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Living with dying children: the suffering of parents

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Abstract

Although the relief of suffering and emotional support are fundamental to children's palliative care, their empirical study has been limited. The research questions for this study address three areas: the lived experience of parents of dying children; how other people's responses shape the parents' lived experience; and the place of emotion and suffering in the parents' lived experience. Implementing a qualitative strategy, a collective case study was undertaken in a children's hospice in England, with fieldwork completed between March 2008 and September 2009. Data was collected with nine parents using a range of tools including a focus group, participant observation, documentary observation and individual interviews. Within-case and cross-case modified grounded theory analysis facilitated clarification of emerging themes whilst preserving individual parent voices. The findings show that parents of dying children had existential issues put at stake through the emotional experience of parenting a dying child; these included their identity, place in society, time, and relationships. Such losses could constitute suffering, but in addition they limited the parents' interaction with society so that over time both the 'quantity' and 'quality' of intersubjectivity reduced. The parents perceived that other people tended not to legitimate their lived experience. Emotion was an important influence in this process. The parents of dying children managed their emotions, particularly those of a negative nature, in everyday life and when using hospice services. As a result they expressed somewhat inauthentic accounts of their felt experience, reframed according to perceived feeling rules. This also reduced intersubjectivity and supported the delegitimation of the parental experience. In conclusion, delegitimation of the parental experience stems from feeling rules which are derived from day to day interactions and contemporary social policy. Suffering may be prevented if individual experience is legitimated through improved intersubjectivity. A key factor for this is effective communication through which observers engage with the felt emotion of the suffering individual.

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Preface

Suffering is a term readily applied to those experiencing ill health and their families, both in practice and through the literature. However exploration of individual interpretations of suffering within healthcare research is somewhat poorly articulated, in particular as it applies to children's palliative care. Throughout my career as a paediatric nurse I have been concerned with the well being not only of the children with whom I work, but also that of their families. Whether working in a busy medical ward, a highly technical intensive care unit, or, more recently, the calm warmth of a children's hospice, I have remained curious about two issues: firstly, the ways in which parents, in particular, express their experiences and emotions when their child is unwell; secondly, the behavioural expectations professionals may have of such parents, regardless of the dire circumstances in which the parents find themselves.

As the head of clinical education in a children's hospice, I am well placed to comment on communication in the context of children's palliative care. Through direct clinical nursing activity with parents as well as through my training activities I have a window onto a variety of ways in which parents and professionals communicate and interact when caring for dying children. In the context of palliative care in general, and children's palliative care specifically, reference is made to parental suffering and emotion both informally and within the literature, and yet there is limited exploration of either term. The philosophy of children's palliative care emphasises that care extends to the family as well as the child (ACT/RCPCH 1997; ACT/RCPCH 2003). Furthermore, concern for emotional well being is emphasised in the context of the relief of suffering (ACT/RCPCH 1997; ACT/RCPCH 2003). However the limited literature about children's palliative care does not explore suffering in great detail. Moreover, in my observations as a clinician and teacher in children's palliative care, it has been difficult to clarify how the personal concerns of parents or their suffering are articulated in every day practice. There appears to be a silence concerning both the parental experience and their emotions.

In contrast, there is a well developed understanding of the emotional impact upon the clinical staff of working with dying children and their families and clear strategies in place to ensure appropriate support. Significantly, my observations in this respect have been mirrored in other children's hospices. As a senior nurse with an education remit in children's palliative care I am a member of a national consultation group for children's palliative care education. From conversations with this group, it has become clear that similar observations to my own have been made in hospices around the country: clinical staff seem to focus on the emotional impact upon themselves of their work in children's palliative care with a tendency to privilege self over other. Crucially in children's hospices, parents form a priority group of 'other'. Thus my concerns at a local level mirrored concerns amongst senior nursing colleagues at a national level.

From this, and in the context of the limited evidence base for the relatively young speciality of children's palliative care, I developed a focus for research and a PhD thesis. In a clinical setting in which emotional support was a key focus, underpinned by local and national philosophies of care, it was paradoxical to observe a silence around parental experience and emotion. In particular the three areas which concerned me were: inadequate understanding of what the parental experience might be and how it related to suffering; the lack of identifiable space, in terms of opportunity or process, through which parental experience and emotion might be explored to their satisfaction; and the significance of pity as a response to parental experience and emotion. To explore this silence I devised three research questions:

1. What is the lived experience of parents of dying children?
2. How do other people's responses shape the parents' lived experience?
3. What is the place of emotion and suffering in the parents' lived experience?

In the absence of a clear evidence base for suffering in the context of children's palliative care, I was careful to structure the research questions using broad phrases. I could have utilised an existing theoretical framework relevant to death and dying, such as grief. However, I considered that this risked blurring the parental voice by imposing a highly focused preconceived interpretive framework upon their experiences. Likewise, in choosing the framework of suffering, I was also careful not to assume that parents perceived themselves as sufferers. Practically, this required exploration of the parental experience without me making reference to suffering, prior to some more purposeful discussion concerning how they defined suffering and how it related to them.

The purpose of the research was to broaden understanding of a relatively unexplored area of practice. Therefore I devised a methodology and instrumentation to facilitate exploration of individual interpretation, privilege the voice of the participants and integrate a variety of perspectives. I undertook a range of data collection methods, including focus groups, individual interviews, participant observation, and documentary observation. Based on my clinical observations which prompted the research, my initial intention was to study both the parental and the professional perspective. To this end, data were collected from both research populations. However, the parental data proved to be so rich that I decided to focus upon the analysis of their data alone. The professional data will however be reported upon separately to this thesis.

Analysis of the data is presented in four chapters which address the research questions sequentially. Thus the lived experience of parents of dying children is first presented as thematic, cross-case analysis of all the parental data. This enabled me to explore the parents experience in terms of what was at stake for them and also to begin to analyse the relevance of suffering as a term (Kleinman and Kleinman 1991; Kleinman 2006). In the following chapter, however, I present some individual narratives, a strategy which strengthens preservation of individual interpretation and voice within the thesis. The second data chapter takes account of issues of intersubjectivity and communication in terms of other people's responses to the parental experience. The third data chapter extends the communication thread and begins to address more clearly the place of emotion and its management.

Here the negative impact of a pitying response is highlighted. Parents managed emotions in order to avoid this response because it contributed to their perceived identity being put at stake. In particular, I analyse the ways in which the parental voice becomes sublimated through emotion management in day to day interactions. The final data chapter analyses the parents' perceptions of suffering and theorises the place of emotion management within suffering.

In drawing conclusions to this thesis, I was mindful of the practical concerns which drove its conception, namely the silence around parental emotion and experience in children's palliative care. Therefore, whilst empirical and theoretical conclusions are drawn, attention is paid also to the policy and practice implications of the thesis.

Empirically, the research demonstrates that parents of dying children manage their emotions, particularly those of a negative nature, in response to perceived feeling rules. This script for emotion management is reinforced by a societal agenda for parenting where child health and achievement are the measures of success. Consequently, day to day interactions tended to de-legitimate the parents lived experience which was, in contrast, dominated by child morbidity and mortality.

Theoretically, this thesis clarifies the significance of emotion management to suffering. Intersubjectivity, the development of shared understanding, is limited when emotions are managed because the voicing and embodiment of suffering may become inauthentic. Consequently, legitimation of experience may be jeopardised. Both de-legitimation and reduced intersubjectivity risk furtherance of suffering through inappropriate and unhelpful responses to the individual.

The policy and practice implications of the thesis focus upon communication about the lived experience of parents of dying children at both a local and national level. Locally, children's palliative care services need to ensure that appropriate space is available to address the lived experience of parents of dying children. This can be facilitated through more effective communication skills training which takes better account of the significance of emotion management. In this way, professionals will be minded in their day to day practice to create physical and communicative spaces for parents to articulate their personal concerns in ways which suit them. To achieve this, the development of an evidence based quality standard for communication would be useful. Such a standard could be applied nationally and would enable both service users and commissioners to make informed choices about children's palliative care services. In addition, the evidence based quality standard for communication should underpin effective clinical supervision processes. This would rebalance the focus between self and other with respect to the emotionality in children's palliative care.

However, this thesis clearly demonstrates that for parents of dying children it is not only interactions with palliative care professionals which are significant. Their day to day interactions with other people also contribute significantly to a script for emotion management in which negative emotions are de-legitimated, leading to an inauthentic presentation of self and reduced intersubjectivity. As child mortality rate reduce, cultural references for death in childhood become ever more limited. There is therefore a need to better educate wider society about children's palliative care. As well as effective direct care and support for parents, children's palliative care services have the scope to influence this wider societal understanding of such parents' lived experience. Raising awareness at an organisational level of how the vision and values of children's palliative care are aligned with the lived experience of the parents of dying children will ensure that all activities at a local level raise awareness of this minority group in society: through clinical work, fundraising, education and training, and multidisciplinary activities. Furthermore, this alignment will facilitate regional and national collaborations to raise the profile of these families so that policy developments can take better account of their hitherto largely unrecognised needs.

Chapter 1: Policy Context

Introduction

Although since the beginning of the nineteenth century child and infant mortality rates in England have been in decline, albeit contextualised to social class (Drever & Whitehead 1997), some children still die. Whilst improvements in health and technology have contributed to the reduction in infant and child mortality, each year some 6,000 families will be bereaved of a child aged between 0-19 years (Cochrane et al. 2007). This chapter sets out the historical development of social policy relating to children in England, illuminating the context within which such children must be parented in the twenty first century.

In this chapter, I will briefly review trends in childhood mortality statistics, demonstrating the increasing rarity of childhood death. Declining mortality is associated with improvements in health as an outcome of social policy (Haines 1995; Pickvance 2007). To illustrate the context for social policy development, I continue with a review of how social constructions of childhood have changed over time and how they reflect variation in how the value of children is measured. This facilitates an historical review of social policy for children in England since the nineteenth century.

The review illustrates how society and policy demonstrate ambivalent perceptions of children. A view that children are either vulnerable or threatening is shown to persist historically from the nineteenth century until the present day (Hendrick 1997a; Moran-Ellis 2010; Thorne 1987). In this context, childhood is shown to have changed from a variable experience, dependent on geographical location and social class, to a standardised and institutionalised encounter (Hendrick 2005; Moran-Ellis 2010). Having established this as the social policy context for child-rearing in twenty first century England, the final section of the chapter considers what impact this may have upon the minority group of parents whose children die.

1.1 Child and Infant Mortality

Mortality can be used as a measure of life expectancy and health (Pickvance 2007). Mortality statistics are therefore also a useful gauge of the usefulness of welfare provision and wider social policy (Haines 1995). Analysis of childhood mortality since the nineteenth century alongside historical developments in social policy shows that mortality in childhood has decreased as provision in health, education and welfare have improved (Dean 2007). However, the measure of a child's value has changed over the same period, both in terms of the measure used and social perceptions of childhood. Section 1.1 establishes trends in childhood mortality as a context for developments in perceptions of a child's worth and welfare provision.

National statistics record mortality in childhood as a measure of deaths occurring at specific age ranges: neonatal (less than four weeks of age), infant (less than a year of age) and child (over 1 year to a specified maximum age) (for detail see National Statistics Online: www.statistics.gov.uk/default.asp). Infant mortality data clearly illustrate the dramatic reductions in childhood deaths over time. Analysis of data from 1896 give a rate for infants of 148 deaths per 1000 live births (Haines 1995). Although there was an increase to 156 per 1000 in 1897 (Hendrick 2005), which prompted specific developments in policy, this rate declined to 82.8 per 1000 by 1921 (ONS 2010). By 2008 the infant mortality rate had reduced to 4.6 per 1000 (ONS 2010). Examination of child mortality illustrates that even more recently death in childhood has steadily declined. In 1979, death rates for children aged 1-15 years ranged from 37 per 100, 000 (boys) to 26 per 100,000 (girls) (Hughes & Church 2010). By 1995 these rates had dropped to 21 per 100, 000 and 17 per 100,000 respectively (Hughes & Church 2010).

Overall, childhood mortality rates have demonstrated a decline since the nineteenth century (Haines 1995). This is associated with improvements in health technology (such as vaccination programmes and the development of hospitals) and policy developments to promote the health and well being of children (including employment, housing, nutrition and education) (Szreter & Woolcock 2004). However, the declining total rates mask some significant variations according to geography (rural or urban) and socio-economic status (Szreter & Woolcock 2004). That mortality and health continue to have an inverse relationship with socio-economic status is well reported (Acheson 1998; Black 1980). The contemporary position is that childhood death rates have continued to decrease and neonatal rates have stabilised (Cochrane et al. 2007): in 2005, neonatal deaths were 17.3 per 100,000 whilst childhood deaths (1-19 years) stood at 14.4 per 100,000. This decline in overall childhood mortality can be aligned with changes in social constructions of childhood and associated developments in social policy through the course of history.

1.2 Social Constructions of Childhood and Parenting

Over time social constructions of childhood have varied in terms of age and experience boundaries (Davin 1999). Since the early nineteenth century, childhood has altered from an entity determined by social class and geography - e.g. working class, urban children worked, upper class children were cared for by servants - to a more standardized experience (Hendrick 1997b). Standardisation has evolved through a combination of cultural, political and institutional control, exemplified in the provision of universal education (Ariès 1978; Hendrick 1997b; Thorne 1987). Therefore childhood has developed from an early nineteenth century experience which was dependent on the social class of the child and whether or not the child lived a rural or urban experience (Hendrick 1997b), to a twenty first century, generally more homogenous position where children's education, health, work and safety are highly regulated by the state (Hendrick 1997b; Valentine & McKendrck 1997; Vincenten & Michalsen 2002).

During the nineteenth century, mortality rates were high, but marriage began to occur more often and at a younger age and as a result the population changed from being dominated by adults to having a greater proportion of children (Cunningham 1990). Two perspectives on childhood from this period have been noted. Firstly, in industrial areas, the growing numbers of children facilitated their increasing participation in work during industrialisation, but simultaneously their potential for exploitation (Cunningham 1990). Secondly, in rural areas employment of children did not rise (Cunningham 1990), but increasing perceptions of juvenile delinquency related to increased numbers of children caused them to be seen as a threat to adults (Thorne 1987). Therefore, it is clear that ambivalent attitudes towards children and childhood are long standing.

These attitudes and high mortality were influential in social policy developments; however, simultaneously, the notion of the family, arising from the middle classes, became the dominant influence over inter-generational relationships (Hendrick 1997b; Thorne 1987). Thus began the increasing institutionalisation of childhood, driven alternately by philanthropic ideals of protecting threatened children and notions of delinquency and threat produced by children (Moran-Ellis 2010). These types of attitude are indicative of the social construction of childhood by adults, fuelled by 'social, economic, religious and political challenge' (Hendrick 1997b. p25).

Moving into the twentieth century, regulation of childhood continued, with increasing state clarification of the role of 'family' to nurture and cherish children (Moran-Ellis 2010). In addition, increasing direction was provided through law, medicine and education, influenced by politics and culture (Hendrick 1997b). Evacuation during World War II made visible the deprivation of certain groups of children, leading to increased state welfare provision (Hendrick 1997a). Furthermore, in the aftermath of World War II, the work of Bowlby stressed the importance of mothering in early childhood, and provided a long term focus for child development and parenting policy and practice (Bowlby 1968; Bowlby 1973). As a result, a new perspective developed on parenting which emphasised the significance of nurture and bonding. This gave further impetus for the emotionality of parenting to be recognised as well as underpinning the responsibilities of parents – if they did not parent adequately they could harm their child. However, during the 1960s and 70s, regulation of childhood was in tension with increasing recognition of the rights of children, once again illustrating ambivalence in societal attitude (Moran-Ellis 2010).

The ambivalence persists. Currently, children are increasingly protected, for example through restrictions on play, as a response to perceptions of threat to their safety (Valentine & McKendrck 1997). In addition, there is increasing state intervention to maintain children's safety, even a notion that parents are unable to do so in an era of ever increasing technology (Vincenten & Michalsen 2002). Young people's activity is also increasingly restricted, but from a perspective of needing to protect society from this group. Using a range of policies, from prolonging the age of compulsory education to criminalising antisocial behaviour, the state responds to a socially constructed perception of threat arising from this age group (Furlong & Cartmel 2007).

This section has demonstrated that over time perspectives on childhood have differed and have been characterised by ambivalence. The common thread running through these changes is the perceived value of children. Social constructions of childhood have contributed both to developments in social policy (Dean 2007) and the ways in which society measures the value of children (Zelizer 1994). Although more recent trends are to measure the value of children in psychological and social ways (Hoffman & Hoffman 1973), there is a view that the traditional measure was one of utility (Cunningham 1990). In whatever way the value is measured, however, it can be linked to other social factors, including employment and health, and demonstrates the changing social construction of childhood (Cunningham 1990; Moran-Ellis 2010; Thorne 1987). This chapter continues with a more detailed exploration of the value of children before setting out historical developments in social policy.

1.3 The Value of Children: economically useful or useless?

Notions of the value of children have progressed from a greater emphasis on utilitarian value to one which recognises the psychological and social needs they fulfil for parents (Hoffman & Hoffman 1973). Whilst this general trend may be seen, the evidence for it is scant, relying on limited numbers of personal diaries and research based upon historical developments in policy and welfare provision, the measurement of which have been inconsistent over time (Cunningham 1990; Szreter & Woolcock 2004). As such, it provides a perspective on children which is reflective more of their value to society than to parents (Jones & Brayfield 1997). However, this perspective is useful, since it reflects the social and policy context within which children are raised.

Traditionally, the value of children has been associated with economic measures: how the child contributes to family or societal productivity. During industrialisation, in urban areas, children's participation in work and generating income was emphasised (Cunningham 1990; Thorne 1987). Prior to industrialisation, the agrarian economy, as in developing nations today, also emphasised the utility of children and their contribution to family economics (Jones & Brayfield 1997). In both of these examples, the economic value of the child to the family unit is the emphasis. However, societal notions of the economic value of children are also influential, and are demonstrated in policy developments.

In the nineteenth century, policies which regulated child labour were protective, however they also served to ensure their continued presence in the labour force and therefore reflected the imposition of an economic value upon children (Thorne 1987; Wyness 2006). Likewise, contemporary changes to education policy continue to look to the future usefulness of children rather than purely benevolent outcomes (Moran-Ellis 2010). Moreover, policy which seeks to control young people, such as criminal justice legislation, may also be concerned with their future utility as adults: what Moran Ellis (2010 p.190) refers to as a focus on children's 'status as "becomings" rather than "beings"'. Thus both the purpose of social policy for children, and the social value of children, may be seen as the development of healthy, educated adults who can function effectively for the benefit of society in the future (Qvortrup 2010; Wyness 2006). The contemporary emphasis within this perspective is upon the utilitarian value of children to <u>society</u> rather than parents (Jones & Brayfield 1997; Wyness 2006). However, emerging concerns about the impact of longevity and decreases in the proportion of children to adults have refocused the debate upon the utilitarian value of children to both society and parents (Oldman 1990).

The utilitarian value of children has, however, been challenged. As children's lives have become increasingly institutionalised and regulated, their economic worth has reduced so that 'their cost far exceeds their practical worth' (Hoffman & Hoffman 1973 p.19). In addition, as family size has reduced perception of the worth of children has altered. Thus, alternative ways of measuring their value have been developed. Stemming from concerns about fertility, a conceptual scheme of parental needs fulfilled by children was developed in the 1970's which was subsequently tested in various countries across the world (Hoffman & Hoffman 1973; Hoffman & Manis 1979; Kagitcibasi 1982; Nauck & Klaus 2007; Trommsdorf et al. 2005; Trommsdorf & Nauk 2010). The purpose of the original research was to clarify the intrinsic purpose for parents of having children (Trommsdorf & Nauk 2010)

The original research was based upon a conceptual model which was developed using inductive reasoning from existing empirical evidence (Hoffman & Hoffman 1973; Nauk 2005). The model was specifically developed to facilitate study of fertility patterns and originated in psychology, but was intended to be an interdisciplinary tool (Hoffman & Manis 1979). (Hoffman & Hoffman 1973; Trommsdorf & Nauk 2010). The tool identified nine categories of value; significantly, the economic value of children was incorporated, but distinguished from their psychological-emotional value (Hoffman & Hoffman 1973). The original nine categories for this theoretical model of the social value of children are:

- Adult status and social identity
- Expansion of self, ties to a larger entity, 'immortality'
- Morality: religion; altruism; good of the group; norms regarding sexuality, impulsivity, virtue
- Primary group ties

- Stimulation, novelty, fun
- Creativity, accomplishment, competence
- Power, influence, effectance
- Social comparison, competition
- Economic utility

(Hoffman & Hoffman 1973 p.46)

Linked to its inductive origins, questions have been posed regarding the model's comprehensiveness (Nauk 2005). In addition, the language used to describe the nine categories is challenged for its psychology bias (Nauk 2005). The testing of the conceptual model has also been criticised for producing culturally specific results (Trommsdorf & Nauk 2010). However, more recently cross-cultural studies have been carried out, simultaneously testing the model, or variants of it, in multiple countries (Kagitcibasi 1982; Nauck & Klaus 2007) or across generations in a single country (Mayer et al. 2005); such studies have contributed to the validation of the model.

In any case, the criticisms of the Value of Children model do not detract from its usefulness as a tool for broadening understanding of the variety of ways a child's value may be measured; this may be evidenced by the fact that procreation continues when children are no longer needed for their utilitarian benefits (Hoffman & Hoffman 1973). Whilst England is not a country in which the Value of Children model has been tested, similarly developed western countries, such as the United States and other European countries, have been included, which suggest that the findings may be somewhat transferable.

More recent developments of the Value of Children study have led to a model based on three aspects: self esteem, affect and comfort (Nauck & Klaus 2007). Testing of this new tool demonstrate that emotional values are *consistently* highly rated across different cultures, whereas self-esteem and comfort are specifically correlated with fertility and affluence (Nauck & Klaus 2007). Similarly, affect is emphasised in a cross-generational study of a variant of the Value of Children study based in Germany (Mayer et al. 2005). This demonstrates that the value of children has indeed altered over time, with grandmothers having a clearer focus on the economic utility value of children compared to a greater emphasis upon emotional value for younger mothers (Mayer et al. 2005). Alternative research, in which England has been included, has likewise concluded that the value of children is more readily described in terms of psychological and social measures than economic-utility terms (Jones & Brayfield 1997).

Jones & Brayfield (1997) used international social survey data from Austria, Britain, Ireland, Italy, the Netherlands and West Germany to analyse attitudes towards childrearing. The study identified the phenomenon of pronatalism (positive feeling about raising children and children themselves) and how it varied in industrial and rural economies. This demonstrated that pronatalism was less rational in industrialised economies, since childrearing was not required for economic benefit and, instead, the economic value of children in industrialised societies is low (Jones & Brayfield 1997). Thus this research substantiates the Value of Children studies, emphasising the idealisation of childrearing across nations and the associated psychological values conferred upon parents through children (Jones & Brayfield 1997). In clarifying the centrality of affect, or emotion, in the value of children to parents, the work of Jones and Brayfield (1997) supports the notion that children have become 'sacralised' (Zelizer 1994)

Sacralisation refers to 'objects being invested with sentimental or religious meaning' and has been used in the development of a theory of the changing value of American children through history (Zelizer 1994 p.11). Although that theory is focused upon America, its historical origins mirror the pattern of developments in social policy and child welfare in England, justifying its inclusion in this thesis. Somewhat critical of the Value of Children studies, judging them one-dimensional and lacking in consideration of the social context for changes in the perceived values, Zelizer's theory emphasises the influence of culture upon economic value (Zelizer 1994 p.7).

Zelizer attempts to clarify how price and value relate: noting the declining economic value of children, she considers how this change relates to cultural developments in family and social class (Zelizer 1994). In this respect, her work sits well with the Value of Children approach, since both are concerned with understanding values of children which are broader than economics (Hoffman & Hoffman 1973; Zelizer 1994). Moreover, charting American history from the nineteenth century, through the lens of historical developments in childhood mortality, child labour and education, Zelizer concludes that 'the twentieth century economically useless but emotionally priceless child displaced the nineteenth century useful child (Zelizer 1994 p.209). In other words, contemporary parenting is associated with emotional fulfilment rather than economic comfort.

Zelizer's thesis describes how the value of a child has changed from being measured in terms of labour and productivity (both domestic and through employment) to being measured in sentimental terms (Zelizer 1994). Therefore, the worth of the Value of Children models, with their emphasis on the emotional value of children, is reinforced (Hoffman & Hoffman 1973; Kagitcibasi 1996; Nauck & Klaus 2007). However, the new sentimental values nonetheless have an economic price attached, illustrated through death and injury compensation claims, insurance premiums and the costs of child-rearing (Zelizer 1994). Indeed, contemporary workforce developments, namely the increased participation of women, highlight developments yet to come in the study of the value of children, and link it to concurrent studies of changes in childhood (Furlong & Cartmel 2007; Zelizer 1994).

This section has established that the value of children across countries and cultures can be measured both in economic and sentimental terms, and that over time the emphasis has shifted from economic to emotional value. By implication, the death of a child in the twenty first century must be associated with emotional loss and suffering. The next section will re-focus back onto England. Charting social policy developments since the nineteenth century, it will illustrate the interplay of mortality rates, social constructions of childhood and policy and how they illustrate ambivalent attitudes towards the value of children. The section will finish by highlighting the contemporary emphasis on state and parental surveillance, control and sacralisation of childhood as a predominant context for parenting in the twenty first century (Moran-Ellis 2010; Zelizer 1994).

1.4 Policy: a Measure of Ambivalence and Value

The development of social policy related to children over the last 200 years has been contextualised to ambivalent views of children and childhood as well as changing notions of the value of children. Historically, children are alternately perceived either as a threat or as threatened (Hendrick 1997a; Thorne 1987). Whether society perceives children's activity as useful or destructive, for example, has influenced policy development in criminal justice, employment and education (Hendrick 1997a; Moran-Ellis 2010). With respect to value, children's contemporary and future utilitarian value has also been the focus for such policy developments (Cunningham 1990; Moran-Ellis 2010; Oldman 1990; Qvortrup 2010).

There is some debate concerning when social policy underwent significant change with respect to the way it viewed and dealt with children. Ariès (1978) considered the eighteenth century to herald this change in society's perspective upon children, but other author's, including Zelizer (1994) and Moran Ellis (2010), date the change to the nineteenth century. Regardless of the precise timing of the change, the literature is in agreement that it related to increased protection of children, associated with developments in how children were valued, which in themselves demonstrate changing social constructions of childhood (Ariès 1978; Davin 1999; Moran-Ellis 2010; Zelizer 1994).

A combination of philanthropic and market driven concerns steered the change: unease about the welfare of child workers, combined with anxiety about maintaining their presence, led to increased scrutiny and regulation of children's lives through education, health, labour and criminal justice policy (Moran-Ellis 2010). Industrialisation facilitated the visible movement of large numbers of children into the workplace, but in harsh environments such as mines and factories (Davin 1999). The rapid social changes brought about by industrialisation brought into question people's perceptions of family and family life, prompting moral panic, and galvanising action to protect children (Piper 2005). Employment of children during the nineteenth century illustrated clearly the diversity of childhood experience and its dependence upon class and geography. Geography tended to dictate the type of work to which children were exposed: rural children might work in the home, fields, or with livestock, whilst urban children were more likely to encounter industrial work alongside domestic employment (Cunningham 1990). However, the likelihood of employment was dictated by social class as a measure of poverty or wealth (Davin 1999).

During the nineteenth century, therefore, philanthropic concerns for vulnerable, poor children led to increased advocacy on their behalf for employment legislation (Piper 2005). The legal age of employment increased from 10 years in 1874 to 12 years in 1901 (Davin 1999). In addition, specific legislation to structure work increasingly in favour of child protection in mines, factories and shops was passed between 1887 and 1900 (Piper 2005). Alongside such legislation limiting children's participation in the workplace, developments in education also contributed to the protectionist attitude towards children.

Education Acts passed from 1870 until 1918 led to the school leaving age being raised from 10 to 14 years and the employment of personnel to enforce the legislation (Hendrick 1997a). The legal requirement to attend school throughout the working week from the age of five reinforced the compassionate stance towards children taken by both state and philanthropists (Davin 1999). However, simultaneously such reform challenged parents' capacity to determine their own child's upbringing (Piper 2005). This illustrates the ambiguity of public perceptions of children: whilst reforms in employment legislation were rooted in desire to protect the vulnerable child, concurrently they facilitated increased standardisation and state control over childrearing (Hendrick 1997a).

An important influence upon state control of childhood were increasingly strong ideas about the nature of family (Moran-Ellis 2010; Thorne 1987). Arising from middle class notions of domesticity, motherhood and work, these shaped the concept of childhood through employment and education, but also through developments in child health (Hendrick 1997a). Accordingly, the nineteenth and early twentieth centuries saw an unprecedented rise in professional roles associated with childhood, including medicine, psychology, education and social work (Davin 1999). This specialisation of childhood further standardised the experience, through increased scrutiny and monitoring of child development (Hendrick 1997a; Moran-Ellis 2010). Crucially, as well as improved monitoring of the vulnerability of children in the workplace, increasing professional intervention in childhood facilitated greater scrutiny of the domestic environment (Piper 2005). The introduction and implementation of education and employment policy facilitated greater state control over the activity of children (Davin 1999; Hendrick 1997a). Additionally, between 1876 and 1897, specific concerns arose with a rise in infant mortality against a backdrop of generally reducing childhood mortality (see Section 1.1) (Hendrick 2005). This was linked to inadequate childcare, often provided by 'baby farmers' – women paid to nurse infants – as well as notions of inadequate parenting (Piper 2005 p.20). As a result, there was direct state intervention in the family with respect to the parenting and nurture of children: specific legislation was passed concerning child protection, including the 1872 and 1889 Infant Life Protection Acts and the 1889 Prevention of Cruelty to Children Act (Hendrick 1997a). In addition, provision of school meals and school health services sought to counter balance neglectful parenting (Hendrick 2005). Once again, however, philanthropic and state concern for the child was balanced against state interest in securing a future population who were morally sound and appropriately socialised so that they could maintain future national interests and security (Piper 2005).

Therefore, another wave of policy sought to ensure the sound moral development of children, devised to supersede inadequate parental input (Piper 2005; Shore 1999). The Industrial Schools Acts (1857-1889) facilitated the removal of children from the family home to enable state intervention in their moral welfare (Piper 2005). Rising birth rates during the nineteenth century led to an increased proportion of children to adults, fuelling fears about delinquency, particularly in rural areas where child employment was more limited (Cunningham 1990). As a result, criminal justice legislation became more focused upon the problem of youth crime and the threat to social order posed by children (Thorne 1987). Associated changes in the official age of criminal responsibility, supported by law, are another clear illustration of the social construction not just of crime, but of childhood (Davin 1999; Eadie & Morley 2007).

It is clear that social policy both shapes and is shaped by emerging social constructions of childhood (Hendrick 1997a). During the nineteenth and early twentieth century, the tension between protecting young workers and ensuring their ongoing productivity illustrates ambivalence about the value of children: their welfare was of concern, but from both a philanthropic perspective and with particular respect to maintaining their economic utility (Davin 1999). The outcome of the associated social policy developments was that the early twentieth century was characterised by improved standards of living and reduced mortality rates (Hendrick 2005).

During the twentieth century, mortality rates continued to decline (see Section 1.1), associated with ongoing expansion in health policy and technology (Hendrick 2005). In addition, birth rates have reduced, leading to a smaller proportion of children to adults (Davin 1999). After World War II, greater public awareness of deprivation, highlighted through the evacuation programme, led to an expansion of welfare (Davin 1999). However, policy progression in health, education and criminal justice can still be linked to moral panics concerning children, centralised still upon competing notions of the child as threatened or threat (Thorne 1987). State responses through policy to intervene and standardise childhood and produce useful future citizens also illustrate the complex relationship between policy and social constructions of childhood (Moran-Ellis 2010).

Thus during the 1950s and 1960s, emerging youth cultures, such as the hippy movement, raised concerns about the threat they posed to moral order (Thorne 1987). Whereas, since the 1960s an increasing awareness of children's rights and child protection have led to a new focus upon parents: the Children Act of 1989 emphasised children's rights and parental responsibilities (Moran-Ellis 2010). Contemporary moral panics about children's safety have led to both parental and state limitation of their activities in accordance with broadened perceptions of risk (Valentine & McKendrck 1997; Vincenten & Michalsen 2002). In contrast, criminal justice developments, such as the imposition of Anti-Social Behaviour Orders (ASBOs) governed by the Antisocial Behaviour Act of 2003, fuelled by moral panic, continue to emphasise the threat that young people pose to society (Eadie & Morley 2007; Furlong & Cartmel 2007).

Alongside these developments, the standardisation of educational curricula and increasing measurement of achievement have attempted to increase educational opportunity for those not well represented, through barriers of class or race for example (Furlong & Cartmel 2007). In addition, education legislation has increased the length of childhood, prolonging compulsory education until the age of 18 years, whilst also increasing parental choice (Vickerstaff 2007). Meanwhile, the National Service Framework for Children, Young People and Maternity Services (DH 2004) and Every Child Matters programme (DfES 2004a), which focus on standards for wide ranging improvements in the health and well being of children, have increased state scrutiny of children and their development.

This section has articulated the complex relationship between social policy, societal notions of the worth of children and social constructions of childhood (Furlong & Cartmel 2007; Valentine & McKendrck 1997). The combination of cultural and structural influence, through policy and increased institutionalisation, has contributed to somewhat ambivalent social perspectives on childhood, whereby children are seen as both victims and threats (Hendrick 2005; Moran-Ellis 2010). Changes in employment, education, health and criminal justice since the nineteenth century have polarised perspectives on childhood so that contemporary Western children are valued for their emotional worth rather than their economic utility (Hoffman & Hoffman 1973; Jones & Brayfield 1997; Zelizer 1994). Parents are responsible for their child's well being and development along a state defined, standardised pathway, which is increasingly scrutinised (Moran-Ellis 2010). Simultaneously, childhood mortality is at a record low and health technology increasingly facilitates the treatment of previously fatal disease (Craft & Killen 2007). This is the social context in which the parents of dying children must raise their children.

1.5 Parenting a dying child in the twenty first century

Although childhood mortality is at a record low, some children still die. In England in 2005, 5,763 children died under the age of 20 years (Cochrane et al. 2007). This figure comprises deaths from all causes, including accidents. However, 3,924 deaths were from causes likely to have required palliative care, such as congenital malformation, chromosomal abnormality, and diseases of the nervous system (Cochrane et al. 2007). Such disorders are liable to cause significant morbidity as well as childhood mortality, particularly with ongoing developments in technology which prolong life (Craft & Killen 2007). Therefore, although the numbers of children who die each year are relatively small, 68% of these are from causes likely to have required palliative care (Cochrane et al. 2007).

These figures suggest that the majority of deaths in childhood are therefore anticipated, given the nature of the causal diseases. Such dying children follow a different trajectory of care to dying adults, often characterised by a longer timescale and patterns of increasing disability and dependence (ACT/RCPCH 2003; Field 2003). The death of any child is tragic. The social context of increasing sacralisation of children and recognition of the social value of children for parents underscores the wider significance of these children's deaths for their parents and families (Hoffman & Hoffman 1973; Jones & Brayfield 1997).

However, this group has been generally under-represented in policy. The usual path of parenting is to support a child as they grow and develop into independence, underpinned by social policy in education, health, work and criminal justice, as discussed in preceding sections of this Chapter. As Section 1.4 articulated, contemporary social policy focuses upon scrutiny and measurement of child health and development along standardised pathways. Yet the life experience of dying children and their parents cannot measure up to such policy demands. In contrast, parents of dying children have the dependence of their child prolonged beyond 'normality', whilst everyday life must continue (DH 2008). Parents of dying children face uncertainty about timescales or their child's health, but with the certainty that death is inevitable (Hutchinson et al. 2003). Many parents living with dying children will be doing so for protracted lengths of time, albeit that the child is not 'actively dying' throughout, but that the terminal nature of the disease is acknowledged from the outset (DH 2008).

A subset of children using palliative care services are those with disabilities (Craft & Killen 2007). This group, along with adults with disabilities, also have a history of neglect in policy, linked to the medical model of viewing disability as a problem with an individual (Dean 2007). The social model of disability attributes individual's social exclusion to society's inability to accommodate difference, therefore classifying disability as a social construction (Davis et al. 2005). Indeed, it is well documented that families with disabled children are more likely to experience poverty and social exclusion (Beresford 1995; Dobson 1998; Kagan 1998). Wider recognition of the social model of disability has led to improved policy relating to this group, focusing on the disability rights and independent living agendas (Dean 2007). In very recent times there has been limited policy direction for disabled children also. Recognition of the particular vulnerability of this group led to Aiming High for Disabled Children Programme, providing funding of £429m to develop and improve services for disabled children and their families between 2008 and 2011 (DfES 2004b).

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However, it is not clear that such policy is adequate for disabled or dying children. The Every Child Matters programme (DfES 2004a) was established to reform children's services, ensuring that education, health and social care were provided in an integrated manner and according to prescribed outcomes for children. Yet it is not clear that the outcome measures are suitable for disabled or dying children: it may not be possible to gauge the 'achievements' of children with progressive or degenerative conditions using typical measures (Sloper et al. 2009). Since 2006, under the banner of 'Every Disabled Child Matters', campaigners have questioned the policy, seeking equal recognition in policy and services for children with disabilities (EDCM 2010a). Critical of the lack of direction concerning services for disabled children, their most recent campaign highlights how the recent coalition government spending review has jeopardised both current and future services funded through Aiming High (EDCM 2010b).

Meanwhile, there has also been recent limited policy recognition of dying children as a minority group. Measurement of the scale of the issue (Cochrane et al. 2007), alongside a review of support services (Craft & Killen 2007), has led to the establishment of Government priorities for children's palliative care service development (DH 2008). However, the reality is that the funding and sustainability of the palliative care support services which government has sought to regulate are dependent upon the voluntary sector (Craft & Killen 2007). This is a clear illustration of ambivalence in attitudes towards dying children and their parents. State and individuals increasingly focus upon protecting children and valuing them for their sentimental worth. Simultaneously the most vulnerable children have been largely ignored both in policy and practice. Meanwhile their parents, who face the loss of both the child and the values they fulfil, are unable to protect them or enable them to achieve state measures of well being.

1.6 Comment

Childhood mortality rates in England have been, overall, in decline since the nineteenth century (Haines 1995). This is associated with improvements in the health and well being of children, linked to developments in social policy, particularly those concerning health, education, and employment (Haines 1995; Pickvance 2007). Such developments are associated with societal views of children which have been somewhat ambivalent and are reflected in social policy developments wherein the child is seen alternately as a threat and as vulnerable (Hendrick 2005; Moran-Ellis 2010; Thorne 1987). Whereas children in the early 19th century were viewed as an economic resource for their parents and for whom minimal state intervention was required, subsequent social reconstruction of childhood and parenting centralised the role of state as a reflection of the altered value of children.

Philanthropic activity, the rise of the middle class ideal and state concern with maintaining economic prosperity and world power led to greater focus upon childhood, and therefore parenting, being reconstructed as a means to a state end – children needed to be brought up in ways which ensured their future utility to the state (Cunningham 1990; Hendrick 1997b). As a result, childhood became ever more highly regulated. For example, in the nineteenth century, concern for the welfare of child workers, combined with national economic need to maintain their employment, led to increased scrutiny and regulation of children's lives through education, health, employment and criminal justice policy (Moran-Ellis 2010). Moreover, the role of the parent altered from one focused upon personal gain to one of responsibility to the state, whilst the emotional value of children was emphasised as well as the need for state vigilance in ensuring their adequate upbringing.

These themes have persisted in both social policy and social constructions of childhood and parenting (Fletcher & Hussey 1999; Furlong & Cartmel 2007). Matters such as the age boundaries of childhood and the activities a child should participate in have changed significantly over time (Davin 1999), indicative of the way in which societies measure the value of children: whether they are a form of economic utility to be exploited or a priceless entity to be treasured and nurtured (Hendrick 1997a; Zelizer 1994). Whereas historically in England children have been valued for their contribution to the economic wellbeing of family and society (Davin 1999; Piper 2005; Thorne

1987), more recent research has identified that the value of children to parents is measured more accurately through the psychological needs they fulfil for their parents (Jones & Brayfield 1997). The contemporary situation is that children have become sacralised (Zelizer 1994).

The sacralisation of children in England has been supported through contemporary developments in social policy and social constructions of childhood. Twenty first century childhood is maintained for longer through compulsory education (Vickerstaff 2007). Contemporary moral panic about children's safety means that their activities are highly controlled and freedom is limited (Valentine & McKendrck 1997; Vincenten & Michalsen 2002). Children are scrutinised with respect to their health and development, measured against prescribed objectives and norms (DfES 2004a). Whereas in the nineteenth century children's experiences varied and were dependent on geographical and class influences, today's childhood is standardised through institutional control (Moran-Ellis 2010).

Children have become sacralised: they are increasingly seen as vulnerable and in need of protection, for which parents are held responsible. Meanwhile they are no longer valued so much for their economic contribution as for their sentimental worth and the psychological needs they fulfil in parents. These are the contemporary social constructions of childhood and parenting around which social policy is built. Yet in this society where childhood is sacralised, scrutinised and standardised, some children will die. Moreover, this is the social context within which dying children must also be parented, but the needs of such children and their parents have been somewhat neglected in social policy. One reason for this may be the lack of data about these parents and children. There has been some limited recent consideration of the numbers of children and families affected, the kinds of support services available to them and the standards of care which should be established (Cochrane et al. 2007; Craft & Killen 2007; DH 2008). However, there exists a paucity of empirical research involving this group (Craft & Killen 2007). Therefore, the purpose of this thesis, seeking in a small way to tend to this gap, is to investigate empirically the range of experiences of parents of dying children.

Chapter 2: Literature Review

Introduction

The preceding chapter has established the increasingly precious nature of children and childhood and the influence of those social changes upon parenting. Should circumstances arise which jeopardise the well being of a child, it might seem right to assume that the parents would suffer and their experience would be characterised by emotion. Within healthcare, there is a tendency to overlook emotion and suffering whilst giving primacy to physical health (Cassell 2004; Kleinman 1988). In addition, how suffering and emotion affect care givers rather than patients is even less well explored. Chapter 2 therefore contextualises this thesis within the theories of suffering and emotion management.

The scope and method of the literature review reflect a mixed strategy. A literature search using the key words 'suffer', sufferer' and 'suffering' in the library catalogue and databases including Medline, Cinahl and IBSS, yielded a proliferation of work related to experiencing symptoms, such as pain, and physical sensations. Although such studies may be of significance to a general study of suffering in individuals, in this thesis the illness is that of a child, but the suffering experience being analysed is that of the parent. Therefore, I judged that physical pain and symptoms as experienced by research subjects were not significant aspects of the work. As a result, I have not reviewed the literature on pain and symptoms as suffering. Useful insights into this literature can be gained through the work of Cassell (2004), Wilkinson (2005) and Bendelow (1995 & 2006).

I therefore focused the literature review on sociological studies, using the key term 'suffer', sufferer' and 'suffering'. Analysis of the resulting range of articles then gave rise to further searches using the terms 'loss', 'intersubjectivity', 'emotion' and 'emotion management'. In addition, the reference lists of all selected articles were searched for further relevant books, reviews and research papers. This latter strategy was then repeated within the health literature to ensure inclusion of all relevant papers. The literature demonstrated that the term 'suffering' is readily applied to those receiving health care generally and palliative care specifically. However, there is an absence of research which takes account of how individual healthcare users interpret suffering. As a result, it seems that people have a label of suffering imposed upon them, both in practice and theory. Moreover, although there is a well developed sociological literature in the subject, there is limited reference to that literature within the healthcare or palliative care literature.

In the first section of the literature review I explore current theories of suffering. Initially, I offer a definition of suffering as loss, derived from the existing literature and research, and which might empirically examined. Following on from this, key themes emerging from the literature are summarised: judgement of suffering, communication of suffering and responses to suffering. From this I establish a focus of study for this thesis: further development of theory concerning the emotions of the suffering individual, how the individual chooses to express their suffering in terms of those emotions, and the impact of not expressing their felt emotions.

The second section of Chapter 2 therefore focuses specifically upon emotion theory, specifically emotion management. Initially, my position on the nature of emotion is established, as a context for the ensuing review of literature pertaining to emotion management. I begin the review with definitions and critique of the concepts of emotion management and emotion work. The related concepts of feeling rules and scripts are then defined. Finally, the issue of the cost of emotion management is considered, particularly with respect to its relationship with authenticity of emotion.

At this point, I identify a clear link between suffering, wherein the concept of authenticity of voice is privileged, and emotion management, wherein the notion of authenticity of felt emotion is contested. It is this convergence of the two theories upon the issue of authenticity which this thesis aims to study empirically, alongside the nature of suffering in the unique context of parenting dying children. Chapter 2 concludes therefore by setting out the research questions to be addressed through the empirical study and a summary of the unique contributions this thesis makes to the theories of suffering and emotion management.

2.1 Suffering Defined

Suffering is a fundamental concern in palliative care. Indeed the very definition of palliative care includes a stated aim of improvement of 'the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of *suffering*' (WHO 2002 p.84 emphasis added). Achievement of such a goal is requires understanding of what suffering is. Whilst anyone can experience personal suffering and anyone can share in the suffering of others, through observation or empathy (Farmer 1997), defining suffering is more problematic. It is difficult to define because in many senses it is 'an absence', as Frank points out: 'suffering resists definition, because it is the reality of what is not' (Frank 2001 p.355). Individuals build their frames of reference for their lives based on their experiences. They plan their future lives based on those experiences and integrate their hopes and ambitions. Suffering might be perceived to be the antithesis of all those hopes and plans.

Despite the difficulties, many writers continue to attempt definitions. In so doing, their research is framed within social phenomena, such as physical pain (Bendelow 2006) personal illness (Charmaz 1983; Charmaz 1999; Frank 1995; Frank 2001; Hallowell 2006; Sacks & Nelson 2007), or social violence (Kleinman Arthur 1997; Ramphele 1997; Schwarcz 1997; Wei-Ming 1997). What concerns researchers is the effect of suffering upon individuals (Charmaz 1983; Hallowell 2006; Sacks & Nelson 2007) and, in the context of social suffering, how the expression of those effects are moderated by the individual's social world (Kleinman Arthur 1997; Wilkinson 2005). Within the literature, therefore, suffering is explored using a variety of human experience, but whichever vehicle of experience is utilised a common feature is that of loss.

