Beyond childhood cancer: Bringing primary carers into focus

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BA (Hons)

Submitted in fulfilment of the requirements for the Degree of Doctor of Philosophy

University of Tasmania

March 2012

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Terrance Cox

30 March 2012

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Abstract

Childhood cancer is no longer a universally fatal disease. Four out of five children diagnosed with cancer will now survive the disease due to advances in paediatric oncology in recent decades. Much social science research has focused on children and primary carers dealing with childhood cancer through the acute stages of diagnosis and treatment. Emerging data has also examined the long term health and social implications of children and young adult survivors of childhood cancer. However, primary carers of children whose cancer has abated have not been a focus of research attention. In this sociological thesis I investigate the everyday lived experiences of primary carers of children who have survived cancer in an Australian context. I look beyond the medical success story and beyond the 'back to normal after cancer' rhetoric by regarding childhood cancer as a significant disruption in carers' lives.

I paid particular attention to the ways in which carers constructed meaning and responded in the cancer aftermath by drawing on the symbolic interactionism perspective and a constructionist version of grounded theory. Qualitative data from 38 primary carers was conceptualised to represent a new normal. The findings illustrated how pre-cancer identities and taken-for-granted assumptions and expectations are no longer tenable. Carers responded by constructing a new sense of normality, characterised by insidious cancer memories and the knowledge that they had lost control of their child's life and well-being. With the abatement of cancer the carers gave new meanings to define their self and

situation, and with particular front stages and back stages of interaction according to their insider or outsider audiences. They also developed new understandings of being a carer of a child in remission; by weaving together new meanings of hope and uncertainty with strategies of emphasising everyday life to mitigate the impact of cancer in their lives. The extent of child morbidities deriving from cancer treatment is the most pertinent constraint in shaping everyday life after cancer rather than cancer *per se*.

By examining childhood cancer and its survival from the participants' perspectives, the thesis offers understandings of health and illness as an ongoing social process that sits between the binaries of acute and chronic illness, cancer and survivorship and children and primary care. The findings offer ways to enhance current and future families impacted by childhood cancer, with policy direction to inform health and allied health professionals and cancer support services.

Acknowledgements

In developing this thesis my gratitude extends to a number of people. My heartfelt appreciation goes to the participants who shared and entrusted me with intimate aspects of their lives. Your accounts convinced me that this research is important and you gave me the motivation to complete it; I sincerely thank each one of you. My thanks go to Camp Quality for the support with this study, and for making laughter the best medicine.

I remain grateful to Dr Kristin Natalier and Dr Karen Willis, your supervision and intelligence helped me maintain clarity and further sharpen my sociological perspective. My appreciation extends to Professor Gary Easthope for the supportive comments in reviewing an early draft of the thesis. I am humbled by the comments from the two anonymous examiners who spoke so highly of my work. My thanks extend to my academic colleagues for the support and advice through seminars and in-depth corridor conversations.

To my family and those I am blessed to have as close friends, thank you for your support and believing in me. My one regret is how this thesis represents time taken away from those who I love and cherish.

I dedicate this thesis to past, present and future families impacted by childhood cancer; may you be blessed with health and happiness. And finally, I pay my respect to the memories of those who will stay forever young …

Contents

Preface

In this thesis my personal and sociological selves fluctuate and are not easily

through this research. In the late 1980s my 11-month-old son was diagnosed with

leukaemia. Fortunately he survived and is now a healthy young adult although

intensive treatment resulted in minor morbidities that continue to impact on his

life. He generously gave permission to discuss his history in this study. I reflect

on those raw if somewhat remote memories: the shock of his diagnosis, hoping he

might survive and the relief of his remission. It was a crucial phase of my life,

but to adapt a cliché, it was one day, procedure and pathology result at a time. It

was a life-changing period which made me acutely aware that life assumptions

can change in an instant and to value the present. I also found that people are

reluctant to discuss cancer; the topic 'should' be redundant as my son survived.

My sociological perspective helps me to realise health and illness are a complex

of biological, biomedical and social experiences shaped by broader cultural and

structural forces. I now look at childhood cancer survival being promoted within

a medical success discourse and the end of cancer, yet the story of being a carer

of a child in remission is seldom heard. I therefore approached this research with

some intuitive understanding of being a carer of a child in remission, but also

with a sociological quest to examine the complexities of constructed meanings

and identities in everyday life. Foremost though, in this thesis I give precedence

to the participants whose valuable shared knowledge and experiences made this

research possible.

Chapter One: Introduction

This qualitative study investigates primary carers of children who have survived childhood cancer. In recent decades childhood cancer has shifted from a universally fatal disease to being potentially curable, yet it remains the leading cause of childhood death from disease in Australia (ABS 2006; Heath 2005). National incidence rates are relatively stable, with around 15 per 100 000 children in the 0-14 age group (AIHW 2009). Due to medical advances around 80 per cent of children are now likely to meet the five year criteria of long term survival (Ziegler, Pozza, Waters and Marshall 2005: 78; Smith 2000). This equates to around one in 640 people aged between 20-39 being a survivor of cancer in childhood and this number is likely to increase as treatment protocols are refined (Drew 2007: 278). However, nearly three-quarters of these young survivors have ongoing health conditions impacting on their quality of life (Oeffinger, Mertens, Sklar, Kawashima, Hudson, Meadows, Friedman, Marina, Hobbie, Kadden-Lottick, Schwartz, Leisering and Robison 2006; Heath 2005).

The accumulative survival rates per annum, together with each child connected to family and community has established a substantial social group impacted on by childhood cancer; which Drew (2007) refers to as an epidemic of survival. To explore all dimensions of this phenomenon sociological research must account for carers' understandings of their experiences both through and beyond the disease as they are central actors in how life after childhood cancer takes shape.

The focus of this thesis considers primary carers' experiences in the aftermath of childhood cancer. Much research relating to childhood cancer has appropriately examined children and young adult survivors (Drew 2003, 2007; Parry 2003; Grinyer 2007), and survivors' siblings (Barlow and Ellard 2005; Murray 2002; McGrath 2001. Research has also paid attention to carers but predominantly during the early stages of their child's diagnosis and treatment. This literature represents the onset of childhood cancer as a biographical disruption from carers' pre-cancer taken-for-granted assumptions (Young, Dixon-Woods, Findlay and Heney 2002; Bury 1982). Sociological scholarship has examined how carers deal with the acute uncertainties of their child's life/death situation, and their multiple roles as parents, advocates and guardians through cancer (Dixon-Woods, Young and Heney 2005). However, it has been noted how carers are often represented as proxy sources of information about their child, which has a 'double-silencing effect', as neither children nor carers' voices are represented from their own perspective (Young et al. 2002: 1835). The available data on carers has also been referred to as a 'reified and partial account' of childhood cancer survival, which supports a research gap in examining carers of children in remission (Dixon-Woods, Young and Heney 2005: 13).

Carers are under-represented in different ways through various research disciplines. The available data suggests that sociological research has not addressed primary carers' lives after their children's cancer has abated. Medicine promotes remission as the 'prize' of childhood cancer and the end of the cancer

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script (Drew 2007: 279), but discounts carers' obligations and contributions to their child's ongoing health after cancer. The psychological approach focuses on carers' ongoing stress levels and coping abilities after their child's illness (Grootenhuis and Last 1997). These approaches support an ideology of 'winning the cancer battle' (Sontag 1991) and comes with the expectation to return to normal after a life crisis (Becker 1997). But without focused research in the area of carers' lives after the abatement of their child's cancer there remains a significant knowledge gap: there is a social expectation for carers to return to a normal life, but there is little knowledge as to what 'normal' might entail or how it is constructed and enacted in everyday life.

A sociological approach: Carers' new selves

Despite the absence of any dedicated sociological research into the experiences of primary carers living with a child in remission, I discovered some indications to guide the thesis forward. In my Honours study I conducted a small qualitative research project with 10 carers of child cancer survivors in order to examine their transitional experiences of leaving the medical world after the end of their child's treatment (Cox 2007). A mother of a childhood cancer survivor (10 years post-cancer) offered a glimpse of how cancer had shaped her sense of self:

> The grief I felt was that I had lost that life and somehow had to build a new one.
> I think it was the centre of my world, everything evolved around that [child's cancer] … I mean I'm not driven by it and I'm not obsessed by it or think about it 24 hours a day and I'm not upset about it, but it is essential to who I am today.

This mother's account illustrates how childhood cancer marked a distinct loss of a former life and of defining her identity as different from her pre-cancer self. It is an identity she developed through cancer that continues well after cancer has abated. Her account might also reflect a sensitivity to assumptions from 'traditional approaches' that have 'tended to characterize families experiences of childhood cancer in terms of maladjustment' and ongoing 'psychological distress' (Dixon-Woods, Young and Heney 2005: 94). Explaining her current situation with reference to not being continually fixated by her experiences through cancer is an affirmation of her new identity, but an identity that rejects being characterised solely in terms on ongoing cancer related stress.

Some sociological work on carers' experiences through cancer has touched upon the possibility of what their lives after cancer might entail. In a qualitative study with 20 mothers of children being treated for cancer, Young et al. (2002: 1844) claim that having a child with cancer intensifies carers' everyday roles and contributes to 'altering their sense of self and their social identity'. These mothers 'although not ill themselves, experience many of the consequences [of their child's cancer]', including biographical disruption, compromised quality of life and 'a set of new responsibilities and role expectations, including an obligation of proximity, being physically close to their child to provide comfort' Young et al. 2002: 1835). These findings suggest that childhood cancer creates a situation in which carers' pre-cancer self-concepts and sense of normality are no longer sustained, and instead, construct an identity that accords with their cancer

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related context. The marked shift in carers' identities through cancer was raised by Zebrack and Zeltzer (2001: 2) who note that carers and children 'adapt to extraordinary life changes and in most cases embrace their futures' after the threat of cancer alleviates.   The presence of childhood cancer is therefore seen as altering carers' identities, but also with the capacity for carers to respond and make a new life after cancer. However, these studies treat cancer experiences and a life with a child in remission as discrete categories. What has yet to be thoroughly examined is the experiences of having a child survive cancer in shaping how primary carers construct their everyday lives, the ongoing impact of cancer and the socio-cultural context in which carers are located.

A way to examine primary carers in their childhood cancer survival situation is by examining how notions of normality are defined and constructed in changing health and illness contexts. The concept of normalcy and/or normalisation is used in a broad range of health and illness research to represent ways that people 'attempt to normalise in the face of disruption' (Bury 1982: 177; also Deatrick, Knafl, and Murphy-Moore 1999; Gregory 2005; Sanderson, Calnan, Morris, Richards and Hewlett 2011). Bury's (1982: 177) explanation of people constructing a new sense of normality is evident in much childhood cancer scholarship (Comaroff and Maguire 1981; McGrath 2001; Young et al. 2002; Sullivan 2004; Dixon-Woods, Young and Heney 2005), which suggests that normalcy, although altered from carers' pre-cancer lives, is an important way for carers to define and give meaning to their identities and situations.

In reviewing childhood cancer literature I came across comments by parents who regarded their child's cancer diagnosis as a 'fracturing of reality' as they had previously known it, and who referred to the need to build a 'new normal' through the treatment period (Clarke-Steffen 1993: 285). In a later study Clarke-Steffen (1997: 278) outlines a number of attributes of the parents' 'new normal', including: role strain, information management, contracting future plans, and dealing with treatment regimes. Another study revealed a similar theme; represented by one of the participants who said how 'it's never going to be the same as it was before [child's cancer]; we must build a new normality' (Earle, Clarke, Eiser and Sheppard 2006: 3). Both studies by Clarke-Steffen (1993, 1997) and Earle et al. (2006) were located within three months of carers having their child diagnosed with cancer, which suggests carers describe their situation as a new normal in the early phase of illness. In a longitudinal study across two years of cancer treatment (but not remission) Woodgate (2006: 16) developed a similar theme, in which 'normal as the families knew it in the past was now experienced as something different for them'. The notion of 'new normal' supports a rupture from a pre-cancer normality and carers' active responses to define their current self and situation. The preceding researchers did not examine carers of a child in remission so the concept of new normal was not advanced to represent these changing conditions. However, their scholarship offers a useful way in which to consider carers as constructing a new sense of normality through their child's cancer and remission.

Focus of the thesis

This thesis responds to the need to advance knowledge of primary carers by examining how they define and assign meaning to their situation and how cancer consequences influence their ongoing lives. My research aims are:

1. To explore how primary carers give meaning to their experiences through their child's cancer in their post-cancer context.

2. To investigate how primary carers construct their current everyday lives after the abatement of cancer.

3. To examine how primary carers define and deal with the consequences of their child surviving cancer.

To achieve these aims I developed the following research question:

> *How do primary carers construct their everyday lives in the context of their child surviving cancer?*

The study draws out the way in which carers configure the realities of their everyday lives. Throughout this thesis I argue that childhood cancer survival is an ongoing and complex social process involving, of course, children, but also carers who shape and give meaning to their own altered lives and interact with significant and generalised others to construct identities as carers of a child in remission.

The findings illustrate the ways in which childhood cancer establishes a radically altered situation where primary carers' pre-cancer identities, prior notions of normalcy and taken-for-granted assumptions of their own and their children's immediate and future life expectations are difficult to maintain. In response, I develop the concept of 'new normal' to represent how primary carers construct their everyday lives through cancer, and sustain this ongoing social process after cancer. This 'new normal' forms the central concept and key finding of the thesis. The concept is characterised by multiple, overlapping and ongoing processes: it includes carers assigning meaning to their own and child's cancer experiences, and in particular making sense of insidious cancer memories and feelings of being powerless to control their child's life.

The 'new normal' after cancer represents how carers negotiate a heightened awareness of cancer and living with its shades of uncertainty. Carers develop strategies to mitigate the impact of the disease by emphasising everyday life rather than the cancer and, paradoxically, developing a 'living in the present' focus while hoping for a future without cancer. Carers also realise a disparity between their own cancer related experiences and new definitions of normality, and the cultural expectations of others to return to a pre-cancer normal. In response to this difference and as a way to normalise everyday interactions with cancer 'insiders' and non-cancer 'outsiders', carers enact particular front and back stages according to their audiences (Goffman 1959). These characteristics of the 'new normal' illustrate carers' capacity to adapt and make a meaningful

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life after cancer, although different from their pre-cancer lives and at odds with cultural expectations of what their normal should be (Sontag 1991; Becker 1997). The findings also illustrate that carers' everyday lives are significantly shaped by their child's ongoing morbidities that arose from cancer treatment. Being a carer of a child in remission means there is no orderly end to the cancer story, but rather, ongoing interpretations in constructing a new sense of normality.

My approach to the thesis

Informed by my sociological perspective and life experiences I have an epistemological assumption that primary carers subjectively interpret their selves and situations (Berger and Luckmann 1984; Schutz 1970). I chose an interpretive methodology to analyse how carers articulate their experiences through their child's cancer. My perspective is informed by the tenets of symbolic interactionism, which assumes that carers' meanings and responses arise through interactions with the self and others as the 'world of everyday experience' (Blumer 1969: 35). This standpoint aligns with my research method which uses a constructionist version of grounded theory in which to gain and analyse descriptive accounts of carers' meanings and responses (Charmaz 1990, 2000).

My theoretical starting point is supported by scholars who propose the advent of childhood cancer as a particular biographical disruption in carers' lives (Bury 1982, 1991; Young et al. 2002; Dixon-Woods, Young and Heney 2005). Bury's

(1982) framework offers a theoretical account of people's experiences of the impact of chronic illness as a disruption from their 'normal' taken-for-granted biographies; and requiring new explanations and resources to manage their ill health constraints. However, I argue that Bury's framework requires revision to represent the changing context from being a carer of a child with cancer to the ongoing process of being a carer of a child in remission. I maintain but extend Bury's framework by drawing on theories of identity, normality and survivorship to represent primary carers of childhood cancer survivors whose lives after cancer incorporate cancer experiences (Young et al. 2002).

Data for this thesis was generated through semi-structured interviews with 38 Australian primary carers of childhood cancer survivors whose children were diagnosed with various cancers. After transcribing each interview, I conducted an initial analysis and used this process to inform further enquiries by integrating open, axial and selective coding with constant comparison, theoretical sampling and memo writing (Charmaz 1990, 2000; Strauss and Corbin 1998). The concept of 'new normal' emerged early in this process and was sustained throughout data collection, analysis and the writing process to represent how carers construct their lives through and after their child's cancer. The term new normal was also expressed *in-vivo* by two participants. The carers spoke of their child being in remission on average for 10 years, with a minimum of 5 years to a maximum of 20 years. Participant profiles are further detailed in Chapter Four.

Within the vast array of health sociology research, this thesis represents an under-explored aspect of social life by considering the aftermath of childhood cancer on primary carers' lives. Berger and Luckmann (1984: 168) explain how 'the imminence of death profoundly threatens the reality of one's previous self-identification'. The findings suggest the 'imminence' of a child's death poses a comparable threat to primary carers' identities. The study describes carers' responses to this threat by constructing new identities in the context of remission.

Research definitions

The key research terms in this thesis are: primary carers, children, cancer, and survival. I use the term primary carer(s) to incorporate those who identify as assuming principal moral, legal and cultural responsibility to care for their children regardless of parental or biological status. I take carers as having dynamic identities as individual agents and relationally interdependent identities in requiring a cared for child to maintain their carer identity (Stets and Burke 2000). To have a child's life threatened by cancer calls into question carers' capacity to protect their child's well-being (Young et al. 2002). Yet medical advances have created the conditions which allow for the development of a new social identity; a primary carer of a childhood cancer survivor.

I define child/children as those under the age of 18 who are supported by adult primary care. Beyond this aged based definition there is little consensus as to what constitutes children as a social group: from emphasising children as

competent active social agents (Dixon-Woods, Young and Heney 2005), as unruly and in need of social sanctions, or as highly vulnerable and in need of protection (Jenks 1996). When childhood and cancer collide, children are depicted from a protectionist perspective but also as optimistic and brave in the fight against cancer (Dixon-Woods, Searle, Young, Findley and Heney 2003). This latter approach draws attention to the health of children being 'inextricably linked' to the quality of carers, who in turn experience 'particular obligations to secure that well-being and face censure and possible legal redress if they fail' (Dixon-Woods, Young and Heney 2005: 12). Hence, this study is underpinned by a childhood cancer/survival context in which carers negotiate their own lives within the cultural context and expectations of their social categories.

Cancer represents a generic category for more than 100 diseases, characterised at the cellular level by uncontrolled division of abnormal cells that invade and destroy healthy tissue (McGrath 2001). The anatomical distribution of cancer varies between adults and children. Adult cancers are mostly located in lung, breast, genital and bowel sites. In contrast, childhood cancers are located in the blood (leukaemia), brain and central nervous system solid tumors, bone cancer (osteosarcoma), the lymphatic system (lymphoma) and the kidney (Wilm's tumor) (Heath 2005). Cancer treatment protocols are broadly based on chemotherapy, surgery, radiation therapy, bone marrow and/or stem cell transplantations (Tritter and Calnan 2002). Ongoing electro-magnetic radiation,

chemicals, genetics, viral infections and environmental research has yet to detect a single cause of childhood cancer (Dixon-Woods, Young and Heney 2005: 23).

The medical definition of a cancer survivor is five years in remission without cancer related clinical intervention. This definition is based on the statistical probability of cancer fatality being no greater than that of the broader population (Heath 2005; Ekert 1989). I employ this definition as a starting point of reference and an institutional 'way in' to access participants that is endorsed by medical and cancer support agencies. However, carers acknowledge the ambiguity of cancer remission and construct meaning in terms of hope and uncertainty.

Chapter synopsis

In Chapter Two I highlight the limited literature examining primary carers in a post-childhood cancer context. I argue that carers of children in remission are marginalised from much professional and public discourse by the way in which bio-medical discourse has largely constructed health and illness (Turner 1995). I also argue that scholarship representing carers through cancer offers useful insights into how they construct their lives after cancer had abated.

In Chapter Three I develop the conceptual framework in which to advance the thesis. I drew on Bury's (1982, 1991) 'biographical disruption' as it offers an appropriate framework to examine primary carers through childhood cancer (Young et al. 2002), but limited in representing carers in the cancer aftermath. To

theorise carers in their post cancer context I extend Bury's framework with theories of identity (Stets and Burke 2000), survivorship (Little, Paul, Jordens and Sayers 2002) and normality (Deatrick, Knaft and Murphy-Moore 1999).

Chapter Four describes my interpretive methodology and research methods. I explain my epistemological and reflexive position as an insider/outsider researcher. I discuss my methods of applying a constructionist version of grounded theory which integrates the collection and analysis of data representing how carers articulate their everyday lives. I then provide details of my ethical research conduct and conclude with a profile of the research participants.

Chapter Five is the first of my three research findings chapters. Here I illustrate how carers reconstruct their cancer experiences through four illness phases: pre-diagnosis, diagnosis, treatment and the transition of leaving the medical realm. I argue that carers' experiences through cancer remain deeply embedded in shaping their current lives. The findings illustrate the loss of prior notions of normality and the genesis of a 'new normal' in the post-cancer context.

Chapter Six reveals how carers shape and give meaning to their current lives. I argue how the concept of 'new normal' represents how carers develop a new sense of self and develop a host of strategies to mitigate the impact of cancer: with new meanings of hope and uncertainty, emphasising everyday life rather

than cancer, mediating their new social identities with cancer and non-cancer audiences, and the cancer community (Goffman 1959).

Chapter Seven builds on the thesis by illustrating how carers respond to medical intervention which saved their child from a fatal outcome but with ongoing morbidities derived from treatment. I argue that child morbidities significantly shape how carers construct their lives and deal with the cancer related consequences. Carers enact the role of late effects managers and develop complex strategies to deal with child's morbidities. They also evaluate medical intervention according to their child's quality of life outcomes and discuss the limits of medicine when their child's life is notably compromised.

Chapter Eight concludes the thesis. I draw together the thesis findings and argue the concept of 'new normal' appropriately represents primary carers of childhood cancer survivors. Carers' lives were significantly disrupted through cancer but being a carer of a child in remission entails constructing a new reality that remains cancer related but not cancer-focused. The thesis speaks of a reality that is constructed as new and distinct from their pre-illness notions of normality. The findings offer stakeholder, policy and research directions to ultimately enhance the lives of those impacted by this insidious disease.

Chapter Two: Literature review

Introduction

> Whatever you do, don't say 'cancer'. The unspoken word, written on everyone's lips, must not be voiced (Stacey 1997: 65).

The above quote captures a key theme in cancer literature whereby a 'cancer equals a death sentence' metaphor limits those experiencing cancer from expressing their experiences (Tritter and Calnan 2002: 164; Sontag 1991). A theme equally pertinent to this research suggests 'a satisfactory discourse of survival has yet to enter the public domain' (Little et al. 2002: 170). In this chapter I argue that primary carers of children in cancer remission are under-represented in much professional and public discourse. Much literature privileges successful medicine outcomes but discounts carers as both individual agents and contributors to their child's health. I then illustrate the value of examining emerging scholarship on carers' experiences through their child's cancer in order to provide important insights that foreshadow their lives after cancer has abated. I argue that having a child diagnosed with cancer radically alters carers' pre-cancer self-concepts and life assumptions. Yet carers renegotiate their identities and define new ways to normalise their disrupted lives.

I begin this literature review chapter by illustrating that childhood cancer survival is a relatively new phenomenon. I draw attention to how childhood cancer survival is represented as the 'prize' (Drew 2007) of medical advances, defined as

remission, but with a 'price' of treatment consequences. Within this medical discourse carers are left to negotiate both hope and uncertainty in their child's future survival. I examine how primary carers are represented in social science research: from a narrow psychological stress perspective, and under-represented from sociological research attention once their child is in remission (Chesler and Parry 2001; Cline, Harper, Penner, Peterson, Taub and Albrecht 2006). I then explore literature that focuses on primary carers' experiences through their child's cancer. Research findings illustrate that carers experience a significant fracture from their pre-cancer lives and construct a 'new normal' to define their selves in their childhood cancer context (Clarke-Steffen 1997). In reviewing the scholarship on primary carers, I argue the need for a sociological approach to examine how they construct their lives in the childhood cancer aftermath.

This study is located within a broad multi-disciplinary body of scholarship detailing a diversity of primary care/child relationships and responses to a host of acute and chronic illnesses, including childhood cancer (for example Harden 2005; Cunningham-Burley, Backet-Milburn and Kremmer 2006; Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane and Grey 2003; Rehm and Bradley 2005; Barlow and Ellard 2005; Gregory 2005; Williams 2000b; Morse, Wilson and Penrod 2000; Gilding 1999; Sanchez and Thomson 1997; Cohen 1995; Baruch 1981). This literature depicts children as an important population, both 'as children now and as people in the future' (Mayall 1998: 275).

Children also publically convey private childcare practices and carers carry cultural expectations to rear the 'perfect child' (Collett 2005: 328; Clarke 2006). When children and a life-threatening illness collide, primary carers are socially, legally and morally charged with a heightened duty of care to take control of their situation and to seek medical intervention (Collett 2005; Dixon-Woods, Young and Heney 2005; Cunningham-Burley, Backet-Milburn and Kremmer 2006). Carers are also socially condemned and legally sanctioned as perpetrating a form of child abuse if they fail to seek medical support for a seriously ill child (Gilding 1999; Lupton 1997). Childhood cancer therefore establishes a critical situation for primary carers to negotiate within their private and public worlds. Medical progress over recent decades has established current primary carers as the first generation in human history to have their child survive cancer. However, the following discussion illustrates that a medical discourse of cancer remission, while vital for carers and children, only partially represents their everyday survival processes. Childhood cancer survival is represented as a medical achievement but the 'limited survival discourse' means that carers are under-represented in professional and public scholarship (Little et al. 2002: 170).

Childhood cancer: From certain death to remission

Childhood cancer remission has only occurred in recent decades (Barnes 2007; Heath 2005). To gain an understanding of the situation for primary carers requires locating childhood cancer survival in its socio-historical context. Until the 1960s and 1970s childhood cancer was a universally fatal disease.

Achievement in medicine has seen remission rates steadily improve from 50 per cent through the 1980s to current long-term survival rates of around 80 per cent of all childhood cancer diagnoses (Smith 2000). Kruger (2007: 98) offers a stark reminder that long-term survival rates are confined to advanced Western countries, and that around 80 percent of the world's children have no access to oncology care. In an Australian context enhanced childhood cancer survival rates are attributed to international clinical trial outcomes and advances in surgical, pharmaceutical and radiation technologies (Kruger 2007; Heath 2005).

The improvement in childhood cancer survival is also an historical outcome of collaboration between US paediatric, oncology, haematology and pharmacy researchers, along with advances in medical technologies (Barnes 2007: 254). Treatment that began in the 1920s to the late 1940s at Boston and New York hospitals consisted of antibiotics, blood transfusions and experimental treatments; however, these medical interventions had little therapeutic effect and the disease remained universally fatal (Faber, Diamond, Mercer, Sylvester and Wolff 1948). One 1950s study, for example, involved 172 leukaemia patients whose mean survival time from diagnosis was 20.3 weeks and 90 per cent of patients died within 36 weeks (Southam, Craver, Dargeon and Burchenal 1951: 50-51). During this era, clinicians focused on palliative care to reduce patient suffering and were reluctant to prolong life as experimental toxic drugs only added to a child's suffering before their eventual death (Smith 2000: 568). Social science research through this era is sparse, with descriptive accounts of parental

bereavement counselling and medical staff debriefing after the death of a child

(Orbach, Sutherland, and Bozeman 1955). However, research on carers' and

children's experiences of childhood cancer was notably absent through this era.

During the 1950s paediatric oncology progressed when UK and US clinicians

began collaborative experimental clinical trials with various combinations of

chemical compounds that are currently referred to as chemotherapy. These trials

effectively shifted childhood cancer from a fatal disease to one that was at least

potentially curable. Through the 1960s and 1970s, remission times had extended

to around two years but long-term cure remained rare (Smith 2000). This

evidence was reflected in Bluebond-Langer's (1978) 1972 study in which all 32

of the young informants died of leukaemia. Barnes (2007: 254) argues that

during this period US clinicians took a 'remission at all costs' approach, as

treatment regimes 'were far more intensive than those recommended by clinical

researchers'. In contrast, UK oncologists were reluctant to follow aggressive

treatment protocols which prolonged child suffering and 'appeared to be curable

for a substantial minority of sufferers' (Barnes 2007: 254). Through the 1980s

survival rates increased to current rates of around 80 per cent for all childhood

cancers (Zeigler et al. 2005). These rates vary according to cancer typology,

tumor stage growth and location; with survival of Hodgkins disease at over 90 per

cent, acute lymphoblastic leukaemia at 80 per cent and neuroblastoma at 20-30

per cent chances of remission (Dixon-Woods, Young and Heney 2005: 19-21).

The medical prize of survival

Advances in paediatric oncology have established childhood cancer survival as 'one of the major medical success stories' of the 20th century (Kruger 2007: 98). Yet in her study of young adult survivors of childhood cancer Drew (2007: 293) argues that 'medical narratives still uncritically posit cure as the prize, continuing to promote a storyline of survival in which cancer has little place in the lives of survivors'. Cancer remission represents the pathological end of the disease (Sullivan 2004), but the health of children who survive cancer is often compromised by intensive cancer treatment (Oeffinger et al. 2006; Hudson, Mertens, Yasui, Hobbie, Chen, Gurney, Yeazel, Recklitis, Marina, Robison and Oeffinger 2003). Childhood cancer represents an immediate threat to a child's existence, but cancer treatment which saves them from a fatal outcome affects their long-term health. In this context of children, medicine and cancer survival, primary carers rather than clinicians are left to deal with the cancer aftermath, as children are effectively 'cured' of the disease. Yet the available evidence suggests that carers are given little recognition as contributors to their child's health in the childhood cancer aftermath (Young et al. 2002; Ribbens McCarthy, Edwards and Gillies 2000; Little et al. 2002).

Gilding (1999: 225-226) argues that health professionals are pivotal in defining the cultural values of acceptable child rearing practices. Carers, particularly mothers are socially constructed as altruistic and absorbed in a child-centered structure of family life (Young et al. 2002). Carers are socially ascribed as their

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child's legal and moral guardians, with children constructed as dependant, innocent and vulnerable, and in need of protection. When children are impacted on by cancer, carers experience a 'fundamental re-defining of their identities', an intensification of their existing roles and obligations while incorporating new technical and nursing roles (Young et al. 2002: 1844). The advent of childhood cancer thus increases cultural expectations on carers as a child's well-being is an indicator of the quality and adequacy of primary care (Petersen and Lupton 1996: 73). Primary carers have a particular expectation as guardians of their child's biography and protectors of their child against external threats (Young et al. 2002: 1843). Yet cancer is a 'disease in which cells go berserk and attack their host body', and represents a striking threat to a child's life (Stacey 1997: 63). Carers must negotiate and give meaning to the intersection of their child and the threat of cancer, but in a cultural context that privileges the medical success story.

The 'prize' of cancer survival is sustained through public discourse. The media has a dominant role in representing how 'dominant metaphors and terms within which the public discourse around childhood cancer' are assessed and constructed (Dixon-Woods et al. 2003: 161). Media accounts privilege medical advances in cancer treatment but represent adults and children affected by cancer in a different manner in order to reflect cultural assumptions of age and personal responsibility for health (Stacey 1997). Adults with cancer are represented in public discourse from two perspectives. The first approach is a victim-blaming discourse, such as the linking cancer to smoking, alcohol abuse and obesity.

Cancer then becomes a value laden term inferring moral culpability as a disease self-inflicted by consumption, lifestyle choices and environmental causes (Lupton 1994: 66; Ziegler et al. 2005: 78; Seale 2002). The second approach is represented through popular adult media personalities (for example Kylie Minogue, Olivia Newton-John, Lance Armstrong) who are depicted as heroic, ideal types in surviving cancer (Frank 1995; Stacey 1997). Seale (2002: 108) explains this binary by arguing for the close links between the medical profession and media accounts which valorise medical advances in cancer treatment as the promise of human control over illness. Seale (2002: 108) also captures Sontag's (1991) analysis of media accounts using military metaphors: of having 'fought or battled to overcome cancer', and cancer survivors represented as 'living examples of the victory of medical intervention'. Stacey (1997: 15), who survived cancer as an adult, describes how the culture of cancer is reduced to a success/failure binary where 'the lucky ones [cancer survivors] are celebrated while the rest suffer in defeat'. A consequence of this public discourse is the limited way for cancer survivors to express their ongoing experiences other than in terms of triumph or defeat over cancer.

In a childhood cancer context media accounts represent children as 'courageous, stoical and inspirational', while carers are characterised as 'co-confederates in winning the war against cancer' (Dixon-Woods et al. 2003: 143). In their comparative analysis Dixon-Woods et al. (2003) revealed both similarities and differences between carers' experiences and newspaper articles representing their

experiences of childhood cancer. Twenty carers were recruited for the study and 358 childhood cancer media articles were selected. Dixon-Woods et al. (2003) found a high degree of symmetry regarding carers and media accounts of cancer as an assault on children and endorsed carers' obligations towards their child within the dominant discourse of parenting. However, carers regarded media accounts offering little resemblance to their actual distress and anguish. Carers experience a reduced quality of life and severe role strain yet felt an expectation to be 'brave and uncomplaining; to do otherwise would involve violating the dominant cultural metaphor of stoicism' (Dixon-Woods et al. 2003: 162). Carers also regarded media accounts as a source of tension by creating public expectations and stereotypes which they found difficult to live up to and achieve.

Media accounts therefore 'allow insights into the socially constructed nature of the idealised image of childhood' which has been argued as contributing to 'the marginalisation of parents into the role of a resource in the battle against cancer' (Dixon-Woods et al. 2003: 162). In this way the biomedical prize of childhood cancer survival is sustained through public discourse and carers are represented as contributing towards their child's benefit. In addition, the cultural expectation of 'putting the children first' is sustained and reinforced through medical and media accounts of childhood cancer (Dixon-Woods, Young and Heney 2005: 103). Yet little media attention is given to carers negotiating their own experiences and responses through their child's cancer.

Ambiguity of remission

The medically defined cancer status of remission offers carers an uncertain point of reference in which to give meaning of their post-cancer situation and suggests they need alternative explanations. Achieving remission from childhood cancer is the primary goal of medical clinicians (Heath 2005; Clarke and Fletcher 2003; Ziegler et al. 2005). Remission is a medical term which means the pathological evidence of no active cancer cells (Ekert 1989). Reaching the remission stage of cancer means that carers can begin to anticipate their child's long-term survival (Parry 2003; Speechley and Noh 1992). Much significance is therefore given to remission, as it represents medical confirmation of a child's potential life after cancer treatment and a desired outcome through the life/death situation at diagnosis and the long period of painful clinical interventions (Cohen 1995). However, the available literature portrays remission as an ambiguous means of characterising life after cancer as it offers both hope and the uncertainty for an indefinite period of life without cancer. Such ambiguity was indicated in Comaroff and Maguire's (1981) study involved 60 families of children in remission from leukaemia. In contrast to earlier studies examining the death of a child (Bluebond-Langer 1978; Orbach, Sutherland and Bozeman 1955), Comaroff and Maguire's (1981) research occurred in an era when cancer survival was a relatively new phenomenon. Comaroff and Maguire (1981: 115) argue that medical advances create a situation where parents' search for meaning becomes a 'fragile balance between threat and hope' in the context of uncertain and unpredictable outcomes.

Primary carers of children in remission have to reconcile the diminishing threat of their child's disease with the ongoing uncertainty, possible relapses and potential morbidities of cancer treatment. Comaroff and Maguire's (1981: 121) study illustrates the fundamental tensions 'between meanings and values attached to illness by the sufferer [and carer] and by clinical definitions'. Cancer remission follows neither a classic 'sick role' (Parsons 1951) acute/recovery model of illness, nor a relatively permanent chronic illness trajectory (Strauss and Glaser 1975). Rather, remission is a 'phase of uncertain length and status, during which major symptoms are in abeyance, but its clinical definitions remain tentative' (Comaroff and Maguire 1981: 120). Comaroff and Maguire's (1981: 122) findings illustrate how increased cancer survival rates establish a 'doubly ambiguous' situation in which carers have difficulty grasping the changing meanings of their child's cancer and remission: 'the more medicine appeared to control but when knowledge was still lacking, the more threatening and alienating childhood cancer became from control over its effects'. Their study highlights how childhood cancer; as a once fatal disease with meanings of tragic certainty, has shifted, but the search for a meaning to remission involved carers coming to terms with chronic uncertainty.

Cohen's (1995) study of 10 parents reveals a similar tension in making sense of remission. Cohen (1995: 68) argues that remission forms part of the 'medicalisation of survival' discourse used by health care professionals, whose

'language, knowledge, values and beliefs' promote a sense of authority. This statement describes how medicine has 'the power of knowledge to define others and control them, and spells out what this means for health' (Petersen 1994: 5). Yet in Cohen's study, parents express their acute awareness that despite their child's disease being under apparent control, a relapse can reoccur at any time. One parent for example gives a metaphorical meaning to remission as 'living with a time bomb, never knowing when it is going to go off' (Cohen 1995: 66).

To shed light on how meanings of remission have developed, Barnes (2007) provides a useful historical concept analysis of how the definition of remission has evolved from the 1970s when childhood cancer survival rates started to show incremental progress. Barnes argues that the term 'cure' is seldom used, as clinicians are unable to guarantee a permanent end to the disease, unless a patient dies at a later stage of an unrelated cause (Barnes 2007: 257). Barnes reveals how UK clinicians recognise the difficulty in representing a clinical remission in a way that enables family members to define their lives after cancer, particularly when remission represents an unknown duration for being cancer-free. Clinicians adopted the term 'indefinite remission' to indicate that the chance of a cancer relapse was no greater than for the general population, but this left children and carers with a fundamental uncertainty of ever being free of the disease (Barnes 2007: 253).

In consultation with patients, parents and psychologists, clinicians then reconfigured remission as a 'psychological cure' (Barnes 2007: 261-262). However, this definition resulted in dispute between clinicians who rejected a 'cure' definition because it was unquantifiable, and those who endorsed the term in order to give family members some acknowledgement and meaning to the end of the cancer experience. Clinicians who supported the term 'cure' argued that 'the very definition of childhood presupposed that children had futures' and to assume a child would not survive was 'tantamount to psychological euthanasia'; as clinicians were expected to treat all children as potentially curable so that those successfully treated could resume a normal life (Barnes 2007: 262).

Barnes' study reveals that clinicians sought to develop a term representing a potential life after cancer, while acknowledging that the term 'remission' implies cancer related uncertainties. Current notions of remission are located between clinical remission and psychological cure and there is little consensus on an agreed definition of what constitutes a post-cancer health status (Barnes 2007: 263). Sullivan (2004: 255) similarly describes how post-cancer definitions include either a 'complete' remission to represent the absence of active cancer cells or a 'partial' remission to indicate a regression of the disease at the time of a pathology test. Medicine represents legitimate and authoritative scientific knowledge (Petersen 1994: 6) and remission offers those affected by cancer with some hope and respite that the immediate threat of cancer has abated. The term nevertheless carries an implicit until-further-notice clause (Little et al. 2002).

These definitions reduce remission to an objective measure but offer few insights from those affected by cancer and discount the social processes involved in making sense of cancer survival. Scholars such as Frank (1995), Sontag (1991) and Stacey (1997) survived cancer and all testify that with no medical assurance of a permanent disease-free future, the term 'remission' provides little confidence in people's lives. Some scholars also raise the issue that remission may not be the ultimate objective of a cancer patient. Instead, a timely death may be the desired outcome if quality of life is compromised to a significant extent (Zebrack 2000; Little et al. 2002). Cohen (1995: 69) also proposes that if relapses occur after remission has been achieved then people come to see 'the end [of life] implicit in the word [remission] itself'.

Medical definitions of remission therefore align with lay meanings of uncertainty. The literature on childhood cancer justifies carers' uncertainty of a heightened chance of their child relapsing (McKenzie and Curle 2011; Parry 2003; Young et al. 2002; Cohen 1995; Comaroff and Maguire 1981) and the impact of cancer and its treatment causing ongoing morbidities and increased risks of early mortality (Oeffinger et al. 2006; Heath 2005; Dixon-Woods, Young and Heney 2005). Emerging US and European surveys reveals that 'almost half of childhood cancer survivors will have or will develop disabilities severe enough to affect quality of life' and the mortality rate for five year survivors is greater than tenfold that of the normal age adjusted population (Heath 2005: 761). Nevertheless, remission

from childhood cancer is a health status aimed for and, once achieved, gives children and their carers some comfort and hope in a life after cancer (Cohen 1995; Little and Sayers 2004). Remission is a value-laden medical metaphor representing a post-cancer health status but offers a partial account for people to develop a meaningful post-cancer discourse (Stacey 1997; Comaroff and Maguire 1981). The scholarship of Cohen (1995), Little et al. (2002) and Barnes (2007) suggests that primary carers need to interpret and give new meaning to medical remission by drawing on a discourse of hope and uncertainty. I elaborate on this theme in Chapter Three where I review theories of survivorship.

Childhood cancer survival is represented as a great achievement in medical advances but the 'prize' comes with the 'price' of children suffering ongoing morbidities from the cancer treatment which saved their lives. These 'late effects' form a major constraining factor in shaping children's lives after cancer has abated (Drew 2003, 2007; Heath 2005; Ziegler et al. 2005). Yet few studies have examined how these child late effects impact on their primary carers, despite carers being accountable for dealing with their child's survival consequences.

The price of survival

The medical literature on the success of childhood cancer treatment also acknowledges the 'price' of survival manifesting in child chronic morbidities as a consequence of intensive cancer treatment (Hudson et al. 2003; Heath 2005; Oeffinger et al. 2006). The late effects of cancer treatment represent a plethora of

adverse health outcomes that vary according to clinical protocols designed for

cancer typology and location, tumor growth stage, the child's age, era of

treatment and individual responses to therapy (Ziegler et al. 2005). Morbidities

manifest as serious health issues, including: organ dysfunction, infertility,

physical and cognitive deficits and early mortality (Friedman and Meadows 2002;

Hudson et al. 2003). Scholars refer this outcome as the 'medical paradox' of

childhood cancer survival, as current treatment protocols sustains children's lives

but late effects are a major consequence of this technology (Oeffinger et al. 2006;

Cantrell and Conte 2009; Rodgers, Horrocks, Britton and Kernahan 1999).

Paediatric oncology treatment protocols are in an ongoing state of refinement, yet

between 50 per cent (Heath 2005) and 75 per cent (Lacker, Benesch, Schagerl,

Kerbl, Schwinger and Urban 2000) of childhood cancer survivors have

morbidities affecting their quality of life. Furthermore, late effects in children

'may not become evident for many years', and children and carers are therefore

left to deal with manifest and potentially latent chronic conditions as part of their

ongoing lives after cancer remission (Oeffinger et al. 2006: 1573). Rosoff (2006:

1522) metaphorically represents current survival rates and the unintended

consequences of late effects as 'the two-edged sword of curing childhood cancer'.

Carers are given little attention in the late effects research but are actually socially

positioned to make sense of this medical paradox and mediate their child's

morbidities into their everyday lives after cancer has abated.

International childhood cancer survivor surveys illustrate the extent of child morbidity trends. A longitudinal European study representing 223 childhood cancer survivors found that 167 (75 per cent) children were identified as having chronic physiological and neurological deficits (Lacker et al. 2000). Major physiological late effects impacted on central nervous system and endocrine (gland) systems, sensory (eyes, ears) as well as liver, kidney, lung and heart malfunctions. Neurological deficits were identified in 87 children (39 per cent), with causation due to a combination of damage caused by the original cancer and medical intervention. A larger American survey representing 10 397 childhood cancer survivors shows similar results: where 73.4 per cent of participants showed persistent physiological impairments, including coronary and renal dysfunction, fertility loss, hearing and visual limitations. Amongst this population, 42.4 per cent had late effects rated as severe, disabling, or life-threatening' (Oeffinger et al. 2006: 1572). In addition, sudden onset heart failure and strokes with adult survivors of childhood cancer have been linked to late effects of cancer treatment (Craft 2000: 338; Hudson et al. 2003; Cohen 2008). The 'price' of survival also manifests in a range of neurological deficits, with reduced concentration, short-term memory and learning dysfunction, all of which impact on a child's quality of life and life-chances (Oeffinger et al. 2006).

Less aggressive therapies have been trialed to reduce child morbidities but this 'killing with kindness' approach to childhood cancer treatment has ceased because less toxic treatment regimes failed to contain the original cancer and

increased fatal outcomes (Brink 2008). Clinicians therefore maintain a precarious balance between sustaining children's lives with aggressive treatment and long-term survival where quality of life may be compromised through treatment late effects. Australian clinicians have responded to this medical dilemma by implementing 'late effects clinics' to monitor post-cancer treatment morbidity (Heath 2005; Ziegler et al. 2005). A 'health passport' information booklet program has also been developed to provide survivors, carers and GPs with relevant cancer history and treatment information (Moore 2006; Goodenough, Johnston, Casey, Foreman and Cohen 2008: 57-58). Young cancer patients have been metaphorically referred to as 'canaries in the mineshaft' to highlight ways in which experimental clinical trials have eventuated in their long-term survival, but with compromised lives (Rowland, Hewitt and Ganz 2006: 5101).

