Time to Feel

Understanding Cancer Carers' Emotions and Support Preferences

A thesis submitted for the degree of Doctor of Philosophy of The Australian National University, School of Sociology, Research School of Social Sciences

Rebecca Eileen Olson, B.A. (Hons)
June 2010

I declare that this thesis is my own original work and is in accordance with The Australian National University thesis guidelines for higher degree research.

Word Count: 81,117 (not including the reference list and appendices)

Acknowledgements

Few theses or research projects are the outcome of just one person. This thesis is no exception. While the work is my own and I take responsibility for its contributions and flaws, it would not have been possible without the moral sustenance, financial support and intellectual stimulation provided by so many generous people.

I am indebted to the participants, many of whom were time-poor, for sharing their inspirational stories. I would also like to thank Cancer Australia and the Cancer Council ACT, especially Joan Bartlett and Joanne Grant, for their support, financial and otherwise. Without their funding, this project would have at best taken twice as long or at worst never have been completed.

To the *PhDivas*: Shanti Sumartojo, Vanessa McDermott, Kirsty McLaren, Catherine Strong, Janecke Wille, Sarojini Martin, Angela Lehman, Sarah Maslen, Sarah Spiller, Justin Iu, Emily Rose, Ellie Kirk, Daphnée Lee, Suzy Marsh and Sudeepa Abeysinghe. Sharing the postgraduate experience with you has solidified my belief in the value of camaraderie and informal support groups.

I would like to thank Dr James Connor, Dr Alastair Greig and Dr Maria Hynes for their auxiliary guidance. Your feedback has challenged me to think about research, analysis and drafting in new and better ways. To Anton Naef, Andrea Olson, Colleen and Richard Olson, and Angela, Gerald and Chantel Naef, thank you for your support, understanding, patience and comments on earlier drafts. I am truly fortunate to have such an encouraging family.

Finally, I am grateful to my supervisors Dr Kevin White and Professor Dorothy Broom. You have been a winning duo: pushing me to refine my intellectual contribution, facilitating opportunities and providing sage advice. I will be forever grateful for your mentoring.

Table of Contents

Acknowledgements 3
List of Figures 6
Abstract 7
Introduction 9
  Giving Care 9
  Outline of the Thesis 17
  Notes on Terminology 21
Chapter One: Literature Review 23
  Biographical Disruption 23
    Carers' Biographical Disruption 27
  Patients' Needs 29
    Do Carers' Coping Strategies Intensify Patient Needs? 31
  Cancer Carers' Needs 36
  Support Services for Cancer Patients 41
    Carers' Support Services 46
Chapter Two: Methodology 51
  Epistemological and Ontological Issues 52
  Methods 53
    Participant Observation 53
    Questionnaires 54
    Interviews 59
    Focus Group 67
  Emotional Impact of the Interviews 67
  Analysis 68
  Valuing Qualitative Research from a Realist Perspective 70
  Final Notes 72
Chapter Three: Indefinite (future) Loss, Indefinite Grief 73
  Illness Narratives 73
  Identifying Oneself as a Carer 75
  Grieving 77
    Anticipatory Grief 81
    Ambiguous Loss 82
  Indefinite Grief 84
  Implications 89
    Carer Identification 90
    Caregiving Trajectories 91
    Indefinite Grief 91
Chapter Four: Managing Emotions for the Present and Future 96
  Are Carers in Denial? 96
    How do Carers Cope? 98
  Staying Positive 99
    Stress and Immune System Health 103
    Control 105
    Support 105
  Temporal Orientation 106
    Temporal Anomie 108
    Positive but Realistic 110
    Optimistic 111
    Normalcy 113
  Medical Professionals' Influence 114

Fighting Denial? ... 115
Graduated Prognosis ... 116
Positive ... 117
Implications ... 118
Chapter Five: Time to Feel ... 123
Phone and Emotional Support: Nuisance or Necessary? ... 123
Time: a Central Variable ... 126
Vignette One: Fred & Jane ... 127
Vignette Two: Joe ... 127
Vignette Three: Anne & Sally ... 128
Time: a Closer Look ... 129
Time to Feel ... 137
Time for Support? ... 138
Time: Understanding Quantitative Research ... 138
Implications ... 140
For the Sociology of Emotions ... 140
For a Sociology of Cancer Caregiving ... 144
For Social Welfare Research ... 145
For Health and Support Professionals ... 146
Chapter Six: Time for Support? ... 148
Carers' Experiences of Emotion Work ... 150
Informal Support ... 153
Counselling ... 157
Interviews ... 159
Support Groups ... 160
Why do you Not Attend Support Groups? ... 162
Practical Support ... 165
Respite ... 166
Financial Aid ... 166
Centrelink ... 167
IPTAAS ... 170
Questions for Future Research ... 171
Implications ... 172
Chapter Seven: Relying on Carers at Home and in the Hospital ... 175
Carers' Hospital Experiences: Inconsistent and Bureaucratic ... 175
Relying on Carers ... 180
Home at the Hospital ... 186
Relying on Carers Negatively Impacts on their Wellbeing ... 188
Information Distribution ... 194
Chapter Eight: Recommendations to Improve Carer Support ... 202
Changing Medical School Curriculum ... 203
Cancer Nurses ... 208
Conclusion ... 215
Reference List ... 228
Appendix A: The Questionnaire ... 245
Appendix B: Consent Forms ... 248
Appendix C: Interview Guide One ... 250
Appendix D: Interview Guide Two ... 251
Appendix E: Focus Group Questions ... 252
Appendix F: Summary of Participants ... 253

List of Figures

Figure 1 - The relationships of carers to patients in the questionnaires in this study and in a UK study (Thomas et al., 2001) (percent)…………………………**56**
Figure 2 - Cancer types affecting the patients in respondents' care (percent)......**56**
Figure 3 - Respondents' ages in this study and a UK study (Thomas et al.,2001)……………………………………………………………….……….…**57**
Figure 4 - Questionnaire respondents' paid work categorisation (percent) **57**
Figure 5 - Gender distribution of interviewees (whole numbers)………..……....**61**
Figure 6 - Age range of interviewees (whole numbers)…...……………...…….**61**
Figure 7 - The caring stages of interviewees: active or retired (whole numbers).**61**
Figure 8 - The paid working categorisation of interviewees (whole numbers)….**62**
Figure 9 - The types of cancer affecting interviewees' spouses (whole numbers)…………………………………………………………………………**62**
Figure 10 – (y) Percentage of (x) responses, to the open questionnaire item, "What actions or behaviours of others do you find supportive? Why?" by gender ……………………………………………………...………………...**124**
Figure 11 – (y) Percentage of (x) responses to open questionnaire item "What actions or behaviours of others do you find supportive? Why?" by age. **125**
Figure 12 - Hours spent caregiving, in percentages, as reported by questionnaire respondents to the open question "How many hours each week do you spend providing care?".. **126**
Figure 13 - Categorisation of carers autonomy based on (x) the time-demands of caregiving and (y) the time-demands of their other roles..……………………**135**

Abstract

Family carers assume responsibility for much of patients' treatment coordination and emotional support, saving medical systems billions by reducing the number and duration of hospital admissions. However, in doing so, they tend to suffer high rates of psychosocial morbidity. While much is known about the experiences of cancer patients and carers of a family member with other diseases, little is known about the experiences and support services preferences of people caring for a spouse with cancer. Past research on this population is largely psycho-oncology based and emphasises carers' stress, burden and coping strategies. Using qualitative methods including participant observation, questionnaires, interviews and a focus group, this research provides an experience-driven understanding of these carers' experiences and support service preferences.

Findings suggest that these carers experience a distinct kind of anticipatory grief: *indefinite loss and indefinite grief*. These concepts, referring to vacillating and uncertain anticipatory loss and grief, are presented as a more accurate conceptualisation of these carers' experiences of mourning and uncertainty about the future. Findings also show that carers of a spouse with cancer experience *temporal anomie*, a challenged sense of orientation towards the future. Using Hochschild's concepts of "emotion work" and "feeling rules" during analysis allowed for an interactive and social complement to the focus on individual coping strategies that dominates within psycho-oncology. Using this approach to analyse carers' emotions revealed the sense of lost direction towards the future that challenges carers' positive outlooks and showed that to overcome this temporal anomie, carers manage their own and their spouse's emotions towards their illness or the future.

Further, interview accounts indicate that some carers' responsibilities are so time-consuming, they are unable to experience and explore their own emotions; they do not have time to feel. Much of the poorly understood variation in carers' needs and support preferences can be explained using a time-sovereignty framework. Those carers who do have time for emotions valued support groups and counselling as a means of emotion management clarification. Practical support, such as financial aid and respite care, however, is rarely accessible to those who need it most: carers who lack time-sovereignty. Current Australian medical

system practices do not ameliorate this strain, as medical professionals tend to exclude carers from the consumer-role while relying on carers to provide patient care.

Thus, caring for a spouse with cancer often entails a sense of confusion about complex and contradictory emotions, but little time to reflect on these emotions. These experiences are, in part, a product of a medical system which simultaneously relies on carers – thus increasing their burden – and excludes carers from important information, leaving them under-resourced to deal with their partners' needs and their own emotions.

Introduction

On one of the last warm days of autumn in 2007 I entered a house on a quiet suburban street in Canberra. A soft-spoken man, Ian, let me in. Pictures of him with his wife and children looking close, happy and satisfied with life hung on the walls. But, these were moments from the past. His home appeared to be weathered and worn both inside and out. The garden was overgrown, the open garage revealed stacks of boxes and piles of toys. The interior was in a similar state: books overflowing from bookcases and a carpet that probably had not been vacuumed in weeks.

I was there to interview him about his experiences as a carer for his wife when she had cancer. As we began our interview it became clear that he too had seen better days. He told me how severely his wife's initial cancer diagnosis and subsequent recurrence had affected him and their relationship. Anxiety and depression had taken a crippling hold on his life. Everyday he fought with his fear that his wife may die and he may have to raise their children alone. This fear had been affecting his work and his relationship with his wife. Her physical scars were a constant reminder of their mortality. Ian said, "it's quite the loss….From the aesthetic point of view, it reminds you of the, you know, possibility…it reminds you of the dangers you are in." His fear and anxiety made it difficult for Ian to care for his wife, forcing him to rely on his wife for emotional support when he wanted to be providing her with emotional support. "I didn't react as well as I should have….I was a bit of burden on her…[and my wife] felt somewhat under supported…she would sort of say that I was measuring the grave…which is not that helpful." This seemed to be a source of guilt and embarrassment for Ian. Clearly, cancer had had a psychosocial impact, not just on his wife, but on Ian, her husband and their entire family. This thesis examines the impact of the disease on carers of a spouse with cancer, their needs, support preferences and the barriers they face in accessing those services.

Giving Care

Carers or caregivers are the friends or family members who provide informal physical and emotional support to a patient. The approximately 15 percent of the Australian population involved in caregiving have increased "responsibilities due to looking after someone who is sick, handicapped or elderly," and provide care within the home without pay (Evandrou, 1996:205; Howe et al., 1997). The form of caregiving that now prevails is relatively new. Throughout history, most deaths were sudden with little if any period of disability before death (Kellehear, 2007). Today, the end of life is characterised by chronic illness and a 2 - 4 year period of disability, not to mention intermittent periods of illness throughout the preceding decades (Wilkinson, 2006). Fifty years ago, periods of serious illness would have most likely been spent in an institution.[1] Diseases such as tuberculosis (Roth, 1963) and mental illness were treated on a long term, inpatient basis. Hospital care followed a "total" care (Goffman, 1968a) and paternalistic, "doctor knows best" model (Irvine, 1996; Skene, 1990:43; Surbone, 2006). Thus, care of patients' with serious illnesses rarely took place at home. When it did, practical and emotional care was performed by a female (Hochschild, 1995).

Shorter inpatient stays have shifted care to the home. Carers have become the "central plank of service provision" (Allen, 2000:150) on which "health care policy through out the western world depends" (Braithwaite, 1990:1). Periods of disability or debilitating treatment following medical procedures in conjunction with the medical system innovation of having the "hospital at home" (White, 2006:105) necessitates the role of a carer so much that between 55 (Nijboer et al., 1998) and 80 percent (Lewis, 2006) of long term care is provided by informal caregivers. Changes in the structure and funding of the Australian medical system over the past few decades have resulted in this significant shift from hospital to home in patient care. The decades following the 1960s mark significant ethical, legal and political changes: an ongoing feminist movement (Oakley, 1985), the introduction of universal healthcare coverage with Medibank and Medicare (Duckett, 2004; Van Krieken et al., 2006; White, 2006) and a re-conceptualisation of the individual, from in need of protection, to self-sufficient during Thatcher-era politics (Opie, 1992). This "coming together of left-wing critiques…and right-wing policies" had an impact on the organisation and distribution of medical care (Allen, 2000:150). The format and approach to providing medical care in Australia and many other countries changed from institutional and paternalistic care to community-based and autonomous care.

---

[1] Earlier parts of the 20th century were characterised by care in the home in many locations.

There were four main forces behind this healthcare reform. One impetus was the growing sentiment that hospitals are too “impersonal” (Little, 1995:2). The cold interactions in institutions detailed in exposés such as Goffman’s (1968a) motivated a desire for more personalised and holistic patient care, especially for those patients in palliative care (Kissane & Bloch, 2002; Opie, 1992).

Simultaneously, an increasing dislike for paternalism in medical interactions provided a second force behind the move from hospital to home (Duckett, 2004). The public began questioning the practices of lying to patients about their prognoses and allowing patients little say in their treatment (Surbone, 2006). An increasingly well informed public, with access to the internet, formed consumer groups, took legal action and pushed for patient autonomy (Duckett, 2004; Fallowfield & Jenkins, 2006; Irvine, 1996; Turner, 2006). To escape paternalistic practices patients and families were demanding that they be more involved in patient care.

An arguably false nostalgia for a sense of community that Australians believe they once had, but lost, also compelled the move from hospital to home, providing a third impetus for change (Petersen, 1994). Policymakers responded to this judgement and relocated much of the caring from the hospital to the community. Improvements in technology facilitated this shift (National Cancer Control Initiative, 2003). Now, “care in the community” has replaced institutions and hospitals as the location where most medical services are provided (Duckett, 2004:206, 228) and community services are the “glue” (Burns et al., 2004:501) or quick fix (Petersen, 1994) that allow cancer patients to spend the majority of their infirmity at home.

The need to curtail government spending, however, provided the strongest and fourth incentive for healthcare reform. Equity in access to healthcare became an ethical and political imperative (Davis & George, 1993; Duckett, 2004; Little, 1995; Turner, 2006). Although there was much initial resistance from medical professionals towards Medibank and Medicare, it has since become perceived as a right by most Australians and politicians (Van Krieken et al., 2006). With universal insurance, however, came a more urgent need to contain medical spending (Davis & George, 1993; Duckett, 2004). Governments perceived higher taxation to cover increasing Medicare prices as too politically costly (Little, 1995). Limiting medical spending, however, is problematic with calls for more spending coming from both the supply and demand side: a higher than anticipated number of Australians relying on Medicare, an aging population driving up current and predicted rates of morbidity and service use and increasing specialisation and technology pushing up the cost of medical services (Allen, 2000; Anderson & Hussey, 2000; Burns et al., 2004; Davis & George, 1993; Duckett, 2004; Little, 1995; Skene, 1990). So the demand for costly services was and is increasing while government expenditure remains limited.

To balance the moral necessity (universal access to healthcare) with a financial reality (restricted public spending), economic principles were brought in to lower costs (Davis & George, 1993). The principles of economic rationalisation have been used to analyse healthcare, reduce cost and potentially improve effectiveness and speed (Davis & George, 1993). Indubitably, treating patients outside of pricey hospital wards and having families provide the bulk of the care in their homes is more “cost-effective” (National Cancer Control Initiative, 2003:47) in *economic* terms.

Currently, primary informal carers, the persons upon whom patients rely for daily practical and emotional support, are central players in patient care (Franks & Stephens, 1992; Laizner et al., 1993). This role is usually performed by a close relative: a spouse (40%), parent (20%) or child (25%) (Duckett, 2004:242) and includes performing practical and medical tasks for the patient such as help with shopping, transportation, hygiene, cooking and treatment administration (Franks & Stephens, 1992; Laizner et al., 1993; Thompson, 2005). It is also a very emotional role, with patients identifying carers as the people with whom they “share” their illness journey (Thomas et al., 2001:22; Thomas et al., 2002).

Although carers are often overlooked by medical professionals and many researchers as not the patient, and thus not in need of aid, caregiving can be detrimental to a carer’s health (Chambers et al., 2001). More specifically, it has been found to have an impact on a carer’s finances, physical health and mental health. Braithwaite’s (1990) study of Australian carers shows they often suffer financial losses. The Australian Bureau of Statistics (1999) indicates that caregiving is correlated with a decreased income. They report that nearly two thirds of all carers are outside the labour market, compared to one third of the general population. Of all carers, 56 percent have a pension or allowance as their main income (ABS, 1999).

Caregiving has also been found to be detrimental to the carer's physical health. In addition to pre-existing health problems (35% of cancer carers in Thomas et al.'s (2002) study had pre-existing health problems), having to carry, transfer and physically support another adult can injure a carer's posture and overall musculoskeletal health (Braithwaite, 1990; Evandrou, 1996). Caregiving tasks also take time away from beneficial physical exercise (Evandrou, 1996; Toseland et al., 1995). Further, a carer's reduced income can have a negative impact on their physical health. Evandrou (1996) points out that a lower income when another family member's medical bills are overwhelming may force the carer to leave his or her own medical problems unaddressed because of the now less-affordable cost of treatment (see also Braithwaite, 1990).

Further, caregiving can be stressful and burdensome, with multiple studies showing that caregiving is a mentally and physically tiring role with carers suffering from higher rates of neglected health problems, major depression, anxiety, panic attacks and stress than their non-caregiving counterparts (American Cancer Society, 2006; Evandrou, 1996; Haug et al., 1999; Hodges et al., 2005; Kramer, 1997a; Northouse et al., 2000; Toseland et al., 1990; Weitzner et al., 2000). Feelings of worry and anxiety that erode a carer's psychological wellbeing are directly related to the emotional strain of caring about a loved one who is seriously ill (Braithwaite, 1990; Toseland et al., 1995). The psychosocial toll is often worse for carers than patients. When compared with patients, carers often have greater levels of distress, anxiety and unmet psychological needs because they are overlooked within the medical system (Braithwaite, 1990; Harrison et al., 1995; Hodges et al., 2005; Northouse et al., 2000; Thomas et al., 2001).

Studies, such as Braithwaite's (1990), Evandrou's (1996), Northouse et al.'s (2000) and Toseland et al.'s (1990; 1995), have sufficiently established that being an informal carer is stressful and burdensome. Attention now needs to focus on how to improve their experiences. In Zarit's (1989:147) words, "since we know caregiving can be stressful, what can be done about that?" Taking a salutogenic approach and asking, "what helps carers to go on caring?," "what are carers' needs?" and "how best can support services meet these needs?" is more likely to inform support service improvements for carers (Lindstöm & Eriksson, 2005). That is the purpose of this thesis, examining carers' experiences and psychosocial support preferences to inform policy and the revision of standard practice.

The focus however is not on all carers. Most research is on carers of the elderly with dementia. Few studies have taken an experience-driven, salutogenic approach to examining the experiences and support needs of carers of cancer patients.[2] There are many similarities between caring for Alzheimer's patients and cancer patients. Regardless of the disease afflicting the patient, as mentioned above, being a carer can be a stressful, emotionally, financially, and physically taxing role that is typically undertaken later in life. The disease, however, can make a significant difference to a carer's experience. A degenerative disease like dementia typically occurs in old age, can be slow in onset, long term, and follow a sequential pattern of decreasing mobility and increasing dependence. Cancer, in contrast, affects people of every age, can be physically painful for the patient and follows an uncertain trajectory that vacillates between sickness and health, dying and wellness, making the experience far less predictable for the carer (McNamara, 2001).

Few researchers, however, have examined cancer carers' needs and support preferences (Thomas et al., 2001), which lends impetus to this research into carers of cancer patients' experiences. Considering that cancer is the leading cause of death in Australia (accounting for 29.4% of deaths in 2005) (ABS, 2007; National Cancer Control Initiative, 2003), that it is the primary reason for "potential life years lost" (Duckett, 2004:41), that 322 per 100,000 men and 245 per 100,000 women in Australia are diagnosed with cancer each year (PHRC, 2002) and that an estimated "one in three men and one in four women will be directly affected by cancer before the age of 75" (Cancer Council Australia, 2003), it is surprising that cancer carers' experiences have not been more thoroughly examined. Further, most studies of cancer carers are psychological, descriptive and narrowly focused (for exceptions see Allen et al., 1999; Grbich et al., 2001; Kramer & Lambert, 1999; Thomas et al., 2001). Much of the previous research, going back as far as the 1970s when psychosocial oncology first emerged (Remennick, 1998b), is

---

[2] A greater number of studies, it seems, have examined carers of cancer patients in palliative care settings. Few have analysed cancer caregiving at earlier stages of the disease.

limited to measuring the efficacy of support services in units of burden-relief, listing cancer carers’ psychological needs or limited to quantitative techniques.

Studies on cancer carers and support services have examined the effectiveness of support, but efficacy is often limited to measuring the extent to which psychosocial interventions decrease carers’ reported levels of burden or distress (Boulton et al., 2001; Thomas & Morris, 2002; Weitzner et al., 2000). Few have assessed the quality of these services based on cancer carers’ evaluations in their own terms (Herron, 2005). To understand the value of and variation in support service utilisation, researchers such as Askham (1997:1) advocate a “needs-led rather than a service-led” approach to understanding carers’ experiences, needs and support preferences. Instead of imposing units of measurements on carers’ experiences, the efficacy of support services should be based on carers’ definitions of needs and carers’ definitions of what is valuable. Studies that have examined cancer carers’ coping strategies are similarly narrow in focus (Nathan, 1990; Sabo, 1990). Psycho-oncological research has classified carers’ responses to illness, including stress, depression and anxiety, but the social aspects are largely missed in these approaches (Thomas et al., 2001). Instead of examining the source of the stress, the focus is largely on the effect. Research with a more social lens to examining the needs of cancer carers is described as “under-explored,” with most studies of this nature being predominantly quantitative (Thomas et al., 2001:21).

Quantitative studies on cancer carers’ experiences have found statistical variation in carers’ needs (see chapter one). Age, for example, has been found to be a noteworthy factor with younger carers reporting more emotional and unmet needs (Ciambrone & Allen, 2005; Sharpe et al., 2005; Thomas et al., 2002). The reasons for this variation, however, are unclear (Burns et al., 2004; Laizner et al., 1993; Thomas et al., 2001; Thomas et al., 2002). Further, quantitative research is limited to those categories analysed by the researcher and does not take into account all possible causes and correlations.

Although these past studies have made significant contributions to understanding cancer carers’ experiences, qualitative sociological research would allow for a cancer carer led conceptualisation of carers’ needs and why they vary. As Remennick (1998a:7) explains, to “unravel” the “complex and multifactorial etiological webs” in which cancer carers’ experiences are wrapped, “diverse research perspectives" and theoretical perspectives need to be applied. As such, previous writers have suggested that future research examine caring from carers' perspectives, using qualitative methods to try to explain this variation in the needs of cancer carers and to inform improved targeting of social support (Burns et al., 2004; Ciambrone & Allen, 2005; Dow et al., 2004; Herron, 2005; Nathan, 1990; Thomas et al., 2001). Thus, this study's research question is: *what are the experiences and support service needs of carers looking after a spouse with cancer?* By responding to this question, I am making a practical contribution to the cancer caregiving literature and a theoretical contribution to the sociologies of emotion and time.

To answer my intentionally broad research question, an examination of carers' narratives and accounts of interactions with medical and support services was required. The inclusion of each carer's whole "story" allows "input from real-world situations" to indicate which variables best explain the variation in carers' needs (Taylor & Dakof, 1988:98). Questionnaires, interviews and participant observation are used to collect whole accounts of carers' experiences. Further, a quasi-grounded theory, semi-structured and "unfiltered observation" approach was adopted to avoid prematurely imposing categories on the analysis and to allow for the creation of new thematic categories (Becker, 1998:85). Refinement of the research question to include only those carers looking after a spouse with cancer was done to avoid confounding the data with too many variables.

An "action-based" approach, typical of psychosocial studies, where a central aim of the research is positive change, was taken to answering the research question (Remennick, 1998a; White, 2006:3). The lack of significant change over the past 20 years in how carers are supported within medical systems calls for research that not only fills a gap in academic knowledge, but bridges the distance between academics, service providers and policy-makers. Thus, this research not only adds to the limited body of research on cancer carers, but does so in conversation with those organisations responsible for policy and practice: Cancer Council ACT (Australian Capital Territory), a not-for-profit organisation with the goal of "reducing the incidence and impact of cancer in the ACT region" (Cancer Council ACT, 2007), and Cancer Australia,[3] the Commonwealth department primarily

---

[3] I submitted a report of my findings to Cancer Australia in 2009. It will be made available via the Cancer Council ACT website later in 2010.

responsible for “trialling innovative service delivery approaches and coordinating information management” related to cancer care (Parliament of Australia Senate, 2005:16) (see chapter two).

Thus, this research may be crucial to the ongoing stability of the Australian medical system. If the current cost-cutting “hospital at home” practices, which rely heavily on family carers, are to continue, then support and medical professionals require a better understanding of cancer carers’ experiences, needs and support preferences. The medical system needs to adopt a more systematic means of assisting these family carers. This research provides that information. It equips relevant support service providers and medical personnel with a social, carer-driven and less psychometric understanding of carers of cancer patients’ needs and experiences. It arms them with a new means of measuring cancer carers’ needs, based on orientations to time and how much control they have over their time. Perhaps most importantly, this research raises questions about possible ethical issues in how carers are currently treated within the medical system and proposes a structure-wide resolution.

Outline of the Thesis

Below is a summary of the contributions of this research, as they will be presented in the chapters that follow. The chapters are not presented in a positivistic or deductive format, where results and discussion are separate. Instead, empirical outcomes are presented and related to relevant debates in six chapters to allow for a more fluid conversation between past and present research. After a literature review and discussion of the methods used, chapters are structured to progress from a micro to a macro focus. In early chapters, I describe carers’ emotional experiences, individually and as a couple, and the implications of these findings for social workers, future research and theory building. In later chapters I focus on carers’ interactions with formal support and within and across medical systems, and offer practical implications based on these insights.

Chapter one provides a necessary overview of previous literature. It begins with a review of the literature on cancer patients’ and carers’ experiences of biographical disruption, needs, coping strategies and the value of support services. The literature on cancer patients is presented with the literature on cancer carers to demonstrate the relative paucity of research on carers and highlight the interactive nature of the relationship between carers and patients. Questions are raised about gaps and contradictions in previous studies: Do cancer carers experience biographical disruption in the same way as cancer patients? What coping strategies do carers of cancer patients employ? Why do younger and female carers tend to report more unmet needs? What value, in participant driven terms, do support services have for carers? What are carers of a spouse with cancers’ overall experiences within the medical system and how does the medical system help or hinder carers’ access to psychosocial support? These questions form the foci of chapters three through seven.

Details of the data collection and analysis process as well as the philosophies of knowledge that informed this project are presented in chapter two. Data collection included participant observation, questionnaires, longitudinal interviews and one focus group. Using a quasi-grounded theory approach, each method is linked to the one before it; that is, analysis of the data collected using the former method informed the focus of the latter. Because interviews provided the most sustained contact and provoked the most detailed information, interview data contributed substantially to analysis and making recommendations. Nineteen carers of a spouse with cancer were identified through questionnaires. An additional 13 participants were recruited through purposive convenience and snowball sampling to ensure that both users and non-users of support services were represented, and to ensure that the sample included a relatively balanced number of male, female, younger and older carers. Each participant was interviewed twice, approximately six months apart to allow for longitudinal comparisons, clarification and the exploration of themes that emerged from analysis of the first interviews. *Nvivo*, a qualitative research software program, was used to analyse and organise questionnaire responses and interview transcripts, as data collection generated a large amount of data. A thematic approach to coding was adopted to highlight carers’ interpretations, to avoid imposing categories on the data and to allow categories to evolve from continued reading and questioning of the interview data.

Cancer carers’ experiences of their spouses’ cancer are explored in chapter three. Much past research has focused on cancer patients’ illness journeys, from diagnosis through to palliative care or survivorship. For patients, cancer is often associated with a statistical probability of death. Few patients hear the word "cured." Because of this, patients are rarely sure of their futures (Crouch & McKenzie, 2000). Cancer patients often feel as though they are *Dancing in Limbo* between life and death (Halvorson-Boyd & Hunter, 1995; see also Nathan, 1990); like they are at the borders, but lacking meaningful identification with either the "kingdom of the well" or the "kingdom of the sick," in Sontag's metaphor (1991:3).

There is a comparative dearth of literature, however, on cancer carers' illness experiences. In chapter three I constructively add to the few studies that exist and present carers' illness narratives. I question whether carers of cancer patients find meaning in their experience and whether they identify themselves as carers. I identify three differing patterns of grief in the analysis of carers' narratives, and I argue that carers of a spouse with cancer do not experience anticipatory grief like dementia carers. Like cancer patients', carers' experiences are characterised by uncertainty and oscillating emotions of hope, grief and a desire for normalcy. Carers of cancer patients experience what may be called *indefinite grief*: an uncertain pattern of mourning connected to an illness trajectory which waivers between periods of extreme illness and relative wellness. Identifying this type of grief is significant as it may mediate carers' feelings of guilt and confusion and inform support personnel's approaches to providing psychosocial support.

Although many carers experience grief and other associated emotions individually and internally, their emotions are also social: a shared experience with their spouse, family, circle of friends and even culture. Chapter four depicts the emotion management that most carers of a spouse with cancer feel obligated to perform using distraction, pep talks, listening, acting/lying, and blocking undesired communication. Past research has been largely restricted to examining cancer carers' coping strategies, with Sabo (1990), for example, arguing that the husbands of women with breast cancer adopt denial coping strategies. This research offers a social view of carers' emotions and emotion management. While carers of a spouse with cancer do use coping strategies (though none in this study used denial), they also do emotion work to actively manage their own and their partners' emotions towards the future. This approach to conceptualising carers' emotions is an attempt to move beyond individualistic conceptualisations of emotions within cancer caregiving studies. It provides a more complete conceptualisation of carers' emotional experiences and allows for more accurately targeted recommendations of how to support carers: with advice on both coping strategies and temporally located approaches to emotion management.

In chapter five I examine the variation in cancer carers' perceptions of informal support that led me to question the importance of time in understanding carers' experiences, needs and support service preferences. Quantitative studies show age and gender are predictors of variation in cancer carers' experiences, but why this variation exists is unclear. It became clear, however, during qualitative analysis that carers' experiences greatly vary depending on how much control cancer carers have over their time. Carers with little to no control over their time, due to juggling multiple roles, lacked time to feel. They had little time to themselves to sort through their emotions and little time to enjoy the benefits of caregiving: feeling closer to their partner. Carers with little to moderate control over their time due to managing one intensive caring role had more time to feel and were more likely to describe the cancer as a source of enhanced closeness with their partner. Conceptualising carers' differing emotional experiences based on the amount of control they have over time illuminates the impetus behind much of the poorly understood variation in cancer carers' experiences and support needs. This information will help providers of psychosocial support to tailor their recommendations. For sociologists of emotions, this finding highlights the importance of incorporating temporality into interactionist and determinist theories on emotion.