Suffering as loss is illustrated in various studies, including those focused on bereavement (Ramphele 1997); old age (Black & Rubenstein 2004); trust (Sacks & Nelson 2007); and identity (Cassell 2004; Charmaz 1999). Concrete losses such as role changes, material wealth, and variation in social capital may also precipitate suffering (Putnam 2000). The loss of health is a common vehicle to explore suffering (Cassell 2004; Charmaz 1983; Frank 1995; Wilson 1991). Within this context loss may be associated with self image (Charmaz 1983), self concept (Charmaz 1999), self-belief (Sacks & Nelson 2007), role or death (Black & Rubenstein 2004) and there is evidence that each of these domains inter-relates.

Whilst the precipitating event to suffering might be a concrete event, such as ill health, the abstract meanings attached to that event may be the driver for the suffering experience, such as loss of trust (Sacks & Nelson 2007). However, the studies also demonstrate that both the loss itself and the consequences of the loss pertain to the suffering of the individual (Black & Rubenstein 2004; Charmaz 1999; Sacks & Nelson 2007). For example, loss of health can lead to loss of a favourable self image [illustrating both concrete and abstract losses which contribute to suffering]; however, one consequence of these losses may be a negative self image which itself can bring about suffering (Charmaz 1999).

One means of considering suffering as loss is to account for what is at stake for the individual who suffers (Kleinman 2006; Kleinman & Kleinman 1991). In taking such an approach, the intention is to comprehend *from the perspective of the sufferer* the nature of the suffering experience (Kleinman 2006; Kleinman & Kleinman 1991). Whilst this might seem to be elemental to work on suffering, there is much evidence that the perspective of the sufferer is apt to become blurred. This can occur through judgements imposed upon suffering experiences and in the ways in which suffering is represented, or given voice.

2.2 Judgement of Suffering

When suffering is viewed as loss, it presupposes that whatever was lost held value for the individual and that the individual therefore judges the experience. Whilst it has been noted that suffering is an experience common to mankind, Wilkinson identifies that it is at once 'common to all, yet can only be known uniquely as our own' (Wilkinson 2005 p.16). Suffering is thus a profoundly individual experience and as such is subject to personal value judgements, perhaps through the search for meaning (Clark & Seymour 1999; Morgan & Wilkinson 2001; Wilkinson 2005). Suffering is difficult to define, because it is what a person's life should not be, and this fact impedes its articulation (Frank 2001). However, precisely because it is in opposition to the life a person planned, it is judged as it relates to those plans and preceding experiences, and indeed the whole of the person: body, mind and spirit (Cassell 2004).

For some, then, 'suffering is ultimately a personal matter – something whose presence and extent can only be known to the sufferer' (Cassell 2004 p.33) This is exemplified when individuals report suffering unexpectedly, or conversely, do not seem to suffer when expected so to do, and also relates to the significance of violation of the individual's sense of self in suffering (Cassell 2004). Loss of self is well documented as both a form of and outcome of suffering, relating to judgement of the nature of the self and its continuity (Charmaz 1983; Charmaz 1999; Sacks & Nelson 2007). From empirical study of adults experiencing chronic illness it emerges that the loss of suffering includes losing a favoured self-image and gaining an identity which is judged as unwanted and incorporates such issues as living a restricted life, social isolation and becoming a burden (Charmaz 1983; Charmaz 1999). In contrast, those whose suffering abates are seen to judge their experiences as a means to greater insights into self (Charmaz 1983).

Research with hospice patients has similarly noted that suffering may be perceived as loss associated with an event, such as loss of health, as well as the consequences of the loss for the individual's meaning of self, who they perceive themselves to be (Sacks & Nelson 2007). In this study, individuals judge suffering to be a negative experience which affects the reality they construct for themselves and the meanings they attach to life experiences; it challenges previous belief systems, undermining trust in oneself; as a result individuals experience vulnerability and uncertainty (Sacks & Nelson 2007).

Such studies demonstrate that those who suffer judge <u>their own</u> experiences against preconceived notions which are individual in nature, surely emphasising the importance of a subjective perspective upon suffering being maintained. However, it is remarkable that the necessity of suffering being considered from the subjective perspective can be questioned. When this happens and the individual, subjective perspective is no longer emphasised, their suffering becomes subject to judgement by other people.

As an example, modern medicine developed as 'a response to suffering' (Edwards 2003 p.59), but is criticised for its focus upon the biomedical aspects of disease and disregard for the wider aspects of individual personhood (Edwards 2003, Kleinman 1988, Kleinman 1980). In other words, the individual illness experience and its meaning, which incorporates non-physical suffering, tends to be overlooked (Kleinman 1988; Kleinman 2006). Even when suffering is the focus of illness, some researchers privilege the ability to objectively measure the experience. Thus individuals may be objectively judged as suffering when they experience particular circumstances such as poverty and deprivation, whether or not they interpret their own experience in such terms (van Hooft 1998). Even when individual interpretation of experience is incorporated into models of suffering, there can be a tendency to privilege objective measurement if the individual is thought to lack mental capacity (Edwards 2003).

Some argue that objectifying suffering may be a means of its alleviation, allowing the profoundly personal to become intersubjective and therefore open to mitigation (Cassell 2004). However, objectification risks further suffering if the assumptions made do not reflect the individual's perspective (Bourdieu et al. 1999). In fact, it will be argued here that much contemporary research into suffering tends to assume its existence according to a given definition, based upon the analysis of individual experience, without reference to whether or not the subjects agree with that judgement. However, it remains that whilst some argue that it may only be possible for suffering truly to be known by the sufferer (Cassell 2004; Morris 1997), suffering is, even so, subject to judgement by society (Frank 1995). Societal judgement occurs with respect to the nature of the suffering experience itself, how an individual responds to that experience and the social capital of the individual. In these ways observers call into question the legitimacy of suffering and sufferers alike.

Suffering experiences are judged by society according to moral norms (Charmaz 1999; Ramphele 1997). Moral order is imposed upon suffering by the overriding moral community within which the individual resides, the boundaries of which are influenced by culture and history (Morris 1997). Moral judgement of suffering has implications for the status and life experience of the individual in terms of legitimation of their suffering experience and their position in their society (Frank 1995; Morris 1997; Ramphele 1997). The status of a suffering experience is both acknowledged and gauged by a moral hierarchy: consequently, causes of suffering deemed to be out of the control of the individual, may be afforded high position within the hierarchy of moral status (Charmaz 1999). This is illustrated by the responses to HIV infection in the 1980's, when infected haemophiliacs were viewed quite differently to infected drug users.

Whilst the nature of the suffering experience itself is judged by society, its position on the moral hierarchy may be accompanied by a set of behavioural and circumstantial expectations, signifying judgement of the individual sufferer (Charmaz 1999). The suffering inherent in alcoholism, for example, might not be legitimated if it is judged to be self-induced (Connolly 1996). Alternatively, how a sufferer endures their experience is exposed to judgement: whether or not they suffer in silence appropriately to their circumstances, for example (Charmaz 1999). Additionally, judgement of suffering may have consequences for its amelioration. Rationing of healthcare resources in the developed nations is a clear example of the judgement of suffering associated with certain lifestyle choices, such as smoking and diet (Farmer 1997).

The agency of the individual therefore has consequence for their moral status when suffering is judged by society. However, as well as individual action, the social capital of the sufferer can contribute to societal judgement of their suffering (Charmaz 1999; Ramphele 1997). 'Love, power, money, or special knowledge sustain moral status' (Charmaz 1999 p.368). This is clearly illustrated through the disproportionate suffering experienced by those who live in poverty, powerless to resist the outworking of society's judgement of and responses to their varied experiences (Farmer 1997). A simple interpretation of the Holocaust might see it as a powerful and extreme example of individual lack of social capital resulting in societal judgement which had profound consequence for individual suffering experience. It should also be noted that the suffering experience may lead to the erosion of social capital. Those same resources [love, money, power or special knowledge] may be undermined by social structures and institutions, such as work and healthcare models, resulting in poverty and social exclusion (Beresford 1995; Dobson 1998; Kagan 1998).

Thus suffering can be defined as loss and, as such, it is subject to judgement by both the individual sufferer and society according to moral norms which are historically and culturally specific. The judgement of suffering is significant in at least two ways: firstly in the way it relates to communication about suffering; secondly because judgement, alongside communication, both forms and shapes responses to suffering. In the next section the analysis is developed by considering communication around suffering and responses to suffering.

2.3 Communication about Suffering

Issues concerning communication about suffering are prominent in the literature, and include the worth of giving voice to suffering, the means of giving voice to suffering, and authenticity of voice. There is debate within the literature regarding how to convey the individual experience without diminishing the voice of the sufferer. For some, suffering is beyond words, it is unspeakable and silence might be all that the sufferer can manage in the face of overwhelming circumstance (Frank 2001; Morris 1997). Conversely, the prevention of suffering might be hindered by the sustained silence of those individuals or organisations that have the capacity to influence (Wilkinson 2005). Where caution is employed to preserve the unique nature of individual experience, giving voice to suffering could achieve positive outcomes, including enlightenment of society and organisations about the individual experience and how to respond (Frank 1995; Frank 2001; Wilkinson 2001; Wilkinson 2005).

When giving voice to suffering the means employed requires careful consideration. Language, both the words chosen and the patterns in which they are reconstructed, contextualise suffering (Bourdieu et al. 1999; Cassell 2004). The language through which suffering is communicated is a reflection of both the individual and their culture (Das 1997; Morris 1997; Skultans 2003). Whereas historically religion has been a route for the expression of suffering, in modernity technology and rationality have been emphasised (Wilkinson 2005). However, the use of technology may expose individuals to more suffering even when its purpose is the relief of suffering (Wilkinson 2010). Furthermore, the adequacy of rational-technical language to express the truth of personal suffering can be questioned (Kleinman & Kleinman 1997, Wilkinson, 2005) and the language used to communicate suffering can also be a tool for expression of moral judgement, as explored previously (Das 1997). The language and means used to give voice to suffering cause some to question the 'authenticity' of the voice which expresses suffering (Bendelow 2006; Kleinman & Kleinman 1991; Kleinman & Kleinman 1997).

The nature of 'authenticity' must be carefully explored when considering it in the context of sociology. Since phenomena are encountered and recognised in everyday life according to complex mechanisms it is necessary to clarify the philosophical basis guiding this thesis and thereby comprehend the significance of 'authenticity'. A social constructivist position recognises that individual realities are constructions based on how individuals interpret experience (Guba & Lincoln 1989; Heron & Reason 1997; LeCompte & Schensul 1999b). In addition, these constructions are also individually contextualised by cultural, historical, temporal and psychosocial means (Charmaz 2008; Guba & Lincoln 1989). In this way, the meanings which sufferers place upon their experience are seen to be individually constructed and contextualised (Guba & Lincoln 1989; Holstein & Gubrium 2008). However, it is equally as significant that realities are multiply contingent (Brown 2009). Individuals interpret phenomena according to the characteristics of both the phenomena and the individual (Prus 1996). The characteristics of the phenomenon may not have been intended for interpretation in the way that the individual chooses, however, particularly when the phenomenon is another person or their behaviour (Berger & Luckman 1971). Regardless, the individual interprets 'the other' and constructs individual, subjective realities (Heron & Reason 1997).

Given this philosophical basis for the nature of reality, it is appropriate to question the worth of considering 'authenticity', since any reality is seen to be an individual interpretation of phenomena. The issue, then, is whether or not the interpretation of suffering which is presented when voice is given to suffering is a reflection of *the sufferer's* own construction, or if it more accurately reflects the construction of *the provider of the voice*. Thus, when an individual directly gives voice to their own suffering, they might be seen to be providing an authentic account *of their own construction*. However, when a third party gives voice to the suffering of another, through the mechanism of multiply contingent realities (Brown 2009), the authenticity of their account, in terms of its accuracy of reflection of the sufferer's own construction, may be questioned. The significance of authenticity of voice within suffering theory is the risk that metaphorical violence may be done to sufferers through misrepresentation of their voice (Bendelow 2006; Kleinman & Kleinman 1991; Kleinman & Kleinman 1997; Wilkinson 2005). This may be clarified by considering three methods of giving voice to suffering, namely through research, through the media and through professional representation.
The perspective of the sufferer is vulnerable throughout the research process, from the conception of the research questions through to dissemination of

findings (Frank 2001). Ethnography, narrative, and phenomenology are all suggested as appropriate means of giving voice to suffering experience, particularly since they attend to the quality and individuality of an experience (Frank 2001). However, whichever methodology is employed, maintenance of authenticity becomes an issue when sufferers become research subjects: the process of reducing original conversations into manageable sound bites which reflect research agendas is problematic for truthful representation of personal suffering (Bourdieu et al. 1999; Frank 1995; Smith 1999, Frank, 2001). As noted in section 2.2, even in research about suffering, there is a tendency to assume its existence according to a given definition with no apparent clarification of whether the individuals see themselves as suffering.

Research has a particular audience and a limited sphere of influence, however, suffering is communicated more widely through general media sources such as newspapers and television, and here, too, authenticity of voice becomes problematic. Media sources have the potential to draw attention to suffering with both positive and negative outcomes for the sufferer (Wilkinson 2005). There is value in the authentic voice of the individual sufferer being made available to fellow sufferers (Morris 1997; Schwarcz 1997). However, just as the sufferer is vulnerable in the research process, in the same way media coverage can appropriate suffering (Kleinman & Kleinman 1997). The voice of the sufferer can become blurred or misconstrued in order to achieve the objectives of the portrayer, and both image and meaning are selectively utilised in this process (Kleinman & Kleinman 1997; Morris 1997). It may also be necessary for the sufferer to tacitly comply with the agenda of the portrayer in order to change their situation, such as allowing themselves to become victims in order to receive support (Kleinman & Kleinman 1997). The same mechanism can be seen to function when professionals represent suffering.

When an individual suffers they may respond in various physical, psychological and social ways and these reactions may be grouped together and given a name for professional purposes. For example, 'post traumatic stress' may be the label applied to somebody who has encountered a traumatic event and as such is a professional representation of the individual's suffering (Kleinman & Kleinman 1991). In order to obtain recognition of and support for their responses to their experience, sufferers may accept such professional misrepresentation of their authentic voice. However, it is suggested that this type of *misrepresentation* is a means of delegitimation of the individual suffering experience, and, moreover, the delegitimation itself becomes a part of the suffering experience, perhaps in the ways in which subsequent behaviour becomes prescribed (Kleinman & Kleinman 1991; Ware 1992). What each of these means of communicating suffering has in common is how the way in which they represent the individual suffering experience influences responses *to* suffering.

2.4 Responses to Suffering

Responses to suffering arise from both sufferers themselves and observers of suffering, and the two inter-relate. As noted above, both individual sufferers and observers judge suffering experiences according to a societal-driven moral gauge, and judgement is a form of response to suffering. In addition, communication about suffering influences judgement as much as judgement shapes communication about suffering. Thus responses to suffering are shaped by communication.

There is debate regarding appropriate responses to suffering. The literature generally seems to support the view that suffering is unique to each individual (Frank 1995; Charmaz 1999; Frank 2001; Cassell 2004; Wilkinson 2005). However, there is still some debate about whether suffering can be measured objectively as well as subjectively (Cassell 2004; Edwards 2003; Morse 2001; van Hooft 1998). Some question the notion that there can a rational response to suffering other than listening (Frank 2001). Others contend that it is essential to incorporate consideration of how to ameliorate suffering (Cassell 2004). Seeking a cure for suffering might suggest that it is a phenomenon which can be analysed and for which a set of responses can be formulated, and some researchers maintain that it is possible and therapeutically useful for suffering to be judged objectively by an observer

(Edwards 2003; van Hooft 1998). Clearly, this debate dovetails with that of how to give voice to suffering, articulated in section 2.3.

When giving voice to suffering, the perspective of the sufferer can become lost, as the literature review has demonstrated. However, responses to suffering go beyond value judgements to encompass concrete outcomes for the lives of sufferers. When the authentic voice of suffering is subjugated to social and cultural agendas other than those of the sufferer, responses to suffering may be moderated through processes of social suffering. Social suffering is a term used to describe how societies influence both suffering and responses to it (Kleinman & Kleinman 1997). When groups consider that suffering can be measured objectively and that intervention to relieve suffering is justified even if the 'sufferer' does not perceive themselves to be in that role (van Hooft 1998), this would seem to be an example of social suffering. In the debate about how suffering is best expressed, whether this can or should be achieved by others or whether it is truly only possible through the voice of the sufferer themselves (Cassell 2004; Frank 1995; Frank 2001; Wilkinson 2005), social suffering must be a potential consequence if attention is not directed at the impact of the means of expression.

How an individual responds to their own suffering and whether they are empowered to give true expression to their experience are shaped by societal expectations of behaviour and responses (Charmaz 1999; Ramphele 1997). Social suffering focuses upon the influence of the structure of society (Bourdieu et al. 1999), in particular 'what political, economic, and institutional power does to people and, reciprocally, from how these forms of power themselves influence responses to social problems' (Kleinman et al. 1997 p.ix). Social suffering is therefore closely connected with intersubjectivity.

Intersubjectivity concerns the development of shared meanings about social phenomena (Prus 1996). Without intersubjectivity, facilitated through insight into the experience of suffering as articulated by the individual concerned, there is surely limited possibility of offering any meaningful interaction with the sufferer. It is argued that intersubjectivity, through effective communication, may be the first step toward restoring a loss of self (Cassell 2004). However, suffering may be judged, its voice may become blurred, and communication about suffering can be difficult, all of which may limit intersubjectivity. When intersubjectivity is limited, whether deliberately or not, and whether at an individual or societal level, the individual's suffering or their perspective upon it, may not be legitimated.

When an individual's suffering, or their perspective upon it, is not legitimated there may be consequences for their lives and for their own response to their suffering (Kleinman & Kleinman 1997). In social suffering, political bodies can appropriate suffering and determine how the individual sufferer's experience is judged as legitimate or not and under what circumstances. Examples of this include widowhood in South Africa (Ramphele 1997), Western portrayal of the deaths of Iraqi soldiers during the Gulf War (Morris 1997), and individual expression of the meaning of social change in China (Schwarcz 1997). In each case, the suffering of the individual is appropriated and reframed by the dominant political movement and it is the reframed version of suffering which is legitimated. The same can be seen to happen in health care when primacy is given to physical symptoms and lack of attention paid to psychosocial outcomes of ill health (Kleinman 1988). When this happens to individuals, they must choose whether to submit to the 'official', legitimated representation of their experience, which may not be an authentic representation of their own perspective.

If the legitimacy of suffering is dependent upon it being framed in certain ways, sufferers may have to demonstrate particular behaviours in order to receive recognition, support or status with which the legitimate suffering is associated. Thus the poor may submit to the label of victim (Kleinman & Kleinman 1997), the sick submit to the label of a physiological disease (Cassell 2004), the politically challenging submit to the label of casualty of war (Ramphele 1997), all in order that recognition and vital ongoing support may be secured. The price of legitimation, however, may be a loss or disregard of the personal perspective upon the suffering experience which itself forms part of the suffering, albeit perhaps unrecognised (Wei-Ming 1997).

However, one type of response to suffering, through which the personal perspective may still be articulated, even when submitting to a legitimated version of events, is through emotion. Emotional responses to suffering may be by the individual and by wider society. There is evidence in the literature of concern for the politics of compassion (Wilkinson 2005), and acknowledgement of the need to generate concern about suffering within society (Langer 1997). However, this is on a grand scale and does not detail the intimate, inter-subjective out-workings of emotion around suffering. There is empirical work to explore the emotions of suffering, some of which relates specifically to caregivers (Gregory & Longman 1992; Hinds 1992). As with research into social suffering (Ramphele 1997; Schwarcz 1997; Wei-Ming 1997), such work demonstrates how and why the individual voice and emotion may be subsumed by social structure on a grand scale.

Yet the emotion of the sufferer, whether or not it is given voice, persists as a response to suffering, and merits further exploration as an intersubjective phenomenon, particularly at the more intimate, individual to individual level. Of particular interest in this study is the way in which emotion may both facilitate and be facilitated by intersubjectivity in suffering, through interpersonal interaction. There are some situations of suffering that can be made good: poverty can be relieved, health may be restored, and victims of crime can be compensated. However, there are instances where the relief of suffering is problematic, such as when the context of the suffering is incurable disease or when a loved one dies. Such situations cannot be rectified and a response which pretends or attempts to do so could be damaging (Langer 1997; Schwarcz 1997). Therefore, in the absence of being able to prevent or resolve the suffering experience, itself it is important to consider how further suffering as a consequence of interpersonal interactions might be prevented. Therein is the focus of this thesis.

If suffering may be defined as loss it reflects judgements being made about the nature of suffering experiences. Judgements of suffering are made by sufferers and observers and may be seen in how suffering is communicated. When suffering is communicated, the authentic voice of the sufferer may be subjugated to other's judgements and agendas. This may be a reflection of the degree of intersubjectivity in suffering and represents a response to suffering. Responses to suffering may determine its legitimation and that in turn has consequence for the experience of the sufferer. Since emotions may form and influence communication, how the suffering individual responds emotionally must be significant in how suffering is communicated, judged, responded to and legitimated. This project is therefore concerned with the emotional response of the individual: the emotions they experience, how the individual chooses to express their suffering in terms of those emotions, and the impact of not expressing their true emotions. This requires consideration of emotion theory. In particular, the review will consider the role of emotion in communication, specifically with respect to emotion management.

Emotion Theory

2.5 Emotion Defined

A key issue in the sociology of emotion is the definition of emotion. The components of emotion comprise a situational stimulus, physiological arousal, expressive behaviours and cultural labels [situational definitions] (Shott 1979; Thoits 1989 p.318). These components suggest that there are both biological [physiological] and social aspects to emotion. There are at least three major theoretical perspectives on emotion, distinguished according to their relative focus upon biology or social/cultural construction: biological (also known as organismic); constructionist; and interactionist (Lyon 1996; Thoits 1989; Turner 2009; Williams & Bendelow 1996). Although in reality the three perspectives overlap within the literature, and indeed one may find a given author labelled as a different type of theorist by different reviewers, it is worthwhile to review each perspective in contextualising this thesis.

Biological theorists focus upon the influence of biology in the evocation and expression of emotion and empirical evidence of involuntary physiological responses is cited to support this perspective (Darwin 1873; Hochschild 1983; Williams 2001). In this way the autonomic nervous system is seen to bring about physiological change and sensation in response to the situational stimulus (Rosenberg 1990). Such theorists favour the existence of automatic responses to given stimuli and tend to underrate the influence of individual interpretation (Kemper 1981; Thoits 1989; Turner 2009). Thus subjectivity, autonomy and agency are also under-represented in these theories. Instead, 'primary' emotions, those with a physiological basis and which can be mapped in evolutionary terms, are contrasted with 'secondary' emotions which are acquired, socially interpreted derivatives of the primary emotions (Kemper 1987). Critics of this approach argue that whilst the physiological elements of emotion cannot be ignored, insufficient account is made of agency and social shaping of emotion (Hochschild 1979).

In contrast, constructionists have a greater focus upon the social or cultural construction of emotion (Jackson 1993; Shott 1979). Emotions are seen as reactions to stimuli, embodied and labelled according to social or cultural norms (Shott 1979). Thus individuals are seen to interpret stimuli through culturally / socially derived models (Lyon 1998). This is upheld through the recognition that whilst there are clear physiological changes associated with certain emotions, such as crying and sadness, other emotions, such as pride, do not have the same clarity of physiology (Kemper 1987; Williams & Bendelow 1996). In recognition of the variations of emotional expression and meaning across cultures, emotions are thus seen to be constructs (Jackson 1993). Further, constructionists recognise the intersubjectivity of emotion: individual narratives of emotion are constructed through interpretation of contemporary and past cultural representations of emotion (Jackson 1993). Constructionists are criticised for acknowledging the biological origins of emotion but not recognising their significance (Kemper 1981). Additionally, 'strong' constructionists -who claim reality to be entirely socially constructed and bereft of 'facts' (Sayer 1997) - are criticised for not conceding the existence of certain biologically determined and physiologically expressed emotions (Thoits 1989).

Both constructionist and biological approaches to emotion are criticised for upholding traditional dualisms of mind/body (Lyon 1998; Williams & Bendelow 1996). It is clear that the biologists and constructionists tend toward a polarised perspective on emotions rather than recognising range of interactions between the stimulus, physical response and interpretive elements of emotion (Freund 1990). Mapping the chronological development of the theories in the literature demonstrates that the polarised positions may be maintained even when attempts are made to integrate positivist and constructionist positions (Kemper 1987). There is however a third theoretical perspective on emotion which aims to recognise both physiological and social aspects of emotion: the interactionist position.

Interactionist theorists recognise the existence of biological elements of emotion, but do not isolate that from the constructionist components, seeking rather to integrate the two (Hochschild 1979; Williams & Bendelow 1996). Rather than specifying physiological reactions as emotions, the state of physiological arousal is said to be interpreted and subsequently labelled utilising socio-cultural means (Thoits 1989). In addition, a new dimension of intersubjectivity is incorporated, since integration of both the profoundly personal and the broadly social are seen to realise individual narratives of emotion which are derived in part from social interaction (Craib 1995; Denzin 1983; Freund 1990). Thus the interactionist recognises that "the experience of emotion, which involves both physical and phenomenal dimensions, has also a social relational genesis" (Lyon 1998 p.55). Lastly, individuality is emphasised, since the argument moves away from biological or social imposition of emotion or its labels and integrates an element of agency into the genesis of emotion (Shott 1979). However, some suggest interactionist theorists neglect agency in the emotional life of their social actors (Bolton & Boyd 2003). Despite their attempts to integrate biology and sociology, interactionist theorists are still criticised for failing to adequately account for the biological origins of emotion and for retaining more focus upon social and cultural construction of emotion (Denzin 1983).

Each of the theoretical perspectives on emotion has positive aspects as well as weaknesses, as identified. For the purposes of this thesis I take an interactionist perspective. As a biological scientist, I recognise the physiological aspects of emotion. However, as a social scientist, it is clear that emotion is equally shaped by and embedded within social and cultural systems. The interactionist position is both congruent with the philosophical basis of the thesis and reflective of its methodology, whereby emotion is studied both in terms of observation of expression and as descriptions of felt emotion (see Chapter 3). In addition, the interactionist position is compatible with the philosophy of children's palliative care within which this thesis is also contextualised. That philosophy seeks to provide holistic care rather than the dualistic approach which tends to separate mind and body and for which the biomedical model of mainstream medicine is apt to be criticised (Freund 1990; Kleinman 1988). Thus, in children's palliative care, emotions are seen to be an integral aspect of the whole person for whom care is required, alongside physical and spiritual and social need (ACT/RCPCH 1997). Therefore, the definition of emotion upon which this thesis is developed is as follows:

> Emotion is a social, interactional, linguistic and physiological process that draws its resources from the human body, from human consciousness, and from the world that surrounds a person
> (Denzin 1983 p.404)

Thus emotions are at once physiological, psychological, social and cultural. Each of those aspects may provide a situational stimulus for emotion and equally each may influence what emotion is felt and what is expressed. It is this translation of felt emotion into expressed emotion upon which the thesis is based, focusing in particular on how human interaction influences emotion. That humans take careful account of the way in which they are encountered by other people, utilising physical, psychological, social and cultural means, has been studied in detail (Goffman 1969a).

2.6 Emotion and Communication: Presentation of Self & Stigma

Goffman developed the dramaturgical metaphor, a device for analysing human interaction, to clarify the ways in which individuals monitor how they present themselves (Goffman 1969a). An individual is shown to engage in complex impression management based in his 'definition of the situation' which is arrived at using information gleaned in the moment of interaction, sometimes with the benefit of past information or experience (Goffman 1969a p.20). Situations become defined according to social rules with which the individual may be more or less familiar or comfortable (Goffman 1961; Goffman 1969a). Integration of the rules with present and past information facilitates the individuals' creation of an impression.

The means by which impression is created and managed include language, expression, gesture and posture, appearance and activity (Goffman 1969a). In turn the observers also define the situation and provide a response which is equally an example of impression management and which contributes to the ongoing complex of interaction (Goffman 1969a). A complexity of such interaction is that at any time the individuals may choose to present a truthful version of self or a misrepresentation (Goffman 1961; Goffman 1969a). One area in which this may be the case is with respect to emotion.

An individual may find him or herself presenting one version of self whilst simultaneously experiencing emotion at odds with that version: in this situation the same means of impression management may be utilised in order to manage the emotion of that moment (Goffman 1972). The process of defining which emotions are appropriate to a given situation is also noted to be subject to social rules (Goffman 1972). Two key issues arise for this thesis from Goffman's writing: interaction generally, and emotion specifically, is subject to social rules; conforming to those rules involves effort on the part of the individual (Goffman 1963; Goffman 1972). Both of these issues are taken up in later work on emotion theory and will now be explored in more detail.

2.7 Emotion and Communication: Emotion Management & Emotion Work

Individuals struggle to reconcile inner feeling with external display and the mediating factor is social expectation (Goffman 1969a). The effort required to produce an emotional response and external display suitable to a particular set of circumstances has been labelled as emotion management (Hochschild 1979; Hochschild 1983). This is further differentiated into emotion work, which refers to private emotion management, and emotional labour which refers to emotion management undertaken to fulfil the requirements of a work environment (Hochschild 1983; Lewis 2005). It is emotion work which central to this thesis.

The management of emotion involves both prevention of inappropriate emotion and evocation of appropriate emotion (Hochschild 1979; Hochschild 1983). The 'work' in emotion management relates not to the outcome, but to the effort of managing the emotions and has more recently been compared to hard physical labour (James 1992; James 1989; Kane et al. 2004; Smith 1992). Emotion management can be done 'by the self upon the self, by the self upon others, and by others upon oneself' (Hochschild 1979 p.562) and examples of these variations of emotion management can be found contextualised to airline staff (Hochschild 1983), the adoption process (Ruane 1996), the adult hospice environment (James 1992; James 1989) and student nurses (Smith 1992).

Whereas Goffman (1969a) focused upon external display, Hochschild considers emotion management may involve actually changing the felt emotion (Hochschild 1979; Hochschild 1983). She articulates three methods of emotion management: cognitive, expressive and bodily (Hochschild 1979; Hochschild 1983). The cognitive method uses thoughts and ideas to change individual feeling. The example is given of a person telling herself unpleasant things about another individual in order to alter feelings about them. The expressive method utilises means of expressing emotion in order to change feeling: the examples provided include making oneself smile or cry. The bodily method makes use of biological processes, such as breathing techniques, in order to alter feelings.

For Hochschild, emotion management thus incorporated two facets, external display and felt emotion (Hochschild 1983). The effort required to accomplish each of these is aligned with a performance metaphor, following Goffman's approach, so that surface and deep acting are drawn upon to alter external display or felt emotion, respectively (Hochschild 1983). Whichever method is chosen, the aim is to facilitate a match between what a person feels in a given situation and what they want to feel, which in itself is seen to be determined by society.

2.8 Emotion and Communication: Feeling Rules

Decisions concerning appropriate emotions for social situations are shaped by social feeling rules (Hochschild 1979). Emotion management facilitates alterations to feeling, or its expression, from what is felt to what the feeling rule dictates should be felt. This might be illustrated by the convention of sadness at funerals or happiness at weddings. Feeling rules are shaped by society; they may be universally accepted or may be explicit to specific groups, shaped for example by culture, religion or workplace (Hochschild 1979; James 1992).

This perspective on the social determination of emotion through feeling rules has been challenged, with the suggestion that relationships rather than rules govern emotion (Kemper 1981, Kemper 1983, Ridgeway and Johnson 1990). This challenge, however, stems from a broader dispute regarding the relative importance of biology and society, between positivism and constructivism (Kemper 1981, Kemper 1983, Hochschild 1983a, Hochschild 1979). The philosophical assumptions upon which this thesis is based have been set out in section 2.5 of this Chapter as well as in Chapter 3. Therefore, although I am aware of the debate concerning the origin and control of emotion, for the purposes of this thesis I will treat it as forming part of the interface between the biological and the social.

Whichever perspective on the social determination of emotion is taken, it is agreed that individuals choose what emotions to display at any given moment according to social determinants (Goffman 1969a, Hochschild 1979, Kemper 1981). More recent research has identified that individuals are subject to numerous influences upon their emotions. Individuals may be exposed to multiple sets of feeling rules from which they must choose how to react to given situations (Bolton 2000; Bolton & Boyd 2003). These sets of feeling rules pertain to both emotion work [private] and emotional labour [public, work orientated], and could include rules associated with organisations, professions or peer groups for example (Karabanow 1999; Ruane 1996; Wiley 1990).

Whilst sets of feeling rules, such as professionally orientated and organisational, could be said to have some overlap, they may be simultaneously facilitating different agendas (Karabanow 1999). For example, a nurse adheres to notions of professionalism in manner towards clients which reflects a professional agenda of dignity and respect for the client and an organisational agenda of avoidance of litigation. Therefore, in order to differentiate the agendas which the feeling rules support, the terms 'script' and 'scripting' will be used to describe the ways in which people are directed in their emotion management.

Studies show that individuals are exposed to multiple scripts in their daily lives and must decide which script to follow (Karabanow 1999; Korczynski 2003; Lewis 2005; Ruane 1996). In the original theory of emotion management, a clear distinction was maintained between public and private emotion and Hochschild's work (1979, 1983) is tended to promote absolute adherence to the dichotomy of the private/personal and was subject to criticism for that reason (Bolton & Boyd 2003). In addition, Hochschild paid scant attention to the agency of the individual undertaking emotion management (Bolton & Boyd 2003).

Individuals have multiple roles in their lives and those roles can influence each other in terms of emotion management (Craib 1995; James 1992; Rafaeli & Worline 2001; Wharton & Erickson 1993). It may be that the skills from one role can be transferred and used in another, such as the domestic to the work role (James 1992) On the other hand, it may be that the demands of one role have implications for the performance of another (Wharton & Erickson 1993). Both scenarios suggest the existence of multiple scripts for emotion management and individual agency regarding which script to employ from moment to moment (Bolton 2000; Bolton & Boyd 2003; Hochschild 1983).

Since individuals can access different scripts for emotion management, it is useful to consider how the scripts are communicated and in particular those of organisational, peer group and personal origins. Organisational scripting of emotion management can occur through formal means such as training, performance appraisal, customer surveys and covert observation (Bolton & Boyd 2003; Hochschild 1983). Workers can be recruited specifically for a personal profile which endorses organisational perspectives (Karabanow 1999). Once employed, workers may be subjected to induction and training programmes, both formal and informal, as well as management policies such as performance review which further support the organisational script (Karabanow 1999; Korczynski 2003). Practical means can also be employed to communicate emotion management scripts such as manipulation of organisational practices and environments (Ruane 1996). Image can also be utilised to promote a script for emotion management, both for workers and clients (Smith 1992; Treweek 1996).

Elsewhere, there is recognition that emotion management is not given equal organisational attention as other skills and may be more reliant on informal means of communication. Emotion management skills may be developed through experiential learning and this, in turn, is dependent upon the demeanour and skill of peers (Smith 1992). Alternatively, emotion management skills may be attributed to age and life experience rather than professional training (James 1989). These findings suggest that the feeling rules, or scripts, can be less explicit and rather more open to interpretation, further supporting the notion of individual agency in choice of script to apply.

This opens up the possibility of personal scripts being employed in preference to those derived from the organisation. Through unmanaged spaces - one to one encounters to which no-one else is privy and which can occur in both commercial and non-commercial organisations – individuals may subvert an organisational agenda (Bolton 2000; Karabanow 1999; Korczynski 2003; Lewis 2005). However, as well as personal scripts for emotion management, there is the potential for peer group scripts to emerge. Emotions are inter-subjective and emotions can be seen to be organised within relationships, be that between two people or more (Burkitt 1997; Craib 1995; Rafaeli & Worline 2001; Theodosius 2006). With respect to relationships and groups, 'members construct meanings given a set of social constraints which are perceived as affecting the boundaries of permissible behaviour' (Fine 1979p738). Within a large group such as an organisation, therefore, subcultures may exist (Craib 1995; Fine 1979; Karabanow 1999). Such subgroups are seen to develop a shared emotion management script which may have the capacity to subvert other scripts such as those driven by the organisation, for example scripts relating to service standards (Karabanow 1999; Korczynski 2003).

However, what remains unexplored within the literature is how individuals make the choice of which script to apply in a given situation. To reiterate, individuals are subject to multiple roles and potentially multiple scripts for emotions management (Craib 1995; James 1992; Rafaeli & Worline 2001; Wharton & Erickson 1993). These roles and scripts will interact and have implications for each other (Wharton & Erickson 1993). In addition, and of interest for this thesis, is the question of how individuals choose which feeling rules to apply when there is no obvious script to follow? In the case of parents of dying children, geographical isolation and rarity of disease mean they may not have a peer group. Furthermore, whilst they may encounter an organisational script when interacting with professionals, research shows that the communication of that script may be flawed (James 1989; Smith 1992). A better understanding of the emotion management scripts employed by parents of dying children may therefore have implications for different aspects of their lives.

For professionals, such insight could have implications for improved communication. If there is misunderstanding between social actors concerning the feeling rules which are being applied, there are consequences for individuals (Goffman 1972). In addition, the process of engaging in emotion management is seen to be hard work (James 1992; James 1989; Kane et al. 2004; Smith 1992). Lastly, it has been acknowledged that there are costs to the individual who engages in emotion management (Hochschild 1983).

2.9 The Costs and Consequences of Emotion Management

The final issue to explore with respect to emotion management is how it affects the individual, taking into consideration whether or not there is a cost to those who manage their emotions. Consideration of costs leads to proposals concerning the relationship between emotion management and suffering. By conforming to feeling rules, and undertaking emotion management, the individual may achieve a level of social comfort through conformity, but there remains the choice of not conforming, albeit with an associated cost (Hochschild 1979). 'Emotional labour is hard work and can be sorrowful and difficult. It demands that the labourer gives personal attention which means they must give something of themselves, not just a formulaic response' (James 1989 p.19).

Emotion management within a work context is noted to be hard work, in the same way as physical work, however, there may be little acknowledgement of the effort required for emotion management and therefore little support offered to those that undertake it (James 1989; Smith 1992). Alternatively, the issue of cost to the individual can be questioned when they are seen to be able to transcend the difficulties of emotion management and avoid having their 'private feelings .....transmutated' (Bolton & Boyd 2003). In alignment with this assertion of employee self-determination in emotion management, there is evidence of organisational emotion management scripts being subverted by employees in order to avoid personal cost (Karabanow 1999; Korczynski 2003).

What is not reflected within contemporary literature about emotion management is whether emotion management has a cost for the 'client' of an organisation as well as the employee. Few researchers seem to consider whether or not the costs of emotion management extend to the client, preferring to focus upon employee and employer. Whilst Smith (1992) suggests that this is a potential outcome, she fails to provide empirical evidence to support her assertion. In other research there seems to be an assumption of passive acceptance of the emotion management processes by clients (Ruane 1996).

In child health, professionals direct care to both the family and the child, so that the family unit becomes the client. It has been noted that emotion work is a key aspect of caring in a family context generally and specifically when caring for family members who are critically ill (Erickson 1993; Wharton and Erickson 1993; Devault 1999; Thomas, Morris et al. 2002). Emotion work in the family context has a cost for the individual, both when 'performed' and 'performed on', which may be evidenced in feelings of well being (Erickson 1993; Exley & Letherby 2001). Similarly, emotion work in caring for sick relatives can have psychosocial consequences for carers although these may not be acknowledged by either carer or professionals (Thomas et al. 2002). Furthermore, authenticity of expressed emotion may be jeopardised if other people fail to legitimate what is being expressed (Rimé 2009).

Hochschild (1983) is clear that the costs of emotion management for employees are manifest in a loss of authenticity in feeling. This may reveal itself as stress or burnout, but significantly leads to the loss of 'a central means of interpreting the world around us' (Hochschild 1983 p.188). Further consequences of inauthentic emotion have been suggested as loss of self when the 'core identity' is worked upon in order to conform to social rules of feeling (Duncombe & Marsden 1998 p.218). However, in the context of illness, individuals have equally been noted to use emotion management to uphold the identity they perceive as their authentic self (Exley & Letherby 2001). This latter research borrows from work on 'stigma' in which individuals' efforts to reconcile differing social identities are closely linked to interactions with other people, a key aspect of which is impression management for which issues of authenticity have already been highlighted (Goffman 1963; Goffman 1969a).

Authenticity is also an important issue in suffering literature. As described in section 2.3, the means used to give voice to suffering and the motivation of those who give voice may both jeopardise the 'authenticity' of the account (Kleinman and Kleinman 1991; Kleinman and Kleinman 1997; Bourdieu, Accardo et al. 1999; Bendelow 2006). The fear is that inauthentic accounting of suffering can do actual and metaphorical damage to the sufferer (Kleinman & Kleinman 1997; Ramphele 1997; Wilkinson 2005). Incorporating the literature on emotion management, there is worth in exploring the impact of emotion management upon authenticity of voice in suffering and legitimation of experience. Focusing upon these two issues will also highlight something of the cost of emotion management for 'clients'.

2.10 Comment

Suffering is judged by both sufferers and observers and judgement influences communication about suffering. In particular, the authentic voice of the sufferer may be subjugated by others' judgements and agendas as a response to suffering - this may also reflect the degree of intersubjectivity in suffering. Responses to suffering may determine its legitimation and that in turn has consequence for the experience of the sufferer. Since emotions may form and influence communication, how the suffering individual responds emotionally must be significant in how suffering is communicated, judged, responded to and legitimated.

Emotions both shape and are shaped by communication. This is facilitated through impression management for which individuals follow feeling rules to determine which emotions to display, irrespective of those which are felt. In this way emotions are managed and the effort of moderating expressed emotions in a private context is called emotion work, reflective of the effort required. When emotions are managed in the work context there is a cost to the individual which may be reflected as loss of authentic feeling. Emotion management may result in presentation of inauthentic feeling.

The focus of this research therefore, and its unique contribution to the literature, is the interplay of emotion management and suffering. The hypothesis which this thesis aims to test is that emotion management influences the communication and legitimation of suffering. Whilst suffering has been explored in a variety of contexts, the author has found none relating specifically to the parents of dying children. This project therefore also represents a unique contribution to the theory of suffering through its choice of research subject. The research questions for this project are therefore as follows:

1. What is the lived experience of parents of dying children?
2. How do other people's responses shape the parents' lived experience?
3. What is the place of emotion and suffering in the parents' lived experience?

Chapter 3 Research Methodology

Introduction

The methodology chapter articulates both the philosophy underpinning this study and the methods used in the generation and analysis of the data. The chapter begins by introducing the rationale for the qualitative research strategy which guides the project. Next the philosophical assumptions upon which the study is built are set out, taking account of ontology, epistemology and axiology (Bryman 2004; Cresswell 2007). Having established the methodological context for the work, I discuss the research design including detail about sampling, data collection methods, analysis and ethics.

As well as justifying the chosen research design, this chapter clarifies alternative approaches which might have been undertaken and why they were not. I consider how to address rigour in qualitative research initially within the sampling section of the chapter and the with respect to data collection and analysis. Finally, I conclude with a rationale for the integration of a dramaturgical element in the methodology and the presentation of the data chapters.

3.1 Research Strategy

The purpose of the research therefore is to understand individual meaning associated with suffering and emotion management, with a secondary consideration for how to use the data to influence clinical practice. Since, therefore, this thesis concerns the meanings which parents place upon their experiences, a qualitative research strategy was employed (Strauss & Corbin 1988). My review of the literature of suffering did not identity any published empirical work on suffering or on the relationship between suffering and emotion management of parents caring for dying children. To employ a quantitative research strategy would therefore be inappropriate as there is little known about what the issues are, nor yet how to measure them.

In addition, there are legitimate concerns about the nature of research into suffering and its impact upon the experience of its participants. As I indicated in Chapters 1 and 2, whilst a voice needs to be given to suffering, any research with that intent must give due diligence to the authenticity of the voice which is produced (Frank 1995; Frank 2001; Wilkinson 2005). In other words, research must ensure that it is truly the voice of the sufferer which is heard, in order for the research process itself not to engender further suffering through distortion of the sufferer's perspective.

It may be that future research could be designed from a quantitative perspective. Having established a greater understanding of the phenomena of interest, it may be possible to design intervention-based studies, the outcomes of which necessitate quantification. However, at this stage a qualitative research strategy enables further exploration of the phenomena. Having established the overall research strategy, it is necessary to clarify the philosophical assumptions which underpin the strategy.

3.2 Philosophical Assumptions

Philosophical assumptions include issues of paradigm, ontology, epistemology and axiology (Bryman 2004; Creswell 2007; Heron & Reason 1997), each of which will be discussed in order to contextualise the design and analysis of the thesis.

Paradigm and Ontology

Paradigms are sets of beliefs which steer the conduct of research (Bryman 2004; Cresswell 2007). Overall, this thesis is guided by both an advocacy / participatory paradigm and social constructivism (Creswell 2007; Heron & Reason 1997; Heron & Reason 2006). Concerning advocacy, if parents of dying children claim they suffer and the interactions with hospice care workers are shown to influence that experience, the research would be flawed if it did not address how to use the findings to influence future such interactions (Creswell 2007). The nature of the research problem lends itself to establishing action plans which might improve the experience of the research participants. This will be considered further in the Conclusion of the thesis wherein an 'action agenda for reform' will be constructed through practical suggestions for improving professionals' communication with the parents of dying children (Creswell 2007 p.22).

In accordance with a participatory approach, the research is focused upon working *with* the research participants in order to further their issues, rather than researching *on* them (Heron & Reason 2006). This is particularly significant with respect to the theoretical framework of the study, set out in Chapters 1 and 2, within which the importance of hearing the authentic voice has been stressed. Therefore it can be seen that the research is loosely based upon a participatory paradigm which embraces 'democratic dialogue as co-researchers and co-subjects' (Heron & Reason 1997 p.280). However, it should be acknowledged that, being informed by this paradigm, the research takes elements of this approach rather than its entirety: due to time and resource restrictions of the PhD process, the participants are not full co-inquirers (Heron & Reason 1997). Participants have been involved in the design of the research through use of a focus group to guide sampling and topic guide. Implementing a modified grounded theory approach to data analysis which incorporates sequential analysis and an iterative method ensures that analysis is driven by the participants' perspectives. Finally, analysis of data has been fed back to participants for their perspective to be incorporated.

Ontology concerns the nature of social entities and what can be known about them (Bryman 2004; Heron & Reason 1997). Basing this thesis upon a qualitative research strategy establishes an initial ontological position: that there is not a single, objective reality waiting to be revealed, but rather multiple realities, some of which will be explored through this research (Creswell 2007; LeCompte & Schensul 1999b). Therefore, a relativist position is taken (Denzin & Lincoln 2008; Guba & Lincoln 1989). The major ontological foundation and overarching paradigm of this thesis, meanwhile, is social constructivism.

