every day occurrence really. But those are the things that really stick with you”.

“It’s just never left me. I actually don’t think many people realized what we had done to that family...and that’s a huge, huge burden to bear”.

“I remember...”

“He was a wee red headed lad in the room opposite the nurse’s station...I still cry when I think of him”.

“It just never left me...”

The phrases used by participants indicate the indelible images left by their experience of being in dilemma. It is not just these above phrases that point to the experience of dilemma; it is every story told in this study, each memory revisited that indicates the imprint left by such an experience. The imprints health professionals are left with are not just cognitive impressions that reside in memory rather they are reminders of discomfort, of uncertainty, of what presses on them long after the event. Michaels

(1998) says that “history and memory share events; that is, they share time and space. Every moment is two moments” (p.140). Being in dilemma is simultaneously a meeting of the past, present and future. History would tell us that *this* event happened *then*. But the phenomenon of being in dilemma, the memory, the resonance, the reminder, of the discomfort persists through time as an imprint.

An imprint is a collage of memories, or an effect or image retained as a consequence of experience. For Heidegger (1968) the collage of memories arising from experience is the gathering of thought. He suggests that memory is perhaps more than the ‘container for the thoughts of thinking’, because ‘thinking itself resides in memory’. Not only do we remember events, but we are also taken back to revisiting the experience. When we remember we are there again.

Memory does not just reside in the past but meets us in the present and future. For health professionals it is the thinking of ‘*what if...*’, ‘*how could I do this differently next time*’, ‘*if only...*’, ‘*was it the right thing to do?*’ that contributes to how they think about their past, present and future. The unresolved ness of dilemma means it persists in memory. There is no end to the story, only further questions with no apparent answer. In a sense dilemma is rhetorical, there are no answers only unresolved ness. There is a risk that if we use ‘dilemma’s’ from an epistemological perspective as an rhetorical device to explore possible answers we may contribute to a fallacy that there is some resolution to the thorny circumstances of life. There is no answer to ‘*what should I do*’ yet one is still compelled to act. The experience of dilemma is about being thrown into *having* “to be” [Dasein] not just thrown into some neutral existence.

Heidegger (1968) tells us that the word memory did not initially mean the power to recall. Rather memory is our disposition, our intimate concentration on things that speak to us. Heidegger (1968) says that “out of the memory and within memory the soul then pours forth its wealth of images – visions of envisioning the soul itself” (p. 140). Here, Heidegger links memory to the gathering of thinking (and thanking) to what “concerns us, what we care for, all that touches us insofar as we are, as human beings. What touches us in the sense that it defines and determines our nature, what we care for, we might call contiguous or contact” (Heidegger, 1968, p. 144). Heidegger suggests that only because we are by nature gathered in contiguity can we remain

concentrated on what is at once present and past and yet to come. Therefore memory or the gathering of thought is never an after the fact recollection, but the tidings that overtake all our actions and what we are committed to beforehand by being human beings (Heidegger, 1968).

For health professionals this points to what we are close to, what concerns us and the thinking that persists after the event. It is this worrying thinking, the 'sorge' that declares what it is we care about prior to being in dilemma; of what we are committed to as being health professionals and human beings. What 'speaks to us' is the 'face of the other' and our 'conscience'. Imprints therefore signal not only the resonance of what we are left with, but what it is that concerns us. This suggests a certain moral character to what it means to be human. Although Heidegger explicitly avoided discussing ethics, he did offer us ways of thinking what it means to be human. Rather than ethics, Heidegger turns to the notion of 'dwelling'.

Woods (2002) says Heidegger's notion of ethics as ethos or dwelling is the recognition of human fragility and finitude. This recognition calls to it "certain complex dispositions, ways of remembering, bearing witness to, honouring, acknowledging the significance of such an experience" (Woods, 2002, p. 34). The imprints left by being in dilemma bear witness to what concerns and what is significant to health professionals. It is a way of remembering and honouring the suffering of others whilst affirming the contested ground of what it means to human. The 'ways' of remembering are often not pleasant, and memory bears witness to another's suffering as well as one's own.

Michaels (1998) says "history is amoral: events occurred. But memory is moral; what we consciously remember is what our conscience remembers. History is the Totenbuch, The Book of the Dead, kept by the administrators of the camps. Memory is the Memorbucher; the names of those to be mourned, read aloud in the synagogue" (p. 138). For health professionals their everyday practice is recorded in the case notes and files. Ethical dilemmas are presented as an historical account of what has passed or decisions yet to be made. Yet this does not tell us of the experience of dilemma, only of the facts. It is almost as if the flesh has been taken away, and what gave something body and form has been stripped down to a version of the bare bones and facts. It is memory that points to the flesh; to those to be honoured, those to be mourned. Memory

is a reflection of our own conscience, being authentic, what is important to Dasein and what it means to be human. Levi (1995) says that for some the memory of suffering is extraneous, something painful that has intruded into their lives. He says for others remembering is a duty, they do not forget because they understand that their (and others) experiences are not meaningless. For Woods (2002) there is an ethical resonance in our very willingness to stay with our experience; to honour it and ponder it.

Conclusion

Living with dilemma is to have to find ways of living both with being thrown into circumstances where one has to act, and living with the consequences. The doubt raised by being in dilemma reminds health professionals of the turbulence and contested nature of life. Living with dilemma is to have to be courageous and brave, and notions such as authenticity are not ones that are free and easy. Living with dilemma is the acknowledgement of the thrownness of life, but also a reminder of health professionals and the others' humanity. Being in dilemma is to remind health professionals that they are a human being for who the suffering of another is an issue.

Chapter nine

Families experience of being in dilemma – a fusion of horizons

Chapters six, seven and eight have explored and revealed health professionals experiences of dilemma. This chapter focuses on families' experiences of dilemma and the insights this may offer health professionals.

For Gadamer (1989) the task of hermeneutics is more than a procedure of understanding itself because of the hermeneutic circle. The hermeneutic circle involves not only interpreting one view point, but all the parts which contribute to the whole (although the 'whole' is never a finished project). Drawing on the work of Heidegger, Gadamer argues that no interpretation is possible without pre-understandings, traditions or as Gadamer describes it 'prejudices'. For Gadamer the traditions, prejudices and interests we come with contribute to our 'horizon' of meaning. All understandings and interpretations are movement between the parts and the whole and contribute to a 'fusion' of these horizons.

For health professionals the experience of dilemma and understandings that arise from this are from the horizon of being a health professional and a human being. For families this horizon differs in that families are there as parents and human beings. It follows then that although experiences of dilemma may be similar between health professionals and families, they arise from different horizons of tradition, interests and commitments. This chapter, rather than offering to show the similarity of experiences (of how families experience not-feeling-at-home, being thrown, feeling caught and having to live with dilemma) seeks to explore two issues experienced *as* dilemma by families. Drawing on Gadamer's notions of 'fusion of horizon' this chapter offers a way of looking at how the different standpoints and horizons families and health professionals occupy may contribute to different perspectives on the experience of dilemma. The fusion of these two horizons contributes to a fuller understanding of the whole. In the stories families told, feeling 'totalized by indifference' and 'the significance of being a living history' are enduring themes.

For families feeling totalized by indifference is experienced as feeling the object of health care rather than a person(s) whose life encompasses more than just this moment or interaction in time. Families worry when their child is seen indifferently as ‘just another child’ or ‘a diagnosis’ and battle to ensure their child’s needs are met. Feeling totalized for families is highlighted in both the absence and presence of acts such as advocacy and kindness. It is often not until these acts are brought into presence that what was absent is fully revealed. Although indifference is experienced as dilemma by families, the fusion of families and health professional’s horizons reveals that this may be a semblance of what is.

For families the significance of being a living history is also one of importance to them. Dilemma is experienced in the disruption to the continuity to their lives. Health care interactions often only represent discrete events that do not incorporate the fullness of what it means to be family, what has gone before and what will follow. For families, their lives and that of their children are temporal not only as their past, present and future but also in the continuity of existence that continues throughout generations.

Totalized by indifference

Indifference experienced as “just another child”

For Levinas (1999) totality is what renders everything the same, where everything is homogenized or organized into categories. Levinas argues that when things are represented in such a manner, they lose contact with the concreteness of being in the world. For Arendt (1958) this acts as a mechanism of mass indifference and for Levinas (1999) others become ‘faceless’. For Libby it is the worry that her child may be seen as another textbook case of meningitis that causes her to worry.

You have to trust people you are with and yet they are really busy. And it’s kind of ‘just another child’. And you have to put your faith in the doctor that they know what they are doing. [When the doctor came in] I felt “ohhhh is he going to know what he is doing?” I think it is a protection of your child. And he clearly didn’t have children, but you almost feel like you want someone who does have children. It’s a silly feeling but you almost feel that people with children know more instinctively about how children are feeling. Because they’re not like text books! And if you’ve learnt it like that! If they’re only just

like a text book; it's not the same. I know that's not a correct type feeling because there is no reason why he should be any different than any other doctor [Libby: parent].

To entrust is to commit something or someone into another's care, with the belief and confidence that they will meet this obligation. Families are thrown into a situation where they must entrust the care of their child to a health professional but often this trust is not one that has been judged, rather it is born out of necessity. For families, dilemma is experienced in having to entrust their child to someone whose trustworthiness may not be proven yet. For health professionals trust may be assumed by the fact that families seek their services, yet what is sometimes lost sight of is that families do not come willingly into this situation, rather they are thrown into it by the necessity of their child needing to receive health care. Gasquoine (1996) termed the trust that parents must put in health professionals as 'the trusted stranger'. A stranger is someone unknown or unfamiliar and for parents not someone they would be likely to be able to trust with their child without knowing them better first. There are by the nature of their profession, those strangers who we are more likely to trust, such as teachers, police, and health professionals. There is an assumed trust. But families are still left with lingering doubts and watchfulness – can this person be trusted?

For Libby dilemma is experienced in how she can measure trust in this health professional. Should she place her trust in this health professional's knowledge and competency? How important is his knowledge of the physical body; the anatomy of a child mapped out, the intricacies of the cellular level detailed in action? Is his epistemological knowledge of her child enough? Libby suggests not. For Libby dilemma is experienced in fearing that the totalizing impact of medical knowledge from a text book may not capture the embodied knowing she has of her child. She worries that if James is only seen as a category of illness will this doctor see him as an individual? And if this doctor sees him as just 'another child' with suspected meningitis can she trust him to act on 'her child's' best interests? For families dilemma is revealed in the question 'will health professionals hold their child's best interests at heart because they are *this* child rather than because they conform to this or that diagnosis'? For families, dilemma is experienced as being thrown into having to trust because their child needs health care, not being able walk away from the child or the situation and feeling worried that their child will be seen as just 'another' child, rather than 'their' child.

For health professionals dilemma is revealed in the tension of being able to generalize to all children (at the heart of diagnosis) and the particular of each child (as individual). Often in the busy and ‘thrown’ world of practice being able to generalize is the first priority in order to ensure a child’s physical well being. The physical diagnosis of how the child appears is based on the health professional’s general and specialized knowledge of other children who have presented with these signs and symptoms. These signs and symptoms are landmarks waiting to be read to inform the health professional what should be done. But what makes the child an individual, and unique, is often best read by the parents, who understand this child. For health professionals the challenge is to find ways of incorporating both the general and the particular; their expert knowledge of pathology and the parent’s expert knowledge of who the child is.

Libby raises the point that she perhaps would have felt more trusting of someone who was a parent themselves. This raises the question of do health professionals have to have similar experiences in order to be able to empathize or instil trust in others. Would all oncologists have to have experienced cancer, and all midwives be mothers? How do health professionals instil trust that incorporates epistemological and ontological understanding of others?