In chapter six I examine the value of both psychosocial and practical support for carers from a sociological perspective. Better understanding the value of these services, and why so few carers access them, will inform support providers of ways they might change their services to better meet the needs of cancer carers. Past social research has examined the value of counselling and support groups from a patient point of view, but few studies have examined the meaning and value of these forms of support from a cancer carers' perspective. There is a similar paucity of literature on the value of practical support for carers of cancer patients. Building on the findings presented in chapter five, I investigate the value of support services for carers depending on their time-sovereignty. Analysing carers' perceptions of support services using this framework clarified the reasoning behind some of the variation in support service use. Those carers with moderate control over their time, in particular, experience complex and often conflicting emotions related to their contradictory roles of both carer and spouse. They needed help in understanding and managing their emotions. Hence, they often sought and valued counselling and support groups as consultations on their emotions. Conversely, those carers with little to no control over their time, who had little time to feel, more often sought practical support including financial aid, respite and childcare. These services were sought to give the carer more time, but often had the reverse impact. Researching, applying and accessing these services was often so time-consuming that those carers who needed the benefits of practical support most, were the least likely to access these services.

Other barriers to accessing both psychosocial and practical support are examined in chapter seven. In this chapter carers' experiences within and perceptions of the medical system are analysed. This investigation builds on research that shows hospitals are now providing only limited inpatient services and family carers are relied on to assume responsibility for much of patients' care and emotional support (Laizner et al., 1993). I question the adequacy of the support provided to carers within the hospital in the roles they are compelled to assume. I question the outcomes of these practices on carers' wellbeing and I question the root cause of these practices. Recommendations on how to improve current practices are discussed in chapter eight.

This research is one of the first studies to add qualitative and empirical conceptualisations of cancer carers' experiences, using the sociology of emotions, to expand on previous literature. Understanding carers' experiences of grief, emotion management and differing needs based on time-sovereignty can help support services to provide better informed and targeted support. Investigating what changes need to be made in policymaking, based on carers experiences with the medical system, is also of practical importance, as systematic changes need to be made to protect carers' vulnerable health and ensure they can continue providing support to their sick family members.

Notes on Terminology

Before moving on to an overview of the literature, a few notes needs to be made about terminology. "Carer" is used more frequently in Australia and the United Kingdom, while "caregiver" is more often used in the United States. Both terms are used interchangeably in this text to denote the same meaning: a family member providing informal medical, practical and emotional support to a patient. “Carers of cancer patients” and, the less cumbersome title “cancer carers” are also used interchangeably in this thesis.

“Emotion” and “feeling” are two more words used reciprocally in this text. Some distinguish between emotions as the physical and psychological state and feelings as the embodied sensory clues or environmental clues that help a person interpret their emotions (Goldie, 2002). Others, Hochschild (1979) for example, emphasise feelings as learned and controlled states that are worked on to conform to social expectations. I use these two terms correspondently throughout to denote interlinking and inseparable parts of an embodied, personal, social, cultural and interactionist process.

The term “health care consumer” has been used since the 1960s in place of “patient” (Irvine, 1996). I, however, use the term “patient” to denote the person who is suffering from cancer. I do this because it is more convenient and because “consumer” obscures the unequal power dynamic inherent in the doctor-patient relationship and implies there is a choice in engaging with the medical system, where little choice exists (Irvine, 1996; Skene, 1990). At times, however, the terms “consumer” or “co-consumer” are used to refer to carers as users of medical services who are not the primary users (the patients).

“Health care system” is another commonly used phrase. This system is more aptly referred to by Duckett (2004:xxii) as an “illness care system” because the overall focus of most employees and structures is treatment and not prevention. For this reason and because it denotes the biomedical focus to which this system is restricted, this structure will be referred to from here on as the Australian medical system, medical system or, more specifically, the Canberra medical system when referring to the hospitals, practitioners and medical services used most frequently by the participants in this study.

Chapter One: Literature Review

The experiences of cancer patients are well documented. Their biographical disruption, their needs and the value of support services for cancer patients have been thoroughly investigated within sociology, anthropology and social psychology. Comparatively little is known about the experiences of carers of cancer patients. In the following sections, a review of the literature on cancer patients is presented with a review of the literature on cancer carers to emphasise the relative paucity of literature on carers and to underscore the interactive nature of carers' and patients' experiences. Below, an overview of the literature on cancer patients' illness experiences is followed by a brief summary of what little that is known about carers' illness experiences. In the section that follows, studies on carers' coping strategies are examined along with research on patients' needs to raise questions about potential conflicts between certain coping strategies and patients' needs. Then, the gaps in the literature on cancer carers' needs are highlighted with an overview of the research on the value of support services for patients and carers. The issues raised by the gaps and inconsistencies in the literature inform the analysis questions on which the subsequent chapters are focused.

Biographical Disruption

Cancer begins with a "damaged" or "imperfect" cell that reproduces, causing a tumour of abnormal cells (Capra, 1982:389). In a system with a healthy immune system, the cells will either be destroyed or quarantined. In a system with a compromised immune system, the imperfect cells are allowed to proliferate and spread or metastasise (Capra, 1982; Parliament of Australia Senate, 2005). Sometimes this causes a bulge to push on the skin and swell the nearby veins. The resemblance of this veiny mass to a crab with legs is how this disease got its name; cancer means crab in Latin (Sontag, 1991). The effect of these over-reproducing abnormal cells or malignant neoplasms on patients' bodies and identities is startling, and well known (Remennick, 1998a). It begins with the diagnosis. This is the defining moment at which a person experiences "biographical disruption" (Bury, 1982:167; Bury, 1991; Remennick, 1998b).[4] Hearing a *cancer* diagnosis from a doctor can change a person's sense of self and

---

[4] This is also referred to as "diagnostic shock" (see Sourkes, 1982; White, 2006:58).

future direction (Parliament of Australia Senate, 2005; Remennick, 1998b). Although this is not the whole of their cancer experience and not the experience of all cancer patients, for many, the label “cancer patient” becomes dominant (Gear & Haney, 1990; Grbich, 1996). It invades all aspects of their life and results in an “altered self-image” and “loss of personal identity” (Davis & George, 1993; Gear & Haney, 1990:275). It may also be a “marginalising” identity that can stigmatise the patient (Grbich, 1996:23) as the “‘other’ to a society that defines health as its norm” (Frank, 1993:48).

Amongst cancer patients, the dominance of this patient identity may be due, in one part, to their dependency and, in another part, to hierarchical and bureaucratic hospital processes. Gear and Haney (1990) argue that, to maintain order and control, hospital staff manage patients’ diseases, not patient care. That is, to ensure decisions are made efficiently, medical staff typically overemphasise that the person being treated is a patient and undermine their capacity to understand treatment and be involved in decision-making as a competent and mature individual. Thus, medical system practices encourage identification with the patient role.

The overwhelming perception amongst westerners in the twentieth century, that cancer is synonymous with death, has caused the *cancer* patient identity to be particularly pervasive (Jalland, 2006; Sabo, 1990). As Sontag explains, “in the popular imagination, cancer equals death” and not just death, but a slow, painful and “spectacularly wretched” death (Remennick, 1998b; Sontag, 1991:7, 16). AIDS (acquired immune deficiency syndrome) was probably the only disease more feared (Remennick, 1998b). Over the past several decades, however, cancer mortality rates have decreased. Cancer is now feared, not because it is certainly connected with death, but because it is uncertainly connected with death. A comparison with heart disease illustrates this phenomenon. Although cancer is less often fatal, it is not as “clean,” clear cut and certain as the risk of fatality from heart disease (Bard, 1997:44). Cancer “carries the threat of disability and, even more frighteningly, recurrence and the repeated threat of death” (Bard, 1997:44). Currently, being labelled a cancer patient has a “secondary consequence” of being persistently seen as possibly, but not certainly dying (Short et al., 1993:88).

Many cancer patients begin a battle with their bodies and the cancer, perceived as an intruder. As Capra describes it, "[patients] see the tumour as a foreign object and want to get rid of it as quickly as possible and forget the whole episode…[because] for many cancer patients the body has become their enemy, one they mistrust and from which they feel thoroughly alienated" (Capra, 1982:389). As part of this process, patients and doctors often employ "warfare" and "military terminology" in their understanding and description of treatment (Sontag, 1991:65). Radiotherapy and chemotherapy, for example, can be viewed as symbols of atomic and chemical warfare on a destructive mission (Sontag, 1991).

For those who survive treatment and surgery, which is often more painful and disabling than the disease at the time of diagnosis, the journey is not over (Sontag, 1991). Cancer patients whose disease is in remission experience ongoing uncertainty (McNamara, 2000; Nathan, 1990). The probability of a cure hinges on type, stage, surgical and treatment factors. No one is sure if they are cured or doomed and many patients suffer from death anxiety (Gear & Haney, 1990; Nathan, 1990; Taylor & Dakof, 1988:96; Woof & Nyatanga, 1998). Even after five years of remission (commonly used as a statistical marker of survival) many people still feel as though they are living in cancer's "shadow" (McNamara, 2000:139), like they are caught between being a patient and person, "between living a sick role and living a life, and ultimately between life and death" (Frank, 1994:13; Gear & Haney, 1990; Nathan, 1990).

Increasingly researchers are recognising survival as a period of uncertainty, potential distress and change for cancer patients. Often those within the "remission society" feel as though they are *Dancing in Limbo*[5] between life and death, continually aware of their own temporal limits (Breitbart, 2006; Crouch & McKenzie, 2000; Frank, 1993; Frank, 1995:8-9; Halvorson-Boyd & Hunter, 1995; Nathan, 1990). These feelings of abnormality and mortality can persist despite an appearance of recovery and normalcy (Crouch & McKenzie, 2000), because "cancer narratives refuse to offer the reassurance of complete resolution" (Stacey, 1997:7). Many survivors may remain, stuck between patient-hood and personhood.

---

[5] This is the title of Halvorson-Boyd and Hunter's (1995) book.

Little and colleagues use the term “liminality” to describe this sense of being between statuses: to refer to the heightened feelings of mortality one has as a cancer patient after being on the threshold, but not actually crossing over to the next phase: death. They chose this term after witnessing in their cancer patients “a persistent awareness of being a cancer patient, regardless of the time since treatment…or absence of recurrent or persistent disease [as well as] a state of alienation from social familiars” (Little et al., 2001:139). They distinguish between two kinds of liminality. An acute or intense liminality follows diagnosis, while a less intense liminality may last the entire life of the cancer survivor (Little et al., 1998). They found that it was typical for patients and survivors of cancer to swing back and forth between states of acute liminality to feelings of resolution, depending on a patient’s ongoing medical state and their capacity to communicate how they are feeling to the people who are important in their lives (Little et al., 1998).

According to Little (1998), liminality is very lonely. First, “more than any other life-threatening disease…cancer brings about social isolation and deterioration of social networks” (Remennick, 1998b:121). Family and friends tend to distance themselves from cancer patients, as if cancer was contagious (Remennick, 1998b; Sontag, 1991). The taboo surrounding death and a desire to avoid being reminded of one’s own mortality may also keep others away (Crouch & McKenzie, 2000:209; Remennick, 1998b). Second, and more specifically related to liminality, few understand that people need support, not just when they are in treatment, but afterwards as survivors as well.

> Survival poses more problems than illness…the survivor is a puzzle. What can be wrong with someone who is ‘better’? Why is it so difficult to get back to a ‘normal’ life? Why is it so hard to relate to this person, whom I knew so well before he became ill? (Little et al., 2001:125)

To reclaim their personhood and move past the “biographical disruption” and stigma caused by cancer and its uncertainty, many patients seek meaning in their cancer experience (Breitbart, 2006; Bury, 1982:167; Bury, 1991; Frank, 1993; Surbone, 2006). They ask the questions “why me?” and “why now?” (Clarke, 1990:93; Sontag, 1991:39). To answer these questions, they examine their life stories and construct illness narratives that allow for an interpretation of why health has been lost (Neimeyer, 2001; as cited by Whiting & James, 2006:3).

Often, these answers are filled with spiritual significance or blame, such as a sign from God, the result of a bad relationship with one's family, stress or a chance to address unresolved issues and make changes (Bard, 1997; Clarke, 1990). Whatever the meaning, it is culturally shaped, likely to be deeply personal and allow the cancer patient to regain a sense of control over their past and present (Bard, 1997; Bury, 2001; Capra, 1982; Clarke, 1990).

That is, illness narratives allow cancer patients to rebuild a sense of order and logic in their lives and reclaim a positive self-image through a kind of narrative rebirth (Allsop & Mulcahy, 1998; Bury, 2001; Clarke, 1990; Frank, 1993; Radley, 1999). As Frank (1993:42) explains, severe illnesses are crisis points that result in epiphanies, "moments that are privileged in their possibility for changing your life." The suffering inherent to patient-hood is believed to produce truth, "enhanced subjectivity," reflection and self-change (Frank, 1993; Frank, 1994:8). Telling one's illness narrative allows the person to connect their past and present in a new light, redefine who they are and move past patient-hood (Frank, 1993; Radley, 1999).

Carers' Biographical Disruption

While patients' experiences of biographical disruption, liminality and seeking meaning are well documented, the literature on the experiences of their carers is "fragmentary and diverse" (Thomas & Morris, 2002:179). Many researchers recognise that a cancer diagnosis impacts on the whole family system, yet few studies have examined the impact of the illness on carers of a spouse with cancer (Firth, 2006; Gregory, 2005; Hoffman, 2002; Nathan, 1990).

Studies that have begun to explore cancer carers show that the experience has a considerable impact on a carer's life and emotional wellbeing. Just as patients experience biographical disruption, family members also feel that their life narratives have been interrupted by the diagnosis (Harden, 2005). Overall, this interruption entails a "loss of certain future, loss of role within the family and the outside world, concerns about the burden of caring, issues about sexuality [and] loss of financial security" (Woof & Nyatanga, 1998:77). Spouses are often the family member most upset by cancer because of the change in their roles, increased responsibility and most acutely, "'their fears and shattered dreams'" (Quinn & Herndon 1989:46; as cited by Nathan, 1990:222). Husbands of breast cancer patients specifically have been found to feel anxious, depressed, incompetent and distracted by “hypochondrial preoccupations” (Sabo, 1990:75). The following quote illustrates the intensity of a carer’s reaction to a cancer diagnosis and the invisibility of this reaction to others:

> I’d go to work and be in a daze. I didn’t know what to do. I wanted to do something, but didn’t know where to begin. I didn’t know what the next person was thinking. I didn’t know what my wife was thinking. Should I cry with her or be strong? Should I talk or should I shut up? Should I take her in my arms or would this make her feel worse than she already did? I felt extremely isolated. No one knew, or really even cared to know, what I was going through. (Sabo, 1990:76)

In addition to the emotional impact of a cancer diagnosis, becoming a carer means taking on new practical responsibilities to assist the cancer patient during what may be debilitating treatments. These tasks might include “help with activities of daily living” such as grooming, cooking, housework, buying groceries, washing clothes, managing medication and helping the patient with mobility and transportation (Braithwaite, 1990; Thomas et al., 2001:107). A study of UK cancer carers found that 42 percent reported that they complete these kinds of tasks (Thomas et al., 2001). Often carers feel unprepared in taking on these new responsibilities and receive little informal help, but are keenly interested in helping their spouse (Braithwaite, 1990; Surbone, 2003). Neighbours and friends may be unlikely to offer support, and support from relatives is typically forthcoming only if the couple has young children (Laizner et al., 1993).

A few studies have found cancer to be a lonely experience for carers as well as patients. Friends and neighbours often avoid not just the cancer patient, but also their family because the disease scares them or they do not know what to say (Kramer, 1997a). Few husbands whose wives have cancer, for example, have anyone to confide in (Sabo, 1990). Perhaps husbands and wives relied on each other before the diagnosis, but after, carers may feel (and perhaps are told) that they are supposed to comfort the patient. Many find their relationship changes as they take on their role as carers (Nathan, 1990). For instance, despite experiencing their own fears, many carers hide their feelings from the cancer patient, leaving them with few people, if anyone, to confide in (Breitbart, 2006; Burns et al., 2003; Thomas et al., 2001; Thomas et al., 2002). Carers with no one to share their problems and frustrations tend to have higher levels of subjective burden and lower levels of perceived quality of life (Mellon et al., 2006; Pruchno & Resch, 1989).

If cancer patients survive into remission, some research shows that carers find it hard to cope with the liminality that cancer patients experience (Gear & Haney, 1990; Nathan, 1990). For carers, the remission and survival stages of cancer may be characterised by an attempt to restore the life they knew before cancer which can be a point of conflict with patients seeking to change their sense of self through constructing an illness narrative and finding meaning in their ill health (Gregory, 2005). Other studies argue, however, that in their everyday interactions, families "develop a story of the illness, what caused it [and] what it meant" to help all of them move on and regain a sense of control over their lives (Boss, 1999; Firth, 2006:69; Gregory, 2005; Harden, 2005).

In sum, while there is some consensus in the literature on cancer patients' experiences, more research is necessary to address contradictions in the literature on carers' experiences. The overview presented here suggests that cancer has a substantial impact on a carer's emotions. It increases the number of their responsibilities and often depletes the number of their confidants. However, it is not clear whether carers impede or foster patients' desires to construct a cancer story. Nor is it clear if carers find meaning in their caregiving experience, as many cancer patients do in their illness, or how they describe their own illness experiences. In chapter three I focus on the questions raised here and describe my analysis of cancer carers' illness experiences to add to this growing body of literature.

Patients' Needs

While some research shows that patients need to communicate their fears, other research asserts that carers' coping strategies get in the way of patients' abilities to meet that need. The following section presents an overview of patients' reported need to communicate followed by a review of the literature on carers' coping strategies.

While there is no singular and overarching definition of needs, researchers have asserted that cancer patients have a need for information, a need to talk about their fears of death and the meaning of cancer within their biography. Many patients want to know as much as possible about their disease. What are the statistics on survival? What are my treatment options? How will I know if I am improving? What stage is my cancer? Answers are sought through doctors, oncology nurses, books, cancer survivors, friends, carers and the internet. Lobb et al. (2001), for instance, found that 91 percent of women with early stage breast cancer wanted to know their diagnosis and projected outcome of their cancer treatment (as cited by Craft et al., 2005). Often information is contradictory (Hardey, 1999). Some cancer patients feel overwhelmed (31%) and confused (27%) by inconsistencies in the literature, but most find information to be helpful and empowering in decision making (Eysenbach, 2003; Fleisher et al., 2002). Not only do cancer patients report it as a need, but research has found that information decreases stress levels in patients (Rees & Bath, 2000; as cited by Bar-Tal et al., 2005). Specifically, information acquired through support groups has been found to improve a patient's confidence when talking about their treatment options with medical professionals (Ussher et al., 2006).

Cancer patients also express a need to talk about illness and emotions. The terminally ill and those with life-threatening diseases (some of whom are cancer patients) typically share a "fear of the unknown, fear of pain and unpleasant symptoms, fear of dying, concern about how to cope, confusion and uncertainty, anger and bitterness, depression, loneliness [and] sadness" (Wilkie, 1998:56). Some cancer patients do not want to discuss these feelings because they think it may cause them to become depressed (Bard, 1997), but many express a desire to talk openly about being in limbo between life and death (Halvorson-Boyd & Hunter, 1995). Discussing their fears and thoughts, however, is often difficult.

Any hope of exploring worries and feelings surrounding cancer is typically dashed by anyone who has not gone through the experience. Ten of the fourteen breast cancer patients interviewed by Sabo (1990), for example, wished that their husbands had been less protective and more open to honest discussions on feelings. Cancer patients in other studies also expressed exasperation about having their attempts at discussing their disease or emotions dismissed (Bard, 1997; Ussher et al., 2006). Attempts at discussing their "compressed sense" of mortality (Kellehear, 2007:15) were often countered with responses such as "buck up," "think positive, be positive," or "keep your chin up it'll be sunny tomorrow" instead of being encouraged to talk about their feelings (Ussher et al., 2006:2570). Crouch and Manderson (1993:151) explain that these types of conversations are usually brushed off because, in western society, “there are no guidelines for practices [and] no routine and established forms of action within which [negative] feelings can be meaningfully accommodated” (as cited by Crouch & McKenzie, 2000:210). Talking about death is largely not socially accepted.

There have, however, been attempts to make people more aware that many patients’ want to have these open conversations. Buckman (1996) has published a book on how to talk with - or more accurately how to listen to - individuals dealing with feelings of acute mortality. He argues that the wide range of emotions cancer patients feel often go unspoken and unaddressed because family members are afraid of upsetting the person who is dying or potentially dying. But not talking about death may have a negative effect on the patient. It may work to block all communication and exacerbate fears because feelings that are not discussed may result in feelings of shame (Buckman, 1996; Ussher et al., 2006). Said in another way, Kuhl (2002) reported that dying patients who *were* offered the opportunity to talk about death found it to be a rewarding chance to reconnect with family.

Do Carers’ Coping Strategies Intensify Patient Needs?

Are the coping strategies carers adopt acting to obstruct conversations patients wish to have? Some of the literature asserts that carers are in denial and that the use of this coping strategy is halting patients’ attempts to discuss the meaning of and their fears about their illness. Sabo’s (1990:80) study, for example, found that husbands of wives with breast cancer generally avoid discussing their own and their wife’s fears. Instead, husbands maintain optimism, which he termed “paternalistic denial.” The most common initial response of husbands’ in Sabo’s (1990) study, for instance, was to say that the removal of the breast made no difference sexually and they were completely confident that the doctor had removed all of the cancer. Denial, in general, refers to the repression or disbelief in a certain reality, such as refusing to believe that someone will die, or disregarding fears that treatment might not work (Dumont & Foss, 1972). Sabo’s (1990) notion of paternalistic denial refers to the way husbands subdued the cancer’s emotional impact by rejecting the life-threatening nature of the diagnosis.

Although denial was shown (in Sabo's and other research) to help carers diminish their own emotional burden, it also frustrated and alienated patients who wanted to talk about their fears and anxieties (Gear & Haney, 1990; Rose et al., 1997; Sabo, 1990). By denying the seriousness of the situation, carers indirectly refused the patient the opportunity to communicate their concerns.

But what exactly is meant by "coping strategies"? Before reviewing the literature on cancer carers' coping strategies further and investigating the contradictory approaches to understanding cancer carers' emotions, defining coping strategies and the aetiology of the term is necessary.

Coping is a psychological concept. In psychology, emotions are classically viewed as wholly internal, biological, private, representations of the subconscious that surface in the conscious as responses to external stimuli (Abu-Lughod & Lutz, 1990; Bryant & Cox, 2006; Heise & Weir, 1999; Lutz, 1995; Petersen, 2004). Although, over recent years, psychologists have been increasingly incorporating "social context and learning" within theories of emotion, "psychological research has continued to focus largely on biology and on individual cognition" (Petersen, 2004:3). In cognitive psychology specifically, emotions are perceived as "responses to events" and as precursors to action based on a person's evaluation of an event as meeting or hindering one's goals (Booth & Pennebaker, 2000; Frijda, 2000:68). Coping strategies are the "internal mechanisms" that serve to moderate emotional responses to threatening events such as illness (Frijda, 2000; Haar, 2006; Maex & De Valck, 2006; Remennick, 1998a:6) (see Bury (1991) for a critique of the varied uses of the terms "coping" and "strategy" within the chronic illness literature). According to cognitive psychological theory, a situation is first "evaluated with respect to what is at stake" (Folkman & Lazarus, 1980:223). If it is appraised as threatening, then coping strategies are used to decrease the stress of the response through either changing the environment (problem-focused coping) or changing feelings about the situation (emotion-focused coping) (Braithwaite, 1990; Cobb, 1976; Folkman & Lazarus, 1980; Haar, 2006; Maex & De Valck, 2006).

These two broad coping strategies (emotion- and problem-focused) contain several different sub-types. Emotion-focused coping strategies may include "wishful thinking, denial, suppressed feelings, self-blame and avoidance"

(Carpenter & Miller, 2005:110), “thinking things could be worse [or] telling yourself there was no alternative” (Braithwaite, 1990:135). Problem-focused coping might include seeking information, assessing the problem, getting guidance and acting or preventing action (Braithwaite, 1990; Folkman & Lazarus, 1980). In general, studies of carers find that emotion-focused coping strategies are linked with negative psychological outcomes such as higher rates of anxiety, depression and burden, while problem-focused coping is linked with positive psychological outcomes (Braithwaite, 1990; Carpenter & Miller, 2005; Chambers et al., 2001; Saad et al., 1995).

The extent to which the emotion-focused coping strategy denial is used by carers of cancer patients is inconsistent in the literature and open to sociological questioning. Some research emphasises denial as the central coping strategy employed by husbands of wives with breast cancer (Sabo, 1990), other psychological studies suggest that carers use a number of coping strategies to reduce the impact of a life-altering diagnosis. One study of husbands of newly diagnosed breast cancer patients found that both withdrawal (spending time apart from the patient) and denial were frequently employed coping strategies (Carter & Carter, 1994; as cited by Bultz et al., 2000). Nathan (1990), Rose et al. (1997) and Saad et al. (1995) found that carers of cancer and dementia sufferers use a range of coping strategies such as denial, problem-focused coping, normality maintenance (accepting the seriousness of the situation, but trying to maintain the life led before the diagnosis) and escapism (distancing through drugs or alcohol). Thus, the prevalence of denial amongst cancer carers is unclear.

Determining the prevalence of denial is important to assessing the extent of the conflict between a patient’s need to communicate and a carer’s coping strategy. In exclusively examining coping strategies, has the cancer caregiving literature missed other important aspects of carers’ emotional experiences? Sociologists might challenge this focus on coping strategies as short-sided, as the impacts of language, culture, history and even authority on thoughts, emotions and coping are neglected (Abu-Lughod & Lutz, 1990; Galasiński, 2004; Geertz, 2007; Lutz, 1995; Petersen, 2004; Sayer, 1984; Stocker & Hegeman, 1996). Unlike psychologists, sociologists generally view emotions as both an internal process and social performance or “contextually embedded social practice” (Galasiński, 2004:5; Petersen, 2004). Sociologists generally agree that emotions are simultaneously private, public and embodied. There are three main approaches to theorising about emotions in sociology: social determinism, social constructionism and social interactionism (Heise & O'Brien, 1993; Powell, 2008). Social determinists (see Barbalet, 2002; 1998; see Collins, 1990; 2004; 2008) view emotions as powerful tools that work collectively to determine the strength of social cohesion. Emotions either reinforce and “uphold the cultural order” or challenge social norms, patterns, structures and solidarity (Denzin, 1999; Heise & O'Brien, 1993; Powell, 2008; Scheff, 1997). Social constructionists emphasise the cultural nature of emotions, the influence of one’s society in recognising, experiencing and constructing one’s emotions (Abu-Lughod & Lutz, 1990; Heise & O'Brien, 1993). Social interactionists see emotions as both shaped by social contact and managed to adhere to cultural expectations (Heise & O'Brien, 1993). They argue that while emotions do “erupt” from the body during social encounters, they are also judged against cultural expectations and manipulated to conform to them (Heise & Weir, 1999; Powell, 2008).

Using a sociological approach to emotions raises questions about the social aspects of carers’ emotions and interactions with their spouses. Denial may not fully encompass carers’ emotional experiences. Instead of denial, for example, it could be that carers who reject the seriousness of the diagnosis in conversations with the patient are trying to help the patient to be optimistic. Or, it could be that they feel they cannot talk about death because their culture lacks the accepted and expected dialogue needed to enter into such discussions (Clark, 1990b). Elias supports this premise. He explains that “a shift towards informality has caused a whole series of traditional patterns of behaviour in the great crisis-situations of human life, including the use of ritual phrases, to become suspect and embarrassing for many people” (Elias, 1985:27). Thus, many carers do not know what to say because traditional offerings on appropriate interaction seem tired and insincere. Further, people may avoid talking about death because, as is often the case with sex, the subject provokes embarrassment or intense emotion. To avoid a social faux pas, people typically do not talk about death out of consideration for those around them (Kellehear, 1984). And so, instead of exclusively examining denial or coping strategies, examining the possible social basis of a carer’s reluctance to talk about death may also be fruitful.

Instead of focusing solely on coping strategies, sociologists of emotions might ask if emotion work more accurately describes their experiences. Hochschild's (1979; 1990) concept of "emotion work," arising from the interactionist branch within the sociology of emotions, refers to the manipulation of emotions that people perform on themselves and others to comply with feeling rules or basic cultural norms of how a person should feel in terms of emotional intensity, direction (positive or negative) and duration in a particular situation (Hochschild, 1990; Small, 1996; Turner & Stets, 2005). So, instead of carers using a coping strategy like denial, social interactionist sociologists of emotions might view carers as trying to manage the patient's and their own emotions to conform to the social norms and the norms of their relationships.

Thomas and colleagues (2001) have taken this approach to studying carers emotions. They found that only a few patients described their carers' emotion work as discouraging to open discussion of their fears (Thomas et al., 2002). They also reported that the work carers do for cancer patients is largely emotional. Their focus on emotion work allowed them to perceive patients and carers not as "passive victims," but as active creators of their cancer experiences, located within "specific social settings and socio-cultural circumstances" (Thomas & Morris, 2002:181; Thomas et al., 2001). This approach enabled identification of the impetus behind emotion work in cancer: to promote a feeling of control over the cancer, to help the patient to be positive and maintain a degree of normalcy despite the major interruption of the sickness (Thomas & Morris, 2002; Thomas et al., 2001; Thomas et al., 2002). Finally, focusing on carers' emotion work (instead of their coping strategies) also allowed for a conceptualisation of carers as both co-consumers and co-carers: as both in need of support from the medical system and as co-providers within the medical system.

Despite these potential strengths, little research conceptualises cancer carers' emotions as both psychological processes and interactional processes. The need to more accurately understand carers' emotional processes is great (Stocker & Hegeman, 1996). There is little sociological literature in this area. Calls for more research on carers' emotional experiences have been made to follow Thomas and colleagues (2001) initial step and complement the psycho-oncological focus that dominates the cancer caregiving literature (Burns et al., 2003; Ciambrone & Allen, 2005; Thomas & Morris, 2002). Careful attention to both the internal and external nature of carers' emotions is necessary, because the level of inquiry (internal or interactional) matters, as it influences a study's recommendations.

In chapter four, I answer this call and explore the psychological and social aspects of cancer carers' emotional experiences to take the understanding of their journey a step further and address the questions arising from the review of the literature above. These questions include: to what extent do cancer carers employ individual coping strategies and which ones? Are preferred coping strategies silencing patients' attempts at open communication? Do carers perform emotion work on themselves and the cancer patient? If so, how do they manage the patient and their own emotions? What informs their emotion work? Shedding light on these questions aims to provide information that may be of use to support services, social workers, counsellors and medical personnel interacting with carers, potentially prompting a deeper appreciation of carers' emotions within these services.