Constructivism concerns subjective understanding of the life world and the ways in which individual meaning is created and recreated through social interaction so that individual realities are constructions based on how individuals interpret experience (Guba & Lincoln 1989; Heron & Reason 1997; LeCompte & Schensul 1999b). Moreover, these constructions are also individually contextualised: the interactions upon which they are based are framed by cultural, historical, temporal and psychosocial means (Charmaz 2008; Guba & Lincoln 1989). In this way, the meanings which parents of dying children place upon their experience and what they do with emotions are seen to be individually constructed and contextualised (Guba & Lincoln 1989; Holstein & Gubrium 2008).

Whilst the preceding point emphasises the significance of context when designing research based on constructivism, it is equally important to recognise that individual realities are multiply contingent (Brown 2009). Individuals encounter and interpret phenomena in everyday life (Heron & Reason 1997). Interpretation takes place according to the characteristics of both the phenomena and the individual (Prus 1996). Moreover, when the phenomena of encounter are other people, particular mechanisms direct the encounter, of which language is noted to be particularly important (Berger & Luckman 1971).

When individuals encounter other people, 'the other' is presented through signs as an 'objective reality', and one such sign is language (Berger & Luckman 1971; Mead 1967). However, although 'the other' present themselves, using such signs, in specific ways, they do not control how they are interpreted (Berger & Luckman 1971). Thus the individual interprets 'the other' and constructs individual, subjective realities (Heron & Reason 1997). When investigating intersubjective experience, therefore, it is essential to clarify that individual realities may not accurately reflect the 'objective reality' projected by another person precisely because they are contextualised interpretations (Berger & Luckman 1971). Moreover, in research, the realities of the participants are presented in particular ways to the researcher who in turn interprets those realities which are themselves interpretations of individual life experience (Charmaz 2008; Prus 1996).

Applying constructivist theory to this thesis, both the interactions the parent participants have with other people and their individual interpretations of reality are formed through the interface of multiple other realities. However, the collection of multiple sources of data may enable the researcher to better understand why and how individual realities are constructed and therefore shed light upon the theoretical constructs of interest.

The phenomena of study are not suited to objectivist ontology. Both emotion management and suffering occur in and are shaped by the context of interaction with other people, as well as political, historical and cultural influences (Hochschild 1979, Kleinman et al. 1997, James 1989, Bolton and Boyd 2003, Kleinman and Seeman 2000, Frank 1995, Charmaz 1999). To attempt a study which is founded in the assumption that there exists an definitive, objective reality 'out there', which can be somehow captured through research, would be inappropriate when the phenomena of study are firmly rooted in individual interpretation of social interaction.

The constructivist foundation of the study is therefore reflected in a research design which values the perspective of the individual and which intends to preserve the character of the individual interpretation. Strategies for data collection and data analysis are chosen to privilege the voice of the participants and the variety of perspectives they bring. These include the use of multiple sources of data and different methods for its collection. The use of focus groups, interviews, participant observation and documentary analysis is intended to bring depth and breadth to the data, reflective of the multiple realities which might be represented in the study. Thus, rather than a positivist approach, an interpretive stance is adopted, which leads on to clarification of epistemological issues: how realities become known (Bryman 2004; Hughes & Sharrock 1990).

Epistemology

Being concerned with how the researcher gains knowledge, epistemology must take account of what is accepted as knowledge, the relationship between researcher and participant, and methods for generating knowledge through data collection and analysis (Cresswell 2007; Hughes & Sharrock 1990). Since the research has been set within an constructivist frame, it is acknowledged that the study does not seek an objective view, but rather takes account of the subjectivity of both researcher and participant throughout (Guba & Lincoln 1989). Therefore the key epistemological basis of the study is interpretivism rather than positivism (Bryman 2004). Knowledge is seen to be generated through individual interpretation of reality and the researcher's attempts to understand the meanings which individuals attach to their experience (Miller & Crabtree 2008).

A positivist approach to measuring and explaining human behaviour would assume that the behaviour of interest, emotion management and suffering, is straightforwardly accessible and measurable as 'facts'. As I have argued, the nature of suffering and emotions are complex as are their interactions. Therefore it is appropriate, given the current limitations of understanding of these phenomena, to adopt an exploratory and interpretive approach to facilitate a broader understanding.

Concerning the relationship between the researcher and the field, the empirical study for this thesis was conducted through and within a children's hospice. Children with life limiting or life threatening diseases and their families are supported through the children's hospice movement in the UK; indeed, such disease is among the criteria for access to a children's hospice (ACT/RCPCH 2003). The researcher is a children's palliative care nurse, employed by a children's hospice, a relationship which facilitated access to the research population, but created potential ethical problems.

Being known to the host organisation and having relevant clinical skills was supportive in the application for ethical approval which extended beyond university ethics procedure to include the host hospice clinical governance channels. Trying to gain access to another hospice as an outsider may have been more problematic because of a lack of insight into the researcher's clinical skills or knowledge base and the cautious stance taken towards researching sensitive topics (Burke Drauker 1999, Michelson et al. 2006, Wellings et al. 2000). However, whilst acknowledging the benefits to the researcher of the prior relationship with the hospice, it is important to recognise the potential effects of that relationship on both the participants and the research, which requires attention to issues of axiology.

Axiology

Axiology concerns the researcher position on values and their influence upon the research process and outcomes (Bryman 2004; Creswell 2007). From the outset it must be recognized that the data can only ever be a representation of the participants' perspective, since it is presented on their behalf by the researcher. However, by articulating the position of the researcher and the relationship between researcher and participant within the methodology, it is intended that researcher values are recognised but relegated to a supportive position behind the perspective of the participant, in order that the thesis reflects the realities of the participants (Charmaz 2008; Guba & Lincoln 1989).

Accordingly, the research was designed to facilitate immersion in the *participant perspective* through multiple data collection methods (LeCompte & Schensul 1999b). Additionally, a reflexive approach was employed throughout the study, through ongoing reflexive note taking and a modified grounded theory approach to data collection and analysis, including the devising of reflexive memos, and taking the findings back to the participants for their views (Corbin & Strauss 2008). However, it must be acknowledged that the researcher's clinical experience had the potential to be a barrier to good research, both through retention of *a priori* knowledge and in terms of imbalances of power. Because of my extensive clinical experience there was a risk that I would make assumptions about how and what parents of dying children might communicate and the associated meanings of behaviours. Whilst acknowledgement of this was essential, further steps were required to ensure that participants' perspectives were upheld.

Care was taken during sampling to identify families with whom there was no prior relationship with the researcher so that the parents' stories were heard for the first time during the interview. Had their narrative been encountered in a care context, the purpose of its recounting would have differed as would its use. Such prior knowledge may have influenced my interpretation of the data. Yet, while this strategy focused my perspective on the parents' narratives, it did not address how the dual role of nurse/researcher may have impacted upon what story the parents chose to tell. Whilst choosing parents with whom there was no pre-existing relationship was also supportive in this respect, the design of the research needed to take account of this issue.

3.3 Research Design

The study was originally developed in response to researcher observations of parent / professional interactions within the setting of a children's hospice. The interactions were notable for their limited communication about parental experience and the researcher had assumed that this was primarily due to the communication skills of the professionals. Therefore, the research design combined two separate designs: case study and ethnography. This was to enable the study of both the parental experience (case study using ethnographic methods) and the professional responses (ethnography). However, in accordance with the axiological concerns articulated in the previous section, as well as the modified grounded theory approach to analysis, the design of the study was changed during the data collection phase to accommodate the emerging issues from the parent participants.

Data for both parts of the original design were collected simultaneously, between March 2008 and September 2009, in recognition of the time and resource restrictions imposed by the PhD process. Parent data was analysed initially in order to prioritise their perspective. Parental communication was complex, requiring more in depth exploration and the reporting of that data alone fulfil the thesis word limitations. As a result, analysis has focused upon the parental perspective and the development of the case study and the professional data will not be reported on in depth within this thesis. However it should be noted that the professional data demonstrates that professionals' communication may take scant account of emotion management.

The documentary analysis illustrated that there was little reporting of parental emotion or well being which meant that any interactions of this nature were not effectively communicated amongst team members to allow for consistent support to be offered. In interview, professionals described how they waited for verbal or behavioural cues from the parents with respect to personal concerns for which support may be required. However, during participant observation it was clear that professionals engaged with particular parental behaviours but did not acknowledge others (see Chapter 5). In so doing, the professionals may have been responding to cues from the parents, but this strategy did not necessarily lead to support being offered. Professionals tended to minimise or ignore behaviours with a negative emotional tone (e.g. expressing anxiety) whilst reinforcing those with a positive emotional tone (e.g. laughing). Thus parental perceptions of certain experiences being de-legitimated appear to be reflected in the professional data.

Whilst the detail of the professional data is not reported upon within this thesis, it will be utilised in the future, both through publication and the development of further research upon the themes emerging. In anticipation, links have already been made with researchers in three other institutions to further this aspect of the work through collaboration. The methodology section of this thesis will therefore focus upon clarifying the choice of case study methodology in conducting the research with the parent participants.

A case study approach is noted to facilitate exploration of specific issues within a similar context in order to highlight dimensions of that experience (Cresswell 2007). A case is said to be a specific entity within an identified situation (Bryman 2004; Cresswell 2007). In this thesis, 'the case' is the experience of being the parent of a dying child who uses a children's hospice. Several types of case study are identified within the literature, illustrating the degree of focus upon either the case or the issue being illustrated by the case (Cresswell 2007; Stake 2008). A collective case study facilitates the exploration of several different cases in order to deepen understanding of the issues of study (Stake 2008). For this thesis, a collective case study design was implemented to enable detailed exploration of the issues of suffering and emotion through several people's experience.

Features of case study methodology are noted to include: 'study over time, detailed and in depth data collection involving multiple sources of information, e.g. observations, interviews, audiovisual material and documents' (Cresswell 2007 p.73). In order to fulfil these criteria a number of ethnographic data collection strategies were devised which will be elaborated upon in section 3.7. Use of these strategies permitted insight into the parental experience in a number of ways: a window onto parental perspectives on both their experience and the way in which they communicate with other people; observation of parent participants communicating with each other and with professionals, specifically hospice care workers; insight into how professionals, specifically hospice care workers, document their own perspective on the parental experience.

An alternative research design would have been ethnography of parents of dying children. This might facilitate greater immersion in the field and a more detailed study of individual families through spending time with the parent participants in their day to day life. However, two issues arose in considering this alternative design. Firstly, parents using children's hospices do not necessarily interact with each other in everyday life: there are 44 children's hospice services in the UK (CHUK 2010) and access to the hospice may cover a wide geographical or highly populated area. Therefore, it is not possible to research such parents as a group for ethnographic study.

Secondly, to observe individual parents in everyday life would place a burden of time upon the parents who already live complicated lives. The researcher did not feel such an approach was appropriate. This decision appeared to be validated by the negative responses from parents when they were asked to complete a diary as a data collection method, citing lack of time as a reason. Prior to the implementation of the research, ethical approval was sought, for which the details of the design and associated paperwork were submitted.

3.4 Ethics

Since the hospice is a voluntary organisation and all parents access it independently of the NHS, the proposal did not need to be submitted to NHS ethics. However, ethical approval was sought from both the university ethics committee and the hospice (see Appendix 1). Having the research proposal scrutinised by both organisations ensured that the participants' well being was prioritised both ethically and clinically and in accordance with suitable ethical guidelines (BSA 2002). Issues of anonymity, confidentiality, access, and post-participation support were addressed.

Anonymity & Confidentiality

To preserve anonymity and confidentiality, participants were codified initially using a numbering system and then the subsequent assigning of pseudonyms. Recorded interview material was secured in a locked office until transcription and destroyed once transcription was completed. Information stored on computer was accessible by password only through a secure IT environment. However, there are more detailed issues of confidentiality and anonymity to be considered with this particular population.

Some of the children of the parent participants have extremely rare disorders. This, together with the small number of children's hospices, meant that extra precautions were necessary to preserve the anonymity of the parents. Therefore, neither the children's diseases nor the location of the children's hospice are specified within the thesis. Throughout the study parents were made aware of these precautions and consulted on procedures for maintaining confidentiality and anonymity when disseminating the research.

Access

Access to the research participants was facilitated through the researcher's place of employment. Children with life limiting or life threatening diseases and their families are supported through the children's hospice movement in the UK; indeed, such disease is among the criteria for access to a children's hospice (ACT/RCPCH 2003). The researcher is a children's palliative care nurse, employed by a children's hospice. This facilitated access to the research population, which otherwise may have been problematic. Being known to the host organisation and having relevant clinical skills was supportive in the application for ethical approval. Trying to gain access to another hospice as an outsider may have been more problematic because of a lack of insight into the researcher's clinical skills or knowledge base.

Meanwhile, the researcher's employment by the hospice could place an imperative upon the parents to participate, perhaps through concern that future care services were dependent upon cooperation. As an employee of the hospice, the researcher holds a leadership position [head of clinical education] and is a care provider. These factors could potentially pressurise the parents into participation. To address this power imbalance and to empower the parents, the following actions were taken:

- invitations to participate were sent to the parents by the hospice, not the researcher
- whilst the researcher was identified as a hospice employee, information about the research was provided on university headed paper to reassure parents that the research was distinct from the hospice and did not influence care provision
- the researcher chose participants who did not have an existing relationship with her in her capacity as a nurse

Individual parents were sampled from the hospice database by a hospice administrator using the sampling criteria set out in section 3.5. The hospice administrator mailed information about the study to the parents as well as the invitation to participate for return to the hospice [stamped, addressed envelopes were also provided]. When a parent thus indicated their willingness to participate they were contacted directly by researcher and a date was established to meet for interview. The location was chosen by the participants, the choices being home, the hospice or an external location of their choosing. All parents who undertook individual interviews chose home as the location.

Selection of parents for the focus group followed a different process. The focus group was a self-selected group of parents who formed the Parent Forum at the hospice. The group was approached by a deputy head of care and asked if they would be interested in participating. Having agreed, the researcher was given the contact details of one member who circulated more detailed information about the study to the other three members. All four members agreed to participate, and three attended the focus group interview [the fourth citing last minute work commitments as the reason for withdrawing]. The focus group was held at the hospice as a mutually accessible location for all participants.

Post Participation Support

Of prime ethical concern was the minimisation of distress to participants and in both the design and implementation of the research strategy, the researcher was careful to take account of this potential. In this respect, the clinical qualifications, experience and hospice employment of the researcher facilitated an empathetic approach as well as supportive communication skills should distress become apparent (Kavannagh & Ayres 1998). As the data was collected, a number of parents did become emotional and were given opportunities to stop or withdraw from the research (Kavannagh & Ayres 1998). None did and the knowledge and experience the researcher brought as a nurse was utilised to ensure that the well being of the participants retained primacy in the conduct of the research.

Each parent was contacted a few days after the interview or focus group to check for any unresolved issues. The hospice bereavement support team were available to offer further support, independent from the research process, should the need arise. However, no parent identified any issues. In contrast, several parents commented on the personal benefits of participating and having the opportunity to talk about their experiences: one parent volunteered that it had been the best therapy he had encountered. This is consistent with comparable research into sensitive subjects (Emanuel et al. 2004; Michelson et al. 2006).

3.5 Sampling

Purposive sampling was employed in the study, specifically convenience and maximum variation sampling, selecting informants who were judged to be capable of informing the phenomena of study (Cresswell 2007; Guba & Lincoln 1989). Participants for the focus group were recruited using convenience sampling, whilst individual interview participants were chosen through maximum variation sampling.

Due to the sensitive nature of the research, it was considered, and agreed through ethical approval procedures, that a pre-existing group where the parents already knew each other would be more comfortable for group discussion (Kitzinger 1994). Some features of the group have been outlined in section 3.4. The focus group was intended to be 4 members, considered to be among the ideal sizes for such a group (Kitzinger 1995). Despite the withdrawal of one member at short notice and the lack of further members to draw upon in the pre-existing group, quality data was generated: all participants shared individual perspectives and debated the issues.

Whilst there exists the potential for 'the articulation of group norms to silence individual voices of dissent' (Kitzinger 1995 p.300), the parents in the focus group all spoke in depth about their own personal experiences, contributed to discussions arising and posed individual perspectives throughout. Whilst one member of the focus group was already bereaved of her child, the data she provided did not present a deviant case and therefore her perspective has been included throughout. The lack of deviance may be reflective of the long term nature of the experience such parents have: some of the other participants had sick children of 18 and 20 years of age and the bereaved mother's child died at age 19.

For the remainder of the individual interviews, maximum variation sampling was employed in order to establish depth and richness of description. Utilising data obtained from the parent focus group, the sample took account of both researcher-identified and member-identified characteristics (Kuzel 1992; LeCompte & Schensul 1999b). A sampling frame was developed to include the following features:

- Relationships: marital; with the hospice
- Ethnicity
- Time: age of parent and child; how long the child had been diagnosed
- Family size: number of children; number of sick children

Recruitment of parents was undertaken by an administrator employed by the hospice and guided by the researcher using this sampling frame. A number of parents were approached by letter from the hospice, inviting them to participate in the research project. The resulting parental sample and how it fits the sampling frame is illustrated in Table 1.

In purposefully sampling for these characteristics, a number of obstacles were encountered. Regarding relationship with the hospice, parents who were known to have complained about the hospice or were known to be less engaged were purposefully sought, including those who had terminated their use of the organisation. This was important to consider in terms of the type of communication between such parents and the organisation's staff. However, all such parents refused to respond to letters inviting them to participate in the research project. It was assumed that this was due to the letters being sent from the hospice, in order to comply with ethical approval conditions. As an alternative, the parental perspective on the hospice was judged through their conversations with the researcher, which demonstrated that there was a range of relationship between the parents and the organisation and not only close, positive relationships were represented.

With respect to ethnicity, the hospice does not have a diverse population of clients. The majority of families accessing the service are white British and so the recruitment process purposefully sought out parents of alternative ethnicity. However, parents either did not respond at all or declined to participate. Therefore, diversity in ethnicity is represented by a white Eastern European parent. With respect to both ethnicity and relationship with the hospice, the sample may therefore be judged as not representative of the population of parents of dying children using hospices. This leads to consideration of the quality of the research undertaken.

Table 1: Parent Sampling Frame

Data Log ref /Pseudonym	Interview or Focus Date	Age	Gender	No. Children	Child Age	Ethnic Group	Marital Status	Relationship With Hospice	Work and Type
P1 Sarah	F 13/03/08	48	F	2	18	W	M	Distant	PT Education Admin
P2 Valerie	F 13/03/08	58	F	3	19 RIP	W	D	Close	LSA
P3 Michael	F 13/03/08	46	M	2	10	W	M	Distant	PT Teacher
P4 Mary	I 21/08/08	47	F	2	20	W	M	Distant	PT Health Admin
P5 Diana	I 17/10/08	42	F	1	11	W	D	Close	None
P6 Jane	I 22/12/08	32	F	2	2	W E. Euro	M	Distant	None
P7 Imogen	I 08/01/09	38	F	2	3	W	M	Distant	PT Teacher
P8 Carol	I 15/01/09	46	F	3	18	W	M	Distant	PT Nurse
P9 Charles	I 15/01/09	49	M	3	18	W	M	Distant	Postal Worker

3.6 Reliability and Validity

Traditionally the quality of research has been accounted for through reliability and validity measures (Graneheim & Lundman 2004). The reliability of a study measures the possibility of its results being repeated and particularly takes account of the consistent measurement of variables (Bryman 2004). Whereas validity judgements concern the legitimacy of the conclusions reached through the research (internal validity) and the extent to which the findings can be generalised (external validity) (Bryman 2004; LeCompte & Goetz 1982). However these measurements of research quality are derived from positivist, quantitative principles which do not fit the philosophical basis of this thesis (LeCompte & Goetz 1982; Whittemore et al. 2001; Wolcott 1994).

In considering rigour, the nature of the research paradigm and questions as well as how the results are intended to be applied, must be considered (LeCompte & Goetz 1982). The philosophical underpinnings set out in section 3.2 establish the focus of this study to be the exploration of multiple realities which are context dependent. The research questions seek to enrich understanding of the phenomena of study rather than define explicit, causal relationships. The aim of the research is to increase understanding of suffering and emotion management and to highlight ways in which this increased knowledge might impact upon communicative interactions between hospice professionals and the parents of dying children. In considering these three aspects of the research, it is clear that data and analysis must take account of individual contexts and the values of the researcher, both of which make application of traditional measures of validity and reliability, where certainty predominates, problematic (Whittemore et al. 2001).

Since the application of such criteria to this thesis is thus questionable, it is essential to consider how to translate the concepts of validity and reliability into meaningful measures of scientific rigor within a qualitative context (LeCompte & Goetz 1982). Therefore, in establishing the rigor of the study, more qualitatively orientated criteria have been applied, focusing on 'trustworthiness' (Guba & Lincoln 1989). These take account of the ways in which research is designed, data is generated and analysed, and how findings are presented, suggesting strategies to improve credibility for application throughout the research process (LeCompte and Goetz 1982; Guba and Lincoln 1989; Whittemore, Chase et al. 2001; Cresswell 2007). In this section sampling trustworthiness will be established. However, credibility in the research design, data collection and analysis will be addressed in the relevant ensuing sections of this chapter.

With respect to research design, sampling techniques should demonstrate trustworthiness. In recruiting participants, certain characteristics were sought using purposive sampling, but it was not straightforward to achieve the intended variation. In this respect, the sample may be judged not to be representative of a larger population, influencing the traditional perspectives on the validity of the study. However, the sample is not intended for generalisabilty in the quantitative sense (Guba & Lincoln 1989; Kuzel 1992). Indeed, the philosophical assumptions set out in section 3.2 make clear that phenomena are context dependent, which automatically places limitations upon generalisabilty in terms of 'broadly applicable laws' (Schofield 2000 p.76).

Moreover, the purpose of this study, in particular, is to explore variation in perspectives on suffering and emotion management. Whilst more perspectives remain to be explored, the sample presented in this thesis represents a range of perspectives of parents who have a dying child using a hospice. Therefore, the sample generated can be seen to facilitate the study aim of exploring multiple realities with respect to the research questions and therefore supports the credibility of the research (Graneheim & Lundman 2004).

Lastly, in considering generalisabilty, the term 'transferability' might be substituted, for which it is recognised that both researcher and reader are responsible (Graneheim & Lundman 2004; Guba & Lincoln 1989) Through inclusion of detailed description in both methodology and data analysis, particularly in the narrative data, the researcher facilitates comparability with other settings (Guba & Lincoln 1989; Schofield 2000). The next section of this chapter articulates the specifics of data collection, taking account of how their rigor might be judged.

3.7 Data collection

I used several ethnographic methods in order to provide richness of data and 'intimate familiarity' with the participants (Prus 1996). These included focus group interview, individual interview, participant observation and documentary analysis. Such a combination has been used successfully in other research focused on understanding parental perspectives on health care (Bluebond-Langner et al. 2007). Moreover, a combination of these types of data collection have been recommended by experienced researchers in the field of suffering (Kleinman 1992). Parents were also asked to complete a diary over 4 months to provide further detail and insight into their experiences and reactions. However, the parents were reluctant to undertake that aspect of the research, citing lack of time.

I played a key role as sole researcher, since being the sole researcher increases consistency in data collection, but also the risk of bias (Guba & Lincoln 1989). Reflexive consideration of *a priori* constructs throughout data collection as well as 'peer debriefing' mitigated bias. In addition, observer consistency was tested through a colleague checking two transcripts against the coding frame (Bryman 2004). The choice of methods can be justified in four ways.

Firstly, the research was designed under a constructivist paradigm, for which two of the criteria are use of human instruments implementing such methods (Guba & Lincoln 1989). Secondly, strategies for collecting data were considered according to the differing benefits they brought to the study through variation in factors such as time, context and type of data (LeCompte & Schensul 1999a). Thirdly, data analysis incorporated both narrative and thematic approaches, for which such data collection methods are considered appropriate (Cresswell 2007). Fourthly, triangulation of data collection methods was designed to improve the trustworthiness of the research (LeCompte & Schensul 1999a; Stake 2008).

There is debate concerning the value of triangulation within qualitative research. Whilst some authors dispute the use of triangulation for testing reliability and validity, citing the absence of 'unchanging phenomena' (Guba & Lincoln 1989 p.240), others acknowledge its value (Cresswell 2007; LeCompte & Schensul 1999b). In this thesis, the data collection methods were designed to privilege the voice of the participant and were chosen according to the emerging data and the participants' viewpoint on their use. It is clear that any qualitative inquiry relies upon researcher interpretation and is therefore a subjective process, biased towards the researcher (Guba & Lincoln 1989). However, in this study, triangulation supported constructivist principles of seeking emic (participant derived) information during both data collection and analysis through identifying those issues which were recurring themes for participants (Guba & Lincoln 1989). Each of the data collection methods will now be explained and defended.

Focus Group

Focus groups are useful for identifying norms, behaviours, attitudes and cultural domains (LeCompte & Schensul 1999b). Data collection therefore began with a parent focus group, the purpose of which was to identify initial criteria for the research: the types of experience the parents might have; the range of parents I should include in the study; and the kinds of influences that might have a bearing on their experiences. In deriving these criteria for sampling from the focus group, the study was founded upon emic (participant derived) rather than etic (researcher derived) ideas and was a suitable start point for privileging the parent perspective (Cresswell 2007). Focus groups have also been noted to be useful for exploration of sensitive data through the way in which they can provide mutual support in issues and responses which are not commonly encountered in everyday life (Kitzinger 1995). Therefore as an initial data collection tool it was both supportive of the participants and enabled me to gauge potential reactions to subsequent data collections strategies.

The use of a focus group underpins the philosophical assumptions of the study, whereby the guiding paradigms incorporate a participatory approach

(Heron & Reason 2006; Kitzinger 1995). Accordingly, using the focus group to establish the initial criteria of the research as well as to shape subsequent interview approaches ensured that the participatory approach was incorporated from the outset. That paradigm also guided the conduct of the focus group. A topic guide rather than structured interview questions facilitated more self directed exploration of the research topics by the participants: they were able to take the conversation in directions of their choosing, utilising terminology with which they were comfortable (Kitzinger 1995). It was notable that the participants incorporated laughter and debate into their conversation as well as introducing subjects of a particularly sensitive nature themselves, including consideration of negative impacts associated with their child's survival. In addition, the depth of data captured through the focus group led the researcher to incorporate individual narratives into the main study and to undertake further data collection with two of the participants. (The third participant had been bereaved of her child and therefore further study was not pursued.)

Individual Interviews

Interviews are useful for gaining insight into the lived experience of other people (Prus 1996). In depth, semi-structured interviews were carried out utilising a topic guide derived from both the initial literature review and the analysis of the focus group data. The use of a topic guide rather than structured interview was intended for ongoing preservation of the emic perspective and avoidance of leading the participants (Corbin & Strauss 2008; Cresswell 2007; Guba & Lincoln 1989). In addition, since the research design is a collective case study, some cross case comparison was facilitated through maintaining the general themes of the topic guide (Bryman 2004).

It is acknowledged that an unstructured interview would have facilitated true participant ownership of the interview; however, the PhD process necessitates consideration of theory before data collection and therefore *a priori* theorising.

However, during individual interviews, I gave minimal contextualising information, merely asking the parents to recount their experiences, so that parents were able to direct the conversation and express individual perspectives. Open ended and probing questions enabled me to explore the issues the parents raised with more depth (Bryman 2004). Through iterative analysis, individual perspectives were then used to reshape the topic guide for subsequent interviews, continuing the emic approach to data collection (Guba & Lincoln 1989; LeCompte & Schensul 1999b).

Interviews were recorded (with written consent) so that the researcher could focus on the content and minimal notes were taken to serve as prompts for following up particular issues arising. Recorded interviews were transcribed verbatim by the researcher, taking care to note pauses, and non-verbal communication, particularly that of emotion. Whilst the researcher endeavoured to clarify the meaning of participants' non verbal communication during interviews, by reflecting it back to them for further exploration, it is acknowledged that its documentation supports verification during analysis of data (Begley 1996).

Although interview duration was intended to be 1 hour, it ranged between 44 minutes to 1 hour 28 minutes, following the lead of the participants. Throughout each interview, the researcher made repeated checks about the participant's desire to continue and wellbeing. Thus within an initial meeting of relatively short duration, parents readily disclosed matters of great personal concern. A particular issue arising from the use of interviews was the need for the researcher to constantly refocus on her role. When parents became distressed or expressed difficulties, the temptation was to engage with the topic as a nurse. Both the iterative approach to analysis and maintenance of a reflexive approach ensured that the researcher' awareness of this pitfall was sustained. However, in the interests of an ethics, some issues raised by the parents merited further support. One example was a mother expressing frank suicidal thoughts. In this case, the researcher overtly stated her change of focus and role and sought professional guidance.

Participant Observation

The use of observation provided an opportunity to see the participants interacting with other people, specifically palliative care nursing staff. This facilitated a window onto what was communicated, by whom, and how, particularly with respect to parental experience and emotion. It therefore allowed further exploration of issues identified by the parents themselves within the theoretical framework of the study. In other words, participant observation facilitated recording of events and situations as they occurred, alongside the meanings attributed by the participants (LeCompte & Schensul 1999a; Prus 1996). This was achieved through attention to both verbal and non-verbal communication.

In addition, it was possible to observe how a particular group of people responded to the parent participants. Specifically, the researcher observed the admission of their children to the hospice, since this was the key opportunity to see parent – nursing staff interaction. For two parents the researcher was also able to observe interaction during the discharge of the child from the hospice. Observation was not possible in all cases, sometimes due to bookings not falling within the research period and sometimes because the child was an adult and did not require the presence of the parent at the admission.

The question of how to observe needed careful consideration. To be a covert observer was impossible, since observation was subsequent to interview. However, the researcher considered that such an approach would be neither ethically appropriate for the nursing staff, nor would it fit the paradigms under which the study was designed. Therefore, overt observation was undertaken through the researcher being positioned as a participant observer. However, the degree of participation also merits careful consideration, since the focus can be either upon participation or observing (Bryman 2004; Tedlock 2008).

As the researcher was employed within the host organisation as a nurse, it was possible through participation to reduce her visibility and therefore her influence on how parents and nursing staff interacted. However, the particular activities which were observed tend naturally to be conducted by one of the nursing staff, whilst others move in and out of the activity. Therefore the continued presence of the researcher, albeit in an active role, tended to make her more visible and more of an observer.

Notes were recorded during participant observation, the researcher taking opportunities to write them as close to the events as possible to avoid 'erosion, modification and even falsification of the mental record' (LeCompte & Schensul 1999a p.32). At times it was possible to record impressions simultaneously as events occurred; at other times it was inappropriate to interrupt the flow of events through note taking and so the researcher absented herself when the activity was completed or during a natural break. Notes comprised detailed summaries of events including detail of the date, time, setting, participants, conversation topics, emotions (described or expressed), non-verbal activity and occasionally specific detail of conversation, such as particular words or phrases (Lofland et al. 2006). It was particularly important to note non-verbal communication and to compare it with verbal activity since it could suggest dissonance between expressed emotion and felt emotion (Begley 1996). Such 'jotted notes' (Bryman 2004p. 308) were subsequently written up in detail as soon as possible.

Documentary Observation

The final method of data collection was reading of the child's hospice medical file. Documents are a recognised source of observational data for case study research (Cresswell 2007) and these particular documents served as a point of triangulation for data already collected (Stake 2008). Through interviews and observations, the researcher had interpreted the issues at stake for individual parents and how they were communicated in particular contexts (Kleinman 2006). This led the researcher to consider the child's case file as a data source for insight into how palliative care staff members interpret the parental experience and emotion through their interaction with parents. Since triangulation of data was the goal, I only approached those families for whom data from two other sources were available. The exception to this was the ninth parent, for whom I had only one data source, but who was the spouse of the eighth parent, for whom I had two data sources: the case file to both parents. In each case parental consent was gained to access the medical record and also the consent of the child if aged 18 years or over.

The case file was composed of hospice documents as well as those originating externally to the organisation. Hospice documents included ongoing case recording notes, assessments of care, details of original referral (reasons for and process followed), and correspondence with other professionals. The documentary observation included records of face to face and telephone conversations and written correspondence records held within the case file. Initially each of these sections was scrutinised for evidence of interactions between parents and hospice professionals. In particular, I was searching for instances of personal concerns arising for parents and how these were documented. Simultaneously, I sought evidence of how parental emotion was explored and recorded as wells as records of professional responses to parental issues or emotions. This information was then compared to the data arising from interviews and observations. This data collection strand was driven by, and supportive of, analysis of themes arising from the interview and observational data (Guba & Lincoln 1989; LeCompte & Schensul 1999b).

3.8 Transcribing

Interviews were transcribed by the researcher as soon as possible after the interview. Transcripts of the participants were written verbatim, however, in order to preserve the flow and sense of the participant responses, not all of the interviewer responses are transcribed. This strategy is only applied where the interviewer responses are murmurs of agreement or encouragement which were given as indicators to the participant of the continued interest of the interviewer. Where an interviewer response such as this interrupts the flow of the participant's response, the interviewer response is omitted. Any interviewer response which adds detail to the flow and meaning of the conversation, which includes use of any words, is transcribed verbatim.

Each individual parental interview was transcribed as soon as possible by the researcher and its contents used to inform the collection and analysis of subsequent data wherever possible. Since the researcher was balancing the needs and priorities of the parents and the hospice, some data collection timing did not facilitate analysis prior to the subsequent collection. However, the researcher always aimed to analyse the data sequentially in order to adhere to grounded theory principles whereby the theory is generated within and through the data itself. A range of analytical strategies were employed in order to privilege the perspective of the participants.

3.9 Data Analysis

In this section I will present how data was analysed both in terms of data types and concepts explored, justifying the use of grounded theory, content and narrative analysis and explaining the methodology of each. In addition, the ways in which the analytic methods were applied to individual data types is presented. Finally, the ways in which concepts were identified within the data is identified. All analysis was completed and documented using NVIVO, which facilitated ongoing abstraction of the analysis as subsequent data was incorporated.

Analytic Strategies

Both narrative and grounded theory analysis were applied to the interview and focus group data. This facilitated preservation of the detail of each individual case as well identification of the emergent themes from the collective case study. Since the research design is a collective case study, attention needs to be paid to both the individual cases and the issues which have been explored through them (Stake 2008). The individual narratives were derived from both interviews and focus group and Table 2 details the data collected from parent participants.

Those parents where three types of data were gathered were also written up as narratives i.e. P1, P3, P5, P6, and P8, of which three are included in full in the thesis. The remaining parents' data contributes to the cross case analysis, but are not detailed as full case studies as there is less opportunity to verify information through triangulation of methods. Additionally, word limitations warrant restriction being placed upon the number of full case studies presented within the thesis.

Table 2: Data Collection Matrix for Parent Participants

	P1	P2	P3	P4	P5	P6	P7	P8	P9
Focus Group	X	X	X						
Interview				X	X	X	X	X	X
Observation	X		X		X	X		X	
Notes	X		X		X	X		X	X

It must be acknowledged that analysis was both deductive and inductive. Having situated the research within a theoretical framework, analysis was automatically deductive, fitting emergent themes to existing theoretical paradigms (LeCompte & Schensul 1999a). However, the researcher endeavoured to be guided by the ideas and issues raised by the research participants and in so doing to take an inductive approach where possible (LeCompte & Schensul 1999a).

Using this modified grounded theory approach, analysis proceeded in a systematic fashion following the chronological order of data collection and incorporating emerging ideas into the ongoing data collection and analysis (Corbin & Strauss 2008). In focus group or interview, parents were asked to talk about their experience of parenting a dying child. As a prompt they were asked to consider positive and negative issues. Themes were generated through analysis of their responses noting those issues which individual parents emphasised.

The parent focus group was initially analysed with two objectives: purposive selection of parents for the main study and derivation of initial codes for development through subsequent individual interviews. Analysis of focus groups can establish group norms with respect to behaviours (Kitzinger 1994;

Kitzinger 1995). In this study, the focus group clarified that management of emotions was an important part of everyday interactions for the parent participants. This strengthened the notion that the emerging theory was grounded in the lived experience of individuals (Corbin & Strauss 2008).

Whilst it is acknowledged that focus groups do not ordinarily capture individual narratives (Kitzinger 1994), the data which the parent participants offered was detailed, in depth and wide ranging. This may in part be due to the small number of participants (n=3) and the length of time taken (over three hours, although participants were given several opportunities to curtail the group). As a result, the focus group data was used to shape the collection of subsequent data and also as constituent data of the main study. Therefore, analysis of the focus group data took account of the individual narratives being constructed through the conversations, integrating both thematic and structural analysis (Bryman 2004), as well as overall thematic analysis. Thematic analysis and narrative construction for the focus group data followed the same procedures as for the individual interviews, and these are presented below.

Initially I read each transcript in full to gain a general sense of what the participants were endeavouring to tell me and their reactions to what they were saying (Corbin & Strauss 2008). Thus the start point was a sense of the story they wanted to tell and the significant points within it (Cresswell 2007). Such points included chronological references, key events as well as emotional responses. Following this, I began the process of detailed open coding whereby the data was broken down into component parts (Bryman 2004; Charmaz 2006). These comprised issues, words and phrases in the data which represented significant concepts (Corbin & Strauss 2008; Cresswell 2007). As the coding system developed, axial coding was possible, whereby minor concepts could be related to broader concepts, leading to development of categories and themes (Corbin & Strauss 2008). I undertook both within case and cross case thematic analysis in order to clarify the complexity of their lived experience (Cresswell 2007). Memos were written throughout this process, reflecting emergent codes and categories, methodological issues and reflexive matters (Corbin & Strauss 2008; LeCompte & Schensul 1999a). As analysis proceeded, data from different sources were constantly compared to support the development or rejection of emerging themes (Corbin & Strauss 2008).

Simultaneously, the narrative of the individual was sought in order to preserve the individual cases (Corbin & Strauss 2008; Stake 2008). Narratives were structured in a temporal format, as articulated by parent participants during interviews (LeCompte & Schensul 1999a). This chronological record included the issues they identified as significant in their experience of parenting a dying child as well as how they used emotion. In each case, narrative analysis was followed by a comparison with observational and documentary data, particularly identifying where parental issues identified in the narrative were reflected or not in the other data. This level of comparison served to enrich and strengthen the themes emerging from the overall analysis.

Textual data derived from the children's medical records underwent content analysis. The purpose of this strategy was to clarify when and how staff interacted with parents with respect to experiences and emotion and how they recorded, shared and acted upon such interactions with parents. Additionally, through comparison with interview data, it was possible to consider whether staff members were able to elicit information pertaining to experience or emotion or whether parents were offering such information in their day to day contact with palliative care staff. Data was collected in several ways to support the underpinning constructivist paradigm of the thesis and strengthen the emic perspective, as set out in the data collection and research design sections (Sections 3.3 and 3.7). Therefore, the documentary observation data was incorporated into individual narratives and is reported within Chapter 5. (Within Chapter 5 the documentary observations for each parent are referred to as 'The Official Account' to contrast with the Individual Narrative which is presented alongside.)

Operational Definitions

Analysis for the concepts of suffering and emotion management was directed in specific ways. Since the theoretical framework for the research had been identified as suffering and emotion management, there was a risk that parental narrative would be distorted to fit this *a priori* theorizing. Therefore, it was essential to clarify both through the questioning technique and the analysis how the parents themselves framed their own experience. In the topic guide, parents were asked initially to talk about their experience of parenting their child, considering negative and positive elements. They were asked if they shared their feelings with other people. Towards the end of the interview, and once they had explored their personal experiences, they were asked if they thought they suffered and to define suffering.

With regard to suffering, the analysis had four strands, all aimed at avoidance of the parental voice being subjugated by the research agenda. Firstly, individual parental experience was considered through the way they narrated their 'story'. This was facilitated through the use of a topic guide rather than detailed question schedule for the interviews and focus groups and through the design of the topic guide as described in the previous paragraph. Secondly, since suffering was defined as loss through the literature review, the researcher looked for parental losses, either overtly expressed or implied. Thirdly, the thematic analysis was considered in the light of the definition of suffering as loss and any deviance considered. Fourthly, towards the end of the interview or focus group the parents were asked directly whether they suffered and asked to define suffering. This information was compared with the thematic analysis of their descriptions of experience.

With respect to the concept of emotion management, thematic analysis focused upon how parents both talked about and expressed emotion. This included types of emotion as well as contexts for emotional expression. Analysis therefore included the use of words relating to emotions, such as descriptions of parental feelings (sad, depressed, happy etc); overt expression of emotion, such as laughing or crying; nuanced, non-verbal expressions of emotion, such as facial expression or body movement; detail of contexts for any of the preceding issues; contexts for non-expression of emotion.

Throughout the analysis a reflexive approach was incorporated in order to monitor the bias potential inherent through the researcher's ongoing role as an employee of the host hospice (Corbin & Strauss 2008). This incorporated analysis of the practice rationale for the project; initial consideration of the researcher's perspective upon the research questions; ongoing memos to take account of researcher perspective; and multiple strategies to ensure that the research provides a trustworthy account (see section 3.6) (Cresswell 2007).

3.10 A Dramaturgical Approach

In both the methodology and the data analysis a dramaturgical approach is employed. This reflects the theoretical context for the study, set out in Chapter 2, and is in common with other studies of affect and presentation of self (Wiley 1990a p.19, Goffman 1969a, Hochschild 1983, Reissman 2003). This stance emphasises the choices individuals make in how they present themselves to particular audiences (Goffman 1969a). Therefore, the role of the researcher upon the narrative that individual parents present is brought to the fore, which is in accordance with the philosophical assumptions set out in section 3.2 (Reissman 2003). This role incorporates elements of staging the performance, the performance itself and watching the performance.

Staging is influenced through research design: the setting for data collection, the data collection tools and their implementation. In giving choice over interview setting and using topic guides rather than a more structured questioning technique, I have endeavoured to minimise my influence over the participants' performance. However, my influence can never be eliminated, since the instrument of data collection is my human self, which leads to consideration of the performance.

As another being, my interactions with research participants involved intersubjectivity. The resulting data is a collection of social constructions by both participant and researcher, as explored in section 3.2. However, in choosing to collect data in different ways I have created a variety of contexts for those constructions, allowing for clarification of the trustworthiness of my interpretations. In addition, suffering and emotion management are subject to similar performance criteria in the day to day lives of the participants. Therefore it could be argued that integration of a dramaturgical perspective within the thesis enhances understanding of the concepts.

Interaction with the parents also involved my presentation of self. Some aspects of this are addressed within the consideration of ethics in section 3.4. There is a delicate interplay of my aiming to take the lead of the parents in the collection of data whilst also attending to my own responses and the influence they may have upon interactions. Both the participants and I could be taken to difficult areas of interaction, for which the script was unfamiliar. In these instances, my communication skills were challenged as the dual roles of nurse and researcher at times conflicted (see sections 3.7 and 3.4). However, this also strengthened the thesis: one focus for observations became the ways in which professionals responded to parental emotion or gave opportunity for its expression.

Finally, I was an audience for the parent participants. Once again this requires recognition that their performance for me may have differed to their performance for others. In other words, the way in which the parents presented themselves may have altered in different contexts. The data presented in Chapters 4, 5, 6 and 7 will demonstrate that this was indeed the case. However, that difference illustrates something of the nature of their performance with respect to emotions and therefore strengthens the thesis.

3.11 Comment

I have set out the philosophical assumptions which underpin this thesis and how these have guided my choice of methods by which to conduct the empirical study. Throughout, my main concern has been to privilege the voice of the parent participants. This has therefore also guided the ways in which the data has been collected and analysed. In the remainder of the thesis I set out the analysis of the data and the empirical findings before drawing empirical, theoretical and policy conclusions.

The hypothesis which this thesis aims to test is that emotion management influences the communication and legitimation of suffering. The empirical study draws on the perspectives of parents of dying children as a novel setting for suffering research. The research questions for this project are therefore as follows:

1. What is the lived experience of parents of dying children?
2. How do other people's responses shape the parents' lived experience?
3. What is the place of emotion and suffering in the parents' lived experience?

The data generated through this study is presented as four discrete chapters which support the developing theory of how emotion management may jeopardise the authentic voicing of suffering. Using thematic analysis, Chapter 4 sets out aspects of the experience of the parents, addressing the first research question. In Chapter 5 I concentrate on preservation of individual stories and present three parent narratives. These support the trustworthiness of the thematic analysis, but also draw attention to issues of communication inherent to their lived experience. Therefore, research questions 2 and 3 are the focus of Chapter 6, wherein emotion management is the predominant theme. The final data chapter also attends to research question 3, and refocuses the discussion upon suffering.

Chapter 4
What is at Stake for Parents of Dying Children?

Introduction

This first data chapter presents the results of a thematic analysis of the interview data generated from the parent participants. This facilitates an initial response to the first research question: What is the lived experience of parents of dying children? During the analysis I was looking for both differences and similarities between the parents' accounts of their experience. Accordingly, the accounts spanned different timescales, they related to different disease processes and different family set ups and some were more optimistic than others. However, there were also some apparent similarities, including the meaning of their experiences and the temporal framework within which parents structured their narratives. In this chapter I focus upon the similarities, while more individual issues will be seen in the narrative analysis of Chapter 5.

In order to understand the meanings which parents drew from their experiences, I focused upon what Arthur Kleinman refers to as 'what is at stake' (Kleinman 2006; Kleinman & Kleinman 1991). Rather than considering just concrete experiences, this necessitates taking wider account of individual's perceptions of the impact of those experiences (Kleinman 2006). Using thematic, cross case analysis I have drawn out some matters which appear to be at stake for the parents of dying children in this study. These include: time; their identity; their relationships; their place in society; certainty; and the survival of their child.

The chapter begins by exploring the temporal nature of the parents' narratives and experience, in terms of the structure of their experience (impacts emerge in a time-structured fashion) and that its impacts persist over the long-term. Following this, the issues at stake are identified and analysed, demonstrating how the losses the parents experience accumulate and compound each other over time. The losses are shown to be existential and relational in nature. The significance of this is in how they influence the intersubjectivity of the parental experience by establishing barriers to communication. Thus the analysis begins to highlight some of the difficulties the parents have in communicating their experience. Issues of responses and communication are further addressed in Chapters 5 and 6. Therefore the focus of this chapter is exploration of the character of the parental experience and the dynamic between that character and the establishment of a context for altered communication.

Note: Where italics appear in quotations it indicates the replacement of an identifiable name with a pseudonym in order to preserve anonymity. Brackets (...) indicate omission of interviewer's murmurs of encouragement or words where they reflect those of the participant.

4.1 The temporal nature of the parental experience

When asked about their experience, the parents tended to structure their description in a temporal framework. The interview structure did not aim to pre-empt this response, being led by a broad topic guide which started by asking parents to tell the interviewer about their child. However, parents typically began with their child's diagnosis. The temporal framework with which parents tended to structure their narrative therefore progressed through considering life in the past, life at the time of the interview and considerations for the future. (This temporal framework of individual parent narratives is considered again in Chapter 5.) In addition, the parents' use of time was seen to be radically altered as their experience of parenting a dying child progressed.