Indifference experienced as “an economy of representation”

Lanzmann (1991) says that representation is a way in which we can trivialize and make something banal because it becomes a terminal point in history. What he means by this is that representations of another may exclude or kill off other possibilities that were once included. By generalizing we risk reducing the uniqueness of another. Mary describes how the diagnosis her son is given reduces him to possibilities that she herself sees beyond:

Sam was admitted with pneumonia to hospital. Nothing life threatening or that would have any lasting effects on him. But as soon as I mentioned something, and later went and read the nursing notes, all I read was ‘developmentally delayed’. And to me that’s not a diagnosis I have ever used. He had a hemiparesis, some gross motor delay and he’s beginning to have some specific learning difficulties. But I would never classify his as

that! And to see it written! On a piece of paper like that by people who don't know
[Mary: mother].

For Mary, Sam has become classified, been put into a box and claimed by some category from where there may be no return. For her, his issues are not fixed, written forever on a page; rather they are challenges to be faced and overcome in the future. Dilemma is experienced here in the medical diagnosis that attempts to homogenize Sam, and for Mary does not reflect the person he is. Keen (1991) describes the medical diagnosis as “being written on from the outside” in that it claims the appearance of what is but does not reflect the individual experience or potential (cited in Frank, 1995, p. 71). For Mary this diagnosis represents people who do not know Sam or her. She feels that if they knew Sam they would see him more than just a diagnosis – a terminal point in history. For Mary, the words used are a major weapon of indifference, in which people do not really have to know *who* Sam is, rather just the semblance of *what* he is.

For health professionals dilemma is revealed in the question of how to hold open language to acknowledge the individuality of a person? How can health professionals capture the embodied person, when faced with having to be succinct and brief in the recording of case histories and notes? How can health professionals remain alert to how medical language can claim another, homogenizing them and flattening what it means to be a human being when the language of the profession is medical? Dilemma is revealed in the question of how can a health history take away someone's history? How can health professionals stop diagnoses becoming ‘terminal points’ in history?

Indifference experienced as “being faceless”

For families the impact of feeling totalized is often to feel ‘faceless’. To be ‘faceless’ is not to be seen as person who may be suffering. By losing their identity to a diagnosis they become silenced, as what is of issue and important has already been assumed by the health professional. Jessica struggles between trusting the health professional's expertise of her child's medical problem, and feeling betrayed by his lack of understanding for what this means to her:

He was really matter of fact; he wasn't particularly interested in what you were going through. It was like 'let's deal with this problem and then go away thank you very much'.

And I was feeling totally shattered. Here I was with a baby that potentially had damaged his oesophagus. It was just huge. And it's that feeling of time, just not being rushed through. I felt so insignificant. This little bundle of eighty dollars that is going in for five minutes. But I also have complete trust in his experience because that is what he is doing all the time. But it is a little bit of a dehumanizing process [Jessica: mother].

For Jessica her identity at this point and time has been reduced to a 'bundle of eighty dollars for five minutes'. Time is precious and in this case time is literally money. For Jessica dilemma is experienced as the worth of her experience having been reduced to some monetary value. Although she respects what this health professional has to offer, she feels disrespected and dehumanized, trivialized in return. Not being seen – not having her doubts and fears acknowledged makes Jessica feel insignificant and 'faceless'.

For health professionals dilemma is experienced as always having to work within the confines of time. Often there are others waiting to be seen; just as anxious to be given expert advice or intervention so that they can be more certain and address the issues of what will come next. The dilemma for health professionals is if they give more time to one person who do they have to take it away from? Is it better to see fifty families a day when the waiting lists are so long, or to only see twenty, thereby confining others to longer periods of anxious waiting? The challenge for health professionals is how to acknowledge the anxiety of families when time is so precious, and remembering what is part of their every day ready-to-hand is new and uncharted territory for families.

The semblance of indifference

What may appear as the indifference of health professionals may in fact only be the semblance and highlights the different horizons of disclosure health professional and families inhabit, and what may be concealed by them. In the previous story this paediatrician may have been indifferent to Jessica's anxiety but equally may have been thrown into a practice world of having to be accountable to the clock and those still waiting outside. If we remember back to Brooke's story on page 131, Brooke tells of holding the head of a young girl who is so distressed that her nose bleeds. Brooke is devastated by this experience yet how would it have looked from the outside? Would Brooke's lack of willingness to participate in this situation have been visible? Here a

mother recounts her experience of her child needing an IV inserted and her impressions of the health professionals involved:

One of my worst memories was when they wanted to get a drip into him. And he was quite a chubby little boy and he was absolutely beside himself. I don't know how many people it took to hold him down, but it was just such a nightmare really. And it wasn't right the way they did it, it was frightening! I don't know exactly how they should have done it. I guess I didn't know how much time was of the essence. We were really distressed and extremely concerned, but there had to be a better way. I think it was the fear in his face. They kept having another go and another go and it got worse and worse. I should have had the guts to stand up and say "just give him twenty minutes and we will have another go". But they had their own timetable [Theresa: mother].

Theresa here encounters health professionals as the faceless 'they', who hold her son down and frighten him. Although she is unsure how much time is of essence here therefore making these actions necessary, Theresa never-the-less feels this situation is wrong. As nobody explains what is happening and why, and Theresa has no way of knowing how 'they' should have inserted the IV and the health professionals remain an anonymous but threatening presence. For Theresa dilemma is experienced in feeling caught by not knowing, and passive in the face of what appears to be aggression on the part of others. In normal circumstances a mother would never let another inflict this pain and distress on her child – there would have to be a very good reason – but what is the reason here?

Here dilemma reveals that whilst health professionals remain an anonymous presence families have no way of seeing that 'they' perhaps would not wish to be there and contribute to the distress of this child. The paradox here is that parents have no way of knowing how distressed some professionals may be in doing what is their professional job, yet if parents did become aware of the health professionals distress would it be because the health professional was no longer able to competently carry out this task? Dilemma is revealed in that sometimes health professionals must stay 'indifferent' so that they can carry on with the task at hand. For some maintaining the shield of indifference is the only way not to be overwhelmed by the non-indifference they feel (chapter eight).

For health professionals the dilemma is how to claim their own facelessness. How would honest and open communication have made a difference to Theresa's interpretation of what happened? Would Theresa have been able to rationalize what needed to happen if she'd had more information? Would she have been better able to say 'carry on' or 'stop!'? Would she have seen the health professionals in a different light; just as thrown into the circumstances as she was?

Health professionals are thrown into situations where at times prior explanation becomes impossible. The dilemma is should health professionals explain or apologize for a terrible situation or is to admit that the situation was not optimal to risk opening the door for doubt in the competencies and abilities of the health professional? How open to liability can and are health professionals willing to be?

Having to do battle against indifference

For families the consequences of feeling that health professionals and the health system may be indifferent to their child is to battle against this. Although they recognize the need to overcome and challenge anything that may reduce their child to just another child in the system, they also point to the energy that is required in having to battle. For Mary and Theresa the world of health care takes on a feeling of 'not at home' as they realize that they must advocate in a system that is supposed to be there for the sake of their child:

The things that I have found most stressful along the way are having to fight for the care that your child needs. Having to really advocate! I just think you shouldn't have to do battle. And just going to interviews, knowing you're going to have to do battle, spend time in the interview justifying why they do or don't need to see your child again. [Mary gives this example later of a therapist leaving and the service not able to find another to replace her]. I went to see the manager and she said he probably won't be seen again, her rationale was that if he's had intervention before he was five they've probably fixed him. So they're going to assume that he will not have any further problems. And you just go "well they're requiring intervention for fine motor skills before they are five, and they've yet to be challenged"! How are they suddenly going to stop? When the pressure gets put on? And there is nothing there for you! And when they fail it may be explained as being a boy, and another 8 months in which time they fall behind. So it might be another 16

months before you're back in the system. It's disgusting. It's not a service at all! [Mary: mother].

The world of health care is revealed as less than ideal when Mary realizes there is nothing there for her. The category that Sam has been placed in stops at the magic age of five when presumably every thing would be 'fixed'. There is no plan, no safety net, and no continuity to ensure that Sam will continue to have his health care needs met once he is five. For Mary dilemma is experienced in being caught up in a health care system that should be there for the sake of her child, yet she must do battle every step of the way. Health care is not a right for Sam, instead Mary must keep justifying, battling against the impersonal 'they' of the health system. Here dilemma is experienced because the costs that the healthcare systems measures do not always reflect the human cost – the cost that is borne by families. Mary experiences dilemma because the idea that health is for all is in reality a contested ground of resources.

As for Mary, Theresa experiences battling for Paul as exhausting as she tries to ensure Paul's (acute) health care needs are met:

I had seven nights in a row where I stayed in hospital with him. God it was hard work. After the third night into it his head started to blow up, he had this fluid build up and he looked like ET. It was just awful. I didn't really know what the hell had gone on and there was a nurse there whom I had no confidence in. He didn't have any sureness in his stride or movement; he always hesitated before he did anything. I just felt he didn't know what he was doing. Whether he did or not, I don't know but I said to him "do you know what has caused this?" – this was at 4.00 in the morning – and he said "no, I have no idea". So I said to him "well if you don't know what's caused this you should ring the specialist. Give him a call; I don't care what time it is, just ring him. He [Paul her son] can't keep going on like this!" I think he was caught in a tricky position because he would get a barrelling from the specialist if he was going to wake him up at 4.00 in the morning. Anyway I didn't care. I wasn't concerned about that. The specialist came in and drained off some fluid and things righted themselves after that. But it was really frightening because I was there on my own; I had no one else I could go to. I had to push this guy to do what I wanted him to do because I thought something needed to be done; because he just didn't seem to be in control of the situation [Theresa: mother].

For Theresa having to battle is to push to get her way; taking a stand and saying ‘ring now!’ Here doing battle feels alone, and is frightening as Theresa is one person in the midst of a health care system with experts who ‘know’ what they are doing. For Theresa it is not the act of having to advocate that is hard, as she suggests the primacy of her son’s welfare comes before worrying about upsetting someone; rather it is having to be vigilant, always watchful and not being able to trust the health care system that is tiring. It is constantly being on guard, being prepared to speak up and act for the best interest of her child that is exhausting for Theresa.

For health professionals the dilemma is that they are fallible and do not get it right all the time. This nurse may have been thrown into looking after a sick child beyond his knowledge or capabilities. He may have been caught between the competing demands of this mother’s concerns and not wanting to disturb the consultant. Health professionals work in health systems that are constrained and limited by finite resources of both money and manpower. For health professionals dilemma reveals the paradox of working in a system that is supposed to be for the sake of the child, yet faced with parents feeling they have to battle to have their child’s needs met.

Battling indifference through strategic alliances

For these mothers doing battle became a matter of strategy. Once they realized that they would be responsible for ensuring that their child’s needs would be met they quickly assessed those who would be useful in their campaign and those who would not.

At times I think I p’d the odd person off but quite frankly no one that mattered. Anyone that mattered...I guess again I had made an assessment of which key people could help us and who I needed to have on side [Theresa: mother].

I guess when you know the system a bit you choose to only go to people who you know are right for you. And when you come across people that aren’t right for you then it is awful [Mary: mother].

Here strategic alliances becomes about those ‘faces’ that will help against being lost in the faceless ‘they’. Here the relationship with health professionals is reduced to health

professional's usefulness, their ability to further the health outcomes of the child and the resources they have which are to be harnessed and managed. It is interesting that much of the family centred care literature has focused on how health professionals can better foster the relationship with parents, yet parents are also adept in assessing which relationships will be beneficial to them. Dickinson (2004) in a study of health professional and family relationships describes this as 'going around'. For families dilemma is experienced when they strike health professionals who will not be helpful as then battling becomes harder and 'awful'. The dilemma for families is that in many circumstances they have little control about which health professionals they may come into contact with.

For health professionals, families' experiences of establishing strategic alliances highlights that the relationship can be one where families may feel totalized or powerless, but equally also one which families use to their own advantage. The experience of dilemma reveals that although families are thrown into the family / health professional relationship, strategic alliances are one way of fostering possibilities for the child.