Medical advances have therefore created a population of 'technology-dependant and medically fragile children whose life expectancy is unknown and whose future quality of life are unpredictable' (Cohen 1995: 63). Late effects represent a form of 'iatrogenesis', a concept which Illich (1975, 1976) developed to represent illness originating from the healer. The concept has clinical, social and cultural dimensions; but childhood cancer late effects are a clinical iatrogenesis deriving from oncology treatment. Yet few studies have accounted for how primary carers make sense of or deal with their child's ongoing care responsibilities after cancer. The child/carer relationship, carers' obligations of care and emotional investment in their children suggest late effects are significant

factors in shaping carers' own lives (Young et al. 2002). The issue of late effects deriving from medical intervention is a recurring theme across much cancer research involving adults as well as children (Kaya, Karatepe, Gunaydin, Yetis and Uslu 2011; Oeffinger et al. 2006; Rosoff 2006; Little and Sayers 2004). Although adults with cancer mostly have the capacity to make their own treatment choices, primary carers are required to make treatment decisions on behalf of their child due to age and socio-legal principles that limit children's decision making options (Dixon-Woods, Young and Heney 2005: 137).

When a child is diagnosed with cancer the State delegates its healthcare system with the duty of care to save the child. Once remission is achieved the State's cancer related obligations are fulfilled. Yet carers have a nominal legal capacity to make decisions on behalf of their child through cancer. At diagnosis carers have little choice but to agree to submit their child to medical treatment in the hope they might survive. This situation is a striking example of carers losing control of the capacity to protect a child but retain their ongoing obligations of 'felt responsibility and protection' (Young et al. 2002: 1845). Legally, carers have the right to give consent to their child's cancer treatment as their child's legal guardian, but not the right to refuse their child's treatment (Dixon-Woods, Young and Heney 2005: 151). Heavily imposed social and legal sanctions are in place if carers refuse to agree to medical intervention (Pinnock and Crosthwaite 2005; Zutlevics and Henning 2005).

Carers' duty of care is conditional on medicine's role in enacting the State's legal intervention doctrine of *parens patriae*. This Latin term refers to the State's duty to 'protect the lives of children when parents cannot or will not do so' (McCartney and Beauchamp 1981:135). In Australia the State endorses the United Nations Convention on the Rights of the Child Article 24 which recognises children with the right to:

> The highest attainable standard of health and to facilities for the treatment of illness and the rehabilitation of health, and states that nations shall strive to ensure that no child is deprived of his or her right to access to such health care services (WMA 1998).

Australian children with cancer have fair and equal access to paediatric oncology treatment but carers and child rights are not absolute:

> The law has never treated parental rights as sovereign, or beyond review and control …The principle of the law …is that parental rights are derived from parental duty and exist only so long as they are needed for the protection of the person and property of the child (Pinnock and Crosthwaite (2005: 370).

Children have few rights to make treatment decisions as they do not meet the legal age of consent; but bioethicists argue intervening to preserve a child's life takes precedence over a child's autonomy (Shilling and Young 2009: 7).

Legal test cases involving children challenging clinical intervention have been overruled on the basis of limited child competency to make life/death decisions (Dixon-Woods, Young and Heney 2005: 144-148). There are no available records of Australian cases involving primary carers disputing their child's cancer

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treatment. Nevertheless, Australia's High Court endorses legal intervention through the principle of *parens patriae* if child beneficence is disputed (Zutlevics and Henning 2005: 680; HREOC 2008: 12). The State grants authority to medicine to ensure that a child is treated according to current cancer protocols. Clinicians have a duty of care to achieve remission and save the child from a fatal outcome (Heath 2005) but in doing so create a population of children negatively impacted by the treatment processes which saved their lives (Brink 2008; Hudson et al. 2003). Yet social science has given little attention to the links between child and parent rights, and legal and medical decisions privileged by the State (Dixon-Woods, Young and Heney 2005: 151). This socio-legal context suggests primary carers' lives after cancer are characterised by the knowledge of having little choice but to submit their child to medical intervention; saving their child from a fatal cancer outcome, but left with their child's ongoing care obligations, including their compromised health.

Psychological 'distress' approach to carers

Social science research examining childhood cancer is dominated by the psychological approach of determining carers' capacity to cope with the stresses of having a child with cancer (McCubbin, Balling, Possin, Frierdich and Bryne 2002; Grootenhuis and Last 1997; Barlow and Ellard 2005). This research offers valuable insights into carers' distress through the diagnosis and treatment phases of cancer and the indicators of post-traumatic stress disorder (PTDS) after their child's cancer has abated (Clarke and Fletcher 2003; Bruce 2006). However,

investigating carers only from a singular stress perspective gives inadequate recognition to their capacity to respond and shape their situation, or from expressing their experiences in terms that are not stress related (Young et al. 2002: 1845). The approach of examining carers from a distress perspective can also invite unnecessary psychiatric surveillance on the assumption of their inability to cope (Dixon-Woods, Young and Heney 2005: 96).

The psychological approach offers useful insights into carers' stressful experiences in the early stages of having a child diagnosed and treated for cancer (Young et al. 2002; Parry 2003; Bruce 2006). Primary carers respond to their child's diagnosis with distress indicators of disbelief, anxiety, depression, denial, anger and low self-esteem, which in turn exacerbates problems in social relationships with family members and medical staff (Fotiadou, Barlow, Powell and Langton 2008; McGrath 2001). As the child responds positively to treatment, carers' initial stress levels lessen as they start to consider non-fatal outcomes, become familiar with medical regimes and adapt to the clinical arena (Poder, Ljungman and von Essen 2007; Cohen 1995; Woodgate and Degner 2003). Growing evidence illustrates a trend whereby carers adapt to having a child with cancer with diminishing levels of stress but the psychological approach nevertheless continues to examine primary carers from a distress paradigm (Barlow and Ellard 2005; Dixon-Woods, Young and Heney 2005; Bowman, Rose and Deimling 2006).

Psychological approaches to research on childhood cancer have evolved through various research paradigms that run parallel with medical advances. Research conducted up until the 1970s focused on mourning and grief associated with the death of a child (Orbach, Sutherland, and Bozeman 1955; Comaroff and Maguire 1981). The 'Damocles Syndrome' concept emerged as the dominant psychological research paradigm during the 1980s. This concept is based on the Greek myth of the sword of Damocles, and depicts a metaphorical sword hanging by a single horsehair to represent carers' persistent uncertainties of a cancer relapse and ongoing anxieties about the long-term effects and treatment after childhood cancer (Betz 1983; Zebrack and Zeltzer 2001). The current trend in the psychological approach focuses on determining the prevalence of primary carers exhibiting characteristics of PTSD after the abatement of their child's cancer (McGrath 2001; Clarke and Fletcher 2003; Bruce 2006).

PTSD was initially identified as a psychiatric condition associated with military personnel who had suffering war-related trauma (Kupst and Schulman 1988; Summerfield 2001). The condition has been adapted within childhood cancer research to account for carers' ongoing distress beyond their child's initial diagnosis and treatment (Fotiadou et al. 2008; Poder, Ljungman and von Essen 2007). PTSD manifests in a range of symptoms: a grieving for past selves, loss of normative expectations, avoiding situations that trigger diagnosis/treatment memories, acute panic states, chronic anxiety, depression, increased drug/alcohol use, and suicide (Bruce 2006; Barlow and Ellard 2005).

There is debate about whether PTSD actually exists as a psychiatric condition. Summerfield (2001: 98) argues that PTSD is a tool developed by medical and psychiatric sciences to 'convert human misery and pain into technical problems that can be understood in standardized ways and are amiable to technical interventions by experts'. While giving credence to those suffering significant psychiatric dysfunction, Summerfield (2001: 98) argues that PTSD symptoms form part of everyday responses to distress, and cautions against reducing people to psychopathological symptoms. Supporting this argument, Petersen (1994: 3) claims that stress is a difficult concept to define but is nevertheless legitimised through psychological and psychiatric professions in such a way that leads to a focus on individuals as maladaptive. However, Brunet, Akerrib and Birms (2007: 501) argue that PTSD is an extensive but under-diagnosed disorder. Their argument is based on the changing criteria for PTSD diagnosis, from acute war and life/death trauma to more chronic conditions including co-morbid psychiatric disorders and 'malingering' conditions where people in stressful situations, such as police, paramedics and military personnel, have yet to exhibit and/or report PTSD symptoms.

The literature on primary carers of childhood cancer survivors cut across both Summerfield's (2001) and Brunet, Akerrib and Birms' (2007) arguments. For example, in a literature review of 83 childhood cancer articles Grootenhuis and Last (1997: 482) revealed that primary carers whose children had completed

cancer treatment had 'no serious psychological problems'. A longitudinal study of 128 primary carers of children with cancer revealed similar trends with acute distress at diagnosis but over the course of one year their distress levels had significantly declined. These studies suggest that carers experience acute distress through cancer but that stress diminishes through their child's remission (Hoekstra-Weebers, Jaspers, Kamps and Klip 2001). However, other studies suggest some parents may experience enduring concerns and worries because of the 'ever-present fears' of cancer relapses and late effects continuing to influence the lives of primary carers after childhood cancer (Dixon-Woods, Young and Heney 2005: 105).

The preceding discussion reveals the psychological approach characterises primary carers as suffering acute and/or prolonged distress despite evidence supporting diminishing distress through cancer. However, carers have to give meaning to their own lives: while mediating the medical discourse of survival (Drew 2007), the ambiguous status of their child's remission (Little et al. 2002) and dealing with their child's late effects of cancer treatment. Underlying this process is the cultural expectation of restoring a sense of normalcy after a life crisis (Becker 1997: 147). To deviate from this cultural norm can invite negative sanctions of carers' distress (Young et al. 2002), an inability to cope, the potential for being labelled with PTSD and the need for psychiatric intervention. Each of these approaches to childhood cancer support the multi-faceted ways in which primary carers of childhood cancer survivors are given inadequate attention in

both social science research and public discourse. They have been characterised more by their carer role and less as individual agents who adapt to their disrupted lives after their child's cancer.

Carers through cancer: Responses to disrupted lives

Primary carers have been a focus of sociological research in relation to childhood cancer, but available data illustrates a gap in which carers of children in remission have not been a focused subject of investigation. However, scholarship representing carers' experiences through their child's cancer offers useful insights into the ways in which they construct their lives after cancer. The following discussion illustrates that having a child diagnosed with cancer is a life-changing experience. Carers are acutely aware of their child's life/death situation and the sudden realisation that their pre-cancer identities and taken-for-granted assumptions of certainty and control are no longer sustainable. They respond to their altered situation by constructing a new sense of self, and adopt new roles and obligations in response to suddenly being a primary carer of a child with cancer (Dixon-Woods, Young and Heney 2005).

Sociologists have identified the need for sustained research into carers in response to improved childhood cancer survival rates (Zebrack 2000; Young et al. 2002) but the limited research on carers of children in remission suggests that sociological research has not kept pace with medical advances. Young et al. (2002: 1846), for example, call for researchers to focus on carers and 'explore the

degree to which biographical disruption extends beyond the treatment period'. In examining the source of this research gap it is difficult to agree with Thomas, Morris and Harman (2002: 531) who argue that the 'sociology of cancer *per se* is under-developed' due to a wealth of scholarship on cancer experiences (for example Bowman, Rose and Deimling 2006; Little and Sayers 2004; Aziz 2002; McGrath 2001). A more pertinent argument suggests that 'sociologists tend to be more interested in problems than in people's response to tackling them' (Bury 1991: 451). This claim, I argue, has merit as research trends privilege people's experiences through cancer but discounts their ongoing lives after cancer (Cline et al. 2006; Earle et al. 2006; Hoekstra-Weebers et al. 2001).

This area of study may even deter research because it is located amid acute and chronic illness as well as survivorship categories (Little et al. 2002), examines both health and illness experiences and from the perspective of carers rather than child cancer survivors *per se*. There is also a timing issue, as childhood cancer survival is a recent phenomenon and research responses towards carers of childhood cancer survivors are currently under-developed (Heath 2005; Rosoff 2006). A trend in childhood and parenthood studies privileges a 'children-first' approach and carers' experiences of their children 'remain taken-for-granted and rendered uninteresting' (Dixon-Woods, Young and Heney 2005: 13). Regardless of the causes of the research gap, this study seeks to advance sociological understandings of the social processes in which primary carers construct their lives in the aftermath of their child's cancer.

Carers gendered experiences through cancer

Much of the literature on primary carers illustrates different gendered identities, experiences and responses through their child's cancer. Gender identities are a product of 'historical, structural, cultural and ideological forces that determine and reproduce socially constructed and shared understandings' of how men and women are culturally positioned in society (Chesler and Parry 2001: 364). Connell (1987: 47) argues that gender roles are responses to gender identity where 'role *expectations* or norms define which actions are appropriate to a given position' (original emphasis). Childhood literature conveys how mothers provide the majority of childcare while fathers offer both peripheral support in hospital and maintaining other family and economic commitments (Young et al. 2002; Clarke and Fletcher 2003; Clarke 2006). The traditional pattern of childcare labour arrangements are referred to as a 'culture of childhood cancer' with an intensification of maternal roles and a division of paternal roles of fitting a child's illness into existing work and family life (Reay, Bignold, Ball and Cribb 1998: 50). The outcome of these gender arrangements through childhood cancer results in mothers experiencing severe role strain and fathers experiencing role conflict (Young et al. 2002; Chesler and Parry 2001; Reay et al. 1998). McGrath (2001) also notes how childhood cancer research representing maternal and paternal carers are effectively maternal responses due to mothers' presence in hospital, and their accessibility as research respondents.

The gendered experiences and responses are evident in a study involving 35 maternal and paternal carers of a child with cancer (Reay et al. 1998). The study demonstrated how mothers were physically immersed in the care of their child through cancer. In contrast, fathers attempted to balance the care of their child and support their spouse with ongoing economic and other family commitments. Gender differences were also prominent in mothers' emotional engagement with their child, whereas fathers maintained an emotional distance, but offered overly optimistic and stoical support. This study also illustrated how gender differences shaped carers' responses to dealing with the sense of powerlessness in having a child with cancer. Fathers found it difficult to accept such limited control whereas mothers were more flexible and accepting of their limited control. The study revealed that constructions of motherhood and fatherhood in a childhood cancer context notably shape gender identities and exacerbate gendered divisions of domestic and emotional labour (Reay et al. 1998).

Research conducted on mothers of children with cancer illustrates a similar theme in which social constructions of motherhood shape maternal child carers as 'both a regulator of their lives and a major component of their self-identity' (Dixon-Woods, Young and Heney 2005: 102-103). This construction is evident in a study of 20 mothers of children with cancer as cultural expectations perpetuate and intensify maternal childcare to the extent of 'altering their sense of self and social identity' as well as a profound sense of obligation of 'proximity' in being constantly close to their child in order to provide physical and emotional comfort

(Young et al. 2002: 1835). 'Proximity' represents mothers' enacted sense of duty to focus solely on their sick child during treatment and reduce their priority on other family commitments. The mothers also emphasised how everyday childcare tasks such as sustaining child hygiene, diet and discipline took on new and intensified meanings. Maternal care responses through their child's cancer asserted their status as mothers while mutually serving to protect their child's biographies when they could do little else to ensure their child's well-being. Mothers experienced multiple anxieties, role strain, reduced quality of life and internal conflicts but engaged in 'deliberately de-legitimising their own needs' (Young et al. 2002: 184-185).

Mothers caring for chronically ill children also negotiate and respond according to their child's gender, age and level of autonomy. In a study of mothers of teenage sons with chronic asthma and diabetes, Williams' (2000b: 254) developed the concept of 'alert assistant' to represent how mothers strategically anticipate and subtly assist their son in an unobtrusive and undetectable manner. This process involved the mothers interpreting and negotiating a balance between their sense of care responsibilities but without being seen as overly protective in order to enhance their son's autonomy, self-care and future independence as adults. Enacting an 'alert assistant' role meant that mothers' everyday care involved being sensitive to their child's gender, age and autonomy as proactive childcare managers, performing in subtle, often invisible ways and 'achieved if possible without the knowledge of the person being assisted' (Williams 2000b:

269). Mothers also had to negotiate their obligation to encourage their sons to take on more self-care responsibility but were sensitive to being criticised for 'over-protecting their sons by both health professionals and family members, particularly fathers' (Williams 2000b: 270). In contrast, mothers take a more assertive management styles with young children and babies whose health is severely compromised (Sullivan-Bolyai et al. 2003; Rehm and Bradley 2005). Morse, Wilson and Penrod (2000), for example, found how mothers of children 4-13 years of age with 'severe life-threatening disabilities' responded according to their child's age and expected development capacity. Mothers defined their identities as an ongoing process of 'sorting, deciding and evaluating' their roles to protect their child while attempting to normalise their child's disabilities (Morse Wilson and Penrod 2000: 670).

In a childhood cancer context mothers negotiate multiple child, childcare and cancer treatment factors, including the child's age, comprehension, autonomy, treatment compliance and/or non-compliance. Reconciling these issues shapes how mothers interact with their child and clinicians through cancer treatment, the information they reveal or conceal to their child regarding diagnosis, treatment procedures and chances of survival (Dixon-Woods, Young and Heney 2005: 115). Yet few studies have addressed how mother-child interactions are negotiated with a consideration of a child's gender and age, or how mothers' gendered roles and identities are constructed after their child's cancer.

Research on fathers of children with cancer suggests they are under-represented in much scholarship and most studies are conducted with small samples of participants (Young et al. 2002; Chesler and Parry 2001). For instance, Peck and Lillibridge (2005) describe how four rural fathers engaged in various strategies to normalise their lives: from adapting to their child's illness, changing expectations, using external distractions and avoiding medical details. McGrath and Huff (2003) describe how six fathers felt socially marginalised due to the hospital ward being occupied by mothers, children and mainly female nurses.

One exception in the literature is Chesler and Parry's (2001) study of 167 fathers of children with cancer conducted through a series of interviews and focus groups. The findings show fathers' roles, experiences and obligations were highly influenced by the cultural expectations of fatherhood and masculinity. Fathers experience their child's cancer in a conflicting and ambiguous manner; by reconciling their traditional gender identities as economic providers, while becoming more inclusive and involved with their child, spouse and family due to the threat imposed by cancer on their child's life. Chesler and Parry's (2001) study offer insights into how masculinity shapes how fathers experience their child's illness and respond in ways that challenge traditional expectations of fatherhood. However, Chesler and Parry (2001: 379) argue that clinicians reinforce gendered divisions of childcare by assuming mothers rather than fathers as the child's primary carer and representative.

Childhood cancer literature therefore suggests that fathers are divided between the care of a sick child and other external commitments. The capacity of fathers to provide financially for their family when their child has cancer reveals that their socio-economic position and traditional gender roles as economic providers or 'bread-winners' are closely connected (Chesler and Parry 2001). In particular, research reveals that families from lower socio-economic positions before their child's diagnosis face added economic hardship through cancer (Dixon-Woods, Young and Heney 2005; Heath, Lintuuran, Rigguta, Tikotlian and McCarthy 2006). Childhood cancer treatment in Australia is funded under the Medicare health scheme with access to free treatment in public hospitals. Yet an Australian report found that 'in addition to high social and emotional impacts of childhood cancer, the majority of families reported suffering a great or moderate degree of economic hardship' (Heath et al. 2006: 439). Those impacted by severe financial strain were from lower socio-economic backgrounds, single parents and those from rural and remote areas. Heath et al. (2006: 447) argue that 'the distribution of resources is not equitable and is currently failing to negate significant financial stresses for many Australian families'.

A New Zealand study found similar economic hardship as 87 of 192 family members had had to borrow money through their child's cancer because of increased financial outlays alongside decreased income from one or both carers (Dockerty, Skeggs and Williams 2003: 254). Few available studies have examined how fathers from differing socio-economic backgrounds respond to

having a child in remission or how ongoing financial strains shape their lives. However, the preceding research illustrates that expectations of fathers to maintain traditional 'breadwinner' role through and beyond their child's cancer is important to how fathers construct and manage their paternal identities.

Carers' altered identities

A recurring theme in childhood cancer literature relates to the way in which carers experience an acute rupture between their pre-cancer life expectations and the emergence of new identities and ways of being a carer of a child with cancer. The transition into cancer is characterised by a 'reordering of meaning in the face of a hugely threatening disruption' as carers experience a profound loss of their previous lives which once featured with a sense of control and certainty in protecting a child (Dixon-Woods, Young and Heney 2005: 102). The threat of cancer directly threatens a child's immediate life, which in turn draws into question carers' 'self-identities as adequate parents' (Young et al. 2002: 1843). In Clarke-Steffen's (1993: 285) study, the experiences of 40 family members of a child recently diagnosed with cancer were conceptualised as a 'fracturing of reality' due to the abrupt uncertainty of their child's life, the limited control they had in protecting their child from harm and their reliance on medicine in the hope of a non-fatal outcome.

The fracture of reality is evident in the analysis of 20 mothers of children with leukaemia who experienced a 'biographical shift' from their lives before cancer and a 'fundamental redefining of their self-identities' due the immediate realisation they were unable to protect their child's life (Young et al. 2002: 1844). Carers faced the dilemma of wanting to protect their child but lacked the medical capacity to do so. This diminished control altered carers' identities as they 'could not fulfill the fundamental parental obligation of protection' (Dixon-Woods, Young and Heney 2005: 113). After the acute diagnosis phase, carers begin to restore a sense of control and develop ways of adapting to having a child with cancer. Although reliant on clinicians, the carers assume important child advocacy and mediating roles between clinicians and their child. Carers also became aware that clinicians rely on their intuitive knowledge, constant child monitoring for adverse reactions to treatment, making appointments and to ensure their child's compliance in painful treatment procedures (Young et al. 2002).

Carers construct the partnership between themselves, clinicians and children through cancer as an 'investment in their children's survival' (Dixon-Woods, Young and Heney 2005: 101). Through this partnership, carers are empowered with a new sense of control as a basis for constructing new identities and new realities to make sense of their radically altered situation (Clarke-Steffen 1993; Clarke and Fletcher 2003; Earle et al. 2006). Active participation in the cancer treatment process serves as a new and important way for carers to enact and give new meanings to protect their child in a life threatening situation.

Carers actively shape their situation within the constraints of cancer treatment by assuming multiple roles: as guardians, carers and advocates and where everyday childcare duties such as comfort, support, nutrition and hygiene take on new intensified meanings (Young et al. 2002: 1839). Carers become more empowered through information and familiarity with medical processes while assuming pseudo-nursing roles and extended health care and childcare resources (Dixon-Woods, Young and Heney 2005: 16). Treatment periods for childhood cancer vary from weeks for surgical treatment of solid tumors to 2 or 3 years of chemotherapy treatment for children with leukaemia (McGrath 2001). Once a child's cancer is medically stable she/he is treated as an outpatient, where they live at home but return to hospital for treatment, pathology tests and scans that monitor cancer (Dixon-Woods, Young and Heney 2005: 19). Carers can then start to construct a sense of domestic normality outside hospital regimes while still incorporating their child's treatment and tests into their everyday lives.

Carers through cancer: A new normal

Constructing new definitions of normality represents an importance characteristic of how people respond to illness conditions, particularly when prior notions of normal 'no longer fit with life experience (Becker 1997: 15). The literature offers a useful way to consider ways in which carers attempt to normalise their situation through cancer. A longitudinal study of 32 mothers of children with leukaemia

reveals how carers develop strategies to attain some form of domestic normality despite the severity of the disease and treatment (Earle et al. 2006). Through the out-patient phase, carers are 'encouraged by healthcare professionals to try to maintain a normal a life as possible' (Earle et al. 2006: 1). The study examined how family life was limited due to the presence of cancer and how carers responded at three different stages 3-4 months, 15 months and 27 months after diagnosis (Earle et al. 2006: 5-6).

During the 3-4 month phase carers considered normal family life severely compromised, as life centered on their child's illness and treatment. One mother, for example, explained how her life was 'never going to be the same as it was before', so to find a new way to get through cancer, she said how: 'we must build a new normality' (Earle et al. 2006: 3). At 15 months after diagnosis domestic family routines were starting to take priority while the child's treatment regimes were integrated into a newly constructed sense of normality. A feature of this stage was by 'playing down' differences between their lives and the lives of other families not impacted by cancer. At 27 months they were striving to achieve a sense of normality but as one mother explained: 'Me and my husband have put our lives on hold; it doesn't get any easier, to me it's got harder' (Earle et al. 2006: 5). Carers hoped to achieve a sense of normality but expressed ongoing concern about regaining normality as their lives were shaped by cancer treatment and ongoing uncertainties which had little resemblance to their pre-cancer notions of normal. They also expressed frustration of being unable to achieve a normality

according to the expectations of significant others and clinicians (Earle et al. 2006: 4). Carers were constantly striving for a sense of normality' to deal with their situation, but aiming for normality was 'also potentially damaging when it proves elusive' (Earle et al. 2006: 5).

Earle et al. (2006) describe normality as a goal for carers to aim for through their child's out-patient treatment phase but were still negotiating new definitions of what their normality might entail. However, Earle et al. (2006) seem to dismiss the possibility that carers' constructions of normality might be an evolving process. They describe how carers define their pre-cancer notions of normality as redundant, and while the 'new normal' was discussed *in-vivo* by one mother, Earle et al. do not develop this term to conceptualise ways in which carers construct their identities and situations. Nevertheless, this study shows carers constructing new parameters of normality through their child's cancer phases.

The theme of carers developing a 'new normal' is evident in Clarke-Steffan's (1997) research representing 40 family members (mothers, fathers and siblings) of a child diagnosed with cancer within 7 to 30 days of being interviewed. The study emphasised carers' management and decision making strategies in the early period following their child's cancer diagnosis. The findings indicate that carers' transition into cancer was characterised by uncertainty and helplessness, and of 'reconstructing reality' because of altered routines and a world view based around their child's life, illness and treatment (Clarke-Steffen 1997: 280). The concept

of 'creating a new normal' represents a series of strategies that carers develop to integrate and normalise childhood cancer into their lives (Clarke-Steffan 1997: 284). The new normal strategies include: 'managing the flow of information, reorganising roles, prioritising, assigning meaning to the illness, changing future orientations and managing the regimen' (Clarke-Steffen 1997: 281).

Clarke-Steffen's (1997: 281-284) concept of new normal demonstrates how carers give meaning and respond to having a child with cancer. Information management involves carers gathering, processing and disseminating information to family members and/or filtering to or from their sick child. Carers reorganised their roles to meet the extra demands of having a child with cancer, including mothers who stopped employment and fathers who reduced their hours of work, alternative accommodation, travel and other family commitments. They spent much effort in evaluating what was important to them and initiated changes when their actions did not reflect their values. Their meaning of cancer varied: from adopting a matter-of-fact approach to searching for meanings through religious beliefs. Some were unable to give meaning at all to their child's cancer. Future goals were de-emphasised and carers focused on the more immediate concerns for their child. Carers actively gained knowledge of treatment regimen and clinical protocols, administered medications, predicted treatment side effects and managed their child's compliance to treatment. Clarke-Steffen (1997: 284) argues that carers constructed their 'new normal' to reconcile their fractured realities and to maximise their child's health through the treatment period. The

concept of 'new normal' represents a distinct shift from carers prior notions of normality and their strategies offer a sense of predictability and routine in their altered lives.

Similar 'new normal' attributes are evident in Woodgate's (2006) longitudinal study of 39 carers and their children through two years of cancer treatment. Woodgate (2006: 8) explains how carers' accounts are summarised by the concept 'life is never the same'. The cancer diagnosis was a pivotal turning point for carers where the 'worlds as they knew it, would and did change forever' as they had lost their taken-for-granted assumptions of safety, security and certainty. Several carers describe the magnitude of diagnosis as moving 'from a pleasant dream to a horrendous nightmare' in facing the uncertainty of their child's life (Woodgate 2006: 11). Carers defined their sense of normality by accommodating uncertainties with hope for their child's cancer outcomes. They describe having 'no choice but to move on' and persevere with their immediate situation 'with a sense of cautious optimism' (Woodgate 2006: 16-17).

Woodgate (2006) and Clarke-Steffen (1997) develop different concepts but their research represents similarities as primary carers pre-cancer realities are radically altered and they construct a new form of normality which gives new meaning to their self and situation through their child's cancer. The notion of 'new normal' developed by Clarke-Steffan (1997) and Woodgate (2006) and to a lesser extent by Earle et al. (2006) offers a useful way to consider primary carers seeking a

meaningful frame of reference to define their selves and situation. These studies promote the idea of a 'new normal' representing multiple attributes: that pre-cancer taken-for-granted assumptions of certainty and control have lost their meanings, a way for carers to define their self and situation through cancer, a goal to strive towards and a strategy to manage the stress and uncertainty of the situation.

However, Clarke-Steffen's (1997) research represents carers' responses just weeks after diagnosis, while Earle et al. (2006) and Woodgate's (2006) studies represent up to two years through treatment. These findings suggest that carers develop a new sense of normality in the early stages of their child's diagnosis which is sustained through the treatment period. Clarke-Steffen (1997: 280) advances the attributes of the 'new normal' concept but does so to inform paediatric nurses dealing with patients and carers as a 'model of the family transition to living with childhood cancer'. The notion of new normal nevertheless offers a useful conceptual understanding in which to examine how carers construct meaning as a rupture from pre-cancer notions of normality, and new ways to define their self and situation through cancer. But the concept of 'new normal' has not been used to represent carers in the childhood cancer aftermath. The findings in the later chapters of this thesis support and build on the concept of 'new normal' as representative of primary carers' ongoing constructions after their child's cancer, and perhaps a permanent aspect of their everyday lives.

The process of redefining normality permeates much health and illness literature and illustrate that constructions of normal are context specific rather than universal (Bury 1982; Clarke-Steffen 1997; Deatrick, Knaft and Murphy-Moore 1999; Williams 2000b; Sanderson et al. 2011). For instance, Rehm and Bradley's (2005) study of parents of 'medically fragile and technology dependent children' illustrates how normalcy was impossible to achieve because of the continual priority given to the care of their child (2005: 817). In Morse, Wilson and Penrod's (2000) study of mothers of children 4-13 years of age who were ventilator dependent, participants constructed a twofold sense of normality; 'disabled as normal' and 'everyday as normal'. The mothers acted to ensure their child could normalise between their two worlds from a context of 'normal for them' and discounting how normality might be constructed by other families, with or without a child with a disability' (Morse, Wilson and Penrod 2000: 675). I extend the normalcy discussion in the next chapter as a sensitising concept to consider primary carers of childhood cancer survivors (Blumer 1969).

Conclusion

In this chapter I examined multi-disciplinary literature and argued that primary carers of children in remission are under-represented in medical, social science and public discourse. I supported this argument with evidence that carers are given a peripheral status in relation to the medical prize and price of cancer remission (Drew 2007), are characterised from a narrow stress/coping approach

and are absent from sociological attention once their child is in remission. Second, I argued that literature representing carers through their child's cancer offers valuable insights into their lives after cancer. Literature supports the advent of childhood cancer as a fracture in carers' pre-cancer identities and taken-for-granted assumptions of certainty and control. Studies reveal that carers construct a new definition of normality in response to their fractured prior lives and emerging new identities to accord with their altered childhood cancer situation. The literature represents primary carers in a particular intersection of mediating their own identities with the social constructions of parenting, children, medicine and cultural expectations to return to normal after cancer. Carers' gender and socio-economic status are also important factors in shaping how primary carers respond through their child's cancer. The available literature illustrates an important research gap in research that requires a sociological perspective to examine primary carers of children in remission, as individuals in their own right but whose identities are enmeshed and impacted upon by childhood cancer. In Chapter Three I develop a conceptual framework to represent primary carers in their post-childhood cancer context.

Chapter Three: Conceptualising carers

Introduction

The social context of primary carers of childhood cancer survivors exemplifies

ways that sociologists 'can learn a good deal about day-to-day situations in

routine settings from analysing circumstances in which those settings are

radically disturbed' (Giddens 1979: 123). The aim of this chapter is to advance

the thesis by developing an appropriate way to conceptualise primary carers'

experiences and the social processes in which they construct their lives after the

abatement of their child's cancer. I start with the premise that primary carers'

lives have been significantly disrupted and 'biographical disruption' offers a

suitable way to theorise carers through their child's cancer (Bury 1982, 1991), but

this framework has limited utility to represent carers of a child in cancer

remission. I extend Bury's framework by drawing on theories of identity,

survivorship and normality to conceptualise carers of children in remission. In

this chapter I also raise sensitising concepts to argue that carers construct a new

sense of normality in response to their post cancer context.

Situating biographical disruption

My decision to use biographical disruption for this thesis was in response to the

way Bury (1982) develops a theoretical rather than descriptive account of

people's meanings and responses to the impact of long-term illness in their lives.

Bury (1982) initially used the study of adults with rheumatoid arthritis to develop

the biographical disruption framework in order to represent how people experience the onset of a chronic illness impacting on their lives. Bury's interpretive framework demonstrates how the impact of illness socially disrupts the taken-for-granted assumptions of a person's self-concept and social identity, social relationships and capacity to conduct normal everyday activities. Illness changes prior notions of what was normal in a person's life and brings into question the capacity to manage changing health conditions. A number of studies have drawn on biographical disruption to inform how people respond to a range of chronic illness conditions, which supports the usefulness and utility of Bury's framework (Clarke-Steffen 1997; Young et al. 2002; Williams 2000a; Young et al. 2002; Reeve, Lloyd-Williams, Payne and Dowrick 2010).

Historically, biographical disruption is located in a large body of sociological health theory. It represents an outgrowth of the functionalist 'sick role' perspective of examining acute illness (Parsons 1951) and aligns within the interpretive standpoint of examining health and illness (Bury 1982, 1991; Strauss and Glaser 1975; Corbin and Strauss 1988; Williams 2000a). Bury's (1982) framework also sits within a wide range of qualitative theoretical traditions, including symbolic interactionism, ethnography, phenomenology, feminism, narrative, hermeneutic and postmodern analysis, which combine to offer multiple perspectives for understanding a myriad of acute and chronic illness contexts (Charmaz 1990, 2000; Hyden 1997; Frank 1995; Ezzy 2002; Whitehead 2006). Bury's framework has also been at the forefront of bringing the sociology of

health and illness into a focus where 'lay voice is granted equal legitimacy both inside and outside the medical citadel' (Williams 2000a: 41).

I was drawn to the explanatory power of Bury's (1982: 169) framework, in which illness represents a biographical disruption 'where the structures of everyday life and forms of knowledge that underpins them are disrupted'. To briefly clarify the components of Bury framework I take biography to represent 'life evolving around a continual stream of experience that result in a unique-if socially constituted-identity' (Corbin and Strauss 1988: 50) and disruption as 'a deviation from a normal state' (Reeve et al. 2010: 180). Taken together, biographical disruption represents a deviation from a prior normal experiences that results in identity changes (Bury 1982: 169). The findings in this study support and advance the utility of biographical disruption to incorporate both cancer and its abatement as the context in which carers construct new identities in response to having prior self-concepts and notions of normality fractured.

Biographical disruption represents how adverse health situations can disrupt the 'structures of everyday life and the forms of knowledge that underpin them' (Bury 1982: 169). The literature presented in Chapter Two supports the advent of childhood cancer as a biographical disruption in primary carers' lives (Young et al. 2002; Parry 2003; Woodgate 2006). Biographical disruption was initially based on three key elements which combined to build an interpretive framework to represent the onset of chronic illness:

First, there is the disruption of taken-for-granted assumptions and behaviours; the breaching of common sense boundaries … Second, there are more profound disruptions in explanatory systems normally used by people, such that a fundamental re-thinking of the person's biography and self-concept is involved. Third, there is the response to disruption involving the mobilisation of resources, in facing an altered situation (Bury 1982: 169-171).

The first element of the framework explains illness resulting in a 'disruption in taken for granted assumptions and behaviours; the breaching of common-sense boundaries' (Bury 1982: 169). Bury (1982: 171) argues the onset of illness is a 'biographical shift from a perceived normal trajectory through relatively predictable chronological steps, to one fundamentally abnormal and inwardly damaging'. Childhood cancer represents such a disruption, as carers suddenly view themselves as changed from a 'normal parent to a parent of a child in crisis' (Dixon-Woods, Findley, Young, Cox and Heney 2001: 673).

The second element represents disruptions in the 'explanatory systems normally used by people such that [there is] a fundamental re-thinking of a person's biography and self-concept' (Bury 1982: 169). The onset of illness raises questions that medical clinicians may be unable to answer and so people search for alternative causes for their illness (Bury 1982: 174). The disruption in explanatory systems for having a child with cancer is evident in Woodgate's (2006: 11) study where carers believed their world was no longer safe or secure and had become a 'nightmare'. The onset of childhood cancer significantly disrupts primary carers' biographies and self-concepts due to the life/death

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situation of their child and realising the loss of pre-cancer notions of control and certainty (Parry 2003; Young et al. 2002; Cohen 1995).

The third element of biographical disruption captures how people respond to illness through 'the mobilisation of resources, in facing an altered situation' (Bury 1982: 175). Bury illustrates how people evaluate and respond to managing illness through their capacity to carry out everyday tasks and activities, seek social or medical support and develop strategies to 'attempt to normalise', or withdraw from previously normal situations (1982: 175-176). Mobilising resources is especially relevant to carers when seeking medical intervention to save their child's life (Dixon-Woods et al. 2001). Carers define themselves as their child's principal resource of physical and emotional comfort through cancer and assume new advocacy and guardianship responsibilities, heightened caring obligations and develop new relationships with clinicians (Young et al. 2002; Parry 2006). The three elements of biographical disruption combine to give emphasis to the social impact of illness on a person's identity, interactions and strategies to manage the condition. Bury's framework is therefore applicable to represent primary carers of a child with cancer.

Bury (1991: 453-456) went on to refine the framework by considering how people assign meaning to chronic illness through three concepts of 'consequence, significance and legitimation'. 'Consequence' in Bury's (1991: 453) framework represents meanings that people attach to the effects of the illness on their

everyday lives, including managing symptoms, resource availability and information within an altered daily reality. Primary carers retain a constant vigil beside their sick child, manage their child's cancer treatment symptoms, and de-emphasise their own needs and the needs of other family members (Young et al. 2002: 1845). Carers actively seek cancer related information as a way to understand their child's treatment interventions to restore a sense of control (Dixon-Woods, Young and Heney 2005; McGrath 2001). Clarke-Steffen's (1997) findings show the importance that carers place on seeking and interpreting cancer related information so they can understand and respond to their child's treatment regimes and process of filtering information to or from their child.

'Significance', according to Bury (1991: 453), represents the symbolic meaning of illness in relation to an individual's sense of self, interactions with others and cultural expectations associated with different illness typologies at various life stages. The term 'crisis' is prominent in representing how carers give symbolic meaning to the advent of cancer, as the disease represents a real threat to their child's immediate life, and a threat that carers experience with a profound sense of powerlessness (Reay et al. 1998; Parry 2003; Cohen 1995; Young et al. 2002).

'Legitimation' in Bury's (1991: 455-456) framework represents the process of attaching meaning to attempts at repairing the disruption and gaining a measure of control for maintaining a sense of personal integrity and social status. The efforts in repairing the biographical disruption are evident through the early

diagnosis period as primary carers seek to regain a sense of control and adjust to their childhood cancer situation (Clarke and Fletcher 2003). In the later 'out-patient' period carers seek to integrate their child's cancer and ongoing treatment into their everyday domestic routines, with a sense of normality, while realising their 'life would never be the same' (Woodgate 2006: 11; Earle et al. 2006).

Since its inception, biographical disruption has informed sociological research as a versatile, theoretical framework of meanings and responses to long-term illness conditions (Williams 2000a; Becker 1997; Reeve et al. 2010). Scholars have drawn on Bury's framework to examine a broad range of health, illness and care arrangements, including mothers affected by children with cancer (Young et al. 2002; Dixon-Woods, Young and Heney 2005), mothers with HIV (Wilson 2007), adults with terminal cancer (Reeve et al. 2010). These studies support the versatility and explanatory utility of Bury's framework to inform how carers' lives have been significantly disrupted due to the advent of their child's cancer. But Bury's framework has a number of assumptions that may not always apply as carers of children in remission are distinct from the adult, chronic illness perspective and those with a constant or declining health status.

Williams (2000a: 55) argues that Bury's framework is 'predicted by an adult-centered model' that fails to adequately account for illness at different life stages. Age is an important structural consideration as the focus of this study is on adult carers of children. Adult responses to illness presume a degree of autonomy in

self-care and self-responsibility (Tritter and Calnan 2002) whereas children are dependent on adult care regardless of their health status, while carers are culturally, legally and emotionally invested in their child's well-being (Lupton 1999; Mayall 1998). There is evidence to support children and young adult survivors of childhood cancer survivors reconciling the disruption of cancer in their own lives (Drew 2003, 2007; Dixon-Woods, Young and Heney 2005). However, the focus of this research is to examine primary carers who are 'not themselves ill … [but] experience many of the consequences of chronic illness, including biographical disruption, compromise in role function and deterioration in quality of life' (Young et al. 2002: 1837). Carers' experiences therefore differs from the adult, first-person perspective which Bury (1982) initially proposed.

Childhood and adult cancers are distinct from other chronic illnesses because of the potential for achieving a disease-free remission (Tritter and Calnan 2002). Bury's (1982, 1991) framework makes no allowance for the abatement of cancer or the factor in which around 80 per cent of children survive cancer but more than half of survivors have morbidity trends affecting their quality of life (Oeffinger et al. 2006; Hudson 2003; Lacker et al. 2000). The morbidity trends of cancer survival and carers' ongoing child care obligations suggest multiple disruptions and responses: beginning as an acute biographical disruption at diagnosis, treatment processes and followed by a more chronic disruption as a consequence of cancer treatment morbidities that directly impact on the lives of children and

carers. This study utilises the biographical disruption framework, but from carers' perspectives and in a post-cancer context.

Researchers have also revised Bury's (1982) framework to meet specific health and illness situations. Examples of such revisions include 'biographical reconstruction' of people with arthritis (Williams 1984), 'biographical restoration' of the terminally ill (Reeve et al. 2010), 'biographical flow' of stroke survivors (Faircloth et al. 2004) and 'biographical revision' of young adult survivors of childhood cancer (Drew 2003). However, such revisions may not capture the experience of primary carers of children who have survived cancer as carers are not ill per se. Conceptual revisions of Bury's framework are also characterised by the prefix 're' which infers using pre-illness frames of reference to explain post-illness identities and biographical situations. In contrast, childhood cancer literature is represented by the adjective 'new', which infers a rupture from, rather than a disruption of pre-cancer taken-for-granted assumptions. This is illustrated by the mother quoted in Chapter One who spoke of how she felt she had lost her pre-cancer life 'and somehow had to build a new one' (Cox 2007). Similar trends in other childhood cancer studies support the notion of developing a new realm: such as 'new self identity' (Young et al. 2002: 1837) and a 'new normal' (Earle et al. 2006; Clarke-Steffen 1997). Constructing a 'new' way to define self and context suggests the explanatory utility of biographical disruption has not gone far enough to represent the impact of childhood cancer on primary carers' lives.

Extending on the concept of normality, a recent study examining adults with rheumatoid arthritis brought into question the salience of biographical disruption as a key explanatory concept. Sanderson et al. (2011) argue that that biographical disruption forms a minor part of their participant's multi-layered illness narratives and instead, conceptualised people's responses to the disease within a 'normality typology' framework. The central concept 'shifting normalities' incorporated disrupted, struggling, to maintain, fluctuating, resetting, returning, and continuing normality. However, this critique of Bury's (1982: 177) framework seems barely justified as biographical disruption is based around meaning and responses to illness and 'the attempt to normalise in the face of disruption'. Nevertheless, the scholarship of Sanderson et al. (2011) draws attention to the universality of biographical disruption to explain the situation of primary carers, particularly at the early onset of childhood cancer diagnosis and treatment.

In an extensive appraisal of biographical disruption, Williams (2000a) argues that Bury's (1982) framework retains ongoing explanatory power across a range of health and illness scenarios, but nevertheless argues for its revision to align with the conditions of late-modern society. In particular, Williams (2000a: 60) calls for more theoretical attention to account for situations where 'illness may already be a central part of one's biography' and the onset of disease may readily form part of a 'normal crisis'. Williams also inverts Bury's framework to raise attention to situations in which non-health related biographical disruptions may

actually be a source of chronic illness. More broadly, Williams (2000a: 61-62)

proposes that biographical disruption needs to facilitate illness explanations for

younger and older age groups, and with greater attention to the 'timing, context

and circumstances within which illnesses are normalised or problematised'.

Taken together, the previously cited studies provide important and critical

insights of biographical disruption. Bury's (1982) conceptual scholarship and

critiques around the framework offer a sharpened analytical focus to consider the

onset, treatment and remission of an illness such as childhood cancer as a

significant impact on the lives of children and their carers, and requiring complex

responses through the illness and its aftermath. The common theme emerging

through biographical disruption scholarship is targeted towards a conceptual

understanding of people's attempts to normalise in response to illness.

The experience of having a child diagnosed with cancer is 'an embodied fact

rather than a mere construction' in primary carers' lives (Williams 2000a: 55).