All parents began their narratives with a description of the time when their child was diagnosed and the associated abrupt change to their circumstances. For some this occurred at birth, but for others it came months or years later. Whenever it occurred, it was associated with an immediate change to their expectations for the child and themselves:

> It's almost as if the point at which *my daughter* was born, our lives went along a different, it's a parallel path, but it's a different path
> (Sarah; 18 year old daughter)

For newborns, survival around the time of birth was sometimes questioned. For some older children, a sudden health crisis also called their immediate survival into question. For others, it was not immediate survival that was troubling, but rather continued development along a predictable path. In each case the parents were confronted with the fact that their child was not expected to survive into adulthood as a result of a life-limiting or life threatening condition:

> He um ah was very ill when he was 3 days old and he started taking some protein and was in *a specialist hospital* for, in intensive care, for the first two, oh, first week of his life, um eventually came home just about in one piece, but he has suffered, clearly suffered some sort of brain damage, global delay, particularly autistic traits, some autistic traits, um so, whilst he's a lot better than we imagined he might have been, he's certainly not in full working order, shall we say
> (Michael; 10 year old son)

At the time of their child being given a diagnosis, therefore, a change of direction was imposed upon parents. Their lives began to follow a pathway which was radically different to that of their contemporaries and that which they had anticipated. Whilst negotiating their way along this path, the parents described their difficulties in predicting likely outcomes or how long they would remain on the unknown pathway. At the beginning there was shock and hopelessness:

> The only way I could explain it was that I went into a dark tunnel, at the beginning, and there was no light. There was no light in the tunnel
> (Valerie; 19 year old son – deceased)

Over time the nature of the child's diagnosis and the therapeutic options available may have changed, associated with subsequent developments in medical technology concerning life-sustaining treatments. However, cures for the diseases remained elusive and so the children's survival remained unlikely. Michael was a good example: his son was critically ill at birth and the intervening ten years have brought about significant therapeutic developments, but not a cure. Thus his predicament has changed over time, but the sense of a changed direction in life remains. Describing his reactions at the time of his son's birth and subsequently he said:

> We were in a bit of a hole, and we have got out of it well we're climbing out as is sort of like a hole that you're never out of but you're always......you're just getting a little bit further up
> (Michael; 10 year old son)

The temporal nature of the parents' narratives in some ways mirrors the temporal framework associated with bringing up any child: the child grows and ages and there are societal institutions, including health and education, which impose a temporal structure through surveillance of child development (DfES 2004a; Vickerstaff 2007). However, for the parents in this study, the temporal framework emphasised how different their lives had become compared to their peers. This is particularly reflected in the way the parents' juxtaposed life before and after the child's diagnosis, going on to consider life in the future after their child dies. However, the significance of time goes beyond its use as a structural framework for the parents' narrative accounts. It also emphasises both the longevity of their experience and the way in which time was used differently by these parents. In their experience of parenting a dying child, time was at stake.

4.2 At stake: time

Normative parenting, as described in Chapter 1, is associated with the growth and development of a child, bounded by societal practices and regulation. These are overseen by institutional experts, such as in health and education, with their associated regular regimes and rhythms (Moran-Ellis

2010). However, for the parents of dying children in this study such constancy was jeopardised. In its place, time was taken for extra-ordinary care, for clinic appointments, for care of the sick child in hospital and at home, disrupting those other regular patterns of family life. Parents had limited agency over their use of time: it became subject to the fluctuating state of their child's health and the associated demands of experts and technology. The policy review has demonstrated how childhood has become subject to specialisation, facilitated through the rise in professional roles associated with child health and development (Davin 1999). For the parents in this study, that experience was exaggerated and it imposed restrictions upon other aspects of their lives because it put time at stake.

With the onset of the child's ill-health, there was an immediate consumption of time in order to accomplish nursing tasks. In other words, tasks beyond the normal care expected to be delivered to a child by the parent. Examples of this included artificial feeding methods, moving a child who lacked the ability, or carrying out basic tasks of daily living such as washing and toileting for a child of an age when such tasks would normally be independently achieved. Some of these tasks occurred early on and had a short term focus, such as Imogen caring for her 3 year old daughter before and after open heart surgery. For other parents the tasks related to a growing list of everyday actions which the child could no longer carry out, and time taken for these continued long term and increased as the child's condition deteriorated. Although these tasks were beyond the realms of normal parenting, health or social care support were not guaranteed, compounding the parents' loss of agency in their use of time:

> He was very physically disabled, but he wasn't in need of nursing care in erm, he didn't need a ventilator, he didn't need to be tube fed, this kind of thing (...) but once he needed all those types of things then they would fund it (...) very, very disabled, you know, couldn't, couldn't wash himself, couldn't, you know, couldn't walk, he couldn't wash himself, couldn't go to the toilet by himself, but that is not nursing care (Mary; 20 year old son)

Time was also consumed by the ongoing management of health for the children. The complexity of their conditions meant that the parents typically had to engage simultaneously with several health or social care professionals. This resulted in parents accompanying the child to many regular appointments each year, often with specialists in tertiary centres, necessitating long journeys rather than accessing local facilities. However, health maintenance was also in a state of flux: as the child's condition changed, different specialists would be needed. Once again, the regular rhythms of child development were disrupted and replaced with unknown and changing patterns, over which the parents had no control:

> I mean you have like 4 appointments a year up at the city, so that's 4 visits up in the city a year, so, and this year a bit extra because of her gastrostomy. But now she has her injection for periods and that now, 3 month, 3 monthly injection, so I've done that with her now, because obviously that's, that's a nightmare
> (Diana; 11 year old daughter)

As the child's condition changed, besides incorporating more specialists' advice, parents themselves had to accommodate new caring tasks. Such tasks could be short or long term and could change and increase over time as the child's health deteriorated. These tasks, along with attendance at regular appointments, also had an impact upon parental agency in their use of time. However, simultaneously, the families were trying to meet the ordinary demands of everyday family life with its associated activities such as employment, maintaining a home, or meeting the needs of other healthy children. Managing those alongside the needs of a dying child led to time further being put at stake for these parents. One of the outcomes of such pressures on time, was to restrict some parents' opportunities for 'normal' interaction in society, through work or leisure pursuits for example, as their child's health was prioritised.

Lastly, although time was spent ensuring the ongoing health of the child, health crises were a prominent feature for the parents of dying children, once again putting time at stake. Life limiting and life-threatening conditions are, by nature, dynamic. The condition itself might be a degenerative disorder, leading to deterioration over time; advances in technology might alter the course of a disease; acute crises in health can occur without warning; and, finally, each child is individual and so are any manifestations of their disorder. The integration of these factors meant that for the parents in this study, their individual child's health could change rapidly and radically and their use of time became dictated by their child's ongoing and changing health needs:

> I was working full time, *my daughter* had just been born so she was at home, so I was having to go into the hospital in the evening. *My wife* would come and take over from me in the morning and I'd go straight to work at 8 o'clock the next morning
> (Michael; 10 year old son)

The dynamism of the children's conditions led to unpredictability, but this was confounded further by technological developments. Mirroring the decline in infant and childhood mortality over the last century (Hughes & Church 2010; ONS 2010), children with life limiting and life threatening illness are surviving for longer, but with more complex health needs (Cochrane et al. 2007). For the parents in this study, survival was associated with no known pathway of illness, leaving them with unanswered questions about the most fundamental issues. This had implications for their use of time both immediately and in the long term. Everyday life concerns, such as whether or how to work and how to incorporate leisure became problematic, further emphasising the parents' lack of agency. Some parents gave up work, others altered their work patterns. Several parents spoke of the limited opportunities to spend time socialising. Thus the consumption of time, the parents' limited agency over how time was used, and the unpredictability of the child's illness influenced the parents' opportunities for interaction in society, setting them apart and making them different:

> I work temporarily some of the time, really around *my daughter*, so, um, mostly I'm, you know, at home and the one who's, you know,

> having to drop everything to, to cope with the clinics and the hospital admissions and things like that
> (Sarah; 18 year old daughter)

These parents of dying children used time differently. They undertook a different, more time consuming range of parenting tasks which extended for much longer than the parenting of a healthy child. Maintaining stability in the child's health was time-consuming, but unpredictability remained a feature of the children's conditions. Therefore health crises were frequent and further undermined the parents' ability to have agency in their use of time. The experience of parenting a dying child led to a loss of time and time became an issue at stake for these parents because their lack of agency over its use limited their participation in society and opportunities to interact with others.

Time therefore shaped the experience of the parents and impacted upon the other issues at stake, namely identity, relationships, place in society and certainty. Furthermore, the amalgamation of each of these issues also worked to set the parents apart and make them different, which influenced the ways in which their experience might be communicated. Whilst communication will be addressed more fully in Chapters 5 and 6, the remainder of Chapter 4 continues by exploring each of the issues at stake for the parents which shape their experience, beginning with identity.

4.3 At stake: identity

So far, this Chapter has analysed how these parents' of dying children experienced a loss of time and a radical change in the direction of their lives. An important factor in that altered life course was the parenting role, which became significantly changed through the child's ill health, in terms of tasks and responsibility. The changed tasks and responsibilities in turn influenced the way the parents related to their children and professionals. Accommodating these changes led some parents' to alter their self perception. Overall, whether through role, ways of relating or self perception, the parents' identity was put at stake.

The increased life-expectancy of children with life threatening or life limiting diagnosis means that parents must assimilate a new range of practical tasks with respect to their child's physical health (Craft & Killen 2007). These skills are different to those who have healthy children. Parent participants in this study were caring for children who could not swallow and were fed special diets through tubes inserted into the stomach. They described strict feeding regimes, in terms of dietary content, timing and feeding method, which had to be adhered to constantly. Some parents had to care for ventilated children. Still other had supported their children through life-threatening surgery which left the child vulnerable to infection and recovery from which required the parents to assimilate complicated medication regimes and rehabilitative therapies.

The parents learned to monitor their child's complex health, to assess it, to make judgements about appropriate interventions and their timings. This could relate to diet, or to the timing of medications to prevent seizures or to emergency treatment for life-threatening seizures. Other parents had to judge whether or not their child's ability to breathe effectively was sufficiently compromised to require hospitalisation. One parent focused upon heart function:

> But at the moment she's getting quite blue, and we had her oxygen saturation checked 2 days ago and that was about 85 (...) so she's getting close I think now, erm, so we need to ring, next week we said we'd ring her cardiac nurse and just mention it and see whether she needs to go to the specialist hospital for another echo and see if anything's going on, but I don't think it is I think it's just because she's growing and it's putting a strain
> (Imogen; 3 year old daughter)

Developing and performing the skills of assessment set these parents apart from their peers in terms of the responsibility of this role. Responsibility for a child is expected of every parent, clearly articulated in the 1989 Children Act and supported by policy in education, health, work and crime (see Chapter 1 for a review of relevant policy). Accordingly, parenting activities are subject to scrutiny, for example through the monitoring of child health and education (DfES 2004a; Vickerstaff 2007). An example of this is diet. Parents of healthy children are advised to monitor their child's diet and exercise in order to maintain a healthy body mass index and their child's weight and height will be monitored in clinic or school (DH 2010). In contrast, some of the parents in this study were concerned with ensuring their child received precise amounts of specific nutrients, achieved by weighing, measuring and administering the ingredients throughout each day. If the calculations were inaccurate, the child could require hospitalisation, and perhaps suffer seizures or even brain damage.

It has been noted in education research that measurement of norms in childhood is restricted by the 'developmental paradigm' which fails to recognise broad variation (Barron et al. 2007 p.2). It would seem that the same applies in child health: the parents in this study were not monitoring the well being of an otherwise healthy child, for whom 'norms' were identified and easily measurable. They were managing more complicated health issues and with potentially more serious short term consequences on a day to day basis. They assessed and adapted their child's care to ensure ongoing stability of health: they altered feeding regimes, assessed deterioration, and initiated therapeutic intervention. The outcome of the parental assessment could mean the difference between staying well and being hospitalised. Indeed, the child's survival could hinge upon accurate parental assessment:

> It's about picking things up very quickly, and going into hospital very quickly, everybody doing things at the right time to prevent any further damage and also to prevent death because death is an outcome if things get out of hand (Sarah; 18 year old daughter)

However, there was also at times an individual meaning for parents in these actions. Their assessment skills could also be used as a means of controlling the situation, which helped them to increase agency in their day to day lives through making the task of caring manageable. Some parents achieved this by judging for themselves when their child was sick enough to require hospitalisation and therefore only approaching professionals when they judged it necessary. Another parent described the effort involved in becoming an 'expert parent' with respect to her child's health management and prevention of deterioration. For others, judgements needed to be made in order to function in day to day life:

> So now we've, I've stopped putting her on the pump because it's just, I, something I can't do (...) I mean I don't want to be having to clean her bed at 3 o'clock in the morning
> (Diana; 11 year old daughter)

The list of technologies which parents are expected to master in the home environment is immense and ever increasing (Craft & Killen 2007). For the parents in this study this meant that their parental role and responsibilities changed to incorporate aspects of nursing and social care, varying according to the diagnosis, the age of the child and the stage of their disease. However, what the parents had in common was an alteration in the parent-child relationship and dynamic as professional tasks become integrated into everyday life.

Their child's extended dependence sometimes caused a strain upon the parent's relationship with the child. This might be through the types of task they had to undertake, such as personal care. Alternatively it might be because the child was unable to become age appropriately independent - whether a young child given the freedom to explore their environment, or an older child moving out of the family home. One father had described the difficulties in undertaking personal care for his daughter and went on to explain the impact upon their relationship:

> I think certainly since my daughter's been at college, our relationship has changed. It has become a much more, more like a father-daughter relationship over the last, since September, than it was before. I don't

> The reality is that you do get treated in different ways depending on how you, how people perceive you and if they think that you understand and they think that you're reasonably intelligent, you're reasonably articulate, that you get treat, it's a, in life people will tell you or share stuff with you or come and tell, and you know, you become an expert parent and your child becomes an expert child.
>
> (Sarah; 18 year old daughter)

However, it was not only the altered tasks, responsibilities and ways of communicating which changed the parents' identity. Sometimes this also related to changes in the way they perceived themselves. In conversation, some parents referred to themselves in somewhat 'professional' terms through the type of language they employed, suggesting changes to their self perception. They referred to themselves as 'carers' or the 'primary carer', rather than as mum or dad. This self perception was influenced by the tasks and responsibilities they had imposed upon them as well as the ways in which they related to their child, professionals and other people:

> I do sometimes think that people just see me, her as an appendage of me, or me of her, and that's a very, because I'm the primary carer that's much more the case
>
> (Sarah; 18 year old daughter)

Parents of dying children have their parenting role changed, by means of different tasks of parenting, changed levels of responsibility, altered parent-child dynamic and changes in the parent – professional relationship. The outworking of these matters set such parents apart in terms of their role and identity. The traditional parental role was lost and a new role and identity developed which centred upon mastering these new skills, tasks and responsibilities. Loss of self, or identity, is a recognised theme in suffering research, as both a form and outcome of suffering (Charmaz 1983; Charmaz 1999; Sacks & Nelson 2007). Importantly in this thesis, the ways in which these parents became different began to influence how they interacted with society. In order to understand that, it is necessary to explore the next issue at stake in the experience of parenting a dying child: relationships.

4.4 At stake: relationships

The preceding section has described how the parents' relationships with their children and professionals became altered. In addition, the parents described three other significant areas where they experienced altered ways of relating as a result of their different life experience: family, contemporaries and work. In each of these domains, parents can be seen to have changed ways of relating which not only reinforces their different life experience, but further sets them apart and therefore influences the inter-subjective nature of their experience.

Family

As well as managing the dual roles of parent-carer, the parents in this study found that family relationships were also affected in other ways - specifically the dynamics between the child and the parents, between the child and their siblings and between the parents of the child. Sections 4.2 and 4.3 of this chapter have set out some of the complicated dynamics between the child and the parent, associated with prolonged dependence and an altered relationship associated with caring needs.

The children remained dependent for a variety of reasons. For some, therapeutic interventions circumvented normal processes, for example giving strictly timed metabolic feeds through a gastrostomy (tube into the stomach). The child's disorder may have led to a degree of physical disability, preventing independence in activities of daily living, such as washing, dressing or even turning over in bed. Learning disability, associated with the disease process, could cause the child to lack age related intellectual ability, limiting both capability and safety. Parents sometimes prolonged dependence as a protective mechanism for their vulnerable child. Finally, the organisation of care services meant that even if a degree of age related independent living was achieved, breaks to accommodate vacation times at educational establishments led to continued dependence upon parents.

Whatever the reason for the prolonged dependence, the result for each parent was ongoing limitations upon them being integrated into society, through work or leisure, for example.

However, siblings were also subject to altered experiences and this in turn reflected back upon parents. The prevailing needs of the sick child affected siblings. Siblings missed out on attention day to day. At times they had unnatural periods of separation from the parents, during planned or emergency hospitalisation of the sick child. Sibling activities with school or friends were limited due to time or financial constraints. Parents described siblings taking on unusual responsibility for the dying child, or, contrastingly, establishing some distance as they watched the child's condition deteriorate. Trying to balance the very different needs of their children further complicated the life experience of parents in this study.

In addition, the parents expressed the emotional impact upon themselves of the siblings' experience. The parents spoke a great deal about the siblings of the sick child, expressing concern for their physical, psychological and social well being. They described guilt about the siblings' lives and care, the need to protect them from what was going on, the questions they asked and the direct manner in which they asked them. Short term concerns, such as at the birth of a sibling when the sick child was resentful, or needing to leave the sibling with relatives when the dying child was in hospital, were contrasted with longer term concerns such as the sibling being left ultimately responsible for the sick child in the event of the parent's death.

In the interim, parents remained under scrutiny to ensure that siblings continued to maintain their developmental norms (Moran-Ellis 2010). Parents focused upon assisting the siblings through milestones in life without going off track, for example in education. Parents expressed pride when the sibling demonstrated concern for the sick child and regret when the sibling remained more aloof. The experience of the siblings was fundamental to the experience of the parent. This serves to underscore the change in identity for these parents: their life experience and identity became focussed upon that of their children. This might be reflective of the experience of parenting a healthy child, associated with the value of children being measured through the psychological-emotional needs they fulfil in parents (Hoffman & Hoffman 1973). However such values, which include social identity, immortality, accomplishment and social comparison (Hoffman & Hoffman 1973), are surely more difficult to associate with parenting a dying child.

The relationship between parents was also altered through the experience of parenting a dying child. Parents identified different ways of managing the situation, with each parent taking on particular roles. These included the breadwinner, the strong one, the one making sacrifices, the one fitting in with the family. In addition, a variety of effects upon the parental relationship were observed in the sample for this research. Some parents' relationships did not withstand the demands made upon it, albeit there may have been pre-existing strain. For other parents, the extensive time commitments necessary to facilitate the ongoing management of the child's disorder called for negotiation and compromise concerning roles and responsibilities. One couple achieved this by both working part time and equally sharing the varied responsibilities. However, for others there was more compromise by one party than the other, working along more traditional family roles of provider/breadwinner and homemaker.

Managing such changes to family relationships required time and energy and the impact was again reflected in the parent's sense of self. In common with existing research into suffering, the parents' sense of self was altered: the identity they had imagined before their child's diagnosis was replaced with a new and sometimes unwanted identity(Charmaz 1983; Charmaz 1999). Some parents had to forgo career plans. Others experienced the breakdown of a marriage, altering the anticipated structure of family life. One parent spoke of not having the size of family he anticipated. Still others reflected upon their lack of time and opportunity for friendships. Once again, such roles and adaptations might be associated with parenting any child. However, for the parents in this study, the longevity of the experience, levels of dependence of the child and lack of parental agency or choice, provide a stark contrast.

Contemporaries

Several parents reflected upon a lack of friends or the difficulties of maintaining friendships. Whilst being a clear loss, the significance of this was also that it reinforced how different these parents' lives were from their contemporaries. Friendships which predated their child's illness could be difficult to maintain. In their place were new relationships based on illness or convenience. The parents' individuality was lost as the child's needs were prioritised, illustrating the change to their own identity. Zelizer and others refer to the modern day sacralisation of children as a result of changes in the social construction of childhood (Jones & Brayfield 1997; Zelizer 1994). Changes to the friendships of the parents in this study perhaps reflect an imposed sacralisation of the child through the social construction of parenting the <u>dying</u> child.

Parents made comparisons with their contemporaries which served to illustrate how different their life experiences had become. Comparisons might be made with those in similar health or social situations or with those whose situations contrasted strongly. Comparisons may or may not have favoured the parents' experience: in either case, the parents appeared to judge their experience against a perceived hierarchy. Such a response mirrors the imposition of moral judgement noted within research into suffering in other contexts, including dying adults (Sacks & Nelson 2007) and chronic illness (Charmaz 1999):

> I saw a lot of mothers whose little ones were in hospital and didn't have the support system that we have. And their other children who also had issues were in care and had to be put into care because nobody wanted children with autism and Asperger's and Down's syndrome, or whatever the issue was. They couldn't get somebody to care for their other children, and that, and I was saying to *my husband,*

> you know life might be bad for us, but not that bad
> (Imogen; 3 year old daughter)

Whilst parental comparisons reinforced the reality of how different their lives had become when contrasted to their contemporaries, a particular area of difference concerned friendships. Friendships were shaped by the developing difference between the parents of dying children and their contemporaries. It was difficult to maintain friendships established before their child became unwell. Parents had less time available to maintain friendships as new parenting tasks were undertaken (see Section 4.1). In addition, the parents of dying children were engaged in different activities which separated them from the rhythms and patterns of their contemporaries who were parenting a healthy child (see Section 4.2).

Simultaneously, the fact that the parents encountered new people was the result of the change in their life. However, the function of such new contacts was not often friendship: instead, new people could be professional contacts or other parents met as part of the process of parenting a dying child. Importantly, these did not reflect parental choice, but rather a lack of agency:

> So you lose friendships and try and re-establish new ones really, and I think re-establishing new ones meant that the sort of people that I was able to sort of have something in common with were those with problems either with their children or of their own personal diagnosis of conditions
> (Mary; 20 year old son)

Workplace

The significance of the parents' relationship with work was emphasized by all but one of them talking about their work and careers before the birth of their child. At the time of the interviews, seven parents worked, six of them on a part time basis. They spoke of how they worked and the meaning of work. Most of the families' work arrangements comprised two parents, one full time and one part time worker. However one family had a single unemployed parent and another had two parents who were both part time workers. A common factor concerning work, which limited as well as capitalized upon its potential for parents, was flexibility.

The time required for maintaining their child's health (see section 4.1), both in terms of quantity and unpredictability, meant that any work undertaken by parents needed to be flexible. Flexibility was attained through compromise. The type of work, the number of hours, the level of remuneration, the stability of work or income, or the status conferred by the work could be changed in order to achieve flexible employment. Flexible employment facilitated attendance at routine appointments as well as dealing with emergencies (see Section 4.2).

For the parents or partners who had not built flexibility into their work, there was stability of income which supported a stable home life, to the extent of securing a permanent home. Several parents associated this stability with commitment to full time work. However, such commitment came at a price: attendance at emergency or long term hospitalization became problematic. Parents perceived that such attendance, by themselves or partners, could compromise income, holiday time allowance, stability of employment and even stability of home. It seems that they perceived the 'rules' of society with respect to work prevented them from prioritizing their dying child. Indeed other research has demonstrated that state institutions are structured according to generalized norms (Barron et al. 2007), and, it is notable that, precisely because their experience is relatively rare, such norms may be unattainable by dying children and their parents.

The parents in this study perceived that even services designed to help them were rigidly structured and unresponsive to need. For example, a father asked social services for help to enable him to keep working when his wife was ill and unable to care for his child. His request was denied and he perceived that it was interpreted as him favouring work over the child. Actually, he was concerned that absence from his job would result in unemployment and he was trying to ensure employment and adequate

income in the longer term and avoid dependence upon the state. This perspective is mirrored in the findings of the recent review of children's palliative care services in England, illustrated by the problems children with complex health needs face in accessing school (DH 2008).
Childhood has been described as a social construction which has varied over time and the state institutions of health and education contribute to both the social construction of childhood and its practical outworking (Davin 1999; Hendrick 1997b). In turn this has a bearing on how parents' lives are organised, since access to work and childcare are determined in part by such institutions. This may apply equally to parents of healthy and dying children. However, the rigid organisation of these institutions and their apparent inability to accomodate the different parental needs arising with children's complex health, were perceived by the parents in this study to preclude successful integration into society.

Employment illustrated this point because it provided more than income for parents. It encompassed elements of identity and place in society. Parents took pride in their ability to provide for their family. In contrast, they were dismayed when they could not provide to the level of their aspirations, for example with respect to holidays or the home environment or material possessions. Work facilitated contact with others and conferred status within society, which in turn further built the parental sense of identity, which grew through being challenged at work. However, the overriding necessity to meet the needs of the dying child and the family meant that massive compromise was required by the parents, in which personal goals were always subjugated to the needs of others.

In spite of the overwhelming sense of compromise regarding work, parents' responses to work were remarkable for their tolerance. Parents demonstrated realistic expectations of employment: they required flexibility, but they did not expect special treatment. Parents expected to make choices and compromises which facilitated flexibility; they did not expect this of their employers. For reasons of meaning and in order to maintain a standard of living, parents wanted to work; however, they always prioritized the child.

Whilst this may be an experience common to any parent, for the parents in this study this pattern of work was imposed for longer, perhaps indefinitely, with subsequent outcomes upon the parents' way of life and sense of self.

Therefore, although work provided an element of common ground within society, parents remained confined in the ways they could facilitate work and so still remained set apart. Of the nine parents interviewed, seven were working and one of the remaining two wanted to work. Rather than being a mere reflection of financial need, this indicated the importance of work upon their sense of self in the context of their experiences as the parents of dying children:

> You know I think it's about how people see you and for me, not working, although I am working, I'm completely different when I'm working. I have a purpose I feel part of the world again I feel I've got something different to talk about, I'm me. But most of the time I'm not working and then I just feel like who am I?
> (Sarah; 18 year old daughter)

This illustrates the complex way in which the parental losses accumulated and compounded each other: Sarah could not commit to a full time, permanent job because of her daughter's changing health needs and the impact of that was felt in her self-perception and sense of identify. Like the suffering described in adult hospice patients (Sacks & Nelson 2007) and that of the chronically ill (Charmaz 1983), both the loss of employment and the consequences of that loss for their sense of self had an impact on the parental experience in this study.

So far this chapter has highlighted how parents of dying children are forced to embark on an altered pathway in life which sets them apart and makes them different. The pathway for becoming different and set apart can be seen to follow a temporal framework which begins when the child initially becomes unwell and progresses alongside developments in the child's health. Difference influences the inter-subjective nature of the parental experience, influencing key social relationships within the family, with work and with contemporaries. In turn, the changes wrought in these relationships further reinforce how different the parents experience is and further set them apart. As a result, the parents' place in society can be seen to be at stake.

4.5 At stake: place in society

Each of the previous issues at stake for these parents of dying children – time, identity, and relationships – contributed to another issue at stake: their place in society. For some this was lost and replaced with isolation. The experience of parenting a dying child was isolating in general terms because of how these parents' experience contrasted with that of their peers (see sections 4.1, 4.2, 4.3 and 4.4). However, parenting a dying child could be isolating in three further specific ways: exclusion from the known social world, immersion within a new and different world and isolation within that new world, all of which speak of inter-subjectivity.

On being told their child had a life limiting or life threatening disease, the parents in this study had their lives redirected to a different pathway (see Section 4.1). They became set apart from the world they knew and within which they had made plans. Two parents asserted that they had few friends prior to the experience of parenting a dying child and that their social ties had not been adversely affected subsequently. The others, however, reported a degree of isolation as a consequence of how they and other people related due to the nature of their new experience (see Sections 4.3 and 4.4). The nature of the parents' experience was that they no longer shared the same social experience as their peers, so there was an immediate loss of common ground upon which to relate.

Parents therefore began to experience a degree of exclusion from their known world. The nature of the parents' experience limited their opportunities for contact with other people, such as when management of the child's ongoing health problems or emergencies precluded taking part in normal activities or when parents lacked the energy to take out the child and their associated technology. Alternatively, parents themselves could actively limit the extent of their relationship with others, for example not wanting to speak about their experience or not wanting to invest in a relationship which was doomed to failure:

> Once he was born I couldn't really live that style, I couldn't go out any more, and really the friendships died out really. I was too busy and I didn't want to talk to anyone
> (Jane; 2 year old son)

Simultaneously, parents found that other people absented themselves. Such exclusion could be an active process, such as friends choosing to limit contact because they could not cope with the parents' experience. However, exclusion could also take a more passive form: society's lack of adaptation to disability; friends assuming the parents could not socialise. In either case, it seemed that the parents lost a degree of social capital, the significance of which has been noted in previous research in suffering and associated with judgement by both sufferer and observer (Charmaz 1999; Ramphele 1997):

> If you don't fit the pattern, if for some reason you're different, then people make choices according to that, don't they?
> (Mary; 20 year old son)

Therefore, parents were both subjected to exclusion and *chose* exclusion, although that choice might have been structured by a limited range of options, time, common social ground and energy. Whilst being excluded from the known social world, parents were concurrently becoming immersed in a new and different world: that of illness and its associated activities. Sections 4.2, 4.3 and 4.4 detail the changes to the parental role, how time was taken to manage the child's health and the changes to relationships. These issues demonstrate immersion within the different world. Although for some parents this facilitated development of new and positive relationships with people they would otherwise not have encountered, other parents underwent this immersion reluctantly. As a consequence of the child's illness, activities which would normally remain remote became routine and everyday, and parents had to encounter an entirely new group of people and systems:

> People don't understand, no words, you can't explain to people what it's like. It's very hard, your whole life, personally, my whole life felt like it was taken over with *my son's* condition
> (Valerie; son died aged 19 years)

Parents could resist immersion in the different world, but in doing so became isolated once again, this time within that new world. Although new opportunities to encounter other people could become available to parents, there was a limited choice of opportunity and people. In this situation, some parents chose isolation over relationships which were not wholly beneficial. For example, some parents found that new social contacts were people with health problems and interaction only reinforced the difficulties the parent was experiencing. Another parent resisted support groups because the differences between her experience and that of the other people she encountered prevented the development of affinity with any of those peers. For others, the very services set up to support the parents within the different world caused further isolation by being inadequate to the task. In this way, although immersed in the new world, parents yet still did not fit:

> She had to go in and be, have a new gastrostomy and because my daughter can't sleep in just a normal bed, I had to take all the equipment up, because luckily I've got like comfy chairs that I, we can recline and she can sleep in and everything, but it wasn't until that all happened that they realised what, what the, you know that there's so much going on with my daughter
> (Diana; 11 year old daughter)

The exclusion of these parents by other people as well as services did more than isolate the parents: it also contributed to a lack of legitimation of their experience. The parents described being excluded from their choice of environments and activities and redirected according to the needs and choices of others. This mirrors previous suffering research such as the treatment of political widows in South Africa who had to accept a politicised version of their experience in order to receive recognition of their status (Ramphele 1997); alternatively, Kleinman (1988) highlights how patients must subjugate their health experience to the medical perspective which gives primacy to physical suffering rather than psychosocial consequences. In both cases, like the parents in this study, it was not the experience of the sufferer which was legitimated, but a *version* of their experience imposed by observers.

Parents of dying children became isolated as a result of the nature of their experience. The isolation they encountered was a result of exclusion from their usual social world, immersion in a different world and then further isolation within that new world. In conjunction with altered relationships, this limited the intersubjectivity of the experience of parenting a dying child. In addition, the legitimation of their experience appeared to be limited through their isolation and the lack of intersubjectivity. Parents' interactions with other people became more limited, and opportunities to share their experience and develop shared meanings with other people reduced. One influence upon this was the uncertainty with which the parents in this study were living.

4.6 At stake: certainty

From the point of their child's diagnosis, the parents in this study lacked confident expectations about the future. This was replaced by *uncertainty* which could span the entire childhood. Initially, the uncertainty may have related to achieving a definite diagnosis, or whether or not the child would survive the initial health crisis, or what the progress and timing of the disease was likely to be. Technology played a significant role, as more sophisticated tests and therapeutic interventions were developed. The uncertainty made the parents different to their peers and the difference and uncertainty could persist:

> A lot of our friends, I always feel, sometimes I look at them, if they had a check list when their children were born, they ticked every box, you know? And I look at ours and I think crikey. We don't plan ahead.

> There is no, you know, I could sit here now and say she's 18, but I couldn't have said that 18 years ago. I wouldn't have thought we would get through 6 months or a year (Sarah; 18 year old daughter)

Having overcome the initial difficulties of diagnosis and immediate survival, uncertainty did not abate. The possibility of a health crisis was high: admissions to intensive care were likely; the child's survival during such an episode was questionable; survival for some was associated with altered abilities, both physical and educational. Such experiences are confirmed elsewhere. National hospital bed occupancy statistics confirm that one third of bed-days are taken by children with life limiting and life threatening illness; moreover, the average number of days spent in hospital for the 0-19 age group in general is 0.3, but for children with such conditions that may rise to 8.9 days per year (Cochrane et al. 2007 p.46).

Throughout the uncertainty, the child usually continued to grow and develop; care needs changed and negotiation for support services was challenging. As parents were at the mercy of technological development, so services needed to respond to the needs growing and aging children who required ever more complex care. For some parents, services did not exist, for others they lacked appropriate equipment or staff. Consequently, parents struggled to maintain the care of their child in the absence of adequate health or social care, with an associated impact upon time, identity, relationships and place in society, as discussed in Sections 4.1 - 4.6.

Living with such prolonged uncertainty led to adaptation by the parents. Adaptation was incorporated into their changed roles and identities: they become the experts in their child's disease and care. For some this ensured that the care was of the right standard, reflecting negative experiences of health or social care provision. For others, it incorporated choosing not to take up allocated services if the parent judged them not to be of the required standard. The stability of the child's health was paramount. Therefore, decisions about everyday life became focused on maintaining that stability: where to live; what work to do; whether to go on holiday. Such decision making hinged upon agency: whilst some parents made active choices, indicating some agency, for others there were no choices or a very limited range. Ultimately, even active choice was focused upon maintaining the child's health in the face of uncertain support from elsewhere and therefore reflected questionable agency. Once again, this suggests a lack of legitimation of the parental experience, particularly by the institutions established to help them, such as health, education, and social care.

Parents adapted to uncertainty in different ways at different times, according to the health of their child and the stage of the disease. Parents had to constantly reframe their expectations. For some, focusing on positives was important. Another approach was to find something about which to be hopeful. Alternatively, parents described something akin to denial:

> Do we go through pre-natal testing, don't we? And if we do, will, and if it was an affected child, well do we terminate, because they expect you to terminate if it's an affected child. Or do we go through it and I miscarry and we find out it's a normal child, and unaffected child, and in the end we decided we'd bury our heads in the sand and we'd deal with it when we got there
> (Carol; 18 year old daughter)

Adaptation strategies could be focused on short term or immediate goals, such as supporting the child through a health crisis or therapeutic intervention. However, as explained previously, these parents of dying children faced uncertainty throughout their child's lifetime, further influenced by advances in technology. Therefore, some parents found themselves living with uncertainty for many years. In the absence of a cure for their child, the only prospect of relief from uncertainty was not to have the child to care for any longer: when the child died. Some parents, therefore, found themselves adapting by focusing on a time when their child would no longer be with them:

> I've always wanted to try and hang on to a bit of me, so that if anything happened to her, I wouldn't be so consumed by her that there'd be nothing left of me (Sarah; 18 year old daughter)

4.7 At stake: the survival of the child

Amidst the inherent uncertainty of parenting a child with a life limiting or life threatening disorder, there was one constant for the parents in the study: the child would always have the diagnosis and cure was not possible. The child may have been more or less well, but amidst all the uncertainty the diagnosis remained. In addition, a second certainty persisted: the possibility or reality of the child's death. As reported in Chapter 1, death in childhood has been declining for decades and is now at an all time low (Cochrane et al. 2007). Social policy is increasingly focused upon standardising childhood (Moran-Ellis 2010) and keeping children safe (Valentine & McKendrck 1997), providing ever more scrutiny of both childhood and, crucially, parenting in order to achieve those outcomes. The reality which the parents in this study faced was therefore increasingly at odds with that of their peers whose children were healthy.

The death of the child was constantly anticipated and brought to the fore with uncertain predictions about the child's illness, its progress, timing and outcomes. During interviews, the parents spoke openly about death, without prompting. They anticipated death over the long term. Additionally, each acute health crisis made them anticipate death repeatedly in the short term. Living with the certainty of their child's death was gruelling. Parents watched the child suffer ever greater deterioration, knowing that death was inevitable, yet not knowing when it would occur:

> In fact I, before I go in I have to sort of check – are you still alive? (Charles; 18 year old daughter)

Knowing that death was a certainty, and reflecting the complexity of a life unmade by the impact of their child's diagnosis, some parents thought the unthinkable: how would life have been if their child had not survived, either initially or during a health crisis? Concurrently, parents were exposed to families whose child had already died, forcing them to examine what that would mean for themselves:

> It really brought home to us how quickly things can go wrong, but, the, I always felt envious of them, that they were able to move on, because naively I thought they could
> (Sarah; 18 year old daughter)

Several parents explained that their experience was so all-consuming that they remained permanently changed. The impact of technological developments illustrates this well. Such developments commonly altered the course of the disease without influencing its final outcome of death. Parents were therefore constantly faced with situations over which they had limited agency and that which they had was unpalatable. Some parents chose life: for example when being given the choice to accept or reject treatments which in themselves are life-threatening:

> Do I have a choice? No, because she will die if she doesn't have this. Ok, there's no choice then. Why are you asking me to sign a piece of paper if there is no choice? And he said – you know, erm, we have to go through this routine, and everything. I said – but, there is no choice. Alive or dead.
> (Imogen; 3 year old daughter)

Other parents chose death:

> We just said to *the consultant* what will happen if we don't have my son operated on, and he just said, well he'll die, matter-of-fact. He will die. So we had to think whether or not we wanted *our son* operated on, but, erm we decided no, his quality of life, it wouldn't be one operation it would be one of many (…) And I just said no, but I was crying because I felt that I was killing my son by saying that I don't want him operated on, because I wasn't going to put my baby on an operating

> table and have many operations and just die. He would die with us, not on an operating table.
> (Valerie; son died aged 19 years)

Still others had no such choices and simply had to endure the course of the illness:

> Each of us, you know, we've been through so, so much emotion and you think, that's going to be the end, you know, and there's more to come (...) you don't obviously want it to keep happening, but you know it's going to happen at some point, because the next cold that he develops could be the end for him, you just don't know
> (Mary; 20 year old son)

Given that death was ever present, and that parents spoke openly of it when given the opportunity, it is interesting to reflect upon how they spoke of it, because it reveals something concerning communication about the parents' experience. Parents were literally faced with life or death choices, both of which had far reaching consequences for their own experience and how they related to others within society. However, whilst openly discussing that during the interviews, parents stressed that they could not discuss with everyone their considerations of how different life might have been if their child had not survived. As with suffering research in other contexts, the parents perceived that their experience was open to judgement by observers (Connolly 1996, Frank 1995, Ramphele 1997). Giving voice to their experience was also complex in terms of language. In interview, parents used the obvious terminology (death, dying, etc). However, they were also apt to employ euphemism:

> She's, erm, school hasn't finished, we're down here, this is the school of life and it hasn't finished yet for her, so erm, when she's, when she gets there she'll, you know, but, erm, no, I mean we know it's going to happen and probably sooner rather than later, but erm, it'll happen when it happens (Carol; 18 year old daughter)

The suffering literature emphasises how language reflects the societal context for suffering (Bourdieu, Accardo et al. 1999; Skultans 2003) and clearly has a bearing upon what elements of a suffering experience are conveyed (Bendelow 2006; Kleinman & Kleinman 1991). For the parents in this study, both the obstacles they perceived to discussing their child's death and the language they employed illustrate the difficulty of articulating such a concept in a society where child death is rare, as well as the impossibility of directing the language of death at a living child.

The parental losses in this study related to both the concrete loss, the death of their child, and its consequences: living with uncertainty, the impact upon siblings, changes to self, etc. Again, this is reflective of the suffering literature, which highlights the importance of both loss and the consequences of loss (Sacks & Nelson 2007). The certainty of death did not preclude its anticipation being fraught with uncertainty. A last quote demonstrates how the issues at stake for these parents of dying children converge and create an existence fraught with uncertainty but underpinned by the constancy of death:

> You see, I was told he will never live. I was told he'd never get to three. I was told he'd never get to school, but the day he started *school* we had the transport turned up and I put him on the bonnet of the of the transport and took a photograph of him, because there was this little boy, *my son,* going off to school that day and I cried my eyes out. I was told he'd never get to 14, and at the back of, you don't worry about it, but at the back of your mind, when the birthday comes round, you think is this it, but you have to cope you have to get on. But then I was told that, erm, he'd perhaps not reach 20. 20s would be very, very difficult. And he died six weeks before he was 20
> (Valerie; son died aged 19 years)

4.8 Discussion

The purpose of this chapter is to answer the first research question: what do the parents of dying children experience? Accordingly, the cross-case thematic analysis has highlighted a variety of common themes which begin to characterise the experience. Overall parents are seen to lose their identity, relationships and place in society. These are compounded by their loss of certainty, in life generally and particularly with respect to their child's survival. Time is crucial to this, as over time the parental loss becomes greater and their opportunity to regain their place in society becomes more remote. In addition, the analysis shows that the parents' experiences have a number of features in common with previous suffering research. The discussion section will therefore briefly revise the emergent themes from the data and contextualise them to the suffering literature, particularly with respect to loss, legitimation and intersubjectivity.

Suffering can be defined as loss (for examples see: Black & Rubenstein 2004; Charmaz 1983; Sacks & Nelson 2007; Wilson 1991) and the analysis of data for this project identified a number of topics which may be characterised as issues at stake for the parent participants (Kleinman 2006). These included time, identity, relationships, place in society, certainty and the life of their child, each of which may also be characterised as a loss. Previous research has also shown that suffering results from both the loss itself and its consequences (Charmaz 1999; Black and Rubenstein 2004; Sacks and Nelson 2007) and the same can be seen in the experience of these parents (see sections 4.4 and 4.7).

With respect to legitimation, the parents' loss of place in society, associated with changes to key relationships and a degree of isolation and exclusion, are indicative of a lack of legitimation of their experiences. The parents perceived that neither society nor institutions were able to accommodate their needs or experiences. Existing research has described how suffering experiences may have to be reframed by dominant political movements in order to be legitimated (Morris 1997; Ramphele 1997; Schwarcz 1997). The parents in this study were not subject to overt political reframing, but nonetheless received a powerful message of lack of recognition through their experiences of exclusion and isolation (Section 4.5) and the lack of provision by health and social care institutions (Section 4.6). The lack of recognition suggests avoidance of legitimation.

The consequences of lack of legitimation are seen in the parents' daily lives of exclusion, isolation and lack of support and the impact of these upon time, the parents' sense of identity, their relationships and certainty. The consequences for the individual of suffering not being legitimated are noted within the literature (Kleinman & Kleinman 1997). A key outcome is that the individual's experience becomes subjugated to the agenda of observers with important implications for how the suffering experience is communicated and responded to (Kleinman 1988; Kleinman & Kleinman 1997; Wei-Ming 1997). Therefore, intersubjectivity becomes problematic, and this was also evident in the parent participants' experience.

Intersubjectivity relates to the development of shared meanings amongst people about social phenomena (Prus 1996). The losses which the parents articulated are existential and relational in nature. They fundamentally concern intersubjectivity. However, their loss consistently put intersubjectivity at stake: over time the parents had ever decreasing opportunities to interact with others and develop shared understandings of their experiences. These parents of dying children were set on a new and different pathway in life for which there were no clear plans, nor accessible narratives to drawn on as sense making tools.

Their children, in common with other dying children, had unfamiliar and uncommon disorders, for which there were few, if any, defined or well recognised reference points (Craft & Killen 2007). The parents faced uncertainty throughout the journey which influenced both the parents' responses to the situation and their perceptions of other people's. They described a lack of societal understanding of the situation, perhaps unsurprising in the context of no clear cultural reference for children with life limiting or life threatening illness. Numbers going through this experience are small relative to the population of healthy children (Craft & Killen 2007).

It has been suggested that intersubjectivity is important for the restoration of self in suffering individuals (Cassell 2004). Yet, what emerges from the cross case analysis in this thesis is how the common experiences among these parents of dying children increasingly worked to make them different and set apart from their peers, which, in turn, limited opportunities for interaction with society. Therefore, both the nature of the parental experience and its effects upon communication influenced the separation of this group of parents.

This chapter has highlighted how parents of dying children may describe their experience in terms of particular losses. Taking existing theory into account, the parental experience might be judged as suffering, particularly since it comprises issues of loss, legitimation and intersubjectivity. However, to impose such an opinion, even through thematic analysis of research data, may not adequately preserve the authentic voice of the sufferer (Frank 2001). In fact, there is the risk of subjugating the parents' experience to the theoretical confines of this research agenda, even whilst attempting to give them a voice (Cassell 2004; Wilkinson 2005).

With that in mind, the next data chapter presents the parents' experience in an alternative format, as an attempt to accurately portray their concerns. Chapter 5, therefore, presents a series of individual narratives. There are two objectives for this. Firstly, whilst thematic, cross case analysis facilitated understanding of common themes, narratives may be better able to preserve the participants' intended flow of their individual stories, avoiding some of the subjugation inherent in research (Bourdieu, Accardo et al. 1999; Smith 1999; Frank 2001). Secondly, to further explore issues of communication, the narratives are juxtaposed with observational data which emphasise the different ways and contexts in which the parents' experiences were communicated and responded to. This reiterates the significance of intersubjectivity and the altered means of communication inherent to the parents' experience.

Chapter 5

Intersubjectivity and legitimation of the parental experience

Introduction

This thesis has three research questions:

1. What is the lived experience of parents of dying children?
2. How do other people's responses shape the parents' lived experience?
3. What is the place of emotion and suffering in the parents' lived experience?

In Chapter 4 I started to answer the first research question: through thematic, cross-case analysis of the parent focus group and interview data I identified some common issues at stake for this group of parents whose children were dying. This enabled me to start to characterise the parental experience and consider its relevance to suffering theory. Chapter 5 will continue to answer question 1, whilst also beginning to address issues of communication inherent to the other two research questions. Thus, the main focus of this chapter is to explore how the parental experience is acknowledged or not and the impact of this upon the parents.

As noted in Chapter 4, when considering suffering, it is important to pay attention to the 'authentic' voice of the individual in order that their perspective does not become subjugated to other people's agendas (Cassell 2004; Frank 2001; Wilkinson 2005). Therefore, in this chapter I present some parents' experiences in narrative mode since narratives have been identified as effective in preserving the participants' intended meaning and flow (Bourdieu et al. 1999; Frank 2001; Smith 1999). The narratives are derived from the interview data from individual parents.