Having to 'own' your battle

Both Theresa and Mary suggest that doing battle is about 'owning it for yourself'; that there will be nobody else to step into the breach and that only they have the commitment and endurance to battle for their own child.

I struggle to get the children's needs met and I am a fierce fighter for them. I know the system and know how to deal with them, what to take and what not to take. I feel a seasoned traveller down the road. I wonder about other people...I just don't know what happens to them. They must get lost in the system or give up. Callum and I feel very capable of dealing with what has gone on and I look at friends and think 'I don't know if you would have managed if you had been dealt that hand'. I mean they can't manage if their children won't eat their vegetables at dinner or have their afternoon sleep. I don't know how they would cope with anything other than regular parental anxiety [Mary: mother].

I just found the whole way through the entire process when dealing with the health system, you had to own your own problem and fight your way through it one way or the

other to get the best outcome for your child. You could never leave it to anyone else, because quite frankly you could just end up nowhere. I feel confident in getting the sort of health outcomes I would want for Lilly [Paul's sister] because I wouldn't give up, I'm like a dog with a bone. But I'm not so confident everybody could. Because it is only as long as you take ownership for your own situation [Theresa: mother].

Mary is a fierce fighter and Theresa suggests she is like a dog with a bone. Neither will give up as they feel that if they do not own their own battles, they will end up nowhere. Both families have realized this knowledge but wonder if anyone else would have the fierceness of conviction to battle as they do? For them doing battle is not only to gain sovereignty over being totalized, but also over their own destiny. For Mary and Theresa being authentic is realizing that 'they' (the health care system) will never have the interests or care of their child at the centre of their being as they do. Being authentic here is that they believe that only *they* love their child enough to do what is needed, required to move forward, to gain ground, to win the small and big battles.

For health professionals dilemma reveals that the notion of advocacy may be one that is taken for granted and is more clearly revealed in the face of non advocacy. Families must fight and advocate for their child in the vacuum left by there being no or limited advocacy for them by the health care system. The challenge for health professionals is to look beyond their scope of practice to recognize there are many parts to the whole which act as points of conflict for families. By being aware of the whole of the context in which health care takes place in, health professionals may better understand how this may impact on their part.

Kindness overcomes indifference

If the need for advocacy is revealed because of its absence, likewise the experience of feeling 'faceless' is highlighted in the presence of being acknowledged or treated with kindness. Here the absence of one mode of being (anonymous) is revealed more clearly when it was brought into presence by the opposite (being addressed).

When the student came in it was really nice because she was the first person to who really asked how I was. And you've been so stressed, and you're so emotional that when

she asked I just cried. By nature I am a strong person, but if I had not been she would have been a real life saver. She could have answered questions if it was worse. She came in and asked if there was anything she could do, and she took John (Libby's older son who was with her at the time) to have something to eat. Unfortunately for the nurses they just don't have time to do that for parents [Libby: mother].

Here kindness breaks down the totalizing effects of having to be a strong parent, who copes in the face of adversity. The student in asking how are 'you', addresses Libby as a person, and suddenly she is no longer the coping parent but someone who has been acknowledged as tired, hungry and anxious for her son. Unfortunately it also highlights the absence of feeling 'you' when others are too busy to acknowledge this. This student sees Libby as a person – a worried mother who also has another child with her who has had nothing to eat since lunch time (and it is now late at night). The student sees that Libby cannot leave her younger child alone (and the nurses are too busy) yet the other child also has needs (such as food). The student sees this mother struggling with the uncertainty of what her child may have and trying to remain strong in the face of this concern and competing demands. Her simple 'how are you' addressed Libby as a human being – not just as the mother of this child who has been admitted with suspected meningitis.

Mary too experiences kindness at a time when she is given devastating news:

When Sam was seven months old he was diagnosed with cerebral palsy with a mild hemiparesis, and that was obviously really stressful. But the person we dealt with was fantastic. Any tensions about his diagnosis I don't carry with me. Because, you have to excuse me [Mary cried here in the remembering of this person] ...because he was so lovely about the things that he said that I hadn't wanted to hear. Because they were said in such an experienced and kind way [Mary: mother].

Here for Mary it is the kindness of this health professional that breaks through to her as a vulnerable human being and who is able to tell her gently all the things she most dreads hearing. Here Mary feels supported, although the words that are spoken will change her life and that of her family forever. It is not the diagnosis that Mary cries about, but as with Libby it is the kindness of a stranger that overwhelms her.

Situations may come and go and these may be stressful, but what adds to a family's resilience is how they are supported. This support may be in the little things, the words that health professionals' use, that acknowledges the pain, grief, the difficulty a family are facing. It is not what is said but how it is said. As Levinas (1989) suggests when health professionals are able to say 'here I am' families experience this as an acknowledgement of their humanity. For Levinas the commitment to another is not the 'said' but the 'saying'. Health professionals' kindness, their care not to wound or add further to families suffering through unintentional acts or loose words helps to hold families integrity together. The dilemma is that once families have seen and experienced kindness it makes being 'faceless' an even more bitter pill to swallow.

For health professionals how can they ensure they address each person as embodied here and now in this particular place? How can they maintain someone's personhood when faced with competing faces, demands and time? Although these questions remain pertinent, health professionals experiences of seeing the face of the other (chapter seven) suggests that they do see and feel for the suffering of children and families and are willing to stand there to say 'here I am'.

The significance of family as a living history

The beginning...

For families what overcomes totality, what draws all the parts into the whole is that they *are* family. For them being family is a way of being-with-others-in-the-world; it is not a thing it is who they are. Their family exists prior to birth and beyond death and is a 'standing out – an ecstasies' of the past, present and future. Families exist in lineage, in generation, in language, in genealogy and endure because there are those to remember the arrival and passing of others bonded by ties of kinship. This is the horror of genocide, where the perpetrators seek to wipe out a whole genus and generations by erasing all traces of existence of those who remember. If there is no one to remember then continuity is broken. If there is no one to remember then they no longer exist (Hatley, 2000). Families carry with them a living history, so that it is not just this one experience that exemplifies their life to date, rather it is everything that has come before and will go

after. For Heidegger (1968) one's own past is always the past of generation which does not follow along behind one, rather it is already going ahead. Time for families is understood as a living history

Shall I start with when he was born? [Jessica: mother].

I will start right from the beginning when he was first diagnosed [Theresa: mother].

Every story, every life always has a beginning. **For health professionals** the dilemma is that in health care so often the focus is on the here and now, what is relevant and pertinent to the issue at hand that it is easy to forget the temporal nature of time. Children and their families do not just come into a health care setting with a history of a disease, illness or trauma, but into this encounter with a lived and living history. How health professionals acknowledge this history, the meeting of the past, present and future may either contribute to families feeling that they have been 'written on from the outside', or reaffirm the continuity of their lives. Every thing that has contributed to them being there will influence how they experience the present moment and the future. In essence families' lives are storied, and the story never ends.

Life is a meeting of the past, present and future

For families each experience is not a discrete one that stand as isolated incidents. Each interaction with health professionals contributes to how they will view past experiences and future experiences.

I remember a comment once and it will stick with me forever. She [a dietician] said to me that he's [Mary's son] on the 25th percentile for weight and on the 75th for height and that he was at risk for permanent developmental delay because of nutritional deficits. She told me he was failing to thrive. I said that's a really unhelpful thing for you to tell me as a mum. To say that to some one! Of all the things we had been told that was the worst. It was the way she said it. She didn't take the time...she just got all these figures off me and put them into the computer and then just spat back he was only getting 65% of this and 25% of that. And it made me feel awful as a mother, as if I was responsible for any shortcomings he might have [Mary: mother].

In the span of this dietician's career this is one interaction amongst many. For this mother the interaction marks a specific time which she will never forget. This moment is imprinted on her and becomes part of her history. *For health care professionals* their knowledge and experience is an accumulation of many interactions throughout their career. For families each interaction is particular and personal. For this dietician the information that she gave this family would have been part of her every day practice, in providing a diagnosis and interventions to alleviate what she sees as failure to thrive. Yet for this mother the impact of this one interaction is far more immense than this dietician could perhaps have ever imagined.

For Mary, this health professional has struck a blow at her competency as a mother. Mary feels that not only has she made a statement about Sam's weight with no understanding of the contextual issues, but she has also made Mary responsible for these shortcomings. This interaction does not point only to the here and now of Sam's health issues, but has cast a shadow over all that has occurred that has brought Sam to this point. This one interaction reaches into the past, but also into the future and influences how Mary will feel about future interactions with this health professional.

The dilemma is when language and speech is assumed to be neutral it can blind those who use it to the consequences of the information they share. *For health professionals* dilemma is in the question of how to be aware of how the information they give (and what is demanded of them) will be interpreted. How can they use words carefully when language is all there is? For Levinas (1989) both the speaker and those who are spoken to are made vulnerable by the use of language. Language and speech are never neutral.

As with health professionals, experiences of being in dilemma leave imprints that families carry with them. These imprints not only become part of who the family is and affect future interactions with health professionals, but also mark time as significant.

The whole experience has really affected me in terms of ever going back into the hospital – particularly in the early days I would just shake. In fact the worst time was when Lily had her lip stitched. Because Paul had died in April and that was the following February. That was my first going back and that's why I think it had such a profound impact on me.

But the doctor who dealt with Lily – he was so incredibly gentle, passive and calming. But I still really struggle with hospitals because it runs back to the memories. Not just about Paul, but about trust, and you're just a little bit more reserved really – it's like doubt [Theresa: mother].

Here time is not just a collection of experiences; it is marked by memories that endure. Time for Theresa is marked as the last time in hospital with Paul before he died and now this time, after Paul has died. The enormity of going back, of having to revisit the memories associated with being in hospital means that Theresa struggles and “shakes with dread”. Here the kindness and gentleness of this doctor goes some way towards ameliorating the effects of previous encounters, yet Theresa says she will never be able to totally trust health professionals' again.

For health professionals the dilemma is that once trust is gone how do they win it back? Trust can be lost in seconds, yet it can take hours, weeks and years to regain this lost ground. Dilemma reveals that trust is very fragile thing that can rest on one encounter or the accumulation of moments and encounters. Here dilemma reveals the precarious nature of being thrown into a world of practice for both families and health professionals.

Life is a gradual unfolding.

Time is significant for families; it marks events that have changed the course of their lives. For families time is a passage, a journey with often little idea of what will come next. Mary describes this passing of time as a gradual unveiling:

It's been a gradual unveiling. You get given information at the beginning and I guess it is my experience having a child with a disability is that you just don't know what it will involve. It's just a label. If you were told at the beginning that they might end up with this or that, that at 12 all these things would go along with it...it would just be too much to deal with. It's like as each new stage comes along you're revealed what you will and won't have. And that's how it's been alright [Mary: mother].

Mary suggests that labels such as ‘disability’ say nothing about what might be revealed and the possibilities yet to be imagined. Rather for Mary life is a gradual unfolding of what is yet to be revealed. For her ‘getting the information’ may not prepare families for

what they may or may not have and in fact may overwhelm families. Here life as a gradual unfolding is a way of living with uncertainty and maintains hope for the future.

For health professionals the dilemma is how do they keep the possibilities in play for families, how do they engender hope whilst being realistic and honest about what the consequences may be? How do they prepare families for what may be, whilst keeping in play alternative futures? How do they acknowledge that families have the right to good information, whilst acknowledging that sometimes life must be lived to understand the meaning of such words?

Not knowing is hope

For families not always knowing explicitly what the future holds also paves the way for hope. Families are always embodied in hope for their child even before the physical presence of a child announces itself. The hopes and dreams for this child may be small or grand, not only for a lifetime but generations to come, and is a thread that represents the possibilities for the whole family. For health professionals foresight (chapter six) often contributed to an uncertainty of what the future might hold. For families however not knowing what the future holds keeps hope in play. If there is not definite future then there is still opportunity for different possibilities. Here Theresa describes her son's future as unknown and unsure, but one still with hope.