Cancer Carers' Needs

Like the literature on carers' coping strategies and emotions, further exploration of cancer carers needs is also called for. Although many studies describe cancer carers' needs, needs have been interpreted in many ways, and professionals and "consumers" often propose contrasting definitions (Duckett, 2004:6; Gibson et al., 1996; Soothill et al., 2001; Thomas et al., 2001). Professionals, for example, often define carers needs in terms of a list of the tasks a carer accomplishes to meet the patient's needs (Sharpe et al., 2005; Thomas et al., 2001). Laizner and colleagues, for instance, in their review of the literature on the needs of cancer carers, show that several studies report that carers have "*personal needs* related to self-care, including bathing and mobility" (original emphasis 1993:115). Carers, however, do not need help in showering or getting around. If they did, they would not be carers – they would need a carer. Instead, it seems researchers often list a carer's responsibilities as their needs.

Other professionals in psycho-oncology often define carers' needs in terms of the increased rates of "psychiatric morbidity" and "pathology" that result from their higher rates of anxiety and depression (Alderson et al. 1994; Costain-Schou & Hewison 1999; as cited by Thomas et al., 2001:26). But social aspects are largely missing from these psycho-oncological approaches to psychosocial needs (Alderson et al., 1993; as cited by Thomas et al., 2001). "Psychiatric morbidity," for instance, can be understood as the result of change in a carers' interpersonal and social landscape because of the social tensions related to a cancer diagnosis. Attention should be focused on the cause, not just the effect. In contrast to the psycho-oncology method of defining needs, needs can usefully be defined as the cause of the "under[lying] emotional and psychological distress, rather than this distress itself" or as anything described as an unmet need by the carer (Soothill et al., 2001; Thomas et al., 2001:20).

Therefore, needs here will not refer to what carers do for their care recipient nor to carers' psychological distress. Instead the following list focuses on what carers report as necessary for them to continue providing care (Burns et al., 2004). A literature review of the needs of carers of cancer patients, elderly care-recipients and palliative care patients provides a more comprehensive list of what carers view as necessary in order to continue caring. These needs can be grouped into three categories: training and information, help in managing relationships and help in looking after oneself.

Carers need training in how to perform medical and technical tasks for the patient and in how to modify their home to assist in patient care (Askham, 1997; Hoffman, 2002; Schwersenka & Burt, 2001). They need information on the disease, support services, accessing government financial aid, legal issues, coping with disease and relationship changes, how to access emergency services, the "rewards and benefits of providing care" and if indicated, information on palliative care and funeral services (Askham, 1997; Faull, 1998; Harding & Higginson, 2003; Hoffman, 2002; Schwersenka & Burt, 2001:32; Thomas et al., 2001; Toseland & Durham, 2001; Weitzner et al., 2000; Wilkie, 1998). Carers of cancer patients may even have a need for more information than patients do, because they want to know things the patient might not want to hear (Thomas et al., 2001).

In addition to needing training and information, carers often need help managing their relationships with medical staff, family and the patient. They need to be included in communication with medical staff and to negotiate their role within the medical setting (Faull, 1998; Thomas et al., 2001). They may need additional childcare, information on how to talk to children about cancer and help in dealing with "family tensions" (Faull, 1998; Toseland & Durham, 2001:30; Zmuda, 2006). They may also need guidance in maintaining open communication, especially regarding conversations on death or, in the case of a spouse carer, help in talking about intimacy or changes in sexuality (Wilkie, 1998).

Carers also need help in looking after themselves. They need confidant(s), encouragement that they are doing a good job as a carer and support in managing their social identity and feelings of fear, anxiety, grief, helplessness, anger and frustration (Askham, 1997; Faull, 1998; Hoffman, 2002; Soothill et al., 2001; Thomas et al., 2001; Toseland & Durham, 2001:30; Zmuda, 2006).

Not all carers, however, have the same needs to the same extent. Statistical analysis of cancer carers' reported needs shows that certain categories of carers tend to report more unmet needs than others. Carers and patients have differing needs depending on their stage in the cancer experience. Upon initial diagnosis there is an urgent need for information and familiarity with the medical system before treatment. Following treatment, goals are more geared towards moving past the cancer experience (Harding & Higginson, 2003; Thomas et al., 2001). Recurrence and/or going into palliative care similarly invoke differing needs and experiences, perhaps including requiring less information and more emotional support (Harding & Higginson, 2003; Thomas et al., 2001). For instance, Thomas et al. (2001) found that many carers of lung cancer patients tended to question the need for information because it was often bleak and led to high anxiety.

Other factors where carers' needs vary are age and gender. Younger carers report less knowledge about available services, more burden, more emotional needs and greater unmet needs (Braithwaite, 1990; Burns et al., 2004; Ciambrone & Allen, 2005; Harding & Higginson, 2003; Sharpe et al., 2005; Thomas & Morris, 2002). Female carers (particularly younger ones) report high levels of stress, burden, depression and unmet needs for respite care (Braithwaite, 1990; Gibson et al., 1996; Harding & Higginson, 2003; Pruchno & Resch, 1989; Sharpe et al., 2005; Thomas & Morris, 2002; Zarit et al., 1986).

While the logic behind the differing needs of carers of a patient with terminal cancer is clear, the understanding of why carers' needs vary based on age and gender is much hazier. Several researchers have proposed why younger carers have different and more intense needs, but these estimations are unconfirmed and some are conflicting. For example, Laizner et al. (1993) found that younger carers tend to have more needs related to coping with their emotions. They suggested that this may be because older carers thought of their caring as short term, and thus coped better. Thomas and colleagues wonder whether this variation is "perhaps reflecting their [younger carers'] struggle to accept the premature onset of a life-threatening disease among loved ones" (Thomas et al., 2001:192). Burns and colleagues (2004) also concluded that younger working carers have higher rates of unmet needs. They postulate that "this group may well have multiple needs and competing role claims, [but] they need further attention, including more research and more effective targeting of existing services" (Burns et al., 2004:500). Thus, it is clear that carers needs vary based on age, but *why* younger carers' needs are more often unmet is hazy.

The reasons for gendered variation in carers' experiences are similarly unclear and contradictory. Two explanations for women's higher rates of burden related to caregiving are that females spend more time providing care than males and receive less help with caregiving chores (Stoller 1990; as cited by Allen et al., 1999). Allen (1994), for instance, found that in comparison to male spouse carers, female spouse carers spend twice as many hours caregiving (as cited by Northouse et al., 2000). Further, male carers have been found to do fewer caregiver chores, to receive more help with the domestic responsibilities and to rely more on formal or paid help for housekeeping and caregiving (Stoller 1990; as cited by Allen et al., 1999; Evandrou, 1996; Pruchno & Resch, 1989). In a more recent cancer study, however, Thomas and colleagues (2001) found that male and female cancer carers provide similar amounts of care and emotional support.

Other hypotheses regarding any gender difference in reported carer burden include:

> (1) the differing reporting behaviours of males and females, with males under-reporting psychosocial need and females over-reporting (Thomas et al., 2001; Zarit et al., 1986);

(2) the differing needs of women and men, with men's needs later in life being more "in harmony" with the caregiving role than women of the same age (Pruchno & Resch, 1989:164);

(3) the differing amounts of social support received by patients, with female patients lessening the burden on their husbands by seeking support from friends and family while male patients rely solely on their wives (Northouse et al., 2000); and

(4) the differences in identification with the caregiving role, with women's identities being more strongly tied to caregiving, rendering them less able to distance themselves emotionally (Braithwaite, 1990).

Overall, the existing literature has made the valuable contribution of cataloguing the range in carers' needs and experiences, but why younger female carers have more unmet needs is uncertain. Consequently, past studies have suggested that future research try to explain this variation in cancer carers' needs (Burns et al., 2004; Ciambrone & Allen, 2005; Herron, 2005; Nathan, 1990; Thomas et al., 2001). This thesis addresses these gaps. A better understanding of why needs differ (see chapter five) will potentially allow for the improved targeting of social support (Nathan, 1990).

Similarly, little is understood about the benefits of caregiving to carers. In her research with carers of patients with dementia, Kramer (1997) found several positives: some carers grow closer to the care-recipient, some feel good about fulfilling their filial or spousal duties and some feel a greater sense of importance and satisfaction in their lives as a result of their caring responsibilities (as cited by Weitzner et al., 2000). Here again, however, there is variation, with older couples more likely than younger couples to grow closer as carer and care-receiver (Bleiszner & Shifflett, 1990; Change & White-Means, 1991; Chappell & Kuehne, 1998; Fitting, Rabins, Lucas & Eastham 1986; Navon & Weinblatt, 1996; Thompson, 1993; as cited by Thompson, 2005).

I approach these topics directly in chapters five and six: understanding why caregiving experiences tend to differ, with older carers being more inclined to finding it fulfilling and younger females being more inclined to finding caregiving burdensome. Through a qualitative examination of the needs and support service preferences of spouse cancer carers, these chapters will more specifically illuminate some of the potential causes behind the variation in carers' experiences.

Support Services for Cancer Patients

As is the case throughout this chapter, very little is known about the value of support services for carers of cancer patients. Because of this, an overview of the literature on the value of support services to cancer patients is provided first. As mentioned above, accessing informal emotional support can be challenging for cancer patients. Many patients seek support from counsellors and support groups. While much research has described, measured and critiqued the value of these psychosocial interventions for cancer patients, researchers and policy makers are only beginning to examine more thoroughly the impact and import of practical support.

Informal support, measured as a whole, has been found to have a positive impact on cancer patients' wellbeing. This type of support might include cooking for the patient, driving them to a hospital appointment, researching different treatment methods for them or just including the patient in social activities (Baxandall & Reddy, 1993). Multiple studies show a link between social integration or number of confidants and improved wellness and/or survival (Burns et al., 2005; Antonovsky 1993; as cited by Duckett, 2004; Remennick, 1998b; Spacapan, 1988; Stansfeld, 1999; Taylor & Dakof, 1988).

Emotional support, however, is difficult for cancer patients to obtain from their friends and family. Emotional support often involves initiating conversations on fears and anxieties to foster feelings of validation (Buckman, 1996; Lavery & Clarke, 1999). As my review of the literature on patients' needs revealed, it is difficult for patients to talk about their feelings of liminality with friends and family (Toombs 1992; Broyard 1992; as cited by Little et al., 1998). Optimism is the norm and family and friends often think that to be supportive they must avoid morbid topics (Crouch & McKenzie, 2000; Ussher et al., 2006). For example, a participant in Ussher et al.'s research reported, "When I got my cancer they thought I was going to die so nobody discussed it. I had nobody to talk about it with" (Ussher et al., 2006:2569). Patients' desires to protect their families from their own emotional burden also restrict opportunities for these conversations.

Lavery and Clarke (1999), for instance, found that prostate cancer patients, possibly because of gendered expectations, adopt a stoic façade in front of their wives to avoid distressing them. While religious organisations were found to be an exception, offering a forum within which to discuss spirituality and fears of death, not everyone feels comfortable in these settings or is religiously inclined (Koffman et al., 2004). Thus, many cancer patients are left wanting someone to talk with and some contact a counsellor or support group to meet this need.

Individual therapy with a paid professional can take many forms including directive, informative, confrontational, cathartic, catalytic and supportive counselling. But, as most counsellors use elements of all six, there is usually no distinction made between types of counselling in evaluating their worth specifically to cancer patients (Fallowfield, 1988). Psycho-oncology researchers and patients tend to report on counselling in different terms, but both report that counselling is beneficial.

Psycho-oncology studies have found counselling to be effective at improving patients' psychological and physical health. Stress, anxiety, depression, mood, overall psychological morbidity and emotional health have all been found to improve with the practical and coping strategy focused support from counsellors (Boudioni et al., 2000; Boulton et al., 2001; Parliament of Australia Senate, 2005; Pearson, 2006). The incidence and severity of symptoms such as vomiting and pain have also been found to decrease with counselling which may improve survival rates (Boulton et al., 2001; Parliament of Australia Senate, 2005; Pearson, 2006). Counselling, according to patients, provides "emotional relief" (Boudioni et al., 2000; Boulton et al., 2001). It is a rare opportunity to talk about fears, death and other "powerful thoughts and feelings" and feel understood (Boulton et al., 2001:130; Maex & De Valck, 2006). This relief and understanding results in an improved sense of control and ability to communicate with family and friends (Boulton et al., 2001).

Some, however, argue that counselling promotes normalisation instead of feeling validation (Crouch & McKenzie, 2000; Little et al., 1998). Little et al. (1998) argue that liminality is partly the result of feeling alone and cut off from one's wider social history. To address these feelings of isolation, patients should be encouraged to make meaningful social connections with other cancer survivors who validate their experiences of liminality. When patients are directed instead towards individualistic psychotherapy, it pushes them to resume their past identity, inadvertently exacerbating their sense of loneliness (Little et al., 1998). Crouch and McKenzie (2000) draw the same conclusion from their research. They argue that accepting and coping with feelings in counselling is not the same as "having those feelings meaningfully embedded in a social context which explicitly recognises them as valid, and responds to the suffering involved in an authentic and organic way" (Crouch & McKenzie, 2000:210). They assert that counselling encourages cancer patients to recognise and then shape their emotions to integrate them back into their old identities with their old networks. Developing a *new* normal life, however, with the help of support groups and with an identity and emotions grounded in relationships with others who share feelings of liminality overcomes this emotional isolation (Crouch & McKenzie, 2000; Harpham, 1994). Thus, support groups may be a better forum for emotional validation for cancer patients and survivors experiencing liminality.

A support group can be defined as a gathering of people "who share the same problem and who come together to provide mutual help and support" (Ademsen 2002; as cited by Ussher et al., 2006:2567). There are over 595 cancer support groups in Australia (Herron, 2005). The majority of these groups are for patients with breast or prostate cancer (Herron, 2005). This may be because more embarrassing cancers are more disruptive to identity and those cancer patients require more support to find the meaning in their cancer experience. Thus, people with particularly stigmatising cancers are more inclined to attend support groups than others with less embarrassing diseases (Davison et al., 2000).

In general, cancer support groups involve a few diagnosed individuals engaging in regular face-to-face discussions as a means of emotional support (Herron, 2005:15). While most focus on expressing, exploring and validating emotions, others (especially prostate cancer support groups) concentrate on diagnostic and treatment information (Bryan & Lyall, 1987; Herron, 2005). Cancer support groups are typically sponsored by an organisation such as a hospital or non-profit organisation (Herron, 2005). Some are facilitated by a social worker, counsellor or individual who has gone through cancer, others are un-facilitated (Davison et al., 2000). Formal support groups led by a professional tend to focus more on education, behaviour modification and developing coping strategies (Herron, 2005). Peer support groups or self-help groups are either un-facilitated or led by a cancer survivor (Gray et al., 1997). These groups usually focus more on communication and emotional support (Herron, 2005), however, no difference in psychological benefits has been found between professionally-led and peer-led groups (Ussher et al., 2006).

There are inconsistencies in the literature on how support groups should be assessed, but overall, the psychological benefits of attending support groups for cancer patients include improved role adjustment and coping, decreased levels of distress, and alleviation of depression (Docherty, 2004; Gray et al., 1997; Herron, 2005; Pearson, 2006). In some ways the benefits cancer patients get from support groups are similar to those they report getting from counselling. In other ways, what they receive from support groups cannot be derived from counselling.

First, like counselling, patients say that having an outlet, the support group, where they can laugh and confront their fears, allows them to function more normally in daily life (Bryan & Lyall, 1987; Gray et al., 1997; Harpham, 1994; Pearson, 2006; Ussher et al., 2006). As Gray and colleagues (1997:286) explain, "it is as though the presence of a safe place to discuss cancer allowed them to continue their everyday community life less under the shadow of illness." Second, unlike counselling, support groups offer a community that allows for the development of a new self identity that incorporates cancer into their biography (Crouch & McKenzie, 2000; Davison et al., 2000; Harpham, 1994; Little et al., 1998; Ussher et al., 2006). Third, support groups provide cancer patients with information, which can benefit their wellbeing and confidence (Docherty, 2004; Ussher et al., 2006). Gray and colleagues (1997), for example, found that educational aspects of self-help groups allow participants to feel more in control of their illness and more confident about participating with doctors in medical decision making (see also Broom, 2005; Pearson, 2006).

However, not all support groups provide the same type of benefits. Some focus more on education with conversation following a lecture from a professional. Others offer stress relief or relaxation techniques and some do not talk about death (Herron, 2005; Mathews, 2000). Overall, whatever the emphasis, support groups help patients to feel more human, less like a disease and more in control (Gray et al., 1997).

Despite the well documented benefits of support groups, many patients choose not to participate. Burns and colleagues (2004), for instance, found that 81 percent of cancer patients in their study knew of a cancer society, but only 7.4 percent utilised their services. Some, especially men, find sharing their emotions with others embarrassing (Broom, 2005; Eysenbach, 2003; Hardey, 1999; Herron, 2005; Remennick, 1998b). Others do not attend because they feel they have sufficient informal support, because meetings are too far away, because they do not feel well enough to attend or because they do not know about support groups (Bui et al. 2002; as cited by Herron, 2005). Doctors may neglect to inform patients of these services (Broom, 2005; Herron, 2005).

In sum, although some patients do not seek them out, informal support and psychosocial interventions for cancer patients provide benefits that are well documented. Counselling has been assessed as more appropriate for those experiencing extreme psychological distress or depression and less appropriate for cancer patients experiencing the social liminality of survival (Crouch & McKenzie, 2000; Harding & Higginson, 2003; Little et al., 1998; Toseland et al., 1990). On the whole, however, counselling and support groups have been deemed successful at improving patients' psychological and physical wellbeing as well as relieving feelings of isolation, and enhancing control.

In contrast to the substantial investigations on the benefits (and drawbacks) of psychosocial interventions for cancer patients, there is little research on the value and impact of practical formal support such as housework, transport, childcare and financial assistance (Pearson, 2006). Only a few studies highlight the importance of financial support for cancer patients. Burdess (1996), for example, points to the correlation between lower socioeconomic status and higher risk of some cancers: lung, stomach and colorectal cancer. Others highlight the cost of transport, relocation and lodging for patients and families who live in rural and remote areas and must travel hundreds of kilometres to access treatment, sometimes for weeks at a time (Davis & George, 1993; Firth, 2006; National Cancer Control Initiative, 2003; Parliament of Australia Senate, 2005).

To address this financial burden, the Commonwealth government of Australia introduced a travel reimbursement system for patients called the Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS) (Davis & George, 1993; Parliament of Australia Senate, 2005). Administration of the scheme subsequently became the responsibility of individual states and territories and has been criticised for being inconsistent between states and ineffective for some (National Cancer Control Initiative, 2003; Parliament of Australia Senate, 2005) (see pages 65-66 of the above referenced senate inquiry into cancer for an overview of the differences between the schemes in each state and territory). Giving funding as reimbursement, for instance, is a problem for patients who cannot afford the initial costs (Parliament of Australia Senate, 2005). For others, the paper work is burdensome. Some do not access IPTAAS because they are unaware of its availability (Parliament of Australia Senate, 2005).

Carers' Support Services

In contrast to studies of patients, research on the value of psychosocial and practical support for cancer carers is poorly understood. Psycho-oncology research has measured the value of counselling and support groups in units of burden relief and morbidity reduction, but research on the value of these services in units defined by carers is in its infancy. Although a few studies have examined the value of counselling for cancer patients and their families, there is a shortage of studies specifically on the benefits of and barriers to support for cancer carers. More often, studies on cancer patients only add family or carers as a supplementary focus (Morris & Thomas, 2002). The impact of counselling for cancer carers needs more exploration (Boudioni et al., 2000). Further investigation is required to determine “what types of services are preferred by carers and how far services can meet these preferences” (Pearson, 2006:23). There is a similar paucity of research on the value of practical support for carers, which this thesis seeks to redress.

Informal emotional support and social integration in particular have been found to alleviate a carer's feelings of burden (Thompson et al., 1993), yet carers report not getting enough informal emotional support. In a sociological study of UK cancer patients and carers, several carers mentioned a need for “someone to talk to” other than the patient (Thomas et al., 2001:135). Carers without someone to share their problems and frustrations have higher levels of subjective burden and lower levels of perceived quality of life (Mellon et al., 2006; Pruchno & Resch, 1989). Not having a confidant may be a prevalent problem for carers because, as mentioned above, when the cancer patient is their spouse, many do not want to burden their spouse with their needs. Further, caregiving often consumes the majority of a carer’s day, and there is little time left for socialising and seeking informal support (Funnell, 1998). Thus, it is not surprising that some cancer carers, like patients, seek individual counselling or join support groups.

Past research on counselling for carers emphasises its beneficial impact on psychological morbidity. A meta-analysis of psychotherapy outcomes for carers of older adults found counselling to be effective at reducing the carers’ sense of burden and depression, improving carers’ sense of wellbeing and even decreasing the frequency and severity of patients’ symptoms (Sörensen et al., 2002). This type of support has been found to be particularly valuable to carers exhibiting psychological symptoms such as depression (Harding & Higginson, 2003; Toseland et al., 1990). Other studies emphasise carers’ improved capability as a result of the education, coaching and coping strategy advice given in counselling sessions (Bryan & Lyall, 1987; Clark, 1990a; Harding & Higginson, 2003).

A few studies have begun to take a qualitative approach to measuring the value of counselling for cancer carers. For example, in a survey evaluation of a London cancer counselling service, both patient and carer respondents reported a sense of “emotional relief” after counselling (Boudioni et al., 2000; Boulton et al., 2001). Counsellors gave carers and family of cancer patients space to analyse, interpret and assess their emotions as “normal” (Boulton et al., 2001:130). This helped carers to legitimise the importance of their emotions. Having given attention to their emotions in counselling, carers were more able to “attend to the needs of others” (Boulton et al., 2001:130).

Support groups are another form of carer support. Groups can be organised for both cancer patients and carers or carers exclusively. There are, however, very few support groups exclusively for carers of cancer patients; Herron (2005) estimated that in Australia there are only 16 support groups exclusively for cancer carers and family members. Researchers have reported that support groups are helpful, both to the carers who attend and, indirectly, to patients who may or may not attend (Davis et al., 2005; Herron, 2005; Sörensen et al., 2002). In studies of carers of older adults, cancer patients, multiple sclerosis sufferers and persons with mental health disabilities, support groups were found to be effective forums for sharing information on both the disease and emotion management and helpful in enabling carers to continue caregiving (Chambers et al., 2001; Harding & Higginson, 2003; Knight et al., 1997; Sörensen et al., 2002; Toseland et al., 1990). Few studies, however, have identified *how* support groups are helpful to carers of cancer patients (Pearson, 2006). It is unclear what if any impact support groups have on these carers and it is unclear why people participate. Thus, in chapter six, I examine how support groups are useful to carers.

Practical support from friends and family is also helpful to carers. Researchers are beginning to highlight the centrality of carers' practical concerns (Firth, 2006; Harding & Higginson, 2003). Practical support offered to carers varies based on gender and family status. Male carers receive more help with domestic tasks such as cleaning, laundry and cooking. Female carers receive very little such assistance (Pruchno & Resch, 1989). Overall, as mentioned above, carers appear to receive very little informal practical support.

Financial strain is another problem for which support services are available. Because carers experience significant losses in wages and savings (Wiener, 1997), the Australian Commonwealth provides carers with financial aid in the forms of IPTAAS and a welfare stipend. Cancer carers are eligible for the carers' payment and carers' allowance. Depending on an asset and income test, carers can apply for the carer payment, which pays up to $546.80AUD a fortnight and includes a pharmaceutical prescription discount and rent assistance. A carer allowance of $100.60AUD per fortnight is also available without income and asset testing (Centrelink, 2008). There is little research on the efficacy of these services for carers of cancer patients. Are Centrelink payments enough to make a difference to carers? Often, it is assumed that establishing these programs solves carers' problems. Economic and government reports seem to imply that the "recognition" from having a carer's payment is sufficient (Duckett, 2004:243; Parliament of Australia Senate, 2005:120). It is implied that the payments "help" and thus problems or hardships are addressed (Parliament of Australia Senate, 2005:120). But, do these payments really help?

Janda et al. (2006) have begun to raise questions about this assumption. In their interviews with Queensland carers of patients with brain tumours, Janda and colleagues found carers feel frustrated with long waiting times to meet with government employees and the overall “bureaucratic maze” (Janda et al., 2006:1097). Hughes (2007) reports that a mere 15 percent of carers access these government payments. Further inquiry is needed to determine if other carers of cancer patients also find the Centrelink “maze” frustrating, if so, why? And does this deter them from accessing support?

Respite services (whether trained formal carers in the home or group day care) constitute another form of practical support accessed by some cancer carers that have been insufficiently researched (Haug et al., 1999; Sörensen et al., 2002). Research with carers of older adults shows that respite is effective at diminishing depression in carers of older adults, increasing their wellness and decreasing the older adult’s symptoms (Sörensen et al., 2002). Research with cancer carers finds respite services are well received (Harding & Higginson, 2003). Gibson et al.’s (1996) quantitative research on the respite needs of all Australian carers, however, raises a question. They found that only eight percent of carers in need of respite were getting it. Why are so few accessing respite?

Overall, the existing literature on carers of cancer patients and support services raises many questions for this research to explore. The findings related to these questions are presented in chapter six. In chapter seven I outline the findings about the barriers carers face in accessing support services.

Although past research has established the importance of information for carers, few carers receive advice on available support (Jones et al., 1993; Morris & Thomas, 2001). Medical staff, in particular, may not pass relevant information on to carers. A study of cancer patients’ and carers’ knowledge of community services, found that “medical practitioners” were rarely the source of information (Burns et al., 2004). Broom (2005) similarly found that doctors are unwilling to provide cancer patients with support group information because the information from support groups might erode the specialist’s role as the decision maker. Other medical staff, however, were found to be important sources of information on community services for carers (Burns et al., 2004). By not informing carers of support services, medical practitioners may be preventing carers from reaping the benefits of these services (Hutchinson et al., 2006). This raises questions about how carers acquire information on support services and what role the hospital system plays in helping carers to access support. Responding to these questions is the focus of chapter seven.

Overall information and support are inconsistently provided to carers and more research needs to investigate the role hospital systems play in the provision of information and support (Thomas & Morris, 2002). Most studies focus on burden or stress relief as a measure of the efficacy of support services for cancer carers (Thomas & Morris, 2002). More research is needed on the relationship between carers' social circumstances and experiences (Thomas & Morris, 2002). By exploring cancer carers' experiences with and perceptions of support services, this research attempts to address some of the gaps in the literature and the questions raised in this chapter. Do carers find meaning in their cancer experience? What is their illness narrative? These questions will be explored in chapter three. Are carers in denial? If not, how do they cope and how do these coping strategies support or hinder a patient's need to communicate their fears? What shapes carers' emotion work? Chapter four examines carers coping strategies and emotion work. Why do younger and female carers tend to have higher rates of unmet need? This question is the focus of chapter five. What value do support groups have for carers? Is practical support beneficial? These questions are explored in chapter six. The barriers that these carers encounter in accessing services are the focus of chapter seven. To address these questions, I employ a mixed method approach to data collection which I describe in the next chapter.

Chapter Two: Methodology

This research uses qualitative, action-based methods to expand on the existing cancer carer literature. Few studies have examined their experiences from a qualitative and sociological perspective (see chapter one). There are calls for more qualitative research to take a social lens to understanding cancer carers' needs, because it is currently "an area that is under-explored in cancer studies" (Ciambrone & Allen, 2005; Thomas et al., 2001:21). Dunn and colleagues (2003) for instance ask for research that uses self-reported measurements of what carers define as helpful (as cited by Herron, 2005). Askham (1997:4) calls for a more encompassing understanding of what carer's find supportive to allow for a "conceptual refinement and redefinition" of carer support.

The methods used by past researchers in this area have been predominantly deductive,[6] slanted towards an etic perspective, and focused on prediction (Ciambrone & Allen, 2005; Keat & Urry, 1982; Kellehear, 1993). Instead of drawing conclusions from insider narratives, conceptualisation has been primarily based on researchers' statistical frameworks. Yet, in the words of Albert Einstein, "not everything that can be counted counts, and not everything that counts can be counted" (Bodenheimer & Grumbach, 2005:124). Although quantitative findings are valuable forms of knowledge, statistical inferences alone are not sufficient. As Sayer (1984:97) explains, "merely knowing that 'C' has generally been followed by 'E' is not enough: we want to understand the continuous process." To understand the "continuous process" and the reasons behind the variations in carers' needs and experiences, this research takes an inductive qualitative approach, which values carers' accounts. Interactionist and grounded theory methodology informed by questionnaire, interview and focus group methods are used here to develop a more experientially grounded understanding of cancer caregiving.

---

[6] The word positivist is purposefully avoided here because, as Sayer explains, "so many different doctrines and practices have been identified with these terms that they have become devalued and highly ambiguous, or even purely pejorative. Those who want to continue using them increasingly find they have to preface arguments with tiresome digressions on 'the real meaning of positivism' and these often generate more heat than what follows" (Sayer, 1984:14).

Epistemological and Ontological Issues

To avoid the epistemological and ontological limitations of past research, a symbolic interactionist guided methodology was adopted. As such, this research asks how carers interpret their roles within their relationships and medical systems and how they “construct their reality” (Flick, 2002:26; Kellehear, 1993). Data collection methods were only somewhat structured to give precedence to carers’ narratives, evaluations and priorities, and avoid imposing categories on participants’ accounts.

To allow for the primacy of carers’ interpretations, a quasi-grounded theory approach to data collection was adopted to avoid the imposition of researcher driven categories and to allow themes to emerge from the data. A *quasi*-grounded theory approach was used because the rigorous approach to coding outlined in Glaser and Strauss’s original grounded theory methodology has been found to cause researchers to lose a macro-scope on their data (Grbich, 2007). This technique involved a continuous and systematic approach to research where data is collected and coded together so that the next step in the research is shaped by the themes that emerge from the previous step (Flick, 2002; Glaser & Strauss, 1967; Grbich, 2007; Kellehear, 1993). Using this approach, theory development is primarily the result of insiders’ accounts and only partially informed by the researcher’s assumptions.

An action-based or clinical research approach was also taken. This is where the aim of the research is an improvement of the subjects’ situation, in this case, services for carers (Fritz, 1990; Grbich, 1999; White, 2006). The lack of significant change over the past 20 years in how carers are supported within medical systems and by public policy, despite abundant research on the needs of carers of patients with dementia, cries out for research that not only bridges a gap in academic knowledge, but bridges the distance between academics, service providers and policy-makers. After all, generating research does not automatically result in policy amendments (Kearney et al., 2007; Neuhauser, 2007). Some academics argue that change is the primary aim of critical social research and an ethical imperative (Minichiello et al., 1995; Sayer, 1984). Thus, this research not only adds to the limited body of research on cancer carers, but in working with relevant policy and support organisations, it directly informs change agents. As this research is in part funded by a grant from the Cancer Council ACT, a local not-for-profit organisation whose goals are to reduce the incidence and impact of cancer, and Cancer Australia, a government department with a similar focus, it is in communication with relevant audiences to bring about change in policy and practice (see the introduction).[7] Cancer carer support group facilitators and support service personnel for the Cancer Council ACT have been involved in the research process, facilitating the distribution of questionnaires, participating in a focus group and supporting suggested changes. The state and federal government provide approximately 70 percent of the funding to support the health sector and the federal government is the primary innovator of policy in this area (Davis & George, 1993; Duckett, 2004). These are good reasons to be in conversation with Cancer Australia as well.