However, interviews were only one of several data collection methods, as set out in Chapter 3. As observational and documentary data collection and analysis proceeded, it became clear that contrasting accounts of the parental experience were presented in different contexts. The differences between the two were stark and seemed to hinge upon the communication of the parental experience. Therefore, each parent narrative is juxtaposed with an 'official' account, gleaned from the hospice medical record and observations of parent/professional interactions. This emphasises the different ways and contexts in which the parents' experiences were communicated and responded to and highlights the significance of intersubjectivity and the altered means of communication inherent to the parents' experiences.

Of the nine parents who participated in the research, I selected for within-case analysis those for whom triangulation of interview, observational and documentary data was possible. The purpose of this was to strengthen the trustworthiness of the analysis (Guba & Lincoln 1989). This enabled five individual parent narratives to be constructed. Of these, three are presented here, chosen because they represent a wide range of variation between cases, and each is compared with the corresponding 'official' account. As set out in Chapter 3, the purposive sampling strategy for this research also incorporated maximum variation in order to maximise depth and richness of data.

In the interests of preserving the voices of the individual parents, within the chapter there is limited *ongoing* discussion about the application of their narrative to the emerging theory of this thesis. As each narrative is added, I demonstrate how, despite the variation between the parents, their experiences of parenting a dying child shared common features, showing the links to the thematic analysis of Chapter 4. I demonstrate that these commonalities were associated with both the experience itself and the ways in which that experience was communicated and responded to. However, the chapter finishes with a more detailed discussion highlighting the theoretical conclusions pertinent to suffering and emotion management theory.

N.B Pseudonyms are used for all parents. Words in italics indicate replacement of identifiable names/places with anonymous alternatives.

5.1 Case Study 1 - Jane

> **It's about my life how I've changed myself to be for this child. It's about my heart bleeding for his suffering and this is my suffering**

Individual Narrative

Jane was 31 years old and had two sons aged 2 ½ and 4 years. Although her youngest child had been referred to the hospice at the age of 9 months, Jane had not used the hospice services until he was almost 2 years old. Both boys were present during the interview, and throughout Jane gave the impression of being a caring and loving mother. Her interactions with both children were gentle; she focused fully upon them when they wanted her attention; she did not raise her voice; she was physically affectionate with them throughout the interview. The presence of her children was not a barrier to Jane both describing and expressing emotion constantly during the interview. Overall, her disposition on that day could be interpreted as depressed: her spoken tone was flat, the matters she raised tended to be negative, and she did not smile very much. Her discussions confirmed this interpretation.

The Past: Identity at Stake

Jane was Eastern European and prior to living in England was a secondary school teacher. A combination of events led to her not continuing her teaching career, including her husband's concerns about the 'unruly' young people she might encounter and restrictions placed upon her through her immigration status. Before Jane was able to progress her career options, family life took over: she gave birth to two sons within a short period, after the second of which she recounted that 'everything changed'. Jane's second son was reasonably healthy until the age of 5 months when an acute episode of illness had far-reaching effects:

> He had his brain inflammation. So he was in intensive care with that, and after that he just stopped developing full stop

Following this, Jane entered a period of uncertainty during which her identity as a mother was put at stake (Chapter4, section 4.3). Her son endured a prolonged period of ill health, necessitating three admissions to intensive care within two years, before he was formally diagnosed. During that time Jane described a battery of tests her child underwent in the search for a diagnosis.

The plethora of investigative techniques caused distress for both the child and Jane, and is illustrative of the theory which attributes suffering to both concrete issues as well as the consequences arising from them (Charmaz 1983; Sacks & Nelson 2007). Jane's son was disturbed by the pain and discomfort of the investigations; subsequently, her distress emanated from both the disturbance to her son's well being as well as inability as a mother to prevent his distress. In addition, Jane considered herself to have limited agency in directing the outcome of her child's bouts of ill health. She perceived there was little consultation with her about whether to continue or discontinue treatment.

Jane's perceived parental identity was also at risk through the effects of her son's periodic hospitalisations upon his sibling. Jane had to balance the needs of an acutely unwell baby against those of his sibling, an active, healthy toddler. This situation was sustained by a number of related issues. The intensive care unit limited provision for resident relatives to one parent only. Jane's support network was limited under normal circumstances and therefore not able to rise to this particular challenge. Finally, Jane's husband had limited opportunity to support her through his presence because he had to prioritise work. Jane explained that his work as a lorry driver was not secure and because of their mortgage commitments they could not afford to jeopardise their financial security through him taking leave. Jane was therefore forced to be separated from one of her children at any time. Identifying the compelling and competing needs of each child, she described the separation from either child as 'terrible'.

The Present: The impact of diagnosis

Despite the many investigative tests, Jane's son's diagnosis remained elusive for two years, until a newly developed investigation finally determined that the child had a rare chromosomal disorder. Receiving a formal diagnosis made a large impact upon Jane. The physical problems associated with her son's diagnosis were wide ranging, including issues with his heart, digestion, breathing, vomiting, physical and intellectual development. Such physical problems impacted upon Jane's day to day care of her sons, putting time at stake (Chapter 4, section 4.2). However, what Jane stressed equally was the psychological impact of the diagnosis:

> I had such a depressed, depression, I'm actually on antidepressants. It's only that I really hoped that he will, whether he will catch up eventually and be, but now he's labelled, I know, I know the outcome

Jane had lived with extended uncertainty for almost two years, which was stressful. However, the certainty of diagnosis limited her hope for the future. Prior to his diagnosis, Jane had spent time assimilating his disabilities and planning both the child's and her own future with those in mind. The consequence of a firm diagnosis, even one with uncertain outcomes, was that Jane had lost hope as her son's future survival was put at stake (Chapter 4, section 4.7).

The Present: Suffering

When I asked Jane about the positive and negative aspects of her experience, she stated there were no positives. She articulated the impact of her youngest son's illness upon the whole family:

> It's put a huge mark on everything. It completely changed lifestyles and everything and, basically, every member of the family is suffering

The overriding message from Jane was that her suffering was underpinned by the suffering of her child and her inability to influence the outcome of his experience. However, there were secondary factors relating to Jane herself, which contributed to the conceptualisation of her own suffering. The life she had anticipated for herself was out of reach: career, social life, family life, had all been altered through her experience. The issue Jane discussed in most detail was relationships.

The Present: Impoverished Relationships

The overwhelming feature of Jane's narrative was how her experience at the time of the interview was dominated by her relationships being at stake (Chapter 4, section 4.4). She clarified her marriage, her parent-child relationship and her friendships were impoverished. Jane described her marriage as 'problematic' and stressed that she had almost divorced. Jane's marriage struggled with the stress of a complicated everyday life. Jane suffered with depression and she considered that she and her husband were not able to relate effectively to each other. A shared coping mechanism, which centred upon the escape of a foreign holiday, remained elusive due to lack of effective support either from family, friends or care services.

The way that Jane and her eldest son interacted was influenced by her experience: as a healthy toddler he naturally demanded attention, however, the compromise necessitated by the needs of her other, sick child, led to 'terrible tantrums'. This might be the experience of any parent with two such young children, measurable against developmental norms (DfES 2004a), with the parenting of such a situation open to scrutiny through state mechanisms (see Chapter 1, section 1.4). However, for Jane the unknowns of her son's diagnosis made it difficult to predict when or if the situation would improve or how as a parent she could influence it.

Jane explained that her relationship with her son was not merely related to his being a toddler, and that they related differently to one another when she had dedicated time to spend with him. Again, the lack of state or family support systems meant that such time was severely limited. Jane's own family lived overseas, and her husband's family led busy lives. Jane expressed some anger and frustration at her perceptions of their inability to empathise with her situation. In contrast, she considered her mother in law to have too many issues of her own to cope with, demonstrating a degree of judgement or hierarchy of suffering (Charmaz 1999).

With respect to friendships, although she had lived in the UK for 5 years, Jane described herself as 'a foreigner' when talking about friends, illustrating her isolation. Although she described a limited social circle before her son was born, Jane recognised that since then her social contacts had reduced still further. Jane's place in society was at stake as a result of the isolation of her experience, isolation which was at once both imposed and chosen (Chapter 4, section 4.5). The circumstances of her experience placed limits upon her capacity for friendships – opportunity, activity, time, etc excluding her from previous social contacts. However, Jane also self-excluded to avoid speaking to others about her situation. Finally, Jane avoided spending time with others who shared the same experience, preventing her immersion into a world dominated by illness:

> When you have disabled child you want to detach from your own place, you probably want to mingle with healthy children, healthy, not, to forget about it for a bit, you need some sort of erm, erm, when you communicate with the same people you speak about the same problems and you remind yourselves again

Although circumstance, lack of opportunity and choice all appeared to have increased Jane's social isolation since her son's illness, another influence upon her social relationships was how she dealt with her emotions.

The Present: Emotion Management

Jane described her depression since receiving her son's diagnosis, but that this was not something that she readily shared with others. She chose to whom she would and would not show her feelings. In other words, she managed her emotions (Hochschild 1979). Although Jane identified cultural norms with respect to emotional responses, her perceptions of other people's responses to her emotions also influenced her:

> English people are more polite, more reserved and more calm, *my nationality* are more temperamental. So they think I'm a little much, aggressive sometimes

As an example of this Jane recounted an interaction between her and the hospice staff. Whilst staying at the hospice, her son developed sickness and diarrhoea within 24 hours of Jane telling staff he was well. Jane described herself as feeling ashamed that he became unwell after she had claimed he was healthy. She described how the stress of the situation, coupled with tensions with her husband, caused her to walk out of the hospice when they told her of her son's illness. However, she perceived that the staff attributed her reaction to anger with her son's care, rather than the shame she was actually feeling, and did not ask her what she felt.

Jane described how, rather than following her felt emotions, she tended to judge what emotions were appropriate to express in any given context and altered her presentation of self accordingly (Goffman 1969a; Hochschild 1979). Sometimes she perceived that nobody could understand her feelings unless they were having similar experiences and so she did not show her feelings; elsewhere she altered her response because of the reaction she received. Talking to her husband was fraught with difficulty: talking only served to remind them of the difficulties they faced and she perceived that he dismissed her feelings. At other times, Jane held back her own feelings because she judged them as unimportant in comparison to those of other people. Jane judged her own experience against a perceived hierarchy of suffering (Charmaz 1999) which served as the social context for presentation of self and emotion management (Goffman 1969a; Hochschild 1979). Speaking of her mother-in-law, who had experienced a traumatic childhood, Jane said:

> I think she, she has much more harder deal than I'm in, so I don't dare to complain about my problems, because her life is harder than mine

The Future: Uncertainty

The diagnosis which Jane's son had been given was extremely rare, so that doctors could give little indication about future expectations: certainty was at stake (Chapter 4, section 4.6). No-one could predict the physical or intellectual capabilities of Jane's son, which had a bearing on Jane's future caring responsibilities and therefore her own future plans. Additionally, her son's condition was so rare that his survival, although questionable, remained unpredictable. Apart from the emotional impact of this, the level of support Jane received also hinged on such predictions.

Jane did not have a great deal of support from health and social services, partly due to uncertainty of service provision. Jane's son was supposed to be visited weekly by a volunteer service, but the service was suspended due to lack of volunteers. However, Jane also perceived that there were inadequate resources for the numbers of people requiring support services - meaning access to support was competitive according to severity of need. Her description clarified how the imposition of an institutional hierarchy of suffering by social and healthcare services, albeit to ration limited resources, has a profound impact upon legitimation of experience (Farmer 1997; Frank 1995).

However, in order to cope with her uncertain situation Jane needed something positive to anticipate. Jane enjoyed travelling, but was unable to do so with her son. Provision of respite from the hospice enabled Jane to plan holidays, with both the anticipation and the break itself significant. Hospice support was therefore extremely important; however, even this provision was uncertain. Criteria for accessing the hospice centre upon the children's diagnoses and prognoses. Because Jane's son's diagnosis was so rare, his prognosis was unclear: in order to continue to receive hospice support, his survival needed to be at stake. The shocking implication is that Jane needed her son to be dying in order to access the support she required: another clear example of objective judgement of suffering which has implications for its legitimation (Farmer 1997; Frank 1995).

With respect to her son's survival, Jane presented somewhat ambiguous perspectives. Her interactions with him during the interview, the home environment she presented, and her talk about him all demonstrated affection for him. But Jane appeared to be totally overwhelmed by her son's health and care needs, acknowledging that her depression stemmed from her reactions to his illness. Her longing for him to survive because of her love for him, was undermined by his suffering and her lack of agency over his future:

> You would put it down, if a kitten or a dog, if he was in such pain, but how can it be human to prolong the suffering of a human?

The Official Account

The Hospice Medical Record

The hospice medical record commenced when Jane's son was referred at nine-months old and spanned approximately two years, during which time he was admitted to intensive care on two occasions. Although the initial referral noted the isolation of the family, the sick child's illness and the difficulties of managing both children's needs, thereafter the focus within the documentation was the physical needs and care of Jane's son.

The incident, to which Jane referred during interview, when hospice staff misinterpreted her response to her son being unwell, was recorded in the hospice medical record. It illustrated the discrepancies between parental and official accounts of experience. To recap, Jane's son developed sickness and diarrhoea during an admission within 24 hours of Jane telling staff he was healthy. Jane described herself feeling ashamed, but perceived that the staff attributed her reaction to anger with her son's care. Jane felt she was not given an opportunity to rectify the impression: she described in interview how staff subsequently telephoned her husband, rather than her, to ascertain whether or not she was still angry with them.

Within the medical record, staff reported this incident twice, and on both occasions Jane *was* described as angry with the service provided. The record shows how the service responded to Jane's *display* of emotion. The documented reports suggested that staff interpreted her display, they did so inaccurately and they did not clarify their interpretation. Significantly, in interview Jane described her ensuing feelings of being labelled by the hospice staff which affected her subsequent interactions with them. The official record of the incident was a misinterpretation of events which portrayed Jane inaccurately and influenced future interaction.

For staff wanting to familiarise themselves with Jane and her family prior to an admission, the medical record was the sensible source of information. However, it would be difficult to ascertain Jane's experience utilising the official record because there is so little reference to her within it. In addition, the minimal information recorded was not accurate, as the preceding incident describes. A second issue within the medical record also demonstrates divergence between official and individual narrative, this time concerning how the family were coping.

Initially, concerns about the family not coping were documented with regards to parental experience and emotion and followed up by professional visits to the parents. However, as professional involvement increased, documentation of parental experience and emotion declined as the documentation became increasingly associated with safeguarding concerns for the child. Over time, the documentation of parental emotion and experience related only to the impact upon care of the child rather than consideration of parental need. This impression of safeguarding concern seemed incongruous with both Jane's own narrative and observed interactions between Jane and her children.

The untimely deaths of Victoria Climbié and Peter Connelly have raised awareness of safeguarding issues within child healthcare (HaringeyLCSB 2010; Laming 2003). Therefore, the official account of Jane's experience should highlight such concerns if raised. However, this incident illustrates the impact of objective judgement upon legitimation of experience (Farmer 1997; Frank 1995). State monitoring of parenting alongside the health and well being of the child (see Chapter 1) led to the subjective reality of this parent being subjugated to the official agenda of safeguarding. There was no record of concerns about Jane's coping leading to assessment of her needs, although such input may have addressed some of the documented safeguarding issues. Finally, the official account of safeguarding concern about Jane's relationship with her son contrasted strongly with how she appeared to relate to him in person, observed during both interview and participant observation.

Participant Observation

I observed Jane bring her son for respite. I met Jane, her husband and both children in the child's bedroom, where a health care assistant [HCA] was setting up the laptop to commence the admission. Whilst we waited, I asked Jane and her husband how things were for them currently. Immediately they began to relay their struggle for statutory services' support, simultaneously reflecting upon a recent family crisis related to lack of support. Jane's husband described his anger with social services. Then Jane recounted her child's admission to intensive care, her concern about standards of care and her loss of confidence in that team. Both Jane and her husband spoke candidly in response to a general opening question, although this was the first occasion I had met her husband. Notably, the HCA did not participate in either conversation, although the crises discussed were already logged within the medical record she held.

The HCA started the admission by asking Jane questions, whilst Jane's husband entertained the children. After 10 minutes, the husband took the sibling to play elsewhere, leaving Jane and her child to complete the admission. The HCA concentrated upon the questions pertaining to the child's admission and care plan. Throughout, Jane entertained her child with toys, her play and smiling seeming to convey affection. Jane constantly shifted her gaze between her son and the HCA and frequently referred to handwritten notes about his care. One such note referred to avoiding wastage of equipment: Jane described how the local authority provided just enough equipment, with no room for error. The HCA logged the concern onto the care plan, but did not discuss it.

Having completed the admission in 75 minutes, the HCA left to fetch a nurse to complete the drug chart. Whilst we waited, Jane talked about how she liked the hospice and found it 'brilliant', but also of her concern, previously noted in interview, that her child's uncertain prognosis might jeopardise his place at the hospice and access to respite. Jane talked again about the recent family crisis, when she felt unable to cope and her husband had called social services, concerned for his wife. She was glad that he had, because she was unable to cope any longer. She described how unwell her son was at the time and that she did not want invasive treatment.

Jane described her despair. She spoke of her suffering – 'life ended at 29 with the birth of my son'. She watched her other son and her husband also suffering and she could not cope with that: she considered putting her sick child into care. She maintained that she could deal with her own suffering, but described feeling suicidal during the recent crisis. Her responsibilities as a mother made her afraid to consider suicide further; although she thought she may begin to feel the same again. Jane reflected upon the reasons for her feelings: she was 'nostalgic' for her family overseas, it was difficult to care for a disabled child, she felt she was not meeting the needs of her healthy preschool child, and her relationship with her husband was 'broken'.

I asked Jane about support. She had hospice respite, but no social services' support due to lack of staff. She had been offered anti-depressants and counselling, which she did not want due to previous bad experiences. Jane and I talked for approximately 30 minutes. The family had been present for almost 2 hours, the admission was still not completed and nobody else had engaged Jane in a conversation about her needs or feelings.

The nurse arrived and used a pharmacy reference to carefully check medications. She seemed defensive about her actions, apologising for them and for being slow. She did not assert herself positively or offer reassurance. Instead, she continued the task, focused upon questions relating only to the task. On completing the chart, the nurse asked Jane to complete the future care plan, which detailed the plan of action should the child stop breathing during their stay at the hospice. It dealt with the potential death of the child. Jane queried why this had to be done on each admission, since it did not change. The nurse recognised it as an 'emotive' issue, but explained that a child's health might fluctuate, necessitating regular updates. Jane said she would prefer not to have to keep discussing it. The nurse did not ask why, but asked Jane to read and sign the document.

Jane got ready to leave and asked for a glass of water. As we fetched this, I asked Jane if the hospice could offer any counselling support. She described a bad experience of counselling and maintained that she was a private person, and could only talk to someone with the right 'disposition'. She described me as having the right disposition, perhaps explaining her apparent openness with me. She also commented that unless the person she was talking to had similar experiences it would be hard for them to understand her concerns. Such comments suggest that Jane managed emotion according to social context.

Both parents said goodbye to their child and the hospice staff. No one was escorting them, so I walked them to reception, thanked them and said goodbye. At no point had any hospice staff asked after the family's well being in the light of the documented recent crisis.

Summary

There was a clear distinction between Jane's personal narrative of her experience and the hospice account. On our first meeting in interview Jane quickly eased into discussions of personal issues: lack of support, isolation and depleted relationships. Additionally, Jane both expressed and described emotion. In contrast, the official record neglected Jane's personal experience, either through absence or inaccuracy, illustrated by the different accounts of two specific incidents referred to by Jane and contained within the medical record.

Participant observations demonstrated consistent loss of opportunity by hospice staff to engage with parental experience during interactions, which may have facilitated the contrast between the official record and Jane's narrative. When I asked *open* questions, at interview or participant observation, Jane talked about her experience and her emotions. However, in their interactions with Jane, the hospice staff did not give her such opportunity. In addition, when Jane raised concerns staff did not take the opportunity to open a discussion. Instead, staff focused upon tasks, to the extent of asking only pre-determined questions. It may have been that my participant observation influenced their actions in this instance, but it was a pattern of events which was repeatedly observed. It seemed that hospice documentation and procedure provided an organisational 'script' for interaction, which was not intended for emotion management, but surely facilitated that (Ruane 1996).

5.2 Case Study 2 - Diana

I mean, we've had our ups and downs

Diana was 43 years old at the time of her interview. A lone parent, she had an 11 year old daughter who had used the hospice since the age of two. Like Jane, Diana was a full time mum, but in contrast she was divorced and lived with her daughter alone. Diana also made reference to felt emotion throughout her interview, as well as expressing emotions at times. However, her outlook seemed different to Jane's depressed disposition, and more complex. Throughout the interview Diana had an extremely sanguine self-presentation alongside a pragmatic approach to the complications her life presented, as the above quotation implies.

Diana peppered her speech with laughter and references to lucky outcomes. However, the content of her narrative, which focused on the difficulties she had encountered, was at odds with the positive way in which she presented herself. Diana also structured her narrative in a temporal format, referring to life before and after her daughter's diagnosis. However, her narrative was different to Jane's, having no reference to the future and limited discussion of the past. These features are characteristic of the pragmatism Diana portrayed in her speech: focused on the here and now to address immediate challenges and needs.

The Past: An abrupt change

Diana's past included an unstable marriage and a normally developing daughter. The child became unwell just after her 2nd birthday, with what seemed to be an ordinary infection of diarrhoea and sickness. However, the child unexpectedly stopped breathing and was hospitalised. Investigations led to her being diagnosed with a life-limiting condition. Diana's description of the impact of this demonstrated her understated, sanguine presentation:

> That's when everything just crashed and then went a bit belly up, really

The reality Diana described encompassed a sudden accumulation of personal losses from the point of her daughter's diagnosis, which the phrase 'a bit belly up' seemed to euphemise. Diana's daughter had a respiratory arrest causing brain damage and physical and intellectual disabilities. The conferred diagnosis suggested survival into adulthood was unlikely. These circumstances contributed to the demise of Diana's marriage. Finally, her daughter's disabilities and the end of her marriage led to Diana losing her home. Again, Diana seemed determined to minimise negativity and focus on fortuitous events:

> At the time, erm we just needed to be re-housed, and erm, obviously, because we needed like a place that was suitable for *my daughter*, because obviously, erm, the family home wasn't suitable and he was kicking us out anyway, so erm, luckily this place was vacant and luckily for us they let us have this place

Both Diana's identity as a parent and her relationships were put at stake by the sudden changes (Chapter 4, sections 4.3 & 4.4). Diana became the lone parent of a child with complex disabilities. Time was at stake as Diana accommodated her daughter's extended dependence (Chapter 4, section

4.2). Other than when sleeping, Diana's daughter required one to one attention. Her care was dictated by a strict dietary regime, which the child was unable to feed herself. The regime covered the full 24 hour period and, nine years on, it remained extremely demanding:

Diana	Luckily, erm, I work it all out, so her last, I'll give her her last feed, so, a feed about, between 10 and 11, then I'm up again at sort of 3, and 7. But I work it all out so that
Researcher	Every night?
Diana	Yeah. So that I can get at least 3 hours, in between, sleep

Instead of considering the impact of such a disrupted sleep pattern over that extended time period, Diana's perspective was that any parent would do the same for their child. She compared herself to the mother of a young baby, who must wake through the night. She pragmatically focused on the need to meet her child's nutritional needs, rather than how she might have expected her parenting to be in the past or future.

Her daughter's ongoing care needs meant that Diana lost her independence, contributing to her identity being at stake (Chapter 4, section 4.3). Diana's agency was reduced in many key areas of adult life. Her use of time was dependent upon her daughter's care requirements. For financial support, she was dependent on her ex-husband. She relied on the council to provide and adapt her housing. Lastly, her parents provided a financial boost, helping to purchase key equipment. This final dependence also illustrates another key issue for Diana, which compounded her lack of independence and agency – her perception of a lack of state support.

The Present: Fighting for support

Diana articulated a lack of support from education, health and social services. Policy suggests services should be provided according to the needs of the client (DfES 2004a). In contrast, Diana felt she had to flex around the demands of such services and fight for support to ensure her daughter's ongoing care. For example, the school instigated her daughter only attending for half days, to accommodate a change in the child's sleeping pattern. However, there was no school transport during the middle of the day, so Diana's time was taken up with transporting her daughter. Recognising the benefits for her daughter, Diana accommodated the school's request, but not without personal loss. Diana appeared to judge her own experience according to a hierarchical framework within which her own needs became subjugated to those of her daughter (Charmaz 1999):

> It means I haven't got any time to myself, but, it's better for *my daughter,* because she's more alert

Day to day support was facilitated using the direct payments scheme, through which Diana employed her sister as carer. A complex web of reasons led to this situation, including the care needs of her daughter, the unavailability of appropriate support and Diana's judgements about statutory services, which were influenced by her relationship with the hospice:

> I'm struggling if I'm going to let her go to *the statutory respite centre* any way, to be honest, because I don't know, I don't know, I don't know if the staff are going to be the same as *the hospice.* I know that sounds cruel, because I know I know they've got the qualifications, but I don't think they've got the, I don't know if they'll be like as caring

Therefore it can be seen that Diana experienced a degree of isolation in her situation which came about partly because there was a lack of appropriate support, and partly because Diana rejected what was available: in other words, like Jane, Diana both chose isolation and had it imposed upon her. Like Jane, Diana's place in society was at stake as a result of the isolation (Chapter 4, section 4.5). Isolation went beyond physical company, however, and embraced how Diana related to the people she encountered.

The Present: Emotion Management

At 11, Diana's daughter was adult sized, but with the developmental abilities of a toddler. She had a changing picture of health and dependence, influenced by advances in technology, and an obscure future path. Diana was aware of her own fragility amidst this shifting reality, suggesting that her mental health would have been compromised without the support of the hospice. However, in the face of limited statutory support, Diana felt she was faced with no option other than to cope, because statutory services did not notice.

Describing the lack of statutory support, Diana identified that she did find support in her family, a friend and the hospice. However she was selective in how she related to each. Her descriptions suggest a degree of emotion management guided by the people she encountered and the context within which such encounters took place (Hochschild 1979). Whilst Diana's family provided physical and financial help, their family culture was not one where frequent expression of emotions took place; so Diana described how she did not tend to share her feelings within her family. Sometimes, however, her feelings became overwhelming and she could not contain them:

> If I'm having a bad day I will snap their heads off

Diana was quick to emphasise that she did not tend to show such feelings of anger to other people. She explained that she could relate to a friend whose daughter had cerebral palsy, feeling able to sometimes 'rant and rave at her and let it out'. However, simultaneously, Diana considered this friend's needs to be greater than her own because she had even less support. Once again, Diana demonstrated the judgement of experience against a preconceived hierarchy (Charmaz 1999).

In general, however, Diana 'bottled it all up' when with other people. In particular, she pointed out that she controlled her emotions at the hospice, to protect a service which she viewed as helpful and undeserving of her anger. Although her family could be described in the same terms, Diana was not afraid to show her negative emotions to them. Yet, Diana held the hospice in high esteem, attributing her ongoing ability to cope to the support the hospice offered.

The Official Account

Hospice Medical Record

Diana's experience was absent from her daughter's hospice medical record. The absence of the issues Diana articulated in interview might be attributed to context: Diana choosing what to speak about, to whom and when. However, the absence of Diana's experience from the record was more complete than that: there was simply no reference to her needs.

Diana's daughter was referred to the hospice at two years old. In interview Diana explained that this was for respite. However, any correspondence to the hospice referred only to the child's physiological status and did not mention Diana's needs. Over 9 years, correspondence from professionals to the hospice followed the same pattern, even when issues with an obvious impact upon Diana were documented, such as the child not sleeping. The only deviation from this pattern was one education review from the school which noted the 24 hour nature of Diana's caring responsibilities and her need for respite. Within the hospice-derived documentation there was a focus upon the physical care of Diana's daughter. Additionally, there was no record of the hospice team assessing Diana's needs as a result of issues raised in received correspondence about the child's changing health. The hospice recorded the changing needs of Diana's daughter, but not the impact of this upon Diana.

During interview Diana explored the problematic nature of her own experience and that she chose carefully with whom to share her emotions. In person, Diana appeared to be extremely cheerful. Even when describing difficulties, Diana's language was very mild, and might even be described as optimistic. She peppered her sentences with terms such as 'luckily'. She described her daughter as 'poorly'. She laughed frequently. In interview, Diana described her trust in the hospice service to provide her daughter with good care, but stated that she would not show her frustrations to the service. Observation of Diana interacting with hospice staff provided an opportunity to explore what Diana revealed of her own experience, and in what context, and how this could impact upon the official account of Diana's experience.

Participant Observation

During observation at the hospice Diana revealed the same demeanour as during the interview. She smiled and laughed a great deal and presented herself as very jolly. The hospice staff passing her room called out and joked with her, some stopping to chat. However, concurrently with the jollity, Diana was taking control of her daughter's respite visit in some interesting ways, which suggested a degree of anxiety at odds with her descriptions of trusting in the hospice. Her anxiety was articulated through both behavioural cues and conversational references, however hospice staff did not respond at all to these.

As soon as Diana arrived at her daughter's allocated bedroom, an HCA set up the computer to commence the admission. Diana immediately complained about the length of time the IT system added to the admission, saying she was going to write a complaint. Although the atmosphere was jolly, this comment was made in a serious tone of voice and with serious facial expression. However, the HCA did not respond, but concentrated on checking the care plan, focusing entirely upon the questions contained within the computerised document. The HCA did not attempt to engage Diana in conversation.

Once the care plan was complete, Diana started to unpack and arrange the room whilst she waited for a nurse (RN) to complete the drug chart. Diana arranged her daughter's things, although the staff often did this for parents. The RN arrived after a few minutes and started checking the medications. During this activity, the RN asked Diana about statutory respite, access to which had been problematic due to inadequate equipment. Diana reiterated that she was not being provided with any other respite, and that the statutory centre refused to purchase the special bed required because it would not suit any other child. Although the RN opened this conversation, there was no accompanying enquiry about Diana's well being or feelings about the situation. Instead, the RN asked if Diana would consider using the sister hospice of the organisation as an alternative, perhaps as a base to visit the local city. Diana responded that it was not an option: she needed a total break away from her daughter. She stated 'otherwise I'd go mental'. The RN did not explore this statement.

The HCA then took Diana's daughter out to music therapy, leaving Diana alone with myself and the RN. Diana immediately initiated a conversation about her respite being cancelled: she had been asked to cancel by another staff member because another child had stayed longer when his mother was suddenly hospitalised. Diana was adamant that she would not accept cancellation: she had booked social events and was going away from home. Diana did not verbalise empathy for the other family, instead asking why they did not have family helping them. Diana commented that the potential for having respite cancelled was a problem. The RN only listened; she did not engage Diana in conversation about the comments, even though this had immediately followed Diana's previous comment on her mental state.

Whilst the RN transcribed the drug chart, she and Diana talked about symptoms and doses of medications. Diana asked many questions about doses and timing of medications. Diana repeatedly said 'touch wood' when referring to her daughter's stability with various symptoms, accompanied by reaching to touch the nearest piece of wood. The RN did not remark upon on Diana's comments or gestures. They had a detailed conversation about how Diana managed the medications and the emergency seizure protocol. Diana was constantly asking the RN if the timings and doses seemed correct. The RN responded to each question but did not ask about the source of Diana's apparent anxiety. Once, Diana noticed a potential error by the RN. Diana repeated the correct dose of the medication, commenting that if the RN's amount had been given it would overdose her child. The RN corrected the chart, but again did not follow up on Diana's expressed concern.

The final activity of the admission was completion of the future care plan (the plan of action should a child stop breathing during their stay at the hospice). There was no discussion: the RN picked up the relevant paper work and simply asked '1 - the full works?', referring to option 1 of 3 on the care plan. Diana agreed and signed the document and there was no further conversation. Having completed the admission, Diana insisted on unpacking her daughter's things and arranging the room to her own liking, although she was not going to be resident. Additionally, on the walls around the room Diana fixed hand written lists of equipment and instructions, irrespective of the detailed care plan which she had completed with the HCA. She offered a commentary throughout, attributing her actions to being a control freak, noting that her friend said she had OCD. The RN did not respond to the actions or the commentary. Finally, Diana questioned the nurse in charge about the HCA assigned to her daughter, explaining that the HCA was new to her and asking about the carer's length of service and caring experience.

Although all of Diana's direct questions were answered, the staff made no attempt to explore either why Diana was asking questions about staff or why she wanted to provide so much extra information and arrange her daughter's belongings so exactly. Diana offered these multiple verbal and non-verbal cues which suggested high anxiety levels. However, none was responded to by hospice staff. Instead, interactions between Diana and staff were focused on hospice tasks and characterised by Diana's apparent jolly demeanour, which was at odds with both her behaviour and her speech. Diana's own experience was not explored in the observed interactions between her and the hospice staff even though she provided multiple opportunities to start such conversation.

Summary

Diana's narrative of her life experience was temporal in nature, but with limited reference to the past and no reference to the future. This was matched by her narrative focusing upon the pragmatics of dealing with everyday life, the here and now. Her time, identity, relationships and place in society were put at stake during her experience of parenting a dying child.

She spoke openly about each of these issues during interview, but unlike Jane, Diana did this with a sanguine manner and speech which was pervaded with laughter and positive statements.

She clearly articulated the difficulties she faced and her lack of support, but her speech and manner consistently minimised the issues. Diana did not speak of her emotions very much, but she described how she managed them. In addition, at times in interview Diana's seemingly positive demeanour contrasted with the more negative content of her speech, perhaps illustrating her emotion management. Finally, Diana did not refer to suffering during her narrative and when asked if she suffered was adamant that she did not. Comparing her experience with a preconceived hierarchy (Charmaz 1999), within which starving children and her friend with a disabled child ranked higher than her, she emphasised that her experience was not suffering.

There are commonalities between Jane and Diana's experience, even though the details are quite different. Thus the duration of their experience (2 years and 9 years), the nature of their family set up (married and divorced), and differences between their children's conditions and ages, did not create significant variation in their experiences. Both described similar issues at stake with respect to time, place in society and isolation. In addition, although each parent presented themselves differently, neither of them had their experiences articulated in conversation with hospice staff nor in the hospice medical record.

Jane presented a generally depressed persona, whereas Diana gave the impression of having an upbeat personality and outlook. However, during interview, Diana displayed some dissonance between her demeanour / language and the nature of her conversation. Highly emotive, often negative subjects were discussed almost light-heartedly, with laughter and affirming statements interspersed throughout her narrative. Nonetheless, in interview Diana was prepared to explore some negative aspects of her experience, although she clearly articulated that she chose with whom to share her emotions and that she did so for a variety of reasons. Diana's personal narrative was therefore multidimensional. In contrast, the official record took no account of any dimension of Diana's experience and focused upon the physical care of her daughter alone, in both the written record and the observed interaction between staff and Diana.

Dissonance between language and behaviour was also observed during Diana's admission - much of her behaviour and speech seeming full of anxiety whilst she concurrently laughed and joked with staff. Whilst the dissonance was easily overcome in interview, with Diana responding to open questions, during admission the dissonance created a barrier. Hospice staff interactions with Diana centred upon responding to the bubbly personality she presented. Rather than exploring her more subtle behavioural cues or engaging with Diana's minimally verbalised concerns, staff seemed only to respond to the overt and obvious. In short, a complex picture emerged of both Diana and staff responding to and managing each other's emotion (Hochschild 1979).

5.3 Case Study 3 - Carol

Unless someone actually really does probe, you're not going to say a thing

Introduction

Carol was 46, a mother of three and had been involved with the hospice for 6 years. Her family was different to that of both Diana and Jane. At the time of interview, Carol had been married for 23 years and her three children were 21, 18 and 16 years old. Her 18 year old daughter, who had used the hospice from the age of 12, was significantly disabled, wheelchair dependent and unable to attend to her own physical care. However, intellectually she had developed according to normal expectations. Therefore another significant difference between the parents was that was that Carol was parenting a dying child who understood what was happening, whereas Jane and Diana's children, through immaturity or disability, lacked that capacity.

In interview, Carol neither presented herself as depressed, like Jane, nor as jolly, like Diana. Instead, she vacillated between describing and expressing sadness and happiness. Narrating her story within a similar temporal frame to the others, Carol raised and discussed various concerns. Her initial description of parenting a dying child was that it was "hard work. You spend a lot of time banging your head against brick walls".

The Past: Negotiating for services

Carol's daughter was born with a degenerative condition, but was not immediately diagnosed. Throughout her narrative, Carol articulated her struggle to access health and social care services which began with trying to get a diagnosis. Retrospectively, Carol recognised that she downplayed concerns about her daughter's development initially raised by professionals. However, at a subsequent developmental test both Carol and the professionals identified that a problem was apparent and the child was referred to specialists. Responding to professional management of the situation and her own observations, Carol became concerned for her daughter, only for the professionals to downplay the situation:

> She was just coming up for about 10 months old at that point, erm, and the neurologist thought that I was just a neurotic mother, that I had, that I was seeing problems where there weren't any problems and I was erm, I was causing waves and there was nothing wrong with this child

Carol described the discrepancy between the label she had been assigned and the professional origins of concern for her daughter. The neurologist continued to minimise Carol's concerns for several months, but her daughter was diagnosed with a genetically inherited, degenerative disorder at the age of 17 months, almost a year after concerns were first raised.

The Past: Impact of the Diagnosis

Her daughter's diagnosis had a number of implications for Carol's family. At the time, Carol was pregnant with her third child and had to decide whether to have prenatal tests and consider an abortion. The repercussions of the genetic diagnosis had also been ongoing: both of Carol's sons were tested for carrier status to inform future lifestyle choices. However, not all repercussions from the diagnosis were negative. Initially, it enabled Carol to access help with her emerging situation, help which had been missing through the delay in formally diagnosing her daughter:

> Once you've got a diagnosis you can then start looking things up. You can find out a bit more about it. You can then start sort of saying – well look we need this help, we need that

The Past: Sources of Support

Because she had a neurodegenerative disorder, Carol's daughter experienced many health crises as she grew up. Although provision of a diagnosis initiated some statutory support, its ongoing maintenance was more problematic. Carol described accessing support as 'a battle' and "one of the biggest brick walls that we come across". She discussed a number of issues with regard to support. In coping with life, Carol's faith sustained her, enabling her to view her entire life as planned by god. Her professional training as a nurse also helped: she had relevant skills and knowledge which enabled her to assess her daughter's health effectively; additionally her experience of working within "the system" enabled Carol to quickly access medical support when her daughter needed it, supported by her GP. In contrast, family support was rather more complex. One set of parents were helpful, but geographically distant. The other set were more local, but unhelpful: they were not practical people, but, more importantly, Carol felt they could not face the child's disabilities and they blamed Carol for the child's condition.

The Past: Losses

Her daughter's fragile health affected how Carol experienced day to day life: she had to learn to take each day as it came and not plan ahead. Carol articulated a number of losses, including health, experiences, time, finance and employment. Carol lost her own good health, both physical and mental;

she experienced chronic back problems and recurrent depression. She felt that her two sons tended to miss out on 'normal' life: activities, social events, holidays were all compromised. In short, time, identity, relationships and place in society were at stake (Chapter 4, sections 4.2 – 4.5).

Trying to avoid her sons missing out was further complicated by a loss of financial comfort. Carol's work pattern was dictated by her daughter's needs, which limited her earning power: she worked as a shop assistant on a term-time only contract. Finance was further compromised by a lack of statutory support, both physical and financial. It is well documented that the cost of raising a disabled child far outweighs that of raising an able bodied child whilst parents' earning potential is undermined by extended dependence and caring responsibilities (Beresford 1995; Dobson 1998; Kagan 1998). Carol clarified the limitations of the financial benefits to which she was entitled:

> The disability living allowance and what have you, I mean, is very small, I mean, and you're supposed to be able to produce and pay for carers in that. Well there's no way that you can, that it pays for carers, I mean. It pays the equivalent of £8 a day. Well to pay for carers it's £8 an hour.

Therefore, Carol took a term time job with a newsagent to balance financial and caring responsibilities. However, when her daughter reached the age of eighteen, Carol's manager withdrew her term-time only contract. Carol felt she was unable to work full time, as her employer required, and so she looked for alternative employment.

The Present: Change

At the time of the interview Carol was once again working in nursing. The change seemed to have been positive: Carol both enjoyed the work and earned more money. Another positive development was Carol's parents relocating nearby and providing support day to day and "in a crisis." Carol described how helpful her parents were during her daughter's emergency admission to hospital just prior to the interview. Carol appeared to have reached a stage in life when some issues seemed less difficult. However, her daughter reaching maturity meant a transition from children's to adult care services.

This transition entailed changes to statutory education, health and social care provision. At the time of the interview, Carol's daughter was changing colleges which meant geographical relocation. Health and social care change was even more complex, Carol perceiving that all services were trying to avoid responsibility for her daughter's care. For Carol, transition represented a retrograde step. Having struggled to establish statutory support from paediatric services over the years, she faced an uncertain future with adult services.

The Future: Uncertainty

That Carol's daughter had reached the age of 18 with her diagnosis was significant. However, the reality was that her daughter's early death was inevitable. What remained unknown was when that was likely to happen. Carol was pragmatic in her conversation about this, commenting that death was "the one certainty we all have in life". She even joked about god not wanting the hassle of her daughter yet. In the meantime, Carol regularly faced the terrible uncertainty of whether her daughter was still alive:

> Lately we actually have nights where we don't get up at all, and you suddenly realise, and you, and we get up and we say - well have you turned her? No. You turned her? No. And you sort of, and then you rush in and you try and, and you're trying to see if she's still breathing because you know you've always got that at the back of your mind that erm she might not be and you've missed it

Carol initiated these conversations and although both pragmatic and good humoured whilst discussing her daughter's demise, she also cried openly whilst speaking of it. However, during the interview Carol also referred to managing her emotions, considering what she would share, with whom and under what circumstances (Hochschild 1979). She explained that her felt emotions sometimes differed significantly to what she expressed. Carol managed her emotions in day to day life because she felt that generally people did not have the time or inclination to listen. Mindful of her daughter's understanding, she also managed her emotions to protect her daughter's wellbeing.

The Official Account

The Hospice Medical Record

In common with the other cases, the hospice medical record for Carol's daughter had a focus upon the physical health and needs of the child. The child was referred to the hospice by a social worker, when the child was twelve years old. Correspondence from consultants corroborated the child's diagnosis and life-limiting prognosis, but noted that the family had no outstanding problems. The ensuing six years of the official account maintained scant reference to Carol's own experience.

Throughout the six year hospice record, there were specific problems documented for Carol's daughter, concerning health, social and emotional issues, including two references to death. Furthermore, one instance recorded Carol's request for hospice staff to speak with her daughter about death, whilst another noted Carol's request that hospice staff should act in the child's best interests during Carol's absence should the child suddenly become unwell. Despite the obviously emotive nature of such requests, at no time within the record was there reference to Carol's response or needs.

Although Carol's experience and responses are largely absent from her daughter's medical record, there is reference to the child's emotion. It is noteworthy, however, that there is no corresponding record of how her daughter's emotion has been communicated to Carol or Carol's response. Observation of Carol admitting her daughter for respite facilitated further exploration of how hospice staff interacted with Carol and why her experience and responses were absent from the official account.

Participant Observation

When I arranged to observe Carol, she mentioned that the admission would be very quick and that she let her daughter manage it as much as possible. Accordingly, completion of hospice documentation was negotiated between the nurse and Carol's daughter, with Carol participating in discussion about the medication chart. The admission lasted approximately 30 minutes. It was conducted by the staff in a professional manner: appropriate questions about technical matters were posed and staff members appeared friendly. However the interaction was not personalised for Carol. For example, nobody asked after her own well being or about her plans during respite.

Following completion of the care plan and drug chart, the future care plan was reviewed with Carol and remained unchanged. Carol's daughter was present for the conversation and her presence did not prevent hospice staff asking difficult questions about illness and death. This was an opportunity to open a conversation with Carol about her well being or concerns, but it was not taken. The form was filed and the admission process ended. Staff adhered to the script of the paperwork and did not stray into emotional territory. Throughout the admission Carol was cheerful, smiling, laughing and gave no indication of having concerns. This contrasted starkly with her interview, when she became very tearful when considering her daughter's death. During the admission, the nurse posed direct questions about her daughter's death, but Carol expressed no negative emotion. When completing the future care plan, Carol appeared to manage her felt emotion.

On accompanying Carol her to her car, I asked, "how are things?" She proceeded to talk in detail, in the foyer, about several issues concerning her daughter and wider family. A simple, direct opener facilitated detailed conversation, laden with her descriptions of emotion, and lasting 25 minutes. This compared starkly with the task orientated admission during which only 30 minutes had been taken to complete a care plan, a drug chart and, most significantly, a future care plan concerning the potential death of a child.

Summary

Carol described and expressed emotion during her interview, but to a lesser degree than Jane or Diana. She raised and discussed problems she encountered in her life and gave detailed responses to open questions (e.g. what are the positives and negatives of being the parent of a life limited child?). Although Carol generally described her experience in negative ways, like Diana she did not refer to suffering. When asked, however, she clearly stated that she and her entire family were suffering because of the losses they experienced. In common with Jane and Diana, the issues at stake for Carol included her identity and place in society, certainty, and some elements of her relationships. She also identified that she was careful to manage the expression of her emotions in everyday life.

Like the other parents, Carol's narrative and the official record were noticeably different. Carol's narrative emphasised the uncertainty and struggle she had experienced over a period of 17 years and for six of those years Carol had used the hospice. Yet it was impossible to ascertain from the hospice account how Carol had been affected by or had responded to her daughter's deteriorating health over that extended period. Whereas in interview Carol spoke in detail about personal concerns whilst describing and expressing emotion, during admission to the hospice she did not express emotion or provide any obvious verbal or non-verbal cues suggesting concern or emotion. Likewise, the staff did not enquire about her well-being or provide opportunity for her to express her feelings.

5.4 Discussion

Two key findings emerge from analysis of the parent case studies. The first concerns the relationship between the individual narratives and the research methodology. The second finding relates to the contrasts between individual and 'official' narratives and how these reflected ways in which these parental experiences were communicated and responded to. The final discussion of this chapter justifies these findings and contextualises them to the rest of the thesis.