Childhood cancer significantly alters primary carers' pre-cancer identities, taken-

for-granted assumptions, explanatory frameworks and common-sense boundaries

(Bury 1982). Carers respond to this radically altered situation through mobilising

the self, as well as medical, social and information resources. They construct new

self-concepts and develop new meanings for their care obligations and tasks,

advocacy, guardianship, pseudo nursing and parenting (Young et al. 2002).

Carers construct new meanings of cancer diagnosis in terms of significant losses

of certainty and control in protecting their child's well-being. The treatment

period features carers' attempts to repair the disruption by 'finding explanations

that make sense' in order to 'establish an acceptable and legitimate place' for

childhood cancer in their lives (Bury 1991: 456). Carers give legitimacy to their

situation by constructing a new sense of normality (Clarke-Steffen 1997).

Biographical disruption therefore offers a partially useful framework to represent

carers of children with cancer. Yet this research situates carers of children in

remission rather than with cancer and Bury's framework is unable to

accommodate this changing context. As such, I take Blumer's (1969: 161) advice

that concepts are not fixed but have careers that require amendments to

accommodate changing conditions. Other theories that help in understanding

primary carers of childhood cancer survivors include identity, normality and

survivorship theories. Extending biographical disruption with these theoretical

perspectives allow for the shifting context from being a carer of a child with

cancer to being a carer of a child in remission.

Primary carers' identities

Theories of identity emphasise that people define themselves and their situated

context in order to give meaning and understanding to their lives (Charmaz 2000;

Blumer 1969). People are reflexive in the capacity to evaluate and classify the

self in interaction with others to form an identity. Primary carers have selves that

are 'multi-faceted, reflexive and negotiated' (Stets and Burke 2000: 224), and identities that are 'maintained, modified and even shaped by social relations' (Berger and Luckmann 1984: 194).

Charmaz (1995: 659) argues that the concept of identity implicitly incorporates how people 'wish' to define themselves and how people usually construct 'identity goals' for a 'preferred identity'. Yet cancer is a life-changing event where 'normal processes of identity formations' are disrupted and require a re-evaluation of 'that sense of who, where and what an individual believes he or she should be in relation to norms and expectations ascribed by society' (Zebrack 2000: 240). From this perspective, symbolic interactionism provides a lens to examine how identities and meanings are constructed through social interaction with self and others (Blumer 1969). Primary carers have to reconcile the differences between their actual experiences of childhood cancer and the culturally assigned taken-for-granted assumptions and expectations of their situation. Carers' interact, interpret their audiences and enact strategies to sustain their identities in everyday social encounters, while reflecting back, self-evaluating and re-interpreting their definition of the situation (Goffman 1959).

Primary carers' sense of self and social identities have been fundamentally altered through their diminished capacity to control and protect their child and their reliance on medical specialists and technologies to avoid a potentially fatal outcome (Clarke and Fletcher 2003; Chesler and Parry 2001). Protecting children

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from harm is a fundamental cultural and legally ascribed expectation and carers are expected to be selfless and devoted to the care of their child (Dixon-Woods et al. 2001). The process of becoming a carer of a child with cancer has major identity implications, including a sense of grief and loss for their pre-cancer selves and the construction of new self-identities in relation to their child and their interactions within the medical world (Young et al. 2002: 1845). Thus primary carers experience a biographical disruption that requires a 'fundamental re-thinking of [their] biography and self-concept' (Bury 1982: 169).

The dynamics of carers' capacity to revise their self-concept through the changing contexts of childhood cancer can be usefully explained by the concept of alternation which represents identity changes from 'one self image to another' (Berger 1970: 121). Berger (1970: 68-70) describes how deviations from previous life expectations and taken-for-granted assumptions cause people to evaluate and order the meaning of self-concepts through changing life contexts. The context of cancer represents 'a radical challenge to continuity of identity' (Little et al. 2002: 176). The concept of alternation explains how primary carers' self-concepts have undergone changes according to the phase of their child's illness: from a pre-cancer identity, redefined as a carer-through-cancer identity and again interpreted as a carer-of-a-child-in-remission identity. The sum of identity alternation establishes carers' current self-concepts and gives emphasis to their agency in adapting and defining their identities through the cancer journey. The concept of alternation helps to explain the findings in this thesis, as primary

carers construct a 'new normal' in response to having their pre-cancer lives radically disrupted (Berger 1970; Clarke-Steffen 1997).

Identity theory also draws attention to primary carers as having social identities that are interpreted and constructed through social interaction with others (Blumer 1969). However, carers' everyday experiences are distinct from others who have not had their lives disrupted through childhood cancer. Berger and Luckmann (1984: 104) help explain this sense of social distance as a 'sub-universe', accessible to carers who may identify as childhood cancer insiders, but a sub-universe inaccessible to non-childhood cancer carer outsiders. Maintaining everyday interactions requires strategically interpreting different audiences. To paraphrase Goffman (1959: 111-112), the childhood cancer stage is a particular back stage of everyday life with a select audience of similar cancer-others, and a front stage oriented to a generalised non-cancer audience. This dramaturgical social identity perspective therefore facilitates examining how primary carers interpret their cancer and non-cancer audiences, enact front and/or back stage performances to particular audiences, and develop everyday strategies to maintain their interactional stage boundaries. Goffman's (1959) perspective offers a way to explain how taken-for-granted cultural assumptions surrounding childhood cancer survivors might create a particular cultural script in shaping how primary carers are expected to interact with others in their post-cancer context. Goffman's (1959) approach allows for a consideration of ways carers 'perform' their identities to establish a particular 'impression' of how they wish to be

perceived: from a front stage of enacting cultural expectations, or from a back

stage with other 'insiders' impacted by their child's cancer.

Gender identities

Ideas of gender identity promote how care in general, and primary care of

children in particular, are socially ascribed according to structural and cultural

expectations of masculinity and femininity (Chesler and Parry 2001). Gender

norms play a central role in maintaining divisions of labour in primary childcare

arrangements (Cunningham-Burley, Backet-Milburn and Kremmer 2006; Collett

2005). In a childhood cancer context gender expectations explain how primary

carers' traditional gender identities perpetuate and intensify roles with mothers

continuing to fulfill the majority of child caring roles and fathers as economic

providers (Clarke 2006; Parry 2003; Earle et al. 2006; Reay et al. 1996).

Feminist theories have critiqued motherhood and childcare as a natural activity by

drawing attention to patriarchal power and unequal divisions of domestic and

workplace labour. From this perspective, the role of wife and mother in family

life is 'the site of woman's oppression' (Dietz 2003: 404). Gender inequalities,

although in a state of constant flux, are largely maintained because masculinities

and femininities are constructed through cultural and 'familial ideologies'

(Harrington 2005: 239; Cowdery and Knudson-Martin 2005). Sanchez and

Thomson (1997: 747) argue that 'parenthood crystallizes a gendered division of

labor, largely by reshaping wives', not husbands' routines'. Feminist scholars promote gender equality in childcare arrangements but inequality is sustained by cultural expectations of motherhood.

Identities are constructed through day-to-day interactions (Blumer 1969) but carer-of-a-child identities also develop through the birth, adoption or fostering, and an ongoing relationship with a child. Maternal identities develop by internalising a self-concept as a mother and having that identity confirmed through interaction with their child and others. Mothers construct their identities in a 'gendered set of relationships and social institutions at a particular place and time' (Cowdery and Knudson-Martin 2005: 335). Being a mother means taking a 'socially defined, publicly visible role' which supports a consensus theory of mothers constructing and managing maternal identities (Collett 2005: 328). Mothers also assert their identities through 'maternal gate-keeping' which can inhibit fathers' involvement in family and childcare (Allen and Hawkins 1999).

There is continuing debate about the extent to which gender identities and gender roles are distinct and/or symbiotic (West and Zimmerman 1987; Stets and Burke 2000). Maher (2005: 17) argues that gender identities are of 'less importance than completing and balancing the suite of tasks attached to those identities'. She argues that gender shapes rather than determines maternal identity, yet states that there remains a fundamental tension, as mothers have 'no choice about accepting responsibility for their babies, while fathers are much freer to negotiate their

mode and level of involvement' (Maher 2005: 26). However, my position supports the argument of West and Zimmerman (1987: 127) in recognising that gender identities and roles are interdependent, where 'doing gender' and 'being a gendered person in society' is a managed and negotiated activity. From my perspective of symbolic interactionism I take gender identities as internalised interpretations of self-concepts whereas gender roles are enacted social identities, yet both are constructed within culturally informed gendered social arrangements.

Gender theory informs how primary carers' identities are constructed and sustained within a cultural ideology of gendered expectations of childcare. Komter (1989) argues in Gramscian terms that gender inequalities result from an evolving hegemonic consensus, where ideas of 'normal' gender relations are sustained in an unobtrusive and invisible manner. Childcare generally occurs in the private realm of family life but nurturing healthy children is a public issue if social norms and expectations are not met. Mothers are ideologically constructed and measured by their capacity to raise healthy children (Collett 2005: 328). Yet the threat of cancer in children means that mothers' care capacity is sharply reduced (Reay et al 1998). Young et al. (2002: 1844) argue that the physical and emotional work and felt obligations of mothers of children with cancer forms and validates a major component of their maternal identity. The majority of carers in this study were mothers, which reflect traditional maternal identities and childcare labour both through and after cancer.

Since the majority of childcare labour is performed by mothers (Sanchez and Thomson 1997; de Vaus 2004; Cowdery and Knudson-Martin 2005), it is necessary to consider the concept of care that explicitly or implicitly underpins the vast sociological literature on health and illness (Comaroff and Maguire 1981; Baruch 1981; Grinyer 2007; Collett 2005; Gregory 2005; Harden 2005). Rather than discuss the myriad of care arrangements represented in care literature, I elaborate on the symbolic underpinnings of care. In doing so I illustrate how care is bound within a moral framework characterised by socially constructed gendered obligations of childcare responsibilities which shape how primary carers define their identities. I make no claims here that fathers care less for their children than mothers, but that mothers perform the majority of childcare labour.

The concept of care posits the symbolic meanings of caring about and caring for others as a universal and virtuous attribute of the human condition (Engster 2005; Noddings 2002; Mullin 2006). The symbolic interaction of care requires a motivated carer with an obligation of care and another in need of care. Caring in a carer-child relationship is an 'other-orientated activity but self-care also constitutes a legitimate aim' to fulfill care capacities (Engster 2005: 54-7). The origins of caring for and caring about others are grounded in family relationships and fundamentally within carer-child interactions (Noddings 2002). This study represents a unique microcosm of care arrangements in a cancer and post-cancer context, but it underpins a macro societal aspect of humanity, as social life is dependent on the provision of care to produce and reproduce society. Engster

(2005: 60) explains this in stark terms: 'if no one cared for others, society would cease to exist within a generation or two'. The care of a child is a central component of primary carers' identities (Collett 2005; Young et al. 2002).

However, if societal values of child care are not met, primary carers face social and legal sanctions as 'uncaring' if care obligations are breached (Engster 2005: 53-4). Hence, the care of a child is the tangible and socially defined expression of carers', and particularly mothers' capacities and identities (Collett 2005: 329). The concept of care offers a useful way to inform how having a child with cancer heightens cultural expectations of care obligations and responsibilities (Young et al. 2002: 1844). The everyday care of a child importantly legitimises carers' attempts 'to maintain a sense of personal integrity, and reduce the threat to social status in their radically altered circumstances' (Bury 1991: 456).

Traditional gender identities portray fathers according to their roles as instrumental workers/economic family providers and child rearing is left largely to mothers (Cabrera, Tamis-Lemonda, Bradley, Hofferth and Lamb 2000). Masculine stereotypes also prevail in representing fathers as emotionally distant and rational problem solvers (Chesler and Parry 2001). However, gender studies also recognise cultural changes in which the 'new father' concept represents fathers as more nurturing, committed and involved co-parents (Wall and Arnold 2007). This shift has resulted from mothers' increased employment participation, increases in non-residential fathers and more child involvement with residential

fathers of intact family units.   Traditional maternal identities have also shifted to some extent towards a more shared and egalitarian division of childcare labour (Cabrera et al. 2000: 127; Cunningham-Burley, Backet-Milburn and Kremmer 2006). Fathers' increased childcare labour is located within a 'widespread cultural movement' of valorizing non-gender-specific parenting and more intimate fathering (Sanchez and Thomson 1997: 747).

However, the 'new father' shift has also widened the gap between those more involved and less involved with their children, as well as a gap between fathers' expectation of what they should do, and what they actually do. This gap is evident in fathers with the least socio-economic resources to provide for their families (Cabrera et al. 2000: 132-133). Fathers are also in a position of having to reconcile the tensions between 'new father' expectations with traditional and hegemonic masculinities (Connell 1987; Wall and Arnold 2007: 52).

Identity theory, social constructions of motherhood and fatherhood, and the concept of care combine to offer a useful way to consider primary carers of children in remission. Carers' identities are constructed through their child's pre-cancer, cancer and post-cancer phases, which combine and contribute to form their current cancer related lives. However, the concept of 'new normal' has elements of changing identities and new situational definitions, to represents carers during the early stages of their child's cancer diagnosis (Earle et al. 2006; Woodgate 2006; Clarke-Steffen 1997). Theories of identity, gender and care

therefore need to be considered to inform understandings of carers of a child in remission. They also need to be considered in a cancer survivorship context.

Survivorship theories

In response to biographical disruption having a limited explanatory capacity to represent the conditions associated with cancer remission, I draw on survivorship theory to situate primary carers in their post-childhood cancer context. Cancer survivorship theories are relatively recent and focus mainly on first-person accounts (Dixon-Woods, Young and Heney 2005: 86). Although primary carers are not cancer survivors *per se*, survivorship theory locates carers as having identities as carers of a child in remission. The term 'cancer survivorship' was first used in the mid 1980s by a physician who referred to the post-cancer phase as 'seasons of survival' (Mullan 1999; Aziz 2002). The term is used by health clinicians, researchers and those impacted on by cancer in order to represent the completion of curative and effective treatment.   Zebrack (2000: 239) emphasises that much scholarship has yet to grasp the processes of survivors 'living with, through, or beyond cancer' and how cancer experiences are integrated into ongoing biographies, or the factors that facilitate and impede this integration over time. Childhood cancer is represented as a family disease impacting on the child as well as parents and siblings (McGrath 2001; Sullivan 2004). To have a child survive cancer is an essential aspect of carers constructing their post-cancer identities (Young et al. 2002; Chesler and Parry 2001).

However, sociological literature on cancer survivorship 'is yet to be the subject of so much clarification' but broadly represents a complex process of definitions and meanings in moving from a life-threatening situation to one where cancer no longer poses an immediate threat (Little et al. 2002: 175). Aziz (2002: 3496) defines a cancer survivor as including 'anyone who has been diagnosed with cancer …from the time of diagnosis until the end of life'. Taking survivorship from the point of diagnosis rather than remission infers a 'discourse of hope' (Lupton 1994: 67) for a sustained life during cancer and a potential future without cancer. The notion of cancer survivor incorporates an ongoing, if altered, social identity from being medicalised as a cancer patient or a carer of a cancer patient (Zebrack 2000). Aziz (2002: 3496) refers to caregivers and family members as 'secondary survivors' to encapsulate their vital care support roles through cancer. While the notion of secondary survivor gives recognition to the importance of carers through cancer, the term reduces carers solely to the support roles they perform rather than incorporating their own identities and care responses.

Aziz (2002) conceptualises cancer survivorship as having acute, extended and permanent periods of survival. The acute phase of survivorship begins at diagnosis and continues until the completion of treatment. The extended period of survival is represented by medical confirmation of remission and the ongoing management of cancer and the treatment side effects. This phase is characterised by an ongoing period of evaluation and self-surveillance in order to determine the extent of treatment success with quality of life. The permanent survival phase

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represents an evolving disease-free process where the likelihood of a relapse remains significantly low (Aziz 2002: 3496). Cancer survivorship therefore represents the subjective interpretation of a biomedical remission. The acute, extended and permanent stages of Aziz's (2002) concept of survivorship usefully informs how carers construct meanings to their child's remission over time and the extent in which the impact of cancer might extend in carers' lives after cancer.

Little et al. (2002) elaborates Aziz's scholarship by linking cancer survivorship with identity theory. They examine the changing discourse of cancer in recent decades, from cancer being 'a topic shrouded in silence' to where cancer experiences 'have found a place in our culture' through media, academia and cancer support groups. However, Little et al. (2002: 170) state that 'the same cannot be said, however, about all those who survive cancer'. The survivor's dilemma involves attempts to assimilate cancer experiences into an identity when survivorship has 'no socially validated status' (Little et al. 2002: 176). Little et al. (2002: 176) argue that cancer experience 'produces change in the sense of personal identity' for both those who survived cancer and those who 'care for' the survivor. Cancer survival needs to be considered as an everyday social process involving the 'assimilation of new knowledge into the dynamic evolution of identity in a way that recognises both the continuity of identity and the powerful forces of change inherent in extreme experience' (Little et al. 2002: 176-177). This scholarship again brings into focus primary carers' subjective

understandings in shaping personal identities and adapting through the experience of their child's cancer and survival (Young et al. 2002; Clarke-Steffen 1997).

To gain an understanding of cancer survivorship requires insights into how cancer experiences might influence the temporality of identity constructions. Little et al. (2002) theorise survivor identity as the embodiment of a past cancer memory that is reinterpreted in the present and contributes to a current self. The past and present merge to give biographical meaning to form the basis of identity with a projected and hopeful future. This temporal framework is reflective of Mead (1967) who states that 'reality is always that of the present', but a present built on 'memory and [future] anticipation' (cited Maines, Sugrue and Katovich 1983). Childhood cancer survivorship also links to Bury's (1991: 452) claim that responses to biographical disruption occur in an 'unfolding or emergent' temporal framework. Cancer survivorship theory informs the temporal, biographical and health status context in which primary carers define and construct their cancer past, their current identities and their anticipated futures.

Drawing on accounts from young adult survivors of childhood cancer, Drew (2003: 190) suggests that long-term survivorship is a 'multifaceted, ongoing process, not a static state at which one arrives'. Drew describes cancer survival as a process involving the negotiation of multiple meanings around the physical and emotional consequences of cancer and treatment to develop a resilient life after cancer. She explains how cancer survivors develop an ongoing post-cancer

dialogue by combining illness experiences with fears and hopes for their current lives and their imagined futures. However, 'cancer survivor' was resented as a master status because it devalued their identity and other life achievements.

Drew (2003: 183) argues that post-cancer identity formations evolve from 'reconciling the differences in who they had been before treatment with who they were becoming after treatment'. Drew conceptualises this as a process of 'biographical revisioning and self-reconstruction' in which everyday life after cancer is characterised by much 'negotiation and renegotiation' of survivors continually revising their cancer histories and consequences, within and around cultural constructions and expectations of cancer survival (Drew 2003: 183). In doing so, these young adult survivors of childhood cancer construct a subjectively negotiated cancer identity with a focus on future planning and future health concerns after the abatement of the disease (Drew 2003: 195).

Cultural expectations of surviving cancer

Primary carers have to make sense of their child surviving cancer in the context of broader cultural assumptions and expectations of childhood cancer survival. The culture realm refers to the socially learned, symbolically expressed norms which influence what is considered socially appropriate expectations, and where breaches of cultural norms can lead to social sanctions (Abercrombie, Hill and Turner 2000). Drew (2003: 187) argues that those impacted by cancer 'have been left without a blueprint or map for their journey towards new lives', which

lends support to other scholars who argue that there is a limited discourse for cancer survivors (Frank 1995; Stacey 1997; Little et al. 2002; Becker 1997). Yet childhood cancer survival literature suggests primary carers have a script of cultural expectations: including, having 'gained' in a positive way from cancer experiences (Stacey 1997; Becker 1997) and achieved a sense of personal growth (Chesler 2004), positive thinking (McGrath, Jordens, Montgomery and Kerridge 2006; Wilkinson and Kitzinger 2000) and hope (Little and Sayers 2004). These assumptions combine to depict carers as having to reconcile their experiences with cultural expectations of how their lives are supposed to be after cancer.

The cultural expectation for people impacted by cancer is to have gained positive personal attributes from their cancer experiences. Media accounts celebrate survivors as the 'lucky ones' while 'the rest suffer defeat' (Stacey 1997: 15). Becker (1997: 51) refers to this trend as a 'moral force of normalizing ideologies' and aligns with contemporary individualised approaches to overcoming cancer. This Cartesian philosophy promotes an ideology of personal responsibility, a sense of rational control and a particular mind-over-matter approach 'in which the emphasis is on changing thinking as a means of controlling behaviour that affects the body' (Becker 1997: 168). The idea that bodily change can be willed by cognitive processes is central to self-help and self-healing literature by promoting survivorship as beating the cancer battle (Sontag 1991; Stacey 1997). Cancer survivors are characterised as gaining positive aspects of the cancer ordeal: with a new awareness and enhanced appreciation for life, a profound sense of gratitude

towards those who helped them through treatment, and empathy for those whose lives are still under threat (Rowland and Bellizzi 2008: 191).

The cultural ethos of cancer survival privileges assumptions that cancer experiences acts as a catalyst for a life-enhancing value shift. The threat of death, according to Berger and Luckmann (1984: 168) 'profoundly threatens the reality of one's previous self-identification'. To survive cancer promotes a new symbolic system of meaning stemming from a life/death situation, and one endorsed by a Western cultural ideology in overcoming tragedy (Frank 1995; Sontag 1991). Gaining positive personal attributes from cancer represents a process of self-evaluation but within a culture promoting 'bravery, fortitude and strength of will-power' (Stacey 1997: 13). According to Becker (1997: 52), the cultural expectation to gain in some way because of cancer is promoted by an ethos of rational determinism; where order, predictability and personal responsibility is projected to counter the chaos of cancer.

There is also a cultural expectation that people will have developed greater resilience to distress and exhibit aspects of personal growth through an experience of surviving cancer. The psycho-oncology literature on primary carers emphasises a deficit model in determining the prevalence of distress and PTSD, yet evidence suggests carers suffer few 'lasting psychological difficulties' (Dixon-Woods, Young and Heney 2005: 105). Zebrack and Zeltzer (2001) argue that primary carers retain ongoing concerns and uncertainties but to focus solely

on distress 'will miss the emotional fall-out, psychosocial needs and potentials for personal growth'. Chesler (2004: 1) developed an alternative way to counter the prevailing focus on PTDS in childhood cancer research. His concept of post-traumatic growth (PTG) represents 'the experience or expression of positive life change as an outcome of a trauma or life crisis'. The PTG concept combines sociological and psychological themes that are emerging through cancer survivorship literature. An important attribute of PTG is the distinction between thresholds of coping and measures of personal growth. Chesler (2004) suggests that coping after cancer infers a motivation to deal with illness, with the capacity to integrate and articulate trauma into an everyday biography.

The central feature of PTG promotes how people develop a meaningful definition of their situation that incorporates holistic personal growth rather than a corporeal survival/recovery model and of integrating illness into everyday life (Chesler 2004). PTG incorporates a number of attributes: including a new sense of emotional toughness and resilience, greater compassion and empathy for others, heightened psychological and emotional maturity, an acute recognition of vulnerability and struggle, a deeper appreciation of life with new values on familial and intimate relationships and an enhanced awareness and psycho-spiritual clarity of self and others. The conditions for achieving PTG requires a combination of social support from significant others, medical and social services personnel and from other survivors. PTG is a useful concept to consider how primary carers evaluate their situations as having grown, or not, from their

experiences. However, Chesler's (2004) PTG also seem to represent a cultural ideal type that may or may not accord with primary carers' everyday realities.

Public literature also promotes people impacted on by cancer to 'think positively' as a particular cognitive way to 'do illness' and to 'fight' cancer (McGrath et al. 2006: 665). Positive thinking refers to cognitive attempts to supplant despair with hope. The assumption of positive thinking is that those people who are optimistic about cancer will have a greater chance of survival than those who are pessimistic. The benefits of positive thinking through a life-threatening illness have been much debated (Wilkinson and Kitzinger 2000). People who have an optimistic outlook maintain a better quality of life than those with a sense of despair (McGrath et al. 2006: 666). Positive thinking, according to popular self-help literature, offers those impacted upon by cancer with a belief that they have some control over their illness outcomes (Jouret 2010: 230). However, this idea is increasingly criticised as a form of coping by denial or an avoidance response to an uncertain life/death outcome (McGrath 2001). Positive thinking also represents a form of self-regulation in which, to rephrase Marx, 'optimism is the opium of the people' and negative thinking is a form of deviance (Ehrenreich 2010). Positive thinking promotes individual responsibility as a secular rationale to life/death situations (Bolton 2010; Becker 1997; Stacey 1997).

De Raeve (1997) argues that expectations to think positively can trivialise people's negative experiences and undermine their legitimacy to express anger,

despair and hopelessness. In this way, positive thinking acts as a form of social control, as positive patients are easier to care for than negative patients, and more likely to be compliant to medical authority. Positive thinking is also value-laden with an inferred self-responsibility for cancer recovery, but implicit 'blame' transferred to those with cancer, who are further isolated and burdened with not thinking positively enough (de Raeve 1997: 253-255). Wilkinson and Kitzinger (2000) also argue that positive thinking claims need to be considered in a culture endorsing optimism to counter the mortalities and morbidities associated with cancer. From this perspective positive thinking operates as a conversational idiom to normalise everyday interactions where 'the claim to be thinking positively is made, in part, to protect themselves' against negative social sanctions (Wilkinson and Kitzinger 2000: 797). Positive thinking offers a useful sensitising concept to examine how primary carers define their situation in response to the cultural expectation shaping the construction of their identities.

People impacted on by cancer are also expected to be hopeful and to orientate their lives towards a meaningful and positive future in the cancer aftermath. Lupton (1994: 67) describes hope as a dominant cultural discourse in society and argues that to despair and lose hope is socially denied as a form of deviance while maintaining hope is extolled. The cultural expectation is for primary carers to focus on a hopeful future without the adversities of their child's cancer or the uncertainties of cancer or treatment having lasting effects. The notion of hope in a cancer survival context therefore offers a way to examine carers' current and

future orientations, and the links between carers' lived experiences and cultural expectations of their experiences in the cancer aftermath.

Little and Sayers (2004: 1329) offers a useful definition in explaining hope in a cancer context as 'the subjective probability of a good outcome'. Hope is initially orientated towards life over death for self and/or significant others but if a cure is not attainable or survival entails a significant reduction in quality of life, then hope can be orientated towards a 'good death' (Little and Sayers 2004: 1330). Little and Sayers (2004) argue that hope is always constructed with a future orientation, a comforting emotion and a state of belief in a positive outcome, but encompasses the presence of uncertainty. Hope therefore helps to counter both the uncertainties of cancer outcomes, its treatment effects and medicine being unable to guarantee a complete cure (Comaroff and Maguire 1981; Barnes 2007). Hope has different meanings for those impacted by cancer, carers and significant others. Different definitions of hope can manifest as a source of tension, when apparent hope is configured as unrealistic optimism or when false hope becomes a form of denial that clashes with more pragmatic or fatalistic approaches to cancer outcomes. Cancer survivors and carers can develop differing hope discourses which helps to explain disruptions in close relationships in a cancer related context (Little and Sayers 2004: 1329).

Little and Sayers (2004: 1334) conceptualise distinct discourses of hope that develop at different cancer stages. The initial hope is for a medical cure and if a

remission is achieved then hope develops as a euphoric stage of self-realisation

and expression that life will persist and with an enhanced value of life's meaning.

This form of hope initially breaches common-sense barriers that normally exists

between the social self and the deep self, forcing an unaccustomed encounter with

the realities of consciousness and existence (Little and Sayers 2004: 1334). The

euphoric phase passes with time as people adjust and orientate their lives to a

longer-term focus. This stage is expressed by becoming a 'stronger, more aware

person' in returning to health (Little and Sayers 2004: 1336). However, Little

and Sayers (2004: 1336) state that some cancer survivors find it difficult to

accommodate the hope expectations of others and 'work hard to generate and

capture meaning' beyond the immediate threat of cancer. The concept of hope

offers a useful lens to evaluate how carers construct their lives after their child's

cancer and how its meaning might change over time. The future orientation of

hope also links to the knowledge that cancer remission infers an uncertain future.

Constructing normality after cancer

In developing a framework to represent primary carers I extended biographical

disruption with identity and survivorship theories to situate carers into a post-

cancer context. Normality/normalisation theories add to the framework by

informing how primary carers give meaning to their post-cancer biographies in

which hope and uncertainty become a defining feature of carers' lives. The

cultural expectation to return to normal after cancer is represented in much

scholarship (Sanderson et al. 2011; Little et al. 2002; Cohen 1995; Becker 1997;

Stacey 1997). The findings in this research support how primary carers of childhood cancer survivors construct a 'new self identity' (Young et al. 2002: 1837) as their pre-cancer self-concepts and notions normal is no longer tenable (Dixon-Woods, Young and Heney 2005: 71; Clarke-Steffen 1997: 280). The cultural expectation of returning to prior notions of normality after cancer diagnosis does not accord with primary carers' everyday realities. To reconcile how carers define their new sense of self and situation within this cultural context necessitates an understanding of how the concept of normality informs how carers construct their identities after cancer.

According to Misztal (2001: 312) the concept of normality is not well defined as many scholars discuss normality in general everyday terms. Normality represents a self-defining and subjectively desired state of 'fitting in' in relation to cultural group norms (Misztal 2001: 313). At its most basic, normality represents the subjective self-definition of everyday reality, but a reality that is socially constructed within broader cultural notions of normality and subject to endorsement of rejection by others (Berger and Luckmann 1984; Goffman 1959). Definitions of normality, self-concepts and identity constructions are linked 'in relation to norms and expectations ascribed by people' (Zebrack 2000: 240). The concept of normal is also a defining strategy to counter the negative social sanctions of being stigmatised as abnormal (Goffman 1968) and to maintain 'normal appearances' and interactions in a disruptive situation (Bury 1982: 175). Bury (1991: 461-2) proposes that people attempt to normalise illness by

strategically 'incorporating it more fully into the person's identity' in order to 'minimise the impact of illness on interaction'. The concept of normal therefore represents both a self-defining process and an everyday managing strategy that combines as an attempt to lessen the social consequences of illness.

When the health of a child is adversely affected, primary carers are urged by health professionals and significant others 'to construct their lives as close to normal as possible' (Deatrick, Knafl and Murphy-Moore 1999: 209). Yet constructions of normality are context specific and some illnesses create the conditions where cultural assumptions of 'normal' are no longer valid. This leads to a sense of difference in how normal is perceived and creates another point of reference in which to construct new definitions of normality (Deatrick, Knaft and Murphy-Moore 1999: 212). Rehn and Bradley (2005) argue that cultural expectations of what is considered 'normal' can devalue people's agency in seeking alternative ways of being and expressing their own sense of normality.

Sanderson et al. (2011: 1) propose the concept of 'shifting normalities' to represent the dynamic processes in which people define their lives at different chronic illness phases. Sanderson et al. (2011) argue that multiple constructions of normality include: disrupted normality, struggling for normality, fluctuating normality, resettling normality, returning to normality and continuing normality (Sanderson et al. 2011: 12-13). 'Shifting normalities' offers a way to consider how primary carers construct their lives at different temporal, illness and health

phases of their child's cancer and remission. In a childhood cancer remission context, constructions of normality occur in the context of cancer related uncertainties (Zebrack and Zeltzer 2001; Parry 2003).

Uncertainty as normal

'The real hell of this illness is that you just don't know' (Comaroff and Maguire 1981: 115). This quote from a parent of a child with leukaemia resonates with the uncertainties of clinical intervention achieving remission and the possibilities of cancer relapses, secondary cancers or treatment consequences. The consistent theme of 'living with uncertainty' in childhood cancer literature supports uncertainty as an appropriate sensitising concept to inform how primary carers deal with uncertainty in their lives (Young et al. 2002; Cohen 1995; Parry 2003; Clarke-Steffen 1997). The unpredictability of childhood cancer outcomes means that an understanding of primary carers' requires an examination of the concept of uncertainty as its meaning is implicit in cancer remission (Barnes 2007; Parry 2003; Clarke-Steffen 1997). Uncertainty is closely linked to risk theory (Zinn 2009; Alaszewski 2009). However, risk assumes a sense of control to mitigate potentially negative outcomes associated with danger, threats and harm from natural or social processes (Beck 1992), whereas uncertainty is characterised by the acknowledgement of limited control (Green 2009; Cohen 1995).

To extend this discussion I examined the contours of risk theories before focusing on uncertainty to distinguish the key conceptual differences. Perspectives of risk

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theory represent differing disciplinary stances: from Douglas' (1992, 1993) anthropological account of risk to explain the void left by pre-modern rationales of faith and fate, Beck (1992) and Giddens (1991) 'risk society' perspective of examining macro-structural processes of late modernity, the governmentality approach focus on neo-liberal 'expert knowledge' constructing risk as an individual responsibility and a form of self-regulation (Alaszewski 2009) and socio-cultural risk theory which considers how people perceive and construct risk and the plurality of 'shifting and multiple risk cultures' (Tulloch and Lupton 2003: 134). These perspectives characterise risk with a degree of rationality but once decisions are made to mitigate risk there remains a sense of fatalism and loss of control over outcomes. Tulloch and Lupton (2003: 37) refer to risk as a perception of control but risk remains essentially non-controllable. Despite the prevalence of risk discourse, notions of fate retain an everyday presence in contemporary society (Lupton 2006; Giddens 1991).

Risk theory is problematic in representing primary carers of childhood cancer survivors, as risk assumes latent and/or potential dangers and a degree of rationality and control to mitigate cancer (Beck 1992: 4; Douglas 1992: 24). In this thesis primary carers have dealt in stark form with the manifest and penultimate threat of having their child's life at risk. The diagnosis of cancer is no longer a risk *per se*, but a threat to a child's life that carers experience as a disruption from prior taken-for-granted assumptions, lack of control and uncertainty of cancer outcomes. These characteristics are a crucial point of

departure from the rational mitigation of latent or potential danger attributed to

risk theory. Instead, much data characterises childhood cancer according to

multiple uncertainties: of diagnosis, treatment, relapses, secondary cancers and

treatment late effects (Dixon-Woods, Young and Heney 2005; Heath 2005;

Zebrack and Zeltzer 2001; Clarke-Steffen 1997; Cohen 1995).

Recent sociological debates help to clarify this risk/uncertainty distinction. Green

(2009: 494) calls for the abandonment of an over-reliance on risk theorising and

refers to a sociological 'obsession with treating so much of social life as a

question of risk management (or risk perceptions or risk cultures)'. However,

Zinn (2009: 522) argues in support of risk as a useful concept but one that

requires refining. He proposes a 'sociology of risk and uncertainty' to clarify risk

as a rational calculation and uncertainty as a subjective interpretation. Zinn

(2009: 512) offers a distinction that seems relevant in this study: 'when the risks

are increasingly unknown there is no longer a particular risk but an uncertainty

that has to be dealt with'. This claim offers a useful way to consider primary

carers who have experienced the manifest threat of cancer on their child's life as

well as the ongoing multiple uncertainties coupled with remission.

Cohen (1995) explains the attributes of uncertainty in a childhood cancer context

as having persistence but a varying degree of intensity. She uses a wave

metaphor to capture uncertainty as advancing during cancer then receding slowly

into the background of everyday life with remission. However, certain events can

advance uncertainty despite the absence of cancer, including: routine medical appointments, a child's unexplained crying and energy depletion, keywords that heighten sensitivity to uncertain futures, changes or completion of therapy and late effects deriving from treatment (Cohen 1995: 66-67). Cohen (1995: 73-74) also proposes a 'sustained uncertainty' stage in which primary carers learn 'by trial and error' and living 'one day at a time'. The concept of sustained uncertainty extends Bury's (1982) framework by considering biographical disruption as a chronic form of uncertainty after cancer has abated.

The concept of uncertainty links to cancer survivorship theories (Aziz 2002; Little et al. 2002; Drew 2003), as the ambiguous meaning of remission infers an indefinite and unknown cancer free health status. Uncertainty is also linked to the concept of hope in highlighting the attributes of limited control, although the concepts have dissimilar orientations. Meanings of hope are constructed with a future orientation of a favorable cancer outcome and towards a normative state, initially for life over death but also for 'hope for normality' after cancer (Little and Sayers 2004: 1336). Meanings of uncertainty suggest a non-normative and 'discomforting state that is mediated by feelings of confidence and control' (Penrod 2007: 662). The concepts of hope and uncertainty link to the extent of confidence and/or control in which people perceive they have in their situation.

Conclusion

In this chapter I explained my conceptual framework as a way to consider how primary carers construct their lives in the aftermath of their child's cancer. The framework is based on the utility of biographical disruption in representing carers in a cancer context, once its adult, first-person and chronic illness attributes have been taken into consideration. From the foundation of biographical disruption I drew on identity, survivorship and normality theories as a way to bring primary carers into central focus and in their post-cancer context.

Identity, survivorship and normality are not discrete additions to biographical disruption but instead weave together to direct attention to ways in which primary carers construct their lives after cancer with a new sense of normality. The concept of 'alternation' explains how carers' identities change in response to the shifting cancer conditions (Berger 1970: 121). Theories of identity intersect with biographical disruption to give recognition to primary carers constructing self, social and gender identities and as individual agents in their own right (Young et al. 2002). Survivorship theory intersects with biographical disruption to bring carers into a post-cancer context. Normality theory intersects with biographical disruption to give carers 'an acceptable and legitimate' way to construct their lives as normal (Bury 1991), albeit a 'new normal'. Identity, survivorship and normality theory combine in two ways: first, as a way to inform how primary carers construct their new self-concepts to align with their new situated context and, second, to demonstrate potential discrepancies between primary carers' new constructions and cultural expectations of return to a pre-cancer normal life

(Becker 1997). The framework developed here represents how primary carers of

childhood cancer survivors can be considered as constructing a meaningful

definition of their situation and reconciling their experiences through interaction

with self and others (Blumer 1969: 3-4).

Chapter Four: Methodological framework

Introduction

In this chapter I explain my methodological approach in which to examine how primary carers interpret their situated context in having their child survive cancer. To answer the research question my choice of using a qualitative research perspective is based on my central concern to address the complex and nuanced processes which primary carers use to construct their everyday lives after the abatement of their child's cancer, from their own perspectives (Rice and Ezzy 1999: 1). I chose a qualitative method as the means to obtain and analyse extensive amounts of rich, descriptive data representing primary carers' in-depth accounts of their experiences (Charmaz 2000: 514). Within the multiple theoretical perspectives and practical ways of actually doing qualitative research I chose a constructionist version of grounded theory as this method supported by research aims of focusing on the meanings of experiences 'from the standpoint of those [primary carers] who live it' (Charmaz 2000: 522).

I begin the chapter by explaining my epistemological principles underlying the methodology as an insider/outsider research. In shaping the research design I illustrate my constructionist version of grounded theory and locate my methods within a broader discussion of grounded theory (Charmaz 1990, 2000; Strauss and Corbin 1998). I then discuss my preliminary fieldwork of liaising with cancer support agencies, detail the recruitment criteria and methods, and

participant profiles. I discuss the process of data collection and analysis which is represented in the findings chapters. I then explain my ethical conduct and conclude by explaining the limitations of this study.

Principles of enquiry

My philosophical influences come from the phenomenology of Martin Heidegger and Edmund Husserl (Schulz 1970). In brief summary, I support Heidegger's ontology of emphasising that being-in-the-world and being-with-others is a social experience of interpersonal frameworks (Becker 1992: 10). Husserl adds to my philosophy of privileging individuals' immediate subjective understanding of their everyday lives. My epistemology assumes knowledge is gained in the intentional world of meanings that underlie everyday actions and interactions (Woodruff Smith 2007; Berger and Luckmann 1984). My epistemology links to symbolic interactionism on the premise that everyday reality is constructed through interactions with self and others (Blumer 1969: 2). My epistemology and theoretical perspective merge to complement my research aims in giving prominence to primary carers as active intentional agents who interpret their everyday lives.

To briefly map out my symbolic interactionst approach I paraphrase Blumer's (1969: 2-5) premise that, first, primary carers act towards their situation on the basis of the meanings they attach to it. Second, primary carers develop meaning for their cancer related situation through social interactions with self and others,

in which to mutually establish a meaningful 'definition of the situation' (Thomas 1923: 42). Third, primary carers give meanings of their situation through social processes of interpretation. The premises incorporate the looking-glass perspective of internalising and interpreting self within the presence of others as interpretations of others inform self responses (Charon 2007: 82). Goffman's (1959) dramaturgical perspective adds to the process where interpretations of the self and between self and others involve complex impression management performances. From this methodological position I focus attention on primary carers' everyday interactions while sensitive to broader cultural assumptions in which care, parenthood, childhood and cancer are socially constructed and returns to normalcy are expected after crisis situations (Becker 1997: 199).

Symbolic interactionism is a social constructionist perspective because its underlying assumptions take meanings and realities to be the products of social processes developed through interaction (Charmaz 2006: 189; Blumer 1969: 2). Social constructionism provides a conceptual lens to examine how primary carers develop meaning through social processes of interacting with self and others. However, primary carers interact from a particular social context involving their child's cancer and survival. Informed by the scholarship of Berger and Luckmann (1984: 116), my standpoint assumes that for primary carers to have their child diagnosed is a crisis situation in which the 'symbolic universe [of meaning] allows one to return to reality-namely, to the reality of everyday life'. The symbolic universe is of course the interface of subjective and objective

reality where meanings are interpreted and realities are constructed. My social construction of meaning standpoint informs my choice of research methods used to answer the research questions. Before addressing the actual methods of enquiry I discuss my reflexive insider/outsider position which has both motivated and shaped the research.

Insider/outsider reflexivity

My position in this study consists of more than the philosophical stance and methodological strategies: it also consists of my own life experiences values as both an 'insider' parent of a child who has survived cancer and an 'outsider' social researcher. This duality has informed my approach and shaped both the quality of data collected and the mode of analysis (Ryan and Golden 2006: 1192). My reflexive position means being honest and aware of myself as having an explicit role in this research (Kondrat 1999: 452; Willis 2006: 260). Both the participants and I are active agents who interpret, interact and respond to our everyday lives. As an insider I have shared with participants the experience of having our respective child's life threatened by cancer and the ongoing processes of being a carer of a child in remission.

My insider/outsider status means that the relationship between self and participants is one of shared childhood cancer experiences, which reduces the distance of difference and enhances the understandings between researcher and researched (Kondrat 1999: 456-457). In this study, I believe the distance between

researcher and researched is reduced by our shared childhood cancer experiences. I am therefore a 'connected knower' in using my personal experience 'as a strategy for understanding' participants' experiences and knowledge (Gilgun 2008: 184). While the distance between me and the participants may be reduced, we each interpret our own situation as a unique, distinctive experience and the 'knowing' part of this connection is not absolute. Our shared experience establishes a degree of sameness but there remains a fundamental hermeneutic space between primary carers' self-interpretations and my attempts to interpret their sense-making processes from my own insider/outsider paradigm and cultural context (Rice and Ezzy 1999: 26). Furthermore, I experienced my son's cancer diagnosis more than 20 years ago. The metaphor 'time heals' has a certain truth as my current self is partially informed but certainly not determined by his cancer. My 'insider' status is only a fractional part of my identity, yet my childhood cancer experience is a motivating factor in conducting this research.

I consider my insider/outsider position to have contributed positively in this research. Having some knowledge of the phenomenon being investigated forms an important part of qualitative research (Rice and Ezzy 1999). The participants and I have similar experiences of having a child with cancer: the shock of diagnosis, a heightened awareness of the fragility of life, forcing our child to endure painful medical procedures, dealing with ongoing cancer uncertainties and dealing with ongoing child morbidities. My insider position aligns with the insights of Charmaz (2000: 525):

> To seek respondents' meanings, we must go further than surface meanings. We must look for views and values as well as acts and facts. We need to look for beliefs and ideologies as well as situations and structures. By studying tacit meanings, we clarify, rather than challenge respondents' views about reality.

I sought to maintain the sound qualitative research practices which Charmaz (2000) promotes. My cancer related experiences advantaged my capacity to probe sensitive themes and tacit meanings with a degree of familiarity and confidence such as the shock of diagnosis, entering the unfamiliar world of paediatric oncology, the relief of remission and the shared grief of others whose child died or cancer. I retain a degree of technical familiarity with different cancer typologies, chemotherapy drugs, medical procedures involving catheters and infusaports (for administering chemotherapy), spinal taps, hospital routines and pathology results. So when participants discussed their experiences, meanings and technical knowledge acquired through cancer I had an established understanding by drawing on my own somewhat distant but familiar experiences. For example, when a participant discussed how her child's 'catheter that broke while playing' I understood the implied urgency in getting immediate medical attention to avoid the child bleeding to death. When carers spoke of chicken-pox or measles in a matter-of-fact manner when a child is immune-suppressed, I knew the gravity of their situation as potentially life-threatening and their sense of responsibility in imposing a home and school quarantine to circumvent a potential viral infection. I was also familiar with the acute anxieties involved in a child's diagnosis, the angst of forcing the child to submit to painful treatments and the everyday uncertainties in the aftermath of cancer.