Methods

A triangulation of methods was employed. Triangulation involves using multiple methods and "temporal settings" to increase a study's width, breadth, "rigor…richness" and "external validity" (Denzin & Lincoln, 2005:5; Flick, 2002:226; Minichiello et al., 1995:177-178). Using a mixture of approaches to data collection is also a means of combining "theoretical perspectives" to encourage "multiple points of convergence" at the structuralist, interactionist and psychosocial level (Remennick, 1998a:7). Qualitative researchers are dedicated to getting a "better understanding of the subject matter at hand" and typically use a combination of research strategies because "each practice makes the world visible in a different way" (Denzin & Lincoln, 2005:4). To this end, mixed methods and longitudinal techniques were adopted. Participant observation served an auxiliary role. Questionnaire data provided the platform on which interviews where based. Narrative and semi-structured longitudinal interviews were the main form of data collection, allowing for the most in depth exploration of carers' needs and experiences. A focus group with support personnel was used as a means of confirming the feasibility of these findings.

Participant Observation

---

[7] Please note, however, that these organisations did not impose on the research process, design or analysis other than as stakeholder focus group participants. Their funding in no way limited the focus or findings of this study.

Participant observation was conducted to gain an appreciation of "the actions themselves as they naturally occur," as opposed to the verbal abstraction available through interviews and questionnaires (Flick, 2002:159). To gain this first hand knowledge, I worked with support service personnel as a casual part-time employee of the Cancer Council ACT and participated with cancer carers and patients at Cancer Council ACT fundraisers, information events and support groups. Direct involvement with support services provided the opportunity to better understand the workings of not-for-profits in this sector (Flick, 2002). Participant observation at support groups allowed me to view first-hand how this means of support is provided to carers of cancer patients. When observations or communication provoked questions or ideas, I made field notes. As part of a grounded theory approach, these field notes informed the questionnaire and initial interview guide. This part-time work was also an opportunity to work with Cancer Council personnel and personnel from other cancer support organisations. This made it easier to gain support from these organisations in later stages of the research.

Questionnaires

Questionnaires were a necessary starting point to this research. Three page questionnaires (see appendix a) were designed for this study to assess the comparability of Canberra carers to those studied overseas. In designing the questionnaire, particular attention was paid to areas of concern described in past studies: carer-self identification, the experiences of younger carers, those caring for a patient with advanced and/or terminal cancers like lung cancer, understanding carers' own definitions of support and reasons for accessing support services (see chapter one).

Carer self-identification was a particular concern because non-identification as a carer has been found to be a significant hurdle to accessing this population (McKinnon & Janicki, 2001; Thomas et al., 2001). Thus, consideration was taken in the wording of the questionnaire cover letter to define informal carers and caregiving. Care was also taken to emphasise the positive impact that further research might have for both the carer and care recipient, as this has been found to peak carers interest more than emphasising the possible impact of research on carers' alone (McKinnon & Janicki, 2001).

917 questionnaires were distributed through support services in Canberra between September 2006 and March 2007. Those local support service organisations that assisted in distribution included: the Cancer Council ACT, the Leukaemia Foundation House, Carers ACT, Prostate Cancer Support Group, Look Good Feel Better, Eden Monaro Cancer Support, OvCa and Brain Tumours Australia. An online version was also made available through the Cancer Council ACT website between September 2006 and December 2007. Because of a low five percent response rate (47/917) and the narrow scope of a three page survey, the questionnaires were not as valuable in answering the research question as interview data. They did however play a vital role in initiating this research. Questionnaire data provided (1) a necessary tool in accessing this population, (2) a way of comparing Canberra cancer carers with overseas data on cancer carers and (3) the basis for developing interview themes.

First, the questionnaires were an effective means of recruiting interview participants. Carers are a difficult population to study (Gray et al., 1997). As a dispersed group, gaining access is a challenge. Further, their roles are so demanding that they often do not have time to participate in studies, nor do many want to talk about the intimate details of caring (Hunt & Mintz, 2002). Questionnaires provided an unobtrusive “in.” On the final page of the questionnaire, respondents were asked to write their name and phone number if they wished to be more involved in the study. Most, 28 out of 47, did.

Second, the questionnaires allowed for comparison with overseas quantitative data. Demographically and experientially, the Canberra carers were similar to carers in an overseas study. The response number was not high enough for generalisable statistical analysis, but this is rarely the goal of qualitative research (Sayer, 1984). Instead, qualitative research is concerned with the “transferability” of research or the relevance of findings to other settings (Flick, 2002:230). This questionnaire data did allow for general comparison with overseas data and assessment of this study’s transferability.

Demographically participants in this study were very like participants in quantitative research conducted in the UK by Thomas and colleagues (2001). Of all respondents, 75 percent were caring for a spouse or partner in Thomas et al.’s study and 72 percent were spouse carers in this study. The majority of cancer patients had breast cancer (36% in this study, 42% in Thomas et al., 2001) or bowel cancer (15% in this study, 32% in Thomas et al., 2001). Like Thomas et al.'s sample, and US studies on cancer caregivers, most carers were in their 50s and 60s (59.5% in this study, 55% in Thomas et al., 2001) (see also Laizner et al., 1993). This corresponds with Australian data on patients' ages, with most cancers (58%) being diagnosed in individuals over 65 (PHRC, 2002). A slightly higher percentage of cancer carers, 53 percent, were retired in this study (44% were retired in Thomas et al., 2001) and a slightly lower percentage, 36 percent, were working (42% were working in Thomas et al., 2001). Overall, however, the demographic characteristics of the two samples are remarkably similar (see figures 1 – 4)

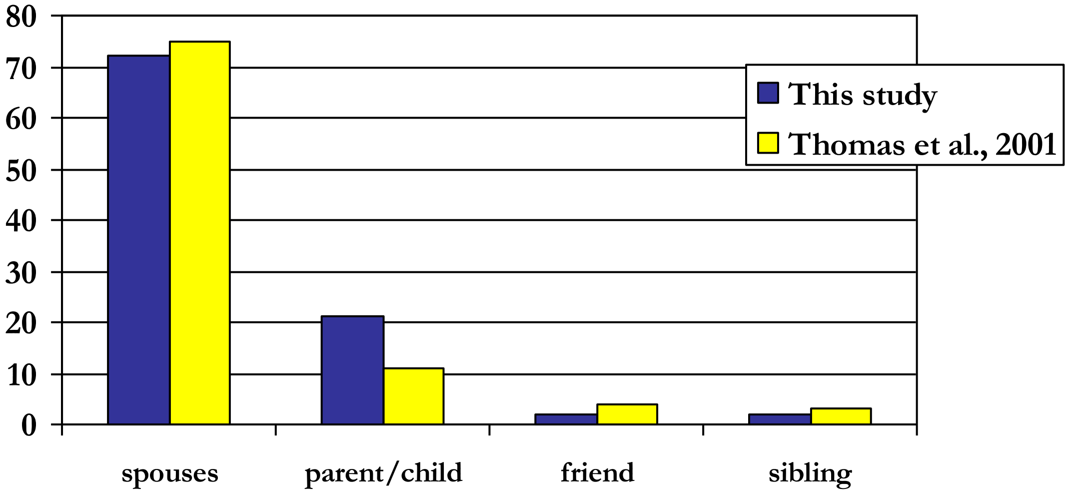

Figure 1 –The relationships of carers to patients in the questionnaires in this study and in a UK study (Thomas et al. , 2001) (percent).

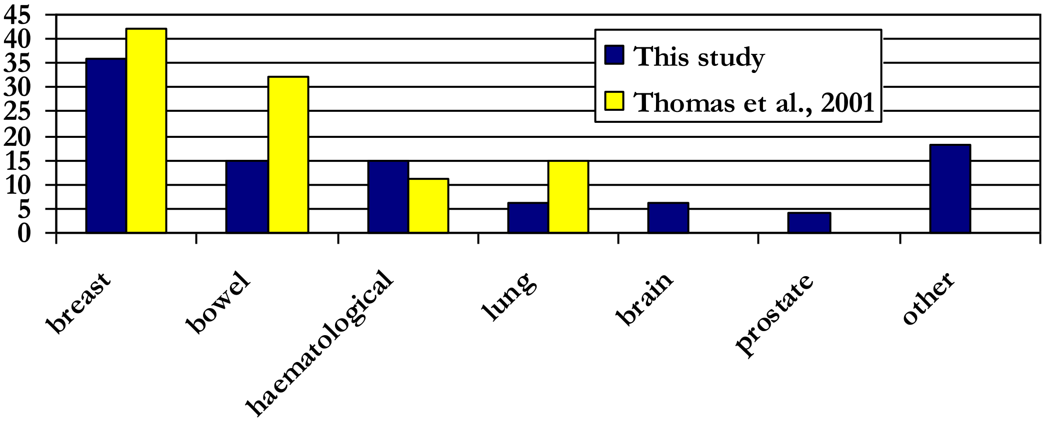

Figure 2 – Cancer types affecting the patients in respondents' care (percent).

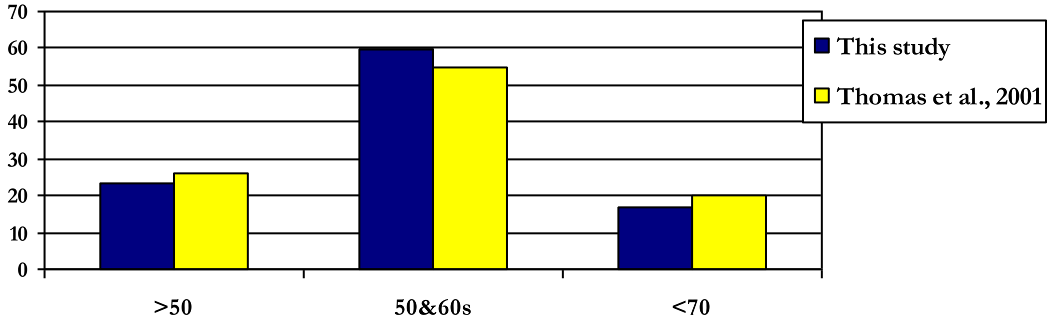

Figure 3 – Respondents' ages in this study and a UK study (Thomas et al., 2001) (percent).

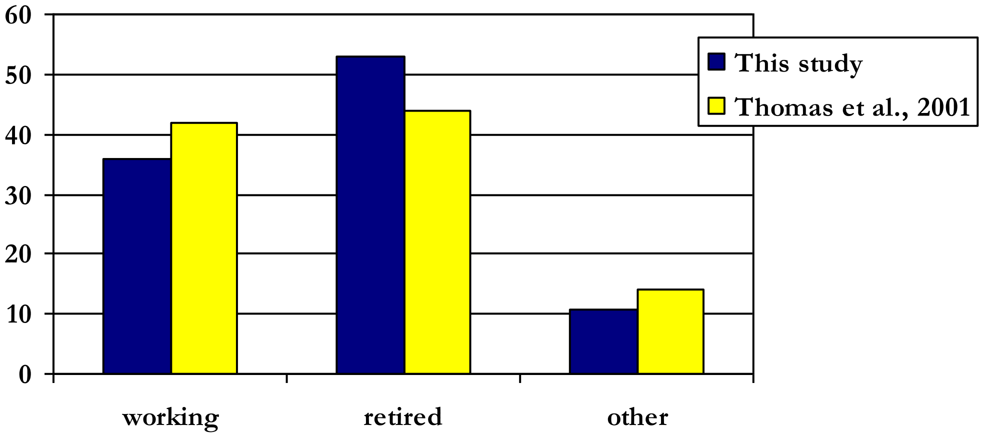

Figure 4 – Questionnaire respondents' paid work categorisation (percent).

Canberra respondents were also very similar to those in overseas research on measurements of the type of assistance provided to cancer patients. Responses to a questionnaire conducted by Thomas and colleagues (2001) and summary of multiple studies on the experiences of cancer carers assembled by Laizner and colleagues (1993) show that cancer carers provide a range of practical and medical tasks and manage the patients' emotions. This was reflected in the activities listed by Canberra carers on questionnaires. Very practical tasks reported in this study included cooking, cleaning, laundry, gardening, shopping, errands, driving the patient to appointments, assisting with dressing, finances, showering, childcare, lifting the patient, coordinating the patient's life schedule, organising palliative care, communicating with the patient's family and scheduling exercise for the patient. Medical tasks included cutting pills, administering medications, coordinating and overseeing medical care, researching the latest studies, helping to make medical decisions and organising complementary medicine. Other tasks were geared towards protecting the patient's emotions and sense of self-worth such as providing emotional support in general, encouraging the patient to feel useful, facilitating social activities for the patient and his or her friends, listening to the patient and providing a "shoulder to cry on," protecting the patient from "difficult family members" and hosting the patient's visitors. Thus, the respondents in my study are not outliers.

Canberra is, however, an outlier nationally because of its high socio-economic status and low rates of disadvantage (ABS, 2006). It is also an outlier nationally, as the state or territory with one of the youngest populations and the lowest rates of general practitioner (GP) consultation (Duckett, 2004). It is a planned capital city surrounded by bush and farmland and filled with public servants, defence personnel and academics. In one participant's words, Canberra is "a civil servant place…for middle class bourgeoisie to raise their families: clean, good schools…completely safe and non-threatening" (*Leo*). These characteristics of Canberra's social landscape, however, seem to have little bearing on its population's experiences of cancer. The similarities between this study and past studies in both the demographics and activities reported by carers led to the conclusion that experiences of cancer caring in Canberra, when compared with overseas data, do not seem to be out of the ordinary.

Third, questionnaire data was essential to developing a grounded theory approach to data collection. Leads and questions that arose from the analysis of the questionnaires informed the interview discussion guide. For example, descriptions of support varied. Some carers preferred optimistic and emotionally withdrawn informal support from friends. Others described realistic and open discussions on death with friends as supportive. Another carer said informal support involved not engaging in conversations at all. Supportive friends were, "people who sent cards, rang, e-mailed with words of encouragement and did not expect a response." This conflicting range of support interpretations prompted interview questions on carers' definitions of ideal support, on who provides support and how.

Although questionnaire data was of limited use statistically or for providing in-depth accounts of carers' experiences, the questionnaires provided an essential background to the interviews. They were an unobtrusive way of connecting with this hard to reach population. Minichiello and colleagues (1995) have suggested that this method of recruitment even has the benefit of establishing rapport with participants before interviews. The questionnaire data also allowed for some comparison of cancer carers in Canberra and overseas, suggesting that Canberra carers' experiences are similar. Contradictory interpretations, such as the ones regarding support mentioned above, informed interview themes as part of a quasi-grounded theory approach.

Interviews

Of the 47 questionnaire respondents, 28 volunteered to participate in an interview. The scope of the study, however, was limited at this point to include only spouse cancer carers using the Canberra hospital system. Spouses and intergenerational carers (parents or children) experience caring differently. Children or parent carers are more likely to view their role as burdensome and seek support. Spouses are more likely to view their roles as part of their marital relationships and to go on caring even when it becomes too much for them (Braithwaite, 1990; Harris, 2005; Kellehear, 2007; Thompson, 2005). Thus, the refinement of participants to only spouse carers was done to avoid confounding the analysis with too many variables, what Becker (1998:75) calls "conceptual drowning."

Limiting the list of interview volunteers to spouses left 19 informants. An additional 13 participants were recruited through purposive convenience and snowball sampling to ensure that both users and non-users of support services were represented and to ensure that the sample included a relatively balanced number of younger, older, male and female carers. Age was of particular interest because past research has shown that younger carers tend to experience caring very differently and have a higher number of unmet needs. A balanced sample of both husbands and wives was sought, because gender has been found to be a significant factor in research on the distribution and experiences of providing care (see chapter one). The majority of carers are women because patients more frequently select carers based on gender models that assign women to roles of care responsibility regardless of age, education, income, and other available potential carers (ABS, 1999; Allen et al., 1999). Wives' caregiving experiences have also been found to differ from husbands' in the amount of time spent providing care, in how much emotional support is sought and in perceptions of stress related to caregiving (Allen et al., 1999; Druhan-McGinn & White, 2004; Evandrou, 1996; Northouse et al., 2000; Pruchno & Resch, 1989; Zarit et al., 1986). Further, a purposive sample including both husbands and wives was sought because men tend to be overrepresented in qualitative studies of spouse cancer carers (see Sabo, 1990), but under-represented in carer studies overall (Mathews, 2000).

Researchers are not physically able to interview an entire population and qualitative research is more concerned with the "the variety of meaningful patterns" and less concerned with the "relative distribution of patterns" (Ragin 1987:52; as cited by Becker, 1998:194; Kellehear, 1993). Thus, recruitment ended after a total of 32 participants were recruited for the first round of interviews and patterns started to emerge from analysis. This purposive sample of interviewees was made up of 18 husbands and 14 wives caring for a spouse with cancer. Most participants were in their 50s or 60s. Nineteen interviewees were actively providing care to their spouse. The remaining 13 had been cancer carers in the past and their spouses' cancer was now either in remission or the cause of their spouse's death. Seventeen participants were employed in part-time or full-time paid work and fifteen were retired from paid work (see figures 5-9).

Each participant was interviewed twice, roughly six months apart to allow for a longitudinal comparison. As Giddens (1979) and Minichiello and colleagues (1995) have argued, social interaction is not static, so social research should not be static either. A longitudinal approach also allowed for validation (Flick, 2002). As Minichiello et al. (1995) define it, validity in research is when the researcher and informant have the same interpretation of meaning from the words used in the interviews. To this end, meeting twice allowed for an accuracy check with each interviewee. In between interviews, I wrote a summary of our first conversation and then presented that summary back to the participant during the second interview to ensure that what I had interpreted was in fact what the carer meant. Thus, this longitudinal interview format allowed for a wider scope and clarification as well as exploration of themes that emerged from the analysis of first interviews.

During the approximately six months between the first and second interviews many carers' lives changed, slightly altering the study's demographics (see figures 5-9). Two participants dropped out of the study: one moved out of state and the other became too busy to participate. Three carers experienced the loss of a spouse. One shed the carer role during the interviewing interval because of remission. Two participants retired from paid work and one returned to paid work during that time.

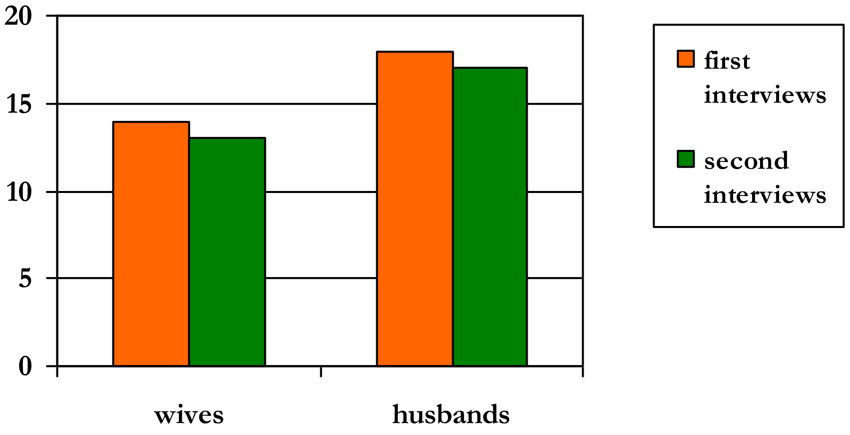

Figure 5 – Gender distribution of interviewees (whole numbers).

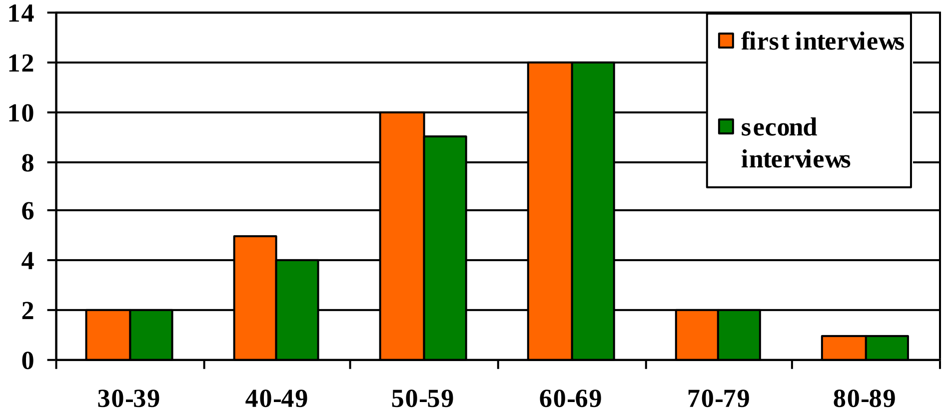

Figure 6– Age range of interviewees (whole numbers).

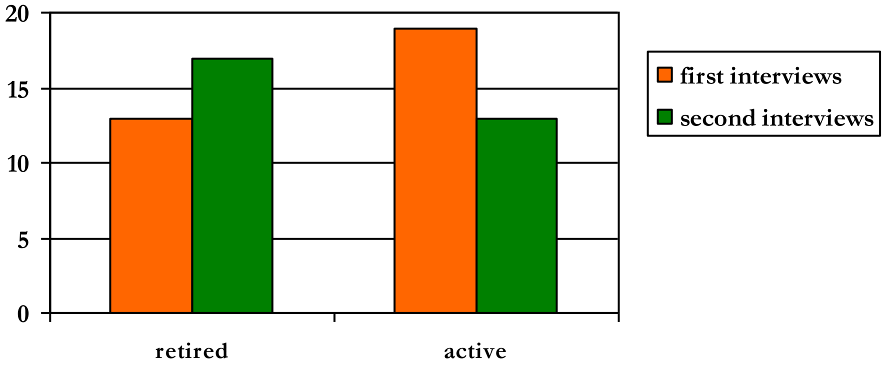

Figure 7 – The caring stages of interviewees: retired or active (whole numbers).

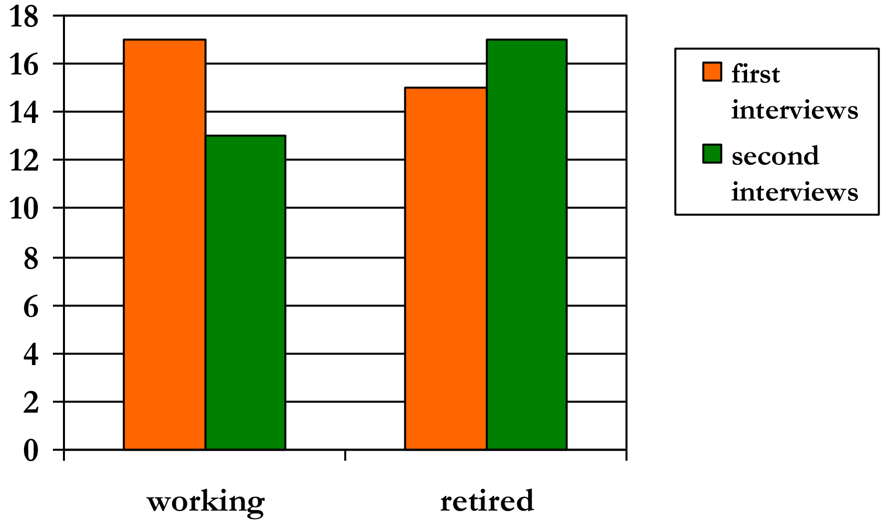

Figure 8 – The paid working categorisation of interviewees (whole numbers).

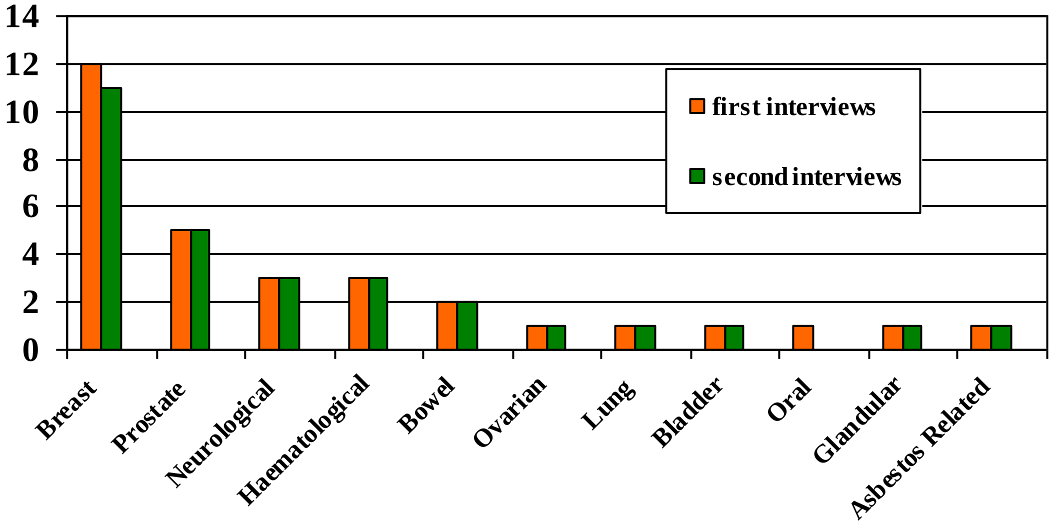

Figure 9 – The types of cancer affecting interviewees' spouses (whole numbers).

Each interviewee was contacted by telephone or email to set up an interview at a mutually convenient time. Participants met with me in their homes, or at cafes. Some met with me at the hospital café as their spouse received treatment. Six carers were interviewed as (three separate) couples who had taken turns as both patient and carer.

To make the interviewees feel more comfortable sharing intimate details about their marital and caregiving lives, each interview began with rapport building. Shaffir (1991) describes this as an essential means of getting full and honest cooperation from respondents. To this end, I dedicated five to ten minutes before each interview to general chit-chat about topics unrelated to the research: news, the federal election, pay parking at the Canberra hospital and other subjects of mutual interest (Minichiello et al., 1995). In most instances, these first few minutes also involved ordering or making tea or coffee, helping this rapport building to feel natural. When we were both settled with our hot beverages, consent forms were presented (see appendix b). I explained that the interview was expected to go for about an hour and then I asked each carer how much time they could spare for the interview. Setting an end time allowed for a smooth and expected close to each interview (Minichiello et al., 1995). Before the interview began, I also asked participants if they would not mind meeting again in six months for an interview and gave each carer two booklets: a directory of local support services and a Cancer Council booklet on emotions and caregiving.

When consent forms were signed, returned and put away, when the microphone was hung from the participant's neck and the digital voice recorder switched on, the interview began. Although Minichiello and colleagues (1995) warn that recording interviews can have an inhibiting effect on interviewees, this was not an issue in my research. This may be because tape and digital voice recorders are so widely used today that they are generally accepted in interviews and then ignored (Flick, 2002). Interviews were semi-structured, only guided by a list of interview themes, but began with demographic and narrative questions. The first questions asked were about the background (see Minichiello et al., 1995) to each participants' caring role: the type of cancer, how long the interviewee had been caring, and the tasks involved in caring.

Next, I asked, "starting from the beginning, tell me about your experiences or story of caring." Adding this narrative element to the beginning of the interview was intentional and done for several reasons. As a twenty-something female researcher with no experience as a carer I held a contradictory position within the interaction as both a lower status younger person (all interviewees were between 30 and 89) and, for many, a higher status researcher. Using a narrative technique was done to shift the power dynamic within the interaction towards the interviewee, so that it was the interviewee leading the interaction initially (Flick, 2002). Then, after leading the interview initially, the aim was to get the participant to see me as more of an equal conversation partner during the second half of each in depth interview (Minichiello et al., 1995).

Further, although semi-structured interviews allow for more openness and depth, they can have a problem of conflicting foci, with the participant and interviewee wanting to talk about different things. Asking questions in narrative to semi-structured or a broad to narrow sequence countered this potential problem by channelling the interviewees focus in the desired direction (Flick, 2002). “Funnelling” interviewees’ focus this way had the benefit of not imposing ideas on participants (Minichiello et al., 1995:85). This allowed for both open and specific discussion of relevant topics in each interview (Flick, 2002).

Narrative interviews have been found to be somewhat confronting to interviewees, because they are antithetical to many peoples’ expectations of how an interview should run (Flick, 2002). This, however, was rarely the case with this research. Most interviewees jumped at the chance to share their story, some saying that this was a rare opportunity to talk about their experiences and focus on their feelings instead of the patients’. The two times it was an issue, respondents conceded to elaborating after some persuasion. Another potential problem to do with narrative techniques, eliciting volumes of data of limited relevance, was avoided by focusing on narratives in the interview to the first half of the first interview and then guiding discussion based on themes afterwards (Flick, 2002).

After carers relayed their stories, recursive probing techniques were used to elicit responses to specific questions and get carers to expand on relevant topics mentioned in their narratives (Minichiello et al., 1995). First, every carer was asked their thoughts and feelings on caring and asked what they would describe as ideal support. Asking about ideals was done at the advice of Minichiello (1995) citing Schatzmann and Strauss (1973). This turned out to be a very effective way to get carers to expand on their experiences without making them feel as though they were complaining, which often held carers back initially from going in more depth on their negative experiences with the medical system. Second, questions on other themes were only asked if they were not discussed in much depth during the narrative section. These questions were centred on themes of informal support, thoughts on support groups, carers’ biggest needs, dealing with emotions and about the roles medical and support services play in how carers deal with emotions.

To remember to touch on all of these themes during the research, I used a research guide (see appendix c). It has been suggested that using standardised checklists in interviews can improve reliability in qualitative research (Flick, 2002). On a practical level, interview guides are required by most interviewers, even those doing unstructured or semi-structured research because, as Minichello and colleagues explain, “the in-depth interviewer…does not suddenly overnight become Superman or Wonder woman [and] gain a flawless memory which can retain all the necessary information to be remembered in the interview setting” (Minichiello et al., 1995:82). My interview guide included themes, suggested phrasings of questions and even reminders about tricks of the interviewing trade to elicit more in-depth responses.

Acting is a standard interviewing technique. All “field research requires some measure of role-playing and acting” (Shaffir, 1991:77). This research was no exception. Following qualitative research texts, I acted as someone who knew little about the topic to get participants to explain themselves in more depth (Minichiello et al., 1995; Shaffir, 1991). To get carers to elaborate more, I changed the way I phrased questions, using words like “about” and “processes” more often (Minichiello et al., 1995:85). To avoid coming across in a confronting manner, I asked “how” questions instead of “why” questions (Minichiello et al., 1995).

I drew interviews to a close by making comments such as: “well, we have covered all the themes I had hoped” or “we are getting close to the one hour mark” and “is there anything else you would like to add?” This allowed for a fluid closing (Minichiello et al., 1995). Then I thanked each participant for their time and said I would give them a call in a few months to set up the follow up interview. As we packed up and prepared to leave, I passed each interviewee my card and requested, “If you can think of any other spouse cancer carers who might be interested in participating in an interview, please have them contact me.”

Follow up interviews (see appendix d for the interview guide) were conducted roughly six months after the initial interviews. The first half of these interviews was focused on assessing accuracy in my understanding of their stories and change. Each interview began with a summary of what was discussed in the first interview to ensure that what I had interpreted was in fact what the interviewee had intended. Then, I asked each participant about their current feelings regarding their carer role. Themes from the first interviews about support, support groups, needs and dealing with emotions were then covered again to allow for the assessment of change over time.