With respect to the first finding, although each case is primarily individual in nature, illustrated by both the variation between parents and the detail of the narratives, there are clear similarities in structure and experience. The three case studies in this chapter vary in several ways. Parents' ages ranged from 32 to 48 years and the children's ages ranged from 2½ to 18 years. The length of time they had knowingly been parenting a dying child varied from 2 to 17 years. Two parents were married, one of whom described an unhappy marriage, and one parent was divorced. All parents were white, but one parent was from Eastern Europe. Finally, they had used the hospice for different lengths of time. Accordingly, each individual narrative reflected a different story of experience. However, within each narrative, clear similarities are seen including the temporal structure of the experiences and the broad issues encountered.

These similarities are set out in more detail in the thematic analysis of Chapter 4. However, in presenting individual narratives, I intended to achieve two things. I aim to privilege the individual voices of the research participants, in keeping with the participatory research paradigm and social constructivist philosophy upon which the thesis is based (see Chapter 3, section 3.2). In addition, the similarities between the individual narratives uphold the findings of the thematic analysis in Chapter 4, substantiating the trustworthiness of the thesis (Guba & Lincoln 1989) in accordance with the methodology set out in Chapter 3.

The second key finding is the contrast between the individual parent narrative and the official hospice account in each case, and how the contrast relates to the communication of and responses to the parental experience, in which emotion is important. The remainder of the discussion focuses upon this finding, since it has yet to be reported within the thesis. In each case I was privileged to spend time alone with the parent in circumstances not associated with a care episode for their child. Whilst my analysis of their data remains an interpretation and multiply contingent upon context and interaction (Berger & Luckman 1971; Brown 2009), I endeavoured throughout to privilege the parental voice.

Therefore, as established in Chapter 3, I intentionally interviewed parents with whom I did not have an *existing* relationship as a hospice nurse. To avoid imposing my own preconceptions of their experiences, I aimed to encounter their experience for the first time as they described it. In addition, I was not reliant on existing relations to facilitate a discussion: I had to employ open questioning and follow the parents' lead to facilitate their revelation of their experience as they wanted it portrayed. During these conversations, parents revealed a variety of aspects of their experience and both described and displayed emotions.

In contrast, the 'official accounts', derived from both observed practice and documentary data, revealed little of the parental experience and, in particular, emotion was notably absent. From my analysis of this contrast between personal narratives and official accounts, I suggest that it derives from two issues: the way in which the parental experience was communicated and the way in which it was responded to: in both aspects emotion was an important issue. As such, the contrast between the individual and official narratives suggests a lack of intersubjectivity between hospice staff and the parents in this study.

Intersubjectivity relates to the development of shared meanings between individuals about social phenomena (Prus 1996). The observational and documentary data shows that the nature of the parents' experience, and specifically their emotional responses to it, were largely absent from the official accounts. Cassell (2004) noted the importance of effective communication in *promoting* intersubjectivity. In contrast, in this study, intersubjectivity between hospice professionals and the parents appeared to be *limited* by communication in its various forms. That is to say, the detail of the parental experience and emotion were excluded by means of verbal, non-verbal and written communication.

The official accounts, held within the children's hospice medical records, were constructed through communication using written documents, accounts of telephone calls and personal interactions, and completed hospice documentation. Therefore, ultimately, all communication of the parental experience, verbal or not, was dependent upon the final written material submitted to the child's record. In the case of personal interactions, therefore, there was a dependence upon individual staff members to interpret and then relay the information. Assuming that parents had communicated their experience in some way, either verbally or non-verbally, the recording of it therefore presented an opportunity for it to be subjugated to the interpretation of the staff, since interaction is understood to be multiply contingent (Berger & Luckman 1971; Brown 2009).

The absence of intersubjectivity may therefore be the result of the interpretation of the parental reality by the hospice staff. This analysis is congruent with social constructivism (Guba & Lincoln 1989; LeCompte & Schensul 1999b) and takes account of the individual characteristics of those interacting (Prus 1996) and the means by which they interacted (Berger & Luckman 1971). However, alongside the documentary data, the evidence of the observations suggests that it was not only the communication of the parental experience which contributed to the lack of intersubjectivity. The way in which the staff responded to the parents was also a contributory factor, associated with what they appeared to legitimate or not. This could be seen in the staff responses to both verbal and non verbal attempts by parents to communicate their experience and emotions.

With respect to verbal communication, *in interview* all parents spoke in detail about specific personal concerns, expressing and describing emotion. In contrast, *during admission to the hospice*, none of the parents raised the same concerns. This may have been because those concerns were no longer valid, but their long term nature (e.g. anticipating the death of the child or the extended isolation the parents felt) would suggest that they remained so. Nonetheless, the parents may simply not have wanted to raise the same concerns in a different context. However, they did highlight different concerns. Jane raised two issues with staff: safeguarding equipment and completing the future care plan. In addition, she spoke openly to me, in the presence of the hospice staff, about personal worries and feelings. Likewise, Diana verbalised anxiety about respite cancellation and asked many questions about medications. In both cases, hospice staff listened but did not attempt to converse with the parents about these issues. In contrast, Carol did not raise any personal concerns with staff during admission. However, like Jane, she spoke at length (25 minutes) with me concerning various worries about her family.

With respect to non-verbal communication, the findings are more complex. *On observation*, the parents seemed to express emotion: Diana laughed and joked a great deal and Carol smiled and laughed; in contrast, Jane did not clearly express emotion during the admission. However, Jane repeatedly described her distress to me in the moments between procedures whilst waiting for hospice staff, and sometimes this occurred in the presence of the staff, albeit not directed at them. In addition, both Jane and Diana seemed to communicate some anxiety through body language. Jane repeatedly glanced at hand-written notes when responding to questions. Diana fixed written lists of equipment and instructions around her daughter's room and took time to arrange the room. Once again, none of these actions were commented on by hospice staff.

However, the parents' communication was somewhat contrary: they expressed either positive emotions (laughing, smiling, joking) or no obvious emotion whilst simultaneously demonstrating anxiety in their actions and words (referring to notes, fixing up instructions, asking questions about care, describing distress). In turn, the hospice professionals appeared to respond to the positive expressions (they joined in with a jovial atmosphere), but did not appear to respond to or record the negative. However, by responding only to the parents' positive emotions, hospice staff appeared to legitimate, by their actions, only the parents' positive reactions.

Legitimation of experience has been noted to influence both outcomes for and behaviours of suffering individuals in a variety of contexts, including poverty (Kleinman & Kleinman 1997), personal illness (Cassell 2004; Kleinman 1988), and politics (Ramphele 1997). In this study, the data has already shown that the parents chose to communicate different things about their experience in different contexts. Whilst this may reflect social constructivism (see Chapter 3, Section 3.2), it also suggests a response to the extent of legitimation of their experience. A particular behavioural observation was that the parents expressed or described different emotions about specific issues in the context of an interview or when being admitted to the hospice: parents appeared to manage their emotions according to context (Hochschild 1979).

In Chapter 2, the literature review noted that individuals choose what emotions to display at any given moment according to social determinants (Goffman 1969a; Hochschild 1979; Kemper 1981). Some researchers refer to these determinants as 'feeling rules' (Hochschild 1979). Shaped by society, feeling rules may be widely accepted or may be explicit to specific groups, for example cultures, religions, organisations or professions (Hochschild 1979, James 1992, Wiley 1990b, Karabanow 1999). Within this thesis, such groups of feeling rules have been referred to as 'scripts' for emotion management (see Chapter 2, Section 2.8). The relevance of emotion management scripts to this thesis is in how the hospice organisational script for emotion management impacted upon the communication of the parents' experience and emotions. This was evidenced through analysis of both the hospice medical record and observations of parent-professional interactions.

Analysis of the hospice medical records revealed that although they were created in part through conversation with parents, they were largely constructed by professional and organisational means. These included official documentation such as letters, care plans and drug charts, the focus of which was the needs of the child. Letters from external professionals tended to mirror this focus on the child and absence of the parental perspective. One explanation of this is that the hospice organisational script for emotion management may not have facilitated communication of the parental experience.

Organisational scripting of emotion management may be facilitated through recruitment, training and performance appraisal (Hochschild 1983, Bolton and Boyd 2003, Karabanow 1999, Korczynski 2003) as well as organisational policy and practice (Ruane 1996, Smith 1992, Treweek 1996). In the case of the hospice, practice was supposed to be embedded in the philosophy of care, which centred upon child health and hospice care. Therefore, this philosophy must surely have contributed to, if not constituted, the organisational script for emotion management. Child health provision is dominated by the concept of family centred care within which the child is viewed and cared for as a member of a family unit (Hutchfield 1999).

Accordingly, whilst ordinarily the focus of a medical record is only intended to be the patient, a child's medical record might be expected to take account of family responses to the child's ill health. Moreover, the stated philosophy of children's palliative care, to which the hospice in this research subscribed, clearly encompasses the care of the family and specifically highlights concern for emotional well being (ACT/RCPCH 1997). Therefore, the hospice organisational script for emotion management, established through the philosophy of care, would promote incorporation of the parental perspective into the care of the child and the documentation of the same.

However, the documentary analysis demonstrated that the parental experience was absent from the hospice medical record. As noted previously, communication of organisational scripts is facilitated through a range of people and procedural management processes (Hochschild 1983; Smith 1992; Ruane 1996; Treweek 1996; Karabanow 1999; Bolton and Boyd 2003; Korczynski 2003). Therefore, one interpretation of this finding could be that the hospice organisational script was either inadequately communicated to staff (not testable through the data) or prevented from being implemented through inappropriate organisational processes, such as care plan documentation. This conclusion assumes that the parental experience was communicated, but that its recording was prevented by inappropriate hospice documentation.

Alternatively, the absence of the parental perspective from the hospice record could illustrate subversion of the organisational script. This phenomenon was identified by Karabanow (1999) and Korczynski (2003) and demonstrated that employees subverted organisational scripts by finding opportunity to employ personal or peer group scripts. Opportunities to do so have been located in one to one encounters to which no-one else is privy, and have been found to occur in both commercial and non-commercial organisations (Bolton 2000; Karabanow 1999; Korczynski 2003; Lewis 2005). Such an opportunity would have occurred regularly during routine admissions to the hospice and might explain the absence of the parent perspective in the hospice record.

My analysis of the observational data suggests that a combination of inadequate implementation of the organisational script for emotional management (through inappropriate organisational processes), as well as a degree of subversion of it, contributed to the absence of parental experience and emotion within the hospice medical record. Although only three parent cases are presented in this chapter, I observed admissions of 5 parents in this study, and 2 non-participant parents (with their permission). In each case, the same issues were noted, although different parents and staff were present on each occasion: interactions between parent and staff were directed more by the documentation than the verbal and non-verbal cues of the parent. Observations of practice and analysis of hospice records demonstrate that the organisational script was subverted by the staff. However, this occurred even as the staff members adhered to the written procedures *derived from* the organisation.

All observations revealed that staff members rigidly adhered to the written scripts of the care plans and drug charts, even to the extent of staff reading the documents word for word. However, as demonstrated in the case studies, the hospice documentation did not facilitate revelation of the parental experience because it did not pose useful questions, focused as it was on the child's needs. To over come this, the staff members could have utilised their own communication skills to draw out the parental perspective. In this way, the organisational script would have been adhered to even if the organisational procedures were not helpful in this respect. However, no such strategies were observed. Such formal, structured communication from the staff did not appear to encourage parents to share their experiences or emotions; moreover, the questions posed did not seek such information. Therefore, the way in which the hospice organisation and staff members structured the admission was a barrier to communication of the parental experience and emotion. There was an absence of opportunity provided for parents to articulate the nature of their experience and their own emotional responses to it.

In their own narratives, the parents described how they carefully managed their emotions in response to a variety of factors, including their perceptions of the listeners' responses. The actions of the hospice staff I observed suggested busyness, anxiety, concentration on important issues such as the child's health, and fixation upon the officially constructed questions. Staff actions were not responsive either to verbal or non-verbal responses from parents. Staff actions did not facilitate the seeking out of the parent experience or emotion. Nonetheless, on occasion the parents did display some emotion and spoke of some concerns. However, they rapidly switched back to straight answers to the official questions posed by hospice staff. The reduction in display and description of parental emotion during observations contrasted with displays of emotion during interviews and seemed consistent with their descriptions of managing their emotions. In short, a complex picture emerged of both parents and staff responding to and managing each other's emotion.

This thesis is exploring the experience of parents of dying children in the context of the theories of suffering and emotion management utilising three research questions:

1. What is the lived experience of parents of dying children?
2. How do other people's responses shape the parents' lived experience?
3. What is the place of emotion and suffering in the parents' lived experience?

With respect to the first question, the use of individual narratives in Chapter 5 has provided evidence of the trustworthiness of the thematic analysis of parental experience provided in the previous chapter. Regarding question 2, I have addressed both the parental acknowledgement of their own experience and its acknowledgement by myself and hospice professionals. I have demonstrated that the parents described and expressed different emotions and issues in different contexts. Through the data analysis I concluded that this related to limited intersubjectivity between parents and hospice professionals linked to processes of communication between them. Both intersubjectivity and communication had an impact upon what aspects of the parents' experience and their own responses to it the hospice staff appeared to acknowledge and therefore legitimate.

As reviewed in Chapter 2, Section 2.3, the means used to give voice to suffering and the motivation of those who give voice have both been shown to jeopardise the 'authenticity' of the account (Kleinman and Kleinman 1991; Kleinman and Kleinman 1997; Bourdieu, Accardo et al. 1999; Bendelow 2006). The complex interplay of limited intersubjectivity and legitimation of experience, underpinned by emotion management, appeared to impact upon how both the hospice professionals and the parents gave voice to the experience of parenting a dying child. With respect to question 3, therefore, these findings support the notion that the authenticity of both the hospice professionals' and the parents' accounts may have been questionable as a result of emotion management. However, this conclusion is derived from data only pertaining to the parents' interactions with myself and the hospice personnel. Therefore, the next chapter explores in more detail the parents' perspectives upon emotion management in their day to day interactions.

Chapter 6

Responses to the experience of parenting a dying child

Introduction

In the preceding two data chapters I have analysed what issues were at stake for the parents of dying children in this study . By comparing interview, observational and documentary data, I have established that communication about the parental experience was different under different circumstances and particularly seemed to relate to presentation of self (Goffman 1969a) with respect to emotion. The parents appeared to alter their expression of emotion according to social context: they managed their emotions (Hochschild 1979). These conclusions related to interactions in two specific contexts: an interview and admission to a hospice.

In interview, the parents responded to my own presentation of self and gave a version of themselves and their experience which was rich with emotion. However, within the hospice medical records, the parental experience was largely absent or represented differently and emotion was omitted. Furthermore, when interacting with hospice professionals the parents presented a version of themselves and their experience which was largely devoid of emotion. In Chapter 5 I linked this finding to intersubjectivity, in terms of the development of shared understandings about social phenomena (Prus 1996). Intersubjectivity between the parents and hospice professionals was limited through the responses each gave which were influenced by an organisational script for emotion management (Hochschild 1979; James 1992; Karabanow 1999; Wiley 1990).

To improve the trustworthiness of these conclusions, drawn as they are from data relating to specific contexts, in Chapter 6 I deepen the analysis of parental emotion management (Guba & Lincoln 1989). In so doing, I broaden the focus beyond specific interactions between the parents and me or the parents and the hospice professionals. Instead, I consider the parents' perceptions of their interactions in day to day life and what this suggests about the place and role of emotion management. To that end, the chapter will specifically address research questions 2 and 3 for the parents of dying children in this study:

2. How do other people's responses shape the parents' lived experience?
3. What is the place of emotion and suffering in the parents' lived experience?

I begin the chapter by analysing how the parents acknowledge their own experiences. This establishes the emotional nature of their responses and clarifies that they do manage those emotions. Next I consider the extent of these parents' emotion management and reasons for it. Finally, I note the outcomes of emotion management, suggesting that the parents' emotion management and its scripting jeopardise the authenticity of their own accounts of their experiences. The chapter concludes with a discussion of how these findings relate to suffering theory.

6.1 The inherent emotionality of parenting a dying child

The parents' narratives of their experiences, meaning their reflective, interpreted, accounts of their lives, were rich with emotion. They incorporated emotion, either their own or that of other people, throughout their interviews. The parents described what happened to their own emotion in their day to day interactions and their perceptions of how other people responded emotionally to them. In this section, the *parents'* emotional responses are set out, both those they described and those they physically expressed. The way in which their physically expressed emotions appeared at times to be discordant with the felt emotion they were describing is established as an example of emotion management.

Parents' descriptions of felt emotion and physically expressed emotion

All the parents talked about their own emotions during interviews, describing how they felt in a variety of contexts:

> When *my son* was first born we thought that was difficult to deal with, but I find that easy to deal with now because you think that you've become conditioned to what your life is. And when things are down, when things are bad, and you're in and out of hospital quite a lot, you,

> that's when you think, this just isn't fair, but on other days, when the world is ok, I think sometimes we look at each other and think bloody hell, we're doing a bloody good job here, aren't we?
> (Michael; 10 year old son)

The parents offered this information about their emotions as part of the ongoing narrative description of their lives, rather than in response to a direct question. Emotion thus seemed inherent to their reflective experience. The extent to which emotions were described and the range of emotions described varied between the parents. The felt emotions which parents described can be crudely categorised as positive or negative in terms of affect. Tables 3 and 4 present the range of negative and positive emotions the parents described.

Table 3: Negative Described Emotions

Anger	Disappointment	Frustration	Lonely	Sad
Concern	Distrust	Grief	Misery	Shame
Coping or not	Envy	Grumpy	Not fair	Shock
Denial	Exhaustion	Guilt	Regret	Tearful
Depression	Fall Apart	Hopeless	Resentful	Upset
Desperate	Fear / worry	Isolated	Resignation	What if

Table 4: Positive Described Emotions

Brave	Lucky	Relaxed	Strong
Confident	Pleased	Relief	Trust
Happy	Positive		

Analysis of the way in which parents included information about feelings throughout their accounts suggests that emotions are a significant part of the experience of parenting dying children. Importantly, these parents described a larger range of negative emotions than positive and tended to describe negative emotions more often than positive emotions. Suffering is associated with negative affect (Kleinman et al. 1997; Wilkinson 2005) and a simple analysis of the descriptions of these parents' felt emotions would support the notion that parents of dying children suffer. However, descriptions of felt emotion were only one of the ways in which parents included emotion in their accounts of their experience. In addition to describing felt emotion, some parents expressed their emotions bodily during interview.

The parents physically expressed a more limited range of emotion: crying, laughing, sadness and irritation. In addition, such physical expression of emotion was observed in parents less often than they described felt emotion. Finally, there was a clear predominance of <u>positive</u> affect when parents expressed emotion bodily: they laughed more frequently than they physically expressed the negative emotions. This contrasted with their described emotions, wherein <u>negative</u> affect predominated. Therefore, there was dissonance between the general tone of their narrative, within which described emotion was predominantly negative, and their expressed emotion, which tended to be positive.

Dissonance between parents' described and expressed emotion

Further analysis of interview data revealed there were additional specific instances of dissonance between the parents' described and expressed emotions. Moreover, on each occasion of dissonance, the displayed expression of emotion was laughter, whereas the described emotion was negative. Laughter was expressed when speaking about day to day frustrations, such as the difficulties of shopping whilst manoeuvring a wheelchair. The complexity of a child's diagnosis elicited laughter, as did the difficulties of accessing appropriate services. A mum laughed when reflecting upon her and her husband's sadness about his father's unexpected death when their child was undergoing life threatening surgery. One parent recounted with laughter her struggle to deal with the ramifications of her second child being diagnosed with a genetic, inherited condition whilst she was pregnant with her third child. Finally, parents laughed when describing the anxiety of their child dying at home:

> In fact I, before I go in I have to sort of check – are you still alive? (Laughs) To like, sort of, see if she's still breathing, you know
> (Charles; 18 year old daughter)

Clearly none of these issues were amusing and to attribute meaning to the parents' expression of emotions would be a futile exercise: only they can reveal the clarity of feeling at those moments. However, they are specific examples of dissonance between expressed and felt emotion. As in Chapter 5, what the parents expressed visibly did not appear to correspond with their described emotion. This is interpreted as the parents managing their emotions: they altered their emotional display according to social context (Hochschild 1979).

Dissonance between described and expressed emotion was one illustration of emotion management by these parents of dying children. In addition, throughout their interviews they recounted *instances* of emotion management in their day to day lives. The next section will highlight the extent of these parents' emotion management by considering the range of people around whom emotions were managed and the variety of reasons they gave for so doing.

6.2 Emotions: hidden here, there and everywhere

The parents identified emotion management occurring around a broad range of specific people, from intimate relations to strangers. These boundaries signify the degree to which they moderated their presentation of self. In addition, it was clear that parents deliberately communicated a different message about their experience through an altered presentation of self. They seemed to acknowledge their experience differently in public and in private. Parents managed their emotions for themselves, partners, children, wider family, professionals and people *in general*.

Emotion Management for the self

Perhaps the most intimate relationship is with the self, and some parents articulated actions to manage their own emotions for themselves. The parents described negative emotional responses (see Section 6.1) such as feeling upset, tearful, depressed, and lonely. Correspondingly, they articulated the ways in which they worked on themselves to alter their negative feeling (Hochschild 1979; Hochschild 1983). Sometimes such responses occurred in a crisis:

> Do we go through pre-natal testing, don't we? And if we do, will, and if it was an affected child, well do we terminate, because they expect you to terminate if it's an affected child. Or do we go through it and I miscarry and we find out it's a normal child, an unaffected child, and in the end we decided we'd bury our heads in the sand and we'd deal with it when we got there
> (Carol; 18 year old daughter)

Alternatively, the situation could be longer term:

> If you stopped and thought you would, as I say, you would be in tears every day, every, every time, you know, you would be just, you wouldn't do anything, you'd be sort of .... You've just got to take the positive side of it with the negative side and just get on with it. And you've got to look at the happy times and the fun times with my daughter as well as the, the end times, as I refer, call them, but the negative times that we've had and will have in the future
> (Charles; 18 year old daughter)

However, whether the issue was short or long term, the purpose of the parents managing their emotion was self protection, to enable them to live through difficult situations and cope. The parents appeared to be undertaking deep acting in order to change a felt emotion as well as the expression of emotion (Hochschild 1983). It was not clear whether they succeeded in altering their felt emotion, or just distorted their physical expression of emotion. However, the effort of their emotion work is evident in the action they described to work on their feelings (Hochschild 1979). The parents described refusing to think about the situation, distracting themselves with activities, focusing upon positives, eliciting further information, or actively changing circumstances.

The preceding section illustrates that the parents were undertaking deep acting when managing their emotions for themselves (Hochschild 1983). However, parents more often described emotion management in the context of interactions with intimates other than the self, including partners, children and other family members. However, their descriptions of emotion management when interacting with such people suggest that they worked on felt emotions in order to manage display, but not necessarily to change the feeling. In other words, their actions facilitated impression management (Goffman 1969a) through surface acting (Hochschild 1983).

Partners

The parents who recognised that their interactions with their partner could be subject to emotion management were married. Of these, only one alluded to any marital disharmony, but several asserted that they had suffered episodes of depression since the birth of their child. A range of circumstances gave rise to emotion management: emergent crises, ongoing stress, perceived imbalances in responsibilities and different ways of coping. The way in which parents managed their emotions around their partners was underpinned by situational definitions (Goffman 1969a).

The nature of their relationship with their partner, associated with the roles they assumed within it, determined the definition of a situation. The parents described roles such as 'the strong one' or 'the one who stayed at home' or 'the practical one'. Certain behaviours and activities were associated with these roles and these facilitated emotion management, such as taking control, undertaking specific tasks, talking about an issue, or withholding information. For example, having previously described how horrible she found it to have her daughter undergo surgery, Imogen went on to describe how she managed her emotions with her husband:

> All the time I'm in hospital I'm the strong one. *My husband's* rubbish .... rubbish – that's awful – he finds handing, he can't hand over, he, you know, he just stands there and cries and that's fine, and erm I can do all that, I can hold her whilst they're injecting her and putting her under and all of that, I'm fine. All the time the team's there I'm fine, because I'm talking and I'm controlling and I'm, I come home, I stand in Sainsbury's and cry because I don't know whether, what, what I want for tea and then *my husband's* the strong one.
> (Imogen; 3 year old daughter)

In each example of parents managing emotions around partners, the emotions being managed were negative: anxiety, fear, anger and frustration. Whilst each of these emotions might seem appropriate to the situation of parenting a dying child, in their definition of the situations, the parents sought to suppress such expression. This was perhaps because the parents' managed their emotions in order to cope and negative emotions were ambivalent in these contexts– they did not serve a purpose. Therefore, the parents concealed such emotions in favour of rationality in order to cope with a short term emergency or deal with the long term nature of their negative feelings:

> We just, we don't talk to each other. We, probably just hanging out, we don't want to remind ourselves of what we have, so we try not to talk about it
> (Jane; 2 year old son)

Children

Some parents described management of their emotions around their children. This could be both healthy and sick children. Although the examples differed, the purpose in each case focused upon protection, either of the child or the self. One parent managed her emotions to protect herself: she tried not to love her daughter when she was diagnosed in case the child did not survive. Protection of children covered a variety of issues. Parents tried to avoid children taking responsibility for the parent's negative feelings. They wanted to prevent the child from feeling they were a burden. They wanted children to feel they had a normal family life. The actions parents described to achieve these purposes entailed avoidance of expressing or talking about issues and feelings:

> Invariably you are asked "oh how are things?", and the child is there. So you say "oh fine, yeah, everything's ok", because you don't want the child to worry
> (Carol; 18 year old daughter)

Wider Family

Moving slightly further from the most intimate relationships, parents referred to managing their emotions around their wider families, such as the child's grandparents, aunts and uncles. Once again, the parents articulated that the management of emotion conferred protection, either upon the other person, or the self. Parents protected family by avoiding adding to an existing burden of caring or by shielding them from the detail of the harsh reality they and their child faced. Emotions were also managed around the family to protect the self from unhelpful responses or to keep going, rather than focusing on negative feelings:

> I would probably put up a bit of a front, even with my family and not particularly show all the down times, although there were plenty of those. And you know, I would share them, but not all the time though, I needed to be positive to have enough energy to sort of carry on
> (Mary; 20 year old son)

Health Professionals

With respect to professionals, in interview parents spoke of both health professionals generally and hospice staff specifically. Again, in each case, the overarching context for emotion management was protection, of both self and professionals. Parents perceived that expression of certain emotions, such as mistrust, anger, upset, anxiety, could jeopardise their own well being and so suppressed them:

> We're taking *our son* to the hospice for him to have a nice break and for us to have a bit of a break, so to actually pour out your inner feelings at that time would feel wrong because you'd then not be in the right frame of mind to go and do what you were thinking of doing
> (Mary; 20 year old son)

When their children were acutely unwell trust in professionals was important, but not always felt by the parent. However, parents described trying to visibly express trust whilst feeling anxiety and even distrust, so that their child's care was not jeopardised:

> I put my confidence and trust in people that should have known and didn't, but I still have to see those people, erm act, you know have a relationship with those people so I can't let that show even though, actually, it's undermined my whole relationship with those professionals because I feel that they are responsible for what happened
> (Sarah; 18 year old daughter)

Whilst parental management of emotions with professionals clearly facilitated protection and coping, situational definitions and perceived roles were also important (Goffman 1969a). Analysis of the parents' descriptions suggest they assumed an asymmetrical relationship with professionals, akin to Parson's sick role (Parsons 1975). With the situation for interaction thus defined, it appears that the parents subjugated their negative emotions to an alternative perceived agenda. In this way, the parents did not legitimate their negative emotions. Whilst this action may have been focused upon ensuring adequate care of the child or the self, as in the previous examples, the same processes allowed the feelings of the professionals to be privileged:

> They said – did you have a nice time? And I went "oh fine". That's it, I don't say, "no, he was a right miserable git, actually". Because they worked so hard to have her, and erm they make such a big fuss of her as well (Imogen; 3 year old daughter)

Other people in general

The final group around whom the parents in this study identified that they managed their emotions was *other people in general*, with some parents specifying that they did so around *most people*. Analysis of the contextual factors reveals once again that the parents managed emotions to protect both themselves and the other people. They were protecting themselves from what they perceived the other people's responses might be: embarrassment, lack of interest, lack of understanding, pity. However, simultaneously, the parents sought to protect *the other people* from feeling those reactions.

> People don't want to hear it, they don't, they can't deal, you know. I can't become emotional because they can't deal with that and, actually, rather than isolate me completely, I accept it on their terms, which is that I have to say what they want to hear
> (Sarah; 18 year old daughter)

Summary

So far this Chapter has established that emotions were inherent to these parents' experiences of parenting a dying child, with negative affect predominating in the parents' reflective accounts. In contrast, the parents expressed emotion much less and when they did, positive affect predominated, both in general and in specific instances. This apparent dissonance between felt and expressed emotion signifies emotion management (Hochschild 1979; Hochschild 1983). When the parents' reflective accounts were analysed more closely with respect to emotion management, it became apparent that they managed emotion across a wide range of people in their day to day lives. The emotions which were managed were those of negative affect: the parents appeared not to legitimate negative feeling. The parents controlled their expression of these in order to protect themselves and others. They perceived that expression of such emotion may jeopardise their own or other people's well being. The next section will consider further the context for emotion management.

6.3 The context for parental emotion management

The parents referred to three other influences upon emotion management: time, experience and other people's responses. Analysis of the parents' accounts suggests that the interplay of these three created scripts for emotion management (Hochschild 1979; Wharton and Erickson 1993; Bolton and Boyd 2003). Importantly, it appeared that the parents adhered to these scripts much of the time in their day to day lives.

Time

Time was significant to emotion management in two ways: firstly how close or distant in time the parents were from experiences was important; secondly the passing of time facilitated the accumulation of experiences. To address the first issue, the closer the parents were to an issue, the less they managed emotion. Emotions were strong and intense: parents described them as powerful and exposed. In this state, emotions were less suppressible. Emotion management was more effective, perhaps possible, when the intensity of feeling had lessened:

> It depends how close and raw it is I suppose. Whereas, a lot of the parents they're still going through it so they will need to talk about it, whereas I've gone through it and come out the other side.
> (Imogen; 3 year old daughter)

Over time, parents learned to manage feeling in order to cope: the need for respite or support or friendship or to maintain a relationship over time meant that skills for emotion management had to be employed in order to suppress emotions which were perceived to impinge on those interactions. Crying must stop; worrying must cease; life must be lived; resentment must be squashed. It was as if the situation definitions changed over time as the parents assimilated the ongoing experience of parenting a dying child and the types of interactions that imposed. Diana described her anxiety at leaving her daughter in respite care and how, over time, she learned to manage that feeling in order to have a break:

> You just got to forget about it, and now as I, as it's got on, gone on, I've now let myself really relax. I actually go away for the weekend, you know? And be big and brave and say, "no, they can put the nappy on where, however they like – if she's gets wet they'll change her and have to wash her clothes"
>
> (Diana; 11 year old daughter)

Experience

Over time, the parents accumulated encounters which taught them what, for them, constituted effective and ineffective interaction. They learned what was difficult and what was less so and became adept at managing their emotions accordingly:

> My expectations of other people were very high at the beginning, and what I've learned is that actually people, I don't know if it's that they don't care, I think people just get bogged down with the stuff that's going on everyday for them. And when something becomes normal for you, it becomes normal for them and they stop thinking beyond that. It's a bit like you say, you know, you say you're tired and people will always come back with something else which is worse, except it never is.
>
> (Sarah; 18 year old daughter)

The parents described how such interactions set a context for what feelings they would and would not share with other people. Parents managed their emotions in the moment as a result of such accumulated past responses. They chose which emotions to express during an encounter based on their experience of past responses from a range of people, including family, friends, acquaintances, professionals and strangers. Describing the difficulty she had in the past with communicating her anxiety to her husband about caring for their daughter, Carol explained how she had learned from that experience:

> I've learned since, learned a long time ago, that I actually have to tell him, I can't, you can't drop hints, you actually have to tell him straight, to his face
> (Carol; 18 year old daughter)

As a result of the accumulation of such experience, the parents anticipated their emotions for experiences to come and managed them according to past experience. For example, with respect to respite visits to the hospice, parents spoke of wanting to enjoy every moment of their break and not wanting to explore their negative feelings with staff at that time. However, in implementing their learning from past experience some parents became more isolated:

> I'm now at a point where I don't feel that I have anyone apart from my, my husband really to confide in because I've learned that people don't want to hear it
> (Sarah; 18 year old daughter)

It has already been noted that parents manage their emotions around a wide range of people. This appeared to relate to accumulated experience of interactions: the parents learned how some people responded to them and used that learning to guide emotion management in subsequent interactions.

> The bog standard reply is "yes, oh yes, everything's fine". Because at the end of the day, I mean a lot of people will say "oh how are you?" And you say "oh yes, fine." Because you know that they're not going to want to stand there for half an hour while you actually unload, so you don't bother. You just have a bog standard "oh yes, fine, everything's fine, we keep going".
> (Carol; 18 year old daughter)

A complex picture emerges of parents building a context for emotion management. Emotion management theory stresses the significance of feeling rules which dictate the appropriateness of responses to given situations (Hochschild 1983; Ruane 1996). Such rules can be accumulated into scripts for emotion management which are driven by particular social groups, such as organisations, the home and peer groups (James 1992; Karabanow 1999; Rafaeli and Worline 2001). In the case of these parents of dying children, the passage of time and accumulated experiences of interpersonal interaction moderated present and future management of emotions.

In other words, these parents derived feeling rules from their various interpersonal interactions associated with their role as parents of dying children (Wharton & Erickson 1993). Those rules evolved as their parenting experience developed both over time and in nature (breadth and depth). Consequently, the parents cultivated an emotion management script based on their interactions over time. Their narratives suggested that they interpreted other people's visible responses and used those interpretations to devise feeling rules.

Parental perceptions of other people's responses

The parents in this study described some of their previous interactions in terms of the ways in which they perceived other people responded to them. Although all parents made some reference to helpful, positive responses from others, in the main they recounted negative responses. The parents' perceptions of positive responses equated to other people providing practical and psychological support. One parent identified grandparents as especially positive, but there was more frequent reference by other parents to care services. Practical support included providing living accommodation during a crisis, respite care, and equipment for day to day care. Psychological support was more indirectly provided, being seen to derive from receiving the practical support. When parents recounted positive responses, they identified them with clear outcomes for their personal experience. Support was improved, isolation was reduced, the ability to cope increased, a more positive outlook developed and difficulties reduced:

> As long as I get a break and the help and support from social services I think I'm not suffering
> (Diana; 11 year old daughter)

> It is hard work, but when you actually get the services that you actually know are out there to help you and everything is going well, life is fine
> (Carol; 18 year old daughter)

However, parents more readily reported negative responses to their experience. Through data analysis some key themes emerged of how the parents perceived that other people responded to them: inability to cope, pity, lack of understanding, and lack of empathy. Therefore this section presents a thematic analysis of the parents' perceptions of negative responses to their experiences and the impact such responses had upon the ongoing parental experience.

Inability to Cope

Some parents perceived that other people were unable to cope with their experiences, identifying a range of other people who could not cope: family members, friends, professionals, strangers and society in general. This emphasises the pervasive nature of perceived negative responses across the spectrum of interactions the parents had in day to day life. The parents thought that these people were unable to cope with physical caring, emotional caring, or the child's disability. They perceived this to limit other people's interactions with the child and parents and therefore the amount of available support.

Parents attributed their perception of others not coping to various actions: family members who showed a lack of helpfulness towards and interest in the child and parents; friends who excluded the child or parent from social activities; education services who lacked vision for the child's potential; care services which were unable to provide adequate support; strangers who proffered negative opinions; society which failed to provide physical access to facilities. The parents had both emotional and experiential outcomes from these responses. The emotional outcomes for the parents included anger, fear, frustration, loneliness, upset, feeling abnormal, and feeling judged. The experiential outcomes were that parents became isolated, either emotionally or physically, due to lack of support:

> If you don't fit the pattern, if for some reason you're different, then people make choices according to that, don't they?
> (Mary; 20 year old son)

These outcomes clearly relate to suffering theory, wherein judgement of suffering by observers is noted to influence outcomes for sufferers (Charmaz 1999; Morris 1997; Ramphele 1997; Skultans 2003). The parents in this study perceived that other people observed and interpreted their experiences and could not cope. The parents also perceived that inability to cope influenced other people's actions towards the parents. The ongoing parental experience was therefore in part derived from their perceptions of other people's responses. Another way in which parents perceived that others judged them was by acknowledging their experience with pity.

Pity

Parents perceived that others pitied them when they were asked *how* they coped and told they were brave. They attributed this response to people *in general* rather than specific groups, which suggested that pity could be encountered anywhere, perhaps unpredictably. The parents did not appreciate this response: they were concerned about what such a response reflected about their own identity. It made them feel weak; they preferred a more practical demonstration of concern, such as listening; they did not want to be seen as a victim since this was detrimental to self esteem. The parents in this study found themselves losing preferred identities and simultaneously having unwanted identities imposed upon them, mirroring findings from previous research into suffering (Charmaz 1983; Charmaz 1999).Thus, there is a clear link between the response of pity and the parents' identity being at stake, an issue explored in Chapter 4 (Kleinman 2006; Kleinman & Kleinman 1991).

The parents' reaction to perceived pity was to be seen to cope. Existing suffering theory maintains that the legitimation of suffering may depend upon particular behavioural expectations imposed by observers and society (Frank 1995; Connolly 1996; Farmer 1997; Charmaz 1999). Certainly, data from this study shows that the parents altered their behaviour according to their perceptions of other people's responses. In order to avoid the response of pity and the feelings it engendered, the parents managed their emotions, through alteration of what they expressed to other people (Hochschild 1979; Hochschild 1983).

> I don't think I cope a lot of the time, I just keep it hidden, but I want people outside to think that I'm a coper, because that's about my self-esteem and about people not feeling sorry for me
> (Sarah; 18 year old daughter)

In being seen to cope, the parents presented a version of self which was different to their felt experience and was thus an *inauthentic* account of their experience. Such action meant that people encountering these parents interpreted their experience through these inauthentic accounts. On the other hand, the parents' interpretation of their experience drew on the felt emotions which they did not express. Therefore an important finding from this research is the way in which emotion management limited intersubjectivity, since the data suggests that interacting individuals were developing meanings about phenomena based on different information. Reduced intersubjectivity would lead to a lack of understanding of the parental experience by observers. However, the parents drew attention to a lack of understanding as a distinct response from other people. Therefore, whilst it may be the outcome of pity, simultaneously lack of understanding may be the origins of pity.

Lack of understanding

Parents perceived a lack of understanding from a variety of other people, in the family, workplace, hospice, anyone who did not share their experience and people generally. The perceived lack of understanding could relate to concrete experiences, such as a child's treatment, or to more nebulous issues, such as the long term nature of the child's disease and the associated implications. Parents recognised that other people did not necessarily have the same experience and that this compromised their ability to understand. Nor did parents necessarily have an expectation that other people would or could understand. However, a range of outcomes arose from a perceived lack of understanding which directly impacted upon the lived experience of the parents of dying children. Depth of relationships was limited, feelings were hurt, isolation increased, work was stressful, talking to others was difficult, and support became limited.

> People don't understand. I really, I personally felt that we became a handicapped family not just *my son*, but myself, I couldn't do things because of *my son*, that I couldn't do things with the boys because of *my son*, and at times I was very isolated. There were times when people wouldn't invite you to certain things because automatically they would assume that you can't go because of *my son* and it, it became very, very lonely at times, and people didn't understand
> (Valerie; son died aged 19 years)

The lack of understanding was particularly felt in the workplace by five parents, the impact of which was felt more widely than at work. The ongoing nature of the child's illness meant that health crises were likely. Parents who recognised a lack of understanding at work described specific actions and feelings associated with managing the conflicting demands of their sick child and the workplace: they lied, begged, felt guilty, and felt tortured. Such strong reactions reflect the significance that parents placed in work. In Chapter 4 the nature of the parental experience was explored, within which the significance of work with respect to identity and role were highlighted. These parents of dying children juggled many roles for both practical and existential reasons. However, caring for the child was the main role of the parent, to which other roles had to subjugate. Parents were searching for a way to maintain each of those roles, and in doing so were seeking empathy.

Lack of Empathy

Empathy speaks of putting oneself in the position of another person and endeavouring to view their experience <u>from their perspective</u>. In empathising, one tries to 'understand someone else's feelings as if they were one's own' (Collins et al. 2006 p251). This differs from merely understanding. Empathy suggests an active process of altering one's perspective and taking on that of the other person. One may understand without empathising and empathise without understanding. Parents of dying children described a desire for empathy, but perceived that responses from colleagues, friends and other people in general lacked it. This suggests both day to day as well as unpredictable exposure to this response.

Parents perceived that friends and other people were unable to balance their own problems or needs in day to day life with empathy for the parents of dying children. This related to the length of time over which empathy might be required and the depth of problems which parents faced. In this respect, other people were perceived to judge or weigh up the parental situation to determine their response to it. Some parents referred to friends and other people falling away over time; others parents related the lack of empathy to their perceptions that other people's inability to engage with that feeling.

With respect to work, parents perceived that colleagues fail to empathise with parents' attempts to work and to maintain work in the face of their child's repeated health crises. Work was significant for these parents (see Chapter 4), but the diagnoses with which their children were living meant that health crises were likely and the parents needed to take time off work to deal with them. Parents described leave not being made available when the child was acutely unwell or undergoing life threatening surgery. Flexible working was uncertain. A mother whose husband was the breadwinner had to manage her son's time in intensive care alone, since he was not given leave and was concerned for his job security.

The outcomes of a perceived lack of empathy impacted upon some of the key issues of the experience of parenting a dying child. Parents' choices with respect to work, lifestyle and relationships became limited. Parents experienced more stress, related to work, finance and relationships. Finally, parental isolation was reinforced once again. The following quote illustrates lack of empathy in the workplace and its repercussions within the parents' life:

> I managed to get a Christmas temporary job to start with because we were just desperate for money, erm and they kept me on, but, and I had this term time contract, but last, this time last year, the manager said – well, *your daughter's* 18 now, I'm not prepared to put up with it, I don't have to, erm I think I've been good enough to you and supportive enough. And I was thinking - well, if you're telling me - and then he was actually saying that I've either got to work full time and take the five weeks holiday like anybody else or I had to look at my alternatives and go and find something else. And I, at the time I wasn't prepared to work full time, I still needed to be able to have holidays off. I didn't feel that I could do that
> (Carol; 18 year old daughter)

This section of the chapter has outlined the parents' perceptions of how other people respond to them. Parents tended to describe more negative responses than positive. They attributed the responses to a variety of people, indicating that they can be encountered throughout everyday life. In section 6.1 the data analysis confirmed that emotions were integral to the experiences of the parents in this study. This section has demonstrated that the impact of other people's perceived responses was also seen in parental emotions, as well as their ongoing experience of parenting a dying child. That parental emotion was influenced by other people's responses suggests the development of feeling rules and the scripting of emotion management (Hochschild 1979; Hochschild 1983). The parents described a variety of interactions in everyday life which influenced their emotion management, which affirms previous research that individuals are exposed to multiple sets of feeling rules (Wharton and Erickson 1993, Bolton and Boyd 2003, Hochschild 1983). In adhering to emotion management scripts, the parents appeared to de-legitimate the expression of negative emotion.

6.4 Discussion

In Chapters 4 and 5 I highlighted that specific issues were at stake for the parents who participated in this study and that the communication of them was complicated. In particular, my analysis demonstrated that the parents managed their emotions when communicating about their experiences in interview and with hospice professionals. The purpose of Chapter 6 has therefore been to broaden my analysis of the parents' emotion management. To that end, I have shown through my analysis that the parents of dying children who participated in this study acknowledged their experience with emotion. They did this both through their own reactions to their recounted experiences and through their interpretations of the interactions they had with other people. Parenting a dying child is therefore interpreted through this research to be an inherently emotional experience. Whilst that finding may not be surprising, the nature of the parents' felt and expressed emotions were rather more remarkable.

The emotional behaviour the parents described was comprised of felt and expressed emotions (section 6.1). The findings from this research are that *felt* emotions were dominated by *negative* affect: the parents described a wider range of negative emotions than positive and described feeling them more often than positive emotions. In contrast, they *expressed* emotions less often, and when they did so the emotions were predominantly *positive* in affect. Supported by both narrative and observational data, this finding illustrates that the parents in the study managed their emotions through emotion work (Bolton & Boyd 2003; Hochschild 1979; Hochschild 1983).

Therefore, the findings of my research show the experience of parenting a dying child is inherently emotional, but the communication of it is not. The parents managed their emotions across the spectrum of interactions in every day life. They did so from intimate relations to strangers and with respect to all kinds of issues, from birth to death. The range of interactions described supports the notion that emotions are managed and presentation of self adjusted according to social rules (Goffman 1969a; Hochschild 1983). However, not all emotions were managed equally. Overwhelmingly, the evidence points to negative emotions being managed: even though they predominated as the felt emotions, the parents worked at not expressing them.

It seemed that the feeling rules which the parents employed did not legitimate negative feeling and therefore it was suppressed. Previous research has demonstrated that individuals may choose whether to submit to a legitimated representation of their experience and may alter their behaviour accordingly (Cassell 2004; Charmaz 1999; Kleinman 1988; Ramphele 1997). The parents in this study altered their behaviour through their suppression of negative emotions, based on their interpretations of the rules and scripts for emotion management. Whilst these scripts derived from ongoing interpersonal interactions, they were concurrently contextualised to society.

Contemporary society in England is characterised by declining mortality, associated with improvements in health and well being as an outcome of social policy (Haines 1995; Pickvance 2007). Childhood death is now less than 20 per 100,000, from birth to 19 years (Cochrane et al. 2007). As set out in Chapter 1, current social policy stresses the health, well being and survival of children for both their future utilitarian value to society and their psychosocial value to parents (Hendrick 1997a; Jones & Brayfield 1997). However, in both individual and societal measures of the value of children the emphasis is upon the sacralisation of children (Zelizer 1994). Modern-day childhood and parenting is therefore standardised through institutional scrutiny, monitoring and control (Moran-Ellis 2010).

With respect to most children, such social policy reflects contemporary social constructions of childhood and parenting (Cunningham 1990; Dean 2007; Moran-Ellis 2010). However, as set out in Chapter 1, in general such policy neglects the needs of dying children and their parents. Their lack of representation in policy, as well as their small numbers, means that they are less visible in society. In a society where constructions of childhood are built upon children's long term survival and well being, cultural references for childhood death become ever more limited. Other people may rarely encounter a dying child, since numbers are small, and so the experiences of the parents in this study may be largely invisible to society and therefore unknown. Thus it is possible that the parents managed negative emotions because, in the context of contemporary social constructions of childhood and parenting, those emotions were not legitimated. Therefore, social policy and social constructions of childhood may have provided a script for parental emotion management.