More relevant perhaps, I have interacted with many other primary carers for several years preceding this research and have acquired an intimate understanding of this population's nuanced and tacit meanings and types of expressions. With this 'insider' knowledge I gained valuable data that may have otherwise been missed or discounted as unimportant. I gained an intimate rapport with the participants, often with little effort on my part, as we discussed our experiences through and beyond our children's cancer in an open dialogue (Charmaz 1990). The participants were aware of my own family cancer experience through information sent to them before the interview. They often asked about my experiences through cancer and remission, and my son's health. As such, the interviewer and interviewee positions were at times reversed. At other times I used my experiences to strategically draw out participants' responses to particular enquiries. For example, I discussed how my son's short-term memory impacted on his school life as a leading enquiry into how participants give meaning of their child's learning difficulties and their strategies in dealing with their child's health and education. Interview interactions developed as a flowing dialogue and provided immensely rich and detailed data.

An important issue arose during the interviews when at least half the participants stated they had limited prior opportunity to discuss their own experiences through and beyond their child's cancer. The interviews provided a forum for carers to speak of their lived experiences with a similar other. On several occasions they

discussed the personal value for them 'just to be able to talk about it', so an 'interview-as-therapy' theme emerged through my data collection and reflexive memos to illustrate participants' need to give meaning to their experiences through interaction (Rice and Ezzy 1999; Becker 1997; Stacey 1997). By listening intently I was privileged to hear their accounts of constructing meaning in their everyday lives. In writing this thesis I remain convinced that being an insider/outsider researcher enhanced interview interactions by providing a productive forum for participants to articulate their lived experiences.

As an 'outsider' researcher in this sensitive study I share an empathy with the participants. I also refute the idea of being a detached researcher, due to the affinity and rapport that mutually developed through the interviews. I am incapable of bracketing my bona fide self from present or past experience (Charmaz 1990). Instead, I incorporated rather than segregated my insider and outsider selves in a research position between these dichotomous positions. I was also able to keep a certain degree of distance by engaging analytically and systematically through the research process. This distance was not difficult to maintain as the emotional rawness of experiencing my child's illness is much diminished. However, conducting this research has forced me to revisit and reflect my own experiences of cancer. In keeping a degree of critical distance I strategically kept my own experiences at a personal level (which I shared with participants), but predominantly focused on analysing their accounts. In this way I established an informal and fluid boundary: of sharing and comparing my

insider insights with the participants, but also comparing each of their experiences and childhood cancer literature. Combining rather than segregating my positions allowed me a space 'between' to compare and analyse participants accounts as I was neither 'inside' nor 'outside' the data collection/analysis process. From this reflexive position I focused centrally on primary carers' realities of everyday life both through and after the abatement of their child's cancer to capture their biographical context of experiences.

While I consider my insider/outsider position an advantage I concede being in a position of power as a professional social science researcher endorsed by the University of Tasmania, the Human Research Ethics Committee Tasmania Network and Camp Quality, a national cancer support agency. In this context I was concerned with being perceived by participants as an 'expert' researcher with some insider understandings. This issue did not explicitly emerge through the interview interactions but I was sensitive to the need to conduct the interviews by maintaining a 'socially acceptable incompetent' approach by keeping an open dialogue but giving precedence to the participants as lay experts of their own lived-experiences (Atkinson and Pugsley 2005: 230; Hillier and DiLuzio 2004). My position of power also means I carried a moral responsibility towards the participants, as they entrusted me with very intimate details of their lives.

The research process to some extent impacted on my own well-being, as I found some of the interviews confronting. Participants described in great detail their

insidious memories: their child's distorted body, the painful and invasive

treatment procedures, their sense of helplessness, the ongoing effects of cancer

treatment, the death of other children and the grief shared with other families. I

protected my own well-being through the emotionally draining aspects of the

research process by debriefing with my academic supervisors and colleagues. I

also drew particular strength from participants whose responses illustrated their

resilience and adaptability through and beyond their child's cancer.

Method: Constructionist grounded theory

In this section I illustrate my modified constructionist version of grounded theory

which I locate within a more general discussion grounded theory methods. I

discuss my preliminary fieldwork, participant criteria, recruitment and interview

processes of generating data. I then explain my analytical use of constant

comparison, theoretical sampling, open, axial and selective coding, observations

and reflective memo making (Charmaz 2000; Strauss and Corbin 1998).

In designing this study I evaluated other methodologies and analytical methods

including narrative analysis, a thematic approach or grounded theory.

Sociological research has benefitted greatly by examining health and illness

accounts through a variety of thematic and narrative approaches (Williams 1984;

Frank 1995; Hyden 1997; Woodgate 2006). Analyses drawn from various

thematic and narrative approaches provide valuable insights into ways that people

construct and present their illness accounts. Frank (1995) for example developed

a chaos-quest-restitution framework to inform the variety of ways in which

people give meaning to their illness through constructions of identities and the

overall plot structure of illness narratives. However, I was guided by the research

question and the limited available research to choose the constructionist version

of grounded theory because it provided the most useful methodology in which to

answer the research question. More specifically, I was more concerned with

'discovering' how primary carers give meaning to their lives in response to being

a carer of a child with cancer and a carer of a child in remission, than I was with

analysing the plot structure of carers' narratives (Charmaz 2006).

In saying that, grounded theory compliments elements of thematic analysis as

coding and memo writing generated data themes. Participants' accounts were

also analysed within the context of their overall narratives. However, more

emphasis was placed on examining carers' sense-making processes and responses

within their story and less emphasis was placed on their overall story. Grounded

theory provided a cohesive and flexible methodology within the overall research

process, whereas thematic and narrative approaches are solely analytical methods.

In an area where little was known about, the grounded theory tools of theoretical

sampling provide a valuable data collection and analysis tool that thematic and

narrative analysis did not offer (Rice and Ezzy 1999: 193). Ultimately, grounded

theory aligned with my theoretical and epistemological positioning to examine

retrospective and current cancer related accounts as reconstructions of experiences rather than the original experiences themselves (Charmaz 2000).

My version of grounded theory aligns closely to the social constructionist version employed by Charmaz (1990; 2000). I say closely because there are many similarities but also certain differences. Our versions recognise the researcher's 'dialectical and active' position in participants' social constructions (Charmaz 1990: 1165). Our versions share the interpretive principles derived from symbolic interactionism: to incorporate participants' multiple voices, views, values and visions of their lived experience through and beyond their child's cancer (Charmaz 2000: 525). We share the value in the flexible rather than prescriptive use of grounded theory. The versions of grounded theory align in the claims we make for research findings that are based on socially constructed knowledge. We also value the use of sensitising concepts to gain greater conceptual depth and breadth of understanding (Blumer 1969; Charmaz 2000).

Charmaz (1990: 1161) employs a constructionist version of grounded theory with influences from Marxist theory to link subjective everyday experiences and responses to broader social structures. However, I found it necessary and useful to consider the influences of cultural assumptions and expectations informing primary carers' social constructions (Becker 1997; Stacey 1997; Tulloch and Lupton 2003). This departure is not a critique of Charmaz's scholarship, but rather, a careful consideration of the most suitable way to achieve my research

aims. Put simply, my emphasis on the culture of cancer and cancer survivorship takes precedence over a political economy paradigm (Little et al. 2002; Dixon-Woods, Young and Heney 2005). In this way I focused on the socio-cultural realm in shaping how the participants constructed their everyday realities.

Grounded theory

The grounded theory method of enquiry was initially developed in collaboration by US symbolic interactionists Barney Glaser and Anselm Strauss (1967). Drawing influence from the philosophy of pragmatism and the insights of Mead, Glaser and Strauss developed grounded theory as a qualitative interpretive method in response to and as a rejection of the 'logico-deductive' tradition of theory building and verification (Glaser and Strauss 1967: 17). The grounded theory premise is based on theory generated from the observations and analytical insights of inductive empirical research. Broadly, grounded theory methods support my aims of generating and analysing information from primary carers that is 'grounded' in data. My decision to use the grounded theory method was based on the limited available data on primary carers after the abatement of their child's cancer, as noted in Chapter Two.

Grounded theory is referred to as a 'discovery method' and used when little is known about the phenomenon under investigation (Glaser and Strauss 1967; Strauss and Corbin 1998; Charmaz 1990, 2000). The research gap in the

literature thus informed my research questions which in turn informed my

qualitative grounder theory approach. My decision to employ constructionist

grounded theory was taken after reading how various versions of grounded theory

are used to achieve different research aims (Rice and Ezzy 1999; Strauss and

Corbin 1998; Orona 1997; Charmaz 1990; Corbin and Strauss 1988; Strauss and

Glaser 1975; Glaser and Strauss 1967). Using grounded theory achieved my

research aims of developing a conceptually rigorous understanding of primary

carers as little was currently known about their situated post-cancer context

before this research.

The symbolic interactionism principles underlying the use of the grounded theory

method follow those outlined by Strauss and Corbin (1998: 9-10):

> (a) the need to get out into the field to discover what is really going on; (b) the relevance of theory, grounded in data, to the development of a discipline and as a basis of social action; (c) the complexity and variability of phenomena and of human action; (d) the belief that persons are actors who take an active role in responding to problematic situations; (e) the realization that persons act on the basis of meaning; (f) the understanding that meaning is defined and redefined through interaction; (g) a sensitivity to the evolving and unfolding nature of events (process); and (h) an awareness of the interrelationships among conditions (structure), action (process), and consequences.

Grounded theory has evolved from its original Glaser and Strauss (1967) version

(for example, Corbin and Strauss 1988; Fujimura 1997; Orona 1997). I have also

considered the sharp debates between Strauss and Glaser regarding the issue of

'emerging or forcing' theory from data (Glaser 2004; Bryant 2003) and applying

grounded theory from a constructionist perspective (Glaser 2002; Charmaz 2000).

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In considering these debates my position situates data deriving from grounded theory is socially constructed through three hermeneutic stages. First, participants and I interpret and construct meaning of our own cancer and post-cancer experiences through interaction with self and others. Second, though the interviews the participants and I constructed meanings of our cancer and post-cancer related experiences through shared interaction. Third, I constructed analytical meaning of the interview interaction from my own socio-cultural context and sociological perspective.

I agree with Charmaz (2000: 510) who critiques traditional grounded theory on important methodological points, particularly in terms of how the method permeates 'with its assumptions of an external reality, a neutral observer who discovers data [and the] reductionist enquiry of manageable research problems, and objectivist rendering of data'. Charmaz (2000: 510) also regards Strauss and Corbin's (1998) modified version of grounded theory as moving into a method of post-positivism by giving voice to the participants, yet 'discovering' and acknowledging how respondents view of reality conflict with their own. Charmaz (2000: 524) argues that Strauss and Corbin's (1998) version of grounded theory is more 'didactic and prescriptive', less 'emergent and interactive' and therefore an overly structured approach to qualitative research.

In addition Strauss and Corbin's (1998: 4) grounded theory assumes researchers are neutral and 'allows the theory to emerge from the data'. I found this

assumption problematic because my own childhood cancer experience informs

my insider/outsider position, which has shaped the research process and

ultimately the emergent findings. My constructionist version of grounded theory

therefore supports the coding processes, constant comparison, theoretical

sampling and memo tools, but applied in a flexible non-prescriptive way to

advance interpretive understandings of primary carers lives (Charmaz 2000: 510).

Therefore, I value and employ the central tenets of grounded theory but my

epistemological assumptions of the findings are based on socially constructed

knowledge rather than an external reality to be discovered (Charmaz 2000: 513).

Preliminary fieldwork

Before commencing participant recruitment I informally liaised with

representatives from key Australian cancer support agencies: Canteen, the

Leukaemia Foundation, Camp Quality and the Cancer Council to build a

collaborative network of relationships. I also sought their institutional support in

recruiting potential participants who were unidentifiable on leaving the medical

arena. These agencies expressed great interest in my study but Camp Quality

offered the greatest capacity in participant recruitment due to their policies and

programs of ongoing child and family support beyond cancer. Through my son's

past involvement with Camp Quality, I used my established relationship with the

organisation to liaise with the Chief Executive Officer (CEO), who endorsed the

study on the provision of receiving ethics approval from the Human Research

Ethics Committee (Tasmania) Network (HREC). Through Camp Quality I

accessed an otherwise anonymous cohort of primary carers once their child's

medical treatment had finished. My research hinged on the success of this

collaboration and participant responses through this recruitment process.

The preliminary fieldwork allowed me to implement the recruitment process on

receiving HREC approval. Through Camp Quality's institutional structure I

liaised with their three regional managers and 13 area managers across Australia.

I initially contacted each area manager and explained my research focus and

requested their assistance to recruit participants. I emphasised the key criterion of

primary carers being at least five years past their child's cancer diagnosis, but

otherwise I asked each manager to use their discretion in distributing my

information to reflect a representative sample of their family clients. The

recruitment process formed an ethical blind as I had no knowledge of who was

contacted and Camp Quality had no indication from me as to who responded.

The recruitment process was necessary to access participants but raised the

potential for Camp Quality's area managers to selectively sample their clients

according to their own perceptions. I had no control or knowledge of who was

chosen or whether area managers made random, representative or selective

choices as to who they considered 'appropriate' interviewees. Throughout the

interviews I did not raise Camp Quality during discussion, as my research was

focused on carers' experiences rather than their cancer support affiliations.

Although Camp Quality was raised on occasion, the organisation was a minimal topic of discussion as carers were far more orientated towards explaining their own lives, the lives of their child and significant others through and after cancer.

Participant criteria and recruitment

The key criterion was based on participants identifying as primary carers of a child who had survived cancer. The criterion was inclusive of carers' legal, social and/or biological relationship with their child, irrespective of gender, age, socio-economic position, religion, ethnicity and locality. Participants were also eligible regardless of their current primary carer role, whether their child was living dependently, independently as an adult or in alternative care arrangements. I had no outer limits of elapsed time since cancer as this was effectively and sadly established by childhood cancer being invariably fatal in the 1960s and with few survivors in the 1970s (Barnes 2007). Through the recruitment process, participants were selected through 'criterion-based' sampling in that they identified as primary carers of a child who had been cancer-free for a minimum of five years (Patton 1990: 177). The criterion was institutionally endorsed by Camp Quality's membership procedure requiring medical validation of childhood cancer as eligibility for children and their family members to receive their support services, both through cancer and in remission.

For this thesis, cancer remission means a child is cancer free for a minimum of five years without clinical intervention (Ekert 1989). This period was a nominal starting point for this study, and was based on locating carers in a post childhood cancer context rather than the intense cancer and hospital period. The five year criterion is distinct from empirical data illustrating that some patients and carers consider survival from the day of diagnosis (Aziz 2002). However, using the medical definition of five years as clinical remission meant I gained Camp Quality and HREC endorsement which allowed this research to advance.

Through Camp Quality's area managers I sent a total of 260 recruitment packages containing information sheets, consent forms and an explanatory letter and return-addressed envelope (n=20) which they distributed to their clients. I recruited 38 participants over the period from December 2008 to September 2009. I deliberately recruited participants over the 11-month period to allow time to conduct and transcribe each interview, draw a partial analysis and use this data to theoretically sample later interviews (Strauss and Corbin 1998). I initially contacted one participant who agreed to conduct a pilot telephone interview. This interview helped to refine my interview questions and ensure my audio recording technology was working effectively for later transcription. \

Participants were located throughout Australia, and as such, I conducted all interstate interviews via telephone to overcome the economic and time constraints of travel required for face-to-face interviews. When interstate primary carers

(n=29) initially contacted me, we arranged a mutually convenient time to conduct the telephone interviews. Tasmanian participants (n=9) were offered the opportunity to conduct the face-to-face interviews at their home, my residence or a neutral venue and we agreed on a mutually suitable time to conduct the interview. They all chose to conduct the interviews in their own homes, with the exception of one who requested a late evening telephone interview because of work commitments. After the final interview I notified Camp Quality's CEO and area managers to express my gratitude and indicate the completion of their commitment to the research.

I initially intended to conduct around 10 face-to-face interviews and 30 telephone interviews but these numbers were arbitrary as my aim was to achieve theoretical saturation when no new properties, dimensions or relationships emerged through data analysis (Strauss and Corbin 1998: 143). I achieved a degree of saturation in most areas of my enquiry after analysing 28 interviews and completed theoretical saturation after 33 interviews. The remaining five interviews confirmed I had reached this point, as interview data fitted into my developed coding categories and the central category of 'new normal'. I say a degree of saturation, as I believe that no single interpretation of human complexity can exclude the potential for another complementary or even richer account (van Manen 1990). I think it is more accurate to describe saturation as a period in data collection and analysis in which I had no further theoretical sampling questions.

Participant profiles

My recruitment aims were achieved, as I obtained rich and detailed first-hand data directly from primary carers who had experienced their child's cancer and survival. The outcome of my research design, methodology and recruitment methods resulted in 38 participants who were interviewed over the period from December 2008 to November 2009. All the participants identified as biological parents of their child who had cancer and comprised of 30 mothers and eight fathers. Two fathers participated in joint mother/father interviews. Their ages ranged from 37-59 with an average age of 45. In socio-economic terms most identified annual combined family incomes of \$50 000 or more (n=33), between \$20-50 000 (n=1) and under \$20 000 (n=4). Their educational attainment included trade/diploma level (n=9), degree/postgraduate qualifications (n=10) and high school certificate education (n=19). Their occupations incorporated a variety of careers ranging from accountants, teachers, a health scientist, a general practitioner and nurses, an electrician, bricklayer and small business operators. Ten participants identified as active church members. All carers identified as Australian nationals of Anglo/European descent and one Aboriginal Australian.

Thirty-two participants identified as currently married, five were divorced or permanently separated and one was widowed. Participants currently lived in New South Wales (n=15), Queensland (n=7), South Australia (n=5), Western Australia (n=2) and Tasmania (n=9). Six participants were living in regional or remote areas at the time of their child's cancer diagnosis which meant extended

relocation to metropolitan specialist oncology care. The number of years since the participant's child was diagnosed ranged from 1989 to 2004, which means they have been living with the presence of cancer from 5-20 years with an average of a little over 10 years. Cancer typologies represented here were consistent with international, although mainly Western childhood cancer data (Dixon-Woods, Young and Heney 2005: 19). The participants in this study describe their child's cancer diagnosis as mainly leukaemia (n=16) while other childhood cancers (n=22) consisted of neuroblastoma, Wilm's tumour, Ewing's sarcoma, hepatablastoma, hemophagocytic lymphohistiocytosis, germ cell tumour, T-cell lymphoma, hystiocytosis, oesteosarcoma, astrocytoma and rhadbomyofarcoma (Also see Appendix one: Demographic table).

The participant profile raises a number of important points that shaped the type of data I obtained. In line with existing trends in childhood cancer research, the majority of participants were mothers, thus highlighting the gendered culture of child-caring and the mainly maternal responses in the findings (Young et al. 2002). Socio-economic markers of income and education indicate a mostly middle-class cohort. The majority of participant responded in a highly articulate and thoughtful manner which reflected their various professional and semi-professional backgrounds. The circa 45 year age profile reflected the biographical context of child-rearing as well as the minimum five year post-cancer criterion of eligibility for this study. In summary, I was privileged to

obtain rich and detailed data from a mainly maternal, middle-class and urban

cohort of primary carers.

The interview process

The interviews were conducted in telephone and face-to-face formats. I

considered the appropriateness of telephone interviews for discussing the

sensitive issues surrounding this research. I apologetically explained my resource

constraints and the necessity to conduct telephone interviews but interstate

participants responded positively and discussed the advantage of telephone

conversations as convenient due to their hectic family and work commitments.

Several participants requested interviews during late evenings when work and

evening meals were completed and their children were settled for the evening.

Logistically, I found it convenient in having ready access to participants and

telephone interviewing was non-invasive as I was not physically in their homes.

However, the disadvantage of telephone interview was that I was unable to

observe participants' behaviour, unspoken gestures or body language responses.

This format however did provide the means to pay attention to their vocal tones,

silences, pauses, expression of grief and a host of subtle vocal nuances. During

the face-to-face interviews I noted vocal tones and observed non-vocal gestures.

I added this data to my field memos so that when I revisited the transcripts I had

useful information about the tone and atmosphere of the interview. Through both

interview formats a mutual rapport developed, as I was a genuinely interested researcher and the participants expressed much interest in the study.

My aim was to gather and analyse data representing how primary carers make sense of their own experiences of their child's cancer and survival in their everyday lives. My epistemology and interpretive theoretical framework emphasised the participants and I constructed meaning of our own cancer and post-cancer experiences through a process of 'self interpretation', from which we shared experiences through interview interactions (Blumer 1969: 3). I aimed to elicit rich, thickly descriptive and relevant data and chose a flexible in-depth interview format (Charmaz 2000). I conducted the interviews with a specific focus on primary carers' meanings and interpretations while mutually availing them of the freedom to respond from their own perspectives. My input varied both within and between interviews as I partly guided the conversation. At times I received short matter-of-fact responses to my open-ended questions despite my attempts to engage an open dialogue. But mostly I would simply ask participants questions beginning with: 'Tell me about …' or 'What was it like …', then actively listen and probe particular areas as participants discussed their experiences through and after their child's cancer. Their responses often pre-empted several lines of enquiry from my interview schedule. The interviews flexibility gave participants ample scope to discuss what they deemed relevant and important, and in an order that made sense to them.

Throughout the interviews participants were aware of my focus on cancer survival rather than cancer *per se* but their usual starting point was their child's diagnosis from which they progressed through the various cancer treatment phases and to their current situation. This meant I obtained much retrospective cancer diagnosis and treatment phase data, which I discuss in Chapter Five as it illustrated how carers construct their whole biographies regardless of my initial research focus on their journey through the cancer aftermath. Carers' starting point began at or just preceding their child's cancer diagnosis, moved through treatment, leaving hospital on their child's completed treatment and their current context as carers of a child in remission. They spoke of life before cancer as a way of explaining their sense of loss or grief for the normality they once had. Their retrospective accounts and sequence of cancer phases reflect Mead's (1967: 351) temporal ordering theory; as a biographical flow of experience in which carers articulated their childhood cancer experiences to give their present situation meaning and continuity for their uncertain and hopeful futures.

In following the advice and experience of Charmaz (1990: 1167), I approached the interviews by strategically ordering enquiries according to open-ended, exploratory, probing and closing questions to enhance the interview interaction. I began with short information and demographic questions, followed by reflective and feeling questions, and concluded with strategy and ending questions. The short informational and demographic questions around age, marital situation, location and number of children were designed to move the interview into a

flowing dialogue. I then enquired about their child's cancer typology, age at diagnosis and type of treatment in order to draw participants into a more health and illness focused discussion. My feeling and reflective questions focused on their meanings of how cancer has impacted on their own and significant others' lives. I had difficulty in getting some participants to initially discuss their own rather than their child's experiences. They explicitly stated being so immersed in their child's health that it felt inappropriate and selfish to consider their own selves. The strategy questions focused on how carers made sense of their situation and their everyday responses through and after cancer. This enquiry prompted participants to regard themselves as active agents in shaping their own lives and the lives of their child and family members. The ending questions finished the interview in a positive way as I reminded participants that they are among the first generation to have their child survive cancer and were experts of their own experiences. I found ordering the interview questions in this manner gave the participants a particular tempo in which to slowly but deliberately engage in their own lived experiences and progressively discuss their accounts in more detail and in a reflective manner.

The depth of discussion was based on the extent to which participants were willing to articulate their cancer related experiences. It was also influenced by my own interest and in encouraging them to talk in detail and asking probing questions. In each interview I 'tuned in' to participants' use and style of language and spoke in a similar manner when asking comparative and probing questions

(Rice and Ezzy 1999). In this way, the interview progressed from participants describing their experiences to a progressively richer dialogue of explaining their meanings and definitions of their situations. All of the participants' accounts reflected that they had thought deeply about their past and current situation. As such, the quality of these interview interactions and the depth of data were shaped by a combination of factors: the extent in which carers were prepared to articulate their experiences, my interviewing techniques and interview rapport.

The particular questions guiding the interview process were initially derived from both my own 'insider' experiences and from my literature review where I converted sensitising concepts and key themes into interview enquiries (Charmaz 1990; Blumer 1969). For example, Little and Sayers (2004) and Aziz (2002) develop the concept 'meanings of survivorship' which I used to examine how and when participants started to construct a sense of hope in their child's remission and survival. From that sensitising concept I asked: 'When did you start to relax about the threat of cancer?' Their responses raised themes of hope, uncertainty and temporality across different cancer and post-cancer phases. Through theoretical sampling, which I discuss shortly, participants' responses informed subsequent questions such as, 'How has cancer impacted on your own well-being?' I started with relevant but broad interview questions but my level of enquiry delved into progressively deeper enquiries and richer analysis by evaluating changing, adding and/or eliminating interview questions in light of emerging data themes. Theoretical sampling was a valuable research strategy.

My initial interview schedule was a guiding but changing document which I used to develop greater analytical clarity and depth of understandings. The audio-recorded interviews ranged in duration from between 45 minutes to a little over two hours. I personally transcribed each interview, developed open representative data codes and initial analysis which informed further theoretical sampling lines of enquiry in subsequent interviews (Strauss and Corbin 1998).

Methods of analysis: Coding to concept process

My data analysis followed the principles of grounded theory by repeatedly reading and constantly comparing the data while integrating open, axial and selective coding methods. Open coding identified and assigned data into manageable representative concepts. Axial coding examined the relationships between emerging concepts, and reassembled them into sub-categories and categories. Selective coding integrated the dominant concepts represented from both open and axial codes into a central explanatory concept which was then compared again to the transcript data from which it derived (Charmaz 2000; Corbin and Strauss 1998).

My initial analysis began in transcribing my first interview by closely examining words, phrases, sentences and paragraphs and assigning data to representative open codes. Analysing the data in this manner reduced the data into a

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manageable framework while still representing the data at a conceptual level. For instance, one of my early interview transcripts was 20 pages in volume but after coding I reduced the transcript to one page of *in vivo* phrases and codes which represented the context, properties and dimensions of the data. After transcribing and coding my third interview I assembled the open codes and started the process of constant comparison by looking for regularities and irregularities. In this manner I began raising open codes into concepts (Corbin and Strauss 1998: 101-103). The coding and concept building process was particularly useful during my preliminary analysis because it allowed me to develop micro-level analysis from each participant, a comparative meso-analysis between participants, and an overall macro-analysis of the key data themes. Preliminary analysis informed further interview enquiries throughout the theoretical sampling process.

The following data extract provides an example of my open coding process (in bold) to represent the data. I chose this extract from my third interview because a key interactional category 'different self/other interactions' started to emerge, remained for the duration of my analysis and formed an important interactional concept of the central 'new normal' category:

> I asked: Do you think people outside your family like friends and other colleagues see you or treat you differently because of your family cancer experience?
>
> Louise: I don't know if it's my imagination or not but I think they did, (**perceived as different by generalised other**) like you're the family who … that's the boy who had cancer, that's the mum … you sense it and feel it and sometimes you're emotions are so crazy you don't know if your paranoid or not (**questioning self**) but I'm sure that's how it was for a long time (**feeling labelled as the cancer other, but changing**). It's best

if they don't try in some ways, they can't fathom it, even people ... if you actually have a talk to them open the doors (**Open the cancer door)** and they're happy about it they're truly shocked, like they could have known you for years and known you were going through it but until you talk about it they can't comprehend it, and I couldn't have either. (**Others can't comprehend).**

My open codes then represent Louise's account at an initial conceptual level:

Perceived as different by generalised other, questioning self, feeling labelled as the cancer other, but changing, opens the cancer door, others can't comprehend.

Open coding occurred concurrently with initial axial coding. Where open coding broke the data down into representative codes, axial coding brought these codes together to develop an analytical story through concepts and categories (Strauss and Corbin 1998: 123). Louise's data extract was then represented as an axial code of 'different self/other interactions' through cancer. I then compared the axial code to the attributes of similar substantive concepts in the literature and found 'interactional dissonance' as being similar to represent Louise's interview response. This concept derives from McKenzie and Crouch's (2004: 144) research to represent an interactional breakdown in meaning and communication between the ill self and carer other due to cancer experiences. Although similar, Louise's self/other perception was her response to a generalised rather than significant other. Through further comparisons of 'different self/other interactions' with other interviews and literature I found Goffman's (1959) dramaturgical framework more representative in capturing Louise's front stage/back stage of interaction because of her generalised audience of 'different

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self/other interactions' rather than familial and/or significant others. The concept derived from Louise's account was comparable with other participants and formed an important attribute of the 'new normal' category, with explanatory power to represent primary carers constructing and negotiating their social identities and realities with generalised others in the aftermath of cancer.

On finishing data collection and preliminary open coding I repeatedly read my complete data set of transcripts and refined my axial codes through further constant comparison and selective coding. This gave further legitimacy to the core concept of 'new normal' and supported sub-categories, including intensified/de-intensified biography, changing realities, a new identity, normalising through and after cancer, evaluating medicine and ongoing late effects management. Louise's data extract represented her construction of reality as a disruption in everyday interaction with generalised others, which linked empirically and conceptually to the category of 'new normal' and identity theory (Little et al. 2002; Goffman 1959).   The data extracts presented in the findings chapters were deliberately chosen after extensive constant comparison to represent all carers whose accounts clearly articulated and typified the major attributes of 'new normal'.

Throughout my research process I adopted Strauss and Corbin's (1998) and Charmaz's (1990, 2000) strategy in maintaining research memos. My fieldwork memos were working documents that include whom I was interviewing and

when, personal reflections on the highs and lows of the research process, and explanatory, process and theory notes. I wrote memos about each interview so when I re-read transcripts the memo notes reminded me of the mood, context and character of the original interview. My fieldwork memos therefore became a 'repository' of my data collection and analytical ideas (Charmaz 1990: 1169), which complemented my repertoire of earlier thesis chapter drafts, notes from meetings with my academic supervisors, coding and transcript data. My memos were time intensive but an intellectually rewarding and engaging part of the research process as I could review how my analytical ideas had developed through the research process.

Ethical research conduct

I am both personally and professionally aware that investigating primary carers of childhood cancer survivors is a sensitive research area and I take my ethical conduct in this study with great sincerity. The University of Tasmania's Human Research Ethics Committee (HREC) granted approval for this research project in October 2008. The principles of merit, respect, integrity, justice, beneficence, voluntary participation, informed consent, confidentiality were core reference points of my research conduct (NHMRC 1999). I also engaged with the participants in a respectful, perceptive and professional manner.

The merit of my research was based on gaining insights into the everyday lives of primary carers of children who have survived cancer to contribute knowledge to

social science and to inform health clinicians and cancer support agencies of ways to benefit current and future families impacted by childhood cancer. I conducted this study in a way to enhance rather than harm the participants and believe I achieved this aim, as participants often stated that their reason to contribute in this study was motivated to benefit others impacted by cancer. They also regarded the interviews as personally beneficial and 'therapeutic in itself' by simply telling their experiences in their own words to an interested listener (Rice and Ezzy 1999: 39). Participants received no economic reimbursement for sharing their experiences but they all received my final report in which I acknowledged my appreciation for their contributions to my research. I also distributed this report to Camp Quality as they were interested in my research findings to enhance policy directing their family support programs.

The ethical issues of respect, justice and integrity form the key principles governing my research conduct. In following the NHMRC's (1999: 1.1) ethical guidelines I respected participants' autonomy and capacity to make their own decisions regarding participation and responses in the interviews. They were aware of their rights to choose not to respond and/or to withdraw from the interviews at any time, although this situation never occurred. My respect for the participants was not compromised by the aims of my research. Principles of justice were adhered to as I treated all participants fairly, equally and ensured there was no exploitation through the interviews. My ethical integrity is illustrated by my honesty with myself, the participants, academic colleagues,

Camp Quality and other cancer agencies. These principles guided my overall research design and practices of voluntary participation, informed consent and participant confidentiality.

My ethical conduct was an absolute reference point through all stages of the research process in which the NHMRC (1999) and HREC principles and procedures formed my minimum standard. I was constantly sensitive to the power disparity between researcher and participants. I made no attempt to coerce the participants by using my 'expert knowledge' position as a social researcher with HREC, University of Tasmania and Camp Quality endorsement (Habibis 2006: 55). My representative position of power was not raised by the participants but the power disparity sharpened my awareness to maintain a 'listen more, talk less' interview approach. I deliberately avoided sharing my empirical and theoretical knowledge but did share my personal experiences to diminish the power gap and to promote discussions in an equitable way.

The researcher/researched power disparity was somewhat alleviated as the participants and I share unique childhood cancer experiences and interview interactions proceeded with this connection. Participants offered informed and articulate responses with a high degree of confidence and spoke with authority of their own lived experience. I believe that disclosing my own childhood cancer experiences considerably reduced the power differences, as several participants briefly 'interviewed' me, thus at times reversing the researcher-participant

relationship. A further indicator of reduced power disparity was demonstrated through participants explaining medical protocols and offering post-cancer related advice and strategies which they developed and applied. In this way, the participants responded to my 'acceptable incompetent' position by teaching me up to their level of knowledge (Atkinson and Pugsley 2005: 230).

This research has taught me the difficulty in achieving a sense of research equality. For example, one participant's situation after cancer involved a broken marriage and ongoing care of her young adult daughter who has permanent brain damage as a result of surgery. The interview was emotionally intense and insightful and we developed a strong rapport. I left the interview with an information rich audio recording to advance my thesis. The participant was left with my heartfelt gratitude for sharing her story, a memory of the interview and the ongoing care of her teenager, whose quality of life is unlikely to improve. She spoke of how the interview was personally helpful and while her token of thanks was uplifting, I felt I gained more from the interview that the participant.

My ethical conduct continued after the completion of data collection, as I was separated from the participants but had control of their personal interview accounts. I felt compelled to represent the participants 'voices' directly in the thesis. However, the selection of their accounts remained my decision and hence my interpretation and analysis of the interview interactions. I sit with the knowledge that my study is an honest representation of primary carers' accounts.

I have opened up a previously underdeveloped body of research that may advance knowledge as more beneficial than harmful to those impacted by childhood cancer. I also realise that no matter how ethically sound I attempted to design and conduct my research, there remained a fundamental inequality.

Limitations

This research enters a new empirical and theoretical domain of primary carers' everyday experiences through and after their child's cancer. However, I acknowledge the research has certain limitations. The findings represent the interpretive processes and responses of the 38 Australian primary carers of childhood cancer survivors who participated in this research. I make no claims of representing people from the broader community. Participants discussed the cancer related experiences of their child, spouse, siblings, significant and generalised others. This data provided valuable information but the findings are limited to primary carers' perspectives and interpretations 'of' significant others and do not represent the accounts 'from' significant others.

Using Camp Quality as an institutional gatekeeper supported my research in accessing an appropriate sample of participants. However, recruiting through Camp Quality raised the potential for participants' to sustain a certain carer-of-a-cancer-survivor identity, due to their ongoing organisational membership that may have otherwise diminished over time. The study's findings are therefore limited to primary carers whose children are Camp Quality clients so I make no

claims here to represent carers not involved with this organisation. The recruitment process also raised the possibility for Camp Quality staff to send recruitment information to clients they deemed suitable or by having particular qualities to make suitable interviewees. I have no recruitment bias knowledge but the implications of Camp Quality accessing certain clients and not others may have ultimately skewed the data I obtained.

My reliance on Camp Quality meant my theoretical sampling was partly restricted. For example, through data collection and analysis, an enquiry emerged 'child late effects impacting on carers', which required further theoretical sampling carers of children with extensive physical and cognitive morbidities. I eventually spoke with participants who met the theoretical sampling criteria, but only because I recognised the child late effects and carer identity link early in the analysis and was able to make enquiries when participants met this criterion. The recruitment process therefore limited the range of my theoretical sampling capacity, but I nevertheless achieved my overarching research aims.

The thesis has limitations regarding structural and health related variables. I have taken primary carers' experiences of their child's cancer and survival as a relatively uniform unit of analysis because my aim was to capture the depth of participants' everyday meanings, actions and interactions, and the cultural context in which they construct their lives. My interpretive approach means I have limited my examination of structural conditions that shape carers responses

through and beyond their child's cancer, including participants' gender, class, age, marital status and urban/rural locality structures. Furthermore, child and cancer variables have been given limited research attention in shaping carers' responses to a child's gender and age, and various cancer typologies, treatment protocols, time since treatment and treatment related morbidities. Taking a homogeneous approach to carers of childhood cancer survivors means that the findings have not considered in detail how specific structural and or cancer variables might shape how primary carers construct their lives.

Furthermore, I identified the prevalence of mothers who participated but decided to accept this discrepancy rather than seek Camp Quality to recruit more fathers because the gender disparity reflects how mothers remain the primary source of childcare through and beyond childhood cancer (Young et al. 2002; Chesler and Parry 2001. The findings are therefore more representative of maternal than paternal responses. My focus on primary carers means that family inter-relationships through and beyond childhood cancer have not been a central focus of research. The study is also limited by the cross-sectional way I gathered data at one point of time in primary carers' lives. This meant I could analyse comparisons between primary carers' accounts as well as individual primary carers' accounts over time, but was limited in observing or evaluating carers' cancer/post-cancer experiences at different temporal or health and illness phases.

Conclusion

This chapter has mapped out my methodological framework of investigation. The aim of my interpretive research approach was to collect and analyse rich, descriptive and detailed data in an ethically sensitive way. As such, this chapter provides the methodological bridge between the limited available data on primary carers after the abatement of their child's cancer, as outlined in the earlier chapters, and the body of knowledge this thesis has developed. My constructionist grounded theory method integrated my epistemological and insider/outsider position, with the actual process of participant recruitment and data collection in conjunction with analysis through open, axial and selective coding, theoretical sampling and fieldwork memos. The research methodology provided a process through which I have developed a greater conceptual understanding in which primary carers construct their everyday lives. The quality of data mapped out in the following chapters provide rich and detailed accounts of carers constructing and reconstructing their retrospective and ongoing cancer-related experiences in ways to give meaning to their current everyday lives.

In Chapter's Five, Six and Seven I demonstrate the central category of new normal that emerged to represent primary carers: from having a child with cancer, being a carer of a child in remission and dealing with their child's morbidities as a consequence of cancer treatment.

Chapter Five: Carers' wild ride through cancer

Introduction: The phases of cancer/survival

This is the first of three research findings chapters in which I reveal how primary carers reconstruct their lives after their child's cancer. The findings in this chapter establish the context for the following chapters by illustrating that having a child diagnosed with cancer represents a profound biographical disruption in primary carers' lives. Carers' pre-cancer taken-for-granted assumptions of control and certainty, and their capacity to protect their child's well-being, were fundamentally disrupted as they had little choice but hand over their child to clinicians in the hope of a non-fatal outcome. They came to accept their limited control of the cancer situation and responded to the disruption by constructing new meanings and roles in being a carer of a child with cancer. I present the findings in the order in which participants reconstructed their cancer experience through pre-diagnosis, diagnosis, treatment, and the transition phase of remission. Through these phases, I argue, carers' responses represent the genesis of new normal definitions of self and situation.

Carers' accounts illustrate their experiences through cancer are deeply embedded in their current lives. They consistently explained their journey through their child's cancer to situate their current situation and future hopes. Their temporal trajectories illustrate ways in which 'past experiences influence the interpretation of who one is at present, while the past and an unfolding present together form

the basis for who one shall be in the future' (Corbin and Strauss 1988: 52-53).

Participants' accounts varied but shared a common theme: their child's cancer diagnosis was a radical departure from their previous lives, requiring the construction of a new sense of self and new ways of responding to being a carer of a child with cancer. In a rich metaphor Louise[1] typified carers' experiences through cancer:

> It's such a wild ride. You go through all your fears as a parent of a child with cancer, all these stages, it's like someone's died. You go through the disbelief, then you go through the anger, then you go through the 'get on with it' stage, then you accept it and there's another stage you go through all this stuff at the end when it's finished, like treading really carefully and being really scared. It would have been nice to know what to expect.

Louise gave different meaning to her cancer experiences according to her child's various cancer phases. Her wild ride and potential death represent the initial sense of loss and being out of control at diagnosis, integrating the cancer treatment process, coming to accept cancer into her everyday life, and remission characterised by trepidation. She reflects on her wild ride as a cancer journey as having an uncertain destination.

The pre-diagnosis phase

The majority of participants spoke of their child's quick diagnosis after consulting with their family doctor. Carers generally have little medical knowledge and rely on their own intuition of their child's sometimes subtle symptoms. Robyn, for example, recalled her child 'sleeping a lot, no energy, fine

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[1] Pseudonyms used throughout to maintain participant confidentiality.

sitting down but trouble if she tried to get up and walk around, quite anaemic

which we didn't pick up at the time but we thought it was mumps or measles'.

As such, carers are usually the first agents to initiate action by seeking advice and

support from their general practitioner (GP). Most participants complimented

their GP in making a quick referral to paediatric oncology care. Freda, for

instance, said:

> I had a brilliant GP and he would not give up until he had the answer, he was
> absolutely brilliant in that so we were able to catch it [cancer] earlier than normal
> because of him. So when you get GPs like that you can trust explicitly, you're
> on a darn good wicket and you appreciate them.

Freda attributes her child's life to the doctor's positive action but underlying her

explicit trust is an inferred vulnerability and reliance on GP medicine to initiating

further action. However, Mimma was assertive in demanding the GP conduct an

immediate blood test which quickly confirmed her child's leukaemia diagnosis:

> Like you have a right as the parents to say 'look I want my child to have a blood
> test', you know yourself that something is not right; I don't care if that doctor is
> a doctor. If I want my child to have a blood test I will ask for a blood test.

However, seven participants explained the period leading up to their child's

diagnosis with frustration, anxiety and inability to convince their GP to respond

to their child's abnormal symptoms. Thus, before their child was actually

diagnosed, these carers experienced a loss of trust in their family doctor and their

own failure to access medical support. Carers were left with a sense of guilt in

their child's late cancer diagnosis. Their sense of frustration stems from knowing

a child's successful cancer outcome is reliant on a prompt diagnosis and treatment before cancer advances to a terminal stage (McGrath 2001).

Chloe lived in a remote mining town and recalled her desperation and inability to convince the GP of her child's abnormal pre-diagnosis symptoms:

> Trying to get help in the beginning, I think that was the biggest thing, for me it was, I took her to the doctor that many times, they made me feel like I was a lunatic because it was depression, she couldn't walk straight, her head was swelling up, they just said, Oh a virus … that was the hardest thing … All we needed was a blood test, and that's what frustrated me more, it was just a blood test and it could have been solved quite quickly. We were supposed to fly down to the city because her head and chest kept swelling up, and she got sick that night before we were due to fly out the next morning, so they called the Royal Flying Doctors in and they took x-rays, she had a big mass on her chest and they said she had two days to live … it got to the extremes before anyone would actually listen.

Chloe's taken-for-granted assumptions of trust in her GP were severely disrupted. Her unsuccessful attempts to persuade the GP to respond to her child's abnormal symptoms almost resulted in her child's death. She emphasised her frustration in not receiving immediate medical support despite the visibility of her child's symptoms. Michelle described her child's cancer diagnosis from 12 years ago[2] as the 'usual misdiagnosis story'. This claim contrasts with the majority of participants but Michelle states that a child's misdiagnosis or late diagnosis is a relatively common occurrence. She took her two-year-old son to a GP three times because of his lethargy and unusual swelling in his neck, abdomen and scrotum. She recalls her doctor saying 'I am 99.9 per cent sure there is nothing wrong with him', so 'for three weeks we basically let him scream'. Her child was

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[2] Time elapsed since cancer diagnosis is taken from the 2009 interview period.

eventually diagnosed after a friend intervened and spoke directly to a

paediatrician who quickly diagnosed her child's neuroblastoma. Michelle

stressed that her initial inability to access medical support caused her child's

unnecessary suffering. As such, her sense of control and capacity to protect her

child were fundamentally disrupted. Dave discussed similar anguish in trying to

convince a number of GPs before his four-year-old daughter's cancer diagnosis:

> We went to five different doctors before she was actually diagnosed and that was very frustrating, four days before she went into hospital with diagnosis, we had been to a doctor … because she was constipated for three months. They basically told her she was a bad mother and shouldn't give her cordial and this and that, very frustrating, then to have her diagnosed and to find out she was very advanced, that hurt, we both lost our faith in GPs, and you beat yourself up about it because you've taken their word, you know, and in the end you could see there was something seriously wrong and everyone telling you you're a bloody idiot. …This was the hard bit, the next step of getting to the paediatrician, when we got to the paediatrician he even said to us, and this might sound cold but 'why now'? Man that hurt. I felt I had to go there and start smashing on tables to get some sense out of someone you know. Yep, he could see that it was pretty tragic, in the end I mean you belt the piss out of yourself because you think you should have stood up a bit harder you know, so in hindsight now, if I wasn't getting the answers I want to hear I'll start rattling cages, but at the start your faith is in doctors and they're people you think are a bit smarter than the average bear, but they're like tradesmen, there are good ones and bad ones, and we found that out the hard way, that bloody hurt.

Dave spoke with a sense of failure in not being forthright enough to influence the

GP to respond to his child's symptoms. Despite his disillusionment and loss of

assumed trust in GP medicine, he remains burdened with personal guilt for his

daughter's late diagnosis.