The second half of these follow up interviews was focused on exploring the themes that emerged from the analysis of the first interviews as part of a quasi-grounded theory approach. These themes were to do with emotions, time and support services. During the first interviews several carers talked about being emotionally unsure or feeling guilty about their emotions. One carer even asked if I thought her emotions sounded normal or “right.” For this reason, I asked carers if they had ever felt uncertain about their emotions. A few carers talked about refraining from sharing their emotions with their spouse, either at the direct request of their spouse or because of a desire to prioritise their partners’ emotions. Thus, a question about censoring and prioritising emotions was included in the second interviews. Several carers talked about emotional reciprocity being central to the primacy of their spouse role as opposed to their carer role, so a question about feeling appreciated was included in the second interviews.

A lack of time was another theme that emerged from the first interviews, thus a question about the role time plays in the caring experience was included in follow up interviews. Because carers had a wide range of responses to booklets, I asked if interviewees remembered the booklets I gave them at our first meeting and asked if they found them or any booklets to be helpful. Finally, because several carers made surprising comments regarding the positive effects of the interview, a question asking if our discussions had any impact on how the interviewee thought or felt about being a cancer carer was included as well.

At the close of each follow up interview, I again thanked each participant for their time. Then I asked if they would like me to mail them a summary of my findings. Most said yes. All interviews were transcribed using Olympus Digital Voice Recorder software that features an adjustable metronome and background noise cancellation. These tools allowed for quicker and more accurate transcription than playback alone. Although “maximum exactness” in transcription is often encouraged, Flick (2002:171) argues that this may be a case of “natural science ideals of exactness in measurement sneaking into interpretive social science through the back door.” Thus, the interviews in this research were transcribed “only as exactly as [was] required by the research question” (Flick, 2002:171-172). Because the research question was not related to speech patterns, but to concepts and meanings, a standard approach to transcription was taken with all words, affectations and displays of emotion recorded. Short pauses, hesitations and injections such as “um,” however, were left out.

Focus Group

A final method of data collection was completed in January 2009: a thirty minute presentation of my findings and hour long focus group with Cancer Council ACT personnel, including support group facilitators. After presenting my findings to the group, my role in the discussion was limited to responding to questions and “topical steering” (Flick, 2002:116). The group first discussed their corroborating reactions to the presentation, with facilitators and staff strongly identifying with research themes. They said the findings provided terminology that helped to clarify their experiential support group knowledge about cancer caring. This feedback supported the plausibility of these research findings.

Only after this open feedback dwindled did I present a list of discussion questions regarding credibility and reactions to system management suggestions (see appendix e). The discussion that resulted evaluated different ideas on overcoming hurdles in support service delivery and medical system and non-profit service linkages. This discussion has informed implication sections of this thesis.

Emotional Impact of the Interviews

Before the interviews began I was nervous and unsure of how I should respond to the inevitable expression of emotions that would occur during the interview process. To assuage these nerves, the Cancer Council ACT invited me to participate in an “accidental counselling” training session held at their facilities in September 2006. In the session I learned the standard protocol on how to respond sensitively to highly emotional interactions. The importance of debriefing after emotionally intense discussions was emphasised by the facilitator of this session as a means of venting to prevent burn out.

Despite the advice given in the training session, I did not talk with others enough about interviews initially and it caught up with me. I had an intense week in May 2007 of interviewing four carers who were particularly emotive in sharing their caring experiences. I watched as Joe cried telling me how much it meant to just hold his wife as they lie in bed before she died. I listened to Kyle vent his anger at how unfair it was that his wife had died of cancer, that bureaucracies were so unhelpful and that he did not know how to deal with his anger. I listened to Ian's depression and embarrassment as he recounted how his paralytic fear of cancer and anxiety forced his wife, the patient, to care for him emotionally while she was undergoing treatment for breast cancer. I watched Sue frenetically retell her cancer carer voyage as a wife with limited knowledge of the medical system and a need to do everything she could to help her husband counter his cancer. By the end of the week I too felt helpless and distraught. While with friends watching an episode of *Grey's Anatomy* where a main character's father dies from cancer, I sobbed for half an hour.

After this semi-public outburst it became clear that I needed to make a few changes if I was going to get through the remaining 50 interviews and still participate in social gatherings. Thus, I made a conscious effort to debrief weekly with my fellow PhD students. I noticed that I started subconsciously decreasing the amount of empathy I invested in each interview. This helped me to get through the remaining interviews.

The strong emotional response that I had to these interviews, however, almost certainly had an impact on the research process (Kleinman, 1991). The intense empathy I felt for these carers has probably caused me to emphasise the negative or underdog aspects of their caring experiences, something Dixon-Woods (2008) has argued is typical of most medical sociology research. Out of an empathetic desire to help these carers, the representation of their experiences may be skewed away from the positive aspects of caring and towards the less enjoyable aspects of their experiences.

Analysis

As mentioned above, this research used a quasi-grounded theory approach. As such, analysis was ongoing, with data collection and interpretation being part of the same process, and with the latter influencing the direction of the former (Flick, 2002). In line with these grounded theory goals, a thematic or "theoretical" coding approach was taken to unravelling and ordering participants' texts, giving participants voices precedence (Flick, 2002:177; Grbich, 2007). After each data collection stage, the transcribed text was read for initial interpretations and then uploaded into *Nvivo*, a qualitative research software program. This program did not and computer software cannot "replace the analytical thinking processes underpinning 'interpretive' research" (Minichiello et al., 1995:269). It was, however, valuable in helping me to organise the 663 pages of text during analysis and make analysis more manageable (Minichiello et al., 1995). While coding, I did not need to print multiple copies of each transcript and physically cut and paste text onto index cards. Instead, cutting and pasting was done electronically, allowing me to more easily merge and rename codes.

Within this computer program, I started the analytical process by organising the questionnaire data into "constructed codes" based on the question eliciting each response (Flick, 2002:178). As mentioned above, the questions and contradictions found from this analysis informed the themes covered in the first interviews. Next, in coding interview transcripts, an emic and cyclical approach was taken (Minichiello et al., 1995). This was done to avoid reinforcing the statistical categories of previous research based on age and gender and instead focus on the diversity in carers' actions and concepts of support (Becker, 1998). I started by openly coding these texts based on "interviewees' expressions," known as "in vivo coding" (Flick, 2002:178). During this step, for example, I noticed that several carers talked about cancer as having a positive effect on their relationship with their spouse. Judy, for instance, said, "We have grown closer. I could never believe people once upon a time who would say 'oh I am not sorry I lost my legs…it has made me grow as a person.' I would think, 'full of shit'.…But [the cancer diagnosis] has certainly strengthened our relationship." Joe said, "I think it brought us closer together and made us realise our own mortality." I highlighted and coded texts like these under an in vivo code titled: cancer brought us closer together.

After coding a few interviews, the connections between existing codes became clear, so these categories were linked with other categories to form tree nodes. Tree node is the *Nvivo* term for a connected coding category with one large heading or bough from which smaller subcategories branch off. Codes on how carers view their role, for example, became a tree node. It started off as an in vivo code called "spouse carer role." Everything said about being a carer was slotted into this coding category. As more and more variation was discovered in how carers described their role, new codes were linked with the carer role code, resulting in 13 branched codes or tree nodes. These branches ranged from "carers' roles as hospital care supervisors" to "spouse vs. carer," where text about the conflicting nature of the two roles was coded. Eventually this category, "Carers' Roles," and all of its smaller branches were linked to a larger branch, "Roles," where the following code headings lie: "Carers' Roles," "Doctors' Roles," "Nurses' Roles," and "Patients' Roles." This step in coding, where categories are "refined," linked and merged is known as "axial coding" (Flick, 2002:181). This process was done repeatedly throughout the ordering of both the initial and follow up interviews. It resulted in ten main categories or boughs and over 170 sub-categories or branches. The ten main boughs included themes on breast cancer, emotions, the hospital system, informal support, information, needs, philosophies on life and death, questionnaire data, roles and support services.

When all transcripts had been coded, the themes of each category were summarised to allow for "selective coding," where study wide, instead of case by case, themes are examined to allow the phenomena of the study to emerge (Flick, 2002:182). This was the most analytically demanding part of the coding process. It involved comparing conflicting experiences, analytic induction or questioning the impetus behind deviant cases and subsequently refining concepts (Becker, 1998; Flick, 2002). To test theoretical concepts about one's data, Becker says to "identify the case that is likely to upset your thinking and look for it" (Becker, 1998:87). This trick was especially useful when trying to understand carers varying definitions of support. Another useful trick during this selective coding and summarising step was the "null hypothesis," assuming that everyone has an equal chance of X. As Becker explains, disproving this shows how a social structure or practice "deviates from random assignment" (Becker, 1998:22). This was particularly useful in examining the allocation of support service information within the medical system.

Valuing Qualitative Research from a Realist Perspective

Although efforts were made during analysis to highlight emic perspectives, it needs to be acknowledged that this research is not free from researcher input. Data collection, analysis and the production of knowledge is never "theory-neutral nor theory-determined, but theory-laden" (Sayer, 1984:78). The way a researcher makes sense of the world has an impact on how he or she orders a study (Becker, 1998). As such, this research should not be valued as "naïvely objective"; it should not be assumed that the environment or researcher's background has had no influence on the analytic empirical process (Sayer, 1984:66). Nor, however, should it be perceived to be "radically relativistic," as just one of many equally valuable circumstantial truths based on a researcher's perspective or individual variation (Sayer, 1984:66).[8]

Instead, these findings should be valued as "practically adequate" or realistic (Flick, 2002; Sayer, 1984:66). The goals of researchers who take this approach are not to discover an absolute truth, but to gain insight into reality (Flick, 2002). The idea of absolute truth or knowledge is rejected by these researchers (Flick, 2002). Our academic backgrounds and ways of viewing the world are acknowledged as having an impact on the analytic process. Objectivity is recognised as an impossible achievement because some subjective knowledge is required to understand the shared social world of respondents (Sayer, 1984). Thus, the outcomes in this study should be assessed as inevitably somewhat influenced by the researcher, but not so relative that the knowledge produced is "whatever we [researchers] care to make it" (Sayer, 1984:66). Instead, a middle ground should be taken in evaluating this and all qualitative research: a road called adequacy between scientific ideals of objectivity and extremely subjective relativistic opposition to the production of any widely acceptable theories.

An adequate judgement of qualitative research findings is warranted when, as is the case with this research, researchers are conscious of possible bias and make efforts to let patterns emerge from the readings of carers' narratives and transcripts using methodologies such as grounded theory. Further, qualitative research findings should be assessed as sufficiently "plausible" when they "generate expectations about the world…which are actually realized" (Flick, 2002; Sayer, 1984:66). The theory produced in this research has been assessed as valid and credible by audiences of cancer carers and support service personnel. Therefore, this research should be accepted as satisfactorily credible.

It should be kept in mind, however, that the conclusions of this study are made from contact with a limited number of informants, and may not be representative of every spouse cancer carers' thoughts, emotions and experiences (Broom, 2005). Thus, the findings presented in the chapters to follow should not be taken as

---

[8] Individualising and relativising knowledge in this way can lead to "nihilism…and the collapse of knowledge" (Grbich, 2007:11).

indicative of all carers' experiences, but as a source of insight into these carers' needs and into implications on how to address those needs.

Final Notes

Two final notes should be made before embarking on the next chapters. First, ethical obligations to participants were considered in the design of this study. In addition to obtaining approval from the Australian National University Human Research Ethics Committee and gaining consent from each participant, each informant's identity has been kept private in the pages that precede and follow. Pseudonyms have been used in place of real names (Kellehear, 1993). Quotes from participants are either overtly indicated by making reference to the participant's pseudonym in the text or cited using their pseudonym in italics and in parentheses (see appendix f for a list of participants' pseudonyms and their corresponding characteristics).

Second, the title of this thesis has multiple meanings that resound throughout the chapters (particularly in chapters four, five and six). "Time to feel," primarily denotes the finding that some carers are so busy, they do not have time to feel. Additionally, caring for a spouse with cancer is widely perceived to be an emotionally rich experience and this closeness is not available to time-destitute carers. Further, this title is a plea to those working within and around the medical system to acknowledge that current medical system practices are perpetuating time-poverty for cancer carers. Finally, "time to feel" represents the absence of theorising about time within the sociology of emotions. In the next chapter the focus is on carers' grief and their overall responses to their spouse's disease.

Chapter Three: Indefinite (future) Loss, Indefinite Grief

Studies have explored cancer patients' experiences of illness and constructions of illness narratives. These studies show that cancer patients often experience uncertainty, but find meaning in their cancer journey (see chapter one). There is a paucity of research on cancer carers' responses to their spouses' illness. Thus, based on interviewees' narratives, in this chapter I provide an answer to the question, "how do carers react to the illness?"

Illness Narratives

Radley (1999:781) explains that, for patients, illness narratives "begin at or near diagnosis….[as] the immediate mobilisation of medical treatment, with its technical vocabulary and its promise of clinical intervention, displaces the everyday world." This was true for carers in this study as well. When asked to tell their carer story in interviews, they typically began with their spouse's discovery of a worrying lump, a suspiciously attentive x-ray technician, the shock of the diagnosis or the speed with which they were funnelled towards surgery and treatment. Their caring journey also began with "biographical disruption": an interruption and alteration of their life history (Bury, 1982:167; Dow et al., 2004).[9]

While carers' illness narratives also began with the life-changing diagnosis or onset of symptoms, this is where similarities between cancer patients' and carers' illness narratives end. In the illness narrative literature, cancer patients are said to adopt the patient role as their primary identity, often experiencing an enhanced sense of truth and reality in their suffering and finding meaning in their illness experience (see chapter one). Carers' stories lacked these characteristics. Only one interviewee, Phyllis (whose unique story is told later in this chapter) adopted the carer role as her primary identity. All others saw themselves as spouses first and carers second. Further, carers' narratives lacked a sense that their lives were touched by an improved insight on life, where the meaning of their spouses' illness helped them to make sense of their altered biography (see Little et al.,

---

[9] In Duke's (1998:833) and Grbich et al.'s (2001:31) studies of bereaved carers, family recounted similar feelings of "devastation" after hearing the diagnosis.

2001). Instead, carers' experiences were characterised by a large workload and uncertainty about their future and their potential loss.

After recounting the abrupt change in their life direction after hearing "*the* word [cancer]" (*Fiona*) carers typically described how life was different and what tasks they completed as part of their changed biography and new responsibilities. For the majority of interviewees, cancer caregiving meant doing everything possible to prolong their spouse's life on the "off chance that something in [the patient's] body might switch and might be able to fight" (*Marian*). This was no small matter. One widower said that caring for his wife was the most challenging job he had done in his life (*Kyle*).

Prolonging a patient's life entails many practical tasks such as assisting with mobility and the management of the patient's medical requirements at home (see chapter two). As part of a commitment to doing everything possible to prolong their partner's life, some carers researched and tried diet changes and complementary medicine. This often involved cooking organic foods, making beetroot juice, buying Chinese herbs and expensive immune system supplements, practicing meditation, thinking positively and believing the patient would be cured. In addition to undertaking new practical, medical and complementary and alternative medicine (CAM) responsibilities for the patient, the carer role involved fulfilling those other family and financial commitments that the patient could no longer manage, such as housework, childcare, earning an income and paying household bills. To complete these tasks and keep the family afloat, many carers ended up juggling multiple roles.

Completing these tasks was particularly challenging for younger and inexperienced carers. Older carers often had some previous experience with caregiving. Many had cared for a parent in their final years or months, seen more people die and overall had more opportunities to interact with or care for friends or relatives as they were dying. Having had these experiences, the emotional, support service and hospital system challenges inherent to giving care might still be confusing, but they were mysteries that these more experienced carers felt confident in solving.

However, those who had not cared for anyone before or had seen few people face death felt ill-prepared for their role. In the absence of relevant experience, some relied on their work experience to guide their actions, prompting one carer to act like a nurse to her husband, concealing her emotions and shutting out her husband (*Millicent*). Many said caring required self-education through internet research, seminar attendance and counselling. After caring for his wife through palliation, one husband even said he wished there was a course on "dealing with dead loved ones at school" saying that "the two certainties in life are death and taxes" and they do not teach either one in school (*Kyle*). Even those who had been carers before, found it was a very poorly understood role with many reporting uncertainty about their emotions, the ideal degree of hopefulness, their role within the medical system and the support available to them.

Identifying Oneself as a Carer

Yet, despite the many challenges, changes to their lives and added responsibilities, all but one saw themself primarily as a spouse. Judy, for instance, said:

> No, I just think I am a wife. I can remember when Richard was first quite ill when he came out of hospital and [my daughter] said, mum if you need a weekend off…I will come and look after Dad. I said I don't need to go away love. This is what being married is! And sometimes when Richard is grovelling, grateful for some small thing, I say that is what I am here for. So I just think it's my job.

The caregiving literature shows that this view is widespread. Few carers actually identify themselves as carers. They see themselves in their family roles, as children, parents, husbands and wives instead (see chapter one). Support service providers highlight this lack of identification with the carer role as a challenge to getting services to carers. In a study conducted by the American Association of Retired Persons, the National Family Caregiver Association and the National Alliance for Caregiving, identifying as a carer was found to be the most significant factor in determining whether the carer took part in supportive services (Hoffman, 2002). Not recognising themselves as carers means they do not seek support from services designed to help carers. With so many changes to their lives, why do most spouse carers see themselves as spouses first and carers second?

A lack of comfort with the term was one reason. Marian, for example, did not think “carer” adequately captured what she did for her husband during the final months of his life. But when I asked her what would be the most appropriate label she said, “I don’t know what is.” Leo saw “carer” as meaningless and used only for political correctness and bureaucratic convenience. Mary saw it as associated with performing physical care, whereas she was doing more; she was supporting her husband emotionally as well.

Marriage is a second reason. Interviewees said that as the husband or wife, they saw themselves as the expected carer. It was “automatic” (*Blake*). Caring was seen as the “in sickness or in health” part of their marital vows. For instance, Leo, (married 27 years) said, “we’re [a] family, standard, old-fashioned, you know, for life type of marriage and it’s just normal…it’s just unfortunate that this [cancer] happened to us.” Giving care was also seen as a way of “returning the favour” to their spouse for times past when roles were reversed. Leo did, however, qualify his statement with “I think it depends on the quality of the bond between husband and wife.” He and several other carers told stories of friends or celebrities whose marriages were not strong, who had not fulfilled their marital vows and had left their spouse unsupported through cancer.

Reciprocity was a third reason why carers saw themselves as spouses first and carers second. Only when physical ailments hindered the emotional and interactive bonds of their relationship would the spouse role give way to the carer role. Judy, for example, said the carer role would remain secondary to her wife role until the point when her husband could no longer respond in conversations, when his disease prevented her from feeling as though she was part of a loving and reciprocated relationship. She said:

> J: I don’t really think of myself as a carer. I mean we still have a life. It’s not like someone who…can’t give anything back. I mean Richard does give back enormously. We still talk about politics. We still laugh at the cartoon in the paper…there is still a lot of giving from him.
>
> RO: So, when do you think you will define yourself as a carer?
>
> J: I don’t know, when he can’t answer me back (laughter).

Although the spouse was the automatic carer and all but one desperately wanted to care for their spouse as long as they were mentally able to communicate (“answer me back”), there were limits to the care they could provide. These limits had to do with the patient’s mobility and modesty. Very old and women carers especially said lifting, bathing and toileting had been or would be the turning point, when outside help or hospitalisation would be needed to assist the patient. Braithwaite (1990) found that carers of older adults have similar breaking points to do with the patient’s declining mobility and incontinence. A few male carers in my study did help their wives with these types of tasks, but others did not because of their wife’s modesty. Seamus’ wife, for instance, became embarrassed and refused to let him help her to the toilet, requesting that he call their daughter for help instead.

Carers view themselves as spouses undertaking a larger workload as part of an interruption to their regular married life. This may be one reason why, unlike patients, carers do not find meaning in the illness journey. Patients seem to experience a substantial change in their sense of identity and life purpose after a cancer diagnosis (see chapter one). They often seek meaning in their cancer to try to make sense of their altered world. Patients often reconstruct their identity to account for the biographical disruption of the illness and to overcome their grief: to “affirm or construct a personal world…that has been challenged by loss,” the loss of their health and independence from the sick role (Neimeyer et al., 2002:239). Instead, carers often grieved not for an actual loss, but for the loss of their assumptions about the future. They grieved for the future plans they might not achieve with their spouse and struggled to orient themselves towards a future that potentially, but not certainly, does not include their spouse. The differences in Phyllis’s, Marian’s and Linda’s stories help to illustrate the particular nature of cancer carers’ grief.

Grieving

Phyllis and her husband were living in a country town outside Canberra when her husband suddenly became ill. They thought it might have been a stroke, but soon learned that he had a terminal neurological cancer. The effect was immediate. He became confused and fixated. His personality changed substantially and his cognitive abilities had decreased, not unlike a person with dementia. He was so forgetful that Phyllis had to provide ongoing guidance. She said, he “was a bit like a two year old.” He would often forget how to perform basic tasks such as brushing his teeth or shaving and she had to re-teach him how each time he forgot.

His personality also changed. He withdrew, refusing to hold her hand, virtually ending their married relationship.

> P: He wasn't the same, there wasn't a lot of emotional interaction.…We were a very close couple so when we went for a walk we would always hold hands wherever we went, and all of a sudden we stopped doing that....I would do it [hold his hand] and he would just drop it straight away.…So all of that sort of stuff stopped. So that was hard.
>
> RO: Kind of a huge – it sounds like breaking up before you –
>
> P: Yes it is. It's almost like that. When he first got sick I think I cried for about six weeks.

For Phyllis, grieving began the day her husband withdrew. After their relationship as a couple ended, she wanted to be free of her caring role; she wanted him to die so it would be over. As this is a socially unacceptable sentiment, however, Phyllis felt compelled to lie to most family and friends about her feelings. MRI scans, for example, would come back showing that the tumour had not grown and her husband was going to live in the near future. The doctor presented the news as if it were a blessing, but Phyllis did not see it that way.

> You just think, "I wish it would be over," but you feel really guilty, because you didn't want it to be really over but you wanted to be out of the situation and you didn't want them to be sick.…The real conflict was when he had MRIs and half of you would be saying "please," I'd groan, "say that it's going to be over soon." And then the other half of you is thinking, "Oh that's awful." And then it would be awhile and it would come back and if it was normal…I would go into a depression for days and I'd feel really guilty because there had been no change. And I'd think "this could go on for years and I could be locked into this situation." And people say "that's wonderful, isn't it?" And I would have to put on this big act and say, "Oh that's great there's no change. I'm so happy!" I'm not a very good actor. This sort of farce would go on, 'cause that's what people expect you to say, and I am thinking, "if only you knew this is just a nightmare." And then of course if there was a change you couldn't say "oh it's great, he's got worse! It's all going to be over soon for me."

Phyllis's desire to be freed from her carer role was not just because her relationship with her husband had ended months before and she was practically caring for a stranger, but also because of the demanding nature of the work involved. She had to watch him constantly to be sure he would not, for instance, confuse glass cleaner with cordial and poison himself. She could not leave him unattended and was limited to six hours of weekly respite. She felt trapped and desperate for genuine interaction.

When he did die, it was a relief for her. By our second interview it had been a year and a half since his death. She had moved on and was settling into a new relationship, though not without resistance from some family members. They thought it was too soon. But, as Phyllis explained, she began grieving the loss of her husband the day his personality changed. "I went through a lot of anticipatory grief because I knew he was going to die and he wasn't the same person anymore. So that made it a lot easier for me when he did die because I had already been through all this, I had separated emotionally." Phyllis mourned the loss of her husband when his personality changed, well before his physical death.

Marian's experience of grief was quite different. Although Marian's husband also had a neurological cancer, his personality did not change. She spent her caring days wishing and believing her husband would live: doing everything possible, from organic hummus to dried herbs, to help him and his immune system. Our first interview was on the one year anniversary of her husband's death. Marian said she was going to see a grief counsellor because she was still working through her grief. She explained to me on our second interview that she was still grieving her loss, that she was actively making time and space to experience her emotions.

> I need to make more time for me just to feel….[I am] trying to work out ways of me slowing down, not rushing around doing things but making time for myself, so I can just feel…I haven't yet [fully felt] the pain of the sadness, which to me is an ongoing thing. There is not an end to that, feeling the pain of the sadness. Yes, and I am not doing that. I will get sad and I will say, come along, get up and do something….I [now] try not to do much. I try just to say well I will just sit and go and look at the lake and have a cup of coffee. I think the jargon is sitting with the grief. (laughs).

Marian's grief followed the more "conventional" pattern for a widow (Gilliland & Fleming, 1998:543). It followed the death of her husband and was an "ordinary loss…codified by official verification – a death certificate, a funeral ceremony, and a ritualized burial" (Boss, 1999:9). It began with physical death, though it did progress along a non-linear course that required her focused efforts.

Linda's pattern of grief fell somewhere in between Marian's and Phyllis's. Linda's husband was given a terminal prognosis following a bowel cancer diagnosis. Two years after radical surgery, however, he was living well despite the oncologist's first prediction. The surgery involved a multiple-day long procedure where the surgeon

> opens you up completely from neck down to pelvis…removes all the cancer. They cool your body dramatically down, pack you in ice and they soak your insides. They fill a basin with heated chemotherapy, 40 degrees Centigrade and then soak you in it for two hours. Then they drain all that out and they put you all back together and then over the next five days you have tubes that are in you and you get more chemotherapy put in, cold chemotherapy. They are soaked in that for 23 hours and you are turned during that time to [ensure it] makes it round your body and then they pump it out. And then after that you just go into convalescence.

It is extremely risky, as this quote suggests, and rarely performed, but it meant that Linda's husband went from a terminal prognosis and palliative care to an improved chance of surviving five years. Going from a terminal prognosis, through a highly dangerous surgery to a good chance of living five years drastically altered Linda's expectations about the future with her husband. Instead of planning for a long term future together, they were "liv[ing] for the now." The future was too painful to consider and too uncertain. Thus, on one hand, Linda was grieving their lost future together. On the other hand, she was trying not to focus on the future, because the loss was not certain. Her experiences shortly after returning to work exemplify the uncertainty of her grief. She talked about being unable to plan very far into the future. She explained that during an exercise at a work planning meeting,

> the facilitator did this first exercise and she said "well lets do your personal life first and here is a sheet and I would like you to fill in what you think your goals will be for the next year, for the next three years, for the next five years, and also write down what you think will be happening then." Now that was too painful for me because I had stopped looking ahead. I was too busy enjoying the here and now.

During our second interview she said that if she thinks about financial plans that exclude her husband she asks herself, "Why am I having these thoughts? It's almost like saying here is your hat, what is your hurry?"

The contrasts between Phyllis's, Marian's and Linda's experiences of grief peaked my interest. It was clear that Phyllis experienced her grief before her husband's death and Marian had not. (The impact of CAM and belief in Marian's caregiving is explored further in chapter four). But, how might one explain Linda's experience? To address this question it is necessary to first examine the existing literature on caregiving and grief.

Anticipatory Grief

The caregiving literature is dominated by studies on the grief "symptomatology" of carers of the elderly, dementia sufferers and palliative care patients (Fulton et al., 1996:1352; Lindemann, 1944). These carers experience what is called anticipatory grief: when the emotions related to loss occur a substantial time before the person stops breathing (Boss, 1999; Femiano & Coonerty-Femiano, 2005; Fulton et al., 1996; Fulton & Fulton, 1980).

Carers and relatives of the very elderly grieve anticipatorily because the older person goes through a social death before their physical death (Gilhooly et al., 1994). Patients become increasingly dependent on others for pain medication and mobility (Nash, 1980). Dependency on others may result in a shameful and "spoiled identity" (Goffman, 1968b) and a slow loss of dignity: a loss of "those characteristics of a person and the environment which allow [them] to feel an identity, a sense of self worth, a sense of stature" (Nash, 1980:65). Consequently, the elderly often suffer a loss of value to their family and wider community and exclusion from family decisions and community events. Their decline in status, inclusion and dignity results in a tacit and unofficial social death (Elias, 1985; Nash, 1980; Pine, 1980). The family and carers of the elderly tend to mourn this social death, or loss of the person they knew, and adjust to a life without them well before the patient's physical death. Family often experience the bulk of the physical and psychosocial responses to their loss, the anxiety, depression, sleep disturbance, digestive trouble, loneliness and sense of meaninglessness, while the person is still alive (Fulton & Fulton, 1980; Gilliland & Fleming, 1998; Neimeyer et al., 2002).

Dementia carers grieve anticipatorily, for similar reasons. As their family member grows less lucid, they mourn the loss of the social person with whom they had a relationship (mother, father, spouse) as well as the future "bodily death" (Meuser & Marwit, 2001:659). Braithwaite, for example, found that the loss of the social person was cause for anticipatory grief amongst dementia carers. Watching the dementia patient's "intellect and personality degenerate" was statistically related to “minor psychiatric symptoms in carers” while physical deterioration was not (Braithwaite, 1990:77). These carers detach from their relationship, but not without guilt. They continue to care emotionally and physically for the patient, but often under a redefined relationship where the carer views him or herself as the parent and the patient as the child (Meuser & Marwit, 2001). Carers of a parent with dementia often grieve for the lifestyle they have lost after taking on the many responsibilities associated with caregiving (Meuser & Marwit, 2001). Carers of a spouse with dementia often grieve for their lost relationship (Meuser & Marwit, 2001). The death of the dementia sufferer is experienced as both a relief and cause for further mourning (Gilhooly et al., 1994; Gilliland & Fleming, 1998; Meuser & Marwit, 2001).

Carers and family of palliative care patients are said to grieve anticipatorily as well. But, as these patient’s are more often fully capable and lucid they do not grieve the social or psychological loss before the physical death. They more often offer “mutual support” to each other (Meuser & Marwit, 2001:659) and share a pattern of emotions with the dying patient including shock, denial, guilt, anger, separation anxiety, acceptance, relief and sorrow (Fulton et al., 1996; Sweeting & Gilhooly, 1990).

Marian’s grief was most similar to the grief experienced by carers of palliative care patients. During the bulk of her husband’s illness she believed he would survive. Over his final weeks, however, after he decided to accept no further treatment, they shared an awareness and emotional response to the pending loss. Phyllis’s grief was most similar to that experienced by carers of dementia patients. She mourned the loss of their marriage and her husband’s psychological death before she mourned his physical death. At his funeral, instead of devastation, her husband’s death was a relief (Fulton & Fulton, 1980; Jackson, 1980; Pine, 1980; Sudnow, 1967). It was an alignment of the social and the physical: matching the person’s social death with their biological death.

Ambiguous Loss

Pauline Boss (1999) refers to the mismatch between the physical and social death of a loved one as *Ambiguous Loss*. As Boss (1999:6) explains, “people hunger for certainty.” With ambiguous loss, however, the loss is anything but certain. It occurs in two types. In one, the lost person is “physically absent but psychologically present, because its unclear whether they are dead or alive" (Boss, 1999:8). A person who has gone missing is an example of this first type of ambiguous loss. Typically the family have difficulty in moving forward and creating a life without the missing person because it is unclear if or when they will return. In the other setting, "a person is perceived as physically present but psychologically absent" (Boss, 1999:9). A family member who has Alzheimer's disease is an example of this second type of ambiguous loss, which leads to anticipatory grief.