We were under an oncologist and they came in and said that she had been taken off the job and that they were evaluating all of the cases. We had been led to believe prior to that that we were on a winning thing...they said we had to make a decision about radiotherapy, but that he would be a different boy if we radiated him but that without it he had a very limited chance of survival. We didn't come away thinking that we were fighting for nothing because you still hold on to hope, even though it is still a pretty tough battle that you are fighting. You still hold on to each other and you never let go of it until they let out their last breath. That's part of nature's way I think and it allows you to cope [Theresa; mother].

For Theresa and her family, dilemma is experienced as a break in trust with what appeared known about how Paul would survive his cancer. It appeared there was no doubt or uncertainty in the positive outcome predicted for Paul's recovery. Now Theresa

is faced with uncertainty of what the future may hold and questions of should they go ahead with radiotherapy and will Paul survive? However not knowing what the future may hold, also functions as keeping possibilities in play, therefore contributing to being able to cope in the face of such an uncertain future. Here time is hope, that there still are possibilities for Paul, in the duration that carries on until his 'last breath'.

Levinas (2000) writes that "what is not yet is not, and is nowhere" (p. 95). He suggests the future cannot pre-exist as some sort of "predetermined end of history" (p. 95). Dilemma is disclosed in that we can never truly know what the future holds as it always lies just before us. This contributes to the future as being seen as uncertain and unknown, but Levinas also suggests an alternative view of the future as 'pure hope', in the possibilities that still lie before us.

Dilemma is also revealed in the idea that to know unequivocally what the future holds is to have none. To know explicitly what lies ahead is to no longer have hope for alternative possibilities. Hope is like a thread, a promise that simmers in the distance so that if we do not know the future, then there is the possibility that predictions and forecasts may have it wrong. Hope is holding on to what is possible and what may still be possible. It is the antithesis of despair and signals that the battle is still worth fighting. Sacks (2005) writes: "Hope and tragedy do not differ about facts but about interpretation and expectation. But they make a moral difference. Those who hope, strive. Those who are disillusioned accept" (p. 166).

How do health professionals foster hope with the realistic expectations of what is to come? How can health professionals foster hope, when if their predictions are wrong, they may be accused of getting it wrong, of giving false hope and promises? In the face of giving false hope, which may wound, and distress, how do health professionals frame their statistics, what they know may be possible in the future? Do health professionals lean to the more generous side of hope, or stay in the safety of the margins of what they know are the realistic or predictable outcomes? How can health professionals be authentic in which possibilities they must seize upon?

Whilst Heidegger suggests authenticity is seizing those opportunities before us (because life is finite), for Arendt (1958) the notion of natality is just as important as that of death.

For her natality is that of birth, where the presence of something new makes itself felt in the world. This newness is what makes possible new possibilities and hopes for the future. For families it is the possibilities and hopes that children carry that ensures presence through time. Being authentic then is being rooted in natality so that we preserve the world for newcomers and hope for the future. For Arendt what is anew, what is possible is of more importance than the finiteness of possibility.

The resonance and continuity of life

If actual possibilities end with death, the resonance of another does not. The passing of a child in death does not signal the end of their existence or significance in memory.

It was quite lovely the day he died. He was lying in bed and I was tidying up the room. I'd just read him the story of the little black hen, which was a family favourite, and Lily was sitting on the floor. And it was funny because he was getting pissed off with Lily having his toys. He said "I want my boat" and I said "yes you can have your boat". And slowly all the toys were coming off the floor and going to Paul! And you could see Lily thinking "what's going on here!" He couldn't move but you could see his head and every time something would go up he would be more satisfied. And that was really the last thing he did before he slipped into a coma. As I called to Andrew I wonder if there were tears in his eyes; I wonder if he knew what was going on. A few friends and family came around and it was quite special. We were just holding his hand; we just kept talking to him and comforting him. When he died they all left the room. We stayed with him and actually I slept with him because I thought you can't leave him there, cast him out and because he was sleeping in our bed. You can't...I just couldn't leave him alone [Theresa: mother].

Sometimes we the readers need to pause. The pause that comes before any interpretation of what this may mean to the phenomenon of dilemma or the experience of being a mother whose child dies. As a mother I cannot begin to imagine what it would mean to lose a child – it is perhaps an experience that I do not want to or could not imagine. But before giving a possible interpretation, we the readers should perhaps pause and acknowledge, honour the experience of this mother by our attentive silence. The silence that comes before any possible explanation...

For families the death of child does not mark the end of time, rather it is the event that marks a passing into another mode of time, where the child becomes lived in memory. Didion (2006) writes that Episcopalians at the graveside say ‘*in the midst of life we are death*’. It is not that death is ordinary or that life is extra-ordinary. Death comes in the midst of living, and it is in the ordinariness of this day that Paul dies.

When a loss or tragedy occurs we remember the detail, the ordinariness of the day that holds the memory of loss in it as some sort of referential point from which to navigate. Paul’s death is not an isolated event that stands out alone amongst other experiences; rather it is the normalness of this day, his mischievous interaction with his sister that holds itself in memory. It is the day that is remembered, the incidental detail that marks this as the day that Paul died. This day marks the end of a long struggle for Paul but also marks the beginning of time where the family must mourn his loss.

Dilemma is in the question when does presence become absence, when does the passing of time erase what has been? Does physical death signal the end of something or the beginning of another presence in the world? When does a child stop being a child? For Theresa Paul’s death does not mean that he stops being her son and in the hours after his death she sleeps with him, as she couldn’t abandon him, leave him alone. Even in the loss of Paul’s physical presence, what embodied Paul stays strongly with this family. Paul’s photos hang everywhere on the walls, and each year on the anniversary of his death the family set off bouquets of brightly coloured balloons. Paul’s presence in this family is still palpable years after his death, and even in the living his absence is brought into presence by thinking that “*Paul would have started school this year*” or “*Paul would have been doing this or that*”. Paul will always be Theresa’s son; it is a relationship that defies an ontical description, it needs to be understood ontologically.

Ontologically we are bound by our family ties in perpetuity – everyone has a mother and father; everyone is a son or daughter. There are always those that passed before us and there will be those who will follow. These relationships do not pass with old age or death. Heidegger (1962) suggests we cannot experience death, but in the death of another we can experience the vacuum left, the resonance of their Being. It is the absence of someone that we are aware of their presence. Michaels (1998) asks “at what moment does wood become stone, peat become coal, limestone become marble? The gradual

instant” (p. 140). Death may signal the instant moment of a physical death, but does not diminish the memory or significance of this event. The gradual instant is absence held in presence through memory, a resonance through time.

Simpson (2002) points to the significance of remembering, that if death is only seen as a physical event, if we try to pretend that it doesn't happen, we lose the ability to remember, honour and mourn the significance of the other. The other has become totalized. He says that:

We strive to make death a stranger, to live safe lives, to hope against all reason for immortality, and yet death is the one thing that defines us all. It is never far distant from life and the dead are never far from the living. The problem is that we shut death out of our lives and so our dead become strangers to us instead of the friends they once were (p. 69).

Death and loss is not something that can be theorized, or bracketed out of our lives. Didion (2006) in reaction to being theorized (by health professionals) writes:

Were you there? ...were you with me and “the one who died” at the Punchbowl in Honolulu four months before it happened? ...Did you catch a cold with us in the rain at the Jardin du Ranelagh in Paris a month before it happened? ...I don't need to “review the circumstances of the death.” I was there...I didn't get “the news,” I didn't “view” the body. I was there (p.56).

For families and their children they are ‘there’ not only in the moments before, but also in the moments to come. For families, receiving health care is only part of their journey as a family. To break this into discrete interactions of time does not capture the fullness of what has gone before (prior to even birth) and beyond death. Health professionals come in and out of the families' journey through life, yet for families this journey is continuous with these interactions marking events that occur on the way. Families are witness to their child's presence in a way that incorporates the fullness of their lives, rather than encounters defined in definitive space and time. For families the past, present and future

is held in the promise that a child holds prior even before conception, and the loss of possibility when their presence withdraws. For a parent a child is the possibility of a continuation of their own storied existence, to be part of the thread, the weave in the fabric of life. Le Guin (1989) says:

To tell a story is...a way of leaving a trace, of telling how someone lived and died. If nothing else is left, one must scream. Silence is the real crime against humanity (p.27).

For Levinas (1985) every story, every person leaves a trace and every life has significance. To disrupt the story, to reduce someone as faceless is the silence in which Being is totalized.

The dilemma for health professionals is how they can incorporate everything that has come before and everything that will follow when their interactions are bounded by a finite space and time? How do they acknowledge the ‘gradual instant’ for families while working in a system where the ‘instant’ is prevalent? The instant is what is written down, which becomes a documented history of what happened then and here in this moment. How do health professionals keep this open as a testament to the significance of the gradual instant? Open to lives that are a storied existence rather than a case history? How do they hold on to the meaning of ‘Being’ for children and their families over physical being? Peter and Rosemary suggest that one way is to say “here I am”, which acknowledges the significance of another’s existence and possible suffering. For health professionals, families experiences of dilemma reveals that representing them as an objective facts, and a series of disconnected events does not help to understand the meaning of what it means to be human. Such descriptions do not either help health professionals or families to understand what it means to live rather than to be reduced to a category, a theoretical perspective, or a series of interactions and interventions.

For Levinas although ‘my’ possibilities end with death, in the other as *humanity*, life goes on. He suggests that Being-with-others continues in the other, as family, generation and community (of health professionals). Michael’s (1998) says “it is the Hebrew tradition that forefathers are referred to as ‘we’ not ‘they’. This encourages empathy and a responsibility to the past but, more important, it collapses time... If moral choices are

eternal, individual actions take on immense significance no matter how small: not for this life only” (p.p. 159-160). For Levinas this is the ethical where humanity does not exist as an anonymous ‘they’ or individual ‘I’, rather we exist in a world as ‘we’. For families being a family is always embedded in ‘we’. For health professionals being-in -a -world of practice is to always be with others. This collective sense of community reaches not only into the past but also the possibilities and hopes for the future.

Conclusion

For families the experience of dilemma reveals that they feel ‘not-at-home’, ‘thrown’ and ‘caught’ in a world of paediatric practice. For families their concern is that others may be indifferent to their child and rather than ‘helping’ health care may totalize their child. They worry that their child may be just another diagnosis, another fact or figure, another appointment in the midst of many. For families their child is more than ‘just a child’ and ‘this particular situation’, rather their child embodies the hopes and dreams of generations before and those yet to come. Although exhausting, and often frightening families feel protective of their child, and will do ‘battle’ to ensure their health needs are met.

The fusion of horizons between health professionals and families reveals that the concerns and interests one brings to the situation influence how dilemma is experienced. Both health professionals and families are thrown into a world of paediatric practice where the commitments they bring may impact on how they are thrown and are able to act. Often health professionals are required to act in ways that may be hidden from families so that what health professionals experience as feeling caught may be experienced as feeling totalized by families. The dilemma becomes one of finding ways of reconciling the realities of practice with families’ experiences as a living history.

Chapter Ten

To end is to go back to where one first began

Discussion and recommendations

We shall not cease from exploration
And the end of all our exploring
Will be to arrive where we started
And to know the place for the first time
(T.S. Eliot, 1969, p. 197)

This thesis has explored the meaning of experiencing dilemma for health professionals and families. To return to the beginning, to return the findings of this thesis to the original question of ‘what is the meaning of being in dilemma’, is as T.S. Eliot suggests, to understand the meaning of being in dilemma *as if* for the first time. The understandings uncovered in this study bring with them a sense of ‘seeing anew’ what was already known; of understanding at the end what was already understood at the beginning. The restless ‘to’ and ‘fro’ within the hermeneutic circle, between the parts and whole, and the beginning and an end¹⁴ (of this thesis) has brought understandings of dilemma back to something that is not different, but rather as something that has become itself. In ‘seeing anew’ this thesis brings a deeper understanding of the meaning of being in dilemma in pediatric practice.