Primary carers generally acknowledged having little medical expertise or

authority to initiate specialist paediatric oncology care. But those with medical

knowledge also found themselves in uncharted territory. Elizabeth, who has a

medical degree (not in Paediatrics or Oncology), spoke of missing her son's

subtle symptoms before his eventual diagnosis:

> It was just disbelief, his presentation was actually predominately one of a febrile [fever] illness so you know it wasn't like he'd lost weight and looked sick even though he was ill. Within a couple of days of diagnosis he had abdomen pain but we'd had no idea, it was absolute disbelief. I think also in the very early stages because his was a solid tumour as opposed to leukaemia, you're going to know very quickly on a blood film what you've got, with a solid tumour until you've got … pathology you don't know what you're dealing with, and the prognosis differs you know quite dramatically depending on what tumour type you've got obviously so for us it was a real rollercoaster because originally they hadn't picked it up.

Elizabeth talked of having a double burden of guilt in not meeting her care

responsibilities as either a parent of a medical professional: 'I tell you what else

comes with this territory and that is guilt. You kind of think, Oh my God, how

could I not have known that my child had this going on'. In contrast, Claire used

her paediatric and intensive care nursing skills to diagnose her daughter's cancer

and therefore bypassed the GP referral system. However, Claire was labelled as a

neurotic mother until the diagnosis confirmed her nursing and knowledge:

> I diagnosed her myself, I actually took her to hospital and presented her for blood tests and they said, 'Why are you here'? And I said, 'Well my daughter has got leukaemia', and they all went, 'Oh God, bloody mother hasn't got a clue what she's talking about', and of course that's exactly what she had.

In contrast, it took Louise ten months to get medical staff to respond to her son:

> We finally got to see one of the [oncology] doctors and only because I made the appointment, not because the GP recommended it. By that time he was stage two[3] which I reckon he would have been stage one when we picked it up. At first you're angry about it and very annoyed but when you hear of others with the same thing, it's not an isolated case.

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[3] 'Stage' is a term used by clinicians to determine the degree of cancer spread (Ekert 1989: 17)

Louise had no medical background but she eventually had her son diagnosed after taking an assertive stance and demanded a GP referral to specialist care. She suspected the delay in diagnosis resulted in her son's cancer's progression. Her account suggests the late diagnosis was a frequent occurrence.

The accounts of seven carers in relation to the pre-diagnosis phase are disturbingly similar to the Dixon-Woods et al. (2001) study in which late diagnosis and carers not being taken seriously by clinicians were a source of anguish, and severely lessened carers' previously assumed trust in GP medicine. Despite emphasising the GPs discounting their intuitive carer knowledge, the seven participants in this research nevertheless expressed personal responsibility and self-blame because of their own inability to access initial medical support for their child. Before their child's cancer diagnosis, the findings illustrate a fundamental disruption in their capacity to protect their child's well-being, and 'let down by the limits of medical intervention' in realising their family doctors had failed to refer their child to specialist care (Bury 1982: 178).

Diagnosis as disruption

This study supports the advent of childhood cancer as part of a biographical disruption to primary carers' lives (Bury 1982; Young et al. 2002). Participants frequently recalled the exact date and circumstances of their child's cancer diagnosis as a distinct and sharp break from their pre-cancer lives. Natalie recalled her 13-week-old daughter's neuroblastoma diagnosis 13 years ago: 'It

just feels like yesterday, I can remember everything, the comments, everything'.

Several carers search for a 'stable set of meanings' by drawing on a discourse of disease causation (Bury 1982: 174; also Comaroff and Maguire 1981; Dixon-Woods, Young and Heney 2005). They speculated about the possible cause of cancer by questioning their own child-caring practices or certain events that may have been a cancer catalyst. Mimma spoke of whether her daughter's chicken pox contributed to her cancer, while Emma wondered if her child's measles vaccinations may have triggered her leukaemia. Alice considered if inherited genetic factors caused her child's cancer:

> They couldn't tell us 100 per cent it was genetic … I feel guilty about [daughter's] syndrome, again it was random, it was only recognised as a syndrome from the 1960s, they're still working out the inheritance factors, and there is no one in our family that has it, but it's a genetic mutation that happens in a family and that's what's happened with [daughter], but I still feel guilt, as I carried her around for 40 weeks and was it something I ate, something I did …

Alice's search for genetic and lifestyle answers to explain her child's cancer disrupts her taken-for-granted assumptions of both creating and raising a healthy child. Her guilt is located in an embodied context – she created, carried and gave birth to the child in which cancer manifested. June referred to breastfeeding and other healthy lifestyle choices while searching for a cause of her child's cancer:

> I just feel so much that, yes we are really lucky but at the same time you question yourself, 'what did we do wrong'? There's no rhyme or reason and we've gone over this [cause of cancer] with the doctors and other families but … it just annoys me with this healthy eating and she was breast fed and I used to exercise and always ate well and didn't drink or smoke.

While June searched for the cause of childhood cancer, its origin remains unknown, except that congenital factors can make some children more prone to

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cancer than others (Ekert 1989; Dixon-Woods, Young and Heney 2005). Carers

spoke with frustration of the unknown cause of their child's cancer but their

accounts also illustrate that they bear a heavy sense of inherited and

intergenerational responsibility.

Robyn describes the intense phase of her child's leukaemia diagnosis 15 years

ago in terms of shock and disbelief:

> The fear of the unknown, you walk into a world that is just so unknown to you
> and suddenly your life changes and you're sort of given statistics of 70 per cent
> survival rates, one in three won't survive and you know particularly for the first
> two years when they're on treatment it's just not knowing what side of the
> equation you're going to fall on. I guess having very little control, as a parent
> you know as our role and practically you know for years your role is to keep
> your child safe and suddenly that is stripped away from you. There is nothing
> you can do to influence what the outcome of their treatment of this disease is.
> You literally have to hand your child over to the doctors and I remember
> thinking at the time, should I tell the doctor, does he understand how special my
> child is. You literally just have to put your faith in their hands.

Robyn's account represents a fundamental disruption to ideas about control,

certainty and her capacity to protect her child. She used medical statistics to help

make sense of the uncertainty and acknowledged her inability to influence the

cancer outcome. This required her to submit her child's care to medicine and

necessitated 'faith' in clinicians which, in the absence of alternatives can be seen

as a form of 'forced trust'. Having a child's life hanging in the balance between

life and death is a relational crisis because if a child dies, the child/carer

relationship and carer identity is severed. Robyn's taken-for-granted assumptions

and meaning systems were chaotically 'stripped away'. Yet as her child became

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immersed in medical care, she affirmed her carer self by asserting the importance of her child and the uniqueness of their relationship.

Carers' described their child's cancer symptoms of lethargy, nausea, fevers and pain, while desperately seeking and interpreting medical knowledge and terminologies to gain some understanding of the cancer and treatment process. Their most immediate concern was to make sense of medical statistics to determine the chances of their child's survival. Lee felt initially overwhelmed at diagnosis and torn between anticipating her child's death and a survival outcome: 'part of you is planning the funeral, but on the other side thinking, no, that can't happen, we've got to get through this'. Magda recalled how 'he [clinician] told us she [daughter] would be dead before her first birthday or way before then, she was nine-and-a-half months old'. Magda made 'all the funeral arrangements, planned all that and everything and he [George] was just stuck in the bed being a blubbering mess'. But her husband George recalled that 'if she died I would carry her [daughter's body]'. Making funeral plans while a child is alive 'breaches common-sense boundaries' (Bury 1982) but for Magda and George it represents a meaningful symbolic act of regaining control in planning to give their daughter a dignified ceremony when they felt there was little else they could do. George also recalled his child's diagnosis, treatment and remission as a form of resurrection: 'It sort of went from that you're dead, back to life again'.

The diagnosis period was profoundly isolating, particularly for rural and isolated participants who were forced to relocate to a paediatric oncology hospital. The dislocation meant an immediate severance from other family and social support networks, the suspension of everyday plans and making alternative life arrangements (McGrath 2001). For example, Michelle was told by clinicians to 'go home and pack your life up because you know you'll be there anywhere from three and six months'. She ended up in hospital with her child for nine months and long distance phone calls became the normal way in which family and significant others interacted. Fathers discussed having to reorient their lives to support their child and spouse, maintain an income, care for siblings and sustain hospital time and travel. Dave, for example, worked all week and cared for their other 18-month-old son while his wife and daughter were in hospital: 'I would go up on the weekend to spend most of the time at the hospital just to give my wife a break and you wouldn't not want to be there'.

Having a child diagnosed with cancer is a sharp departure from carers' prior taken-for-granted assumptions and life expectations. Alice explained the disruption in her life when her two-month-old child was diagnosed with cancer 15 years ago: 'You think life is going to be perfect, you have your babies, but my God, it shatters your dreams, what you had in mind and what happens'. Lee's experience was particularly stark as her child was diagnosed with hepatoblastoma as a new-born baby nine years ago and had chemotherapy administered at six days of age, followed by surgery. With such a young baby, Lee described the

unfairness that her child 'hadn't had a life yet', how her initial mother/baby bond

was disrupted and of siblings who never saw their baby brother until he was

medically stabilised. Louise spoke of diagnosis as a loss of control and certainty:

> Just the feeling that it was surreal, and having no control and the uncertainty the whole time, like you were thrown on a roller-coaster ride that you didn't want to go on, it was a nightmare you didn't want to wake up from, taking all the control out of our lives 'cause every day depended on what was happening with him [son] and the results … so we couldn't wait for it to end … the total worry of watching and waiting, just making sure he was … it was like having a brand new baby again, always keeping an eye on him and sensitive to everything about him, every look, every breath he took, it was just totally tiring.

Louise spoke with powerful metaphors: a roller-coaster', 'a nightmare' and a re-

birth analogy 'having a brand new baby again' (her son was diagnosed at 10 years

of age) to make sense of her breached common-sense assumptions in protecting

her child, submitting her child to medicine, and an unknown outcome.

The fundamental loss of control at diagnosis is consistent with other childhood

cancer research (Young et al. 2002; Cohen 1995; Comaroff and Maguire 1981)

but carers in this study adopt a form of fatalistic acceptance as a strategy to deal

with their sense of helplessness and uncertainty. Pauline explained how

accepting her disempowered situation was a source of peace when her daughter

was diagnosed with a brain tumour 15 years ago:

> Do you know the story of Abraham where he had to offer his son up to God? That was how I felt, I identified with Abraham offering his son up, that's how I felt, and I had a sense of peace about it, like if God is going to take her, that I was OK with that because she's so special.

Pauline's biblical metaphor represents a sacrificial submission of control which gave her a particular form of solace.   Victoria expressed a similar theme in response to her daughter's leukaemia 11 years ago: 'That lack of control …, now in life if I don't have that control, that's all right, I accept that, because I think I lost control for the most important thing, you know, my child's life'. Victoria gave particular meaning to accepting rather than resisting her lost control through cancer. She defined the situation in a way where surrendering control to medicine was conducive to her child's well-being. She spoke of accepting finite control of her child's live as a defining feature of her cancer experiences. Victoria's account supports Charmaz (1995: 674) who argues that surrendering the 'quest for control' importantly allows people to construct new and altered meanings to their illness situations.

Carers' accounts through their child's cancer diagnosis represent a profound disruption from their previous notions of certainty and control. They spoke of being disempowered in losing control of their child's life and well-being, but realised they had no option but to submit their child to medicine in the hope of a non-fatal outcome. However, once over the initial shock of diagnosis and the prognosis of their child's potential survival, carers actively responded to the disruption by evaluating and constructing new meanings of hope and uncertainty in being a carer of a child with cancer.

Beginning treatment: A new realm

Carers discussed the early treatment phase as developing a new sense of normal

by accepting their limited control, developing partnerships with clinicians and

seeking knowledge of their child's treatment process into their understandings

and care practices. All participants spoke of coming to terms with the loss of

control of their child's life and cancer outcomes. Grace took a period of time to

accept her limited influence in her daughter's cancer outcome:

> After that first six months I took the view that I can't control this and once you
> learn to let go, that it makes it a little bit easier. It doesn't stop your heart from
> hurting but it makes it a bit easier to get through every day and go, 'One way or
> another this will be over, she'll either be cured or we'll lose her, I can't think
> either way, we just have to do what needs to be done.

Coming to realise and accept that her child would either live or die, and realising

the futility of trying to control a situation in which she had no control gave Grace

the symbolic space to focus on the everyday care of her child through cancer.

Through the early diagnosis and treatment period carers emphasised the

importance of observation in attempting to re-establish a sense of control of their

situation. They spoke of monitoring their child's body for cancer symptoms,

scrutinising medical scans and test results and their surveillance of clinicians.

They placed much importance on their monitoring practices as a new way to care

for and protect their child. Eve's account was typical of carers who maintained

close 'proximity' in monitoring their child and providing a key source of comfort,

as well as scrutinising the medical treatment processes (Young et al. 2002):

I guess initially we didn't trust, we didn't leave her side. Through the day my husband was there as much as I was, but I wouldn't let him stay for that first couple of weeks, I guess it was a control thing, I couldn't let her out of my sight, it took me a good couple of weeks, and I was exhausted before I'd let him come and stay. We'd watch her like a hawk, then eventually you give over your trust, you learn to trust them because they know what they're doing and we don't, we're just there to comfort her.

While Eve attempted to regain a sense of control by her close physical presence, her husband Adam described his new instrumental proficiency in anticipating his child's blood pathology results from his own observations: 'We could read the bloods and half the time we could tell what the bloods would be towards the end, and we'd be close, just by her colour and how well she was feeling'. Michelle similarly spoke in detail of neuroblastoma ravaging her child's body, with a sense of authority in her acquired medical knowledge and interpreting technologies such as magnetic resonance imaging (MRI) which indicate tumour size:

The tumour was so big, it was 13 by 10 by 6 centimetres when they found it. Yeah, it was like a coke can sort of size but the neuroblastoma was a tentacle one that wrapped itself around all the … it started on his kidney, it totally consumed his right kidney, he doesn't have a right kidney. It had wrapped itself around all of his blood vessels, he doesn't actually have a vena cava, it smothered it and the blood vessels. Because he's only 2, I mean if he was an adult he would have just died. So because he's only two, he was so young, the blood vessels grew around it so he lived without it, even now you can't see his vena cava go all the way through.

Michelle's vivid visual memories and her merging of medical and lay discourse of her child's cancer are for her, a brutal reminder of the insidious nature of childhood cancer. She metaphorically 'visualises' the damage to her child's main heart vein through MRI scans in a way that illustrates her immersion in the medical world. Other carers described the visible changes in their child's body, through abnormal growth, bruising and lethargy. Raul explained how his four-

and-a-half month old daughter's cancer resulted in 'the tumour lapsing out of her

vagina'. Natalie recalled her child's body swelling abnormally:

> The tumour through her liver got quite big and hard and it got to the point where her liver was actually into her groin, it was huge, she was measuring almost a metre around and I had to get special clothes made for her and she couldn't sleep on her back because the organs wouldn't have enough room.

Rae described the speed with which a tumour enlarged her daughter's body:

> She went from having a barely perceptible bulge under her rib cage to looking like she'd swallowed a netball in a period of five to six days. This gross abdominal tumour which then had already developed metastases had included the base of the lung and the heart as well as spreading through the whole abdominal cavity.

Rae's use of medical and lay language reflects both her carer self and nursing

career background. She utilised her medical knowledge to instigate early medical

intervention and an early diagnosis which contributed to her daughter's survival.

Rae explained her daughter's symptoms using an everyday 'netball' simile but

described the cancer in medical terms of 'metastases and abdominal cavity'. In

doing so, she constructed meaning of her daughter's cancer by drawing on both

her carer and nursing knowledge and enacted roles in which she was immersed in

the world of paediatric oncology.

The treatment phase was also characterised by the strategies participants used to

incorporate medical knowledge into their own everyday understandings; much of

which was expressed by combining the language of statistics and chance. Carers

were informed by clinicians of the medical probability of their child achieving

remission and long-term survival according to various malignancy, site and growth of cancer. As such, carers' immediate concerns were to make sense of medical statistics to determine the chances of their child's immediate survival; as Victoria explained: 'It was a 90% chance [of her child's survival], but we didn't know that we won't be that small percentage'. Magda was initially told not to expect her nine-month-old daughter to survive cancer or live to her first birthday. Michelle was told of a '10 to 30 per cent' long-term survival' chance for her 12 year old child. Carers of children with leukaemia spoke of 70 to 80 per cent survival prognosis. Molly was given a '98 per cent success rate' for her child surviving hepatablastoma. Participants interpreted these percentages and evaluated clinical explanations in order to instill a sense of hope in their child's survival. Lee explained:

> I remember I used to hang on to their every word and analyse it and think that's not good … but if there was something, a little bit of positive in there where they can talk about when you get to that stage where your child is past that point, as a parent, it gives you a bit of understanding of what you have to go through.

Acquiring medical knowledge was also important because it enabled carers to understand their child's diagnosis and to deal with medical regimes. Adam discussed his need to know his daughter's survival chances:

> The doctors told us about the percentages and we needed that, we needed information, it didn't matter if it was bad information, we weren't so scared of bad news but we needed to know. If something was bad we wanted to know about it so we could get our heads around it and work out what to do and know what happens next, we didn't want to be softened or mollycoddled at all.

Adam's refusal to be insulated from medical information, whether positive or negative, illustrates his need of knowledge to help him construct a meaningful understanding of his child's condition and his own situation.

Participants (n=5) with health careers drew on their carer and professional knowledge and discussed how they had initial trust in their child's medical intervention. These carers also had to explicitly define their situation to health professionals as carers rather than carer-clinicians. William for example has a health science career and spoke with an initial high degree of confidence in his child's clinicians: 'We felt like we were safe and we trusted them'. Grace explained having 'a lot of faith in the [health] system' but refused to use her nursing skills for even basic treatment like dressing wounds. She described how being a nurse gave her insights into her child's treatment protocols, 'but it doesn't change the fact that this is your child who you can't fix, which is a huge thing and suddenly [you] have to hand her to someone else and say fix her because I can't, so you're very vulnerable as well'. Elizabeth clearly prioritised her identity as a mother more than her professional identity as a doctor:

> We kind of understood everything, which was, kind of, can be very helpful in some ways, like there's not a nasty shock in terms of you know what to expect, however you also know all the bad stuff. But you just want to be treated as a parent not a doctor but … you get what's going on, you get the risk as well as the side effects.

Drawing on their medical knowledge was instrumental in ensuring these carers had a sense of trust in their child's treatment. Their concerns, however, were to ensure clinicians treated them as carer despite their medical careers. However,

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the majority of carers described having limited medical knowledge and learning to develop trust in their child's clinicians and treatment processes.

The findings illustrate the early treatment phase represents a period of disrupted normality, certainty and control. However, carers responded to being a carer of a child with cancer by accepting their limited capacity to protect their child and developing a degree of trust in specialist medical care. They attempted to restore a sense of control by seeking and applying medical knowledge into their own understandings and practices, and by strategically staying close to their child and constantly monitoring their child and clinical practices. Carers then started to normalise the treatment process with the realisation of their child's potential non-fatal outcome, and becoming a carer of a child with cancer.

Treatment: Responding to disruption

While carers became more familiar with the treatment processes and adapting to hospital regimes, the uncertainty of their child's cancer outcome remained a central concern. Carers developed strategies and active partnerships with medicine to maintain the well-being of their child. In doing so, they orientated their everyday lives with a more purposeful direction than that associated with loss and shock at diagnosis. They described various chemotherapy radiation and/or surgery protocols as sinister and invasive but necessary to sustain their child's life. Tom explained how his daughter's osteosarcoma involved 'up to 20-something operations. Some are big and some are small but they all have to be

done, screws in-screws out, plates in-plates out … we've got that used to it, you just get on with it'. Tom's approach typified all the participants who attempted to normalise their abnormal situation by constructing cancer treatment as a necessary process, and separating treatment from the disease itself. Partitioning the actual treatment process established a focal point of meaning that was not directly defined by cancer *per se*. Carers constantly defined their situation with the possessive pronoun 'we' and referred to being centrally situated within their child's cancer treatment with phrases such as *we* had cancer, *we* had chemo and radiation, *we* had surgery, *we* finished treatment and *we* survived. This intimacy and connectedness of carer/child relationships through cancer also demonstrates that carers' identities are deeply embedded to that of their child.

Earlier in this chapter I described the situation of participants with health careers emphasising their carer identities and roles in dealing with clinicians through treatment. But carers without medical knowledge described taking a more active pseudo-nursing role through treatment as a source of empowerment and control. Tom explained, 'I never used to let the nurses do anything except the medication so I'd shower her, make her bed and absolutely everything for her'. Cheslea took much control in organising her child's treatment:

> I use to prepare [child's] medicines myself, we'd go down onto the ward and I'd have them all prepared when she was having the tablet form of chemo. I used to make it up in syringes. I'd put the tablet inside the syringe and then draw the quick into the syringe and it would dissolve within it, you know, in the syringe and I used to prepare it like that, in advance. I used to like to take control of things myself in that way and I'd go into the ward and the girls [nurses] used to say, 'Oh she's alright, let her go, she's all organised', you know, and I used to like to take charge sort of thing.

Chelsea's spoke of being a proactive health care contributor during treatment and of nurses who trusted her in this capacity. She also spent much effort to observe and record minute details through her child's treatment as a personal diary:

> You are so helpless and there's not a darn thing you can do about it, you can't make it better, all you can do is to make sure you're on to everything and nothing gets missed. No one knows, I mean the nurse and the doctors they've got God knows how many patients, you've only got one so you can be onto everything, I kept a diary and I used to write all the temperatures down and everything, so if anyone had a question, if the doctors had a question back in [home town] or something that had happened in Sydney I'd just look through my book and say, well this is what happened on that day and this is what the temps were, I would just know absolutely everything and in my way of thinking that would help … if that was only ever used twice then it was worth doing that. All the time you sit around on the ward and you know keeping notes was nothing really.

Chelsea incorporated the care and comfort of her daughter with ongoing child and clinical supervision and documentation through the two years of her child's leukaemia treatment. She described her surveillance and recording practices as 'nothing really' yet emphasised the value of her diary: as a personal journal, an extended medical resource in case of clinical errors and a treatment reference for metropolitan and regional clinicians. Chelsea therefore integrated her cancer treatment knowledge and surveillance practices into a new form of expertise as a carer-pseudo-nurse identity.

Participants spoke of coming to terms with clinical intervention to sustain their child's life, but found it difficult to accept chemotherapy injected into their child's body, despite knowing it would potentially save their child's life. As Dave explained: 'It's not a win-win with chemotherapy treatment, they load them

up with poison, that's the thing, but she's alive but not without costs'. Molly described the surreal experience of beginning the treatment process:

> The first time they hooked up chemo: 'Is her hair going to fall out'? What a vain question. The other thing was walking into the cancer ward, it was the most confronting experience because you see the kids without hair, hooked up to drips and nasal gastric tubes … very confronting knowing this is in front of us and this is going to be your life.

Louise saw the necessity of chemotherapy to save her child but treatment nevertheless contradicted her beliefs:

> I never use drugs ever; I'm not into doctors and giving my son all the chemo was like direct poison. I'm into natural therapies and healthy foods and have been raised that way. For [child] to have chemo was horrendous, it was a nightmare for me to let them inject that stuff into him when they had never had any chemical in their bodies aside from natural therapies. The nurses would dress up in these space suits, the purple chemo gloves, glasses and head thing on and looked like a spaceman and I took a photo, I took photos all the way through and I couldn't believe … this is wrong like she doesn't want to get a drop on her yet she's putting it into his veins …

Adam recalled his daughter's chemotherapy treatment by its toxic smell:

> You're not allowed anywhere near the stuff … when we'd put a potty under the toilet to collect urine to test, the fumes coming off it would make your eyes water.

George similarly thought his daughter 'just smelt of death'. Raul described his child's treatment in sheer volume of procedures, with '78 general anesthetics, 300 injections and that sort of thing, but we just did what we had to do'.

Carers spoke of cancer as abnormal and being out of control, but mothers in particular drew on their intuitive knowledge to affirm their maternal roles through the treatment period. Natalie had her baby diagnosed with neuroblastoma at 13-

weeks-of-age. She ironically described the difference between her maternal expectation and the reality of having a baby with cancer as 'welcome to motherhood'. Lee spoke of the 'absolute unfairness' of having her newborn baby diagnosed and feeling 'like a black hole you get thrown into and you don't know if you're going to keep going down and never get out'. Two mothers gave birth while their other child was being treated. Mary recalled:

> At the early time it is so all consuming, but you just get on with it, we actually had a baby in the middle of it, that's what was going on with us. At the time it seemed like a good idea and three to four hours later it seemed like a really bad idea.

Similarly, Eve accommodated the birth of her newborn while maintaining care of her other child on cancer treatment:

> Well, I went into labour in the kid's ward and the nurse panicked and said you must go up to the delivery ward … I said I can't and had to wait for my husband to get here. It was all right; I waddled up the corridor to the delivery ward, had my baby and came back.

In hearing Mary's and Eve's accounts I mentioned the rich imagery of creating a new life in the context of cancer with its threat of death and hope of survival. However, they both emphasised the birth of their child as a special event in their lives, but still normal despite their cancer related situation. Michelle stated the importance of breastfeeding her baby through her older child's treatment:

> So I'd go home and I'd express milk because I just … I could have gone onto a bottle and it's just on my mind it's only your second baby. I wanted to do the right thing and I don't know how I did it but eventually he got back on and we breastfed until 13 months so you know that's a credit to me as well.

Breastfeeding represents an important everyday care practice in order for Michelle to have a sense of control and normality in her nurturing capacity, while caring for her other child as clinicians instigated chemotherapy, a bone-marrow transplant, radiation and surgery protocols.

The treatment period also sheds light on how traditional gender roles are intensified and reinforced (Young et al. 2002; Chesler and Parry 2001). The number of mothers who participated, and their responses, reflect that the majority of childcare tasks through treatment were mainly performed as maternal care roles. Mothers spoke of both having and needing to do the majority of childcare. Natalie, for example, explained that 'when it comes to one of the kids being sick, its Ostrich Syndrome, he [husband] just puts his head in the sand and hopes everything will go away'. Mary discussed her role as her family's primary care-giver through her child's leukaemia treatment:

> I think a woman's place in the family dynamic is usually one as the major care-giver but it perhaps reinforced that in our family because my husband had to continue going to work so the endless trips to hospital and the day to day medication and stuff fell on me … it just reinforced the natural order of things.

Eve said her husband was supportive through their daughter's treatment but nevertheless felt a responsibility to stay beside her child: 'We didn't leave her side, through the day my husband was there as much as I was. I guess it was a control thing, I couldn't let her out of my sight'. Eve's need to stay constantly close to her child symbolises the importance she gives to her care role and maternal identity.

Fathers discussed how their child's cancer was a catalyst for greater involvement

in family life. Dave noted that the threat of cancer made him re-evaluate his pre-

cancer taken-for-granted assumptions by becoming more focused and concerned

to spend more time with his children:

> Your house, your job, all those things were important and you think the family
> unit is just rolling along, when something like this [child's cancer] happens, well,
> it changed my focus on everything. My kids are more important to me than
> anything now.

Fathers also described 'tag-teaming' in which at least one parent was constantly

beside their child. Tom and his wife maintained a 24/7 vigil and 'anytime she

woke up I was there. My wife and I used to do a day each and swap over,

sometimes doing that for a month straight'. Anne and her husband developed

similar strategies through treatment:

> I used to do the day and dad [husband] would work, then he would come of a
> night which meant I would come home and be at home, one of the boys was still
> here, so in a sense I could not so much switch off but put it a step away and by
> the morning I was ready to go again, it worked quite well … I just needed my
> privacy, to come home at the end of each day and do my own thing was my way
> of proving everything's normal.

With some carers, however, home and hospital distances, as well as work and

other family commitments prevented shared childcare arrangement through

cancer treatment. Raul felt separated from his family through treatment:

> Not actually being there for a lot of it [treatment], that was tough as well, you
> would rather be standing there next to them than on the job laying bricks. So
> that was a major difference between her and I, she was doing it tough seeing that
> side of it whereas I was doing it tough not seeing it.

These findings are consistent with other childhood cancer research showing traditional gendered trends where mothers provide the majority of childcare labour and maternal roles are reinforced while fathers act in both childcare support and bread-winner roles (Young et al. 2002; Chesler and Parry 2001). Although both mothers and fathers enacted traditional but intensive childcare practices through treatment, the findings indicate that fathers underwent a shift in being more aware and involved with their family, but mothers nevertheless did the majority of labour associated with being a carer of a child with cancer.

Carers responded to the disruption of childhood cancer by being deliberately and centrally involved in their child's treatment processes; providing their child with comfort and support, but also as proficient pseudo-nurses with acquired monitoring treatment practices. The findings show that childhood cancer treatment profoundly disrupts carers' taken-for-granted assumptions of childcare but they construct new meanings and new ways to deal with their radically altered situation. Co-existing with their cancer experiences were the tensions of reconciling the toxicity of chemotherapy being administered to their child with its potentially life-saving effects.

Normalising the disruption of treatment

Through the treatment period carers described their lives as fundamentally new. Their environment was reduced to the immediate confines of the hospital ward.

Their everyday tasks were centrally based on responding to their child and dealing with treatment procedures, while realising their prior life plans and taken-for-granted assumptions were no longer tenable. Eve explained her new definition of self and situation: 'You're actually starting a whole new life because your outlook has changed, your perception has changed, the health of your child has changed forever'. Participants frequently discussed the need to 'live in the moment' and respond to their child's immediate needs, along with medical procedures, pathology tests and scans. Lee's account is typical of those who described how cancer and treatment disrupted future plans: 'I don't see too far into the future, you know when you look at your kids and imagine them when they're older, I don't do that, I don't have that power any more'. Lee could no longer take for granted that her child would become an adult in the future.

Everyday relationships were disrupted during treatment due to the dislocation from home and community to hospital. Some carers adopted social avoidance strategies because of their child's suppressed immunity while on chemotherapy treatment as everyday childhood viruses like measles and chicken pox became life-threatening conditions. Victoria imposed a partial quarantine to protect her child from potential viral infections:

> I didn't want her to be around people who might give her something, but I would never say not to come. Those two years [of chemotherapy treatment], like, we'd go to the park and the minute someone turned up we'd go, because I didn't want to get a virus so we'd just casually take ourselves away from people. So in a sense that's what we had to do, that's with strangers, but with people that we knew, they were welcome to [come in] but the sign on the door meant you respect our particular circumstances.

Victoria enacted a particular gate-keeping role as a way to protect her immune-suppressed child through cancer treatment. She constructed people in public with a stranger-equals-danger perspective who could potentially contaminate her child, yet more familiar others had conditional entry into her private quarantined realm. Victoria's partial isolation was a necessary child protection strategy.

Carers also defined the treatment phase as a process to endure. They gave medical scans and pathology test important meaning as markers of successful life-saving treatment. Angela drew on an everyday shopping metaphor to represent treatment as a new normal part of her everyday life:

> I think once you knew what you had to do, and they [medicine] mapped out what was planned, I felt a lot better about it. Once she had that protocol and you knew where you had to go and what you had to do, I think that was more calming for me … initially you think, shit, does this mean she's going to die and all those worries but then it got into a routine of doing stuff, which was our life. Instead of going grocery shopping, we used to go to the hospital and have chemotherapy, we adjusted to it because you don't really have a choice and that's what we did.

Angela's strategies to normalise her child's cancer as a treatment process gave her the focus in which to persevere and normalise her situation. Natalie implemented a 'No Cry Zone' sign on the hospital ward door to conceal negative emotions from her child. Annie used humour to normalise hospital life:

> She'd just got her hair and then she lost it, so we used to put sticky tape in where it was coming off, then she'd do it in the mirror, it was pig tails today or pony tails … it is still going to be horrible so you may as well get some fun out of it yourself.

Carers constructed significantly new perspectives to their everyday lives. Grace gave new meaning to what a 'good day' meant through her daughter's treatment:

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> A good day was if she smiled, a good day was if she didn't throw up [vomit], we're talking the first six months which is so intense because the cycles of chemo are just so powerful, when they get on to maintenance treatment for the last 18 months I found a sense of normalcy.

Grace initially focused her definition of a normal everyday life on the immediacy of her daughter's simple gestures and reactions to chemotherapy, then constructed a new sense of normal as the treatment intensity lessened.

Carers also dealt with disruptions to their child's cancer treatment through shared interactions with clinicians and other carers and children in hospital. They spoke of developing close relationships with clinicians and nurses, including those mentioned earlier who were critical of their GP's role in their child's late diagnosis. Lee described clinicians as a source of security through treatment: 'The nurses had become like family, the doctors you know, we felt safe when we were at the hospital'. Similarly, 15 years after cancer, Angela said that 'the surgeon she [daughter] had, I will adore to the end of my days'.

Participants described the importance of close and lasting 'cancer friends' and 'hospital friends'. Angela spoke of the importance of sharing the cancer journey:

> We went through something together and that tends to be like that, the people that are diagnosed around you, you get a close friendship with, although I have a very close friendship with a lady whose daughter wasn't even on treatment when we were, her child had died and we just clicked for some reason. She came into a support group and I was in awe of how she had dealt with her child's illness and her death, and we became great friends from that, it's the shared experience.

For Angela, having a shared experience with other parents was an important way of getting through the ordeals of treatment, and friendships built on the intensity of the experience were ongoing even when circumstances changed. Edele called this shared connection a 'thread':

> Once the shock wore off one of the things for me was the overwhelming feeling of hope and positivity within what I call the community at [hospital], in the ward and at out-patients, going back and forth for treatment. You might not know people's names but you are bonded by this, whatever kind of cancer you have, you're bonded by this bizarre thread … I'm not sure what you call it … 'a thread' and 'how are you going, what are the blood counts and so on'. You share this language and bizarre way of looking at the world. So as stressful as it was, once you got the information about how you are going to proceed forward, like this bad thing has happened, this is how we're going to deal with it, it was a very positive experience in lots of ways and lots of love, compassion and caring by other families and nurses and medical staff.

A sad but important aspect of getting through the treatment phase was the realisation that some children would not survive. Several carers acknowledged the children they met through cancer and made particular reference to naming children who died and sharing their grief with other carers. Lee recalled a child who died: 'then they [family] all left and the ward people came to take her away, it was here one minute and gone the next, on a cold silver trolley'. In attending child funerals, Victoria felt both guilty and grateful in her child's survival:

> We've been so close to people who have lost their children. Like, in the short time we were there, I think I went to four funerals and also in a sense you do feel a bit guilty that your child survived because you know there's someone in the next room that you know are dying … I'm just so lucky for what I have.

Joe developed a new awareness of his son's understanding of death through attending child funerals. He reflected on his child's wishes and the friendships with families of deceased children that had stemmed from the oncology ward:

> I remember his reactions to friends dying and that sort of thing which kids aren't supposed to, like kids two and three years old, they aren't supposed to understand death but he certainly did, he had a couple of really good friends die, I think he went to his first funeral at about four years of age, a good friend, we didn't want to take him but he wanted to go.

Michelle similarly spoke of the loss of other children as an ongoing form of guilt:

> You feel guilty when friends' children die and we've seen a lot of death as well. As a matter of fact a friend of ours now, her little girl is dying of a brain tumour. I've got to be there and support her and yet I've got a happy ending and she's not going to have a happy ending so it makes me feel angry too and guilty, guilty that my child survived and hers isn't going to. I've got a lot of, yeah, you feel guilt too. When you've still got, when you've got the survivor, you feel guilt too.

The findings illustrate that carers develop particularly intimate relationships with similar others during treatment. Participants sat beside their child's bed for months at a time and with little respite. Beside them, other family groups were in a similar situation of uncertainty while hoping for their child's survival, but with the presence of other children who died. A child's death further intensifies carers' experiences; through grieving for family members of a child who died, yet also grateful their respective child was alive. The death of other children starkly symbolises the threat and potential loss of carers own child.

Carers defined the treatment period as a process to accept, deal with and get through. They developed new ways to normalise the disruption of control and certainty by becoming immersed in their child's treatment and the processes of monitoring, seeking information and interacting with clinicians and similar others. Carers' responses represent 'attempts to normalise in the face of disruption', albeit with new definitions of their situation, new taken-for-granted

assumptions and mobilising new resources through treatment (Bury 1982). The

next phase, with successful treatment, involves carers shifting from paediatric

oncology to the non-medical world of everyday life.

Transition: Returning to a world of everyday life

The transition of leaving hospital represents the genesis of life after childhood

cancer. The transition is less urgent than diagnosis or treatment phases but the

findings illustrate ongoing disruptions as carers start to construct their lives after

cancer without the immediacy of medical support. They also re-enter the world

of others who have little understanding of their experiences. They experienced

the transition as an abrupt break from what had become their 'hospital normal'

routines. Raul, for example, described the transition with a sense of loss:

> In that two-and-a-half years [of treatment] I think three days was the longest stay
> at home, so that [treatment period] was our life for a few years. When we left
> there, you're glad to be finished but it certainly left a bit of a hole, like the rest of
> your friends and family have gotten on and continued their life, but we're driving
> home thinking: What do we do now?

During the treatment phase carers focused on their child's remission and the

prospect of leaving the medical world. When the transition eventuated, carers

spoke of a sudden abandonment from the securities of hospital routines,

pathology results and clinical affirmation of their child's cancer being under

medical control. Anne remembered leaving the medical world as 'a pretty sharp

break: on the one hand we were rapt because we could watch her week by week

getting better, on the other hand I felt a bit like I was just chopped off and left'.

Lee felt 'like your umbilical cord has been cut and you're floating around all alone, you've relied on these people, they're your help, your saviours and then they're not there, it's a very scary feeling'. Ruby emphasised feeling the loss of security from regular health checks to confirm her child's health status:

> A scary thing, not having those regular checks, hoping nothing is happening, no one monitoring it closely, so you do feel very lost and left to your own devices to a certain extent, hoping everything is clear when you come back in another month or three months, you're sort of abandoned even though you know you're not, you have to learn to float on your own.

Molly anticipated leaving hospital but suddenly realised that life after cancer involved ongoing uncertainties. She then saw remission as an ongoing process:

> The day you finish treatment, I couldn't wait because this is it, it's like this red dot on the calendar, and I can always remember that last day, leaving the hospital and thinking, 'This is not the end', you know, you're looking forward to that last day but really, it's never the last day and you realise there is no guarantee. It took me to the last day to realise 'Oh my God, it's always there'. That day I walked out: 'You bloody idiot, it is not really over', as much as you want it to be … Coming back to that red dot on the calendar, that's not the end of the journey, the journey changes but it's not an end … you're like a bit of an iceberg, it gets warmer and therefore the chance of seeing another iceberg gets less and less.

Molly's melting iceberg metaphor represents diminishing uncertainty over time and a sense of hope for a life without childhood cancer. Participants also explained the transition as a social loss from the immediacy of similar other carers. Ruby, for instance reoriented new meaning to her definition of a family by incorporating her 'cancer family' with her immediate family:

> Other families that you meet along the way as well, it's very hard to explain, your life totally changes as you've known it and takes on a totally new concept as far as what family is. You get a lot of support from immediate family but not like at hospital.

Margie compared her hospital arrival and departure experiences: 'I think they've got better at preparing people for when they arrive at the hospital, but they don't really tell you about the departure and the letting go part'.

With the abatement of cancer, the journey back into everyday life gave carers the opportunity to evaluate their own well-being after the protracted treatment period. Several carers felt physically and emotionally depleted and of needing a period of restoration. Louise explained how hospital staff supported carers entering the medical world with their children but thought they were inadequate in preparing them for the departure:

> They have the hospital part worked out so well and it's so good and so comforting and caring that to leave it is devastating, it's very scary. Other mums talk about this too; we all speak of the same thing. You're knocked about and bruised because your emotions are so drained and you run on adrenalin, you're so tired for the months and months of chemo, there's this huge load that can set in straight away or later, you're just lost for a bit and it takes a while to kickstart yourself because your routine is hospital, running around madly trying to get everything ready for the kids at home, then a mad dash to the hospital at two in the morning, then all of a sudden, what do you do with your life, you can't go back to work because you don't feel comfortable, it's an amazing drain and change, I remember getting really sick afterwards, a really bad flu it was like I wasn't allowed to get sick for so long, then all of I a sudden I felt really tired.

Similarly, Emma speaks of being physically and emotionally fatigued:

> I was so incredibly tired and my husband got it too, just burn-out, he couldn't cope with his work, tired all the time and … our local doctor is our friend and he just said you've allowed yourself now to fall to pieces, you couldn't allow yourself to for all that time and pushed yourself to the limit, now everything is OK so you're indulging yourself basically. You hold it together for so long then you need a break.

Carers therefore describe living at an intense level for an extended treatment period and needing respite and a period of time adjust to an everyday life after

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cancer. Yet they were advised by clinicians and significant others to return to a normal life. Carers also realised that they needed to consider and respond to their own well-being as instrumental in the ongoing care of a child in remission.

Remission also required carers to reconcile their childhood cancer experiences in a way that made sense to them, while interacting with extended family members and colleagues who had not had the same experiences, but with the expectation of returning to pre-cancer normal (Becker 1997; Stacey 1997). Bury's (1991: 456) concept of legitimation explains this trend where carers seek to 'repair disruption, and to establish a legitimate place' in which to give meaning to their experiences. Dave explained the discord between his own definition of the situation and the expectations of others in a remission context:

> The silly thing is, it comes back to people outside your family circle looking at [daughter] and saying, 'She's all better, let's have a party, it's all finished, it's all better'. Well guess what, Dad and Mum have copped this emotionally, belted to the shithouse and you are living it. It might look all rosy on the outside front, it's not like you chop your arm off and it's finished with, but it's not finished. It took us a long time to recover everywhere, financially, emotionally, trying to get some normality back into your routine.

Dave was acutely aware of how his new worldview, which now encompassed cancer experiences and having his child in remission, differed from the taken-for-granted assumptions of others. Similarly, Marilyn felt compelled to return to a sense of normal but said how: 'People who don't go through anything like this, they don't understand, it [child's hair] is not a visual reminder for them, they don't see the things that go on underneath, with what you're left with'.

Participants talked of the tensions of reconciling their own experiences yet felt compelled to be openly grateful that their child survived and, 'get on with their lives'. Louise explained the ongoing disruption of her everyday interaction as others having little understanding of her experiences: 'They can't fathom it ... if you actually have a talk to them, they're truly shocked, like they could have known you for years and known you were going through it but until you talk about it they can't comprehend it'. She negotiated everyday discussions away from cancer in a way to normalise interactions:

> I don't really talk to anyone about it now, and I used to talk to a couple of friends but no one really wanted to talk about, like, who wasn't part of it, no one … they know that [cancer] happened, they know that it's there and after it's finished they ask 'How is he is he well?', and you just go, 'Yeah' … and that's it, they don't know what to say and you don't want them to say something that is really stupid anyway… it always comes across as trivial, they don't get it.

Louise's account represents the 'disjunction between the definition of the situation held by self and others' (Bury 1991: 456).

Other participants celebrated the end of cancer. Magda and George were initially given little hope of their child surviving cancer so with their family and friends they celebrated with a 'made it' party. Raul and Angela organised a post-cancer celebration with family, friends and their child's treatment team:

> We invited virtually every nurse and doctor we could …they were blown away because they had gone to a lot of funerals but never to one of these, we had gifts for all of them because what they did was far beyond their job. And our surgeon, to this day I still owe the surgeon because nothing else was working and he did the surgery and got rid of it, so to me, he saved her life, To have him there and present him with gifts was all very emotional. My wife and I were both bawling and half the people there were bawling, but it was such a great night.

Emma described how a family holiday symbolically represented the end of cancer: 'We hadn't had a break in that two-and-a-half years and that was our marker, this was the end of that life and now we're starting a new life'. Freda and her family had an extended European holiday to recuperate and 'get away from the whole sickness thing'. Grace ritually purged her home of cancer after a post-cancer holiday:

> When we came back from the States [US] it was like it was over, it felt quite good, we went through the medicine cupboard, we threw everything out and for her that was really good, she just stood there and put everything in the bin and just laughed.

Carers evaluate the transition as the symbolic start of an important new life phase; marked by both uncertainty and the hopeful closure of childhood cancer. In doing so carers began to establish 'an acceptable and legitimate place' for cancer and remission in their lives (Bury 1991: 456).

Conclusion

The findings in this chapter revealed that biographical disruption was an appropriate framework; all 38 carers spoke of having a child diagnosed and treated for cancer as a profound shift from their pre-cancer taken-for-granted assumptions of control and certainty of their child's well-being. Their accounts resonate with the need to construct a more viable explanation in being carers of a child with cancer. The 'mobilisation of resources in facing an altered situation' was clearly evident as carers sought clinical interventions through GPs and medical specialists, and redefined their roles and identities as carers, advocates,

guardians and pseudo nurses. Unlike the findings in recent study (Sanderson et al. 2011), the concept of biographical disruption was universal in this study. Carers sought to reconcile the disruption of their child's cancer with new meanings and responses through treatment: by accepting their limited control, developing partnerships with clinicians and incorporating multiple care, guardianship, surveillance, knowledge-seeking and pseudo-nursing tasks. Hence, carers interpreted childhood cancer as a fearful and intensive life-changing event at diagnosis that became a process involving multiple meanings and changing care practices through the treatment period. They marked the transition with trepidation due to the loss of clinical securities, but also as the start of a hopeful life in being a carer of a child in remission.