Those experiencing ambiguous loss typically feel very alone in their mourning. There is no funeral or other religious or community ceremony to mark the loss (Boss, 1999). As a result, "their experience remains unverified by the community around them, so that there is little validation of what they are experiencing and feeling" (Boss, 1999:8). Those feelings typically consist of mixed emotions and thoughts. Ambiguous mourners, like anticipatory grievers, typically feel both anger towards their loved one for "keeping them in limbo" and guilt for feeling angry (Boss, 1999:61; Gilliland & Fleming, 1998). Or a person experiencing ambiguous loss might simultaneously "cling" to and push away their loved one (Boss, 1999:63). This uncertainty and the lack of finality makes it difficult for people to move on, to restructure "the roles and rules of their relationship with the loved one" and restructure the direction in their lives (Boss, 1999:7).

While these concepts, anticipatory grief and ambiguous loss, resonate with Phyllis's and Marian's experiences, they do not fit with Linda's experience or the majority of the other carers I interviewed whose grief was similar to Linda's. Although perhaps not evident to her family or friends, to Phyllis, there was a clear loss before her husband died. She had lost a reciprocated loving relationship and she knew that neither her marriage nor his personality were going to return because the tumour was inoperable. She knew her husband was not going to be part of her future because he had been given a definite terminal prognosis and limited future. Linda's loss, on the other hand, had not yet occurred and it was unclear if and when it would occur. These two aspects of her grief, that it has not yet occurred (physically or psychologically) and that it is uncertain, represent the distinct nature of cancer carer loss from the ambiguous loss and anticipatory grief that many dementia carers experience. Most cancer carers, like Linda, are unsure of how to anticipate the future, and so they experience, what I call, *indefinite loss* and *indefinite grief*.

Indefinite Grief

Of the 32 cancer carers in this research, 26 experienced *indefinite grief* at some point in their caregiving career. This type of grief was characterised by an acute sense of mortality, a sense that planning, travel and quality of life were limited and the replacement of old priorities with new ones. Many carers alluded to a sense that they had become keenly more aware of the finite nature of life. They talked about cancer as “a cloud of metastatic possibilities hanging over” them, representing their partner’s and their own awareness of their indefinite futures (*Sally*). Carl, for example, spoke about mortality saying, “you can see it [death] sort of looming.” Despite ongoing treatment and the continuous improvement being made in cancer therapy, Carl was very aware that statistics for lung cancer were not in their favour. He knew that he would soon have to plan a life that did not include his wife, but when was not yet clear. Andrew said cancer is “there all the time…as soon as you wake up…then the realisation hits you almost every morning”: the realisation that his wife had metastatic breast cancer and, very probably, a limited future. Anne’s anecdote provides some comedic relief, but also shows the primacy of cancer and mortality in her thoughts. She and her husband became very worried about a lump that was growing more evident above his collarbone.

> He had this lump growing here at the base of his…throat. And I had been sitting across from him having breakfast or dinner, and I was looking at this thing and…I finally said to him, “you have got a lump on your throat.” He said “yeah, I am a bit scared I have been watching it now for awhile. I noticed it about 2 weeks ago.”… He waited for his next check up and he finally went and he said, “what about this lump? We have been panicking about it”…It is very difficult the minute you see a change not to think shit its back. It hangs over your head even if you are trying not to let it….And he [the doctor] goes “it is your Adam’s apple!”…He has lost so much weight that he has actually got an Adam’s apple….And we couldn’t stop laughing, we were laughing for days about that one.

In addition to a heightened awareness of their mortality, spouse carers’ indefinite grief was also characterised by a sense that future planning was limited. Charlie, for example, said “the future has got down to what I am doing this afternoon almost. Never mind next week stuff." Rodney's experience provides another example. During out first interview he talked about being a "chronic planner" and making financial plans that excluded his wife. He said, "I found in making sort of investment decisions, well hang on we can't really rely on Chloe's income and then feeling guilty for even thinking that" as if he was wishing her away in planning. Although he tried to make plans, he could no longer do so with a sense of certainty and without guilt. Many other carers reported similar feelings in making important decisions such as purchasing a car or buying a house. They would ask themselves questions such as, "should I buy a house that would be more suited to a single person?" and then berate themselves mentally for planning a life without their spouse. This inability to plan for the future and their emotional response when they tried meant that many carers felt paralysed. They could not move forward with their lives, but they could not return to their pre-cancer life either.[10]

Changed priorities was another characteristic of indefinite grief. Sharon noticed a change in how she approached family arguments. Instead of addressing their concerns directly, when her children squabbled she would yell, "Look for goodness sake, there are more important things in this world. Your father has got a lift-threatening disease. Just, stop arguing about who has the last Tim Tam!" Charlie noticed a change in what he worried about and his tolerance for people who worry about "the small things." He told me about a story he had heard that rang true with his new priorities.

> A university lecturer, he had a…big glass jar and he filled it full of golf balls and said…."Is the jar full?" [The students said] "yes, it's full…absolutely full." Then he said, "Well, it is not really. Look at this." He poured a whole lot of stones in it and filled all the holes in between. "Now what do you think? Is the jar full?" [The students said] "Yes, it's full now." He took some sand and he put the sand in it and that filled it even further. He said…treat the golf balls as the real things in life the real issues and the stones as the medium and the sand as just the little bits that fill all the little holes in there….You should look at the big picture….Look at those big things. The golf balls were your life, your health…all those sorts of issues. The stones were maybe your car and goods and chattels. The sand was all the other noise and shit that you worry about. Don't worry about all that rubbish, just worry about the golf balls….I probably got like that, all

---

[10] Meuser and Marwit (2001:266) found that spouses of dementia sufferers also say they can no longer "look backward" or "forward."

> these people worrying about other things - go away. Go and worry about something real!

Because of cancer, Charlie only concerns himself with the golf balls: health, life and milestones. He ignores the sand. Sally noted that after her husband's life flashed before her eyes she too reassessed what was important.

Carers also talked about mourning their displaced "dreams, wishes and fancies" and previous plans for the future (Radley, 1999:781). Charlie's wife's cancer metastasised to her brain causing her to feel constantly nauseated and necessitating ongoing radiotherapy which limited their ability to travel. Charlie said "the biggest disappointment," as a result, was not accomplishing "the hope [from] a few years back that at this time we would be out and about all the time, care-free" enjoying their retirement. He lamented their inability to travel outside the Australian Capital Territory because she would need to be close to her oncologist in an emergency. Frank also described a sense of sadness and frustration at not being able to realise his retirement dreams of caravanning around the country with his wife. He said, "It is just all cancelled." In an email to me following our interview he wrote, "Personally, I envy every retired couple that I see on the road in their caravan. I do hope that they appreciate their situation." In couples where the cancer had a debilitating impact, doctor's appointments and ill-health got in the way of achieving the plans that couples had made for their future.

For others, cancer raised questions about their expected plans for the future. These carers mourned for the taken-for-granted sense of a distant mortality they once had, for their lost sense of a clear life direction that could be anticipated and worked towards, and for the assumptions they had about their futures. To replace these old plans, several carers made new and more immediate plans to accommodate the uncertain future. Fred and Jane, for example, planned a three month holiday around Australia on which they embarked almost immediately. Linda and her husband made arrangements to visit Melbourne within the month to watch a football game. (This is illustrative of what I refer to as being positive but realistic in chapter four.)

All of these causes of grief and ways of coping were characterised by a lack of certainty. Decisions had to be based on limited information and, consequently, planning was limited to the near future, leaving carers feeling immobilised in their life course. Their lack of certainty about the future is more like cancer patients' experiences of survivorship than like the anticipatory grief experienced by carers of palliative care patients and dementia sufferers.

For the family of palliative care patients, the future is certain: death in a matter of days, weeks or possibly months. With that certainty, the family can begin to prepare themselves for the changes they will face and the loss of a close relationship. They begin to grieve anticipatorily. For carers of Alzheimer's and dementia sufferers, the future is also certain. Initially, some carers, adult-child carers more than spouse carers, question the diagnosis and, over the course of the disease, the patient may share rare moments of lucidity with the carer (Meuser & Marwit, 2001). However, after the dementia sufferer's symptoms become moderate, the illness trajectory is certain (Meuser & Marwit, 2001). For how long may be hazy, but it becomes clear that the patient will continue to experience decreasing cognitive function and increasing dependence. Consequently, their "grief escalates linearly" (Meuser & Marwit, 2001:665). Alzheimer's carers often see their caring career as akin to walking down a series of steps, with each step representing a crisis in the patient's mental and physical health and the final step being their spouse's death (Boss, 1999).

The cancer carers in this study, other than Phyllis, did not watch as the patient slowly and predictably declined: losing dignity, mobility, bodily control and social identity. Instead, illness trajectories were uncertain. Millicent, for instance, confessed that "neither of us knows how far down the track he is towards death…I don't know how he will go. Nor does he and the doctor's haven't really said." The diagnosis was clear, but the future was not. Unlike families of palliative care patients, for families of cancer patients who have not yet reached the palliative care stage, the physical loss is not impending or certain. Unlike carers of dementia sufferers, the loss of the psychological and social person has not yet occurred for cancer carers. While many carers of cancer patients experience the loss of their future plans or assumptions of a future shared with the patient, when or if they will lose the physical, social and psychological person is uncertain (see Fulton et al., 1996; Sweeting & Gilhooly, 1990).

Prognostic information was often little help in clearing up this uncertainty. Prognoses and illness trajectories were often vague. Blake, for example, asked the doctor diagnosing his wife, "'is she going to die?' And he [the doctor] said, 'well, everyone dies' and didn't have a very happy look on his face. He said to me, 'she will need a lot of support.'" This lack of clarity in the prognosis delivery may be because medical professionals find it difficult to engage in conversations on death and the consequently poor quality or contradictory nature of this communication exacerbates this uncertainty (McNamara, 2000; McNamara, 2001; McNamara & Rosenwax, 2007). Even a clearly delivered terminal prognosis was no guarantee of certainty or predictability for cancer patients and their carers. Several patients, who had been categorised as terminal initially and given only months to live, were still alive two or even five years later! Prognoses were often vague and even with a terminal prognosis, carers were rarely certain about their spouse's future. Only when patients entered hospice care or began displaying clear signs that death was approaching (such as acute difficultly breathing, extreme weight loss, jaundice or going into a coma) could these cancer carers begin to feel certain about their spouse's future and thus begin to grieve anticipatorily and plan with certainty for a life without their spouse.

Cancer is no longer associated with a sure death sentence as it was in the past, but instead is now associated with several statistics that hinge on factors to do with the type and stage of the cancer and the type and success of surgery and treatment. This means that the future is based on multiple probabilities and is thus uncertain (Little, 1995). Further, the illness trajectory for cancer follows a jagged and very unclear path that can vary between periods of extreme illness and relative wellness. However, periods of wellness are not necessarily indicators of likely longevity; nor are periods of severe illness during chemotherapy an indicator of the brevity of a patient's future. So, neither statistical nor observed indicators provide reliable assurance about the future. This ambiguity about the future shapes carers' grief. Fulton and colleagues argue that "as medical technology prolongs life and facilitates the early diagnosis of terminal illness," the conceptualisation of loss and anticipatory grief "require[] further scrutiny" (Fulton et al., 1996:1349). The term *indefinite loss* answers this call and reflects a carer's uncertainty in response to this vacillating trajectory and the ambiguity of when and if they will lose their spouse to cancer. *Indefinite grief* is offered to describe the increased awareness of mortality, changed priorities, challenged assumptions about future plans and inability to plan that carers experience in response to indefinite loss.

The impact of this uncertainty on *cancer survivors* has been described as liminality (see chapter one). Little and colleagues use this term to describe the heightened sense of mortality that cancer patients experience after being on the threshold of death and continuing to feel uncertain about the future (Little et al., 2001). They also use it to describe the oscillation cancer patients experience between identification with those who are future-life oriented and those who are future-death oriented (Little et al., 1998).

Like cancer patients' experiences of liminality, cancer carers' sense of loss is typically characterised by uncertainty and a dual identification with the living and the mourning. Thus grief for the cancer carers in this study did not occur anticipatorily. With so much uncertainty, how could carers achieve anticipatory grief? "The primary task of mourning is detachment form the lost object" (Whiting & James, 2006:2). With the future loss being ambiguous, carers cannot grieve in anticipation of the loss. Instead, many carers experienced *indefinite loss* and consequently *indefinite grief* characterised by a heightened awareness of mortality and vagueness about the future which stifled carers' abilities to plan and move forward, prompted them to mourn their possibly lost future plans, reprioritise and make plans only in the immediate future.

Implications

In this chapter I analysed carers' narratives to assess the extent to which carers find meaning in their illness experience to aid in rebuilding their sense of identity after the biographical disruption of the diagnosis. Instead, I found that while carers do experience the cancer as an interruption in their life course and marriage, it is only perceived as an interruption and often not a shift in how they view themselves, their identity and their relationship to their spouse. Thus, the cancer carers interviewed in this study did not seek meaning in their cancer experience, but felt indefinite grief in response to their new sense of uncertainty about the future and indefinite future loss. These findings fill a gap in the literature on carers' of cancer patients' illness experiences. They build on previous research to do with carer identification and caregiving trajectories. Further, they add to the contradictory literature on anticipatory grief and provide validation to carers experiencing confusing and uncertain emotions by identifying their distinct pattern of grieving.

Carer Identification

These findings add to the literature on carer identification by underscoring the validity of past research, helping to identify why carers of cancer patients, in particular, do not to see themselves as carers and informing providers seeking to more effectively target their services. Past research highlights the problem associated when carers do not identify with their role: they do not get any help. As Twigg and Atkin (1994:28) explain, "services are not allocated but negotiated" and if carers do not see themselves as carers they do not negotiate. This rejection of the carer role can have a detrimental effect not only on the carer, but also on the patient. As Hoffman explains, "when [carers] do not acknowledge the role, they are less likely to take actions that protect their own physical and mental health and financial security, and consequently they are also less prepared to provide the best care possible for their loved one" (Hoffman, 2002:2). For the patient's benefit as well as their own, a carer needs to recognise him or herself as a carer before he or she can seek support, because services are labelled as "carer support."

Some carers do recognise their role after they have been providing care for several years (Hoffman, 2002). Others do not identify with this label because they feel it might "change their relationship with the care recipient" (Hunt & Mintz, 2002:23). This research builds on these findings, showing that identification with the carer role for carers of a spouse with cancer may be linked to the effect of the illness on a patient's cognitive abilities and the patient's subsequent ability to maintain a degree of reciprocity within the marriage. The contrast between Phyllis's and Judy's caregiving experiences highlights this discovery. Phyllis's husband's cognitive impairment and personality change meant Phyllis redefined her relationship to the patient and saw herself primarily as a carer. She was receiving so little emotional engagement from her husband in response to her efforts that it was like caring for a stranger, and she did not anticipate any return to a personal relationship with her husband in the future. A study of carers of a spouse with dementia suggests Phyllis's experience is quite widespread (Meuser & Marwit, 2001). Judy, on the other hand, said she was still getting a lot from her husband in return: love, conversation and appreciation. She, like many other carers in this study, saw herself as engaged in a reciprocated marriage and thus, she identified herself as a wife first and a carer second. This observation could be pertinent to researchers wishing to recruit carers of cancer patients into research projects and support service providers wishing to target clients. Instead of using the term carer, “family,” “spouse,” “husband” or “wife” of a cancer patient may be more congruent with how carers define themselves.

Caregiving Trajectories

The finding that reciprocity is central to a spouse carer feeling compelled to care also builds on Allen et al.’s (2004) research on caring trajectories, or understanding the places where the patient will receive care, the persons who will provide that care and why. To predict the outcome of “integrated service provision,” Allen et al. combined Strauss and colleague’s (1985) concept of “illness trajectories” with Elias’ (1978) game theory to understand the impact of many players, the patient, social worker, specialist and GP, on when and how a patient will be cared for (Allen et al., 2004:1009). While their research showed that the number and relative power of the other players had a substantial impact on a person’s caring trajectory, this research indicates that reciprocity between the caregiver and receiver may also be significant in predicting where a patient is cared for and by whom. Caregiving is a big undertaking. If a carer is likely to feel as though they will not receive much in the way of a fulfilling relationship, they may be less likely, as in Phyllis’s case, to want to go on caregiving. Supporting this claim, Meuser and Marwit (2001) found that dementia carers often wish to stop caregiving by the time the patient’s cognitive functioning has moderately degenerated and many do so by transferring the dementia sufferer into a nursing home. This finding adds another informative layer of complexity for future research to explore in understanding and predicting the dynamics of formal and informal care.

Indefinite Grief

The findings presented here on carers’ experiences of loss also add to the literature on grief and loss. First, the concept and terms *indefinite loss* and *indefinite grief* give names to the specific pattern of mourning that carers of cancer patients experience when the patient’s cognitive functions have not been significantly compromised and the future is uncertain. These terms will help to decrease the mystery and guilt surrounding carers' emotions. As Boss explains, "the devastation" brought on by uncertain grief is "only intensified when no one validates it" (Boss, 1999:59). Labelling what many cancer carers are experiencing may bring comfort to them by giving it a name, helping them to communicate about their grief more succinctly, helping carers to understand that others have similar experiences and they are not alone in their mourning (Boss, 1999). Support group facilitators, during my focus group, confirmed that giving carers of cancer patients and those who work with them a term for their particular pattern of grief validates and gives some sense of relief to their confusing emotions and personal difficulty.

Second, these concepts add to the literature on anticipatory grief. Anticipatory grief has been the topic of much debate and confusion within psychology, nursing and medical sociology. The concept has been used to refer to multiple phenomenon and there are many inconsistencies in the literature (Sweeting & Gilhooly, 1990). *Indefinite loss* and *indefinite grief*, however, point to some of the reasons for contradiction in this literature and propose a way forward for future inquiry into loss and grief.

Anticipatory grief is the term offered by Lindemann (1944) to describe the experiences of depression, fear of loss and adjustment to life without their spouse experienced by wives whose husbands were at war. Fearing them dead, these wives had so thoroughly detached from their husbands that, to protect their emotions from the loss, they asked for a divorce when they returned from war. This study was subject to criticism for failing to "present the frequency and variability of responses, the duration of his observations, the presence of associated factors, or to provide any measure of statistical control" (Duke, 1998; Gilliland & Fleming, 1998:542). Nonetheless the concept was "compelling" to many and was the subject of much research in the 1950s and 1960s (Duke, 1998; Sweeting & Gilhooly, 1990:1073). These studies, however, did not tend to investigate the grief experienced by those who *may potentially* lose a loved one. Researchers studied the experiences of those who *most probably* will lose a loved one: parents of children with terminal diseases (Sweeting & Gilhooly, 1990) and family watching as their close relative lie dying in their hospital bed (Kübler-Ross, 1969). In these studies, anticipatory grief was reshaped to describe the decathexis (or detachment) and patterned emotions (shock, denial, guilt, anger, anxiety, acceptance, relief and sorrow) similar to conventional grief that families experience when they know their loved one will die (Meuser & Marwit, 2001; Sweeting & Gilhooly, 1990). These studies have also been scrutinised for their contradictory findings, inconsistent units of analysis, methodological limitations, insufficient evidence and lack of a consistent operational definition (Fulton et al., 1996; Gilliland & Fleming, 1998; Sweeting & Gilhooly, 1990). Rando (1988) may be the most well known critic of the term. She argues that *anticipatory* grief is the wrong name, because the families in many of these studies are already suffering a loss: a clear loss of the future plans that will not be achieved and often a loss of the social person that was once a significant attachment. She also argues that attachment and detachment happen simultaneously.

Based on the insights provided in this chapter, I argue that much of the confusion surrounding this term is related to the need to clarify the variations in the types of grief that occur before a person's physical death. All anticipatory grief is often assumed to be the same, but the way a person grieves depends on the type and certainty of the loss. The literature on anticipatory grief amongst family of palliative care patients and dementia sufferers shows that being certain that the (physical and/or psychological) loss will occur leads to stages of emotional responses, detachment, redefinition of the relationship between the carer and the patient, and for some, grief for the life and person they have lost. The qualitative accounts of carers' grief described in this chapter, however, show that facing a potential loss prompts a very different response. Indefinite grief can immobilise planning, change priorities and lead carers to question the assumptions they had about the future. These findings suggest that using the one concept as an umbrella for so much variation is confounding. Fulton and colleagues support this assertion. Studies need to differentiate "between grief that is being expressed for past and present [and future] losses….Previous research has assumed that these time foci are of secondary importance to the emotional response exhibited" (Fulton et al., 1996:1356). Thus, as the findings in this chapter indicate, future studies should clearly differentiate between emotional responses to (1) the loss of a social person (e.g. the very elderly), (2) the loss of a psychological person (e.g. with dementia), (3) the imminent loss of a person (e.g. a person in palliative care), and (4) the uncertain potential loss of a person (e.g. a person diagnosed with a serious illness such as cancer).

While the findings presented in this chapter provide conceptual refinement and help to further develop the understanding of the loss and grief experienced by spouses as they are caring, the experiences of these 32 carers may not represent the experiences of all carers of a spouse with cancer and certainly cannot show the extent of the variation amongst this caregiving population. Further qualitative research would help to identify the variation in grief amongst, not only those experiencing certain and uncertain loss, but amongst carers of patients with diverse types of cancer, at various stages and amongst carers with differing relationships to the patient. Perhaps a replication of the qualitative study performed by Meuser and Marwit (2001), where dementia carers were interviewed in separate focus groups depending on the stage of the patient's disease (mild, moderate, severe and deceased) and the relationship to the patient (child and spouse) would provide further insight into various patterns of grief experienced by cancer carers and the impact of the disease progression and regression of these different patterns of grief (Sweeting & Gilhooly, 1990).

Past research underscores the importance of using qualitative methodologies in collecting data on grief. Fulton and colleagues (1996:1354) highlight the need to understand the "the psychological, social, physical, and spiritual aspects of daily living" that shape loss. As Marian's unique (to this study) conventional grief shows, grief needs to be viewed not as a uniform process affecting everyone the same way, but as a constructed reality born from social circumstances (Fulton et al., 1996; Sweeting & Gilhooly, 1990). Studying carers grief using qualitative methods allows for this complexity and avoids the problems of many quantitative studies of imposed operational definitions on carers' experiences (Fulton et al., 1996; Meuser & Marwit, 2001).

Further, future inquiry should be a study of carers' *current* experiences of grief and loss, not retrospective accounts of their emotions, because in interviewing after death, researchers run the risk of the "recall of complex affectively laden events [being] more construction than reproduction" (Fulton et al., 1996:1354; Sweeting & Gilhooly, 1990). Meuser and Marwit (2001) confirmed that this is a real problem in their own study and the rich findings presented in this chapter attest to the benefits of examining carers’ emotions *as* they are caregiving, not solely when they are bereaved.

In the next chapter, the focus moves away from illness narratives and grief towards an examination of carers’ coping strategies and emotion work from psychological and interactionist perspectives.

Chapter Four: Managing Emotions for the Present and Future

The emotions carers experience are socially shaped. Emotions are the outcomes of interactional processes in which carers both experience and manage their own emotions, as well as those of their spouses. A review of the literature (see chapter one), however, shows that most studies adopt a psychologically individualised approach to studying carers' emotions. Some of these studies depict carers' emotions as mediated by denial. Few, however, have taken a sociology of emotions approach to understanding the multidirectional (internal, social and cultural) aspects of carers' emotions and emotion work. In this chapter, I report findings from my own research investigating the questions: what coping strategies did carers use? What emotion work did carers perform and what informed their approach? These data suggest that carers do employ coping strategies to deal with their own emotions, but on a short term basis. In the long term carers manage a joint approach with their spouses to time which serves as a framework to remaining positive.

Are Carers in Denial?

Much of the literature (see chapter one) emphasises the prevalence of denial amongst carers of cancer patients. As denial can have the undesirable effect of blocking communication between the carer and patient, I looked for evidence that the carers I interviewed might be in denial. Do they reject the seriousness of the cancer diagnosis and the uncertainty of the future? "No" became the clear answer, after reading and coding interview transcripts. Analysis shows that spouse cancer carers typically experience a range of emotions that denial would circumvent: anger, anxiety, depression, fear, guilt, frustration and sadness. Further, the accounts of Mitch, Anne, Blake and Bernard illustrate carers' awareness of their spouses' liminality.

Mitch told me about his rarely articulated, but clear awareness that his wife's future was uncertain.

> We are just focusing on Melanie and then we will reconsider. Its one thing Melanie has made very clear, no plans. No plans. I said, we always said we would go to the state of origin in Sydney, so this year we were watching the state of origin game and I said how about next

> year we go and she looked up and said I could be dead by then. First time she ever said that…we don't talk a lot. I just give Melanie time and I am here.

Anne said she and her husband work to *not* think about a recurrence or the possibility that he may die. "We try very hard to talk about it and say, we can't think about it. Because then you don't focus on everything else day to day. You don't focus on the good things, you focus on the negatives." She and her husband are both clearly aware of the gravity and uncertainty of her husband's diagnosis, but to reintegrate with the living, working and parenting world, it was necessary to control their anxiety by bracketing off their thoughts of his cancer.

Blake's wife had metastatic breast cancer before our first interview and died a month before our second interview. He said during our first meeting,

> You don't want to think about it, we hope that she doesn't die; I mean I really need her a lot. And she doesn't want to die now, no one wants to die, but we don't [know]. Well, we are just hoping for the best. So I am trying to sort of keep her spirits up and just hope, just wanting to please her more. Trying to help out more.

Like Anne, it was clear to Blake that the future was uncertain, but focusing on the positives was better than focusing on the negatives.

Bernard, whose wife died a month prior to our first interview, explained outright that he was not in denial. "I don't believe it was denial of what was happening because that was very clear, so I think it was just to try and keep it out of the major thoughts." Instead of denial he said it was about consciously focusing on the positives and the present. He said he was a "spin doctor that [wa]s trying to put the best spin on the little positives - you would emphasise those and ignore the big negatives."

So it is clear that these carers, whether their partner's prognosis was certain or uncertain, were well aware and acknowledged the gravity of their circumstances and, thus, were not in denial. The positive approach adopted by many carers, which could be misinterpreted as denial, was actually a direct response to a carer's awareness of the disease's gravity and the uncertainty of their spouse's future.

This finding supports the socio-historical critique of denial as over diagnosed, individualistic and often mistaken for interaction norms where discussions or a focus on death are categorised as taboo. As Mitch's account shows, a lack of open communication about death is not necessarily an indication of denial. It can also be a reflection of the marginalised positions of death in many contemporary societies. As death becomes less visible, more medicalised and as the diseased and dying are separated from society in institutions, people have fewer opportunities to talk about death or talk with the dying. Thus, accepted scripts for communication and behaviour surrounding death are harder to find (Buckman, 1996; Clark, 1990b; Cox & Fundis, 1990; Elias, 1985; Jalland, 2006). Preferring to avoid the awkwardness, emotional eruption and interruption that might follow, many people, like Blake and Bernard, actively silence these conversations (Kellehear, 1984). Instead of being in denial, they are adhering to culturally prescribed standards of etiquette.

How do Carers Cope?

If these carers were not in denial, what coping strategies did they use? Some of the coping literature asserts that men and women tend to cope differently, with males favouring problem-focused and females favouring emotion-focused coping strategies (Braithwaite, 1990; DeVries et al., 1997; Harris, 2005; Thompson, 2005).[11] My study, like Folkman and Lazarus' (1980) and Saad et al.'s (1995) research, found that coping was not gendered in a traditional way. Instead, both male and female carers shared a range of strategies to temporarily delay and distract themselves from their emotions. Coping strategies were not overarching and ongoing, but used inconsistently and interchangeably. Various strategies were employed at different times to help carers in the short term to get through the night or day.

Distraction was the coping strategy most widely employed. More than half (18 of 32) reported using this technique to push their mind onto other thoughts and away from their fears and anxieties surrounding their spouse's diagnosis. To keep from always focusing on the cancer, these carers plunged into "busy work," paid work, housework, holiday planning or exercise (*Judy*). Rodney, for example, said he noticed he was working longer hours. "I found myself…just absolutely burying myself in my work and working longer and longer hours and spending less and less time with [my wife] and [daughter]." A quarter (8 of 32) of carers interviewed

---

[11] Petersen (2004:18) and Galasińksi (2004) critique these types of studies for implying that gendered differences in emotions are "hard-wired" as opposed to socio-historical and cultural.

compartmentalised or “shelved” their thoughts and worries while caring, for fear that focusing on the resulting feelings would inhibit their ability to provide care (*Fiona*). Sally, for instance, said

> I don’t do a lot of talking about emotions…I don’t consciously think about it. I probably dream about it, but I don’t spend a lot of [time on emotions]…. It’s partly that…if you delve into the emotional and it doesn’t resolve in a way, then you are in a mess…

Four of the 32 interviewees reported using escapist coping strategies such as drinking to help them momentarily forget the diagnosis and corresponding uncertainty. Leo said, “I drink more. I started smoking a few times again. But that’s just self-indulgences. By and large I manage.” Other strategies, reported by only a few carers, included taking anti-anxiety medication, meditating, expressing emotions to friends and family, avoiding information on the disease, distancing oneself from the patient, finding “happy outcomes to things that are distressing”[12] and taking action to address problems (*Kyle*). These strategies were not mutually exclusive. Most carers reported using more than one coping strategy throughout their caring careers, in different situations. What was consistent, however, was the effort to manage their own and their spouses’ emotions to be positive.

Staying Positive

Unlike much of the psycho-oncology literature which focuses on either carers’ or patients’ emotions and coping strategies, research that takes a sociological approach emphasises the shared nature of the cancer experience and the need for research to jointly examine carers’ and patients’ interactive emotional processes (Chattoo, 2002; Thomas et al., 2001). Adopting this stance, I next consider the question: do carers manage their spouses’ emotions? If so, how and why?

All participants, to varying extents, reported doing emotion work (Hochschild, 1979). That is, their emotions were not just experienced as being solely about themselves. Carers actively tried to change their own and their spouse’s emotions to conform to culturally defined “feeling rules” and “good patient” display rules (Small, 1996:267). Davis and George’s (1993:171) review of the literature shows that the definition of a good patient by hospital workers is dependent on the care

---

[12] This is what Hochschild (1983) refers to as cognitive emotion management: thinking or recalculating a situation to feel a different way about it.

"regime." Overall, however, good patients are those who cooperate with and are pleasant to staff, maintain motivation, avoid complaining and do not consume too much of the medical staff's time (Davis & George, 1993; Short et al., 1993).[13]

Adding to the way hospital staff define the "good patient," carers' definitions of the good patient centred around being positive and stoic. It was clear from carers' displays of pride during interviews that their readings of the "model patient" included being positive (*Leo*). Carers were proud of spouses who were emotionally "strong" instead of down (*Sally; Tyler*). Stoic patients were also admired.[14] Carers regarded highly those spouses who showed bravery during medical procedures, in facing the public and in facing death. Anne, for example, spoke with awe about her husband's bravery at returning to work, despite his ongoing radiotherapy and being disfigured. Tyler said his wife's "strength of mind," approach to patient-hood and her matter of fact decision to stop dialysis and die was impressive and a relief. He said she never showed any "histrionics," she was "realistic," "courageous and dignified." Leo, a medical doctor and carer, spoke about this in the most depth to me and his wife.

> When she was really really sick in the hospital everybody was saying what a nice lady she is because…she was so polite and pleasant and cooperative. Model patient. So, I was proud of her, we all were….We loved you even more because of that. I thought…if you are really hideous…it would be harder. That would separate the saints from the mortals.