However, the parents provided reasons other than legitimation for managing their emotions. They perceived that expression of negative emotion might jeopardise their own or other people's well being in some way and sought to protect themselves and others from that (Section 6.2). This too may relate to contemporary social constructions of childhood where the death of a child is rare and largely invisible. Any societal script for emotion management by parents is likely to be more heavily influenced by the visible, social constructions of childhood, than by the largely unknown experience of parenting a dying child. Thus, contemporary parents are responsible for the protection and nurture of children, so the parents in this study managed emotions around children to achieve that. Likewise contemporary children are valued for the psychosocial benefits they bring to parents, and so negative emotions associated with parenting, which expressed an alternative perspective, were managed around family, friends, acquaintances and strangers.

Simultaneously, the parents perceived that other people provided particular visible responses in their interactions which further promoted management of negative emotions (section 6.3). These responses were perceived in a variety of everyday life interactions and again they influenced the parents' emotion management through the development of rules and scripts (Hochschild 1983; Wharton and Erickson 1993; Bolton and Boyd 2003). In the commercial context, Hochschild (1983) argues that individuals lack agency in managing their emotions. In this study, however, in common with more recent emotion management research (Bolton & Boyd 2003), the parents' appeared to choose how to script emotion management, albeit their agency was still a response to their perceptions of social rules. Their choices enabled them to avoid perceived responses which elicited further negative emotions within themselves. Therefore, they managed their own emotions in order to manage the emotions and responses of others, so that their own subsequent emotions could be further managed. In other words, the parents spoke of managing emotion 'by the self upon the self, by the self upon others, and by others upon oneself' (Hochschild 1979 p.562).

Thus far, this chapter has demonstrated that emotions were inherent to the experience of parenting a dying child. However, the parents in this study generally managed their emotions in their day to day interactions, particularly those of negative affect. Whereas Chapter 5 demonstrated the influence of an organisational script over the parents' emotion management, this chapter highlights the possibility of a societal script derived from contemporary social policy and social constructions of childhood. In addition, the parents derived a script for emotion management based upon their day to day interactions. This script was underpinned by situational definitions generally (Goffman 1969a) and specifically by those who defined the emotional agenda (Bolton & Boyd 2003). Importantly, the parents appeared to define the emotional agenda, demonstrating agency. However, they did so through assimilation of their perceptions of how other people acknowledged their experience over time. Furthermore, their narratives suggest that over time they utilised past experience to manage their emotions *in anticipation* of other people's responses, rather than managing emotions in the moment.

Significantly, in day to day interactions, other people's responses must have been derived in part from the way in which the parents acknowledged and presented their own experience. However, the parents managed their emotions in everyday life, particularly limiting the expression of negative emotions. Over time and with the accumulation of experience, the parents perceived that their version of self *with* its negative emotions was incompatible with social rules in a variety of contexts. Therefore they presented an alternative version of self (Goffman 1969a), through managing their emotions (Hochschild 1979; Hochschild 1983).

It has been argued that intersubjectivity is important in the relief of suffering and may be facilitated through effective communication (Cassell 2004). However, suffering theory also maintains that communication about suffering can be difficult with authenticity of the voice given to suffering being questionable (Bourdieu et al. 1999; Kleinman & Kleinman 1997; Wilkinson 2005). The version of self which the parents presented to other people was often devoid of negative emotion. This was an inauthentic presentation of self, since it *misrepresented* their felt emotions. However, this was the self with which other people were presented in interactions and from which intersubjectivity was derived. Therefore, the parents in this study limited intersubjectivity through their management of emotions and presentation of self.

Other people's acknowledgement of the parental experience was therefore seen in their responses to the inauthentic accounts provided by the parents. Such responses, which included inability to cope, pity, lack of understanding, and lack of empathy (section 6.3) were generally categorised as negative by the parents and had clear outcomes for them. In particular, other people's responses, based as they were upon limited intersubjectivity, had an impact upon the issues at stake for these parents (Kleinman 2006; Kleinman & Kleinman 1991). Thus, inability to cope was connected with isolation; pity was associated with a loss of identity; lack of either understanding or empathy was linked to impoverished relationships and changes to identity (see Chapter 4).

Previous research into suffering has demonstrated that individuals may submit to the reframing of their experience by observers in order to secure support of some sort (Kleinman and Kleinman 1997; Ramphele 1997; Cassell 2004) (Kleinman & Kleinman 1997). However, in so doing, the sufferer risks loss or disregard of the personal perspective upon the suffering experience and this in itself forms part of the suffering (Wei-Ming 1997). The parents in this study managed their emotions, however, in order to *avoid* submitting to other people's reframing of their experience: they avoided pity, being a victim, etc. However, in so doing, they nevertheless disregarded, albeit temporarily, their own perspective on their experience, or at least hid it, through management of their negative emotions. This disregard of their authentic perspective on their experiences contributed to their issues at stake because it reduced intersubjectivity.

In this thesis I have thus far set out what these parents of dying children experienced, the ways in which it was acknowledged and the impact of it being acknowledged or not. A number of parallels have been drawn between the findings of this research and existing suffering theory. In particular, my analysis has demonstrated that the processes of emotion management contributed to a lack of intersubjectivity in the parents' day to day interactions. In turn, reduced intersubjectivity set the context for responses to the parents which contributed to certain issues being at stake for them. It would therefore be straightforward to conclude that the parents in this study were suffering and that emotion management was a factor in their suffering. However, in reaching such a conclusion I risk subjugating the parents' experience to my own research agenda. Therefore, in the final data chapter, I explore the parents own perspective upon suffering.

Chapter 7
Suffering

Introduction

The conclusions I have drawn from the data analysis so far are that these parents of dying children experienced existential and relational losses. These constituted some of what was at stake for these parents in their every day lived experience. The communication of these matters was complicated. In their reflective experience, the parents acknowledged them with emotion. However, my analysis of triangulated data in preceding chapters suggested that their negative emotion was not legitimated and, furthermore, its expression was managed. The parents' seemed to sublimate their own voice through emotion management. As a result, in some contexts they presented an inauthentic account of their felt experiences. From these findings, and their resonances with existing theory, it would seem reasonable to conclude that parenting a dying child is a suffering experience. Furthermore, the voice of the suffering parent becomes sublimated through processes of emotion management as parents submit to what they perceive to be a legitimated version of their experience.

However, in reaching those conclusions, I risk imposing a label of suffering upon these parents, even if supported by theory. Therefore, the final data Chapter explores the parent's own perceptions of suffering. To recap from Chapter 3, initially in interviews I encouraged each parent to talk freely about their experiences and took care not to introduce the concept of suffering. However, towards the end of the interview I deliberately asked them if they considered themselves to be suffering and asked them to define suffering.

Each parent shared their personal views which cannot be discounted: suffering must always be explained from the individual perspective (Morgan & Wilkinson 2001; Morris 1997). Therefore the chapter begins with a review of the types of definition of suffering the parents gave. However, whilst the parents each gave individual responses, three key themes recurred. Firstly, the parents often made comparisons in their definitions of suffering reflecting the perception of a hierarchy of suffering. Secondly, most parents referred to their children in some way. Thirdly, suffering was associated with the complexity of everyday life. After exploring each of these I focus upon whether or not the parents in fact characterised themselves as suffering. When I analysed the parents' views on their own suffering three distinct narratives emerged, one dominant and two subsidiaries. These are discussed before a final discussion section theorises the place of emotion management in suffering.

7.1 What is suffering?

In defining suffering, the parents provided a range of personal meanings for the term. Suffering was defined with respect to issues remote from the parents' own experience and reflecting a world view of the concept. Thus starvation, poverty, war and living in the third world were incorporated into notions of suffering. Alternatively, suffering was defined with reference to more intimate issues, in terms of personal lives. In this respect suffering was clearly identified with loss. As set out in Chapter 2, this mirrors research in which losses such as age, trust, identity and bereavement are identified as suffering (Black & Rubenstein 2004; Charmaz 1999; Ramphele 1997; Sacks & Nelson 2007).

In this study, the loss for some parents was a general sense of having 'missed out on things'. For others there were specific losses such as holidays or activities. Still others linked suffering to loss of health. Parents identified physical ailments or mental health problems, such as depression, as forms of suffering. Finally, suffering was categorized as a lost identity - individual circumstances changed so greatly, for which personal adaptation was required to such a degree, that the sense of self had altered:

> The suffering for me has been the complete loss of who I am – I don't know who I am any more (Sarah; 18 year old daughter)

The parents perceived that suffering might be short or long term in nature. For some it related to specific instances in the child's life: thus, the child receiving a diagnosis, or being acutely unwell, or undergoing a particular treatment could be *occasions* of suffering. However, there was also *extended* suffering, and the parents might have experienced both:

> It took us, we were probably still in shock for up to 5 or 6 years after he was born and so the two combined, the, the shock of having the situation thrust upon us and the, the, the, our day to day lifestyle being pretty difficult
> (Michael; 10 year old son)

Although parents provided their own definitions, it is clear that there was some similarity in the concepts they utilised and the examples they provided. In addition, once individual definitions had been drawn from the data, cross case analysis for the same concepts established that different parents raised the same issues, while not necessarily referring to them as suffering. However, in raising them, they identified them as significant in their experiences. Finally, parents emphasised that individuality was important. However, in doing so, they also articulated how individual judgement categorised different experiences in terms of severity or importance. In other words, suffering had a hierarchy:

> Everybody's ideas of suffering is different, I mean in some respects we don't suffer. We're not like the third world children that are not fed, I mean that is suffering, erm, but everybody's suffering is different
> (Carol; 18 year old daughter)

7.2 A hierarchy of suffering

Existing suffering theory recognises a moral hierarchy in suffering against which either a suffering experience or the response of the sufferer may be judged or legitimated by society (Charmaz 1999; Connolly 1996). However, the parents in this study compared *their own* experiences to that of other people, and in so doing they appeared to judge *themselves*, as if legitimating their own suffering, or not. The parents articulated different hierarchies. The child's health might be ranked against that of parents or other sick children.

For example, a father compared his own robust health to his daughter's frailty to emphasise that his experience was not suffering when compared to hers. On the other hand, a mother compared her daughter's life *threatening* illness to the potentially longer term nature of a life *limiting* illness. Alternatively, the parents' own health was used as a measure of suffering. Whilst defining suffering as loss of health, the parents might acknowledge the ways in which their own health had deteriorated, but yet reject such evidence of personal suffering when comparing themselves to other people. In each of the three preceding examples, the parents appeared to minimise their own negative experience and therefore to avoid its legitimation as suffering.

In the same way, parents compared the kind of support they received and underrated the impact of their own lack of support when contrasted with that of someone they perceived to be in a worse situation. Diana's 11 year old daughter had a life-limiting disorder and was totally dependent for all her needs. Diana was a lone parent and struggled to secure ongoing care support. In defining suffering she described a friend whose daughter had cerebral palsy, illustrating clearly how the parents contextualised suffering, particularly the possibility of their own, within a hierarchy of experiences:

> She's a single parent. You know, so she knows what it's like, she's got it hard. She don't get no respite, nothing. She hasn't even got direct payments. She's suffering more than I am. She's on antidepressants, you know? [...] To me she's suffering, I'm not.

In an extreme form of comparison, parents ranked their own experiences against those of a remote and vastly different nature. Thus individuals put their own experiences side by side one with people who were living in poverty or war and, in so doing, they afforded their own lived experience a lower ranking. The situations with which the parents compared themselves were extreme and different, and yet they fundamentally concerned matters of life and death, and so mirrored the parents' experiences in some way. Yet they seemed to use the comparisons to justify the delegitimation of their own suffering:

> You see people in famine, you take people in Palestine, they're suffering, you know. They're having to be bombed any second, or shot when they're walking down the street. They're suffering, but we're not suffering
> (Charles; 18 year old daughter)

7.3 Children's suffering

In defining suffering parents often referred to that of other family members, such as grandparents and partners. However, the suffering of their children was particularly emphasised, both that of the sick child and the siblings. The way in which the parents defined suffering not only in relation to their own experience but to that of other people, particularly their children, indicates the significance of intersubjectivity in suffering. This finding is substantiated within the literature, where the seemingly paradoxical nature of suffering is seen to be at once individual and concerned with interaction between people (Kleinman & Seeman 2000; Wilson 1991).

The significance of intersubjectivity is also underscored in the types of suffering the parents describe in their children. With respect to the sick child, inequality of opportunity, exclusion, pain, fear, or psychological trauma all constituted suffering. Siblings were likewise perceived to suffer in a variety of ways: the life experiences they were exposed to from an early age, such as seeing a child in intensive care; the restrictions placed upon their life experience due to lack of time or money; abnormal levels of responsibility placed upon them to support caring; a lack of attention because the parents lacked time. Each of the examples of child suffering which the parents gave reflected a perception of altered interactions and relationships and was therefore fundamentally intersubjective in nature.

It is arguable that the nurture and protection of the child is inherent to the role of parenting (Voysey Paun 2006). However, in this study, the parents were powerless in the face of their child suffering. Echoing the analysis of Chapter 4, whereby the parents' identity and relationships were put at stake through their experiences of parenting a dying child, these parents could not do the things they wanted to do for their children in their parenting role. They could not take away their child's physical discomfort or fear. They could not make their child understand. They could not lessen the child's loneliness. In considering their children's suffering, the parents reflected upon how this comprised their own. The parents obviously wanted to relieve their children's distress but were unable:

> You want the pain. You want their pain to be your pain.
> (Imogen; 3 year old daughter)

With regard to the dying child, suffering was seen in their physical health, in their place in society and in their future opportunities. Parents described how their children were exposed to painful, changeable and often long term therapeutic interventions which they may not have been able to comprehend due to age or ability. The impact of their disease and therapeutic interventions shaped the dying child's social experience: opportunities to spend time with peers and engage in age appropriate activities, including education, became more limited. Whilst this may have had some relationship with the time taken for therapeutic interventions, the parents descriptions also suggested social suffering: the way in which society responded to the children was bounded by norms which were sustained through cultural, political, professional and social processes (Kleinman et al. 1997).

Thus children missed out on leisure activities because access was structured for able bodied individuals: e.g. not being able to take a child to the beach in a wheelchair. Support from health or social care services was structured upon strict criteria which did not reflect individual need: e.g. a young man unable to toilet, wash or dress himself, was not allocated nursing care; because he did not have any invasive technology, such as a breathing or feeding tube he was forced to remain dependent upon his parents for personal care at 18 years of age. Even services designed to meet individual need were perceived to be prone to prejudice: Sarah described her 18 year old daughter's struggle to obtain suitable work experience on completion of her GCSEs:

> What the school actually suggested to her was to go through *an organisation* which is a centre for adults with learning and physical disabilities because it's completely accessible – "So you'll be able to get round". That's completely, I guess that sums up the way society views somebody in a wheelchair. You know, that's completely inappropriate. And she said "no way" and the staff member said to her "do you realise that could be interpreted as you having a problem with people with learning difficulties or disability?" And she said "I'm in a wheelchair. I haven't got a problem. It's just not where I want to be."

The parents perceived that their child's ability to achieve their full potential within the framework of their physical and intellectual condition was inhibited by social restrictions. The parents seemed powerless to overcome such social constraints, which were a reflection of cultural, institutional, political and professional attitudes. However, as stated previously, parental suffering was not found in that of the dying child alone: that of the healthy siblings also had an impact on the parental experience.

Both the actual and the potential experience of the siblings concerned the parents. They saw the healthy siblings exposed to the experience of the dying child, but also having their care subjugated to the overwhelming priority of managing the dying child's health. Healthy siblings were witness to the ever present reality of death, the physical interventions for the dying child, and the impact upon the parents of caring for the dying child. Siblings' care was deputised to others at times of crisis and when they were with their parents they sometimes received limited attention.

In addition, parents looked to future possibilities of the dying child living for longer than anticipated or their own demise and what this meant for the healthy siblings. Finally, and in conjunction with the latter point, parents expressed concern for the healthy siblings being able to reach their potential also, and not to have their lives disrupted through the needs of the dying child. Parental suffering located in that of the healthy children was once again associated with their ability to fulfil their role as parent. These parents were concerned about their ability to protect the healthy child, to enable them to fulfil their potential and in this respect their identity as a parent was compromised:

> *His sibling* suffers. I feel sometimes very guilty in the way we have relations. It should be different. You know it should be completely different. He is always like, erm, out of it, you know, pushed away a little bit. Not because I do. It's because it is impossible
> (Jane; 2 year old son)

Even whilst realising how powerless they were to alter their children's experiences, the parents yet appeared to judge themselves for their inability to fulfil their parental role. In their narratives, these parents seemed to hold themselves to account for their inability to relieve their child's distress. In so doing, they judged themselves against a perception of 'normal' childhood, supporting the notion that contemporary childhood and parenting is scrutinised according to narrow criteria (Moran-Ellis 2010) which the parents and children in this study could not achieve.

With respect to parental suffering being located in the suffering of their children, these findings corroborate current literature with respect to intersubjectivity in suffering, suffering as loss and social suffering. These parents defined suffering through the experiences of other people. In so doing, both the intersubjective nature of those other people's experiences were emphasised as well as how the parents' experience was mediated through the suffering of those others. With respect to suffering as loss, as well as identifying specific personal losses, the parents highlighted loss in their parenting role and identity. This illustrates that suffering related to what was at stake for these parents (Kleinman 2006): their identity and place in society. Their parental identity was particularly at stake when they were powerless they were to prevent their children's distress. Their inability to influence their children's suffering was in part due to the predominance of societal processes beyond their control which shaped their children's and their own experience (Kleinman et al. 1997): the parents narratives spoke of social suffering. Sarah illustrated each of these elements, speaking about the ways in which her dying daughter's life experience was mediated through her encounters with society:

> As a parent yeah, I suffer, because I want so much for her. I could only do what I can do and I will do what I have to do but I want her to have everything. It's not a fair world it's not fair.

7.4 Suffering in the complexity of life

The way in which the parents suffered when their children suffered was in part due to the complexity of family life and trying to balance competing needs. However, this too illustrated a degree of social suffering, since the structure of the parents' lived experience was in part bound by the ways in which society was organised (Bourdieu et al. 1999). Even whilst parenting a dying child, these people still faced the everyday pressures of routine family life. Juggling the different needs of healthy and sick children was difficult and was further complicated by their differing and changing developmental requirements. Practical parenting responsibilities also created pressure:

> Oh my god how is this going to affect my job? You know, how's this going to, how am I going to pay for this, and oh I'm in arrears with my mortgage and all those other conversations that as parents we were having whilst all this other stuff is going on
> (Imogen; 3 year old daughter)

However, these parents' perceptions of how to accomplish family life were structured according to norms which were difficult achieve. Moreover, these norms clearly reflected both contemporary English constructions of childhood and parental responsibility and contemporary social policy (Chapter 1). Thus providing a home, working for income, enabling children to achieve potential, providing a range of activities for children, and ensuring siblings conformed to societal standards such as educational and developmental achievements were all referred to by these parents. Such notions are established and supported by political and cultural developments (Hendrick 2005). However, these parents struggled to maintain 'normal family life' as established through such contemporary structures which took no account of their altered personal circumstances. In this way the parents' descriptions are suggestive of social suffering (Kleinman et al. 1997).

The difficulty of living up to such norms was compounded by the ways in which the dying child's health was managed. Decisions about the child's health were made according to unpredictable technological advances and professional judgements. One mum described her ongoing efforts to maintain normal life for her daughter who was taking GCSEs; simultaneously her son was rapidly deteriorating, and repeatedly collapsed and was resuscitated. Whilst she did not want him to die, she articulated the impossibility of watching him deteriorate, knowing his death was inevitable, seeing the impact of it all upon her daughter, trying to parent them both, and having no control over how it continued:

> I think *his sister*, like us, felt at one point wouldn't it be kinder if that was the end for him, but *my son* battled on and has overcome this bout of illness. And, erm, we all know it's only a matter of time and you know, we're facing having to through it all again at some point and I think that's the hardest thing at the moment (...) That each of us, you know, we've been through so, so much emotion and you think, that's going to be the end, you know, and there's more to come (...) You don't obviously want it to keep happening, but you know it's going to happen at some point, because the next cold that he develops could be the end for him, you just don't know. I think really all the time we can keep it normal for *his sister* here. (...) You know, when, when she wants to go and visit *my son,* you know, that's fine (...). Because, you know, it's a quite difficult time being 16
> (Mary; 20 year old son)

Amidst the personal tragedy of that mother's experience, she referred to clinical decisions which were made according to contemporary institutional and cultural definitions of ethical practice which she was powerless to resist.

The outcome again was a degree of social suffering: her capacity for agency was limited by institutional and cultural norms (Frost & Hoggett 2008).

The participants in this study could not separate the reality of day to day life as a parent from that of parenting a dying child. However, the maintenance of a 'normal' appearance, through work or home or taking holidays remained an important consideration. Indeed, they acknowledged that being unable to achieve the normal appearance in these specific ways was a source of suffering. Goffman's work acknowledges the lengths that individuals go in order to present an acceptable version of self to other people (Goffman 1969a). However, in this study parents were limited in their capacity to alter their presentation of self with respect to 'normal life' as they perceived it to be measured.

One of the issues at stake for the participants in this study was their identity as a parent. The way in which they presented themselves in everyday life upheld that identity and when they could not uphold that standard suffering occurred. Whilst to the observer the issue of 'keeping up appearances' might seem incongruent with the enormity of anticipating the death of a child, it was significant for these parents because it was bound up in their identity as a parent:

> You see other families going off on holidays and you can't and you, so you feel that you've let the family down
> (Carol; 18 year old daughter)

7.5 Not drowning, but waving: do parents suffer?

Each of the parents gave a personal definition of suffering, within which they categorised their own experiences with respect to the term. However, it is clear that there are firm resonances between these individual definitions and the thematic analysis presented in Chapter 4. In particular concerns about time, identity and relationships are common to both sections of the data analysis. Focused cross-case analysis, using the parent-definitions of suffering, demonstrated that the same issues were raised by different parents. However in those examples they were *not always* identified as suffering. In the first instance, this reflects how individual realities are constructions based on personal interpretation of experience, contextualised to culture and history (Guba and Lincoln 1989, LeCompte and Schensul 1999b, Heron and Reason 1997, Charmaz 2008). In addition, this draws attention to the fact that not all of the parents classed themselves as suffering. Thus these findings once again emphasise the importance of ensuring that the authentic voice of the individual can be heard.

Whilst the parents all gave definitions of suffering, they did not all describe themselves in those terms. In this small sample, some were sure they did suffer; some thought they had in the past; still others were adamant they did not. The dominant narrative was that of suffering and there appeared to be no obvious demographic context for this: whilst that group of parents shared the commonality of parenting a dying child, there was also marked variation between them. Their ages ranged from mid 30's to late 40's. The age of the dying child, and therefore the longevity of their experience, ranged from 2 to 20 years. Their children had different types of diagnosis and were at different points in their health trajectory. Although each of the parents who categorised themselves as suffering was female, married and had one or more healthy children as well as their dying child, these features were also seen in individuals in the non-suffering and wavering groups. The features of these narratives of suffering therefore demand further analysis.

I SUFFER

Each of the parents who legitimated their experience as suffering referred to one or other form of loss within their definition of the term. Although all of the parents referred to losses within their narratives in general, this group *specifically* related their definition of suffering to loss. Mirroring existing research, the losses included both definite and less tangible entities. Concrete losses named by the parents included health, finance, relationships, and role. Each of these is characterised as suffering through other research (Charmaz 1983; Wilson 1991; Frank 1995; Putnam 2000; Cassell 2004; Sacks and Nelson 2007).

Previous research has clarified that suffering may be associated with both loss and the consequences of loss, including changes to identity and self (Black & Rubenstein 2004; Charmaz 1999; Sacks & Nelson 2007). Similarly, as identifying concrete losses, the parents reflected upon both specific losses and what they meant in existential and relational terms: the loss of normality, of control, of identity. For example, one parent described the concrete loss of her parenting role when the physical care the child required was beyond her capacity. However, there were additional meanings attached to that loss concerning identity and control:

> The physical handing over of my child to somebody else and relying on their skills and their hands, and it's, they're going to something that I cannot do. [...] Because there's so many tubes and things, you can't actually comfort them very much, all you can do is sort of hold their hand and pat them
> (Imogen; 3 year old daughter)

The losses these parents identified were reflective of the themes arising from their general descriptions of their lived experience (Chapter 4). To recap, the key features of the experience of parenting a dying child included loss of identity, altered relationships, and living with uncertainty and death. Each of these is relational in character, reflecting the effect of the parental experience upon their capacity to relate to others. The most obviously relational loss identified by this suffering group of parents was loss associated with relationships. Both intimate and more detached relationships were implicated, including marital relationships, relationships with healthy children and friendships. Mary described how her friendships had dwindled since her son's diagnosis:

> If you don't fit the pattern, if for some reason you're different, then people make choices according to that, don't they? (...) You get singled out in that way
> (Mary; 20 year old son)

Losses in such relationships could mean either changes to ways of relating or loss of the relationships in total, but in either care such losses had an impact upon the parents' sense of role or identity. Imogen, whose daughter was three years of age, articulated that the complications of her daughter's illness limited her social life because she found it difficult to go out with all the equipment her daughter required. She described how her resulting isolation as well as the responses of others when she did get out changed her perception of herself. The parents' sense of self altered according to changes in the ways in which they related to other people. Sarah's life had altered over a period of 18 years to the extent that her own identity was consumed by her daughter's health. She connected this to the way in which she related to other people: her life was dictated by keeping her daughter healthy, to which her relationships with her husband and daughters and friends were subjugated:

> I don't know who I am any more, I don't have any friends anymore, I don't have a purpose - my purpose is to be my *daughter's* mum

However, longevity of experience was not a criterion for this perspective upon suffering. Jane's son was only 2 years of age, but she also linked her suffering to changes in how she related to other family members, including her husband, sick child and healthy child. In order to accommodate her child's ill health she had to accept significant personal adaptation:

> It's about not me, me, me, it's about my life how I've changed myself to be for this child.

Although not all parents defined suffering in this way, the significance of the loss of self can be found within the isolation which is a key theme of the lived experience of parenting a dying child (Chapter 4). Likewise, when talking about their lived experience, the parents did not characterise isolation as suffering, but altered relationships, altered identities and roles can all be seen to contribute to the parents' being set apart from other people. This was echoed when suffering was defined as loss of normality, as it was by Carol, whose daughter was 18 years of age. Carol related loss of normality to the way in which her immediate family lived their lives according to the needs of her sick daughter, and how this made their lives different to those of other people:

> You go without holidays, you go without, and I just feel that the boys perhaps have, because they've not had a normal, so called normal, they don't do normal things, they didn't go to, they don't go to football clubs, they don't go to this, that and the other

This group of parents defined suffering particularly in terms of relational loss which links to isolation. In this way, the parents appeared to judge their experience against a preconceived notion of 'normal' – be that the way in which they should parent their child, the way in which relationships were conducted and maintained, or lifestyles. Their ability to reach their aspirations of normality was limited by factors beyond their control: their use of time and the types of activity they could undertake were subjugated to the management of their child's illness. The management of their child's illness was dictated by institutional and professional evaluations, contemporary ethical judgements and political influence. Their suffering appeared to have been social suffering (Frost & Hoggett 2008; Kleinman et al. 1997).

I DO NOT SUFFER

A subsidiary narrative was that of parents who denied any link between their own experience and suffering. These parents used their narrative to refocus the spotlight upon other people. The non suffering parents' definitions of suffering were notable for their choice of contexts which were remote from their own experience. In addition, even when their personal definitions demonstrably mirrored their own experience these parents continued to deny suffering. Once again there was no clear contextual reason linking these parents: their children were of different ages; their marital status and genders differed, as did their family size. Therefore, their ideas of suffering were contextualised to individual experience, albeit under the shared circumstance of parenting a dying child.

These parents did not legitimate their own experience as suffering. They focused upon language - suffering was the wrong word and they tried to substitute different terms:

> Charles I don't think we're suffering, I don't think suffering is the right word
> RB OK. What would you say would be the right word?
> Charles Oh that's a tough one [laughs]
> RB [laughing] It's only going to get harder from here on in
> Charles Erm I think, obviously, it's erm, anxiety creeps in there
> (Charles; 18 year old daughter)

Furthermore, as they clarified their definitions of suffering, their descriptions made reference to issues they may have encountered themselves. As this happened, they adjusted their narrative to explain why their own experience was still not suffering: they may have fitted the description, but theirs was a less severe example and therefore not suffering. Finally they adjusted their definition so that they *could not* fit, bringing in the examples of suffering which contrasted starkly with their own experience. For example, when asked how she would define suffering, Diana, who had previously described her own failing health and struggle to secure statutory support in her caring role, answered:

> I'm not poorly, am I? I'm healthy – well I'm as healthy as I'll ever be. I've got arthritis in me knees. No, I don't, I'm not suffering. As long as I get a break and the help and support from social services I think I'm not suffering. I'm not suffering like kids and adults in Africa.

When these parents *contrasted* personal experience with that of others who they perceived did suffer, it was as if to emphasise that their own experience could not be suffering. In so doing they focused upon concrete experiences rather than their meanings: living in a war zone, having a bodily impairment, facing starvation. By discounting the ways in which their own experience corresponded with their own definitions of suffering, they refused to seek legitimation of their own experience as suffering. There was an immediacy and specific personal impact in each of their examples which clearly contrasted with the longer term and more abstract nature of their own experience.

SOMETIMES I SUFFER

The second subsidiary narrative was of wavering between suffering and not. The parents who provided this narrative were different in many ways: their genders, marital status, ages and longevity of living with a dying child all differed. Like the other two groups, the fact that the contexts from which their similar narratives were drawn were quite different supports the notion that suffering is individually constructed. However, that they constructed a similar narrative out of differing circumstances suggests that suffering is simultaneously socially constructed and draws on social interaction for its character.

This subsidiary narrative was characterised by the parents' difficulty with placing themselves centre stage in the spotlight of suffering. In considering the application of suffering to their own lives, they linked its definitions to the influence of time and other people. They reflected that the term might apply to them, but placed clear boundaries around its application. The clearest boundary was that of time: suffering had occurred in the past. The parents focused on concrete and recognisable issues: dealing with bad news, shock, repeated admissions to hospital, trying to juggle the needs of a sick child with everyday life at specific times, their child's critical illnesses, and the prospect of their child being disabled:

> I think we suffer when we are in and out of hospital every 7-10 days over a period of months like we used. We don't, we're not quite as bad as that now but for a couple of years we were doing that
> (Michael; 10 year old son)

Each of these issues had occurred in the past, and was presented as if dealt with. Such issues were contrasted with the present time: the child was no longer acutely ill, the shock had lessened, and parents had become accustomed to the child's disability. This resonates with the analysis of the parental experience as a whole, whereby the child being diagnosed with a life limiting or life threatening illness brought about abrupt change. The parents who wavered in their suffering provided clear metaphors of this, such as entering a tunnel or a deep hole, from which it was difficult to emerge. Once again, it is clear that these parents' definitions of suffering clearly link to the overall experience of parenting a dying child, presented in Chapter 4, whereby a defining feature was uncertainty.

In this complex and unpredictable context, the wavering parents recognised that they had to cope. Over time they adapted to their emerging situations, but in their discussions they related coping to their interactions with other people, both individuals and the institutions they represented. The parents described other people's lack of insight and their own dwindling expectation that others might understand which limited how much they shared with other people:

> People don't understand, no words, you can't explain to people what it's like. It's very hard, your whole life. Personally, my whole life felt like it was taken over with *my son's* condition – you know, in and out of hospital 7 times in 14 months, and people just say "oh is he in hospital again?"
> (Valerie; son died aged 19 years)

Such interactions have been explored in detail within Chapter 6, relating to emotion management. Within that chapter it becomes clear that communication about the experience of parenting a dying child is particularly challenged with respect to emotion. Parents altered their presentation of affect according to other people's responses, tending not to present an accurate picture of their emotional selves.

With respect to suffering, it appears that the wavering parents became accustomed to other people not recognising their plight. As a result, they stopped presenting that version of self and seemed to struggle to recognise it themselves: they no longer legitimated their own experience as suffering. This was born out in the ways that these parents contradicted themselves in their discussions about suffering. They initially denied suffering, but then recognised that they had experienced it, but relegated it to the past. Finally these parents refocused the discussion upon other people, such as the suffering experience of their children.

It may have been that these parents struggled to legitimate their own experience as suffering as a result of other people they encountered not seeming to do so. This occurred in every day life and at moments of crisis. Planning for the future and determining outcomes for their dying child and their family was to an extent taken out of these parents' hands by political and professional processes. Such processes determine the technological and ethical boundaries of health care, leaving the parent to observe and comply with the subsequent decisions. This is clearly illustrated in the experience of a mother in this wavering group, who had been told her newborn son would only live for two weeks.

She took him home, expecting to care for him in the short term until he died. His health cycled between stability and deterioration and she had to decide whether to pursue surgical treatment or symptom control. She consistently chose the latter, but still technological advances in therapies enabled her son to live. When describing the course of his life and the constant changes in outlook, she clearly articulated that her early and ongoing response to his diagnosis was to accept death. Ultimately, this decision was overridden by technology and professionals: her decision making as a parent was subjugated to institutional and cultural norms. This group of parents appeared to experience social suffering, albeit they did not recognise it as an ongoing entity. Their decision making and thus their agency was appropriated by institutions and professionals. In the face of such de-legitimation, it is not surprising that these wavering parents struggled to legitimate their own experience as suffering.

7.6 Discussion

These parents' children were dying. The fundamental and glaringly obvious issue at stake in their experience (Kleinman 2006; Kleinman & Kleinman 1991) was their child's survival. However, there was more to be said: their own lives became reorganised and subjected to forces over which they had little or no control. These included ethical decision making, advances in medical technology, the organisation and regulation of childhood and parenting, all of which influenced and were influenced by social policy. What the parents described was the way in which their experience was an embodiment of culture, politics and society (Kleinman et al. 1997; Wilkinson 2005 p.85), which led to their identity, relationships, certainty and place in society being put at stake (Chapter 4).

The nature of their experience thus was underpinned by issues of intersubjectivity. In Chapter 4, I set out how their place in society was put at stake and they became isolated so that there were fewer opportunities to engage with other people about their experiences as the parents of dying children. In addition, in Chapters 5 and 6, I highlighted how the communication of these parents' experiences was problematic. They perceived that it was not legitimate to express particularities: negative emotion was not acknowledged by other people or was acknowledged with discomfort. Therefore, over time, the parents learned to manage their emotions and in particular to suppress negative emotions. In so doing, however, they presented a version of self which could be classed as inauthentic – it did not reflect their felt experience. In turn, this further limited intersubjectivity by preventing those they encountered from gaining insight or shared meaning about the phenomena of parenting a dying child. The findings of Chapter 7 further connect these parents' experiences to suffering theory with respect loss, intersubjectivity, hierarchy and social suffering.

Initially, the findings in this chapter substantiate the personal nature of suffering (Cassell 2004; Wilkinson 2005). The parents provided individual definitions and examples of suffering. Simultaneously, cross case analysis using those definitions demonstrated that the same issues were raised by different parents, but not always labelled as suffering. In this respect, defining suffering as loss also seems valid, since a number of the issues at stake for these parents, which were seen as losses (Chapter 4), were reflected in their definitions of suffering. However, the evidence of some similarities between definitions suggests that suffering is also socially constructed, based upon shared judgements according to cultural and historical norms (Morris 1997). This is also illustrated by the parents clearly placing their definitions of suffering, as well as their own experiences, within perceived hierarchies.

Within the existing literature, hierarchy in suffering is considered with respect to both the form of suffering and the sufferer. Both are subject to moral judgement and a hierarchy of moral status may exist for both (Charmaz 1999; Connolly 1996; Ramphele 1997). The moral framework through which the individual is judged and judges themselves is established within and through society (Morgan & Wilkinson 2001; Morris 1997). In addition, judgement and hierarchy in suffering are noted to influence the legitimation of the experience for the individual (Charmaz 1999; Connolly 1996; Morris 1997). A number of different hierarchies were suggested by the parents according to the different types of definition and example they provided. Thus the child's or parent's health, levels of support or general lived experience were all ranked according to a hierarchy. Significantly, the parents in this study judged *themselves* against a perceived hierarchy and in so doing they either legitimated their own experience as suffering or *de-legitimated* it.

The legitimation of suffering is addressed within the literature through its attendance to two issues: authenticity of voice and judgement of suffering. There is concern that the authentic voice of the sufferer is essential for accurate communication about suffering (Bourdieu et al. 1999; Das 1997; Morris 1997; Schwarcz 1997). Additionally, there is anxiety that the authentic voice can become sublimated to secondary agendas (Frank 1995; Kleinman and Kleinman 1997; Morris 1997; Smith 1999; Frank 2001). The findings of this project are that for all the parents there was a degree of appropriation of their experience and sublimation of their voice by society through 'political, economic and institutional power' (Kleinman et al. 1997 p.ix). However, my analysis also shows that individuals can sublimate their own voice through their choice of language and application of self-constructed definitions of suffering. This self-sublimation of voice was also noted in Chapter 6 when considering emotion management: in suppressing negative emotion, parents presented a version of self which sublimated their authentic feeling about their experiences. In this way the parents jeopardised their own authentic voice.

Suffering theory goes on to demonstrate how legitimation of experience has significance with respect to securing support of different types, including emotional, social and financial (Charmaz 1999; Ramphele 1997). These parents of dying children identified isolation as a key feature of their experience which was at once inflicted and self imposed (Chapter 4). In refusing to legitimate their own experience as suffering, some parents may have influenced other people's responses to them and risked excluding themselves from support, which may further have disposed them to isolation. However, that is not a criticism of these parents, but an observation of the possible outcomes of their actions. As such, it must be noted that their behaviours and perspectives derived from their interactions in society.

The parents' constructions of suffering and judgement of their own experiences were contextualised to societal norms and expectations which they were powerless to resist. In this respect their experiences again appear to bear relation to social suffering, which 'brings into a single space an assemblage of human problems that have their origins and consequences in the devastating injuries that social force can inflict upon human experience' (Kleinman et al. 1997p.ix). The parents were all at the mercy of society with respect to their child's health and their own subsequent life experience. Their children's health was shaped by technological, cultural and political developments which influenced ethical, therapeutic and funding decisions. This seems to echo Wilkinson's contention, shaped by reference to Weber and Parsons, that modernity exposes individuals to more vulnerability and suffering through greater rationalisation of society (Wilkinson 2005; Wilkinson 2010). For these parents, societal processes in the context of health policy turned the child into a public resource for decision making, reducing the parent to the role of observer. Thus professional and political appropriation of a private experience made it public and sublimated the parental voice.

Likewise, social suffering was apparent when these participants compared their parenting against their perceptions of 'normality'. Through their reflections upon their children's suffering, they judged themselves against societal ideas of parenting. In this they established a loss of their parenting role as measured against those norms, which put their identity and place in society at stake. The norms to which they referred were reflective of contemporary social constructions of childhood and parenting which are upheld by social policy (Chapter 1). Thus they perceived that their role was to protect their children and enable them to achieve their potential and their reflections illustrated instances of institutional scrutiny for their achievement of these goals.

However, the participants in this study were subjugated to the norms of a society within which the death of a child is rare. Indeed, as set out in Chapter 1, the historical development of social policy has in part focused upon securing that rarity. The contemporary position is the parents of dying children are largely invisible in both society and policy so that there is little account taken of how such an event may alter the lived experience of a parent and subvert their ability to achieve expected norms. Moreover, there is no recognition of the profound effect upon the self for parents who fail to reach those expectations. That these parents are not visible in society is thus attributable both to the relative rarity of their experience – infant and childhood mortality rates are at their lowest recorded levels in England (Cochrane et al. 2007) - and to the ways in which their lived experience is encountered within a society where social policy disregards their needs.

Observers may locate the suffering of parents such as these in the death of their child. Yet the parents' descriptions suggest that suffering is located at least in part in living with a dying child. Their day to day experiences were shaped by societal norms constructed and upheld by policy based on the majority of parents whose children are healthy. Their encounters with society therefore reinforced their invisibility: in other words they were perceived by themselves and others as 'superfluous' (Wilkinson 2005 p.95). These parents seemed to experience social suffering. And yet, not all of the parents would define themselves as suffering.

Each parent's definition of suffering bore close relation to the matters that were at stake in their overall lived experience. Nonetheless, cross case analysis using the individual definitions highlighted that the same issues arose from different parents, but may not have been defined as suffering. Suffering is indeed profoundly individual (Cassell 2004). Yet, through thematic analysis of the parents' individual definitions of suffering, I noted three distinct narratives: 'I suffer', 'I do not suffer', and 'Sometimes I suffer'. In a small sample it is difficult to judge why such different narratives might occur – and perhaps that is not necessary, for the significance of this finding is located in how it draws attention to the need for clear communication concerning suffering.

In the absence of asking the parents for their own perspective upon the meaning of suffering in relation to their lives, this research could have concluded that the parents of dying children suffer. Such a conclusion would have been justified through the analysis of their reflective experiences within the theoretical framework of suffering. In reaching that conclusion, however, some of the parents' voices would have been subjugated to the agenda of this research project (Frank 2001). This last finding therefore determines that only through effective communication with each individual, enabling their authentic voice to be expressed, may their personal perspective upon their lived experience be known.

To assume a label of suffering establishes a context for communication which may be inaccurate and may not only hamper effective communication but also prevent ways of interacting with the individual which are meaningful *to them*. Indeed, in Chapter 6, section 6.3, I noted the importance of other people's responses to the parents. The parents' perceptions of how other people responded to them in a variety of everyday life interactions illustrated that the impact of such responses was seen in emotion management through the development of rules and scripts (Hochschild 1983; Wharton and Erickson 1993; Bolton and Boyd 2003). The result was that parents presented a version of self in which negative emotion was managed and an inauthentic account of their felt experience was voiced. The inauthentic account then contextualised ongoing interactions, contributing to the invisibility of this group. Therein is the significance of emotion management in suffering: it reduces intersubjectivity by jeopardising authentic voice.

Aside from the brute fact of their child's death, these parents described a variety of issues at stake in their experience. Whatever label they chose to characterise their lived experience, suffering or not, they described similar issues and interactions. For such parents, their children's diagnoses cannot be changed, but the way in which they encounter the world may be, in particular the way in which they encounter health and social care professionals. Improving communication through attending to emotion management may contribute to improved intersubjectivity and in this way observers may be given a window onto such parents' experience.

After their interviews, I contacted each parent to check that they had experienced no ill effects. None had, but several commented on the benefits of talking about their experience, often likening it to counselling. When I met with parents to feedback my analysis to them, they responded with emotion, visibly crying. At one point I stopped my presentation because I was concerned for their wellbeing. However, they stressed that they supported my analysis and that their emotion reflected relief at having been heard and that such an experience was rare. Ultimately, these parents did not necessarily want to be *labelled* as suffering, even parents who described themselves in such terms, because it might influence how they related to other people. This final finding reinforces the importance of effective communication:

> I think when you talk about the word suffering I my immediate feeling is I don't want anyone to think I'm suffering because I'm not a victim.

And it’s a whole thing, isn't it? It's about the way you want people to see you
(Sarah; 18 year old daughter)

Chapter 8 Conclusions

Introduction

The thesis aimed to examine the hypothesis that emotion management influences the communication and legitimation of suffering. In order to achieve this, a series of research questions were set out:

1. What is the lived experience of parents of dying children?
2. How do other people's responses shape the parents' lived experience?
3. What is the place of emotion and suffering in the parents' lived experience?

The initial sections of this final chapter provide the empirical and theoretical conclusions of this study, using the research questions as a framework. Following those, methodological implications are reviewed, including both strengths and limitations of the study. The chapter finishes with suggestions for policy and future research implications.

8.1 Empirical Conclusions

What is the lived experience of parents of dying children?

Childhood death in twenty-first century England is a rarity (Cochrane et al. 2007). Therefore, the parent participants in this study were a minority group and they described a lack of societal understanding of their situation. This is perhaps unsurprising given that the population of these children remains small relative to the population of healthy children so that there are no clear cultural references for children with life limiting or life threatening illness (Craft & Killen 2007). As a result, this group were already relatively invisible in society. However, elements of their experience conspired to make them still more hidden and this had impact upon their ongoing lived experience.

The experience of the parent participants in this study was characterised by a number of important issues being put at stake. These included time, identity, relationships, place in society, certainty and the life of their child, each of which could also exemplify loss. The losses which the parents articulated were existential and relational in nature and essentially concerned intersubjectivity. Intersubjectivity relates to the development of shared meanings amongst people about social phenomena (Prus 1996) and is achieved through language, relationships, emotion, culture & politics (Kleinman 1992). However, the losses these parents encountered consistently put intersubjectivity at risk.

The evidence for a lack of intersubjectivity was found throughout the data. In their narratives the parents described the ways in which intersubjectivity was limited both through their own and other people's actions. In addition, the observational and documentary data demonstrated that the nature of the parents' experience, and specifically their emotional responses to it, were poorly articulated in certain circumstances. It has been suggested that intersubjectivity is important for the restoration of self in suffering individuals (Cassell 2004). Yet, what emerged from this thesis was how both the 'quantity' and 'quality' of intersubjectivity were limited through the parental experience.

The losses they experienced set these parents apart from their peers and limited opportunities for interaction with society. Over time the nature of their lived experience led to ever decreasing opportunities for these parents to interact with others. Therefore their isolation, as a feature of their time, relationships and place in society being at stake, reduced the 'quantity' of intersubjectivity within which they could participate. Secondly, the nature of their interactions altered the 'quality' of their intersubjectivity. As set out in Chapter 6, these parents altered their presentation of self in everyday life through the management of their emotions, particularly those of a negative nature. In so doing, the voice they gave to their experience was a somewhat inauthentic account, but it was this upon which subsequent intersubjectivity was based. The possibility of the development of shared understanding was thus further put at stake by being founded upon inauthentic voicing of the parental experience.

Arguably, the reality of the parents' lived experience became less visible as intersubjectivity lessened. Moreover, in the absence of intersubjectivity, the legitimation of the parents' experience was also jeopardised. Through their losses, in particular their loss of place in society, associated with changes to key relationships and a degree of isolation and exclusion, the parents perceived that neither society nor institutions were able to accommodate their needs or experiences. The limitations placed upon intersubjectivity had consequences therefore for the legitimation of the parents' experience and thus the way in which the parents' experience was acknowledged was also profoundly affected.

How do other people's responses shape the parents' lived experience?
Through their experiences of exclusion and isolation (Section 4.5) and the lack of provision by health and social care institutions (Section 4.6), the parents in this study received a powerful message of lack of recognition which suggested de-legitimation. This is one way in which the parents' experience was acknowledged. However, a key finding was that emotion was a particularly powerful means of acknowledgement, or not, of the parental experience. The significance of emotion was in how it influenced legitimation of the parental experience.