The findings also support the concept of 'new normal', although in its genesis, to represent ways in which carers constructed a new sense of normality through the experience of being a carer of a child with cancer. However, the concept of new normal developed in this thesis differs from the scholarship of Clarke-Steffen (1997) and Earle et al. (2006), whose concept of new normal was limited to the early diagnosis period of cancer. In Chapter Six I illustrate the ongoing process of being a primary carer of a child in remission. I develop the concept of 'new normal' to represent how carers define their current lives as fundamentally distinct from their pre-cancer lives, with new identities, meanings and practices.

Chapter Six: Life in the cancer shadows

Introduction

In the previous chapter I argued that primary carers responded in new ways to being a carer of a child with cancer. With remission, however, cancer retains an ongoing presence in carers' lives as typified by Dave: 'I don't think it [cancer] will ever go away for us, it never will, we will always have that shadow of doubt there, probably even to the day you die'. In this chapter I argue that carers construct a new sense of normality with new meanings of uncertainty and hope, and develop new strategies and practices to mitigate the impact of cancer. In doing so, the concept of new normal represents the social processes to being a carer of a child in remission. The findings demonstrate that carers emphasise their everyday lives rather than cancer *per se*, but the threat of cancer retains a lurking presence.

The chapter explores three pertinent themes that emerged through analysis to represent how carers defined and constructed their lives with the abatement of their child's cancer. I begin by explaining how cancer experiences cast an ongoing but variable presence in carers' lives, and represented as light, moderate and dark 'cancer shadows'. I draw on the accounts of three participants to typify this variation. Second, all carers discussed their current identities and situations as fundamentally different to their lives before cancer. The findings illustrate that being a carer of a child in remission involves constructing a new sense of self in

the context of chronic cancer related uncertainties; and with a new and meaningful post-cancer discourse characterised by hope, luck and faith and a new sense of temporality. Third, I examine how carers mediate their new selves with significant and generalised others and their sense of commitment to the cancer community. The findings in this chapter therefore combine to represent how carers define and give meaning to their self and situation in the aftermath of childhood cancer as a new sense of normality.

The new normal with cancer shadows

The concept of new normal emerged to represent the central data category. The concept captures the frequency with which participants defined their prior self-concepts and taken-for-granted assumptions as radically disrupted.   Margie was typical of participants who spoke of the extent of disruption from her pre-cancer life: 'You grieve because you've lost your life and you know it'. In response to having their lives radically altered, Grace typified carers' responses to the childhood cancer disruption by explaining her everyday lives after cancer as 'a completely new sense of normal'. The new definition of normality represents ways in which carers describe their self and situation in response to the accumulative impact of childhood cancer, their current context of being carers of children in remission and distinct from their pre-cancer lives. The concept of new normal therefore supports the scholarship of Clarke-Steffen (1997) and Earle et al. (2006) and extends it into childhood cancer remission.

The concept of new normal weaves together the dynamic and ongoing social process of carers' shaping their identities in such a way to de-emphasise cancer and focus on their everyday lives. Yet cancer retains an ongoing presence of insidious memories, an acute awareness of potential cancer relapses, secondary cancers and treatment morbidities which shape their lives. The concept represents an intersection of meaning amid cancer experiences, uncertainties and hope for a future without cancer. Carers negotiate new meanings between uncertainty and hope and continue to acquire cancer information in readiness should cancer return. They emphasise a new immediacy of everyday life as their past taken-for-granted assumptions were severely disrupted and futures are unknown entities.

The concept of new normal therefore encompasses ways in which carers construct a particular discourse to define their own situation and the lives of their children as subject to the vagaries of fate. They also negotiate their new self-concepts and new definitions of normality through interactions with significant and generalised others, and with a particular sense of belonging to a cancer community of similar others. Carers adapt and make a meaningful life after their child's cancer, although different from their previous lives and different from the expectations of others who have not had a similar cancer experience. The concept of new normal thus conveys the ongoing interpretations and responses of being a primary carer of a child in remission.

The concept of new normal also represents diversity; as carers evaluate cancer experiences retaining an ongoing presence, and a future shaped by fundamental uncertainty, but also with hope for a cancer-free future. To capture this variation I categorised the participants on a continuum of light, moderate and dark cancer shadows to represent the extent to which cancer experiences retaining an ongoing presence. I chose the following three participants who typify carers who spoke about the range of cancer related concerns to impacting on their lives after its abatement. For the remainder of this chapter I flag participants with [1], [2] or [3] to represent light, moderate or dark shadow categories respectively. The 'shadow' categories represent the ongoing disruption, significance and consequences of childhood cancer in the lives of carers of a child in remission (Bury 1982, 1991).

New normal with light cancer shadows

I chose as Mary [1] to represent participants (n=21) who define childhood cancer as a significant event but with minor ongoing consequences. Cancer therefore casts a light cancer shadow in their current everyday lives. Mary is married, 40 years of age and her two-year-old son was diagnosed with leukaemia 14 years ago and treated with chemotherapy and radiation over a two-year period. She described the experience of diagnosis as 'a shock, I kept waiting for someone to say they'd made a mistake', spoke of the treatment as 'just being there, all the time in the hospital' and the transition of leaving hospital as 'a sever' to represent

the sudden separation from specialist medical care. Mary spoke of her son's current health as 'very well and strangely enough, apart from having cancer, he was surprisingly well through the whole [treatment] process'. Mary therefore constructs her experiences through her child's cancer as a significant event, but with relatively few consequences through treatment of after remission.

She described how the threat of a cancer relapse 'just lurks in the back of your mind' but emphasised her son as being 'completely and utterly together, very self-confident and very healthy'. Mary enacts a subtle 'alert assistant' (Williams 2000b) strategy by emphasising that she doesn't 'coddle' her son; but said 'I still think more carefully when he says he doesn't feel well … you stop and ask some more in-depth questions'. She also 'asks him if he needs to see a doctor because he's a teenager now'. Mary located cancer as a past event and attempted to transcend the past from her current context:

> When he was sick, that was our life, so in our memory it was 'that's when he was sick or afterwards'. You kind of relate to things backwards in your life to things like that. That's how you mark your life, even though that was a small portion of his life in comparison to how old he is now; almost everything relates back to it at some point.

Mary conveyed an ongoing tension in defining cancer in the background of everyday life, yet claimed 'almost everything' in her current life related in some way to her experiences through cancer. Cancer retains an ongoing presence to an extent that Mary considers her current life as still evolving from the cancer period, despite her son having few ongoing health concerns.

Mary's account typified participants in this category who spoke of childhood cancer as a significance phase of their lives, by locating cancer in its past context, while cancer experiences continue to cast a light shadow that requires ongoing interpretation. Her account starts to build on the concept of new normal by recognising how cancer experiences retain a significance presence in being a carer of a child in remission, in spite of few ongoing cancer related consequences.

New normal with moderate cancer shadows

I chose Dave [2] to represent 'moderate shadow' participants (n=13) as his account represents carers who spoke of cancer casting a stronger presence and a higher degree of uncertainty in their lives than those in the previous category. Dave is married, 43 years of age and lives in a regional area two hour's drive from the hospital where his child was treated. His four year old daughter was eventually diagnosed, after several GP consultations, with a 'very advanced' germ cell tumour and secondary tumours in 2004. He said that despite his child's current remission status, the late diagnosis had increased her chances of relapsing: 'There's no guarantee with her prognosis. They [clinicians] were sure they could cure her of cancer but the odds were diminished in it not coming back because of the delayed diagnosis'. His daughter was treated with chemotherapy and surgery over a six month period and has hearing loss as a result of treatment. Dave spoke of his child's as currently healthy and 'running races, trying hard at school and she's a normal eight-year-old' but cancer retained an ongoing uncertainty:

> It's not like once it's gone it's not going to come back, or an operation where once your arm is cut off it's finished. It's [cancer] a black cloud above your head, because it sneaks up on you, you're always wary, you don't want to be caught again.

Dave defined his child's cancer remission with fundamental uncertainties with a possible relapse, secondary cancers or the long-term effects of treatment. He also spoke of life after cancer in coming to accept that control of his daughter's life and well-being (and perhaps control of life in general) is an illusion:

> I think that changes your whole outlook on life because you realise that nothing is in your control any more. When you accept that, you are a little bit more at peace, it changes your values and you're more accepting of what happens now.

Through accepting the limited control of his daughter's health, Dave importantly recognised how the immediate the threat of cancer was starting to diminish:

> The light starts to get brighter and your days are brighter and you start to see the big positives and no one is sick and they [children] are growing up in front of your eyes. When you see that, you start to realise that one part of the journey is finished, and hopefully the worst of it.

Dave draws on dark/light metaphors to define his current context of moving from uncertainty to a realm more focused with hope in seeing his daughter develop. His account typified participants in this moderate shadow category: of cancer experiences retaining an ongoing and immediate presence, but also the genesis of constructing new meanings to reconcile ongoing cancer related uncertainty with a hopeful future. The concept of new normal therefore represents ways in which carers define their selves and situations as fundamentally changed from their pre-cancer lives, with a greater awareness of cancer and new meanings uncertainty

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and hope. Cancer retains an ongoing presence but its moderate impact varies as carers consider and hope that cancer will be not impact on their current lives.

New normal with dark cancer shadows

In contrast, carers living with dark cancer shadows spoke of their current selves and situations as radically and permanently altered.   Michelle [3] represents a small number of participants (n=4) whose new normal was shaped by her child's cancer casting a dark, ongoing shadow. Michelle is 42 years of age, married, lived in a regional area of Queensland but had to relocate to a Brisbane hospital for the duration of her child's treatment. Her two-year-old son was diagnosed with neuroblastoma in 1997 and cancer progression at diagnosis meant an initial poor prognosis of 20-30 per cent chance of survival. Her child's multiple treatment regime involved chemotherapy, radiation, surgery and a bone marrow procedure over a nine-month period as a hospital in-patient. Michelle described her son as currently 'just a normal healthy boy with a few scars' and subtle learning disabilities and hearing impairments deriving from treatment.

Despite Michelle's son surviving cancer with minor health consequences, she illustrated how the life/death situation through cancer diagnosis and treatment has significantly impacted on her current self. Over the course of treatment she was told by clinicians on several occasions that her child was not expected to live, 'thinking each day was going to be his last':

>Deep inside me I don't know whether that time bomb's there [cancer] and it's going to come, but I would never say that to him [son] but that's just how I feel. You always think the worst, even though you don't want to, you want to think the best you know. Every time he got sick or he got a cold, your guts just churn, you just think that it, this is it [cancer again] … how can you recover, how can you move on when you've got that every week. It's the constant uncertainty and how can you recover from being told your child is going to die four times, how can you ever really recover from that, you know, you're damaged.

The multiple near-death experiences of her son through cancer significantly impacted on how Michelle defines her current self and everyday life after cancer. She spoke of a lost sense of hope and chronic despair:

>I can't see in the future it getting any more normal than it is now and it's really you know, like I just feel like I'll be like this forever, I'll be damaged like this forever, that's how I feel. I feel like I can't possibly be normal again, no I don't feel like I did before it happened, I can't even remember what it was like, it's been so long to be not normal to have that kind of worry.

The experience of cancer caused a radical disruption in Michelle's everyday reality. She spoke of being emotionally damaged from experiencing her child's multiple life/death situations and had lost her sense of normality. However, she then sought to find a way to legitimise her current self and situation 'in the face of radically altered circumstances' (Bury 1991: 456):

>I just want people that are going through it [cancer] to maybe know that, 'Oh, she's feeling like that, is it OK if I'm feeling like that, after that long she's still going through that'. I feel like that, so that's OK, just for them to know that's our normal, our new normal is OK. It's OK to be damaged.

Michelle described being profoundly impacted by her son's cancer, rejected cultural expectations of returning to a pre-cancer notion of normality and constructed a fundamentally new way to give meaning to her current self and her

sense of normality. She also conveyed being socially isolated from others who had difficulty accepting her new normal self:

> People just don't understand, like my sister and my mother … they don't understand how damaged we are from what we've been through and how it has just changed our lives and we can't make us like we were, we will never be like that again.

Michelle's experience through cancer was a distinct rupture from her previous life, while her new sense of normal, 12 years after her son's cancer, involved an acceptance of her 'OK but damaged self'. Her account represents the construction of a new identity in the context of 'powerful forces of change inherent in extreme experience' (Little et al. 2002: 177). Michelle also spoke of being marginalised from significant others who had difficulty in understanding her new sense of selfhood. It took Michelle a period of time to accept the abatement of cancer: 'It probably took us to five years to actually think to ourselves, actually seriously think to ourselves our boy might be going to live'. Michelle's cancer experiences meant that cultural expectations of a 'return to normality after a crisis' was an inadequate way to represent her current self (Becker 1997; Drew 2007). She portrayed cancer as 'an absolute nightmare … it's just our story is just so hard and so long, it's just very, very intense'. Michelle's account represents a new normal in the face of the multiple threats to her son's life and the dark and ongoing shadow in her life.

The findings demonstrate how the experience of cancer retains an ongoing and variable presence in shaping how carers define their lives after cancer. Mary [1]

defined a new normal in which her cancer experiences was a 'lurking' presence; but with her child's healthy outcomes from treatment, cancer cast a light constraining shadow on her everyday life. Dave's [2] account represents a new normal with the presence of a moderate cancer shadow of retreating uncertainty and advancing hope. Michelle's [3] 'OK but damaged' self illustrates cancer experiences casting an ongoing dark shadow in her life. Previous research has represented the diagnosis and treatment phase of childhood cancer as a profound biographical disruption in carers' lives (Dixon-Woods, Young and Heney 2005; Young et al. 2002). The findings here demonstrate that the disruption extends beyond the diagnosis/treatment and incorporates carers whose self-concepts and situated context are altered according to the significance and consequences of childhood cancer and remission. Their accounts link survivorship theory to the concept of new normal by illustrating ways in which carers' identities are shaped by the impact of having a child with cancer, and the emergent new self-concepts that incorporate remission hopes and uncertainties (Little et al. 2002; Aziz 2002).

Carers appraising the self after cancer

In Chapter Three I illustrated how scholarship has captured ways that cancer survival carries the cultural expectations that people will have 'gained' in a positive way from cancer experiences (Stacey 1997; Becker 1997; Chesler 2004; Little and Sayers 2004). The findings support this cultural trend as carers spoke of having to reconcile their actual experiences with ways they felt they were supposed to be after their child's cancer. Carers evaluated their experiences and

developed new meanings and practices, but felt they were expected to have gained in a positive way from having experienced their child's cancer. Carers living with light cancer shadows spoke of overcoming the challenge of their child's illness, celebrating cancer's abatement and gaining from this experience. Those living with moderate cancer shadows resisted the notion of gaining positively but developed a deeper awareness of their capacity to deal with the crisis. Those living with dark cancer shadows were immersed in dealing with their child's cancer outcomes and challenged the idea of gaining positively.

Participants living with light cancer shadows considered their child's cancer as a catalyst in gaining positive attributes. Natalie [1] described how the care demands which resulted through cancer gave her increased confidence to be more socially outgoing, forthright and independent:

> Before [cancer] I never got my driver's license, I would go to work but I couldn't go to the gym by myself, I wouldn't go to the beach by myself, I was just so insecure and now I got so much more confidence because I had to deal with what her issues were and it made me a stronger, more independent person, and I do all of the above now.

Mary [1] spoke of her emotional resilience and capacity to handle stress:

> Emotionally I think you come out the other end stronger than when you went in. I feel more able to deal with stressful situations because you can't afford to fall apart when you're there with your child and it's something you learn after a little while.

Freda [1] explained being more empathetic, caring and open to discussing cancer with others: 'It makes you more aware of your own situation, making sure your own family is all right, but I also think it makes you much more compassionate,

and less scared to talk to other people about cancer'. After getting through cancer

with minor consequences, these carers spoke with a culturally informed triumph-

over-tragedy discourse in overcoming cancer as a new form of achievement

(Lupton 2006; Becker 1997).

Carers living with moderate cancer shadows described how cancer experiences

enhanced a deeper understanding of their existing personal attributes. Louise [2]

conveyed how dealing with her child through cancer confirmed her personal

values but disputed acquiring 'positives' because of cancer:

> You're supposed to have positives, aren't you, I've read those stories where you
> are 'glad you had it because …. I don't really think I have any positives about it;
> I have a bigger awareness of the experience in life that I would never have
> experienced otherwise but we could have done without it. There are all the little
> things like ironing [Son's] school uniform and thinking this is so good and really
> special, but that's all the initial stuff you feel. But now it's more about life
> getting back to normal, the fact that I can iron his uniform means he's better,
> getting better, that he can go to school because he loves school, but no, I could
> definitely have done without it if I had a choice. I wouldn't want to do it all
> again and be thankful for the experience, 'cause I always have an appreciation
> for every special little moment I have enjoyed with the kids, that's why I had the
> delight in seeing them do things and wanted to share the day with them rather
> than go to work. So when people say they appreciate everything their child does,
> I already had that feel of that and was a part of that.

Louise challenged the cultural assumption of having gained positively from her

child's illness. Instead, she asserted the qualities of her carer identity before

cancer, with a sound awareness of her life values and an appreciation of her

relationship with her children. It is also noteworthy how she emphasised

'ironing' her son's school uniform: to symbolise a form of 'ontological security'

and gendered practice to affirm her carer identity and her son's continuing health

status (Giddens 1991). Molly [2] regarded her cancer experiences as giving her a new awareness of her existing emotional resilience and adaptability:

> I guess this has strengthened my strengths, but emotionally it made me more aware of how strong I was. I found that I had it all scheduled and this was how it was going to be [treatment], so in some respects, it made me more flexible than I was.

These participants spoke of cancer experiences enhancing and deepening the qualities of their existing selves rather than acquiring attributes because of their cancer experiences. Claire [2] explicitly disagreed with the cultural assumption of overcoming cancer and becoming more optimistic and stronger because of the experience (Dixon-Woods et al. 2003):

> There really is a culture of … you know, people write all these books about overcoming this and overcoming that and it's supposed to be some badge of honour rather than saying you get your badge of honour for the life you are living now.

Claire instead emphasised valuing her everyday life and without giving her cancer experiences a master status (Sontag 1991). These participants therefore challenged the dominant triumph-over-tragedy discourse of cancer survival (Lupton 2006; Becker 1997). They claimed a sense of personal resilience but emphasised their own agency in adapting through cancer and constructing a meaningful life as carers of a child in remission.

Carers living with dark cancer shadows resisted the idea of gaining from their cancer experiences. Cazzi's [3] everyday life involved dealing with the burdens of her own and her husband's chronic illnesses, as well as her daughter's failing

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health, dysfunctional liver and multiple personality disorder. She summed up her current life with a sense of hopelessness: 'I wouldn't wish this [post-cancer situation] on my worst enemy; your life is not your own'. Similarly, Pauline [3] was immersed in dealing with her adult daughter's intellectual deficits as a consequence of brain surgery: 'Just living with her disabilities every day, you know that is not going to change'. She spoke of her everyday life with a sense of fateful resignation: 'you don't look at it as a choice: you just deal with what you've been given'. Michelle [3] felt she had lost her capacity to think optimistically because of her experiences through her child's cancer. She also transferred the threat of cancer to her own embodied self:

> I feel like I'm going to get cancer all the time, I'm going to get a brain tumour, I'm going to get breast cancer, I'm going to die. I just feel it because we've had it [child's cancer] in our lives and I just think, no, life's been too good, you know, something's going to happen.

Carers living with dark shadows challenged cultural expectations of gaining personal attributes and instead defined their current situation with a sense of despair and their imagined future with little hope.

The findings build on the concept of new normal by illustrating how carers reflect on their current selves in ways that both support and challenge cultural assumptions of being a carer of a child in cancer remission. Carers define their situation according to their cancer experiences and child's remission outcomes: from gaining positively, to a deeper awareness of their existing strengths or with ongoing sense of despair.

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New normal uncertainties

Participants' accounts reveal similar themes to that in childhood cancer scholarship: 'loss of certainty' through cancer and 'living with uncertainty' after cancer due to ongoing concerns with cancer relapses, secondary cancers and the late effects of treatment (Young et al. 2002; Parry 2003; Cohen 1995; Comaroff and Maguire 1981). Most participants spoke of uncertainty having an ongoing presence but lessening in intensity with time elapsed from the cancer diagnosis and evidence of their child's ongoing health. For example, participants such as Laura [1], William [1], Edele [1], Angela [2] and Raul [2] were all now 15 or more years past cancer and their accounts illustrated uncertainties diminishing over time. Their most common metaphor in locating uncertainty in their lives was 'just there in the back of the mind'. The temporal distance away from cancer therefore influenced how participants constructed uncertainty. William [1], for example, said how uncertainty retained an ongoing, but background presence:

> It's [cancer uncertainty] always there but we're not living every day waiting for it to happen. He's doing fine and we're watchful of him and if it happens it will be, 'bloody hell here we go again'. It's not something that takes up a lot of our time worrying or planning.

However, Freda [1], Dave [2], Louise [2], and June [2], for example, were five to six years beyond their child's cancer and spoke of uncertainty as being more in the foreground of their everyday lives. Louise [2] said:

> It doesn't go away, the threat of cancer is always there in my life now, it's just that I don't carry it on my shoulders every day like I was, it's just there in my realm, it's not dragging me down like a big weight, I'm aware of it but dealing with it.

Louise defined the uncertainties of her child's remission as a persistent but less

burdensome presence. Nine years after cancer, Chelsea [1] spoke of deliberately

focusing on her immediate everyday life with a sense of optimism and with a

hopeful future. Nevertheless, she acknowledged that cancer uncertainty retains

an ongoing presence:

> You got to let [child] live and learn and try not to dwell on the past and move
> forward and live for the future and just cherish everyday in a positive way and
> try not to dwell on what might happen …which is really hard to put out of your
> mind and I don't think anybody could but it would be nice if we didn't have that
> hanging over us.

Carers from the situation of dark cancer shadows conveyed being acutely aware

of the unpredictability of their child's remission and emphasised the demands of

their childcare tasks. Marilyn [3] spoke of dealing with her son's hormone

replacement therapy to promote puberty and dealing with his cognitive deficits

and infertility: 'I don't even think about the cancer. Well sometimes I do when

you think down the track they say with all this treatment they're given they can

end up with secondary [cancers]'. Marilyn's account illustrates a fundamental

contradiction; she initially located uncertainty in her background realm, but then

stated how cancer uncertainties retain an ongoing presence. After 15 years of

dealing with her daughter's multiple physical and cognitive morbidities which

derived from cancer treatment, Pauline [3] conveyed cancer uncertainties as a

very real possibility: 'That threat of cancer, this word remission means nothing to

me, because you've got the radiation, the chemotherapy that can cause secondary

cancers'. As such, Pauline's everyday reality means living with a chronic and non-resolvable form of uncertainty.

Carers of children in remission construct their current lives with a form of chronic cancer uncertainty, and distinct from the acute life/death uncertainty with the advent of cancer. Uncertainty is a defining attribute of the concept of new normal, that lessened over time for most participants although serious and ongoing consequences of cancer treatment meant that carers established a more chronic understanding of cancer related uncertainty.

Knowing the cancer enemy

The theme 'knowing the cancer enemy' emerged from the data, indicating that carers continue to acquire cancer information for years after its abatement in order to be more empowered to deal with the uncertainties of their child's potential relapses or cancer morbidities. Carers used the internet, attended childhood cancer seminars and acquired knowledge through their GP, books and the media sources. June [2] sought cancer information as a normal part of her everyday life: 'I just find every cancer story that comes on TV and I'm reading books and so it has definitely taken over my life. Not that I'm sitting around moping all the time but you're so conscious of it [cancer] now'. Louise [2] felt that information provided her with a sense of control in the cancer aftermath:

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> I need to soak everything up, to learn the enemy to know how I can have a bit more control. It's about me having a little control if I have to do it [cancer process] again and I have no choice. At least I'll know what I can do about it.

Louise believed information was a key resource in empowering her to 'do it again' if her child relapsed. Grace [1] equated knowledge with a sense of hope: 'Uncertainty only comes when you don't have the information. Now I think where there's life there's hope and uncertainty only comes when you don't have the information'. Knowledge-seeking practices provide carers with a symbolic and pragmatic source of control, not of cancer *per se*, but as a new normal resource in case their child should relapse. Carers spoke with authority and expertise, equipped with their own cancer experiences and a degree of cancer knowledge. However, carers mutually gave meaning to having little control of their child's cancer through a discourse of normalising uncertainty.

New normal discourse: Luck, hope and faith

Carers constructed a particular discourse characterised by luck, hope, and faith in response to their new and unpredictable situation. Their post-cancer discourse is indicative of pre-modern notions of life governed by fate, destiny and/or God (Giddens 1991: 110-111). In response to meanings of a medical remission characterised by ambiguity and uncertainty, carers constructed a 'new normal' discourse of luck, hope, and faith to provide a definition of the situation that makes sense to them (Barnes 2007).

The notion of luck refers to a sense of 'resigned acceptance' of life circumstances that are deemed beyond the control and rational explanation (Giddens 1991: 112). Carers drew on a discourse of luck because clinicians could explain neither the advent of childhood cancer nor guarantee a permanent remission (Dixon-Woods, Young and Heney 2005; Heath 2005). They expressed how their lives had been shaped by the chance factors of luck in reference to make sense of cancer, remission and ongoing uncertainty. Adam [2] referred to his child's illness and remission in terms of luck:

> We've always considered, and she also thinks that she was unlucky to get leukaemia, she was lucky to beat it, like shit happens sort of scenario. You can't do anything about it, you don't know why, you just do but you're here now.

Grace [1] saw herself as comparatively lucky with her child's curable cancer:

> I look at people with children with diabetes, or cerebral palsy and think 'You've got a lifetime of this'. Mine was finite, mine was this is going to happen, we either go the good road or we'll go the bad road.

Grace defines her current situation in terms of luck with aspects of fate in her child's survival. Elizabeth [1] considered that she was lucky that her child had a type of cancer with a positive prognosis: 'Yeah, we were really lucky with [kidney malignancy]; neuroblastoma is sort of the alternative side, it's really bad and we are very grateful'. Claire [2] spoke of her child's cancer and her own situation as a matter of providence:

> A lot of people ask when [child] was diagnosed 'why'? With my background in ICU [intensive care unit nursing] my answer was 'why not'? It's a lottery and someone has got to pull it … and we have a joke that saying to [child] she should have bloody well won Lotto, but she pulled the cancer one.

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Michelle [3] stated that 'we're very lucky and such a huge tumour didn't go to the bones'; and of her son's survival: 'we're very lucky, he's our miracle'. Alice [1] considered her daughter as 'very lucky… she didn't have a lot of ongoing [treatment late effects] issues'. Laura [1] felt lucky that her marriage survived the cancer period and Natalie [1] considered herself 'lucky because she was our only child, we didn't have to worry about other kids'. The recurring discourse of luck adds to the concept of new normal in offering carers a meaningful explanation in a situation in which they had little control over their child's life/death outcome.

The notion of hope also emerged as a frequent data theme in relation to carers' wishes for their child and their own future selves. Hope refers to the subjective probability of a good outcome but infers a degree of uncertainty (Little and Sayers 2004). Carers constructed a discourse of hope to mitigate cancer uncertainties and a desired future without cancer, or with minimal consequences. Grace [1] illustrated how hope was an internalised and developing aspect of her life after cancer: 'In terms of hope, you can't give that to somebody, it's not some physical thing, it always comes from inside you, hope comes from within and with time'. Eve [2] linked uncertainty and hope into her temporal context:

> We had a lot of hope and a lot of uncertainty when we were in hospital, and we've still got that but it's a much smaller part of our lives now; it's not something that we think about from the moment we wake up to the moment we go to sleep, which is honestly what we did in hospital and even at home. You are so aware of what could go wrong, whereas now, we're just so aware of everything that can go right.

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Eve's new sense of normality was characterised by diminishing uncertainty and advancing hope, to the point where she defined her current life with a sense of optimism. Dave [2] had to translate his daughter's survival chances into his own symbolic realm of tentative hope:

> The long-term prospect, that's the scary bit, from 90 per cent chance they could cure this primary [cancer] to 60-40 per cent chance whether it comes back or not. It doesn't chuck it out of your head … that 60-40 is like a 50-50, isn't it? But then … we don't know but it certainly has put that shadow right in your face.

The metaphor 'shadow right in your face' represents Dave's frustration in attempting to develop a sense of hope from medical discourse which meant his daughter had an equal chance of either life or death. He then defined his current situation: 'It's like being in a boat of hope but caught up in a river of uncertainty … but sometimes those fears you had, others have them too, it reinforces that there's nothing wrong with you, that it's normal'. Dave acknowledged the clinical uncertainties of his daughter's remission but conveyed his own constructed meaning of hope in his daughter's future. The findings demonstrate hope was limited from the discourse of carers living with major cancer shadows due to their child's permanent and extensive late effects. Cazzi [3] spoke ominously of her adult daughter's capacity to live independently: 'she [daughter] will be out on her own having to look after herself … she wants to, she keeps saying she's capable of looking after herself, but she's not'. Cazzi has little hope for her daughter's future chances of becoming an independent adult.

Nine participants spoke of drawing on their faith in God; as a source of comfort through cancer and a spiritual belief for their child's ongoing remission. Mimma [1] became more prayerful since her child's cancer to instill hope:

> I pray every night … I never used to but to this day, since she was diagnosed I've prayed every single night for her. I was just never the type and I think if I miss a night I feel bad 'cause I think something might happen to her tomorrow.

Mimma merged her faith and hope as a source of personal comfort. Her faith expressed a symbolic way of translating 'non-everyday experiences back into the paramount reality of everyday life' (Berger and Luckmann 1984: 40). She described her prayer practices as a new and ritualised aspect of her everyday life: to 'miss a night' posed a symbolic threat to her child. Mimma also passed her cancer uncertainties 'over to God' as an adaptive strategy in being powerless to control cancer. Emma [2] similarly believed in the power of prayer:

> We firmly believe that God answers prayer, he doesn't necessarily take away whatever's happening but he gives you the strength to cope with it, and whatever happens, we had hope for a better life one day.

Emma explained her faith as a source of strength through cancer and as a way to accept her uncertain but hopeful life after cancer. Pauline [3] identified her faith as a fundamental part of her identity: 'my personality, my faith and my patience is who I am and has got me through [everyday]' in dealing with cancer and ongoing child's multiple morbidities. Louise [2] discussed drawing on her Aboriginal spirituality:

> We all believe that we have some of our family members with us, that their spirits stay with us. I drew on that strength … that was my main driving force, like my [ancestor] was holding my hand, he passed away a long time ago and that was really, really good, I really believed in that, it was working for me.

Louise spoke of drawing comfort and strength through spiritual interaction with her ancestor. Her account speaks of an Aboriginal notion of care that is inter-generational, spiritual and cultural: of her ancestor caring for her as she cares for her son.

Carers drew on their Western and Aboriginal faith as an important, internalised resource, offering a source of comfort and peace, an acceptance of having little control of their situation and as a way of dealing with remission uncertainties. Giddens (1991: 109) argues that people seek to control their destinies as rational reflexive, actors but concedes that 'notions of fate and destiny have by no means disappeared'. The discourse of hope, luck and faith adds to the concept of new normal by revealing ways that carers construct meaning through realising that rational control is a fragile perception and subject to 'the vagaries of fate' (Lupton 1999: 75).

Living in the present: Projecting children's future

The findings illustrate that carers emphasised their present everyday life and minimised future plans. They adopted a 'living in the present' approach to deal with the urgency of their child's situation through cancer and sustained this temporal strategy through remission in response to their uncertain but hopeful futures. Temporality refers to 'biographical time' in which people reconstruct

their past experiences in their present context, with an imagined future in a

continual flow of experience (Corbin and Strauss 1988: 60).

Eleven years after her child's cancer Victoria [1] conveyed the immediacy of her

everyday life: 'I only really plan short term, because you never know what is

around the corner, that's what it [cancer] has taught me'. Dave's [2] child had

cancer five years ago yet he remained cautious because his taken-for-granted

assumptions of considering future plans remained disrupted:

> I never take anything for granted anymore. I don't say you look negatively on
> everything but I certainly look more objectively at things. When someone says,
> 'what are you doing in a month's time', I go, 'we might be doing this', but I
> don't commit now, I focus on today and not tomorrow or what might happen
> next week.

Dave emphasised his future plans were provisional and focused more on his

immediate life. Natalie's [2] child had cancer 13 years ago, yet: 'You just don't

know what is around the corner; our future plans are very much in a present

focus'. Lee [2] maintained a present focus nine years after cancer, and infers

other family members follow this un-written code of their future plans:

> We know first-hand that our life can change just like that, in the blink of an eye,
> at any time it can change again, because we've already dealt with it [cancer],
> we've already been through a stage that people shouldn't have to go through.
> You know that it can happen, it has happened, therefore we become a bit more
> wary, a bit more susceptible to knowing that life can change overnight. I don't
> look too far into the future, I try to get through week by week and that is the
> whole family unit. I don't look into three months time, I look into next week …
> we don't dwell on it, and we don't discuss it either, but personally, I don't look
> anything past a week or two weeks in advance.

Pauline [3] was fifteen years beyond her child's cancer yet maintained: 'I still live

in the present … and just living with her disabilities every day, you know that is

not going to change'. She sustained a temporal immediacy in order to deal with her daughter's day-by-day treatment late effects. Carers emphasised the 'living in the present' to achieve a symbolic and pragmatic sense of control of their current situations, with the knowledge that their lives and the lives of their children can change instantly.   The temporal framework of the new normal captures important ways in which carers strategically orientate their uncertain but hopeful lives.

While deliberately reducing their own temporal focus, participants also searched for ways to project their children's futures. They do in the cultural context where carers are culturally ascribed with the responsibility for their child's immediate and future well-being (Lupton 1997), and children are constructed on the assumption of their future as adults (Mayall 1998). Carers discussed their child's future as an evolving process through different cancer phases: of their child's potentially limited future at diagnosis, apprehension through treatment and cautious hope for their future with remission.

The majority of participants discussed their children's future careers, education and family plans with varying degrees of optimism. Mimma [1] portrayed her child's future with a sense of confidence: 'Yes, she'll grow up and have a family and she'll have children'. June [2] discussed how 'she [child] wants to be a photographer … so at the end of the year she'll do TAFE and if later on she wants to take up university, if she gets the grades then she can'. Other carers spoke of their child's adult career plans, such as becoming a chef, a swim instructor and an

army technician, thus conveying a sense of confidence in their children's futures. However, carers like Marilyn [3] expressed grave concerns for her son's future as his health and potential autonomy was significantly compromised: 'I don't think he'll be able to live independently … I just worry about his future, I worry about that more than anything else'. Marilyn's limited capacity to imagine her child's independent future aligned her own future concerns to care for her son.

The findings illustrate that carers construct their child's future with a greater projection than their own. They do so in order to focus on the immediacy of their own lives to seek a sense of control in the face of cancer uncertainties, but project their child's future as a way to instill a hopeful future. However, the extent to which carers project their child's future is linked to how they interpret their child's capacity and potential independence.

Constructing a new normal with others

The foregoing discussion illustrates how primary carers evaluate their self-concepts and situation in the childhood cancer aftermath. In the following section I examine how carers construct their social identities with significant and generalised others, 'cancer friends' and the cancer community, in new ways as carers of a child in remission. They also defined their situation as beyond the comprehension of others who have not had similar experiences: and enact particular front or back stage 'performances' to different audiences as a way to normalise everyday interactions (Goffman 1959). Carers therefore construct new

identities to minimise the potential to be marginalised as not meeting cultural expectations of their carer-of-a-child-in-remission situation, and of being labelled as the 'cancer other'. Yet paradoxically, carers construct a strong social affiliation in belonging to the broader cancer community.

New carer/child interactions: Stepping back from cancer

The carer/child relationship is the socially defined expression of primary carers' identity (Collett 2005: 329). Maintaining carer/child relations therefore sustains carers' social identities. But carers learn by trial and error that being a carer of a child in remission involves stepping back from their cancer experiences in order to maintain a sustainable relationship with their child, as Lee [2] explained: 'You do everything you can to steer and guide them; to help them and I do, my kids are my world, I love them'. Claire [2] drew a clear distinction between being a carer of a child with cancer and a carer of a child in remission:

> Parents of a child with cancer become extremely good at being a parent of a sick child but no one teaches them how to become a parent of a child who is well but with some deficit. That is a completely different role, a role that requires you to step back and to encourage and develop self-management skills.

Claire asserted the need to find new strategies to normalise everyday life after cancer by giving her child the opportunity to develop her own autonomy and future independence:

> There is still going to be in the background some surveillance and how important it is to keep that bit really low key and behind, because what is going to empower that child to go on and live a full a life as possible and for the siblings

and everyone to come back together in terms of a strong family unit, is to actually focus on health, stop thinking sickness, just think health.

Claire de-emphasised cancer and emphasised everyday life as an interactional strategy to sustain family relationships. Louise [2] explained her initial difficulty in learning to shift focus from cancer to life after cancer. Her 10-year-old son was diagnosed with cancer in 2004. She described their intimate bond through cancer and the shifting dynamics afterwards:

> We had really good team work going, him and I, a big bond, and after that it's like, 'I'm better now, Mum, get over it', and he grew up through it and pushed me away. I feel like a few doors are opening now and I think it's a change in me where I'm no longer so paranoid. I don't have that look in my eye where every time I looked at him I saw cancer, or he saw the fear in me and he got to the point where he wouldn't tell me that he had hurt himself.

Louise found it difficult to shift from her overly protective role after her son's remission (and perhaps her identity as a carer of a child with cancer). However, Louise's son responded negatively and made her realise that cancer was no longer a central feature of their lives. Louise then reassessed her carer identity by attempting to establish a new and sustainable relationship with her son by having to 'realign everything … to see him as a normal child' rather than a cancer patient. In making this shift in orientation Louise continued to actively engage with her son and co-manage his ongoing health with remedial physiotherapy support and promoting a healthy family lifestyle. Louise described their newly defined relationship by keeping her ongoing cancer concerns in a background context and by negotiating new ways to interact with her now 15-year-old son.

Margie's [1] child was diagnosed with cancer 14 years ago at two-and-a-half

years of age. Her childcare strategies shifted from a position of overt protection

through cancer to her current and deliberate matter-of-fact approach in dealing

with their child's health after cancer:

> You go from being super-cautious about germs when on treatment, responding
> quickly to their ailments and complaints, then the pendulum swings the other
> way where you think, my child got cancer, what else could go wrong, so I've
> become extremely blasé about things.

Margie reasoned that her child survived cancer so other everyday ailments should

be given minimal concern or attention. Eve [2] adopted a similar approach to her

now nine-year-old daughter's complaints in order to de-emphasise cancer and

normalise their lives:

> I have told her that unless you've got spots, particularly on your legs, or your
> gums are bleeding I didn't want to know about it, it's not leukaemia, so go away.
> That might sound harsh but she needs to know that not everything is life-
> threatening and not everything is going to kill her. There's no blood or broken
> bones so go and play.

Magda's [1] daughter was diagnosed at nine month of age in 2000 and became

blind as a result of cancer. Yet Magda spoke of pragmatic approach by 'not

changing a single thing' in her home to enhance her daughter's visually impaired

search patterns, and to 'treat her the same as anyone else, which she needs to

survive'. In this way, carers spoke of de-emphasising cancer and its

consequences to sustain carer/child relationships and promote their everyday lives

as normal, albeit a new normal as carers of a child in remission.

Several participants (n=29) had their child diagnosed at around four years of age or younger, which was too young for the child to have significant cancer memories. Carers are therefore the main conduit of their child's cancer information. They strategically filter incremental information according to their child's comprehension and in a matter-of-fact manner to normalise cancer in their child's life. Lee's [2] son was diagnosed with cancer as a three-day-old baby in 2000 and she described him as healthy but with 'a massive [surgical] scar across his belly' as he was too small for surgeons to attempt key-hole surgery. She felt obligated to inform her son of his cancer history, but in a way that normalised cancer into his everyday life according to his age and awareness:

> I try to give him little bits of information but not too much information that they can't comprehend either. You don't want them to feel different either, because it is such a rare thing so you have to be a bit of a psychologist because you don't want to give them hang-ups.

Lee needed to filter cancer information her child received according to his age and comprehension. She deemed her strategy as successful and was 'quite proud of the way he's turned out'.

Carers also discussed the need to restore their relationship with their other children due to them being partially neglected through cancer (McGrath 2001; Murray 2002). The issue of siblings was often discussed, in part because of a sense of guilt in giving them inadequate attention through cancer, but also because siblings made carers realise their other family obligations. Eve [2] explained:

> We've got two boys a little bit older and [another daughter] and she was the one who kicked up and felt as if she was being left out; it was a slap in the face to realise we had more than just one child. So we needed that and they [siblings] pulled us through it, otherwise we'd have fallen in a heap. We still have to feed them, get them off to school, we've still got to clothe them, still give them some of our time.

Robyn [1] typified participants who emphasised the need to normalise siblings into everyday family relationships after the disruptions of cancer:

> I tried to rebalance it and because the attention had always been given to the older one [who had cancer] and she thought that she got her way but we sort of tried to rebalance and say, 'No actually the other one needs to have a say as well', and the consequence of that was that the older one felt that I always sided with the younger one.

However, Claire [2] spoke of the consequences of childhood cancer on siblings:

> It makes a difference for the siblings … there is a loss of innocence in terms of 'people don't die', so my kids … they've never reached teenagehood in terms of that idea that 'I'm invincible'. That's a big loss, they know about death, know all about we're all pretty fragile and with that comes a loss of freedom in a way.

Dealing with siblings provides another dimension to the concept of new normal in representing how carers' attempt to realign altered family relationships into a new form of normalcy after cancer. The findings support siblings as instrumental in helping carers maintain a sense of balance between their previously sick child and other family obligations.

Marital accord/disaccord after cancer

Previous research reveals a trend in which childhood cancer puts much strain on carers' marital relationships (McGrath 2001; Lavee 2005), but few studies have

focused attention on the long-term impact of cancer on marriages. In this research a small number of carers were separated and/or divorced (n=6) but most marriages remained intact and some participants described their marital relationships as reinforced through and after cancer. Marital accord/discord adds to the concept of new normal to represent how carers' evaluate their marriages through their child's cancer and remission.

Four of the six divorced carers spoke of their child's cancer as a contributing factor in their marriage breakdown. Alice [1] explained that the earlier death of her other child plus their child's cancer combined to a point where her marriage came 'right down on the priority list' and never recovered. Lee [2] portrayed her husband as supportive through treatment but 'never the same after cancer', which escalated in the marriage separation. She also felt that her child's cancer and marriage dissolution combined to experience a form of gender marginalisation: 'One thing that has stood out is that I do feel isolated from other women'. Pauline [3] felt she was 'doing the best I can' after cancer but left 'angry that I've had to do it alone, angry not just at her father but myself for not choosing a partner that's going to care for his kids'. These participants constructed their lives as single carers of a child in remission but divorced as a consequence.

The majority of participants defined their marital relationships as strengthened through and after cancer. Marilyn [3] described re-establishing their marital relationship after cancer: 'We're actually having date nights and I say to the kids,

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it's not all about you, it's us, we never did that before [through cancer] because that was selfish'. It took her around 10 years after cancer to start defining their marriage as wife/husband rather than solely as a pair of primary carers. Eve [2] emphasised the value of her husband support and their marriage remaining intact:

> I think a lot of it is because [husband] and I are so close afterwards. A few couples we knew split up and that would have been horrendous, doing it on your own.

Participants attributed the survival of their marriages to working together through cancer and reprioritising their marital relationship in the cancer aftermath. It is beyond the scope of this research to examine the complex connections between childhood cancer and marriage survival outcomes. However, the findings illustrate that the majority of marriages survive cancer and the aftermath when spouses have a 'shared definition of their situation and work together as an interactional unit' (Lavee 2005: 117). Adam [2] made this point: 'We just looked after and looked out for each other'; and Annie [1] who emphasised: 'I think we were lucky we were going the same way … that made it immensely easier'.

Gendered care after cancer

The findings support much childhood cancer scholarship in revealing an intensification of traditional gender divisions of labour; as mothers assumed the majority of childcare and cancer related tasks while fathers maintained economic and peripheral family support (Chesler and Parry 2001). However, the threat of cancer caused fathers to become more family orientated.

Mary [1] affirmed her maternal gender identity by assuming the majority of child health responsibility:

> I think a woman's place in the family dynamic is usually one as the major care-giver. If there's something wrong with any of the kids I'm on top of it; my husband really doesn't get a look in. I make the decision, 'they're going to the doctor or no, they'll be right' that sort of thing. It just reinforced the natural order of things.

In a separate interview with Joe [1] [Mary's husband], he said how there was 'no share in the [childcare] load or anything like that, I don't even get a look in'. Joe's response indicates his wife maintains traditional gendered division of childcare labour in order to validate her maternal identity but in a way that inhibited his chance of greater childcare involvement (Allen and Hawkins 1999: 199). Emma [2] similarly defined her maternal identity and role within her family: 'I'm the mother and it is my job to keep it running smoothly and all together'. The majority of mothers also identified their actual family unit rather than themselves as dealing with cancer and its aftermath. Freda [1] noted that 'basically we had to survive as a family unit and rely and support each other'. Molly [1] spoke of her determination not to 'let it [cancer] consume us' and for everyone in her family to adapt because 'there was life after cancer'. Claire [2] emphasised her collective family members establishing their lives after cancer:

> Now what we are about is to do the very best we can to make the rest of our lives as good as it can be. It's about focusing forward and empowering everyone to just get on with it because there is no doubt that through treatment, however long it is, lots of things get put on hold and so it's about getting back to those things and it's about getting it into perspective and say, 'look it is an experience we have had, it will certainly have an impact on us but it doesn't have to break us'. It's about not giving it [cancer] any more importance than it's got.