This thesis has uncovered that the experience of dilemma for health professionals reveals a world that is uncertain and questionable, where they are thrown into having to make uncomfortable choices and must live with the painful consequences of their actions. For families the experience of dilemma reveals a similar phenomenon. However, whilst the phenomenon of dilemma may be similar, the context and concerns into which health professionals and families are thrown reveals differing perspectives.

¹⁴ *I would argue a ‘pause’ as understanding is always on the way and never ‘complete’.*

The chapters of this research report (the parts) have revealed different vantage points that uncover the phenomenon of dilemma. The findings of this study show that the experience of dilemma for health professionals is revealed and announced in the mood of not 'feeling-at-home'. Not feeling-at-home opens the world up for questioning in a way that it now appears uncanny, unknown and there is no certainty in the answers that health professionals seek.

Health professionals in this study are 'thrown' into a world of practice where there is a dissonance between what they would wish to do and what they must do. Health professionals are 'caught' in having to be there, in circumstances beyond their control, being witness to the suffering of others. Here dilemma reveals the fallacy of choice in that health professionals are compelled to act and choose possibilities that are not wished for.

The consequence of having to live with dilemma for health professionals is trying to find ways to live with the discomfort and uneasiness. They try to find rationalizations – what they 'tell themselves' in order to overcome uncertainty and navigate back to some safe shore. For some the only way of living with uncertainty is to accept it, whilst for others 'forgiveness' becomes a way of finding peace. Whilst for health professionals' living with dilemma is an affirmation of their own humanity and that of others, they worry about the precarious balance of trying not to become too sensitive and overwhelmed by the suffering of others; or becoming desensitized and inured to the distress of others.

The experience of dilemma for health professionals reveals the temporality of dilemma where the experience of dilemma reaches into the past, present and future. Dilemma may not only be experienced in the 'here and now' of this particular situation, but also looking back to the past where actions may be interpreted in a different light, or projected into the future as the consequences of any action remains unknown and uncertain. The experience of dilemma for health professionals is one that follows them where they must live with the resonance, the imprints of being in dilemma; of the stories that continue to haunt and dwell within them.

For families the experience of dilemma reveals a similar phenomenon of the world not feeling as 'at-home', of feeling 'thrown', of feeling 'caught' and having to live with the consequences and 'imprints' of being in dilemma. Although families and health professionals may experience the phenomenon of what dilemma 'is' similarly, the context in which dilemma arises 'as' differs. Each group bring with them different cares and concerns, different ways of being thrown into the world of pediatric practice that contributes to a different perspective of the experience of dilemma. For families their concerns are for 'their child', 'their family' and 'their history'. Families experience dilemma in the practices that 'totalize' their child and provoking feelings that they must battle against the loss of their unique child. The experiences and perspectives of families and health professionals' often remain 'hidden' from each other.

Returning from the parts of this thesis to the whole shows that dilemma is not just an event rather it is 'clearing' that reveals what it means to be a human being. Dilemma is not just a situation with certain attributes that are put to question; rather it is an experience where we are put into question by the experience itself. For health professionals being put into question is to be called both by conscience and the call of the other. This 'call' is to be thrown into life, where there is no choice and health professionals find themselves in the midst of having to learn to live, suffer and carry on. Experiences of suffering, meaning and death are not problems to be solved; rather they involve a call to authenticity, commitment and courage, to ways of 'becoming' and living. Being in dilemma reveals moments of authentic being where we truly understand the thrown and contested ways of being human.

This study has revealed that health professionals are involved in the lives of others which cannot be viewed from a distanced perspective. They are involved in the flux and flow of others lives; moments of hope and despair, and feeling others pain, fear and suffering. Health professionals are exposed, and witnessing the lives of others is both a privilege and a burden. Being witness brings with it gifts of the capacity to feel moved and be human. Yet there is also a burden of the imprints such exposure can leave. Dilemma exposes what it means to be human and that there is no escaping this.

Questions of dilemma, or what to do or how to act are in the end reflections of what it means to be human; of how to act humanely and how to live with the consequences of our actions. Being in dilemma reveals what it is that concerns us, the questions that worry us, what we hold as ‘good’ or ‘truth’ and calls us into ways of thinking that are uncomfortable and uncertain. These ways of thinking reveal life as something that cannot be solved; rather how we are thrown and must carry on. Living with dilemma is an act of memory, a moral way of remembering, of trying to find a sense of coherence with one’s experiences and find a place of authentic dwelling. Being in dilemma reveals that we cannot choose the circumstances but we can choose how to be ‘human’.

Although this study has avoided representing dilemma as ‘moral’ or ‘ethical’, how health professionals experience dilemma would suggest there is a moral or ethical nature to this. The findings of this thesis (chapter seven) suggest that being called, and acknowledging the face of the other is the ‘ethics as a first responsibility’ as suggested by Levinas (1998) (chapter four, p. 85, p. 87). Health professionals respond to others prior to any theorising about the person or situation. Thinking of the other (chapter eight) is also a way of ethos or dwelling that Heidegger (1968) suggests is “a remembering of who we are as human beings” (p. x). Sacks (2005) although contradicting others definitions of ‘morality’ or ‘ethics’ provides valuable insights into how we may think about the epistemology of dilemma or the ontology of being in dilemma. Sacks links epistemology to justice:

Justice is and must be impersonal. ‘You shall not recognize persons in judgment’, says Deuteronomy (16:19). The beauty of justice is that it belongs to the world of order constructed out of universal rules which each one of us stands equally before the law (p. 51).

I would argue that there is a need for epistemological perspectives on dilemma, when difficult decisions (such as the ‘big’ issues) need to be made so that there is some referential point from which to navigate. A justice perspective in health care strives for decisions that are equitable and fair and in practice health professionals are also bound by the universal laws that govern providing the highest standard of care possible for children and their families. However the epistemology of practice

without an awareness of families lived reality is as 'duty without compassion being blind'. Sacks (2005) here links ontology to ethics and says:

In contrast [ethics] is intrinsically personal. We cannot care for the sick, bring comfort to the distressed or welcome a visitor impersonally. If we do so it merely shows that we have not understood what these activities are. Justice demands disengagement, ethics is an act of engagement. Justice is best administered without emotion. [Ethics] exists only in the virtue of emotion, empathy and sympathy, feeling with and feeling for (p. 51).

The findings of this study would suggest that health professionals do understand what the activity of health care is for beyond any universal laws ascribed to it. For health professionals in this study, health care is an act of engagement for the sake of another that rests on values such as compassion and feeling for. These perspectives reveal that 'ethos' as a way of dwelling does not occur in an ideal world of ethics of what one should do; rather ethos is understood as dwelling in a world with others that is ambiguous, uncertain and contested. Ethos here is understood as a mode of dwelling that reveals what it is to be human in a world of pediatric practice.

For Levinas ethical [dilemmas] are not based on a premise 'I think, therefore I am' but 'here I am'. For health professionals and families in this study 'here I am' is to be embedded in a concrete practice world and 'here for and because of the other'. Levinas's ideas resonate with the findings of this study when he says:

Ethics is entirely my affair, not the affair of some hypothetical, impersonal or universal 'I' running through a sequence of possible imperatives. Ethics is not a spectator sport. Rather, it is my experience of a demand that I both cannot fully meet and cannot avoid (Critchley & Bernosconi, 2002, p. 22).

Health professionals and families cannot escape the impossibility of being, and that care for another is prior to making sense of suffering. For health professionals and families the experience of dilemma is because of a demand made on them that they

can never fully meet or avoid. Health professionals cannot always understand the other, they cannot presume always to understand another's suffering or alterity; often all health professionals can do is say 'here I am'. 'Here I am' is to accept that at times life is to be endured even as we strive to overcome suffering.

Suffering has been described as something that may threaten one's integrity, autonomy and humanity (Roger & Cowles, 1997) yet the experience of dilemma in this study reveals that this very threat also affirms the meaning of one's integrity and humanity. Although health professionals and families autonomy may not always be fully realized in ways of acting, it is confirmed in ways of authentic thinking.

Relating findings to other studies

The literature reviewed in chapter three gave a comprehensive presentation of material on the different horizons of disclosure related to the phenomenon of dilemma. The findings of this study related to health professional's experiences appear to resonate, be confirmed and go beyond the literature describing moral sensitivity, moral distress and burnout.

Health professionals

What this study has provided is 'rich descriptions' of human life, suffering and existential / moral questions embedded in a concrete life world that has been argued for by many authors as an alternative to descriptions of universal principles to ethical dilemmas (Benner, 1991; Liaschenko, 1993; Spreen-Parker, 1990). This study has not broken the experience of dilemma into parts, such as focusing only on 'moral perception', 'moral decision making' or 'moral distress and burnout'. Rather this study has shown the interrelated nature of the phenomenon of dilemma and the definitions offered by Johnstone (1994) and Sletteboe (1997) that encompasses recognizing a situation as dilemma, having to decide what to do and living with the consequences.

Moral sensitivity / perception

Although the concept of ‘feeling not at home’ described in this study, has not been explicated in other studies, this concept fits with the discourse of moral sensitivity when described as an embodied or preconscious understanding (Hardingham, 2004; Glasberg, 2007; Lutzen, et al., 2000; Lutzen, 2006). What this study highlights is that sensitivity to dilemma is an affective attunement by the health professional, rather than a situation with given attributes. In similar situations different people will have different perceptions of why this situation may be experienced as dilemma for them. What this study offers to the discourse of moral sensitivity is that the ‘feeling of not at home’ is a signal; a warning to look beyond what is taken for granted. I would argue that when health professionals experience the feeling of ‘not at home’ it is an affective attunement and an opportunity to explore and question further what concerns have prompted this call to thinking.

Moral decision making and the fallacy of choice

This study has shown that the experience of dilemma arises in a concrete and embedded world of practice where health professionals cannot stand outside as if a spectator who is asked to make a decision. I would argue that if an ‘answer’ to a dilemma is clear and obvious, it is unlikely this situation would be experienced as dilemma. I believe that focusing only on decision making hides that often health professionals have no choice in making a decision. What is hidden in many accounts of decision making and what this study reveals is that health professionals have to make a decision regardless of what decision is made. This study highlights that any decision may never be ‘right’, rather having to act, having to choose is a matter of then having to live with the consequences. The notions uncovered in chapter seven reveals that choices are something that we are thrown into, rather than a matter of pure free will. I would argue that choices are relative, situational and not always ideal. This confirmed by Greenspan’s (1983) view that in dilemma we are ‘guilty’ no matter what choice we make. I have shown in chapter eight that choosing in dilemma is to have to rationalize this decision, aware at the same time that one possibility will negate others and there may be no ‘ideal’ outcome.

Conscience and rationalization

This study has revealed that 'being authentic' is linked to the notion of conscience as described by Heidegger. I would argue that conscience is not the ability to judge right from wrong; rather it is the disruption to one's being, where health professionals see beyond the taken for granted aspects of practice, and must bear the responsibility for their actions (which are not always freely chosen for). This is borne out by Goldberg (2004) who describes conscience as a courageous reflection of what we can do and what we cannot do, and of having to accept ourselves as less than perfect.

This study has uncovered that rationalizing is a way to carry on when one has no choice but to carry on. I have argued that rationalizing provides a way of accounting for the 'checks and balances' of one's actions, so that although the outcomes may be undesirable health professionals have been able to account for the weight behind these decisions. I believe that although rationalizing becomes a way to carry on, paradoxically it may also 'cover up' and legitimize certain actions. There has been little written in this area although some studies have alluded to 'over intellectualization' (Hale & Hudson, 1992) and 'over rationalizing' (Mekechuk, 2006) in response to moral distress or burnout.