A key distinction between the sources of data for this thesis (individual narratives, participant observations and child health records) was how the parental experience was acknowledged in each of them. In this respect, the ways in which 'other people' acknowledged the parental experience was important. However, equally significant was how the parents themselves acknowledged their experience. The acknowledgement of the parental experience hinged upon how it was communicated and responded to, for both of which emotion was an important issue. The 'official accounts' of the parents' experience, derived from both observed practice and documentary data, revealed little of the parental experience and, in particular, emotion was notably absent. In contrast, in their individual narratives the parents' acknowledgement of their own experience was abounding with emotion.

The parents of dying children who participated in this study acknowledged their experience with emotion. Their emotional behaviour comprised their descriptions of felt emotions and their expressed emotions (section 6.1). They expressed and described emotion as a response to their recounted experiences, through their interpretations of the interactions they had with other people and in their observed interactions. The findings from this research are that the parents' *felt* emotions were dominated by *negative* affect: they described a wider range of negative emotions than positive and described feeling them more often than positive emotions. On the contrary, they *expressed* emotions less often, and when they did so the emotions were predominantly *positive* in affect. Supported by both narrative and observational data, this finding illustrates that the parents in the study managed their emotions through emotion work (Bolton & Boyd 2003; Hochschild 1979; Hochschild 1983)

The parents acknowledged their experience with emotion, but they described and expressed different emotions and issues in different contexts. This was the case with both verbal and non verbal communication and both interview and observational data supported this finding. Concerning verbal communication, *in interview* all parents spoke in detail about specific personal concerns, expressing and describing emotion. In contrast, *during admission to the hospice*, none of the parents raised the same concerns. This may have been merely contextual and reflective of personal choice concerning who to speak to about what. However, analysis of the data demonstrated that it was not that the parents chose not to raise concerns with hospice staff, but instead they raised different concerns. In addition, parents spoke openly to me during participant observation about personal worries and feelings in the presence of the hospice staff. In both situations the response of the hospice staff was apparently to listen, but they did not attempt to converse with the parents about the issues raised.

The findings with respect to non-verbal communication were more complex. *On observation*, the parents seemed to express emotion, but their communication was somewhat contrary. They expressed either positive emotions, such as laughing or smiling, or no obvious emotion.

Simultaneously they appeared to demonstrate anxiety through their actions and words, for example by putting up notices regarding care, asking questions about care, describing distress. When the parents expressed positive emotions, the hospice professionals responded in kind, such as joining in laughing and joking. However, when the parents expressed negative emotions, either verbally or non-verbally, the hospice staff observed reactions were busyness and fixation upon the care task in which they were engaged. They appeared not to acknowledge what the parents were articulating about their experience. In this way hospice staff appeared to legitimate, by their actions, only the parents' positive reactions. Most importantly, by default, the actions of the hospice staff appeared to de-legitimate the parents' negative emotions.

The reduction in display and description of parental emotion during observations contrasted starkly with displays and descriptions of emotion during interviews and suggested management of emotions. Indeed, corroborating the observational data, the parents' narratives were replete with descriptions of how they carefully managed their emotions in everyday life. They did so in response to a variety of factors, including their perceptions of the listeners' responses. The parents managed their emotions across the spectrum of every day life (section 6.2), from interactions with intimates to those with strangers, and with respect to all kinds of issues, from birth to death. However, not all emotions were managed equally. Whilst negative emotions predominated as the felt emotions, the parents worked hard at not expressing them: negative emotions were managed.

The parents altered their behaviour, through their suppression of negative emotions, based on their interpretations of the rules and scripts for emotion management. The feeling rules which the parents employed did not legitimate negative feeling and therefore it was suppressed. The rules and scripts were at once derived from ongoing interpersonal interactions and contextualised to society. The parents highlighted a number of recurrent unwelcome responses they encountered in their day to day interactions (section 6.3). These included inability to cope, pity, lack of understanding, and lack of empathy. The parents learned to suppress their emotions, particularly those of negative affect, in order to avoid such responses, and thus a script for emotion management was derived.

Concurrently, social policy and social constructions of childhood contributed to the development of a script for parental emotion management, through neglect of the needs of this minority group. As set out in Chapter 1, current social policy emphasises the health, well being and survival of children for both their future utilitarian value to society and their psychosocial value to parents (Hendrick 1997a; Jones & Brayfield 1997). Additionally, both individual and societal measures of the value of children focus upon the sacralisation of children (Zelizer 1994) so that contemporary childhood and parenting has become standardised through institutional scrutiny, monitoring and control (Moran-Ellis 2010). When social constructions of childhood are founded on children's long term survival and well being, supported by ever declining mortality statistics (Cochrane et al. 2007), cultural references for childhood death become ever more limited. Instead, the focus of social policy is upon measuring health and achievement.

The contrast was stark between the societal agenda for parenting, epitomised in social policy, and the lived and felt experience of these parents whose children were dying. For some parents this was evident on a day to day basis as they simultaneously parented both healthy and dying children. Social policy for childhood and parenting envelops daily life, particularly with respect to growth, development, health and education, for which institutional monitoring is fundamental. Moreover, the institutions and monitoring to which these children and parents were subject were not designed to serve the dying, but to promote health and achievement. The fact that these parents' experiences are barely recognisable in contemporary social policy seems to de-legitimate both their lived and their felt experience and in fact to reinforce their abjection (Frost & Hoggett 2008). As the context for day to day interactions contemporary social policy supported the development of a script for parental emotion management in which negative emotion was de-legitimated.

What is the place of emotion and suffering in the parents' lived experience?

De-legitimation was both the *experience* of these parents and the *impact* of their experience. The consequences of individual experience not being legitimated are noted within the literature: the individual's experience becomes subjugated to the agenda of observers with important implications for how the suffering experience is communicated and responded to (Kleinman 1988; Kleinman & Kleinman 1997; Wei-Ming 1997). Thus, in this study, the parents chose to communicate different things about their experience in different contexts: parents managed their emotions according to context (Hochschild 1979). Previous research has also demonstrated that individuals may choose whether to submit to a legitimated representation of their experience and may alter their behaviour accordingly (Cassell 2004; Charmaz 1999; Kleinman 1988; Ramphele 1997). The parents in this study did alter their behaviour, by managing negative emotions, and appeared to submit to their perceptions of a legitimated version of their experience, wherein expression of negative emotion was prohibited. However, whilst their behaviour altered, their felt emotions did not. In managing their negative emotions, therefore the parents themselves appeared to de-legitimate elements of their own experience.

Legitimation of experience has been noted to influence both outcomes for and behaviours of suffering individuals in a variety of contexts, including poverty (Kleinman & Kleinman 1997), personal illness (Cassell 2004; Kleinman 1988), and politics (Ramphele 1997). In this thesis, de-legitimation by both the parents themselves and 'other people' had consequences for the parents' ongoing lived experience. Importantly, the impact could be traced back to the issues at stake which the parents highlighted in their narratives and which shaped their day to day life, demonstrating the iterative nature of their experience and its acknowledgement. Thus the consequences of lack of legitimation were seen in the parents' daily lives of exclusion, isolation and lack of support and the impact of these upon time, the parents' sense of identity, their relationships and certainty (Chapter 4). Reactions to their felt experience led to management of negative emotions and presentation of self which was at odds with their felt experience (Chapters 5 & 6). In this way the parents' voicing of their experience was somewhat inauthentic, which itself contributed to a lack of intersubjectivity. However, intersubjectivity was already put at risk through the material facts of their existence and the ways in which their day to day lives were consumed by managing their child's health.

Ultimately, both the brute fact of their child dying and the impact of the parents' experience being acknowledged or not could be seen as suffering, since both exemplify 'resistance to the lived flow of experience' (Kleinman 1992 p.174). More specifically, these parents could be judged as victims of social suffering. Their lives were subjected to forces over which they had little or no control, including medical ethics, technology, and societal regulation of childhood and parenting, all influenced by social policy. The parents' experience was thus an embodiment of culture, politics and society (Kleinman et al. 1997; Wilkinson 2005 p.85). However, most striking about their narratives in general, and their views on suffering in particular, was the significance of communication of their experience. This was underscored by the fact that even suffering parents did not necessarily want to be labelled as such.

The place of emotion was particularly important in the *communication* of the parental experience. This research has found, unsurprisingly, that the experience of parenting a dying child was inherently emotional. Moreover, the predominant felt emotions were negative in affect. Remarkably, however, the communication of the parental experience was notable for its absence of emotion. Emotion was actively removed from communication about their experience by the parents themselves using processes of emotion management. In managing their emotions, however, the parents voiced a somewhat inauthentic account of their experience in which elemental parts of it were not legitimated. Primarily, however, it must be recognised that they did so according to their perceptions of feeling rules and scripts. These were derived from their day to day interactions and supported by social policy and it was from these that de-legitimation of their lived and felt experience stemmed.

8.2 Theoretical Conclusions

Suffering defies definition because it is fundamentally an individual and personal experience (Frank 2001). Yet to not attempt a greater understanding risks further violence to those in pain (Cross 2001; Wilkinson 2005). One means of understanding the features and components of the phenomenon of suffering, whilst retaining the individual perspective, is to consider what is at stake for the individual sufferer (Kleinman 2006; Kleinman & Kleinman 1991). In so doing, both concrete issues and their impact upon the individual lived experience can be contemplated (Kleinman 2006). When issues are at stake, they may be at risk of being lost to the individual, and there is a wealth of research demonstrating the losses associated with suffering and how both the losses themselves and their consequences are meaningful for the individual (for examples seeBlack & Rubenstein 2004; Charmaz 1999; Sacks & Nelson 2007).

The notion of suffering as loss suggests that whatever was lost held value for the individual and was subject to judgement. Judgement is inherent in suffering and comes from the suffering individual as well as observers. Individuals may judge their suffering experience as they search for meaning (Clark & Seymour 1999; Morgan & Wilkinson 2001). Alternatively, sufferers may judge their experience according to how it embodies 'resistance [...] to the lived flow of experience' (Kleinman 1992 p.175). In this way, several studies have demonstrated the significance of loss of self, signifying judgement of lifestyles and identities (Charmaz 1983; Charmaz 1999; Sacks & Nelson 2007). In judging their own experiences, such sufferers emphasise the centrality of the personal perspective upon suffering. However, it is equally clear that judgement by observers blurs the perspective of the individual, with profound consequence for their on-going lived experience.

Such external judgement is ubiquitous. It may occur at a societal level through political processes (Cross 2001; Ramphele 1997); through cultural norms (Charmaz 1999; Lock 1997; Morris 1997); or even through services whose inception was for the purpose of relieving suffering, such as healthcare (Edwards 2003; Kleinman 1992; Kleinman 2006). The judgement that takes place concerns both the nature of the suffering and the response of the sufferer. Each may be judged according to moral norms which are historically and culturally bound and which facilitate the construction of hierarchies within which both individuals and their experience may be ranked (Charmaz 1999; Morris 1997). Such external judgement may have profound consequences for the individual concerning the availability of material or psychological support (Connolly 1996; Farmer 1997; Ramphele 1997). In this respect, perhaps the most influential outcome of judgement is in how it legitimates or de-legitimates experience.

Whether or not a suffering experience is thus judged as legitimate or not is to some extent dependent upon the way in which the facts of that suffering are communicated. Giving voice to suffering and the means of doing so are therefore crucial, but equally problematic. Some would judge that there is limited worth in attempting to give voice to suffering, since no-one but the sufferer can hope to give adequate insight (Frank 2001). Others assert that failing to give voice to suffering risks its continuance through inaction by institutions which may influence the situation (Cassell 2004; Cross 2001; Schwarcz 1997; Wilkinson 2005). Where giving voice is attempted there are concerns about the limitations of language. Language is culturally and historically contingent (Das 1997; Morris 1997; Skultans 2003), however, some situations of suffering are thought to be so extreme as to be inaccessible by language (Langer 1997). So it may be that at times silence is the only possible response to suffering and may thus be a demonstration of agency (Das 1997; Morris 1997). Yet it may be important to 'probe the cadences of silences, the gaps between fragile words, in order to hear' (Cross 2001 p.273), thus the listener should attend to both that which is spoken and that which it is impossible to speak.

Ultimately, then, in any attempt to give voice to suffering, consideration must be given to the authenticity of the account. In this respect, authenticity refers to whether or not a sufferer's experience is being accurately represented. The concern is that misrepresentation risks perpetration of further suffering upon the individual, through metaphorical violence (Bendelow 2006; Kleinman & Kleinman 1991; Wilkinson 2005). Misrepresentation occurs when the suffering of the individual is subjugated to the agenda of the observer and, accordingly, the authenticity of representations of suffering have been questioned where they originate through the media, research, and healthcare professionals. So researchers may engineer individual narratives to correspond to theoretical agendas (Bourdieu et al. 1999; Frank 1995); media sources may appropriate suffering for corporate benefit (Kleinman & Kleinman 1997); and professionals may disregard individual perspectives which are not amenable to the available means of therapeutic amelioration (Kleinman 1992; Kleinman & Kleinman 1991; Ware 1992). The voicing of suffering is thus both a response to suffering and an influence over further responses to suffering. Moreover, both the voicing of suffering and responses to it are crucial for its legitimation or de-legitimation (Kleinman 1992).

The legitimation or de-legitimation of experience, as a measure of its judgement, has consequence for the individual (Connolly 1996; Farmer 1997; Ramphele 1997). Whilst those consequences may arise at a local and immediate level for the individual, they are influenced by the structuring of societies and are representative of social suffering (Bourdieu et al. 1999; Kleinman et al. 1997). Whilst many writers focus upon large scale tragedy as a basis for understanding social suffering (for example Das 1997; Langer 1997), it is equally apparent in everyday life as 'la petite misère' (Bourdieu et al. 1999 p.4). This is because social suffering comprises the ways in which social institutions and norms influence the lived experience of ordinary people both directly and through influencing responses to those experiences (Bourdieu et al. 1999; Kleinman et al. 1997). Social suffering is thus seen in experiences of 'domination and repression, including feelings – humiliation, anger, despair, resentment – that may accompany, for example poverty, class or race' (Frost & Hoggett 2008 p.439).

How an individual's lived experience is structured and responded to is therefore dependent upon the society in which they live and its moral, cultural, political, economic and institutional norms and powers (Kleinman et al. 1997). Both how an individual suffers and whether they are empowered to give true expression to their experience are thus shaped by societal expectations of behaviour and responses (Charmaz 1999b; Ramphele 1997). As a means of developing shared understanding about phenomena, intersubjectivity is a product of language, relationships, emotion, culture & politics (Kleinman 1992; Prus 1996). Therefore, whether or not a person's experience is legitimated in society has import for their own and other people's responses to it, and so intersubjectivity is also significant in social suffering. However, as has been noted, suffering may be judged, its authentic voice may be obscured, and communication about suffering may be problematic, all of which limit intersubjectivity.

If the legitimacy of suffering is dependent upon it being framed in certain ways, sufferers may feel obligated to behave in particular ways to secure recognition, status or support. So the politically rebellious may submit to the label of casualty of war (Ramphele 1997), the poor may submit to the label of victim (Kleinman & Kleinman 1997), the sick submit to the label of a physiological disease (Cassell 2004), all in order for recognition and ongoing support to be obtained. The price of legitimation, however, may be disregard of the personal perspective upon the suffering experience which itself forms part of the suffering, albeit perhaps unrecognised (Wei-Ming 1997).

Suffering has been noted to be rooted in 'resistance'- road blocks to individual hopes and expectations – for which there are both moral and bodily outcomes (Frost & Hoggett 2008; Kleinman 1992). As both an embodiment of the experience and an expression of reflexivity, emotion is important in the voicing of suffering (Frost & Hoggett 2008). Emotion may be the response of the individual or society and accordingly the literature recognises the importance of the politics of compassion (Wilkinson 2005) and the need to generate concern about suffering within society (Langer 1997). At a more intimate level, empirical work has explored the emotions of suffering, particularly those of caregivers (Gregory & Longman 1992; Hinds 1992). However, the expression of emotion is equally bound up in social rules which concern appropriate ways of presenting the self in public (Goffman 1969a; Hochschild 1979; Kemper 1981; Hochschild 1983).

What a person feels and what they appear to feel may be quite different and manifesting a physical appearance which is at odds with felt emotion requires management of emotions (Hochschild 1983). Emotions are inter-subjective and emotions can be seen to be organised within relationships, be that between two people or more (Burkitt 1997; Rafaeli & Worline 2001; Theodosius 2006). This gives rise to feeling rules, which guide emotional expression and may be grouped together into scripts (Bolton & Boyd 2003; Hochschild 1983; Wiley 1990). Feeling rules therefore govern emotion management, which may be further broken down into emotion work (carried out in private) and emotional labour (carried out in public or work orientated) (Hochschild 1979; Hochschild 1983).

Feeling rules may pertain specifically to organisations, professions or peer groups (Karabanow 1999; Ruane 1996; Wiley 1990) and individuals may simultaneously encounter multiple sets of feeling rules from which they must choose how to react to given situations (Bolton 2000; Bolton & Boyd 2003). Likewise, individuals may have multiple roles in their lives, each of which may influence the other with respect to emotion management (Craib 1995; James 1992; Rafaeli & Worline 2001; Wharton & Erickson 1993). Thus, just like the voicing of suffering, the expression of emotion is vulnerable to manipulation according to social context.

Whilst Cassell (2004) noted the importance of effective communication in promoting intersubjectivity, in contrast, this thesis demonstrates how intersubjectivity may be limited by communication when emotion is managed. Emotion is significant in both the embodiment of suffering as well in the voicing of suffering. Management of emotion may jeopardise the authenticity of either and thus impact upon intersubjectivity and legitimation of experience. Therefore it is vital that attention is paid to emotion in whatever circumstance suffering is encountered. In this respect, attendance to the *management* of emotion is critical: finding ways to look beneath what emotions the individual appears to express in order to grasp what they might be feeling.

There are some situations of suffering that can be made good: poverty may be relieved, health may be restored, and victims of crime may be compensated. However, there are instances where the relief of suffering is problematic, such as when the context of the suffering is incurable disease or when a loved one dies. Such situations cannot be rectified and a response which pretends or attempts to do so could be damaging (Langer 1997; Schwarcz 1997). In the absence of being able to prevent or resolve the suffering experience itself, it is essential to consider how furtherance of suffering might be prevented. One means of doing so is to legitimate personal experience which may be achieved through effective communication and improved intersubjectivity (Bourdieu et al. 1999). Until observers engage with the felt emotion of the suffering individual, the possibility of legitimating personal experience will always be limited.

8.3 Methodological Implications for Conclusions

Whilst the empirical and theoretical conclusions are supported by the data of this thesis, it is important to consider the ways in which the study design and methodology might impact upon those conclusions. This section sets out the limitations of the empirical work as well as its strengths as the context for the conclusions which have been drawn.

Location

The research was based in a single children's hospice, the choice of which was justified in Chapter 3. It is located in a rural setting and its client base is predominantly white English. Whilst this may mirror some children's hospices, others are geographically located in more urban settings and have a more ethnically diverse client base. My attempts to address this through the sampling strategy had limited success. Therefore, it must be acknowledged that the sample of parent participants in this research may not necessarily reflect the wider population of parents who access children's hospices and thus any claims regarding external validity are limited.

Small numbers

Although the data collected in this study was extensive, both in terms of variety and quantity, it is clear that the sample size (nine parents) is small. Whilst it is important to acknowledge this fact, there are a number of reasons why it may be less significant than at first thought. Firstly, since the design and methodology were intended to achieve depth of study, rather than breadth, it could be argued that sample size is less of a concern. Secondly, the literature review highlighted a lack of existing research concerning suffering in the context of parenting a dying child, so this study facilitated an initial window onto that experience where none has previously been available. In this respect, the research never intended to provide a definitive answer concerning the experience of such parents, but merely to begin to locate an initial basis for advancing clinical practice. Finally, with respect to the wider population to which the empirical findings of this research might be directly applied, the population of children and families who require palliative care is itself small (Cochrane et al. 2007). Moreover, that population is not yet well understood or defined (DH 2008). Therefore, determining a representative sample would have been problematic.

Nonetheless, in drawing the theoretical conclusions of this research I expect it to be transferable to contexts wider than children's palliative care. In this respect, the study aimed to explore multiple realities of suffering and emotion management and this is achieved, albeit with a very small range. Therefore it is reasonable to argue that the findings of this small study may be appropriately theorised more broadly, since the elements of communication which have been explored are applicable in range of situations. In providing a detailed account of the manner in which the data was collected and analysed, and theory generated, I have provided a framework enabling comparability with other settings (Guba & Lincoln 1989; Schofield 2000). Ultimately, however, the decision to accept or reject the findings of this study lies with the reader (Guba & Lincoln 1989; Wolcott 1994).

Gender

The findings of this study may be judged as gendered since the majority of research participants were female. During the sampling procedure I aimed to engage with both parents involved with a particular child, but in most cases it was the mother alone who responded. Attempts to draw in the fathers were unsuccessful. The reasons given were lack of time or inclination to participate. This latter point may have been due to the research design or the gender of the researcher (also female). In itself this is a significant finding, drawing attention to the need to consider ways of engaging with fathers in children's palliative care. Given the limitations of the small sample size which I have already acknowledged, it must be recognised that this study does provide *some* representation of fathers' perspectives, albeit small in size.

In providing insight into the experience of mothers of dying children, this study makes a useful contribution to a speciality wherein the evidence base for practice is limited. Therefore the issue of gender is of more significance in the theoretical conclusions than those of an empirical nature. In particular, gender is important in the sociology of emotion, since it is bound up in notions of role, stereotypes and power relations and their influences upon emotional expression (Shields et al. 2007). Since this study is particularly concerned with the influence of emotion management upon the legitimation of suffering experiences, the gendered nature of the study is therefore a limiting factor upon its transferability.

Researcher bias

Ethical approval for this study was achieved using standard procedures. Being employed as a nurse in the hospice in which this study was based facilitated straightforward access to the participants, founded upon the organisation being satisfied with the trustworthiness of my skills and knowledge. To gain access elsewhere would have required extensive negotiation because of the sensitive nature of the work and because I would have been unknown. However, being known to the organisation was also a limiting factor in the generation of data.

In sampling I was careful to select parents with whom I had no pre-existing clinical relationship, in order to limit my pre-judging of their experiences. In addition, the research design was intended to privilege the participants' perspectives throughout. However, this research is rooted in concerns around the ways in which sufferers' voices may be sublimated and it must be acknowledged that the fact of my employment in the hospice may have influenced the narratives they presented both in interview and during participant observation. In the defence of my position, the data demonstrates that the parents were content to raise both positive and negative aspects of their experience. However, the possibility of my presence being a mechanism for the sublimation of the parental voice cannot be overlooked.

Perspectives on reality

As established in Chapters 2 and 3, 'realities' are subjective and are individually constructed as phenomena are encountered in day to day life (Heron & Reason 1997). As such, the construction of 'realities' is reliant upon individual interpretation and may be multiply contingent (Brown 2009; Prus 1996) which must be accounted for in the research design. Moreover, when the focus of study is the influence of intersubjectivity, that design must account for different perspectives. As an expert in the study of suffering, Kleinman's emphasis upon local worlds, life trajectories and ethnographic methods in order to understand subjective experience has been considered in the design of this research (for example Kleinman 1980; Kleinman 1992; Kleinman 2006). A true ethnography with families would have been too intrusive - a decision which has been justified given their descriptions of their lived experiences. Instead, efforts were made to gain access to their local worlds through the use of narrative and participant observation, and this is a strength of this research (Kleinman 1992).

8.4 Research, Policy & Practice Implications

Research

The health and wellbeing of children in England have significantly improved over time. Historical developments in social policy have supported that through employment, education, welfare and health strategies. As a result, infant and child mortality are at their lowest recorded levels in England and child death is a relatively rare occurrence in contemporary society (Cochrane et al. 2007). Yet for some families child death remains a reality and palliative care services are provided for cases such as these. Palliative care is fundamentally concerned with suffering (WHO 2002) and children's palliative care additionally sets out to support not only the child-patient, but also their family (ACT/RCPCH 1997; ACT/RCPCH 2003). Importantly, the notion of care within children's palliative care services, which extends to the whole family, is noted to include an emotional component (ACT/RCPCH 1997; ACT/RCPCH 2003).

Both suffering and emotion are therefore fundamental in children's palliative care, yet in reviewing the literature I found no empirical studies concerned with suffering amongst parents of dying children. There was one study which drew on the perspectives of mothers and fathers of children diagnosed with cancer (Clarke 2005; Clarke & Fletcher 2004). However, this research focused upon emotion work inherent to supporting the child's treatment and the notion of 'surplus' suffering, which related to problems inherent to their child's treatment and the interface between those and the healthcare system in Canada. Therefore, a key contribution of my thesis is its exploration of the notion of suffering in a novel area, that of children's palliative care.

Nonetheless, the findings from this study point towards several other avenues of future research. Suggestions can be made for investigating how gender, culture and religion, and type of suffering impact upon its expression and legitimation.

1. The study should be replicated in other children's hospices, with a greater variation of sampling, to reflect the diversity of the population of parents whose children are dying. The completion of the current project to map the user profile of children's hospices (CHUK 2011) will support the design of such a study. The findings would facilitate greater understanding of cultural and religious influences upon the legitimation of suffering.

2. Expanding the previous point, the findings of this research are firmly rooted in the prevailing English culture, which might be summed up in the phrase ‘keeping a stiff upper lip’. As such, this may have contributed to a habitus of suffering which the parents developed. This point was substantiated through the perspective of the non-English parent who reflected upon the influence of that English culture upon her day to day interactions as a foreigner. Exploration of the concept of a habitus of suffering would be facilitated by replicating the project as an international study.

3. Further exploration of the experience of fathers of dying children would further raise the profile of this group in clinical practice. Moreover, such a study would facilitate greater investigation of how gender influences emotion management and its implications for the legitimation of suffering experiences.

4. Examining the theoretical framework across different populations would enhance its rigour. To this end, replication of the study using a research population reflecting a different type of suffering would be beneficial. Furthermore, replication could be in a population which has some similarities, such as dying adults and their families or in a population where the suffering experience is more different, such as poverty.
5. Whilst this study has illuminated some issues at stake for these parents of dying children, there is without doubt more to be said on that subject which should influence future developments in palliative care. Further research in this area would therefore be useful, to broaden and deepen understanding. A larger study, as suggested in point 1 would support this. In addition, a true ethnographic study design would drill further down into the experience of such families. Whilst the difficulties of achieving such a study remain as articulated in section 8.3, a design which capitalised upon existing access to families, such as through community nursing services, may overcome some of those obstacles.

Policy & Practice Implications

As set out in Chapter 1, there is little recognition of the needs of dying children and their families in contemporary social policy. Children have become ever more sacralised, a position that is maintained through contemporary developments in social policy and social constructions of childhood. Thus children's activities are highly controlled and freedom is limited to maintain their safety (Valentine & McKendrck 1997; Vincenten & Michalsen 2002); child development is monitored against prescribed objectives and norms (DfES 2004a); and childhood extends for a greater period of time through compulsory education (Vickerstaff 2007). In short, today's childhood is standardised in many senses through institutional control rather than being dependent upon social class or geographical location (Moran-Ellis 2010). The positive outcomes from such policy developments over time are significant reductions in childhood mortality (Haines 1995).

More recent reductions in childhood mortality are particularly associated with developments in medical technology which facilitate more frequent and earlier diagnoses and greater therapeutic intervention. Developments in medical technology as a feature of modernity are associated with increasing rationalisation of society (Lock 1997). Arguably, however, such developments, rather than reducing risk, increase exposure to vulnerability and suffering (Lock 1997; Wilkinson 2010). The ambivalent nature of the relationship between technology and suffering is clearly illustrated in the findings of this thesis. Thus the findings demonstrated how technology could at once extend life and ameliorate some forms of suffering whilst imposing suffering through extending life and placing limitations on agency. As such the parental narratives epitomised the counterproductive outworking of multiple policy approaches which are developed and implemented without due reference to each other or the people they affect.

A comparison of policy directions with respect to foetal and reproductive technologies, neonatal health, and children's palliative care clearly illustrates this last point. A variety of screening tests can check for the developmental progress and likely outcomes of a foetus during pregnancy, which affords choice to parents about whether to continue with a pregnancy or terminate. As a result, fewer children are being born with known disabilities (Alberman E 1995; Forrester et al. 1998). Concurrently, technological advances continue to present opportunities for saving lives which otherwise might be at the limits of viability. Extremely premature neonates now have a greater likelihood of survival; however as mortality in this population decreases, there is evidence that morbidity is rising (Marlow et al. 2005). Therefore whilst endeavouring to ensure survival, healthcare technologies prolong a life of ill-health. Furthermore, having survived such a traumatic start to life, the mechanisms for child and family support are unclear. Policy in this area is underdeveloped and under resourced and as such it is dependent upon the voluntary sector which is vulnerable to economic shifts (Craft & Killen 2007; DH 2008).

Hitherto the absence of research which makes public the experience of such children and families has contributed to their under-representation in policy. Therefore, this thesis makes an important contribution to the raising of awareness of the needs of this group to policy makers. The timing of the research is also significant since it comes at a point when there is an awakening of the need to consider the needs of this group and consideration of how to ensure secure funding for and continuity of appropriate services (DH 2008).

With respect to the clinical practice implications of this thesis, attention needs to be drawn to both emotion work and suffering in children's palliative care. Emotion work is important in family life (Devault 1999; Erickson 1993; Wharton & Erickson 1993) and is particularly significant in the care of family members who are critically ill (Thomas et al. 2002). It has been noted that there is a cost for the individual involved in emotion work in the family, evidenced in feelings of well being (Erickson 1993; Exley & Letherby 2001). Similarly, emotion work by relatives caring for sick family members has been found to have psychosocial consequences for such carers (Thomas et al. 2002). This thesis lends weight to untested claims in the literature that emotion management, specifically emotion work, in a wider context than the family, has a cost for the client (Smith 1992) rather than being a process which is merely passively accepted (Ruane 1996). Raising awareness of the 'cost' of emotion management to healthcare clients, and how this impacts upon suffering, will thus make a useful contribution to communication skills training for healthcare professionals in paediatric and adult palliative care and in care work generally.

The findings of this thesis should therefore support the effective training of children's palliative care professionals, which has also been highlighted as a requirement in a recent review of services (Craft & Killen 2007). In particular, the importance of communication skills training is already recognised in the field. However, there is little attention paid to the significance of emotion management and the impact of that upon the provision of appropriate spaces to consider service users' personal concerns and emotions. This could be addressed through the development of an evidence based quality standard for communication skills. Drawing attention to the ways in which other people's responses shape the lived experience of parents of dying children, such a standard could highlight a range of communication strategies which are effective or ineffective. For example, professionals should be educated about the negative impact of pity as a response. Understanding how such a response leads to emotion management, inauthentic presentation of self and reduced intersubjectivity in order that personal identity is not further put at stake is crucial for effective communication.

Such a standard could be applied nationally and would enable both service users and commissioners to make informed choices about children's palliative care services. In addition, the evidence based quality standard for communication skills should underpin effective clinical supervision processes. This would ensure that professionals are directed to rebalance the focus between self and other with respect to emotionality in children's palliative care. There is also scope for such a standard to be applied to the wider palliative care genre, since effective communication is a fundamental skill in palliative care.

However, this thesis clearly demonstrates that for parents of dying children it was not only communication with palliative care professionals which was significant. Through their daily interactions with other people in general, as well as palliative care professionals, the parents built a script for emotion management in which negative emotions were de-legitimated, leading to an inauthentic presentation of self and reduced intersubjectivity. Simultaneously, child mortality rates are reducing and cultural references for death in childhood have become ever more limited. As a result, the reality of these parents' lived experience became less and less visible and their suffering was reinforced. There is therefore a need to better educate wider society about children's palliative care.

As well as effective direct care and support for parents, children's palliative care services have the scope to influence this wider societal understanding of the lived experience of parents of dying children. Children's hospices must raise awareness at an organisational level of how the vision and values of children's palliative care are aligned with the lived experience of the parents of dying children. This will ensure that all activities at a local level raise awareness of this minority group in society: through clinical work, fundraising, marketing, education and training. Furthermore, this alignment will facilitate more effective regional and national collaborations to raise the profile of these families. Working with national organisations such as Children's Hospices UK and The Association for Children with Life Limiting Disorders (ACT), children's hospices have the potential to influence policy makers to take better account of their hitherto largely unrecognised needs.

Finally, whilst this thesis has use in clinical practice and the practical out workings of policy, it may also contribute in some small way to the development of policy. Historically, societal views of children have been somewhat ambivalent and have led to children being portrayed as either vulnerable or a threat to society, and these perspectives are reflected in social policy developments (Hendrick 2005; Moran-Ellis 2010; Thorne 1987). In this way education, health, employment and criminal justice policy promoted increased the scrutiny of child workers in the nineteenth century which both ensured their safety and maintained their economic utility (Moran-Ellis 2010). This also illustrates how measurement of the value of children has altered over time from being predominantly one of utility to increasingly reflecting the psychological needs they fulfil in parents (Thorne 1987; Jones and Brayfield 1997; Davin 1999; Piper 2005).

In contemporary society children and childhood are sacralised (Zelizer 1994). Yet some children will die and the suffering inherent to that experience will be in part generated by the social policy which upholds the sacralisation of children. Indeed, it has been suggested that 'short lives are not valued as much as long lives' (Runswick-Cole 2010 p.815). There needs to be greater public debate about the development and implementation of medical technology which takes account of the lived experience of those whom technology touches. Through the empirical investigation of a range of experiences of parents of dying children, this thesis seeks to make an important contribution to that debate.

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Appendix 1: Application for Ethical Approval

SSPSSR RESEARCH ETHICS COMMITTEE (REC) APPLICATION FORM

Please complete this form, sign it, and return it either to your supervisor (where relevant) or direct to the REC administrator to forward to two REC members for approval. Many thanks

Section 1

Title of Project

Children who use hospice care: the experience of parents

Section 2

Name of Main Researcher

Rachel Black

Name of Supervisor(s) and other(s) involved plus affiliation (e.g. SSPSSR)

Andy Alazsewski [CHSS] Susan Kenyon [CHSS]

Section 3

Brief, jargon-free, one or two paragraph outline of the background of the project, its rationale/aims/hoped for outcomes)

This research investigates the experience of parents whose children are dying. The findings will inform developments in children's palliative care services, through which such parents can be supported.

Significant numbers of children and young people die every year in the UK. For the years 2001 -2005, deaths amongst children and young people [aged 0-19 years] have been approximately 6000 per year [DoH 2007]. Of these, approximately 4000 per year would be from causes likely to have required palliative care services [DoH 2007]. Unlike the adult population, children requiring palliative care tend to access services for longer periods of time, often from the time of diagnosis. The most commonly recorded causes of death where palliative care is likely to be needed are congenital malformations, deformations and chromosomal abnormalities [DoH 2007]. Trajectories for such illnesses can demonstrate protracted, fluctuating health and patterns of increasing disability and dependence [IoM 2003]. Interaction with palliative care services may extend over several years until the child's death.

In the period between the diagnosis and the death of their child, parents may need to accommodate significant change and loss, including the loss of an anticipated healthy child and the changing health and dependence of their sick child. The social implications can influence work life, finance, social interaction, and family life. Suffering as a sociological concept has been studied from various perspectives including personal illness, political violence, poverty. There is little empirical study of the suffering experience of family carers and none concerning that of the parents of dying children. The aim of this research is to develop insight into how parents of dying children define their experiences and what factors shape their perceptions of, and how they articulate, their experience. Additionally, the research intends to investigate what children's palliative care professionals recognise as suffering, how they respond to it and what effect it has upon them. The data source will be a voluntary sector palliative care service which provides both residential and community care. The research will comprise two studies: parents will be studied through case studies; professionals will be studied through ethgnography. It is intended that generation of this knowledge within the context of children's palliative care will facilitate recognition of what parental suffering is and is not, and will provide insight into the inter-subjective nature of suffering. It is anticipated that this knowledge will inform improvement in children's palliative care service provision at both local and national level.

Section 4 – Research Method

Study 1, the parental suffering case study, will comprise: 1 focus group, individual interviews with approximately 6-8 sets of parents, and the same number of personal diaries.

Study 2, the ethnography of children's palliative care professionals, will comprise: 2 focus groups, individual interviews with professionals and participant observation.

Study 1 - Parents:

There already exists a parents forum, a voluntary membership group of parents interested in shaping the development of the hospice. This parent forum will be asked to act as a focus group to shape a topic guide for the individual parent interview. In addition, the group will be involved in identifying a range of family subgroups which should form the sampling criteria. These might include families with one sick child, families whose only child is sick, families who have no healthy children.

Potential participants will be approached by a hospice administrator, using criteria supplied by the researcher. This will ensure the protection of especially vulnerable families as well as fulfilling the sampling criteria for the study. Parents will be sampled purposively from the family database to reflect the sampling criteria generated from the focus group. 6-8 families is the intended final number, in order that size of data is manageable and that sufficient variation is integrated. In addition to interviews, families will be asked to maintain a written diary for 4 months in which they will record their experiences and views about their experience. Since a modified grounded theory approach to data collection is to be used, each interview will influence subsequent data collection, and parents will be asked if they can be contacted again if new data emerges which required refinement.

Study 2 - Professionals:

Staff will be given a written invitation to participate in the research by a hospice administrator, which will include an information leaflet and a written agreement to participate to return to the researcher. The researcher will then contact professionals individually, sampling to form two focus groups, reflective of the community and residential nature of service provision. Maximum variation sampling will be undertaken with the aim of reflecting the range of ages, experiences and qualifications of the professionals. In should be noted that, for some groups, such as the community teams, numbers will be small enough to allow all members to participate. The teams are almost exclusively female and therefore sampling will reflect this. The focus groups will shape the topic guide for interviews with individuals. The researcher will subsequently sample for individual interviews with the same aim to reflect the range of ages, experiences and qualifications. Individual professional interviews will also utilise vignettes intended to reflect the type of families who have been interviewed, in order that discussions are focused on the same types of problems but that familiy anonymity is maintained. Individuals may be recontacted if more information is required as the research progresses. The social work team will be also interviewed since they are available to all families. Finally, the researcher will engage in participant observation with the health professionals.

b) How will your project comply with the Data Protection Act?
Details of participants will remain confidential to the researcher and the hospice administrator. Data will be recorded and transcribed by the researcher. Data will be coded and anonymous and stored on the researcher's personal computer and as hard copy. Analysed data will also be incorporated into the printed thesis. Raw data will be accessible to the researcher and supervisors. Hard copies of data will be destroyed by incineration.

c) Anticipated start date and duration of data collection
March 2008 for eight months

d) Details of payment, if any, to interviewees / participants
No financial incentive will be offered. Families and professionals will be given a gift of chocolates to thank them for their participation.

e) Source of funding (if any)
The hospice will be asked to provide paper and postage for the project.

f) List questionnaire and other techniques to be used
The aim of the focus groups is to address the following issues:
1. Family types which represent a range of different of parenting experiences.
2. The experience of parenting a dying child.
3. Whether or not parents of dying children suffer, and if so, how they suffer.
4. What factors and people influence the parents' experiences.

Individual interviews will be unstructured and will make use of a topic guide generated from the focus groups. In addition, a modified grounded theory approach to generating data will be used so that each interview informs subsequent data collection.
Parents will each be provided with a notebook and guidance for the diary activity as follows:
Please use this diary to record any experiences over the next 4 months. You can record as often or as infrequently as you choose. This information will be used along with your interview to help me understand your individual experience and how care services can best respond.

Section 5 - Ethical Considerations

a) Indicate potential risks to participants (e.g. distress, embarrassment) and means adopted to safeguard against them

Development of the study design has been discussed with senior representatives from the host organisation ona regular basis, in order to minimise risk to both parent and professional participants.

Study 1 - Parents: The act of discussing personal experience or suffering risks causing distress. The researcher is a registered nurse with 20 years of varied experience in child health service provision, including intensive care and palliative care provision. Her skills will be used during data collection to respond appropriately to distress and support participants. In addition the reseacher has undergone an enhanced CRB check. The parent focus group will be held at the hospice as this is the usual venue for the parent forum and a convenient location for the diverse group of parents who attend. The location of the parent interviews will be chosen by parents to maximise their comfort and minimise instrusion into their lives. They will be offered home, hospice or a location of their choice. However, the location can also influence the responses given by parents, so they will be asked to make a choice which will facilitate an undisturbed interview. In addition, the benefits and pitfalls of each choice will be discussed with the parents prior to their decision being made. Home offers the benefits of familiarity, avoidance of the need for carers for their child, avoidance of the need for travel, and can accommodate existing patterns of life. However, the parents may be distracted or inhibited by the presence of other people, and may also not want to discuss suffering in their home environment. The hospice can offer a peaceful, familiar, supportive environment, free of disturbance. However, there is the potential for the parents to compromise the feeling of the hospice being a refuge by utilising it to discuss suffering. Other locations need to be judged carefully for their ability to provide an undisturbed space for the interview as well as a safe environment for the parent to discuss personal perspectives on suffering. It should be noted that the research aims to elicit parents' perspectives of on-going suffering associated being the parents of a dying child, and as such is within the boundaries of their usual interaction with children's palliative care services. However, due to the potential for the interviews to generate emotional turmoil for the parents, all parental participants will be provided with contacts within the host organisation who can provide ongoing confidential support. This kind of support is also available through routine parental contact with the host organisation. The support will be negotiated with the host organisation, and will have clear boundaries for both parent and organsisation. The parents will be informed of this support within the participant information leaflet to be sent prior to giving informed consent. A feedback mechanism will be put in place with the confidential support contacts to inform the researcher of any issues arising which should inform the direction of the research. Finally, participants will be able to withdraw their data at any time.

Study 2 - Professionals: Professionals may be concerned about the confidentiality of their opinions and this will be assured. There is potential for them to be relectant to be seen to participate, so although focus groups will be held at the work place of the professionals, for individual interviews, professionals will be given the choice of work place, university or a location of their choice for individual interviews..

b)What confidentiality issues might arise during data collection, analysis, dissemination of results? How do you plan to protect participants' anonymity?
Details of all potential participants will be known by the researcher and the hospice administrator, who will be advised of the need to maintain confidentiality.
Professionals will not be informed of which parents are paritcipating. In order to reflect the family subtypes and guide the interview, vignettes will be designed to use with the professionals. Any professional identified by parents will not be referred to by name or in any other identifiable manner during the collection, analysis or dissemination of data.
The details of the professionals contacted will remain confidential from the parents, to avoid a potential loss of confidence in the professional and to safeguard the views of the professionals.
All interviews will be recorded and transcribed by the researcher. Copies of both will be stored on the researcher's computer and on hard copy. Electronic data will be password protected. Disposal of hard copies of data will be through incineration.
When the data is written up, all names will be changed to ensure confidentiality. Parents and professionals will retain a copy of their consent to participate and a second copy will be retained by the researcher. No information will be retained in an individual child's record. No parent or professional will be identified personally within the research.

c) What difficulties might arise (e.g. regarding power and/or dependency imbalances between researcher and participants) and how do you plan to safeguard against them?
Parents may feel obligated to the host organisation to participate in the research. For that reason, invitations to participate will emphasise the role of the researcher as a student of the University of Kent, with an accompanying acknowledgement of her role in the host organisation. It is anticipated that this will ensure that parents do not feel obligated to participate in recognition of care received in the past. In addition, this strategy is intended to provide parents with reassurance that refusal will not jeopardise future care. By acknowledging the role of the researcher as a children's palliative care nurse within the host organisation, it is intended that parents will be reassured that their participation will involve interaction with a skilled professional.

The researcher is a senior member of the palliative care team within the host organisation. This creates the potential for powerful influence over professional participants. This will be avoided by transparency in information sharing and clarity of the role of the researcher as a separate entity from professional role. The researcher needs to acknowledge bias inherent to her role prior to commencing the research and to endeavour to search out data to support the research questions and not to use pre-formed views from professional experience. This will form part of the analysis in the form of 'bracketing out'. The professional participants need to have clarity about when the researcher is working in a research capacity and when she is working in a clinical capacity, in order that participant observation remains transparent and not covert.

d) How will the project take into consideration cultural diversity (e.g. through provision of interpreters where necessary)?

The host organisation has a catchment area which extends from Southeast Londaon, through Kent and to East Sussex. However, the majority of service users are white English. Where possible, sampling will aim to reflect diversity of service user, but this may be more in terms of family experience than ethnic or cultural background, particularly given the small numbers of parent participants.
Professionals employed by the host organisation are also white English in the majority. Where possible sampling will endeavour to reflect the diversity of the host teams.
e) Why, if at all, are you paying participants? What is the potential impact on them of such financial inducement?
No financial incentive is being offered.

f) What provision are you making for giving feedback to participants about your findings?
Parents and professionals will be provided with feedback at the following times: partway through interviews; at the end of interviews; at the end of analysis; on completion of the thesis. This will be written in plain English and participants will be given the right to choose if they wish to receive it during their interview. For parents this will be posted to their home addresses and for professionals it will be made available at their workplace. Oral presentation of the findings will also be offered to both groups. In addition, use will be made of family and professional newsletters to disseminate the final results.

g) What other ethics review procedures has this project already undergone (e.g. with funding bodies)?
The host organisation is a voluntary sector care provider, and not bounded by the NHS ethical procedures. Instead, a copy of this form will be presented to the host Clinical Governance Team, composed of senior managers from care and human resources along with the Chief Executive of the organisation. The Team will be invited to question the researcher and will be asked to provide ethical approval at an organisational level.

Section 6 – Consent
a) What procedures are you using to secure participants' informed consent (please append any forms etc use for this)?
Both parent and professional participants will be asked to provide written, informed consent prior to participation in the study. An information leaflet will be provided which acknowledges the purpose of the study, procedures, potential harm, confidentiality, and any difficulties which may be anticipated.
The parent forum focus group will be contacted by a member of hospice staff and asked to participate. If they agree, the researcher will write to each of them with details of the study. For individual parent interviews, following a telephone invitation to participate by the hospice administrator, a written invitation to participate will be posted to them from the researcher and will include a written information leaflet. Parents will be asked to return a form consenting to participate.
Staff will be receive a written invitation to participate from the hospice administrator, which will include a written information leaflet.
On initial meeting with each parent or professional participant, both individuals and focus groups, another copy of the written information will be provided and opportunity given to discuss it and clarify any concerns. All partipants will then be asked to sign 2 informed consent forms: one for their own records and one for the researcher. At that point parents will be given contacts for complaints or further support, as well as contact details for the researcher should further questions arise.

b) What procedures will you use with participants unable to give their own informed consent?
It is not anticipated that the participants will include those unable to given consent. For the parents, this is because the nature of the research suggests that they should be fully able to understand and articualte their concerns prior to participation otherwise measures to minimise distress will be impossible to judge. For profesisonals, the nature of their work means that they will all be able to give their own informed consent.

c) Explain, where applicable, why the informed consent of participants is not being sought
N/A