Claire promoted a philosophy of orienting family life in such a way that de-emphasises cancer and focuses on everyday life. Her ongoing reference to 'we' was a self-defining way to locate herself within the collective family unit.

Fathers such as Joe [1] spoke of childhood cancer as a catalyst for drawing their family into a closer relationship: 'We rely more on each other than we do anyone else and I think that started when [son] was crook'. Dave [2] said that the threat of cancer on his child's life significantly increased his family values and self-awareness of his paternal identity: 'I've got a reason for being here. Once it was, I'll do the hard yards and spend time with the kids when they're older. I got my wakeup call, now they know who Dad is'. Dave felt more integrated into family life but in a way that conflicted with his wife's parenting style:

> Because my wife was on the coal face all the time, I found after [cancer] that I was critical of her being too hard where she approached it like life was normal. I was sort of wrap her up in cotton wool a bit and that used to affect how we were, to an extent. We had times after where I was still emotionally grieving and pretty exhausted and we had our arguments. I felt I didn't have that support base where she [wife] could download and had people with her all the time … I didn't have someone to download on as much either, so I carried a lot and it all caught up with me. I think us blokes are our own worst enemy too because you just suck it in, you don't think this is worth talking about.

Dave's account illustrates his paternal and masculine selves causing a tension which hinders constructing a shared definition of the situation with his wife. His protective parenting style contrasted to that of his wife whose approach was to normalise their cancer related situations. Yet Dave maintained a masculine stoicism, of internalising his emotional grief in a culturally defined way rather than 'downloading' his concerns onto others (Chesler and Parry 2001). William

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[1] saw other fathers who, one given the opportunity and forum, were willing to express the emotional impact of their child's cancer:

> I remember going to a father/son weekend and everyone had fun, then the kids went to bed and it was really interesting to see the fathers really starting tentatively to talk about treatment and talk about stuff, and by the end, it was a bit emotional for a lot of them; they didn't really have that opportunity individually as men to talk about that stuff.

Yet Tom [2] felt that since his daughter's cancer he had lost an inner part of his being: 'I don't seem to react. I said to my wife, I've lost my soul, I lost something, that inner driving force, that thing in your heart'. Eve [2] expressed similar concerns: 'I was really worried about my husband because I had so many people to talk to, but that's just the way he is, a closed book'.

The participants constructed a meaningful definition of being a carer of a child in remission through interactions with significant family others. Their accounts represent particular aspects to build on the concept of new normal; of 'stepping back' and de-emphasising cancer, filtering the cancer related information their child received and orientating self and significant others into the private realm of everyday family life. In particular, carers defined their situation by emphasising everyday family life rather that cancer *per se*. The findings illustrate traditional gendered paternal responses to being a father of a child in remission but also with increased involvement in family relationships while negotiating tensions between their masculine and carer identities. In contrast, mothers enacted a multitude of caring and interactional tasks to assert their own maternal identities and sustain family relationships through and after cancer.

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New normal identity: Insiders and outsiders

The previous discussion examined the way in which primary carers construct new biographies in the private realm of everyday family life after cancer. In this section I examine how carers strategically constructed their social identities in the more public sphere of everyday life. The findings revealed that carers define their cancer related situation as beyond the comprehension of generalised others who have not had a child with cancer. They emphasised their attempts to normalise everyday interactions by 'performing' their carer-of-a-child-in-remission identities according to insider/cancer and outsider/non-cancer audiences (Goffman 1959).

Carers recognised their social identities were disrupted with the advent of childhood cancer. Claire [2] explained: 'The minute you have a child diagnosed with cancer, you are the living embodiment of every parent's worst nightmare'. With remission, carers are advised by clinicians, social workers and generalised others to return to their pre-cancer lives. Louise [2] described such advice as a source of tension:

> There's pressure on you: 'You're not coping, why? Your child's healthy, you're all well, so what are you whinging about'? You've got this pressure on you to get on with it and be thankful.

Carers return to the world of everyday live with the understanding that the cultural expectations of remission differs from their own lived realities. Michelle

[3] described how her cancer experiences resulted in a distinct insider and outsider division of understanding: 'The biggest thing is that nobody understands exactly unless you've been through it yourself'. Dave [2] spoke of how others assumed his child's remission symbolised how life was supposed to be back to normal after cancer:

> The silly thing is, it comes back to people outside your family circle looking at [daughter] and saying, 'She's all better, let's have a party, it's all finished, it's all better. Well, guess what, Dad and Mum have copped this emotionally, belted to the shithouse and you are living it. It might look all rosy on the outside front; but it's not like you chop your arm off and it's finished with.

In this cultural context carers sought to legitimise their new social identities with 'hospital friends', in reference to similar others they met through treatment, and sustain ongoing friendships which continue after cancer. Angela [2] spoke of her 15-year-friendship:

> For a long time we made very close friends with other people we met at the hospital, hospital friends and we still have that with some of them, but the intensity is not the same as it was when we were on treatment ...we went through something together and that tends to be like that, the people that are diagnosed around you, you get a close friendship with.

Hospital friendships are maintained after cancer and new 'insider' relationships develop through cancer support networks. These friendships allow carers to validate and legitimise their cancer related experiences with others who have had similar experiences and concerns.

Carers also interpret their insider and outsider audiences and 'perform' in ways to normalise everyday interactions (Goffman 1959). Eve [2] explained:

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I've got a couple of really close girlfriends that I know I can talk to about anything and they listen, but even some friends now, you start talking and you see their eyes glaze over, like, 'She's talking about cancer again'. I guess it's because they don't understand, they don't have any understanding of what it was like, so you become very selective about who you talk to about that, because you feel like you're burdening them and if it seems they don't want to listen, then I can't talk to them about it. There are friends I do talk to and friends I don't talk to, and the 'cancer friends' are the ones I can talk to at any time.

Eve exemplified participants' awareness of childhood cancer being a confronting 'cancer equals death' issue (Stacey 1997) and although friends and colleagues offer empathy and support, they are unable to comprehend carers' experiences. She responded to her different audiences in order to maintain and normalise her everyday interactions: first, by enacting a front stage identity with non-cancer friends rather than 'burdening them', and second, by sustaining a back stage identity with her cancer friends in which she felt able to share the new aspects of her post-cancer self. Eve's account also illustrates her directing the 'interactional setting' in which to enact her front stage or back stage identities (Goffman 1959).

The insider/outsider accounts build upon the concept of new normal concept by representing ways that carers return to a non-cancer world with new self-concepts and new meanings derived from cancer experiences. They enact a front stage with generalised others to establish a shared 'normal' definition of the situation, and a 'new normal' back stage performance with hospital friends who have shared understandings of cancer and remission experiences.

Belonging to the cancer community

The findings illustrate that carers identify with others impacted by cancer and feel a sense of obligation to members of the cancer community who have been impacted upon by cancer. They regard their child's survival as a gift and express gratitude to medicine in achieving a non-fatal outcome. Mimma [1] typified carers who spoke of an obligation towards the cancer community:

> I'm very more aware with it and anything that comes up with it to help the 'cause' I'm there. Because we see how much can be done to help, and all the research and that, so we're there for them, you know, we try and do what we can.

Grace [1] conveyed how her child's survival gave her a new moral obligation to support the broader cancer community: 'We've been given this great gift and if we can't give back, then what have we learnt from it'. Dave [2] felt a similar sense of cancer community membership: 'I hope that whatever happens, we might help someone else because we wouldn't be in the situation that we were in if it hadn't been for someone else'. Dave attributed his child's survival to previous others impacted by cancer who contributed and helped advance clinical trials which aided in his child's survival, as well as his daughter's trial treatment as instrumental means in helping future others. June [2] credited her daughter's life to clinical research and reciprocated through fundraising:

> Without treatment we would have lost her anyway so you just have to believe in them [medical profession] and go with what they say, and I think that's why we do fundraising. I'm sure that 20-30 years ago we could have lost her, as the survival rate was so much lower. So for me that's saying they're going in the right direction.

As a teacher, Victoria [1] enacted her reciprocity towards a child with cancer:

I actually had a child ask to come into my class because she had a brain tumour and I know the parents knew of me through Camp Quality … it was really frightening but when asked, I knew I had to do it … that affected me a lot, I was there for her and somehow I feel like we were meant to be.

Victoria conveyed a profound sense of duty towards the child and of being intimately connected by the shared experience. Others like Michelle [3] spoke of devoting much time, advice and support towards others impacted by cancer:

I'm here to help my friends now who are going through it [cancer], because when I was going through it I would have liked someone to help me and someone to have known what it was like. I'm there for them however they need it. I could just walk away, you know, we're cured. I could just have nothing to do with it anymore but I feel it's up to me now, I feel part of the reason why we've been given this is for me to help other people. Even though you want to forget it, if my story can help in anyway then that's what I've got to do.

Raul [2] spoke of his sense of obligation to those impacted by cancer: 'We joined a charity that dealt with that [childhood cancer], we had a lot to do with Camp Quality, stayed involved with the hospitals, we did talking at different seminars'.

Carers expressed a profound sense of belonging and reciprocity to the cancer community and were motivated to enhance the lives of its members. They attribute their child's survival to medical clinicians, researchers and participants in experimental clinical trials. Their accounts add to the concept of new normal by demonstrating how carers' identities are constructed with insiders, outsiders and the broader cancer community. Cancer community support can also be explained as a symbiotic process where supporting others sustains carers' identities with a sense of authority deriving from their lived experienced.

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Conclusion

The data from Chapter Five revealed carers' acute evaluations and responses to being a carer of a child with cancer, with biographies fundamentally altered from their pre-cancer lives and the need to construct new identities and new definitions of the situation. In this chapter I developed the concept of new normal to represent the more sustained social process in which carers construct their everyday lives in the cancer aftermath. Cancer experiences cast ongoing but variable shadows of uncertainty but carers adapt with complex strategies to mitigate cancer's ongoing influences: by seeking information, 'living in the present', de-emphasising cancer and constructing a discourse of luck, hope and faith. Carers also perform front and back stages to sustain everyday interactions and identify within a broader the cancer community. Their meanings and strategies are dynamic and vary according to each carers' situated context but intertwine with a new sense of normality; by reconciling childhood cancer and its lurking presence into a meaningful identity as a carer of a child in remission. The findings illustrate carers have moved from the acute crisis phase of their child's illness to develop and maintain a new identity and a set of strategies, that makes sense to them, in response to being a carer of a child in cancer remission.

In Chapter Seven I examine how carers' lives are significantly shaped by their child's late effects of cancer treatment and ways they respond as morbidity managers. I also reveal carers' evaluation of medical intervention that saved their child from fatal outcome but with a compromised quality of life.

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Chapter Seven: Managing the cancer aftermath

Introduction

In the previous chapter I demonstrated how the participants constructed meanings and new ways of being a carer of a child in remission. In this chapter I extend the concept of new normal by illustrating that primary carers' lives are significantly shaped by the extent of their child's ongoing morbidities which derived from cancer treatment. Carers emphasised a plethora of child late effects, including: organ dysfunction, compromised sight and hearing, reduced mobility, infertility and cognitive deficits in memory and concentration, which continue to impact on their child's quality of life and life chances. Their accounts align with findings from international childhood cancer survival scholarship (Oeffinger et al. 2006; Hudson et al. 2003; Friedman and Meadows 2002; Lacker et al. 2000). Through this chapter I argue that the concept of new normal incorporates the way in which being a carer of a child in remission with late effects involves much ongoing work as their child's morbidity manager. The role of morbidity manager involves carers constructing new meaning and strategically responding in new ways to reconcile their child's late effects into their everyday lives.

I begin this chapter by describing how childhood cancer treatment manifests in physiological and cognitive morbidities. I then illustrate how carers respond to their child's varying moderate, severe and disabling morbidities as late effects managers: from co-managing moderate and severe late effects with their child, to

proactive management practices for their child with disabling conditions.   Late

effects were examined in terms of how carers make sense of the medical paradox;

with clinical intervention which saved their child from a fatal outcome resulted in

their child's ongoing morbidities. The findings demonstrate the majority of

carers evaluated their child's survival and late effects from a quality of life

perspective. However, carers dealing with their child's disabling cognitive

morbidities questioned the limits of medical intervention, as their child's and own

lives were significantly compromised.

The background of late effects

In Chapter Two I drew attention to the medical discourse emphasising the prize

of childhood cancer survival but with the price of physiological and cognitive late

effects deriving from surgery, chemotherapy and radiation (Rosoff 2006).

Adverse physiological late effects include chronic include: heart, liver, kidney,

thyroid and other organ dysfunction, hormonal deficiencies, infertility,

compromised hearing and sight (Dixon-Woods, Young and Heney 2005: 77-84),

and morbidities impacting on bones and joints, muscles and soft tissue, teeth,

lungs and intestines (Heath 2005: 765). Cognitive deficits manifest in overall

intelligence decline as well as difficulty in focusing attention and processing

information in a coherent way (Rodgers et al. 1999: 321). The findings support

previous research that depict cognitive deficits are 'one of the most debilitating'

of childhood cancer late effects because they impact on the child's life-chances,

their potential to learn and to be 'a productive member of society' (Heath 2005:

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766). Cognitive deficits are prevalent among children treated with cranial

surgery, radiation and/or high dose chemotherapy. Children treated when less

than three years of age are also prone to cognitive deficits due to treatment

impairing brain development (Oeffinger et al. 2006).

Late effects remain an ongoing dilemma, as medical technologies save children

from a fatal outcome but with significantly compromised health and quality of

life (Cantrell and Conte 2009: 312). Yet childhood cancer scholarship gives little

recognition to social arrangements in which carers and children, rather than

medicine, are left to deal with ongoing 'iatrogenic' child morbidities once

remission is achieved (Illich 1976; Heath 2005; Rosoff 2006; Lacker et al. 2000;

Drew 2003). The findings illustrate that late effects are a serious, ongoing

challenge to carers and children despite the abatement of cancer.

Carers as late effects managers

The concept of management and/or managers represents a practical response to

the consequences of chronic ill health (Bury 1991: 453; Corbin and Strauss 1988:

118). Conceptualising carers as late effects managers captures their everyday

practices in response to their child's cancer related morbidities. Management

tasks include monitoring, planning, anticipating, coordinating and accessing

remedial health and education resources. I make no claims of quantifying

physiological and/or cognitive morbidities as clinical conditions or the way in

which children might respond to their own late effects. Instead, the findings derive from carers' experiences and responses to their child's cancer treatment morbidities. Nine participants stated that their child had no late effects of cancer treatment or ongoing health concerns from treatment. Grace, for instance, spoke of her daughter as follows: 'She's great, she's good and it's [cancer] not something that's an everyday thing for her … she's an A-grade student, she's developing normally'. Mary was typical of the nine carers; she described her son's health as 'good' but still kept close surveillance on his well-being:

> You stop and ask some more in-depth questions and say 'How do you feel, do you feel you need to see a doctor'? With the other kids you say 'Oh, you'll be right, a day of rest and you'll feel better'… I don't coddle him, he gets out of the house, plays sport and that sort of thing, but if he says he doesn't feel well I pay more attention to it, for sure.

The need for ongoing child health monitoring was discussed by all participants regardless of the extent of late effects. Carers' heightened child surveillance therefore links to the findings in the previous findings chapters; as a practical response to mediate hope and uncertainty, and constructing their lives as a new sense of normality after cancer. The nine participants maintained ongoing child monitoring but without the added consequences of late effects management.

I categorised the remaining participants by comparing their accounts of their child's morbidities and categorised them as moderate (n=16), severe (n=9) and disabling (n=4) late effects. For the rest of this chapter I flag carers' pseudonyms according to how they define their child's morbidities, and from their responses, categorised late effects as moderate [A], severe [B] and disabling [C] morbidities.

The management categories are not discrete, but form a continuum of morbidities of varying limitations in which carers responded as either co-managers (with their child) or as proactive managers (for their child). The extent in which carers co-manage or proactively manage late effects varied according to their interpretation of their child's capacities to manage their own conditions both currently and as future adults. Physical and cognitive late effects are also examined separately, as carers define these as requiring different responses. The categories emerged through careful constant comparison of how carers defined and responded to the extent of their child's late effects and evaluated their child's capacity to self-manage their own morbidities. My analysis was also informed by the extent to which child late effects represented ongoing disruptions in carers' lives and how they made sense of their new care responsibilities (Bury 1982).

The findings illustrate that carers of a child with moderate and severe late effects adopted a co-management approach (with their child), characterised by strategies to empower their child's current self-management and future autonomy. However, carers of a child debilitated by late effects employed proactive management strategies (for their child) due to their child's reduced capacity to deal with their own morbidities. There are similarities between the late effects categories and 'cancer shadow' categories discussed in the previous chapter as they both derived from cancer. However, late effects emerged as a distinct category due to the emphasis which carers gave to the ongoing impact and necessary management of child morbidities in their own and child's lives.

Managing child morbidities required carers to incorporate complex and skilled practices across all late effects categories: including intensive child monitoring, anticipating and planning strategies, accessing remedial, health, allied health and educational resources, as well as diet and lifestyle approaches. Despite the negative impact of late effects, carers adopted strategies to normalise their situation by de-emphasising their child's impairments, lowering expectations of their child's achievements, and their own everyday expectations. The findings demonstrate carers' traditional gendered arrangements were sustained with mothers taking the majority of childcare/late effects responsibility and practical tasks. Fathers' responses aligned with the 'new father' trend of being more child and family orientated but this value shift did not translate into increased childcare labour or late effects management (Wall and Arnold 2007).

Managing moderate late effects

Annie [A] typified participants who spoke of dealing with their child's multiple but moderate late effects by co-managing the ongoing consequences in partnership with her child. Annie is married with three children and her youngest child was diagnosed with leukaemia in 2001 at three years of age. She referred to the diagnosis and treatment phase as relatively straightforward: 'I think in hindsight she probably sailed through it as much as you can; we never really had any major complications'. Annie spoke of being elated by the prospect of her

child completing treatment but when the transition occurred she said: 'we had no idea of what to do' and felt compelled to conform to medical staff advice and 'get back to normal as soon as possible'. Annie now challenges this expectation:

> When I think about it, nobody ever spoke to us, no professional ever said OK you've stopped having medicine now but it's going to take a little while and when I really think about it, when she was back at school and everyone was saying how lovely she's off treatment, she was still feeling like shit for two years and I know now that if someone had explained to her that that was OK and that was normal and every week it's going to get a bit better, she would have coped much better than constantly being told you're fine, you're fine, go and join the crowd. I can very much remember her in Prep hating play time because they played chasing and she couldn't keep up, didn't have the energy and I thought, Oh you've just got to keep playing you know, you'll catch up. Yeah, little things like that I look back and think, gosh, it could have been made a lot easier if it was explained that it takes time.

Annie attempted to meet cultural expectations to return to an assumed normal immediately after treatment but felt this impeded the time both she and her daughter required in order to physically, emotionally and socially heal. She also needed a post-cancer period of time to develop a new sense of normality to incorporate her daughter's late effects into their everyday lives.

Annie defined her current situation in which 'cancer is not the issue anymore but [her child's] battered body, the healing and rejuvenating side of coming out of it takes quite a long time'. Annie perceived her daughter as needing close monitoring. Her daily tasks included unobtrusively checking her child for cancer symptoms by looking for patterns of lethargy and more obtrusive surveillance for excessive bruising by 'reading to her when she is having a bath', and an occasional 'eyelid test' to monitor her anemia. Annie discussed concerns about her daughter's ongoing throat, ear and chest infections since cancer, due to her

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immune system not functioning correctly. However, she was more concerned

with her daughter's chronic ankle pain 'from the first day she had [chemotherapy]

and that hasn't changed', and how she has pursued 'every [medical] test under the

sun …we just can't find out what it is'. In response, Annie's everyday care tasks

involve 'taping her legs' and ensuring her daughter continues low impact pool

exercises to maintain and improve mobility. She also considered her daughter

'capable and old enough now most of the time' to self-manage her general

lethargy both at school and when out with friends. Annie's incorporated multiple

tasks in response to her daughter's numerous moderate morbidities, but with a

focus on her child's capacity to eventually self-manage her own late effects.

Annie also saw the need to support her daughter's social integration back into

everyday life after cancer after being isolated and immune suppressed through her

'social development years' from three to five-and-a-half years of age during

treatment. She said: 'it took her [daughter] a long time to adjust to social

situations' so Annie would 'subtly put her in different situations' such as social

and sporting activities which had no affiliation with her school or school friends

in order to enhance her social skills. She also felt it necessary to lessen her

daughter's expectation of being the centre of attention:

> I think my daughter's hypersensitive about her body and that's because if
> anything twinged [through cancer] we had to have a test, but now if she says
> 'My finger's sore', I'm like 'you've got nine others, you'll be right'. We pretty
> much put it onto her, 'I've got a headache' … 'well go and have two Panadol'.
> If she comes to me again in two hours with 'I've got a headache', I'll say 'Did
> you take the Panadol' and if she says 'No', [I'll say] I'm not interested, 'You had
> the chance to do something about it, it's your choice not to, so you deal with it'.

Annie felt her daughter needed greater resilience to deal with her everyday

physical ailments so she adopted an intentional matter-of-fact strategy to de-

emphasise her daughter's reliance on medicine. Annie encouraged her daughter

to develop self-care skills and to lessen the social impact of cancer in her life.

Annie also expressed concern about her daughter cognitive late effects. She

spoke of her daughter as 'a very bright little girl' who enjoys school but has a

learning problem which she attributed to 'all that chemotherapy':

> She sort of not seemed to know what was going on in the classroom and early
> this year they picked up that she can spell very well and read very well but had
> no idea of comprehension. Because she'd been reading so well it had been
> missed and as she'd done poorly in comprehension. They thought it was a one-
> off, no one had really put it together, so she ended up having a neuropsych test
> done this year and found out she does have trouble with processing information,
> but she does have the ability to learn so if it's told to her again and again and told
> in a different way she can work it out but if her multiple instructions are sit down
> and do this, a little bit of panic from her part, but she's not even in the ball park
> of what she's supposed to do.

Annie spends most evenings home tutoring her daughter to improve her literacy

and short-term memory skills, but 'in two weeks it's all gone and she doesn't

seem to be able to build on what she's learnt'. Annie was currently managing

this issue and said her daughter would grow up to be 'healthy, happy and

somewhat independent' but was concerned if her child could sustain her current

efforts as she matures. Annie's account represents a new normal in which her

everyday life as a morbidity manager involves multiple emotional, surveillance

and tutoring tasks to normalise her child's late effects into their everyday lives.

In a contrasting and separate interview Geoffrey [A] (Annie's husband) said:

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> The only effects she [daughter] has now is she gets a bit tired and might miss a day off school every now and then, things like that. Then they [teachers] know, and that's all we say, we don't tell anyone else. We don't make a big deal of it … she doesn't get treated any differently because she's been sick or anything like that, she's expected to do everything as normal.

Geoffrey down-played his daughter's late effects morbidities and emphasised what he does not do, rather than what he does, other than informing her teachers. He stressed that he treats his daughter 'as normal' and emphasised the importance of her being perceived in this manner. His account is in stark contrast to Annie's multiple tasks of dealing with their daughter's lethargy, mobility, social skills and learning impairments. Geoffrey's and Annie's accounts are typical of the way in which carer enacted their gender roles in dealing with child morbidities. Their accounts illustrate ways in which traditional gender norms of motherhood and fatherhood are sustained through childhood cancer remission. Annie is immersed in the management tasks and responsibilities of their daughter's late effects as an extension of her maternal identity; whereas Geoffrey is immersed in a stoic form of impression management (Goffman 1959) as his child's late effects 'constitutes a threat to masculine identity' (Dixon-Woods, Young and Heney 2005: 162).

Molly [A] expressed a sense of self-blame and guilt in making treatment decisions which resulted her daughter's chemotherapy related hearing deficit:

> The hearing loss is because we made the decision to save her life, but it's always there, and in [daughter's] case, she's very bright and reads well ahead of her age group. With her language, she had early intervention, a form of speech therapy when she was young. She's with an organisation who believes that every child has the right to learn to speak, no matter how deaf they are, so they don't sign. She goes to a normal school with her sister, she has some issues because of her hearing but otherwise she lives a relatively normal life except for the technology she wears on her ears. So we're lucky in that respect, but guilt is still there.

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Molly expressed responsibility for her daughter's late effects but emphasised accessing audio technology resources to help achieve new sense of being 'relatively normal'. She also changed her career since cancer and now works for the hearing-impaired support organisation that assisted her daughter. Molly employs a deaf-as-normal approach in response to her child's deficits: 'I don't make compensations for her. Like she's deaf, but she's not stupid … we're very conscious of trying to make life normal'. Cancer experiences and late effects have shaped Molly's carer and professional identities with a sense of duty towards her daughter and other deaf children. Molly's co-management approach was not as complex or exhausting as Annie's multiple efforts, but they both focused on incorporating their children's deficits into a new sense of normality.

In contrast, Alice [A] adopted a non-disclosure strategy to deal with her daughter's learning impairment because of her need to be perceived 'as normal' in her small town situation. Her daughter was diagnosed with cancer as a two-month-old baby in 1994. She described her daughter as 'a happy social butterfly but physically under-developed', with a cognitive deficit where she 'just goes off in fairyland and can't concentrate at all, to a point where at 15 years of age she still can't count money'. Alice said she was offered tutoring support for her child but refused assistance because in a small town: 'I just wanted us to be as normal as possible … I didn't want to be pitied or treated any differently'. Alice emphasised her locality, where 'everybody knows your business', as the reason

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not accepting remedial support and for not telling her daughter that her learning problem was caused by cancer treatment. Instead, Alice adopts a 'passing as normal' (Goffman 1968) approach to deal with her daughter's cognitive deficits: 'I wanted to keep her as normal as possible and didn't want to tell her, so I've never spoken about it with anyone before really'. Alice's account differs from that of Annie and Molly, as the socio-cultural influences of her locality informs her non-disclosure approach to construct a new sense of normality despite her child's late effects. Non-disclosure represents a preferable approach rather than face potentially negative social sanctions of her child's cognitive morbidity.

The findings demonstrate that the moderate late effects continue to impact on the lives of children and carers after cancer has abated. Carers evaluate and respond to their child's morbidities by monitoring, planning, accessing remedial and educational resources, and non-disclosure practices. Their differing management practices combine to illustrate strategies aimed towards establishing and negotiating a new sense of normality while enhancing their child's resilience, autonomy and future independence.

Managing severe physical late effects

Carers dealing with their child's severe late effects are more active in initiating medical and remedial resources than those carers in the previous 'moderate' category. They nevertheless enacted similar co-management strategies as they

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evaluated their child with the capacity to eventually self-manage their own

situation as future adults. Angela [B] typified carers dealing with their child's

severe physical morbidities. Angela is married, with three children and said that

her everyday life has currently 'just evolved to where we are now really, we're in

a happy good place'. Her four-and-a-half-month-old daughter was diagnosed in

1994 with a cancer in her bladder area. Angela spoke of the crisis of treatment:

> She had chemotherapy and two lots of radiotherapy and after a while they realised that it had actually failed, it didn't work so then it was very quickly moved to radical surgery and that was going to be the end result. If they didn't get surgical cure, we wouldn't have anything.

Surgery meant the removal of her daughter's bladder and urethra and she

permanently wears a 'urostomy bag' to collect urine. Angela spoke of cancer in

the background of everyday life, and of philosophically of 'living in the present':

> I don't think about relapse and probably haven't for a long time. I guess in the back of my mind there's the worry of a second sort of cancer later in life because of radiotherapy and stuff like that, but I try to keep it where it belongs, in the back of my mind. One thing all this has taught me is that you don't know how long you've got them, so we make the most of now and love them while you can.

She also described chemotherapy treatment resulted in her child's 'rotten teeth'

which will require dentistry and of earlier concerns with radiation impacting on

her daughter reaching puberty, which resolved without hormonal intervention.

Her current focus was to support her 15-year-old daughter to take increased

responsibility for managing her late effects. Angela developed different late

effects strategies according to her daughter's age and competencies. During her

daughter's early school years Angela wrote a booklet explaining her cancer and

urostomy bag instructions to inform her teachers and school friends. The booklet

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included directions for draining and changing the bag as her daughter was unable to physically manage the bag at a young age:

> Going to school I thought, toilets and that sort of thing, so we actually made a little book and that was her first big understanding of it … I had to let go of the care for the bag, because in early school she couldn't physically change the bag if it was leaking, so it was either; 'I go to school, or someone at school had to do that'. So it was sort of handing it to someone else's involvement.

Angela delegated her responsibility for care due to her daughter's age and school situation. The book served as a pragmatic resource to promote her child's trust in others, a degree of independence from her mother and promoting a sense of shared responsibility with her teachers. The book also symbolised an extension of Angela's care parameters into her child's school life.

Angela found it beneficial to de-emphasise cancer late effects in a pragmatic manner. She portrayed her daughter as 'excellent, she's 15 and knows everything and very normal … once in a while she'll say, why do I have to have that stupid thing [urostomy bag], and I say, wake up to yourself, you would have died if we hadn't have done that'. She described her daughter as a 'pretty remarkable kid' who accommodates her 'bag' into everyday life. Angela said that her daughter tucks the 'bag' into her swimsuit as she follows her passion for swimming and that she plans to be a swimming instructor. However, Angela had ongoing concerns about radiation treatment, which resulted in her daughter's partially fused genital tissue that will make future sexual intercourse and natural childbirth problematic. Again, Angela delegated care responsibility to her daughter:

It's something to hand over to them when they start taking care of themselves. That's where I'm in the process with [daughter] now, trying to get her to be more active when I take her to a doctor's appointment so that she has to tell her story. And she knows her story well, I told her that this is important.

Angela also anticipated the future and initiated a relationship between her daughter and gynaecologist as a provisional plan if remedial surgery is required:

I said to the gynaecologist that I only want to come now because [daughter] doesn't know what the future holds, and I just want her to meet you now 'cause I figure it's easier if we come once every two years at this age, then she gradually gets to know you and have a bit of a relationship, rather than try to drag her here kicking and screaming at 16, it's too late then, it's forward planning. A year or two ago, after she had been to the gynaecologist, and talking about sex and stuff and 'yuk' she says but I'm not talking about physically doing it, but it may not be a normal process for you. Who knows, you might have to see a special doctor that talks about that, I just want to plant that seed in her mind so if she wants to come and ask me something she can.

Angela's forward planning strategy established a relationship so her daughter could take control of her own current and future embodied self. She spoke of her moral responsibility: 'It's important for me because, you know, we were the ones that made that decision to cut that bit out of her; although we didn't have a choice, we had to do it'. She raised a fundamental dilemma experienced by all the participants, in having no treatment choices, but left with the ongoing responsibility of a child's care. Angela inferred that her daughter may have a learning impairment as she 'works hard to be an average student', but her key focus was to anticipate and plan for her daughter's future self-management.

Louise [B] adopted holistic and remedial allied health resource strategies for co-managing her teenage son's severe physical late effects which resulted from his

cancer treatment in 2004. She described her son's late effects as general lethargy,

weak eye muscles and a scoliosis-type condition caused by radiation which

impacted on his uneven abdominal muscle growth: 'He's tired all the time and

walks like an old man and he's all bent over'. Her evaluation of her son's late

effects differed from the oncologist who 'won't accept that the small amount of

radiation would affect him'. However, Louise relied on her own intuitive

knowledge and gave the specialist little authority in dealing with her son's

remedial care: 'I don't care to get into an argument or discussion with him

[oncologist] about whether it's the radiation, because we're dealing with it'. She

managed her son's late effects with a holistic lifestyle approach of diet and

exercise with naturopathy, massage and chiropractor support. She felt her

healthy-body/healthy-mind strategy was effective in restoring her son's well-

being:

> You've finished [cancer treatment] but now you need to heal what the chemo
> and radiation did. The faster they get their bodies back and loosened up and
> working better, their brain will work better and they won't be so tired and they'll
> feel strong again. By setting that up, he'll know how to maintain himself;
> otherwise that weakness continues to stay with him.

Louise spoke of her healing strategies as developing healthy, positive behaviour

patterns for her son to follow and was confident that his future will not be greatly

impeded by his current situation: 'He's decided to join the Army, so I want to

keep him healthy and not bring his career into doubt'. Eve's [B] main future

concern was in relation to her child's ongoing reduced mobility since leukaemia

treatment:

> She toe-walks everywhere … she has no flexibility at all, she runs and skips and walks on her tip-toes and it does give her a few back issues at times. We tried physical therapy. She had a cast, they stretch her feet up gradually and cast it, bring her in again and they stretch it up a bit more and it hurts. They had her in a wheel chair and it did no good at all, it just went back to the way it was. So she may have to see an orthopaedic surgeon to have her tendons severed and stretched out. I don't want to consider that until she's in her teens. She can decide if it's impacting on her.

Eve remained uncertain whether her daughter's compromised mobility will improve over time but decided to adopt a wait-and-see strategy as previous clinical intervention exacerbated her daughter's suffering. Eve's ongoing care management was focused on allowing her daughter to enjoy her childhood, but with a heightened awareness of her child's capacity to make her own decisions.

The findings build on the concept of new normal by showing how carers become late effects managers. Carers responded to their child's moderate physical morbidities as vigilant, remedial managers, while sensitive to their child's current and future autonomy. They are also discerning in the use of medical resources, and incorporate holistic, lifestyle approaches and allied health resources. In order to integrate and normalise their child's late effects into everyday life, carers employ strategies so their child will eventually self-manage their own late-effects.

Managing disabling physical late effects

Claire [C] typified carers dealing with their child's more disabling physical late effects. She described her daughter's morbidities as permanent and debilitating, but nevertheless maintained a co-management approach as she sees her now

young adult daughter as having the capacity to deal with her own afflictions. Her

account is also distinctive, as a primary carer who drew extensively on her

professional discourse as a paediatric and intensive care nurse. Claire is married

with three children. Her daughter had leukaemia in 1996 when five years of age

but relapsed 11 months after completing initial chemotherapy. The second

treatment entailed cranial and full body radiation, chemotherapy and a bone

marrow transplant. Claire explained her daughter's initial prognosis:

> She's probably the longest survivor in Australia with the cell count that she had, so she had 243 000 blasts on diagnosis which is almost unheard of and having a medical background, I guess we knew from the beginning that … they kindly said it was a 50-50 chance, so we knew from the beginning it was touch and go.

She stated that 10 years post-transplant 'cancer has certainly had an impact on us,

but it did not break us' and now defines her life as 'about focusing forward …

and not endowing it [cancer] with any more importance than what it is'. Claire

spoke of her daughter's multiple morbidities manifesting in a compromised

endocrine system and metabolic syndrome.[4] Claire's 18 year-old daughter is

menopausal and infertile, with compromised thyroid and pituitary glands, ovaries

and eyes, heart and kidney damage and hypertension:

> Her thyroid has failed so she is on thyroid replacement, she's got cataracts which will have to be operated on at some stage, that's related to the bone marrow transplant. 80 per cent of children who have total body irradiation, their thyroid will fail within the first five years and [child] was spot on with that. It's the same thing, I think 70-80 per cent will develop cataracts and of course she has got complete gonad failure which means that she didn't go into puberty, so she had to have growth hormones as well as hormone replacement in order to go into puberty. She'll have to have hormone replacement for the rest of her life in order to maintain health. Then she's developed hypertension which they can't really decide if it is some sort of renal problem or where it is coming from.

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[4] Metabolic syndrome represents multiple morbidities associated with obesity, stroke, heart disease and diabetes due to compromised hormone producing glands (AHA 2007).

Claire correlated her daughter's late effects with the statistical probability of

treatment protocols and permanent consequences.   She spoke of her daughter's

compromised hormones affecting her health:

> Hormones produced by the thyroid relate to energy levels and so if you have a
> damaged thyroid you put on weight because your metabolism decreases, you
> become very sluggish, you get greasy hair, greasy skin, feeling very sleepy and
> as far as the ovaries and the fact that her pituitary is damaged, that relates to
> whether you grow boobs or not. You get that whole issue of metabolic
> syndrome: of higher cholesterol levels, developing diabetes, you get a central
> kind of fat that puts you in higher risk of heart disease, so she's carrying that
> around as well. It's just a question of you have to monitor her all the time …
> blood levels and whatever is going on.

Claire drew on both her carer and nursing knowledge to constantly monitoring

her daughter's extensive late effects. She evaluated her daughter's overall health

by comparing the poorer outcomes of other childhood cancer survivors:

> Compared to a lot of friends who transplanted at the same time and they have
> had to have hip replacements because of the radiation damage to their joints, she
> escaped that. One of them has had to have a renal transplant as well because it
> damaged the kidneys so bad. In the scheme of things she has no lung damage,
> her heart hasn't been damaged where some of them have severe heart damage so
> it's like weighing up, the difficulty here is, in terms of that she is doing the kind
> of health surveillance that you would expect people in their 60s to be doing,
> because hers is the kind of damage that happens when you age but she will have
> to do all the taking the medication and attending the right screening and being
> aware of all of that from the age of 17 and for the rest of her life so that's the
> difference. I guess it's a blessing in terms of you grow up with it and that's what
> you have to do and just do it.

Her account supports emerging childhood cancer findings for young cancer

survivors with multiple geriatric type chronic illness conditions (Rosoff 2006;

Oeffinger et al. 2006). However, Claire saw her adult daughter taking control of

her own health monitoring as her cognitive capacity is not overly compromised:

> Well, she has short-term memory problems and some degree of … before she had her bone marrow transplant she had psychometric testing which placed her in the top one per cent of the population and post-transplant she is in the top twenty per cent so she's about dropped 20 per cent. It still means she is still bloody bright, she's just not as bright as what she should have been.

She claimed that 'no one would notice' her daughter's deficits and did not expect her short-term memory to impede her future career ambitions of becoming a chef. Claire was stoic about her daughter's situation, in her having paid an 'acceptable price' for surviving cancer with a reasonable quality of life. Within this complex of late effects, Claire singled out her main source of grief was her daughter coming to terms with her infertility:

> I mean the only sadness was when she had to come to terms with the fact that she won't be able to have her own children and that's a huge regret and watching her grieve over that. But at the same time, the other option is she would be dead and she wouldn't have any children anyway.

Claire's account draws attention to the extent of morbidities associated with childhood cancer survival. She nevertheless spoke forthrightly of her daughter's capacity to now manage her own late effects. Her account illustrates the disruption of her previous taken-for-granted assumptions and constructing a new sense of normality in response to her daughter's late effects:

> A very important thing for me was when [child] was diagnosed, her oncologist from the beginning said, 'Life will never be the same', and that is something you have to accept in terms of … you go through life with the expectation that your kids will grow up and be healthy and live longer than you, and all of a sudden you have an event like this which completely turns upside down all of those assumptions. So of course life will never be normal, certainly for a period of time you might go through a period of treasuring every day but from that point of view things are back to normal in terms of … life goes on … it's not at the forefront of your mind which in a way returns to normal, but at the same time you have to live with long-term effects and the surveillance and all those things.

For the last thirteen years, Claire's pragmatic response to her daughter's multiple late effects illustrates her own surveillance and strategies to promote her daughter's own morbidity self-management. Her account demonstrates disabling physiological morbidities being co-managed and accommodated into everyday life, although in a more intensive manner than those dealing with lesser deficits.

Managing severe cognitive late effects

Cognitive late effects emerged as a category as a distinct category from carers who spoke of the permanency of their child's deficits. Carers emphasised their child's positive attributes despite the cognitive deficits as a way to protect their child's identity. They also sought tutoring resources to enhance their child's learning ability but realised the lasting impact of cancer treatment on their child's potential. Carers expect their child's reduced learning capacity will have long term implications on their own care responsibilities.

Adam [B] typified participants who discussed dealing with their child's severe cognitive morbidities. His daughter was diagnosed with leukaemia in 2004 as a four-year-old and treated with chemotherapy. He drew an analogy of a forgetful cartoon character in a children's movie to describe his child's deficits: 'Well, her nickname is Dorrie out of Finding Nemo. She's a real dopey one, that's how she is, she's beautiful but she's a Dorrie. Her goals are small ones and she's still

getting there with them'. Adam felt that tutoring aided his daughter's learning but was nevertheless convinced that her cognitive deficits are permanent:

> Academically she always will struggle. She hasn't got a memory and the way she processes information makes it very hard for her to learn, things have to be repeated over and over again. She's had tutors from while she was on treatment and still is getting tutored. Whether it's reading, writing, maths, she's getting there, six months ago she couldn't read now she won't put a book down.

Adam said that 'the most beneficial part that [daughter] has got from school has been social, the social aspect of school has done her more good than the academic side of it'. His account illustrates a strategy of lowering the expectations of his daughter's education achievements but finding new ways to measure her success:

> She's just happy in herself ... that side of it [school friends] has done her more good than the academic side of it, because her confidence is back up, she's comfortable in herself with who she is and what she can do and the rest of it will look after itself if she works at it.

Adam emphasised school as a site for his daughter to enhance her friendships, restore her self-confidence and emotional well-being, rather than achieving educational attainment. In doing so, Adam also stressed the importance of his daughter's positive attributes, and emphasised what she can achieve rather that what she was unable to accomplish. He also offered a tentative insight of how he might support his daughter into adulthood:

> She'll be right. The more we go on [after cancer] the more confident I am that she will, we sort of joke that we'll have to have our own business just so she's got a job, and that's all right if that's what we have to do.

Adam spoke in a frivolous manner regarding his daughter's future. His account nevertheless infers long-term implications and the need to plan for his daughter's ongoing dependence and care.

Emma [B] explained her responsibility in managing her daughter's cognitive deficits: 'I'm the mother and it's my job to keep it running smoothly and all together'. As part of this responsibility Emma emphasised her daughter's positive attributes: 'She's very positive, very friendly, has a lot of older friends'. Emma saw the need to access tutoring support in response to her daughter's learning impairments but was sensitive to her daughter's sensitivity in being perceived as 'different' from other students:

> Academically is a bit of a difficult one because she works so hard to get her grades but she just didn't have a life. All her teachers without exception were so impressed with her work ethic, and she was getting passes, maths was just too hard. She's becoming a reader … her English language skills were good but writing always took a very long time, she would come home and do most of her stuff on the computer but she'd take her notes to school so she didn't look different, she was allowed to take her lap top to school but didn't like to do that.

Emma also explained the problem of accessing tutor resources because she had difficulty getting her daughter's cognitive deficits legitimised. However, Emma strategically overcame this barrier:

> Because it [child's learning deficits] wasn't a recognised problem, they were branding these kids lazy or not willing to work because they'd missed so much school. I got her moved through the oncology department to the acquired brain injury clinic which took a lot of 'political soft-shoeing' so that you didn't step on anyone's shoes, but because you didn't want … they were afraid you were going to sue them for the treatment that had caused this damage, I think, but initially our specialist was saying it's your perceived concerns.

Emma encountered reluctance by clinicians to legitimise her daughter's cognitive late effects, but manoeuvred around various institutional health care barriers and eventually gained tutoring support. Her account illustrates the socio-legal implications of accessing resources to deal with childhood cancer late effects. She said that an implicit threat of litigation as the underlying cause of limited access to tutoring resources and spoke of how clinicians challenged her 'perceived concerns' in order to discourage Emma from pursuing legal intervention. While frustrated with getting appropriate support for her daughter, Emma nevertheless applauded the health care system as 'wonderful'. Participants therefore manage their child's severe cognitive deficits as 'guardians of their child's biographies' through emphasising their child's positive attributes and accessing tutoring support (Young et al. 2002: 1843). They also realise and accept the permanency to their child's cognitive limitations.

Managing disabling cognitive late effects

The management of disabling cognitive impairments emerged as a category in the findings from carers' evaluation of their child's incapacity to self-manage their own deficits. Carers spoke of a distinctly proactive management approach 'for' their child, as opposed to the previously described categories which represented carers' attempts to co-manage late effects 'with' their child. Marilyn [C] explained her child's cognitive morbidities as significantly shaping her life after cancer. Marilyn is 42 years of age, married and has four children. Her son was

diagnosed at four years of age in 1999 with lymphoma. Her everyday life is

focused on dealing with her son's 'complications' whereby he acquired a

common 'airborne fungal infection' in his brain and central nervous system while

he was immune suppressed: 'They [clinicians] believe it was introduced via a

lumbar puncture through one of his chemo treatments'.[5] She spoke of the many

surgical procedures clinicians used in an attempt to lessen her son's morbidities:

> Yeah, it [infection] crossed over into the brain and [he] ended up with a
> hydrocephalus shunt inserted and everything so to drain the fluid [from his brain]
> into his abdomen. He's got two of them, they're permanent but are very … with
> continual infections in them, he's had about 30 operations on his brain, to try and
> get them … yeah they're permanent but very temperamental, because of
> infections and all sorts of things.[6]

Due to the treatment 'iatrogenesis' (Illich 1976), Marilyn had to 'teach him to

walk again after three or four years'. She also liaised closely with clinicians to

administer her son's hormone replacement therapy in order to 'let him go through

puberty normally'. She summarised her son's current morbidities:

> He has a lot of deficits from that: intellectual deficits, physical deficits and some
> visual deficits. That's why we don't worry about the cancer [and] … he's not
> aware that he can't have children [from testicular radiation] or anything like that.
> He's not mentally or physically able to take that on board yet.