For health professionals in this study rationalizing was often a way of having to overcome their conscience and carry on with what needed to happen. Others have described this as 'deadening one's conscience' (Glasberg, 2007; Miceli & Castelfranchi, 1998). I would argue that although health professionals have to rationalize as way of carrying on, they are aware of the weight behind such decisions, the balance of being attentive to one's conscience (and having to live with this) and no longer hearing one's conscience.

Bearing witness

The notions uncovered in this study show that to bear witness is to 'see' and to be present to another human beings experience of suffering. In this study I have shown that to bear witness is not only to see and be present to another in the moment, but to also bear witness in memory as an ethical way of being. Bearing witness has been described by various authors as a moral way of engaging in the patient – health

professional relationship (Cody, 2000; Milton, 2002; Naef, 2006) which draws on Parse's (1998) work of human becoming. What I add to this discussion is that to bear witness is often uncomfortable and painful for the one bearing witness and although bearing witness has been linked to the notion of 'human becoming as more being' I would argue that it may also contribute to the health professional becoming 'wounded' unless they are able find ways to deal with the impact of being an 'exposed one'.

Moral distress and burnout

Although this study has not labeled health professionals experiences of 'feeling caught', 'dissonance' or 'living with dilemma' as moral distress or burnout, there are similarities that would suggest this study findings are supported by such literature. Many of the seminal definitions suggest moral distress is experienced because external and organizational constraints prevent health professionals from acting as they would want to (Jameton, 1993; Wilkinson, 1987-88; Yarling & McElmurry, 1986) which implies that overcoming these would solve the issue of moral distress.

I would argue that it is an awareness of another's suffering that equally contributes to experiences of moral distress. I believe that this study has revealed it is existential issues of suffering that contributes to moral distress and burnout. This claim is supported by the work of Austin, Bergum and Goldberg (2003), Peter and Liaschenko (2004) and Severinsson (2003) and narrative accounts by authors such as French Blaker (2007), Nouwen (1972) and Tauber (1999). What this study highlights is that there are often no choices of how to act; health professionals are compelled to act, compelled to be there thrown into a world of health care. I would argue that the world in which health care takes place is never neutral, and focusing only on the 'business' of health care (as an institutional or external constraint) conceals its very existence is because of another's suffering due to illness, accident, injury or disease. I believe this is significant as health professionals are already thrown into a world where suffering is prevalent regardless of external or organizational constraints.

Forgiveness

I would argue that in this study the notion of forgiveness rests on being confirmed and accepted as a human being who is not perfect, who is fallible and who must act and choose in circumstances not wished for or always within one's control. There has

been little written in the literature around the notion of forgiveness of self or colleagues in relation to health professionals. Writers have focused on forgiveness as a strategy for clients in counseling to reconcile acts of betrayal, or from a religious perspective (both Christian and Buddhist). For Derrida (2001) forgiveness is only for acts he describes as ‘unforgivable’, suggesting that the act of forgiveness is not one of ease or comfort and removes this notion from an everyday way of being. I would argue that forgiveness in this study is not because of ‘unforgivable’ acts, but acts of everyday ways of having to be, that haunt health professionals, because they are both so awful and so everyday.

Imprints

I believe that the stories in this thesis are stories of significance, representing imprints and memories that the participants carry with them long after the event. This finding is particularly significant in that health professionals must carry the memories of being in dilemma. This may be a burden or a way of acknowledging the significance of one’s own and another’s storied existence. The notion of imprints uncovered in this study is confirmed by other studies that suggest the impact of events and memories embedded in stories persist long after the event (Corely & Minick, 2002; Gunther & Thomas, 2006; Hardingham, 2004; Mekechuk, 2006; Nathaniel, 2006; Rashotte, 2005; Webster & Bayliss, 2000). In this thesis stories of suffering, quandary and trying to make meaning of what it may mean to be a health professional, patient or human being are echoed by the work of authors such as Brody (1987), French- Blaker (2007), Nouwen (1972), Frank (1995) and Tauber (1999).

Families

Feeling totalized

This term appears not to have been used in other studies, however a reading of studies which have examined the experiences families and children in the health care system reveal similar narratives (Alderson, 1991; Darbyshire, 1994; Dickinson, 2004; Gasquoine, 1996). This finding fits with the writing on humanistic nursing by authors such as Paterson and Zderad (1988), Peplau (1952) and Watson (1989) who espouse the importance of ways of caring for others in a way that does not dehumanize them. Much of this literature focuses on what should be done. What this study offers is a

perspective on how families experience health care when this is not done. Much of the writing on humanistic caring focuses on the interpersonal relationship between health professionals and patients (families) which I would argue does not acknowledge the systems and organizations this relationship takes place in. This study highlights that this relationship is on an interpersonal level (where kindness overcomes the effects of feeling totalized) but also embedded in the systems and practices that health professionals and families encounter each other in (such as the reality of health care resources). I would argue that health professionals and health managers, planners and governmental organization need to be alert not only to the interpersonal relationships that humanize or totalize families, but also health policies, structures and organizations that contribute to families feeling totalized.

A 'living' history

There has been suggestion that the Western concept of family relies on an individualistic nuclear model, yet the findings of this study would suggest that the meaning of being a family goes beyond this. The findings of this study support a view of family as generational, temporal and embodied which is interrupted by discrete health care encounters. This finding is particularly significant in the New Zealand context in relation to the importance of Whakapapa for many New Zealand Maori¹⁵ (Roberts et al., 2004). I would argue that the notion of family as a living history is also significant in the way 'family centred care' is discussed. Although there has been a body of literature that describes what constitutes the physical relationships of family, and the relationship between health professionals and families, attention needs to be given to the temporal meanings of being a family.

Implications for practice

This study has revealed significant insights about the embedded and contextual nature in which the experience of dilemma is encountered for health professionals and families. This section will discuss the implications for practice for health professionals in relation to the impact that 'being-in-dilemma' may have on their 'being-in-the-world' as a health professional and the consequences of having to live

¹⁵ *Human descent lines and relationships*

with dilemma. The implications of families' experiences of dilemma for health professionals are offered and the challenges this poses to the delivery of health care services.

Implications for health professionals

Health professionals' experience of dilemma has revealed the tension of being exposed to others suffering; and at times feeling complicit in this; of having to negotiate a fine line between being sensitive to others experiences whilst not becoming overwhelmed in the process; and of finding strategies to cope without becoming desensitized. This study has revealed that 'dilemma' is not only about the 'big' issues but also the 'everyday' issues that arise in being a pediatric health professional. The implication for practice is how to respond to the 'everyday' issues that arise as well as the 'big' issues. Focusing only the big issues may hide that it is the everyday dilemmas that contribute to 'feeling caught', 'dissonance' and 'having to live with dilemma' as moral distress for health professionals.

Another implication for practice is the arbitrary lines we draw around personal and professional. I would argue there is no 'personal' or 'professional' persona; rather there is the personal *and* the professional. Health professionals are witness to suffering in a professional capacity, but it is personally that they also suffer. This has implications for practice where there is demand that health professionals are more responsive to the humanness in others, whilst in the process making their own humanness vulnerable. Health professionals are pressed to recognize the person in the patient, yet at the same time often forget to acknowledge the person in the professional.

The above also has implications for how health professionals experience dilemma in worrying about the balance of not being too sensitive but equally not desensitizing. Health professionals in this study who became too sensitive, and experienced signs of burnout, left the area of pediatrics. This has implications for pediatric areas where the loss of pediatric health care practitioners is a blow to not only the collective knowledge and expertise they brought to the area, but also loss in the time and investment they have made in developing their skills for the specialty. The health care

professionals who left the specialty of pediatrics were reflexive and were able to identify themselves the need to leave. Equally there may be those who have desensitized as a way of coping and no longer see potential dilemmas as areas of conflict. The implications for practice are how do we recognize those health professionals who feel overwhelmed or burnt out? How do we recognize those health professionals who have distanced themselves from recognizing the suffering of others and may equally be experiencing signs of burnout. Ericson-Lidman and Strandberg (2007) suggest that the signs of burnout are difficult to read in colleagues as they are often also the qualities (such as self sacrifice) that are encouraged in the prevailing culture of health care.

The implications for practice and what has been highlighted in this study is how to stay aware and attentive of others experiences without losing one's own sense of self. C.S. Lewis (1961) argues that to bear suffering is dreadful, but equally to no longer be moved by it is even more terrible:

This is one of the things I'm afraid of. The agonies, the mad midnight moments, must, in the course of nature die away. But what will follow? Just this apathy, this dead flatness? Will there come a time when I no longer ask why the world is like a mean street, because I shall take the squalor as normal? Does grief finally subside into boredom tinged by faint nausea? (p. 30).

How do health professionals resolve the tension of 'accepting' with not 'taking the squalor as normal'? I would argue that as Bishop and Scudder (1990) state, dilemmas by their nature cannot be solved, they must be endured. The question for pediatric practice is how can we make this endurance an easier burden to bear? I believe that health professionals need to find ways of learning to live with suffering and to find ways in which they are able to accept that they cannot be a 'super hero' who will save the world. Some suffering is inevitable and the nature of the health care environment makes it likely that we can never fully avoid it. Although suffering may never be solved in this life time (or others) nevertheless we must also always endeavor to try to alleviate suffering and be attentive to the experiences of others who suffer. Suffering cannot be 'fixed' rather it demands compassion. Families suggest that

acknowledging, being willing to say 'here I am' although not taking away suffering may help them endure it. I would argue that health professionals own suffering also needs acknowledgement from colleagues who are willing to say 'here I am'. I would argue that as the health professionals in this study suggest that sometimes the only way to endure suffering is to accept that at times life just is. Accepting is not an abdication of responsibility, rather is a courageous way of being that acknowledges the limits of our abilities and having to carry on with the business of life.

Recommendations for health professional practice

It would be simple to suggest 'debriefing' and 'supervision' as ways of dealing with experiences of dilemma, but this would belie the complexity and controversies that surround these two notions at present.

In the literature, debriefing has been suggested as one way to support health professionals in practice, yet the basis of debriefing is on 'critical incidents'. I would argue that many of the stories described by the participants are of everyday life and would not 'fit' into a model of a critical incident as a discrete major and possibly traumatic event. Debriefing itself has been critiqued as making what is a normal response to a situation pathological (Kenardy, 2000; Wessely, Rose & Bisson, 1999) and has been shown to have no long term benefit (Stephens, 1997) and indeed may have negative consequences (Wessely, Rose & Bisson, 2000). Gist and Woodall (1998) claim that debriefing may make people 'victims' to life's losses and challenges in attempting to 'solve' what may be a reasonable response to the issue. The question arises then how best to support pediatric health professionals in what is 'life' and the 'living' of being a health professional?

There have been suggestions that clinical supervision could be a model to support health professionals in their practice. Swain (1995) suggests that clinical supervision is integral to health professionals maintaining their integrity in response to the human pain and suffering they are exposed to. Several models of supervision have been noted and have been linked to professional development, job satisfaction and patient outcomes (Begat, Severinsson & Berggren, 1997; Halberg, 1994; Kilminster & Jolly, 2000; Lyth, 2000). Many of the models of clinical supervision focus on the

professional capacity of the health professional and I would argue do not deal with the personal suffering or burnout a health professionals may be experiencing. Several studies have found there is no correlation between clinical supervision and reduced rates of burnout (Halberg, 1994) and because the times are 'scheduled' may not take into account the day to day experiences a health professional faces. Others such as Yegdich (1998) suggest that there is no place for clinical supervision that deals with the personal responses of a health professionals, critiquing it as a form 'therapy' which risks becoming a form of self absorption, focusing on the health professionals needs rather than the patient.