A bad patient, as Leo indicated, was said to be one who did not cooperate, show bravery or positivity; one who "throws in the towel and gives up hope" (*Joe, Judy, Cindy, Frank*), "gives up the ghost and lies in bed or moans about things" (*Joe*) or "throws their bum in the corner" (*Judy*) (a boxing euphemism). Frank and Cindy, for instance, repeatedly said that patients should not dwell on the negatives, they should not "drop their bundle" and become reclusive "voluntary vegetables" who wallow in their depression and watch television all day. "I think some people…become…vegetable[s] and sit[] at the TV all day…whether they are looking for sympathy or just dropped their bundle…I'm not sure. But I do

---

[13] Zborowski's (1952) study of pain in patients from different ethnic groups in the United States indicates that these definitions of the "good patient" are likely to be culturally relative (as cited by Davis & George, 1993).

[14] These reports of the emotion work being undertaken to control the patient raise interesting Foucauldian questions about the impact of emotion work done to achieve these ideals on patients; does it narrow their emotional experience or just discussions about their emotions?

believe…a lot of it is a mental approach…you shouldn't give up….I do think you have to continue" (*Frank*). Bad patients were the ones who focused on their fears and remorse, did not manage their own emotions and cried loudly in despair.

One reason for defining bad patients this way was because of the amount of emotion work involved for the carer. Brave and positive patients were said to be easier to care for. As Tyler explained, "90 percent" of caring is emotion work. In other words, when a patient manages his or her own emotions to comply with social and hospital feeling rules, a carer's job is a lot easier. When patients accepted death bravely, this was considered a particular relief for carers and family.

However, not all patients were able to stay this positive and brave. Patients and carers described patient-hood as a very lonely, consuming and dependent identity that was uncomfortable, especially for male patients whose disease prevented them from engaging in paid employment. Rasmussen and Elverdam's (2008) study of Danish cancer survivors found that work is the anti-thesis to patient-hood. This argument resounded with the experiences of several carers in my study (see also Firth, 2006). For Anne's husband, for example, going back to work, meant he felt like he was "living" instead of dying and he was contributing instead of taking. For Linda's husband, going back to work and then leaving work not because of a terminal illness, but because he had finished a contract was very important. This meant "cancer patient" was not the whole of his identity, and he should not be viewed as someone to pity.[15]

Those who could not return to work or other activities felt trapped by their illness and frustrated. Patients' aggravation and fear prompted many patients to lash out or become depressed. Seamus, for instance, said about his wife's occasional expressions of anger towards him, "When you are very sick your temper is not as good as it could be." Mark, as a patient, vacillated between periods of depression and outbursts where he flew "off the handle" at his wife Fiona because he was frustrated about his incontinence. "Scan anxiety" was another commonly cited reason for patients' angry outbursts. Several carers, whose partners were required

---

[15] Some warn that men's connection to work as a primary basis of their self-identity is an overly simplistic generalisation. The strength of the connection is mediated by class, age and race (Morgan 1992; as cited by Cheek & Rudge, 1996). Yet, this does not mean work is any less important to those who do experience it as the foundation to their sense of self.

to get scans every few months to monitor the status of their tumours, said their partners had severe anxiety before their scan results. This scan anxiety caused them to lash out at their partners. Linda’s husband pushed her away, was “awful” and “impossible” the week or two before getting back his scan results. Then, when the results came back and showed no change, he would pull his wife back in, and act pleasant and loving again.

Therefore, carers saw the bulk of their role as helping their spouse to work at being a model and stoical patient. As Tyler’s statement above indicates, carers saw this emotion work as the most difficult part of being a carer. Rodney, for example, said, “It is the emotional part that becomes the greater challenge.” To manage their spouse’s emotions, carers employed a number of techniques. These included: distraction, pep talks, listening, acting, lying and blocking undesired communication. Carers distracted patients by getting them to “focus on something else” such as travel plans or facilitating speedy treatment to curtail any prolonged uncertain introspection (*Fiona*). They emotionally buoyed patients during depression, difficult treatment and even difficulty in eating by giving pep talks, saying “we can beat this” (*Jane & Marian*) and “you can do this” (*Anne*). They helped their spouses to “deal with [their] fears” by encouraging the patient to talk to them and/or a counsellor or support group (*Rodney*). Many carers reported concealing feelings of distress from their spouse or leading the patient to believe that the family was financially and emotionally stable when this was not the case so as to keep the patient from worrying about anything other than him or herself. Several carers talked about organising friends to spend time with the patient to lift his or her spirits. Some facilitated open talk about the diagnosis and prognosis between the patient and his or her friends. A couple of carers even blocked communication from friends and family who were perceived to be too negative or not sufficiently focused on the patient.

It became clear that in the views of the spouses in my study, a carer’s role was to help their partner to be positive and brave again when patients deviated from the emotional displays expected of a model patient. But, why did carer’s perceive this to be a central caregiving task? A few carers said that they maintained a positive demeanour and helped their spouse to do the same simply because that was what they thought their “job” was as a carer. Patrick said that if he was just “hanging round the place being like a stale bottle and being a nuisance” he would not be doing his job as a carer. More often, carers gave one or all of the following reasons for staying positive: because they thought it was good for the patient's immune system, because it allowed the carer a sense of control and because it was thought to help patients to receive more support.

Stress and Immune System Health

Seven carers reported feeling compelled to lift their spouse's spirits because it was thought to have a beneficial effect on the patient's immune system (many others made allusions to it, but only seven cited immune system strengthening specifically). Rodney, for instance, said "the little bits I have read and all the stuff that I have heard and seen, a lot of it is all about attitude and optimism and positive energy." Bernard asked "what would you do to a loved one if you were so negative?" Fred asserted that a "positive attitude…has to help; laughing has to help." Jane's GP told her that her positive outlook is likely what helped her to outlive her six month terminal prognosis.

However, the validity of this assessment is widely debated. On one side, it is widely believed that hope and positive thinking help people cope and overcome illness, while stress and depression are thought to hinder recovery (Cahn, 2000; Kennedy & Lloyd-Williams, 2006; Leventhal & Patrick-Miller, 2000; Miller & Schnoll, 2000; Small, 1996). More specifically, a belief in the connections between emotional inhibitions, stress and cancer have a long history, dating back to 2 AD (Capra, 1982; Remennick, 1998c; Sontag, 1991). There is lay (Bard, 1997; Gould, 1995; Sontag, 1991) and medical evidence for this belief. Sontag (1991:24) guides her readers through a summary of numerous nineteenth century novels where "resignation" and repression of emotions are thought to cause cancer. Several studies show correlations between increased cancer susceptibility and a "Type C personality," that is, people who consistently maintain a pleasing demeanour and suppress their negative feelings (for a review of this literature see Leventhal & Patrick-Miller, 2000; Remennick, 1998c:40). This is similar to the vast body of research linking "Type A personalities" with an increased risk of myocardial infarction (Leventhal & Patrick-Miller, 2000:524). Other studies suggest that depression, emotional inhibition and lack of hope may increase a person's risk of cancer and other diseases (Breitbart et al., 2000; Pennebaker, 1997; Shekelle et al., 1981). The logic behind this side of the debate is that emotions and stress have an impact on the hormone and immune systems and the resulting suppressed or diminished “immunocompetence” increases a person’s susceptibility to “malignant growths” (Remennick, 1998c:39).

On the other side of the debate is a recent study showing that anxiety and depression have no impact on breast cancer survival rates (Phillips et al., 2008). One reason for this contradiction in the literature may be the difficulty in determining a causal relationship between emotions and cancer. Only one carer, Andrew, was on this side of the debate. He said, “People say things like you’ve got to fight it…and it is not that straight forward. It’s a much more complicated set of factors.” Although it is often tempting to think of diseases, such as cancer, as having “a single cause” (Little, 1995:34), malignant growths are “etiologically multifactorial and developmentally multiphasic” (Leventhal & Patrick-Miller, 2000:529). Furthermore, the immune system is complex, making a causal connection difficult. As Booth and Pennebaker (2000:560) explain:

> …immunity is not a unidimensional variable. The experience of a particular stressor associated with a decrease in the number of helper T lymphocytes in the blood has too often been interpreted as an example of ‘stress suppressing the immune system.’ This is a little like claiming that the quality of a symphony diminishes when the violas play more softly.

Further muddying observations of the relationship between emotions, stress and cancer is the simple fact that negative emotional states such as “grief, depression and stress” are part of the “human condition” (Sontag, 1991:51-2). Everyone, at some point in their life, experiences these emotions, but not everyone gets cancer.[16] Some researchers are suggesting that what may matter more, in determining the relationship between emotions and cancer is the “meaning” of stressful events and their corresponding emotions to the individual (Booth & Pennebaker, 2000:567; Leventhal & Patrick-Miller, 2000). Incorporating the concept of meaning into future biomedical research on cancer survivorship is likely to be challenging because meaning is typically seen as being beyond the scope of medical research (Little, 1995; White, 2006).

Although it is unclear if and to what extent being positive has a beneficial impact on a patient’s ability to overcome their cancer, believing that it did and

---

[16] Sontag (1991:56, 59) further critiques this “psychologising” of diseases for making the cancer patient seen “culpable” or to blame for their disease.

maintaining the patient's positive outlook had other benefits for patients and carers.[17]

Control

Managing a patient's emotions was also said (by five participants) to help carers to feel some control over a situation where they otherwise felt helpless. "As a carer you just gotta sit back and watch all this happen," said Jane and her husband Fred, who had both taken turns as carer and cancer patient. They assessed caregiving to be more difficult than being a patient because of the helplessness that many carers experience. From start to finish, they explained, control over nearly the entire process seems to fall in someone else's hands: the surgeon's, the oncologist's or the GP's. While a patient can focus on their own survival and make treatment decisions, a carer has little say in the process and can only watch much of the time.

Managing emotions was the only area where the carer had any direct control. Rodney summed this up succinctly when he said that being positive is "the only weapon [a carer] has in this fight." Whatever the relationship between positive emotions and the chance of survival, *believing* that staying positive is beneficial and managing a patient's emotions to be positive allowed carers to feel less impotent. In Sontag's words, this "seems to provide control over the experiences and events (like grave illnesses) over which people have in fact little or no control" (Sontag, 1991:56). This may actually be beneficial to a carer's health, as improving a person's locus of control has been linked with improved physical wellbeing (Chapman & Pepler, 1998; Goodin et al., 2008; White, 2006).

Support

Another reason to manage a patient's emotions was because being positive made it easier for medical staff and friends to interact with the patient and offer support. Six carers cited this as a reason for lifting their spouses' spirits. During my interview with Leo, a carer and hospital doctor, it became very clear that medical staff do not respond favourably to what he called "rude" and "hideous patients": those who complain and are aggressive or contradictory towards medical staff. Possibly to help his wife maintain a positive outlook and her "model patient"

---

[17] This is an example of the W. I. Thomas theorem: if people think something is real, such as a placebo, it will have real effects (see Merton & Sztompka, 1996:183-185).

behaviour, Leo "put everything in the best possible light" when discussing the prognosis with his wife. Did he see maintaining his wife's hope and keeping her from becoming a "hideous" patient as a way to ensure that she continued to receive the best care from medical professionals? Some research shows a link between being positive and receiving higher quality care. Several studies show that "health-care workers give more care and attention to patients they like" (Coser, 1962; Daniels 1960; Stockwell 1972; as cited by Short et al., 1993:89). Thus, the motivation for Leo's emotion work was well founded.

Outside of the hospital too, carers managed their spouse's emotions to make it easier for friends to offer support. Patrick, for example, argued that it was better for his wife to be positive, open about the cancer and back at work because then she would receive more support from her workmates. If she had been negative and reclusive, others would be unsure of her willingness to accept help and might be reluctant to offer it. Thus, to allow carers a sense of control, to improve the quality of care received within the hospital and make it easier for friends to offer support, carers performed emotion work to help their spouses to be brave, positive and "model patients."

Temporal Orientation

For many, the painful and unknown future that cancer patients and their families faced seemed bleak and full of unanswerable questions. This made staying positive for and with their spouses a particularly challenging task for carers. Some carers, like Bernard, became "spin-doctors" focusing on positives from the day, while acknowledging their spouse's limited future. Other carers felt optimistic and wanted their friends to be optimistic. Blake, for instance, got annoyed when friends were "sombre" or "morose" when they asked about his wife. He asked of a friend who did not know what to say during a phone call, "can't he say she's going to be alright?" He wanted his friends to help him to be positive. Linda, however, got annoyed when friends were overly optimistic about her husband's future. She wanted friends to "acknowledge" that "things aren't going to be alright"; that her husband was not likely to survive. Carers varied in their approaches to being positive at a time when there were so many reasons to be negative. To understand why carers' approaches to emotion management were so varied, I examined the data with the following question in mind: how do carers and patients maintain hope? I found that orientations towards time were key elements in how carers and patients managed, so a brief review of modern western perspectives on time are helpful in understanding these findings.

The past, present and future simultaneously inform people's actions and dreams (Coser & Coser, 1990; Gurvitch, 1990; Jaques, 1990; Lewis & Weigart, 1990). Time is a "mysterious power exerting constraint" (Elias, 1997:22) over all of people's "temporally organised and orchestrated" lives (Adam, 1992:155). However, few are conscious of time's influence on their perspectives and decisions (Adam, 1992). Instead, time is typically taken-for-granted in varying ways by different classes and age groups within society (Adam, 1992).

The young, the middle-aged as well as those in the middle- and upper-classes tend to be future-oriented. They are more likely to abstain from indulging in the present so they can save up their time and money to enjoy the future (Coser & Coser, 1990; Wiseman, 1970). This "optimistic orientation toward the future [which] values success through the clever manipulation of present resources in the interest of planning for future mobility," is the norm in many affluent societies (Coser & Coser, 1990:194).

How it is that the future-oriented perspective became the standard may have its roots in industrialisation. Time, of course, became an "exchange value" with industrialisation (Adam, 2004:38; Hassard, 1990). Work was less often task-oriented and more often time-oriented (Hassard, 1990; Thrift, 1990). In the Puritanical fashion, described in depth by Weber in *The Protestant Ethic and the Spirit of Capitalism* and espoused by Benjamin Franklin, time became something to be "controlled," "commodified," and invested for the future (Adam, 2004:124). In a political and economic sense, these ideas and subsequent work behaviours helped to serve the "capitalist masters" by exploiting workers for profit (Gershuny, 2002:30-1). The result was a predominant idea of time as "inextricably tied to a future-oriented calculative rationality" (Thrift, 1990:129).

Some argue that those who are part of the lower-classes, the underclass and working class, however, do not share the same orientation to the future. Because of their inability to secure a financially certain future, they tend to be oriented towards the present (Burdess, 1996; Coser & Coser, 1990; Wiseman, 1970).

Vagrants and alcoholics, though they are the extremes of the underclass, are the often cited examples (Coser & Coser, 1990; Wiseman, 1970). The unstable and fluctuating nature of their lives makes a future-orientation nearly impossible. Of alcoholics living on the streets, Wiseman (1970:16) writes, “men come and go from the area, are arrested, are in and out of institutions, die, are kicked out of their hotel rooms, and gain and lose money, jobs, and friends with a rapidity that would bewilder the more settled citizen.” Because their present and future lack the sense of control and predictability that the middle- and upper-classes enjoy, the poor are forced to adopt a “now-orientation” which seems “irrational” and immature to those who are future-oriented (Coser & Coser, 1990:194; Wiseman, 1970:135).

Age is also a factor in time perspectives. Older generations are often past-oriented: seeing their present as a “mutilated fragment of a glorious past” (Coser & Coser, 1990:193). Consequently, they tend to display less anxiety when faced with the uncertain future that goes with a diagnosis like cancer (Lewis & Weigart, 1990). For instance, Seamus, my oldest interviewee, who was over 80 years old, displayed far less anger or sadness and more resignation than the carers in their 30s, 40s, 50s and even 60s. Those of younger generations who are middle to upper class (which describes a substantial proportion of my interviewees) tended to experience what I call *temporal anomie*.

Temporal Anomie

Diseases like cancer challenge the taken-for-granted nature of time-orientation in a person and family’s lives (Adam, 1992; Sontag, 1991). For many people in Australia, technology, insurance and savings accounts promote a sense of predictability and control over timescapes (Adam, 2004). A cancer diagnosis, however, confronts this sense of control, interrupting the linear perception of a person’s biography. The aftermath of this confrontation is, I argue, a sense of anomie: a challenged sense of direction and orientation towards the future. Planning is a “key modern organisational and psychological feature” of the young and middle-class (Lewis & Weigart, 1990:94). When a person loses their ability to plan, they lose their sense of control over their lives which leads to “anxiety, depression [and] temporal panic” (Lewis & Weigart, 1990:97).

Roth found this to be true in his study of patients at tuberculosis (TB) hospitals during the 1950s. Many patients were uneasy and worried when first admitted to the hospital because the length of their stay was yet to be decided by hospital staff and thus was out of their control. To overcome this uncertainty and angst and start to plan again, TB patients interpreted how long they would likely have to stay in the hospital based on their x-rays, their prescriptions and treatment in the ward, in comparison to other TB patients who knew their timetables or had been released. When treatment changed and other benchmarks used to predict the length of a patient's stay changed, the unease, uncertainty and purposelessness patients initially felt returned (Roth, 1963).

Carers experiencing indefinite grief (see chapter three) reported a similar loss of control and sense of direction. Matthew, for instance, said "it is not winning or losing the battle against cancer, its learning to live with it." Their spouses' diagnosis curtailed their ability to plan for holidays and future career and financial decisions. This left them feeling confused and often guilty for trying to make plans without their partner. To overcome their temporal anomie, or challenged orientation towards time, many people adopted an alternative temporal perspective.

When people fail in controlling their futures "there is a need to (re)consider…the temporal limits to human beings" (Adam, 2004:147) and a need to question the quest for progress and the "exile" of death "to the margins of awareness" that characterises much of modern life (Bauman, 1998:220). This questioning is said to result in the adoption of a new temporal orientation. Coser and Coser (1990:200), for example, predict that if "there seems to exist no hope for bringing about changes in the future through activity" then conditions are ripe for the adoption of a present-focused time-orientation.

A majority of the carers I interviewed did just that. They posed "normal" people in their age groups as so focused on building their futures that there was little room for concerns with mortality. Linda, for instance, alluded to a similarity between the people at her work and the famous children's story character *Chicken Little* who tells everyone the sky is falling when an acorn falls on his head.

> You get an email and it is marked as critically important…we need to do this now; we have got to have an urgent meeting. You go to the

> meeting and you think this is such a lot of crap. It doesn't really matter….In the scheme of things is this so important?...Is the sky about to fall in?...Everybody got themselves totally wound into a frenzy over…things that really do not matter.

She viewed her co-workers as fretting over nothing, obsessed with trivial matters like meetings, deadlines and conferences that aid career advancement. This illustrates carers' new temporal perspectives as they were facing *temporal anomie*. To address their sense of interruption and purposelessness towards time, patients and carers either (1) readjusted their temporal orientation to be present-oriented or (2) performed cognitive emotion-work to reinterpret their perception of the cancer diagnosis and maintain a future-oriented perspective.

Positive but Realistic

Couples who became present-oriented called this being "positive but realistic." Although Gregory (2005:389) argues that family practices and orientations are usually "accomplished tacitly rather than explicitly," I repeatedly heard these or similar words (in 17 interviews) by carers or couples where the cancer patient was facing a terminal prognosis. Bernard, for example, talked about:

> …managing this gap between being positive and being realistic….When you know that you have got three months to live at best, that's realistic….But again, we didn't sit there with 90 days and mark them off one at a time, right?...You should be positive. But, [being] positive…[was not] necessarily in terms of the outcome of things, they were about a range of peripheral - they were about all the good things that actually happened in the day.

These carers focused on the uplifting or pleasant occurrences each day instead of focusing on the depressing loss that lay ahead. They were well aware and accepting of their spouses' (potentially) limited futures, but felt compelled to be positive about something. Since they couldn't be positive about the longer term, they were positive about what lay immediately in front of them: the time they had with their spouse in the present.[18] Blake, for instance, said "you are not at the funeral…there is still living to do." Linda described being positive but realistic as the best approach because if she were to go too far in either direction (being sure of a cure and optimistic or being sure of the loss and depressed) she thought it would be too difficult to change her direction. She did, however, have occasional

---

[18] Recently bereaved carers in Duke's (1998:833) study similarly described trying to "make the best of the time they had together."

doubts, saying “it’s a bit like correcting course in a sailing ship.…Do I need to correct my course a little bit?” She sought confirmation from a nurse that this was “the correct” approach for her to take.

> I did actually talk to the…nurse educator….I said to her:…I am not sure if my perspective is the right perspective….I sort of joke sometimes you know my middle name is Pollyanna. She said no you have actually got the right perspective, unlike many of the other people we deal with. You have got two extreme reactions a lot of the time. One is there is no hope no matter what we do, you know we may as well slit our wrists now because life as we know it is going to end ….Then you have got the other ones who think because they have had this treatment that it’s a guaranteed miracle cure….She said you have got the right perspective, you know we are not giving you any guarantees…you are just forging ahead and…enjoy[ing] what you have now. That’s where we would like our patients to be.

While only one participant in this study adopted the “no hope” perspective presented by the nurse educator, just over half adopted the “right perspective”: being positive but realistic. Many others took on what the nurse described as overly optimistic.

Optimistic

Instead of adapting to a present-focused orientation, six carers remained focused on the future by believing they would beat the cancer, typically as part of a complementary or alternative medicine regime. Three couples who were facing a terminal diagnosis were consistently optimistic about the future. Two carers (husbands) said they adopted the optimistic approach initially, but after the recurrence of their wives’ disease and less favourable prognoses, they became more realistic about the future and more resigned to a future without their wives (see Firth, 2006). One carer, whose wife outlived her terminal prognosis by five years, eventually adopted this approach.

Rodney and his wife were one of the couples who consistently took on this perspective. They took turns lifting each other up and helping each other to have faith in her treatment and to believe in their future together. Marion and her husband also took this approach. She tried everything she could to help her husband’s system on the off chance that something in his immune system would react and counter his cancer: spending hours in the kitchen making organic foods and buying Chinese medicine. Taking this approach, however, was not easy for her.

> If you go down that path you have to truly believe that you can beat it, which for me was a general dichotomy because…all my sort of logic is to go with the odds…my background was in Science….But the other part of you…goes down the [optimistic path], gets the Chinese medicine, we went to Ian Gawler's meditation for healing workshop.

To maintain their future-orientation, Marian had to do cognitive emotion work to stay optimistic and convince herself and her husband that he would survive.

This approach is widely supported by the complementary and alternative medicine (CAM)[19] literature such as Ian Gawler's (2007) *You Can Conquer Cancer* and Chinese approaches to medicine that criticise western medicine for being too aggressive and disruptive to a body's overall balance (Goldstein et al., 1988). Many CAM therapies "recognize the fundamental interdependence of the organism's biological, mental, and emotional manifestations" (Capra, 1982:380). They emphasise the importance of believing in a cure.

Increasingly, studies are showing the efficacy of CAM therapies like massage and acupuncture at reducing the side effects of cancer treatment, such as nausea and vomiting, and assisting with the psychological effects of caregiving such as anxiety and depression (Parliament of Australia Senate, 2005; Pearson, 2006). Its popularity has increased so much that nearly a third of adult cancer patients use a CAM therapy of some kind (Pearson, 2006).

Carers who incorporated these CAM recommendations into their future-oriented approach to being positive explained that it allowed them to feel more in control (see Davis & George, 1993; Parliament of Australia Senate, 2005). While many carers felt helpless regarding the diagnosis, prognosis and treatment decisions made by the patient and doctor, CAM therapies gave carers something to do. They were not always certain that changes in their spouse's diet, supplement intake and belief would work, but were grateful to feel less helpless. Anne, for instance, described at length the importance of her role as "nutritionist" to her sense of control over her life. While she and her husband did not adopt the optimistic approach to the future, she did seek out complementary medicine

---

[19] Complementary means in addition to western medicine and alternative means instead of western medicine (Parliament of Australia Senate, 2005).

information on simple changes she could implement to improve her husband's immune system, such as decreasing his intake of red meat and increasing his intake of broccoli and beetroot. This gave her, in her words, "something to do" and an improved sense of command over their cancer experience.

For Rodney, however, agreeing to be optimistic with his wife was a source of guilt. While he was consciously trying to believe his wife would survive, thoughts about her possible death crept into his sub-conscious. He would wake up dreaming of her funeral and find himself making financial plans that excluded her. These thoughts and dreams made him feel unfaithful and guilty. It also negated his and another carer's desire to talk about death with their wives. Their optimistic approach made it impracticable for them to ask questions that would challenge their wives' positive determination. But, Rodney said he had so many questions. Did she want to be cremated? Buried? What kind of funeral did she want? Thus, while the optimistic approach provided a greater sense of control to patients and carers, it simultaneously served to block communication for two carers and caused feelings of guilt in one. This shows the extent to which feelings and emotion management have the effect of opening and closing spaces for expression.

Normalcy

Eight couples did not change their time-orientation, nor did they start believing they would beat the cancer. Instead, these couples did cognitive emotion work to counter their fears that anything was different. Two couples who adopted this approach were facing a prognosis that was not terminal, where high success rates had been predicted. For two other older couples, the likelihood of death was becoming a reality, and little cognitive emotion work was required. For the other four, the threat posed by the cancer was years in the past. Along the way they had done emotion work to rejoin the future-oriented, "normal" world.

Patrick, for example, continuously described death as a certainty of life. Using that premise, he argued that his wife's cancer diagnosis did not change anything. He and his wife encouraged each other and their children to carry on as usual and continue "looking forward" and making plans.[20] Mitch and his wife also adopted

---

[20] Bury (2001) reports similar findings.

this approach to the future, but to a lesser extent. He said that Melanie felt “a little bit disappointed that she [couldn’t]…do some things” and occasionally expressed fear that she might not have a future. In general, however, Mitch and Melanie felt they needed to “get on with life. I have got kids to worry about, I have got plans.” They saw cancer and treatment as a “process” that they had to go through as part of life.

Medical Professionals’ Influence

How did carers select these frameworks to being positive: positive but realistic, optimistic or “normal”? Often, they were in conjunction with their spouse’s prognosis and in response to consultations with medical professionals. I found that carers’ and patients’ emotional frameworks and orientations to time were largely influenced by or in opposition to the way medical professionals suggested they manage their emotions. Many carers talked about the delivery of their spouse’s prognosis and other conversations with doctors and nurses as important in shaping or evaluating their outlook. Linda (quoted above), for instance, asked a nurse educator if her positive but realistic approach was the right approach. Fred and Jane said Fred’s urologist helped them laugh about prostate cancer. The delivery (or ongoing deliveries) of the diagnosis and prognosis, in particular, seemed to be influential in shaping a couple’s approach to the future.

Informing patients and carers of the statistical prognosis provided an opportunity for medical staff to present the technical and statistical jargon in a specific light for the couple. The imprecise nature of statistical data and difficulty in translating “frequential probabilities” of a population into a prediction about one patient’s likely response to treatment and disease is what makes addressing temporal orientation so central to interactions within oncology (Little, 1995:63). As Little explains, “the clinician may know precisely the probability of a diagnosis and the likelihood of a cure with a certain treatment, but cannot know the outcome of the individual” (see also Allsop & Mulcahy, 1998; Little, 1995:20-1). In addition to statistical data being difficult to apply to a specific patient’s situation, it can also be difficult for the patient and carer to understand these statistics (Gould, 1995; see also Skene, 1990). Therefore, telling patients and carers the statistical information on its own is insufficient. Little likens it to drawing marbles from a bag: “at best, [clinicians] can express their conviction…as being equivalent to a conviction that they will draw a red marble from a bag containing 70 black marbles and 30 red ones" (Little, 1995:66). Guillemin (1997:76) also criticises this tactic, describing it as "little better than offering a lottery ticket to someone who is destitute." Thus, doctors must guide patients in how they should feel about their prognosis (Small, 1996). They must frame statistical prognoses within temporal re-orientations to clarify their meaning and, at the same time, ensure patients do not become too depressed.

From patients' and carers' perspectives, hearing the diagnosis was said to be very visceral and memorable. Carers and patients vividly recounted how they reacted to the diagnosis using words like "shock", "shook" and out of body experience. Thus, it was the opportune time for medical professionals to frame and guide patients' and carers' temporal orientations and subsequent emotions. The casting, from certainly bleak to probable survival seemed to depend on medical professionals' interpretations of test results as well as carers' and patients' emotional states.

Fighting Denial?

Anne and her husband, for instance, were probably interpreted as in denial by medical staff, so they were given a bleak prognosis in a startling manner. They went to see their GP after months of putting it off. They were referred to a surgeon who seemed to interpret them as being too blasé and insufficiently worried about what they would soon find out was a dire prognosis.

Despite research showing denial to be the least commonly employed coping strategy amongst cancer patients (Docherty, 2004),[21] literature on communication in oncology shows that denial is believed to be prevalent and a danger to open communication with the patient (Bard, 1997; Field & Copp, 1999; Kübler-Ross, 1969; Rose et al., 1997; Stiefel & Razavi, 2006; Zimmerman, 2007).[22] If the patient does appear to be in denial and too optimistic, clinicians are instructed to "underline…that the medical situation is serious" (Stiefel & Razavi, 2006:43).

---

[21] McNamara (2001), however, argues that denial is more common amongst younger cancer patients.

[22] This may be because a lack of evidence "proves" denial's existence. Kellehear sums this up quite succinctly when he writes, "as a theoretical construct it has the best of both worlds-valid with and even more valid without- any evidence" (Kellehear, 1984:713).

Possibly following this advice, the surgeon may have felt obligated to berate Anne and her husband into taking his cancer more seriously, to ensure they were not in denial. The surgeon did so by repeatedly telling them that they were too late, there was nothing more to do and asking if they had life insurance while Anne cried uncontrollably and "just wanted to die." The surgeon just "wrote him off." Then, this surgeon referred them to another surgeon who did remove the tumour and prescribed radiation treatment. But, he too did not seem to want them to get too optimistic. At the completion of the radiotherapy he reminded them that there is an "80-90 percent chance of it returning in the first year." Anne complained that "nothing is ever certain," doctors only say there is a "good chance." Thus, in Anne's experience, the surgeons not only delivered the statistical prognosis information but did so in a way that challenged their future-orientation. Although Anne said that this way of framing the prognosis had the effect of blaming them for the cancer's advanced stage,[23] their subsequent re-orientation to be present-focused helped them to be positive about smaller achievements such as surviving surgery, eating and drinking normally and withstanding radiation.

Graduated Prognosis

For Sally and her husband, the prognosis and reorientation process was less abrupt, more gradual and less certain. She said, "there is a trickle feed of information….They tell you so much at one stage, and then when the results aren't good, the wording subtly but significantly changes and it's a consistent change." Words like, "muscle invasive…it's just this new phrase that you weren't entitled to before."