Marilyn was immersed in dealing with her son's late effects of cancer treatment

rather than cancer *per se*. She described his short term memory function as

follows: 'If he met you, five minutes later he would forget, but apart from that he

would be absolutely perfect. Given all the other things, that is the only thing that

impacts on his life, everything else he's learnt to deal with'. Marilyn nevertheless

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[5] Marilyn refers to the airborne fungal infection as 'Aspergillus'.
[6] Hydrocephalus shunts drain excess cerebral fluid to reduce cranial pressure on the brain, which
is otherwise a life-threatening situation. Infections are common with this procedure (Rivka 2007).

de-emphasised her son's deficits and affectionately described him as 'a lovely boy, always well spoken, well mannered, happy and beautiful'. In this manner, Marilyn protects her son's identity despite his reduced cognitive capacities.

Marilyn also discussed her son's infertility, visual and physical impairments but emphasised the management of his cognitive deficits. She explained his limited memory: 'It's more of a danger thing than anything else, an orientation thing. Like you couldn't put him on a bus and say get off here because he wouldn't remember [where to go]. All those things we have to address'. She defined her situation as adapting everyday life around her son's limitations while attempting to incorporate other family members into a newly constructed sense of normality:

> There are things we don't do … we don't just get up and go to the park; we haven't done things like that because it's a physical limitation with [son] as well. You can't just leave him behind while we take the other kids, unfortunately. Everything else we try and do as a family, we go camping and everything. I look at other families sometimes and, like, we go to Movie World on Saturday for a birthday, so we're going to do that rather than go water skiing, trying to keep them all happy without … just getting a balance.

Marilyn played a pivotal role in managing her family life around her son's limitations. She compared her new sense of normality to 'other families', but drew attention to what they did and minimised what they were unable to accomplish as a family unit in order to normalise their situation. Marilyn spoke of mediating family relationships, including her husband's 'disappointment in not being able to do all the normal physical father/son things together' and reconciling sibling jealousy from her son being the centre of attention through

cancer. She portrayed a sense of acceptance with her current situation but had

grave concerns if she ever lost her capacity to care for her son:

> I just worry about his future, I worry about that more than anything else, I worry
> if anything happens to us … I just know that he'll be with us or there'll be
> someone having to care for him, my husband and I, and when we go, that's one
> thing I haven't thought that far ahead yet in so far as if we went in a car accident
> the kids would be looked after with the grandparents, but I dunno, I don't want to
> think about it.

Marilyn exerted much physical and emotional effort in caring for her son and

accommodating his deficits alongside other family relationships. However,

Marilyn's reluctance to consider her son's ongoing care reflects her immersion in

daily late-effects management, and infers a fear of an imagined future.

Pauline's [C] situation was similar to Marilyn's, in dealing with her child's

disabling cognitive deficits, but has the added factor of her daughter's now adult

age. Pauline is 54, divorced and has six adult children. Her youngest daughter

was four years of age when diagnosed with a brain tumour in 1994. Treatment

involved chemotherapy, radiation and two surgeries after which:

> She had trouble with brain fluid building up so she had a [hydrocephalus] shunt
> put in and for three months after that she was just in absolute abject pain. From
> that time our household was just revolving around pain and screaming. We tried
> to find out what it was with ultra-sounds. The shunt jabbed into her bladder, so
> they whipped it out and she was OK but she has a weak bladder because of that.

Surgical intervention saved her daughter's life but resulted in ongoing suffering

and a permanent weak bladder. The second operation and subsequent radiation

treatment exacerbated her child's late effects:

> She couldn't even sit up because of the damage to her brain. She couldn't sit up, let alone walk. She was in hospital for her fifth birthday so she was supposed to start school while she was having her operation. I took her to school every day in a pusher, 'cause she still couldn't walk. I helped in the class and I'm not sure how long it was but during that term it was like watching a toddler learn to walk for the first time.

Her now adult daughter has permanent balance and mobility problems, limited coordination, double vision, hearing loss, memory and cognitive morbidities:

> She's got a weakness on her left side like a stroke victim would have, from that second operation where that damage was done. It's like she's had a stroke, she's weak … like, if she jumped, she can't jump or skip like a normal child can because of the balance, if she jumped her left leg would give way. When she's cutting things with scissors and tying her shoelaces, her hand will tremble, especially that left one.

Since her daughter's remission Pauline has assumed much responsibility in attempting to manage her daughter's deficits, seeking remedial treatment, exercise regimes, physiotherapy, hydrotherapy and 'just basically everyday stuff' to help her daughter's coordination and mobility. However, she found that support programs were aimed at addressing acute rather than chronic conditions. She spoke of being abandoned by the health care system, which saved her daughter's life but caused her ongoing and significant morbidities: 'once they feel there's no more progress to be made you get dropped, there's no ongoing maintenance treatment'. She portrayed her 18-year-old daughter's potential future in terms of her attributes and constraints: 'She's a nice looking girl, she's intelligent and quite mature in her emotions, so there's no reason a guy can't be attracted to her', but added that 'she has a 13-or-14-year-old capacity for dealing with things'. Pauline regards their relationship as 'close' but said: 'I'm actually trying to push her away a bit … so that she can learn to deal with things on her

own'. Pauline was negotiating a delicate balance between prompting her adult daughter's autonomy while realising her limited capacity to live independently.

The findings demonstrate that a child's late effects significantly shape how carers construct their everyday lives after cancer. Hence, the concept of new normal encompasses carers enacting new late effects management roles of constant vigilance, planning and accessing education and health resources in order to mitigate their child's morbidities. Carers dealing with their child's debilitating cognitive incapacities are more proactive in their efforts to construct a new sense of normality but realise the permanency of their child's reduced capacities. Carers realise that late effects of cancer treatment are a significant price for a child to survive cancer (Heath 2005; Rosoff 2006). The management of child's morbidities symbolises carers' ongoing obligations as protectors of their child's well-being, with new ways to normalise their situation in remission.

Evaluating moderate late effects

The concept of new normal includes the ways in which carers defined their own situation in the context of medical clinicians having saved their child from a fatal outcome but who are left with ongoing morbidities of cancer treatment. Carers evaluated their child's late effects from two perspectives: first, by emphasising their 'no choice' position in seeking clinical intervention and, second, by reappraising medicine according to their child's cancer outcomes. The findings illustrate the way in which carers of children with moderate late effects

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constructed a life before quality of life evaluation, whereas those dealing with

severe late effects constructed a more critical and reflective life with quality of

life appraisal. However, carers of a child with disabling late effects question the

limits of medical intervention, as the quality of life of their child was excessively

compromised and felt their ongoing care was particularly arduous.

The participants who had children with moderate late effects assigned meaning to

the survival/late effects paradox from a life-first perspective. Victoria [A]

constructed a fundamental equation for seeking medical intervention or a fatal

outcome: 'It's a matter of, if you don't do anything, you know, you're going to

die. So, yes, you put your faith and everything into the hands of the doctors'.

Mimma [A] prioritised her child's life and potential infertility as a lesser concern:

> You have to have the medicine, these effects, even if it comes to where she can't
> have children. The main thing is that she survived; these other things can be
> dealt with, when and if the time comes, but I wouldn't have had it any other way.

Margie [A] similarly emphasised having no choice in seeking medical treatment

to save her child's life. From this perspective she incorporated her child's late

effects and his lost potential into a new sense of normality:

> I mean, we had no choice but to allow them to do this to our child, and what long
> term effects that had. You've got to be grateful that you still have them but some
> days you think they're not quite what they could have been, but they're normal
> compared to what they've had to deal with through the radiation and everything.

Ruby [A] spoke of dealing with her son's diminishing physical late effects after

his bone cancer treatment in 1996. She described her son as currently healthy and

pursuing tertiary studies, but with ongoing mobility deficits as chemotherapy,

surgery and radiation treatment took several years to resolve. Ruby negotiated the dilemma between a clinical focus on remission, and trying to ensure her son's quality of life in the context on unknown outcomes:

> You don't think about quality of life because nobody could tell us what it was going to be like down the track. We were asking; 'How will this affect him if we go ahead with this, what is going to happen?' And they're like, 'We don't know, we have never done this before'. So there are issues you are addressing at the time, well, if we don't do this what are our options, just go for it and hope that the quality of life is OK or reasonable. I mean he had very bad quality of life once he started walking, he had a lot of problems and he was on morphine daily and we ended up having to go outside the hospital to find other avenues to help him.

Ruby emphasised trying to make an informed decision for her son's wellbeing when clinicians could offer no assurances with their experimental procedures:

> The surgeon we were seeing, when he said it [hip] will have to be fused and we were asking him a lot of questions that I would think of, and he basically said, 'Why are you questioning my decisions and doubting what I am telling you? This is now it is'. That didn't go well with us at all. He didn't like us questioning his decision on what needed to be done … and we thought, no that's a horrible choice to have to make, that would mean he would have no movement in his hip joints, sitting down, picking up something, driving a car … so we said, no, we're going to look at other things.

Ruby's difficulty was trying to get appropriate advice from which to make a decision to alleviate her son's pain and correct his late effects. After considering but rejecting orthopaedic intervention she eventually chose 'word of mouth' advice from a work colleague and sought chiropractic support. She remained unsure as to how her decisions would impact on her child's long-term well-being:

> He was in bad pain for about six months before we finally found he had scoliosis of the spine and we started to see the chiropractor. So we crossed our fingers and hoped we were doing the right thing and within a month the pain had stopped, it was just amazing.

Ruby justified her intuitive decisions; as her son's initial quality of life was

adverse but progressively improved:

> We have spent, I wouldn't like to think how much on chiropractic visits for him over 10 years, and he still does go because he still needs to keep that spine straight, and maintained and checked on … The chiropractor has managed to keep the difference minimal and you can hardly notice the limp when he walks but you're paying to have that maintained.

Ruby was instrumental in managing her son's late effects in the cancer aftermath.

She portrayed the complexities between her son's life and quality of life, remedial

intervention and the economic burdens of her decisions. However Ruby said:

> You wouldn't have it any other way but save your child. Once you leave the hospital you're cured, then there's no more. You feel it's a slap in the face to say you've cured my son or daughter but he's still got these problems. We need to go to court to get the money now to keep them the way they should be and you just don't want to go down that road, do you?

The issue of litigation was often raised but immediately revoked, which suggests

carers think of but discard the idea of seeking compensation on behalf of their

child. Their reluctance to seek restitution arises from the way in which carers are

culturally ascribed with their child's well-being. To seek compensation infers

carers as less-than-grateful towards clinicians for saving their child's life.

Evaluating severe late effects

Carers of a child with severe late effects constructed a life with quality of life

evaluation of the medical prize/price paradox. Eve [B] assessed the necessity of

medical treatment in saving her daughter from leukaemia against the situation of

not knowing what the outcome might entail:

> I mean, what can you do, you either lose your child to cancer by not treating
> them or you cope with the after-effects and just be as prepared as you can for
> them. It's a double-edged sword isn't it. If there's some chance of them
> surviving, what parent in their right mind wouldn't? We asked the doctors what
> the treatment will do as she's so young, will she be able to have children and will
> she end up with secondary cancers? The answer was maybe, they don't know.

Eve's double-edged sword metaphor encapsulates her dilemma as clinicians

could offer no assurance of late effects compromising her daughter's well-being.

She evaluated her daughter's cognitive deficits from quality of life perspective:

'A learning difficulty isn't such a big deal when your child is still alive, but to us

it was quite important'. Eve gave primacy to her daughter's survival but

integrated her quality of life into the equation. She emphasised tutoring for her

daughter to 'keep the basic standard up but she's so happy and confident … so

that's what we're focusing on at the moment'. Angela [B] explained her

dilemmas through her daughter's treatment:

> She had the chemotherapy and two lots of radiotherapy and after a while they
> realised that that had actually all failed, it didn't work. So then it was very quick
> that we moved to radical surgery and that was going to be the end result. If they
> didn't get surgical cure, we wouldn't have had anything … I have absolutely no
> regrets about any of the decisions we made at what to do because I know we
> made the best choices we could at the time. So knowing the end result I
> certainly would have done everything differently, we would have just gone [to]
> the surgical cure right from the beginning and there would have been minimal
> surgery rather than radical surgery. She may have kept her bladder, but you
> don't know the end result.

Angela emphasised the treatment phase escalating in her daughter's radical

surgery and frustration in not knowing the eventual outcomes. However, she

described her daughter as currently well-adjusted and her family unit as being 'in

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a happy good place'. She also applauded 'the surgeon she had, I will adore to the end of my days, and we had some really great staff'. Emma [B] felt the clinicians were mutual carers who sought a balance between achieving remission and minimising late effects so that her child could maintain a degree of quality in her life:

> I can cope with that [late effects] because what was the alternative? For us I know they took special care with the radiation, for instance, to calibrate it so not one part of her brain was more burnt than another, like on the angles. I don't think they were doing that anywhere else in the world at that time … the other thing they were trying to do was balance what they were going to lose with what they were going to gain and they did discuss that with me because our point was not [survival] at any costs, we're not saving her life at any cost, there has to be the balance of a useful satisfying life for her.

Carers faced the dilemma of having to make treatment decisions on behalf of their child but not knowing what the 'price' of their child's survival might entail. They were also aware they had little choice as the medical profession could enact legal sanctions to ensure a child's life is sustained through paediatric oncology (Pinnock and Crosthwaite 2005; Shilling and Young 2009). Nevertheless, carers defined their current post-cancer situation with a careful consideration of medicine sustaining their children's lives with a quality of life, and beyond the medical 'prize' of remission.

Disabling late effects: The limits of medical intervention

Carers dealing with their child's disabling late effects described a critical balance between their child's life, quality of life and medical intervention. Claire [C] said that both her child's survival and quality of life was vitally importance:

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> I'm not blaming the medical profession. I've worked where we've had young children on ventilators and we would say to the oncologists, 'Listen, we are at the end of where we can ventilate, we can't move any further'. All they were interested in was whether we had a neutrophil [blood test] or not and we were trying to get them to understand that we're blowing this child's lungs to kingdom come: 'And all you're concerned about is whether or not you can get a blood count'. So issues like that were very much in the forefront of my mind … I have worked with too many doctors who were ready to flog a dead horse and basically put children and families through hell, so I wanted to make it very clear from the beginning that that wasn't where we came from as a family.

Claire drew on her nursing experience and familiarity with clinical protocols to initiate the limits of medical intervention and establish treatment guidelines in order to avoid her child's prolonged suffering:

> I had very clear ideas about what I was prepared to put her through because I knew what I had seen and didn't want her to go through in terms of … we actually called a meeting with the whole [treatment] team and laid out very clear guidelines in terms of if she should deteriorate whether we would go to ICU, how far we would go in ICU if that was going to happen and when we would pull the plug.

Despite establishing a quality of life treatment policy (the only participant in this study to do so), Claire evaluated her daughter's cancer outcomes as a tolerable balance between the prize of survival and the price of remission:

> It would have been nice if she didn't have them [late effects] but at the same time it was an acceptable price to pay for the fact she has had another 13 years of life [since cancer]. Especially because it has been 13 years of life where she has been able to do what she wants to do. It has never stopped her from doing anything, and that's the important thing.

Quality of life was at the forefront of Claire's evaluation. She was also sensitive towards carers with less medical knowledge where: 'Survival is above everything else. You have to respect that is what they want because for a lot of them they don't fully recognise what that survival might mean'.

Earlier in the chapter I described Pauline [C] who was immersed in caring for her daughter, who has multiple physical and cognitive morbidities after surviving a brain tumour. Pauline defined her current situation as 'just living with her [daughter's] disabilities everyday and knowing that is not going to change'. She spoke with an unresolved question as to whether the surgeon caused her daughter's deficits:

> I think of that second operation that caused all the damage, and [surgeon's] attitude about being confident he got it all, so he obviously went in to that operation more aggressively than he did the first operation.

Pauline questioned whether the surgeon's determination to sustain her daughter's life actually caused her daughter's morbidities. However, the 'prize' of survival means that Pauline and her daughter are left to deal with the 'price' of late effects. She was circumspect about her daughter's surgical cure:

> He [surgeon] has no idea of what we're putting up with because of that. I mean, I'm grateful that I've got her and she's alive, but I wonder if he could have taken it a bit more gently. I don't dwell on that because he did what he had to do.

Pauline expressed gratitude for her child's survival and to some extent justified late effects as an unintended consequence of medical intervention. However, she stated that medical treatment had exceeded its beneficial limits, as her daughter and her own quality of life are excessively compromised:

> Sometimes I feel, and this is really, really nasty, but the people whose children have died because of cancer are better off. What I have to live with, what others have to live with, is a long term jail sentence.

In one simple but vital statement, Pauline questions a fundamental assumption of life over death, and breaches social constructions of motherhood and 'child-first' care practices. Pauline also rejects the 'cancer as a battle to win' rhetoric and the expectation of gratitude to the medical profession for a non-fatal outcome. The breach of such cultural norms explains Pauline's tentative manner in constructing meaning. She initially made her claim from a third-person perspective in discussing similar others as 'the people'. She then draws of her own lived-experience to claim that medical intervention has negatively impacted on her own, and her daughter's quality of life. Pauline defined her current self as 'just exhausted by life', as her daughter's survival involves an ongoing and high burden of care. Pauline felt like a prisoner locked into a situation because of her carer responsibility and because of advances in medical technology.

Other participants expressed similar concerns and believed medical treatment does at times exceed its beneficial limits. Margie [A] recalled other carers who 'battle on regardless' with their highly dependent child after cancer:

> They're so damaged from the tumor and the treatment; you just wonder whether they are better off or not. One [child] in particular couldn't walk or talk or anything, had seizures all the time and they were resuscitating him all the time.

Lee [A] saw medical treatment that extends a child's misery before his or her eventual death:

> The youngest child I'd seen die was only 12 months old and her Mum was only 19. You wonder what a 12-month old baby had done to deserve such a cruel death: she was swollen, her skin was split and cracking, and she was only one.

Primary carers draw on their experiences during cancer and its aftermath, to evaluate medical treatment, their child's survival and late effects from a life and quality of life lens and question the limits of medical advances. Their accounts illustrate the hopes and desires in non-fatal outcomes, yet late effects situations occur and some carers felt the dignity of a 'good death' may be a preferable outcome to a poor quality of life (Little et al. 2002: 1225-6; Kellehear 1990: 32).

Conclusion

This chapter has advanced the concept of new normal to represents the way in which primary carers lives are significantly shaped by their child's late effects of cancer treatment and adopt a role as morbidity managers. The findings illustrate carers use a range of multifaceted tasks, including surveillance, planning and accessing remedial health, allied health and educational resources to alleviate their child's morbidities. They evaluate their child's morbidities, age and competency levels and respond as late effects co-managers in partnership with their child; or as proactive managers for their child. Carers convey a heightened sensitivity of their child's past suffering and their current embodied selves to enhance their child's future autonomy and independence. The concept of new normal captures the way in which carers evaluate their child's prize/price of surviving cancer. The majority of participants evaluated their child's survival from a life and quality of life perspective. Yet carers managing their child's disabling cognitive late effects explicitly question medical intervention exceeding their child beneficence. The concept of new normal therefore incorporates carers

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enacting the role as their child's late effects managers. They drew on their lived

experiences to appraise the fundamental paradox of medical advances and the

cultural realm in which they are located.

 Chapter Eight concludes the thesis where I respond directly to the research

enquiry and conceptualise primary carers of childhood cancer survivors. I draw

together the significance of this study, review the empirical and theoretical

implications, and discuss limitations, policy and areas for future research.

Chapter Eight: Discussion and conclusion

Introduction

This thesis has examined primary carers of children in remission from cancer. The aim was to develop an informed conceptual understanding from which to answer the research question: *How do primary carers construct their everyday lives in the context of their child surviving cancer?* In this final chapter I draw on the original findings of the study to argue that primary carers shape and mediate their current lives by constructing a new sense of normality. The concept of 'new normal' is therefore at the heart of the answer to the research question. I begin the chapter by evaluating my theoretical framework in order to bring carers into greater conceptual focus. I then draw on key themes of the findings chapters to answer the research enquiry. I illustrate how this study contributes to childhood cancer scholarship and extends the conceptual limits of biographical disruption (Bury 1982, 1991). I then examine the sociological contribution of this study and conclude by offering policy implications and future research directions.

Summary of research framework

While conducting this qualitative research I was surprised by the significant gap in social science which offered only a sparse account of primary carers who are socially positioned with their child's ongoing care in the cancer aftermath. Recent advances in medical technologies have improved survival rates and established the conditions in which it became more likely that carers would see

their child in cancer remission (Kruger 2007; Rosoff 2006; Heath 2005). Medical literature enhances understandings of this disease, treatment processes, survival rates and morbidities trends (Oeffinger et al. 2006; Hudson et al. 2003), but offers an ambiguous definition of remission and inadequately represents carers when their child's cancer is no longer an immediate threat (Barnes 2007).

The findings support existing research representing carers' as experiencing acute distress during the early stages of diagnosis and treatment and diminishing stress after remission (Barlow and Ellard 2005; Bowman et al. 2006). This research illustrates carers' ongoing attempts to reconcile cancer experiences and actively shape their current lives, while shaped by ongoing cancer related uncertainties and late effects. Without discounting the stresses associated with childhood cancer, the data illustrates that carers construct their lives in ways that are less defined by stress and more characterised by their interpretive responses in constructing a meaningful life after cancer.

Sociological research has examined carers' responses during the diagnosis and treatment phase of their child's illness (Cline et al. 2006; Dixon-Woods et al. 2005; Clarke-Steffen 1997). The examination of ways that carers shape their lives after their child's cancer has been a neglected area of sustained study despite research recommendations (Young et al. 2002; Chesler and Parry 2001). The available scholarship offered this study limited conceptual understandings of the experiences of carers of a child in remission. Socio-cultural scholarship,

however, revealed the presence of an influential taken-for-granted assumption of remission as the end of the cancer which promotes expectations to return to a pre-cancer notion of normality (Drew 2007; Becker 1997). In reviewing the available literature I argued that childhood cancer survival is constructed in such a way that primary carers are socially positioned as important but under-represented agents within this medical success story.

The limited available data shaped the design of this research. My commitment to symbolic interactionism and social constructionism was guided by the research enquiry which required an interpretive qualitative perspective to examine how carers subjectively construct their everyday realities (Berger and Luckmann 1984; Blumer 1969). From this interpretive lens I drew on Bury's (1982, 1991) biographical disruption framework, as it offered an appropriate way to examine carers' experiences through their child's cancer. However, I illustrated the necessity to extend Bury's framework with theories of identity, survivorship and normality in order to conceptually align carers with the changing conditions from cancer to remission. The findings support ways that carers experienced a significant disruption of control and certainty in protecting their child's well-being, their reliance on medical intervention and hope in a non-fatal outcome.

The extension of Bury's (1982, 1991) framework provided the initial conceptual lens from which to consider carers in a unique social context: of having experienced their child's cancer, reconciling their current lives after cancer and

dealing with their child's late effects of treatment. In the extended framework, identity theory expanded on biographical disruption by emphasising primary carers as individual agents in their own right who construct their identities within their cancer related situation (Dixon-Woods et al. 2005; Young et al. 2002). Linking survivorship to biographical disruption incorporated carers into a cancer and post-cancer context (Aziz 2002; Little et al. 2002). Normality theory extended biographical disruption by informing the way in which carers construct a legitimate way to define their lives as normal (Bury 1991; Deatrick, Knafl and Murphy-Moore 1999), albeit a 'new normal'. Identity, survivorship and normality theories combined with biographical disruption to offer a conceptual lens in which to consider carers through their child's cancer and its abatement.

From this conceptual position I designed an interpretive methodology to generate and analyse rich and detailed data in order to establish an in-depth understanding of carers' experiences through and after cancer. My insider status advantaged collaboration with cancer support stakeholders, accessing participants and building researcher/participant rapport, which enhanced the depth of interview discussions and the richness of data. The flexible, constructionist version of grounded theory involved simultaneously collecting and analysing data and subsequent analysis. With this developmental method I gained valuable data with which to answer the research enquiry (Strauss and Corbin 1998; Charmaz 1990, 2000). However, the quality of data is attributed to the carers who have reflected deeply on their selves, children, cancer and remission.

I went to much effort to conduct this research in an ethical manner. This research has also taught me that qualitative research involves listening intently to people in a professional, sensitive and virtuous manner. I measured my ethical conduct by following the NHMRC (1999) and HREC principles. I also evaluated my ethical conduct from the responses to carers like Pauline who said:

> Remember I'm getting something out of this too. I mean being able to talk with you, knowing that you've been through similar things and have similar thoughts, it just makes me feel like you're not battling against a brick wall. I'm sure others have got a lot out of talking with you too. Talking to people who haven't been through similar things, you start getting the feeling that they don't understand.

Despite such endorsement, I am left with the discomfort of never knowing the full impact of the interview encounter. Carers often expressed grief in recalling their cancer experiences but also said the interviews were therapeutic. The combination of voluntary participation, the interview rapport and for some carers, to finally give voice to their experiences after many years suggests they have benefited in some way through the interview encounter.

Conceptualising primary carers: A new normal

My key findings build upon and extend existing scholarship around the impact of childhood cancer on primary carers. Foremost, this research has emphasised that a conceptual understanding of carers involves a careful consideration of their experiences through cancer, their current remission context and the extent of their child's late effects of treatment.

The available literature suggests this thesis is the first sociological study to examine the aftermath of childhood cancer from primary carers' perspectives in an Australian and international context. The study therefore contributes sociologically to understanding multiple social implications of acute and life threatening illness, adult care meanings and practices of ill children, mediating medical treatment, survivorship, and chronic morbidities. The complexities of primary carers' identities were explored in radically changing situations: from the angst of diagnosis and treatment to developing new cancer and post-cancer meanings and self-concepts. The findings extend the parameters of much research into childhood cancer by incorporating its aftermath as an ongoing cancer related phase (Clarke-Steffen 1997; Young et al. 2002; Earle et al. 2006).

Neither carers nor children experienced childhood cancer or its aftermath in isolation; so the thesis complements and builds on emerging research on young cancer survivors and the structure of carer/child relationships through and beyond childhood cancer (Zebrack and Zeltzer 2001; McGrath 2001; Sullivan 2004; Woodgate 2006). The study has made a special contribution to examining childhood cancer retrospectively as carers have had time and energy to reflect on their experiences through cancer from the less intensive phase of their child's remission. Their insights were characterised by less acute existential concerns with their child's immediate life, but offered more evaluative and meaning orientated accounts of cancer and survival in their post-cancer context.

The concept of new normal therefore emerged to represent the social processes through which primary carers construct and give meaning to their post-cancer lives. The findings consistently illustrated that carers define their lives as 'new' and a distinct departure from their pre-cancer lives. They also defined their everyday lives as 'normal', although a normal that encompassed new meanings of their child's and their own lives, new temporal orientations and new understandings of hope and uncertainty. The concept of new normal also represents the way in which carers' interact according to their evaluation of the knowledge and experiences of cancer insiders and outsiders.

The findings revealed that having a child diagnosed with cancer was a particular biographical disruption (Bury 1982, 1991). Carers' distress was a response to the potential loss of their child's life, but also the profound disruptions to their pre-cancer assumptions of control and certainty in protecting their child's well-being. Carers constructed new meanings to accommodate their radically changed situations in having their child's life at risk and realising their dependency on medical intervention. Having a child diagnosed with cancer established the conditions whereby carers' previous taken-for-granted assumptions were no longer tenable. But the concept of new normal represents the ongoing processes and responses of carers constructing new meanings to define their situation.

The data in Chapter Five revealed elements of the new normal that emerged during the early stages of cancer.   The process of building a new sense of normality began when carers came to accept the situation of having little choice but to surrender control to medicine in order to save their child from a fatal outcome. This finding supports previous scholarship examining carers during the early cancer diagnosis phase (Woodgate 2006; Clarke-Steffen 1997). Yet their 'surrender is an active intentional process' and is distinct from being beset by their child's disease (Charmaz 1995: 672). So despite their emphasis on being 'forced' to trust medical specialists, carers submitted rather than surrendered control, which represented a symbolic re-ordering of meaning in being a carer of a child with cancer. Paradoxically, the findings illustrated that carers claim a sense of control by relinquishing prior notions of control and by working in partnership with clinicians towards their child's hoped for remission.

Submission of control is also partial, as clinicians relied on carers to fulfil surveillance, pseudo-nursing, guardianship and care roles while sustaining carer/child relationships (Young et al. 2002). Carers realised that clinicians were reliant on their intuitive child understandings as active health resources. Carers also placed much value in 'cancer friends' as a basis of mutual support and understanding of cancer memories, ongoing uncertainties and hopeful futures.

With remission, carers made the transition from the medical world with a new sense of normality defined by both hope and trepidation. They anticipated

leaving hospital but suddenly realised the loss of security that was previously

offered by medical care and pathology results. The transition was a period of

rapid adjustment from a previously constructed 'hospital normal' to a non-

medical world of everyday life. Migrating to life after cancer involved dealing

with societal expectations of an immediate return to normal after 'winning the

cancer battle' (Becker 1997; Sontag 1991). Yet carers returned to everyday life

with a new sense of self, new knowledge and experiences and in insidious cancer

memories. Carers defined the transition as a gradual process of physical and

emotional healing to orientate to a life without cancer.

Within their private family lives, carers adopted a host of pragmatic and symbolic

strategies to mitigate the impact of cancer. They emphasised health rather than

illness, yet maintain ongoing and mostly unobtrusive child surveillance for cancer

and late effects symptoms. Carers spent much ongoing effort in seeking and

interpreting medical knowledge into their own lay understandings, both through

and after cancer, as a stock of knowledge in reserve if cancer should return. They

gave much meaning to remission; which crucially represents the continuity of

their child's life, but also with the inference of uncertainty and no guarantee of a

future free of cancer. Carers sustained a 'living in the present' philosophy for

many years after cancer in response to their first-hand knowledge that control of

life is fragile and uncertain, and can change rapidly. While cancer uncertainties

and child late effects retain a persistent presence, carers deliberately emphasised

their everyday lives and attempted to internalise cancer 'in the back of the mind'.

The findings illustrated that cancer concerns mostly lessen over time away from the medical world and if child health is sustained.

Carers' everyday lives after cancer involved negotiating with cancer insiders and non-cancer outsiders. Interactions were characterised by carers' acute awareness that non-cancer others may sympathise with their situation and hope for a continued successful cancer outcome but have difficulty in understanding their cancer related experiences. Carers therefore interpreted their everyday audiences and performed 'front stage' interactions to fulfil cultural expectations of returning to normal after cancer, but enacted particular 'back stage' performances which they shared rather exclusively with similar cancer others (Goffman 1959). In this manner carers sought to normalise everyday interactions with cancer and non-cancer audiences. The majority of carers constructed their child's survival with a profound sense of gratitude towards medicine and felt obliged to reciprocate through support of fundraising for medical research and cancer support, and providing personal support to others impacted by cancer. It was through these practices that carers identified as members of the broader cancer community.

Child late effects emerged as a prominent and variable constraint in shaping primary carers lives after cancer, as they, rather than medicine, have the ongoing ascribed duty to care for their child. Carers interpreted late effects as the 'price' of medical intervention resulting in their child's survival. They constructed a new sense of normality as their child's morbidity managers and responded

according to the severity of their child's late effects. Their complex late effects strategies of surveillance, planning and de-emphasising late effects, as well as accessing remedial and educational resources were aimed to mitigate and/or incorporate child morbidities into their new construction of normality. Carers co-managed moderate morbidities with their child, but were more proactive in managing severe late effects for their child. Major cognitive late effects entailed carers' demanding tasks due to their child's reduced capacity. The findings illustrated that the greater the extent of late effects, the more critical that carers were of evaluating the impact of medical intervention on their child's and their own quality of life. Carers of children with disabling morbidities inferred how a 'good death' may be preferable to a poor life, when the quality of their own and their child's life was significantly reduced (Little et al. 2004; Kellehear 1990).

Much scholarship supports the way in which cancer establishes 'a radical challenge to continuity of identity' (Little et al. 2002: 176; Drew 2007; Earle et al. 2006; Dixon-Woods, Young and Heney 2005). The findings in this thesis support and extend this claim by incorporating primary carers, who are not ill *per se* but nevertheless have constructed identities significantly different to their lives before and through their child's cancer. The accumulated lived experiences of having a child diagnosed and treated for cancer, its abatement and late effects morbidities establishes the biographical context in which carers construct their current lives. The concept of new normal represents the way in which carers construct their lives through and beyond childhood cancer: with a heightened

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awareness of cancer and the fragility of control, a merging of hope, uncertainty and dealing with their child's late effects. The intensity of cancer tended to diminish over time but carers nevertheless carried vivid cancer memories and experiences which continue to shape their lives post-cancer. In summary, the concept of new normal represents an ongoing social process with the often untidy and unresolvable tensions of being a carer of a childhood cancer survivor.

Theoretical contribution of this research

The thesis has demonstrated both the value of biographical disruption and the necessity to expand its conceptual limits to represent the changing conditions from childhood cancer to remission (Bury 1982, 1991). Empirically, the thesis has drawn attention to carers' responses to both childhood cancer and remission by constructing a new sense of normality; which is represented by the concept of new normal. Biographical disruption and the concept of new normal therefore align to represent carers' experiences through both childhood cancer and remission. Bury's (1982) framework informs the way in which carers' taken-for-granted assumptions, explanations and resources were distinctly disrupted with the advent of their child's cancer. However, extending the explanatory parameters of biographical disruption with identity, normality and survivorship theories offered a useful preliminary theoretical lens from which the concept of new normal emerged to represent carers of children in remission.

The concept of new normal both complements and adds to Bury's (1982, 1991) framework and the amendments of identity, survivorship and normality theories in five key areas. First, Bury (1982: 169-171) explains how the onset of illness disrupts taken-for-granted assumptions from a 'perceived normal trajectory … to one fundamentally abnormal'. The findings support carers' experiences of childhood cancer as a period of crisis. The concept of new normal, however, captures carers' responses to their cancer and remission experiences.

Second, biographical disruption explains how illness disrupts the 'explanatory systems normally used by people' (Bury 1982: 169). The concept of new normal represents how new meanings are constructed through cancer and in remission. Through cancer, carers defined their situation as a fundamental loss of certainty and control, and fear of their child's potentially fatal outcome. Due to the ambiguous status of remission, carers de-emphasised certainty and control by constructing an acceptance of living with the chronic uncertainty of their child's ongoing health. In response to such uncertainty, carers defined their situation by 'living in the present', sought cancer information and drew on a pre-modern discourse characterised by hope, faith and luck. The overwhelming data themes of uncertainty and hope illustrated that carers constructed remission, health and well-being in meaningful ways and not solely in medical terms.

Third, biographical disruption explains how illness represents 'a fundamental re-thinking of a person's biography and self-concept' (Bury 1982: 169). The

concept of new normal incorporates carers' responses to the loss of control of their child's life/death situation and reliance on medical intervention through cancer. The concept of new normal also links with theories of identity and survivorship to represent the active social processes in which new identities are constructed in response to being a carer of a child in remission.

Fourth, the concept of new normal builds on biographical disruption by explaining how carers respond to childhood cancer and remission by mobilising resources (Bury 1982: 175). In response to the life-threatening situation of cancer, carers sought medical support in order to save their child's life. In addition, carers defined themselves as resources: as parents and carers enacting intensive physical and emotional childcare support and responsibilities, and new partnerships with clinicians and other carers through cancer. With remission, carers mobilised remedial and educational resources, and defined themselves as essential late effects managers in dealing with their child's late effects. The concept of new normal therefore incorporates and extends biographical disruption to represent carers through childhood cancer and remission.

Fifth, the concept of new normal further represents ways in which carers legitimise the significance and consequences of cancer in a remission context (Bury 1991). The findings have illustrated that carers of a child in remission construct an altered everyday reality and legitimise their new sense of normality: through the way they defined their sense of self, interacted with insider, outsider

and cancer-community others, and negotiated cultural expectations of their social roles by drawing on their cancer and remission experiences, with new meanings of hope and uncertainty. The concept of new normal is therefore sustained to represent carers constructing their lives in the childhood cancer aftermath.

Policy implications

The findings generated in this research raise important policy implications directed towards health, allied health, education and cancer support sectors that relate to carers through cancer and remission and the impact of treatment morbidities. The ultimate policy implication challenges clinicians and health researchers to aim for cancer prevention rather than cure. Until that goal is achieved, the findings from this research guide paediatric oncologists to refine cancer treatment and reduce or eliminate the late effect morbidities which continue to impact on children's and carers' lives. There is an urgent need for medicine to legitimise childhood cancer late effects, to ensure that health, allied health and educational support services are available and affordable.

The findings draw attention to the need for medical staff and social workers to have a greater understanding of what the transition of leaving hospital at the completion of treatment entails. Carers require appropriate and timely advice and services through this period. Health professionals need a more sensitive appreciation of the time needed for carers, the child, siblings and significant others to physically, socially and emotionally heal. Carers currently face

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unnecessary pressure from clinicians who promote a 'get-back-to-normal' rhetoric after cancer rather than regarding the transition as a gradual form of social integration. Health care staff can offer more targeted advice to help prepare carers for the transition; with follow up support beyond the confines of hospital and into the locations of everyday life where cancer remission is constructed and experienced.

The issue of late effects has demonstrated that carers require ongoing health, allied health and educational resources help to deal with their child's morbidities. The findings illustrate that the post-cancer remedial services focus on short-term outcomes but carers specifically identify their child as requiring ongoing support. Recent international research suggests that child cancer survivors with late effects are expected to significantly contribute to ongoing chronic illness burdens of the healthcare system (Rosoff 2006; Oeffinger et al. 2006). Policies therefore need to be implemented through healthcare, cancer support, educational and service providers in which to prepare for this 'epidemic of survival' (Drew 2007), and in ways that promote late-effects self-management and co-management.

Health and allied health practitioners therefore need to focus on assisting the childhood cancer survivor population and their carers to live independently and enhance their quality of life. Currently, Australian paediatric oncology late effects clinics have been established to monitor child morbidities (Heath 2005). A health passport initiative has also been developed for carers and children to

have specific treatment information available (Goodenough et al. 2008). However, few carers in this research are aware of these initiatives and most have not accessed these services. A national strategy is therefore necessary to disseminate service information to those impacted by childhood cancer. Much advocacy is also required through health, public, media, educational and cancer support sectors to recognise the social implications of childhood cancer and its aftermath on children, their carers, siblings, peers and communities.

Future research directions

This thesis has opened up a body of knowledge from which to generate a wealth of future research. The concept of 'new normal' has potential transferability across a range of research examining health, illness and other crisis situations, particularly when people's prior notions of normal are disrupted to a significant extent. My singular focus on primary carers was to represent this group as important agents in cancer remission research and to complement emerging data on childhood cancer survivors (Drew 2003, 2007). However, future research can usefully focus on carer/child and/or family interactions as the central unit of analysis, with the potential to enhance how these relationships are constructed and sustained (or not) through the cancer and survival journey.

This research revealed a disturbing phenomenon in which primary carers hold grave concerns for their child's future as they reach adulthood, with compromised physical and cognitive abilities and limited capacities to live independently.

Longitudinal research will need to examine carers in order to understand how cancer and remission experiences are incorporated across their life-course. Currently, cancer survivors are still relatively young, ranging from babies to adults up to around 30 years of age. As carers and children age, future research can explore carers supporting their adulthood child when morbidities limit a cancer survivor's life-chances and capacity to live independently. Future research will need to examine how an ageing population will establish the conditions of elderly carers caring for middle-aged adult survivors of childhood cancer with compromised health. The thesis also reveals the need for evaluative research in resource availability to determine whether coordinated support needs for children and carers are being met by government, health and cancer agencies.

The findings illustrate that the traditional gendered division of childcare labour is sustained and intensified through childhood cancer, with mothers more than fathers assuming and providing the majority of care. Future research could gain important information by examining gendered ways in which femininity and masculinity are constructed through the childhood cancer and remission context. Comparative research methods and analysis can usefully explore how both carers' and children's gender might symbiotically shape their respective cancer and survival experiences. Finally, future research can add to an understanding of carers of a child in remission by examining socio-economic status, locality, religious, cultural and ethnic affiliations that may shape their experiences, responses and access to resources.

Conclusion

This thesis contributes to the emerging field of childhood cancer scholarship with new sociological insights into the social processes of primary carers constructing their lives in the context of their child surviving cancer. The concept of 'new normal' has been developed to represents carers' definitions and active responses to childhood cancer and its aftermath. The findings represent a more nuanced understanding of childhood cancer and remission from carers' perspectives, which fill many gaps between the life/death binary of cancer and the prize/price binary of cancer survival. The knowledge generated by this research allows new ways to understand and benefit the lives of those impacted by childhood cancer. The findings inform and challenge the health and cancer support sectors with policy to facilitate carers and their children to live fulfilling lives. In summary, the situation of primary carers, I believe, reflects a microcosm of everyday life; that life is fragile and control and certainty are perhaps illusions of contemporary society. Yet carers actively construct their lives with meaning, hope and continuity, both during and beyond the face of adversity. Such is the human condition.

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Appendix one: Demographic profile

Pseudonym	Relationship	Marital status/ changes	Income	Years post diagnosis	Type of cancer	Child age at diagnosis	Main treatment
Laura	Mother	Married	Wage $50k	20	Leukaemia	1 year	Chemo
Lee	Mother	Marr/Seperated	Pension $20k	9	Hepatoblastoma	Newborn	Chemo/Surgery
Louise	Mother	Marr/Seperated	P-T, Pens $20k	5	Hodgkin's	10 years	Chemo/Rad
Alice	Mother	Marr/Seperated	Wage $50k	15	HLH*	2 months	Chemo/BMT
Natalie	Mother	Married	Wage $50k	13	Neuroblastoma	3 months	Radiation
Margie	Mother	Married	Wage $50k	14	Leukaemia	2 years	Chemo
Mary	Mother	Married	Wage $50k	14	Leukaemia	2 1/2 years	Chemo/Rad
Joe	Father	Married	Wage $50k	14	Leukaemia	2 1/2 years	Chemo/Rad
Angela	Mother	Married	Self Employed $60k	15	Rhabdomyofarcoma	4 1/2 years	Chemo/Rad/Surg
Raul	Father	Married	Self Employed $60k	15	Rhabdomyofarcoma	4 1/2 years	Chemo/Rad/Surg
Michelle	Mother	Married	Salary $50k	12	Neuroblastoma	2 years	Ch/Bmt/Rad/Sur
Chelsea	Mother	Single/Married	Wage $50k	9	Leukaemia	3 1/2 years	Chemo
Will/Edele	Father/Mother	Married	Salary $50k	9	Leukaemia	3 1/2 years	Chemo
Robyn	Mother	Married	Wage $50k	15	Leukaemia	5 1/2 years	Chemo
Claire	Mother	Married	Wage $50k	13	Leukaemia	4 1/2 years	Chemo/Rad
Ruby	Mother	Married	Wage $50k	13	Ewings Sarcoma	6 years	Chemo/Rad/Surg
Cazzi	Mother	Married	Business $50K	16	Histiocycosis	4 years	Surgery
Elizabeth	Mother	Married	Wage $50k	6	Wilm's Tumor	3 1/2 years	Surg/Rad/Chemo
Dave	Father	Married	Wage $50k	5	Germ Cell	4 years	Chemo/Surgery
Chloe	Mother	Married	Wage $50k	7	Leukaemia	6 years	Chemo
Freda	Mother	Married	Business $50k	6	Hystiocytosis	2 1/2 years	Surg/Chemo
Marilyn	Mother	Married	Wage $50k	10	T-Cell lymphoma	4 years	Chemo/Rad
Molly	Mother	Married	Wage $50k	8	Hepatoblastoma	10 months	Chemo/Surgery
June	Mother	Married	Wage $50k	6	Osteosarcoma	11 years	Chemo/Surgery
Tom	Father	Married	Wage $50k	6	Osteosarcoma	11 y.	Chemo/Surgery
Mimma	Mother	Divorced	Wage $20k	6	Leukaemia	4 years	Chemo
Pauline	Mother	Divorced	Pension $20k	15	Astrocytoma	3 1/2 years	Chemo/Surg/Rad
Victoria	Mother	Married	Wage $50k	11	Leukaemia	3 1/2 years	Chemo
Grace	Mother	Married	Wage $50k	11	Leukaemia	2 1/2 years	Chemo
Eve	Mother	Married	Wage $50k	5	Leukaemia	4 1/2 years	Chemo
Adam	Father	Married	Wage $50k	5	Leukaemia	4 1/2 years	Chemo
Rae	Mother	Widowed	Wage $40k	10	Wilms Tumor	5 1/2 years	Chemo/Rad/Surg
George/Magda	Father/Mother	Married	Self Employed $60k	9	Neuroblastoma	9 1/2 months	Chemo/Surgery
Anne	Mother	Married	Wage/Business $50k	8	Leukaemia	3 years	Chemo
Geoffrey	Father	Married	Business $50k	8	Leukaemia	3 years	Chemo
Emma	Mother	Married	Business $50k	13	Leukaemia	3 years	Chemo/Rad
					*Hemophagocytic lymphohistiocytosis		