In spite of the issues I believe there is a place for both supervision and debriefing. I would recommend a model of professional supervision that acknowledges both the personal and professional issues health professionals are faced with (rather than only focusing on clinical issues), and that provides a place for health professionals to take a reflexive stand toward their practice. I would argue and recommend that any model of supervision needs to be based on a trusting relationship between the parties involved, so that there is safe space, a no blame zone, where health professionals can be honest, without fear of judgments or consequences. I also would recommend that any model of supervision incorporates ways of finding acceptance or forgiveness for being a human being as well as a health professional. I believe that even if dilemmas cannot be 'solved' the telling of the story acts as a way of affirming one's humanness in the midst of suffering.

I recommend there is also a place for debriefing, but rather than being focused on debriefing after a critical incidents, it incorporates talking and listening as part of everyday practice. Research on debriefing suggests that what health professionals (and those exposed to traumatic events) found most helpful was the informal support from 'trusted' colleagues who would lend a 'shoulder' or attentive words not only after an event, but as a regular part of their everyday practice (Gist & Woodall, 1998; Stephens, 1997). I would argue and recommend that health professionals find ways of being attentive to each other, albeit in the busyness of their day. I believe that acknowledging, saying "here I am" is as important as any formal ways of debriefing and does not always require a large amount of time. I would argue that listening to one another may also be a way of uncovering moral distress and burnout. Health

professionals in this study suggested it was often not being heard, and feeling that the burden of being witness became too heavy, that contributed to burnout and having to leave the profession. I believe that feeling heard, and that sharing a burden could mitigate some of the effects of moral distress.

I would also recommend that health professionals find both the physical and psychological space to be attentive to colleagues. Does the health care team regularly meet in order to share experiences of what happened that day, week or month? Is there the space which is both private and safe to meet? When health professionals do meet, do they use time to not only discuss the clinical notes, the medical progress but also the impact that a child or family may have had on the team? Is there the space to affirm the suffering and complexity of practice that health professionals are faced with on a daily basis? Are health professionals able to forgive others and themselves for being all too human whilst also being required to be a 'professional'?

Although this study has uncovered the significance of acknowledging the subjective nature of dilemma I would also recommend that at times a certain amount of objectivity is essential to protect health professionals. The place of ethics committees are essential, not only in charting a course forward in a situation where there may be no ideal outcome, but as a way to 'protect' health professionals from bearing the full burden of making the unenviable decisions and bearing the knowledge of the consequences that follow. Equally I would argue that there is also a need for ethics committees to acknowledge the subjective experiences of those whom the decision is being made for, and an awareness of the weight of the consequences that are most likely to be borne by them.

Although this study focused on the meaning of being in dilemma and the existential ways of being that contribute to this, it is important also to acknowledge the specific situations and conditions that make the experience of dilemma possible. Although not offering solutions or 'fix it' remedies for the experience of dilemma, there are everyday practices that if attended to could lessen what may contribute to the experience of dilemma. One of the specific contexts is that of having to carry out procedures on children. Although this study has shown that at times health professionals are thrown into situations they have little control over, I would argue

there may be other times where the use of play therapy and appropriate pain relief could help mitigate the distress for the child and the health professional. Other contextual factors such as time, resources and priorities need to be taken into account by health managers and those who influence budgets in order to enable an environment conducive to enabling the best outcomes for children.

Implications for families

The implications for health professionals working with families are being attentive to those practices that families experience as totalizing and finding ways of incorporating what it means to be a ‘living history’ for families. I believe that health professionals need to be aware what is everyday for them may not be the everyday for families. I would argue that there is a moral obligation on the part of health professionals to advocate for families beyond their immediate engagement with the child and family, to include the broader context of health care organizations that may contribute to families feeling totalized.

The challenge for health professionals is also finding ways to resolve the tension of time and resources available with the time and resources needed. Although it has been argued that this may be an ideal in the midst of the realities of limited resources, preliminary findings of a pilot study at Middlemore Hospital (New Zealand) have suggested that a change in work practices could result in a 50% increase of time being able to be spent in direct contact with patients (Borley, 2008).

Recommendations for family focused practice

Health professionals are thrown into a busy world of practice, however acknowledging families and being able to say “here I am” may overcome how families experience health care as totalizing. I recommend that health professionals find ways to acknowledge the importance of the history families have with their child, such as in the documented case history, and acknowledging that families have a history prior to and following each health care encounter.

Although only one family experienced the death of child in this study, this still raises issues of how health professionals acknowledge the impact on a family's life. I recommend that pediatric areas implement a dedicated follow up bereavement service, which would ensure parents have a support system in place, and acknowledge the significance of the event in the history of the family. I would recommend there is also an appropriate place for health professionals to attend funerals, as a way of acknowledging to families the significance of their child's life.

What are the implications for education?

This study has shown that dilemma arises because of the practice world that families and health professionals are thrown into. The question arises how then do we prepare health professionals? How can the curriculum prepare health professionals for the epistemology of practice such as the knowledge of the physical sciences and the ontology of practice such as the experiential, embedded and contextual nature of practice? Although I would argue there is a place for teaching health professionals about ethics, equally we need to teach them how to deal with the thrown nature of practice and how to live with the consequences of decisions made.

Educators need to be aware of not teaching 'ethics' or 'humanities' (such as caring) as idealized versions of what it means to be a health professional, so that when students are presented with the realities of practice they may experience a sense of failure for not being able to live up to these ideals. We need to help support each other in recognizing that the world of health care happens because of people, not interventions and be aware of the complexity, the suffering and crisis that bring people into contact with health professionals in the first place. As educators it is important to remind students that no action or interaction is ever neutral; there are always consequences positive and negative, intended and unintended. Behind every interaction there are always life histories, experiences and perceptions that remain concealed. As educators the challenge is how to teach student health professionals what it means to be a human being who gives and receives health care, without risking their sense of self.

The findings of this study have influenced that way I now teach and think about nursing and ethics. Alongside lectures and workshops on 'ethics' my colleagues and I now encourage students to share their stories of 'dilemma' and explore these in a reflexive way, considering alternative possibilities, but equally acknowledging that at times they acted in the best and only possible way. Affirming that the environment that health care occurs in is often less than ideal, helps to affirm that often health professionals must just do the best that they can. The challenge for educators is finding ways to teach and coach students to develop strategies to deal with the ambiguities of practice. I recommend that strategies include being reflexive about what can be changed, what has to be lived with and guiding them to find ways to share the burden of dilemma with trusted colleagues.

Presenting stories of dilemma at conferences has reinforced the need to share experiences of practice. Following the sharing of narratives of dilemma, I have often been approached by health professionals wanting to share their stories of dilemma and at times needing acknowledgment of the significance this event may have had for their thinking. As educators we need to be aware that we can not 'solve' these dilemmas, rather we need to be aware of ways of being attentive and acknowledging 'here I am' to affirm and witness their story and experience. This has potential to role model that not all issues can be resolved; some need be shared and to be lived with.

Recommendations for education

I recommend that a narrative approach is one way to help students explore the embedded and contextual nature of practice. Narrative pedagogy has been suggested as a way of linking both *phronesis* and *techne* of practice (Diekelmann, 2001; Ironside, 2003; Swenson & Sims, 2003). For Rogers and Niven (1996) narration of experiences of moral issues focuses students back to the interpretive nature of moral experience and direct their attention and inquiry back towards people at the centre of the issue. I would suggest that it is stories that often provide important cues for moral action, namely the recognition of suffering. Johnstone (1994) says that sharing stories in this way has the potential to reveal the "profound inter-relatedness between suffering and compassion, and the experiential models these behaviors' provide in guiding and developing moral reasoning and conduct" (p.6). Brody (1987) says that if

we listen to the narratives of human beings not only does this provide an insight into what meaning is attached to that experience, but it also reconnects us to others. This has the potential for not only understanding the meaning of being in dilemma for health professionals but also for an epiphanic understanding of the experiences of children and their families. I believe that narrative accounts do not stand as a static way of viewing dilemma in practice; rather they offer opportunities to stay open to interpretation and reinterpretation, and as Johnstone (1994) suggests, open to the plurality of experience and moral view points that reflect the multiple realities of human life.

Limitations

From the onset of carrying out a phenomenological study, the fore structures of understanding, what we already know, contribute to the questions asked, the interpretations made and the phenomenon that is revealed. To undertake a phenomenological study is to take a particular philosophical stance that will influence the meanings that are uncovered. This study therefore has uncovered the meanings of what it means to experience dilemma, but does not answer questions of any power issues inherent in experience of dilemma; discourses used that shape understandings of dilemma; or social processes used to construct meaning of how people act when faced with a dilemma. Using research approaches such as critical social theory, feminist theory, discourse analysis and grounded theory would have uncovered different meanings (with different questions) to what 'is' and 'are' dilemmas. The findings of this study are limited to the philosophical approach that underpinned this study.

There is no expectation that the results of this study will be generalized to all health professionals, all families or anyone who has experienced dilemma or to provide rules, theoretical notions or guidelines that would guide practice. However the findings of this study may be transferable to individuals or groups if they identify with the themes uncovered and provide a way of bringing understanding and insights to the experience of dilemma in practice and implications arising from this.

Another limitation may be the scope of this study due to the participants who offered to take part in the study. Within the health professionals group of participants, all had many years of experience and were seen as expert practitioners in most cases. This may mean that although ‘novice’ or ‘competent’ practitioners may experience dilemma as a similar phenomenon the context in which dilemma arises may be different. Another limitation is that not all health professionals were represented in this study and the voices of social workers, dieticians and speech language therapists who work with children is missing.

The scope of this study was also limited by the demographics of the participants. All participants identified as European / Pakeha. New Zealand is a multicultural society represented by many different ethnic and cultural groups who may not experience similar situations as dilemma. For example some families from a different cultural background may not see it as appropriate to ‘battle’ against the health care system. From the family groups the voice of men is also missing. Although I suggested in chapter five that this does not mean that this is any less a family perspective, the voice of men may reveal another view that is yet to be revealed. Missing also is the voice of children. Researchers such as Dickinson (2004) have argued that we talk of ‘family’ but that voices of children are silenced. Given that the continuity and generational idea of family was significant to the participants it may be useful to include extended family members in any further studies.

The interviewing in phenomenological research could also have been a limitation. As the emphasis was on letting the ‘story unfold’ and indeed this often needed little prompting from the researcher there was the potential to miss moments where questions on related issues could have been raised. I found that in listening and letting the stories unfold I often missed moments where further questions may have taken the participant and I down another path. This is the tension of staying in the hermeneutic circle, and not straying too far from the original research question whilst being aware of what is also still waiting to be revealed.

Areas for further research

Four health professionals left the area of pediatrics during and shortly after participating in this study. Although this could not be generalized to larger numbers the question does arise how representative this may be of those working in pediatrics as a consequence of unresolved experiences of dilemma. Further lines of questioning could include: What is the prevalence of moral distress or burnout for pediatric health professionals in New Zealand? How is this currently being assessed in health care environments in New Zealand? Is this issue addressed in an 'exit' interview when a health professional leaves the service? Are health professionals open to disclosing this information?

Following the initial interviews with nurses and interviewing other health professionals it became apparent that debriefing was an important notion. I began asking these health professionals how or whether they debriefed. Only one pediatrician and two play specialists reported any semi formal debriefing or supervision. I believe that further questioning around the area of debriefing and supervision could reveal more insights into how health professionals can live with dilemma.

A question not asked in this study (due to trying to stay in the hermeneutic circle) but alluded to by two participants was about those beliefs or practices that helped them accept uncertainty and live with dilemma. Peter (pediatrician) alluded to God and Brooke (play specialist) alluded to a belief in Eastern philosophy. I believe further question around 'what beliefs help support health professionals to make meaning of life and suffering?' could reveal further perspectives on how health professionals are able to live with the complexity of the practice world.

In the discussion on 'limitations' I noted that most of the health professionals were seen as 'expert'. During the undertaking of this study I noticed that when working with students in clinical areas, many would tell similar stories to those of the expert practitioners in this study in the first week of their clinical practice yet by the fourth week of clinical practice many of these stories had stopped. The questions I bring are what are the contextual factors that may contribute to the experience of dilemma? A

study by Soderberg and Norberg (1993) suggests that novice practitioners were more bound to rules rather than seeing the complexity and paradoxes of practice. Is there some phenomenon whereby novice or student health professionals see everything as 'present-at-hand', as new and different when they first come to a practice area? Is there a process whereby becoming competent means becoming used to a ready-to-hand way of being in this world? When practitioners become expert as Benner (1984) suggests, does this enable them to see what is ready-to-hand as anew?

Health professionals raised issues such as inflicting pain on children and the questions arises how do children experience being thrown into a world of health care where often they have little control over what may be happening to their bodies? Health professionals in chapters six, seven and eight and a mother in chapter nine describe the terror and distress of some children whilst hospitalized. How do children experience this?

Several studies have linked the incidence of PTSD (post traumatic stress syndrome) or vicarious trauma in children with the experience of a severe disruption to health and medical intervention (Connolly et al., 2003; Dyregrov & Yule, 2006; Kazak et al., 2006; Shemesh et al., 2005; Wintgens, Boileau & Robaey, 1997). There is anecdotal evidence that there is an increase in psychotherapists seeing children with PTSD in New Zealand following an acute hospitalization (often an intensive care experience). Further questions for research could include: How do children experience a severe disruption to health? Is there a need for a better preparation and follow up of children's psychological wellbeing following hospitalization?

One of the limitations of this study was the lack of cultural diversity amongst participants thereby not reflecting the multicultural nature of New Zealand society (although the intent was never to generalize). Further research around the differing meanings of dilemma from differing cultural perspectives could uncover new understandings of the meaning of dilemma.

Returning to the beginning

As I look back to my preunderstandings of dilemma at the beginning of this journey, I realize that much of my naïve knowing then is confirmed by a deeper understanding and appreciation now. When I look back to how devastated I was by the young girl who died (p.p. 3-4), I now see how I too was thrown into a chaotic world of practice; feeling caught, claimed and witness to the significance of this young girl and her family. I now feel more at peace with this experience, and able to forgive myself for not being able to control every eventuality. Phenomenology has offered me a unique way of looking at the world, of uncovering what was always there, and shedding light on my quest for understanding the existential nature of dilemma in paediatric practice. What I now understand of dilemma does not just inform my practice as a nurse or an educator, but has followed me into all aspects of life.

Closing thoughts

This hermeneutic phenomenological study has shown what it means to be human and thrown into a concrete embedded world of practice. The experience of dilemma is not one that health professionals and families can stand outside of. Rather the experience of dilemma throws them into a world where they have to be there; have to act; and have to live with the consequences. For health professionals the experience of dilemma reveals what they care about, and that to care is not to just carry out the expectations of a professional's role but to be aware of the human being before them; to acknowledge and witness both their presence and their suffering. Being in dilemma reveals the ambiguity and complexity of life; that life is never easy or straight forward, rather that it is messy, painful and at times must be endured. However being in dilemma also reveals the beauty in that we still have the capacity to be moved by another. Although being in dilemma may be a burden, it is also one of privilege, honoring the significance of what it means to be human.

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Appendices

Appendix 1 Participant Information Sheet for Health Professionals

Project Title: The experience of dilemma in pediatric practice.

Invitation from Tineke Water: You are invited to join me in my quest to understand more about how health professionals encounter and make meaning of everyday dilemma arising from working with children and their families.

What is the purpose of the study? The purpose of this study is to explore, uncover and thereby promote understanding of how health professionals and families encounter, experience and make meaning of everyday dilemma in the health care of a child. An interpretive approach will be used. This study will contribute to completion of my Doctor of Philosophy degree. I would value hearing your stories of the experience of encountering dilemma in practice.

How was a person chosen to be asked to be part of the study? It is likely that somebody has already asked you if you would be happy for me to contact you. The “third” party is used to make it easy for you to say ‘no’.

Can I join the study? Anyone interested in contributing to this study is welcome to contact me and discuss involvement.

What happens in the study?

As a study participant I would like to interview you and ask you to tell your story of dilemmas you have experienced in pediatric practice. The interview will be like an informal conversation and would last about 60 - 90 minutes. As the study progresses I may ask to interview you once more for up to 60 minutes, to seek further clarification. The number of times I interview you will always depend on your continued willingness to talk with me, which will always be re-negotiated. The time and place of the interviews will be your choice. The interviews will be audio taped, and the data likely to be used in the study returned to you, to enable you to make any changes or to request withdrawal of anything you do not wish to be made public.

What are the discomforts and risks? It is possible that discussion of dilemmas you have encountered may raise issues for you personally. The experience could be pleasant or unpleasant. Time will be built into each interview to address any questions that may arise. If any emotionally distressing situations occur, I can support you at the time but would expect to refer you to an appropriate counselling service through your local health authority.

What are the benefits? Although the study may not benefit you directly it is hoped to provide a basis for further development of a multi disciplinary voice in the field of ethics, and particularly the area of pediatrics. Your stories may contribute to an understanding by other health professionals of the experiences of dilemma by your particular profession.

How is my privacy protected? To ensure your privacy and confidentiality, the data will be coded and no identifying names of participants, institutions or third parties will be used. I will ask you to choose a pseudonym that you will be known by. Only you and I will know your true identity. The information I gather will be confidential and the only people who will have access to it will be myself, my thesis supervisors, Dr Liz Smythe and Annette Dickinson, and a confidential typist. All the study data collected will be kept in a secure place, the audio-tapes offered back to you or destroyed once the work is completed, the data destroyed after six years.

Opportunity to consider invitation If you choose to be involved, you can contact me, either by phone, email or in writing to the attached contact details. If you need further clarification, my supervisor, Annette Dickinson, Liz Smythe or I would be happy to discuss any issues with you. If you consent to take part in this study you do have the right to withdraw at any time, and decline to answer any questions. I will respect your decision and not seek to persuade you otherwise.

At the completion of the study I would expect to give you a summary of the results (if you wish) and you would have access to a copy of the completed thesis. Findings from this study once completed (2006/ 2007) may be published in professional (health) journals and presented at professional (health) conferences. Parts of the data from the uncompleted thesis may be published or presented in professional forums / conferences before this date. You are welcome to read published work or attend public presentations at any time. On completion of study I would be willingly to discuss the findings with you and answer any questions you may have.

Although there is no payment for participating in this study, I would value the time and stories you are willing to share.

Participant Concerns:

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact your professional organization.

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTEK, Madeline Banda, madeline.banda@aut.ac.nz 917 9999 ext 8044.

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Appendix 2 Participant Information Sheet for Families.

Project Title: The experience of dilemma in pediatric practice.

Invitation from Tineke Water: You are invited to join me in my quest to understand more about how families encounter and make meaning of everyday dilemma arising from having a child who receives any form of health care.

What is the purpose of the study? The purpose of this study is to explore, uncover and thereby promote an understanding of how families and health professionals encounter experience and make meaning of everyday dilemma in the health care of a child. This study will contribute to completion of my Doctor of Philosophy degree. I would value hearing your stories of the experience of encountering dilemma in the health care of your child.

How was a person chosen to be asked to be part of the study? It is likely that somebody has already asked you if you would be happy for me to contact you. The “third” party process is used to make it easy for you to say ‘no’.

Can I join the study? Anyone interested in contributing to this study is welcome to contact me and discuss involvement.

What happens in the study?

As a study participant(s) I would like to interview you and ask you to tell your story of dilemmas you have experienced when your child received health care. The interview will be like an informal conversation and would last about 60 - 90 minutes. As the study progresses I may ask to interview you once more for up to 60 minutes, to seek further clarification. The number of times I interview you will always depend on your continued willingness to talk with me, which will always be re-negotiated. The time and place of the interviews will be your choice. The interviews will be audio taped, and the data likely to be used in the study returned to you, to enable you to make any changes or to request withdrawal of anything you do not wish to be made public.

What are the discomforts and risks? It is possible that discussion of dilemmas you have encountered may raise issues for you personally. The experience could be pleasant or unpleasant. Time will be built into each interview to address any questions that may arise. If any emotionally distressing situations occur, I can support you at the time but would expect to refer you to an appropriate counselling service.

What are the benefits? Although the study may not benefit you directly it is hoped to provide a basis for further development of a multi disciplinary voice in the field of ethics, and particularly the area of pediatrics. The stories you share may contribute to a better understanding by health professionals of the realities for families when you experience dilemma over some aspect of the health care of your child.

How is my privacy protected? To ensure your privacy and confidentiality, the data will be coded and no identifying names of participants, institutions or third parties will be used. I will ask you to choose a pseudonym that you will be known by. Only you and I will know your true identity. The information I gather will be confidential and the only people who will have access to it will be myself, my thesis supervisors, Dr Liz Smythe and Annette Dickinson, and a confidential typist. All the study data collected will be kept in a secure place, the audio-tapes offered back to you or destroyed once the work is completed, the data destroyed after six years.

Opportunity to consider invitation If you choose to be involved, you can contact me, either by phone, email or in writing to the attached contact details. If you need further clarification, my supervisor, Liz Smythe, Annette Dickinson or I would be happy to discuss any issues with you. You may have a friend or whanau support to help you understand the risks and/ or benefits of this study or any other explanations you may require. If you consent to take part in this study you do have the right to withdraw at any time, and decline to answer any questions. I will respect your decision and not seek to persuade you otherwise.

At the completion of the study I would expect to give you a summary of the results (if you wish) and you would have access to a copy of the completed thesis. Findings from this study once completed (2006/ 2007) may be published in professional (health) journals and presented at professional (health) conferences. Parts of the data from the uncompleted thesis may be published or presented in professional forums / conferences. You are welcome to read published work or attend public presentations at any time. On completion of study I would be willingly to discuss the findings with you and answer any questions you may have.

Although there is no payment for participating in this study, I would value the time and stories you are willing to share.

Participant Concerns:

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact a Health and Disability Advocate, telephone 0800 555 050.

Any concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTEK, Madeline Banda, madeline.banda@aut.ac.nz 917 9999 ext 8044.

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Appendix 3 Consent to Participation in Research

Title of Project: **The experience of dilemma in paediatric practice.**

Project Supervisor: **Dr Liz Smythe and Annette Dickinson**

Researcher: **Tineke Water**

- I have read and I understand the information sheet dated for participants to take part in the study designed to look at the experience of dilemma in paediatric practice. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.
- I have had the opportunity to use whanau support or a friend to help me ask questions and understand the study.
- I understand that taking part in the study is voluntary and that I may withdraw myself or any information that I have provided for this project at any time prior to data collection being completed, without being disadvantaged in any way. If I withdraw, I understand that all relevant tapes and transcripts, or parts thereof, will be destroyed
- I understand that my participation in this study is confidential and that no material which could identify me will be used in reports on this study.
- I understand that the interview will be audio-taped and transcribed.
- I have had time to consider whether to take part in this study and understand there is no financial payment to take part in this study.
- I know whom to contact if I have any queries or concerns about this study.
- I agree to take part in this research.

Participant signature:
Participant name:
Date:

Project explained by:
Project role:
Signature:
Date:

Researcher
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Appendix 4 Typist / Transcriber Confidentiality Agreement

Project Title: The experience of dilemma in paediatric practice

Researcher: Tineke Water

I -----(Full Name) agree to transcribe the interviews pertaining to the research being conducted by Tineke Water in a confidential manner. I will not discuss the contents of the interviews with any one. All material, audio taped and written, will be returned to Tineke Water on completion of the transcripts. Pseudonyms will be used in the text of transcripts. The researcher will supply the Pseudonyms.

I----- (Full Name) agree to maintain the confidentiality of the material being transcribed.

Signature: -----

Date: -----