This is what is referred to in the oncology communication literature as "partial" (Surbone, 2006:95) or "graduated" disclosure (Field & Copp, 1999; as cited by Kennedy & Lloyd-Williams, 2006:48). Mamo (1999) finds that this is often necessary as many patients and family members need time to absorb the emotionally laden prognosis. The doctor, according to the legal and oncological communication literature, needs to judge how much information the patient can handle in each consultation (Skene, 1990). If patients are "loaded" down with too

---

[23] According to Davis and George (1993) this is very common. In their words, "each consultation can potentially go either of two ways: blame and short shrift for bringing something trivial, or blame for delaying consultation" (Davis & George, 1993:260).

much information on possible outcomes, they might become overwhelmed and lose hope (Stiefel & Razavi, 2006:40).[24]

Probably fearing that Sally's husband might become depressed, the medical staff started with a more optimistic approach, neglecting to mention the statistical likelihood of a recurrence and abstaining from talk about the patient's increased risk of recurrence elsewhere after radiation. Sally concluded that this approach did keep her husband positive before surgery and radiation, increasing his chances of success, but, it left her to "pick up the pieces" afterwards. She had to manage her husband's outlook and associated emotions. Unlike Anne's experience, where their positive outlook on the future was immediately rejected, but slowly reintroduced, Sally's experience was one of ongoing temporal anomie. Because medical staff were positive to the point of withholding information until negative results forced doctors to slowly present a less positive outlook, Sally subsequently lost trust in medical staff and was unsure of what approach to the future she should take. Similarly, Burns and colleagues (2003) found that a family member's uncertainty of the terminal prognosis can actually increase after some discussions with medical professionals.

Over the course of the six months between our two interviews, Sally and her husband seemed to shift from a normalcy to positive but realistic and back to a normalcy approach. Shifting temporal and emotional orientations so rapidly and repeatedly, however, increased the difficulty of Sally's emotion work and exacerbated their temporal anomie. The surgeon told her after removing the cancerous organ that cancer "should be a thing of the past." But, as a result of the changes in their roles and priorities and as a result of the multiple temporal orientations they had adopted, Sally was sceptical, saying, "I don't know if it can ever be that sort of thing."

Positive

Other carers talked about doctors encouraging patients and carers to adopt a more positive outlook. For those patients whose prognosis was terminal, doctors tried to help carers and patients to be more positive, not about their future, but about

---

[24] Little (1995:19) asserts that language hinders clear communication in the clinical setting. With patients using lay language and doctors using jargon, there are "innumerable misapprehensions working on both sides of the consultation." Thus, the medical staff's reluctance may not be the only impetus behind graduated prognoses.

their time in the present. They said things like “she is not dead yet” (*Blake*) or organised for scans to be postponed to allow the patient and the carer to travel and enjoy “the now” (*Linda*). One oncologist said “try to forget that you have got it, try to carry on with your life” (*Judy*). For those patients whose prognosis was survival for the foreseeable future, doctors tried to help the carer and patient to take a “normal” approach and be more positive about the future. To this end, they relayed statistics on the combined treatment’s higher success rates and encouraged carers and patients to live as usual, that is to live and plan with the future in mind.

This is what is referred to as maintaining hope within the oncology communication literature (Surbone, 2006): sustaining hope for a cure for all patients, while emphasising the need to “prepare for the worst” amongst those patients given a terminal prognosis (Kennedy & Lloyd-Williams, 2006:53).

These findings show that carers’ emotion work is directly linked to “prognostication” and the inherently unequal distribution of power in interactions where doctors deliver outcome predictions (Surbone, 2006:98). Carers do not just cope or perform ongoing emotion work of their own volition; they do so in response to the way medical staff frame prognosis information and the way they and their spouse understand and interpret it. Even those carers who were optimistic about the future despite a terminal prognosis did so in opposition to advice from medical staff.

Implications

The insights presented in this chapter, regarding the social nature of carers’ and patients’ temporal and emotional orientations contributes to the growing body of research on the sociology of cancer care (Thomas & Morris, 2002). (1) They provide support for the argument that denial is over diagnosed amongst cancer carers. (2) They offer a clearer distinction between the concepts of coping and emotion work. (3) These findings respond to Thomas et al.’s call for more research to study the interactionist, as opposed to psychometric, nature of cancer carers’ emotions. (4) They provide a more specific conceptualisation of the challenges to hope that carers and patients face and (5) suggest implications for future research into cancer caregiving.

First, these findings show that denial does not fully encapsulate carers of cancer patients' emotional experiences. Several studies (see chapter one) argue that denial is prevalent amongst carers of a spouse with cancer and that adopting this coping strategy has the impact of cutting short patients' attempts at redefining themselves and recreating a social identity that incorporates cancer into their biographies. The findings presented in this chapter, however, suggest that there is far more involved in carers' emotional experiences than just coping strategies. Instead, patients' (and carers') experiences of being unable to communicate with their spouses about their feelings of liminality may be a consequence, as it was for Rodney, of an optimistic approach to cancer and their future, initiated by popular belief, medical staff or in opposition to medical staff.

Second, the insights into cancer carers' emotions presented here help to clarify the differences between the psychological concept "coping strategy" and the sociological concept "emotion work." Coping strategies, such as distraction and escapism, are employed in the short term. Many are used, not just one consistently, to temporarily avoid the emotions, such as fear and anxiety, surrounding the cancer diagnosis. Emotion work, in contrast, is performed on oneself (see chapter six) and others. Unlike coping, carers (and patients) do ongoing emotion work to conform to ("good patient" and good carer) expectations, feeling rules and a specific temporal-orientation.

Third, these findings are a response to the calls made by Thomas and Morris (Thomas & Morris, 2002; Thomas et al., 2001) for research to take a social and cultural approach to understanding carers' emotional experiences. While this chapter by no means completely fills the void in the literature, it does take up their challenge, bringing the sociology of cancer caregiving a step further by refining interpretations of carers' experiences and offering a new concept to discussions of doctor-patient-carer communication: *temporal anomie*.

Fourth, the term "hope" currently dominates in oncology communication studies, with many researchers encouraging practitioners and nurses to both maintain and rein in patients' hope (Kennedy & Lloyd-Williams, 2006; Surbone, 2006). These studies of interactions on hope, however, rarely include both carers and patients. My findings show carers play a pivotal role in maintaining a patient's positivity and hope. Thus, future research in oncology communication should factor carers more centrally into their recommendations to clinicians.

The term “hope” is also quite ambiguous. Reviews of the literature show multiple and conflicting definitions (Fitzgerald Miller, 2007; Kennedy & Lloyd-Williams, 2006). Some link hope to goals (Dufault & Martocchio, 1985), others to life purpose (Owen, 1989), “time refocusing,” “spiritual beliefs,” “uplifting energy” (Herth, 1993:542) and a sense of “inner strength” (Benzein & Saveman, 1998:10). Instead of using the term “hope,” I suggest that addressing a patients’ and carers’ *temporal anomie* more directly communicates what physicians, and a few nurses, in this study were said to do in clinical narratives: re-cast or encourage patients and carers to assume certain orientations to time (Frankenberg, 1992; White, 2006). *Temporal anomie* might also be usefully applied to other life experiences where a person’s orientation to time is challenged such as losing their job.

Finally, these findings show that, in studying carers’ and patients’ emotions, it will be fruitful to widen the scope of inquiry to include the influence of medical interactions, prominent (CAM and other) literature and social support, instead of continuing to examine carers’ or patients’ coping strategies alone. As it has been demonstrated in this chapter, emotions are interactive. Carers’ approaches to emotion management and the future are the outcomes of medical consultations, interactions with the patient and other carers as well as a reaction to the specific diagnosis and prognosis. While there is debate within the psychology of emotions as to the ideal level of analysis, biological, cognitive or socio-cultural (Frijda, 2000), in sociology the reflective nature of our interactions is taken as a given. People’s perceptions of themselves and their subsequent emotional reactions are shaped by their assessments of what others think (Hochschild, 1979; Mead, 2000; Small, 1996; Stocker & Hegeman, 1996).

Some psycho-oncology research is beginning to examine patients’ and carers’ emotions jointly (Kennedy & Lloyd-Williams, 2006; Rose et al., 1997)[25] and oncology communications research continues to highlight the influence of the diagnosis and prognosis delivery on patients’ psychological health (Shapiro et al., 1992; Stiefel & Razavi, 2006). However, there is little understanding of cancer

---

[25] The findings presented here also lend support the conclusions presented in their studies, that a shared approach to coping or managing emotions between carer and patient is beneficial to their relationship.

carers' and patients' experiences as the result of many interactions, internal, financial, social, medical and otherwise. Carers' and patients' emotions do not just exist in a "dyad" (Rose et al., 1997:131) or even a "triad" (Kearney et al., 2007:21) that includes the patient, carer and doctor. As Davis and George (Davis & George, 1993:246) argue, "a consultation…is…only one stage in a series of activities that generate information and help form expectation for the patient" and carer. Nurse educators (as Linda's experience shows), nurses (Hunt, 1991), psychologists, other members of a multidisciplinary care team and the power relations between these members (Allen et al., 2004), as well as family, friends, and culture (Davis & George, 1993; Frankenberg, 1992; Surbone, 2006) all influence patients' and carers' emotional experiences.

Currently, the popularity of individualistic examinations of carers' coping strategies may be resulting in the misdiagnosis and over diagnosis of denial. Carers' and patients' emotional experiences, however, are multidirectional. Before looking for an individual and psychologistic origin in studies on carers' emotional experiences and challenges, future inquiries should first rule out the multi-factorial influences that are likely shaping carers' emotion work. This will improve the quality of researchers' recommendations about how best to support these medical system users, as the level of inquiry shapes a study's recommendations. If, for example, carers are found to be employing unhelpful (to themselves or the patient) coping strategies, then the problem is seen to be located "the psychological make-up" of the carer (Thomas & Morris, 2002:181). Readily available therapy or counselling might then be appropriate. If, on the other hand, carers are found to be performing unhelpful emotion work (on themselves and the patients in their care), the problem is seen to be "rooted in the social management of cancer," in the cultural and medical system norms that guide a carer's emotion work (Thomas & Morris, 2002:181). The scope for change resulting from this kind of finding might include the carer as well as medical professionals, counsellors and the wider society.

Chapters five and six further explore ways that re-examining carers' experiences from a sociological perspective adds to a new understanding of carers' experiences and support service preferences. So as to avoid the "charge, often levelled against the interpretive [sociological] approach, that it concentrates too much on meanings, and not enough on wider structural factors," the scope of inquiry becomes broader in these chapters (Bury, 1991:464). In chapters five, six and seven, the effects of structural factors on carers' emotional experiences, preferences and wellbeing are explored. While time is still central to the foci in these chapters, the level of inquiry changes, from interactionist and micro to increasingly structuralist and macro.

Chapter Five: Time to Feel

Analysis in qualitative research is rarely straightforward and this research was no exception. The impetus behind carers' diverging needs and perceptions of support was not initially clear. Quantitative studies emphasise age and gender as predictors of variation in carers' experiences with younger female carers showing higher rates of psychosocial and unmet needs (see chapter one). Age and gender, however, did not clarify the differences in carers' needs and experiences; looking at their temporal experiences provided more clarity. Carers' sharply contrasting perceptions of telephone calls and emotional support, as either helpful or unhelpful, illustrate the importance of time in understanding carers' needs and welfare.

Phone and Emotional Support: Nuisance or Necessary?

In interviews, some carers described phone calls from friends as a "nuisance." Joe, for instance, found phone calls to be bothersome. He said, "the phone didn't stop ringing…people would get home from work and at about six o'clock the phone would start….I eventually had to take the phone off the hook so I had time to prepare a meal." Answering numerous calls made it difficult for him to complete caring tasks that needed to be accomplished, so he avoided the phone and sent mass emails to family and friends instead. Sally also viewed the phone as a "burden" and disruption from caring.

Others, however, were glad to have the interruption and distraction provided by phone calls. John viewed phone calls as a welcome diversion from his anxiety and distress. Carl called it a vital source of "moral support." Laughing or discussing someone else's life provided them with a break from focusing on cancer. Other carers described telephone conversations as an essential line to inclusion and emotional support. Mary explained phone calls are a means of engaging in more intimate and longer conversations than those she had in public. She even called the emotional support she receives over the telephone a "need." Judy described talking to friends and family as an essential opportunity to release and offload, saying "bawl[ing] [her] eyes out" to her sister over the phone was a helpful release. For two other carers, telephone conversations about emotions and experiences were a "useful" and unobtrusive method to request support. Venting to friends and family made others aware of the carer's troubles and often prompted the listener to offer practical or emotional support.

Why was the phone perceived in such black and white extremes by so many carers? Previous statistical studies of carers' experiences suggest that gender and age may explain the variation in carers' experiences as these two variables are correlated with higher rates of unmet need (see chapter one). Examining gender, however, did not provide clarity, nor did age. Males and females were equally represented among both those who appreciate telephone calls and those who find them burdensome, as were carers in their 40s, 50s and 60s.

I turned to my questionnaire data to check if age and gender clarified the differences in carers' definitions of support. People were asked: "What actions or behaviours of others do you find supportive? Why?" Responses focused around several themes: (a) talking, listening and getting reassurance, (b) respite, (c) information, (d) feeling supported by the company of friends and family, (e) friends or family who make the patient comfortable, (f) acknowledging a terminal prognosis, (g) providing practical help such as cooking and cleaning, (h) being optimistic and (i) flexible work hours (see figures 10 and 11 below). Carers' responses illustrated a range of experiences and perceptions, but neither gender nor age explained much of the variation in answers.

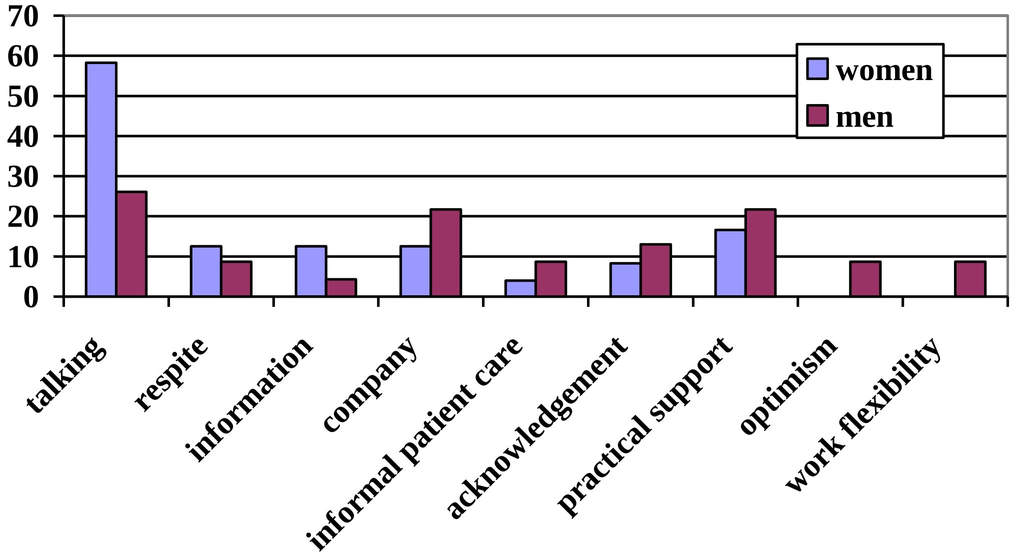

Figure 10 – (y) Percentage of (x) responses, to the open questionnaire item, "What actions or behaviours of others do you find supportive? Why?" by gender.

Figure 10 reports the percentage of male and female participants who reported a theme as supportive. Female respondents cited (a) talking with friends and family as helpful twice as often as males. Males listed (d) having family around as supportive more often than females. A few males, but no females, reported (h) optimism and (i) flexible working hours as helpful. While gender classifications might reveal a few small departures in what carers perceive to be supportive, gender does not clarify why some view phone calls and emotional support as helpful and others see them as a "nuisance."[26] Nor, with one exception, does age, as figure 11 shows.

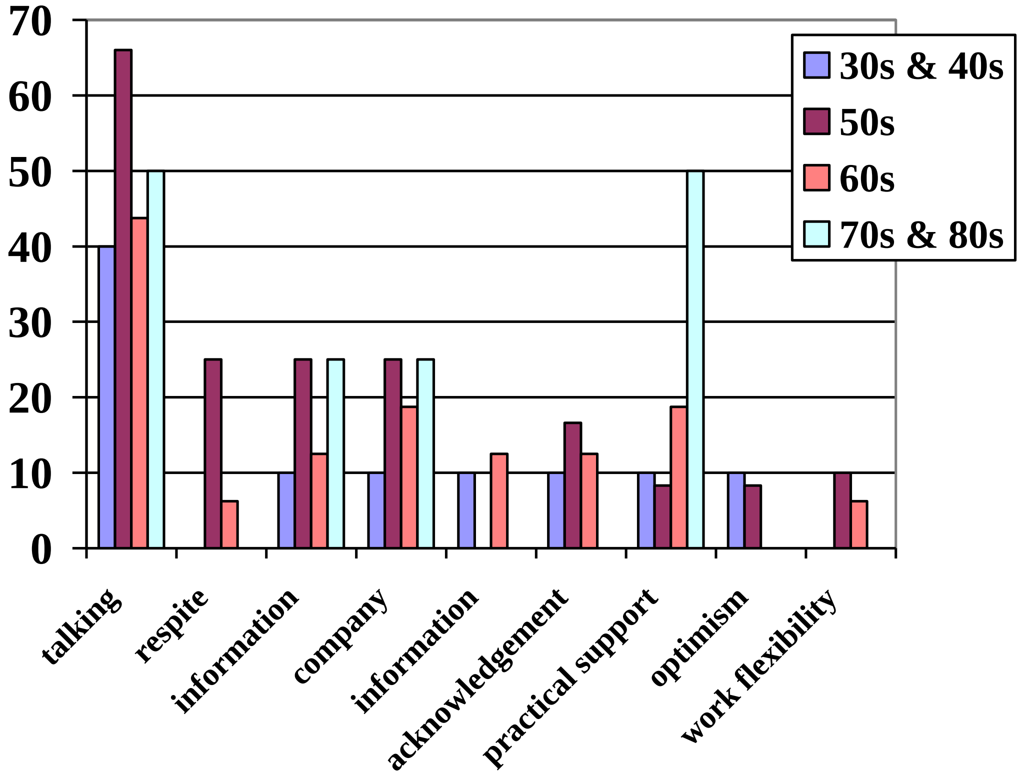

Figure 11 – (y) Percentage of (x) responses to open questionnaire item "What actions or behaviours of others do you find supportive? Why?" by age.

In the above graph, carers in their 70s and 80s listed (g) practical support as helpful far more often than carers in other age groups, perhaps because older carers are more often frail and thus housework is more challenging. Only a few carers, engaged in paid work in their fifties and sixties, cited (i) flexible working hours as helpful. Otherwise, age was not associated with the variation in carers'

---

[26] Further, as noted in chapter four, solely analysing gender differences can have the impact of implying that differences are of a biological origin instead of cultural.

perceptions of support either. Thus, age and gender do not seem to illuminate the reasoning behind the stark contrasts in carers' perceptions of telephone calls and emotional support.

Time: a Central Variable

Next I examined the temporal aspects of carers' experiences, as some of the carers in the study appeared to be extraordinarily busy people while others appeared to have time to spare. Questionnaire data show that the amount of time spent in caregiving varies substantially. Of the 39 carers who completed this section of the survey 30 percent reported caring between zero and 29 hours each week (those carers who reported providing zero hours of care often made a note that while the patient's cancer was in remission, they were not providing any care. However, they had been providing many hours of care in the past and may possibly provide multiple hours of care again in the future if the cancer returns), 31.5 percent provided care between 30 and 120 hours per week, 18 percent reported caring around the clock seven days a week (168 hours), and the remaining 20.5 percent said that it varies (see figure 12).

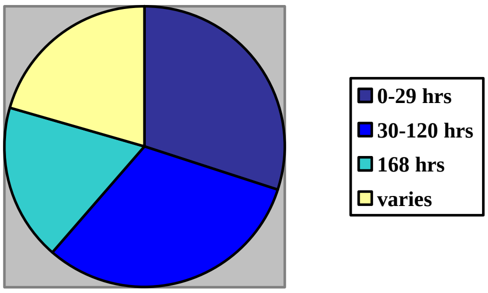

Figure 12 - Hours spent caregiving, in percentages, as reported by questionnaire respondents to the open question "How many hours each week do you spend providing care?"

After further inspecting this variation in carers' accounts during analysis of the interview data, it became clear that time is a central factor in the range of carers' emotional experiences and needs. Carers' experiences vary greatly depending not just on how much time they spend caring, but on how much control they had over their time. Some care work was mildly demanding. For others it was extremely demanding of their time and energy. Others still were giving care to more than one person in addition to fulfilling their paid employment and childrearing responsibilities, leaving them with little control over their time. The following vignettes illustrate the importance of time.

Vignette One: Fred & Jane

Fred and Jane, a couple in their 60s took turns as carers and patients. First Jane was diagnosed with melanoma. A few years later, Fred was diagnosed with prostate cancer. Despite the calls on their time from caregiving, they generally had control over their time. They were retired from full-time work, their children were grown and their cancers and treatment were not physically debilitating. Thus, they had time to experience and interpret their emotions.

Of the emotional side of cancer, Jane said "it actually brought us really close." But, it was a lot of work. "He had a really bad time…for a long time," so trying to lift his spirits was "constant." Jane said this was difficult because she was not sure how to go about doing this.

Fred struggled with feelings of guilt, fear and uncertainty as a husband and a carer when his wife was diagnosed. "I know that it's ridiculous. I felt that I had failed her family because she was in good health when I married her…and I really felt the pending loss." But, they talked to each other and cancer support groups and they learned to manage their emotions. They distracted themselves with a trip around Australia on their motorbike. They learned ways of overcoming sleepless nights. As a result, Fred assessed their relationship to be "stronger."

Vignette Two: Joe

Joe is in his 60s. He retired when his wife became disabled and fully dependent on him for care as a result of metastatic ovarian cancer. They had no children. Joe alone took on the cooking, cleaning and communicating with family and friends, taking only a few hours respite care each week to do the grocery shopping and run errands. He would wake up when his wife stirred at night to turn her in bed because she was no longer able to roll over herself. He managed only a few hours of sleep each night, but said the experience had brought them closer together. He cried telling me how much it meant to hug her. He said: "she was in the later stage of the disease….Just to be able to lie together and hug each other was, I think (crying) that was probably important for Betsy too." Clearly, with Joe existing on little sleep and caring day and night for his wife, he was time-poor. Yet, he did have enough time to experience the benefits of caregiving: growing emotionally closer with his wife.

Vignette Three: Anne & Sally

Anne is in her 30s. She is the mother of a toddler, a receptionist and is caring for her husband who has a rare glandular cancer. Since his diagnosis, disfiguring surgery and radiation treatment, Anne has become the breadwinner in addition to her other responsibilities. This means that Anne works six days a week.

Anne described herself as physically and emotionally exhausted. She cried throughout the first interview and said she was drinking more at night to cope with her lack of control over her life. Anne did not say that the cancer experience brought her closer to her husband. Instead, her emotions were saturated with guilt related to her lack of time. She said:

> Time is the biggest need….There are days when I feel like I am cracking up and I think I can't keep doing this. I cannot keep up this pace….It seems everything I do, I feel guilty. If I am taking a time out at the gym, or playing with my daughter then I am not earning money. But even if I am earning money I feel guilty because you know, money, guilt, time. It's my little horrible triangle.

Sally is another carer, a mother of three teenage daughters, she is a carer for two elderly parents, she works part-time and looks after her husband who was diagnosed with cancer and was undergoing surgery and radiation therapy. She is a clear example of a woman in the sandwich generation: caring for her parents and in-laws, her children and her husband. She uses the analogy of a snowball for her caregiving. She said:

> I have had rapid deterioration in health and the death of my father and deterioration of health of my mother, and my father-in-law all happening over the last two years. It's sort of like a snowball…one that just seems to keep getting a bit larger, and I am aware of a sense in myself that I am pretty sick of it (laughs)….Just so much looking after people to do.

During her husband's time in hospital, she felt extremely angry towards him for continuing to smoke after the doctor advised him to quit. Since that time, though, she has put her emotions aside. She says she sees her feelings as an indulgence for which she does not have time.

> S: I didn't really go work through emotional things….It is partly that, I am a little bit scared what you will find. And then if it doesn't work out, the way I saw my job was to look after [my husband] and 3 other girls [and] two older parents. If you delve into the emotional and it doesn't resolve in a way, then you are in a mess, then what is going to happen. So…keep that gate closed (laughs).
>
> RO: So maybe because you knew so many people were counting on you, you couldn't…indulge yourself-
>
> S: That is exactly the word I was thinking. I do think of it that way. And I don't think it's necessarily the right way to think about it.

With so many people relying on them, neither Sally nor Anne has time to feel.

Time: a Closer Look

It is clear from these narratives that time was significant in shaping carers' emotional experiences. Next, I ask "why was time significant?" and look to the literature within the sociology of time for conceptual tools to help make sense of time in carers' experiences.

Although time was central to the concepts of the founding fathers in sociology, it lay dormant for many years, "as an implicated rather than explicated feature" in social theories and research (Adam, 2004:3; Hassard, 1990) (see chapter four). Adam, critical of time's "take[n] for granted" status in the social sciences, embarked on an ontological study of the conceptualisations of time from ancient Greece through to the twentieth century (Adam, 2004:3). Consequently, Adam's and other's studies (Elias, 1997; Frankenberg, 1992; Hassard, 1990; Roth, 1963) have sparked the beginnings of a time renaissance in sociological studies with more than one theorist describing time as a "crucial" concept in describing and understanding social phenomena (Crow & Heath, 2002:2; Elias, 1997:1).

Ontological explorations like Adam's have been central to time's rebirth within sociology. Of more consequence to understanding carers' experiences of time in this chapter, however, are the theories and historical explanations of time as an empirical measurement of social welfare. As Szollos (2009:336) explains "time shortage and being rushed clearly interfere with quality of life. Conversely, time affluence and some unencumbered free time would likely enhance the quality of life." Many social theorists have studied the number of hours spent in paid employment and found that progress and technological innovation have not had the desired effect; instead of spending increasingly fewer hours in paid employment, workers are spending more time at their jobs (Gleick, 1999; Hamilton & Denniss, 2005; Hochschild, 2000; Nyland, 1990). Technology has resulted in a distortion of the lines between home and work and many employees are experiencing "temporal strain," with work commitments encroaching on home-time (Lewis & Weigart, 1990:100; Neary & Rikowski, 2002).[27] In an effort to address this time-imbalance, social researchers are developing new terms to explain and measure this strain.

Many "concepts of time" exist (Jaques, 1990:30; Szollos, 2009). Early concepts aimed at measuring time-pressure dichotomise time into work- and leisure-time or public- and private-time, with more time spent in leisure- or private-time indicating improved social welfare (Crow & Heath, 2002; Gershuny, 2002; Szollos, 2009; Zerubavel, 1990). These concepts, however, do not resonate with the experiences of the people in my study, for three key reasons.

First, dichotomising time obscures why some people spend more time in paid work than others. For some working long hours is a matter of "two painful alternatives, hunger and work" (Nyland, 1990:151). This was the case for Anne. Her financial situation left her no choice but to work six days a week, despite the guilt she felt for not spending more time with her daughter and husband. For others, however, working longer hours is a "preference" (Nyland, 1990:130). Work is where many people find psychological fulfilment and so they choose to work longer hours than necessary to manage their cost-of-living budget (Goodin et al., 2008; Roberts, 2002). This was the case for Rodney in my study. He worked longer hours than necessary after his wife's initial diagnosis. He did so not only because he enjoyed his work, but because it was an escape from being at home, dealing with the ramifications of an emotionally laden cancer diagnosis. Therefore, categorising time into work-time and leisure-time does reveal, by calculating the number of hours spent in paid work, the strain felt by carers like Anne. It does not, however, account for those carers who have a choice about working longer or shorter hours. Certainly, for those who find work fulfilling or, in Rodney's case, use work as an escape from time at home that would be anything but leisurely, longer working hours should not be an indicator of eroded

---

[27] Some, however, have argued that this sense that life is speeding up is an illusion. It is simply the result of having too much choice (Szollos, 2009).

social welfare. Furthermore, this conceptualisation does not accurately portray the deteriorating social welfare experienced by people who spend most of their time outside of paid work because they are unemployed or unable to work (Gershuny, 2002).

Second, as Rodney's story indicates, dichotomising time can be problematic because "leisure time" or time spent at home often consists of unpaid work (Holmes, 2002:40). Care work is situated on the border of what people consider to be part of one's "private life" and part of one's (un)paid, work life, making the categories of work or leisure inapplicable and inappropriate as measures of social welfare (Davies, 2001:139). Joe, for instance, was not employed, but felt temporal strain as a result of his time-consuming caregiving commitment to his wife.

Third, these measurements of time are open to error because they do not account for time spent multitasking within overlapping categories (Davies, 2001; Hochschild, 2000). As Davies explains, "the nature of care-work presupposes that as a carer you are always *available*" (original emphasis Davies, 2001:141).[28] Thus, when a carer is always on-call, calculating and categorising the time and experiences of temporal strain becomes particularly difficult. Measuring Anne or Sally's leisure time, for example, would be problematic because their time was never their own. Even at work, they were at the ready to respond to a request from a relative, child or their spouse.

Therefore, to better understand the impact of time-strain on carer's experiences and social welfare, a theory on time needs to (1) distinguish between time spent as a result of need and time spent as a result of choice and (2) depict time within a continuum, rather than two categories. Goodin and colleagues' (2008) concept of "discretionary time," and its underlying theoretical framework, meet these requirements and provide a valuable tool for understanding why some carers' experiences are time-pressured. Discretionary time is defined as "time which is free to spend as one pleases" (Goodin et al., 2008:i). Others have used similar terms like "time sovereignty" to denote a person's freedom to control their working time schedule and when to do certain tasks within their work days (Garhammer, 1995; as cited by Davies, 2001:136; Roberts, 2002:176). In contrast,

---

[28] Though Davies is speaking of paid carers working in a childcare centre, her argument applies to unpaid family carers as well.

Goodin et al.'s focus is not solely on work-time, but on the autonomy one has over all of their time.

Unlike the limited categories of work-time and leisure-time, discretionary time incorporates each person's (culturally grounded) commitments and basic necessities into conceptualising time as a measure of social welfare. It is taken as given that everyone must spend a certain amount of time attending to the "necessities of life": doing basic personal care tasks (sleeping, eating, bathing), performing minimal household tasks (cleaning, cooking, [for some] childcare) and working to live at or above the poverty line to afford food, shelter and clothing (Goodin et al., 2008:34). This is largely beyond a person's control as the bare minimums are determined by biology (everyone needs to sleep), cultural norms (to do with cleanliness, for example) and the cost of living.

The amount of time left over after fulfilling one's basic needs and roles to a socially acceptable level is the amount of a person's discretionary time: the number of hours within a person's control for them to spend as they choose. Most people with "temporal autonomy" or "control over how one chooses to use one's own time" do not just spend this time resting (Goodin et al., 2008:30). Long term carer Millicent, for instance, spent an extra six to eight hours each week involved in community organisations. Those people without temporal autonomy who cannot afford (the time) to maintain "socially acceptable" levels in these three categories (personal care, household tasks, income) are said to be below the "time poverty" threshold (Goodin et al., 2008:5). This concept helps social researchers to recognise someone like Joe's experiences of strain as a result of time-poverty. As a result of the household and personal care tasks he had to perform for his wife, Joe was only sleeping three hours a night. Thus, in units of discretionary time, Joe would accurately be defined as time-poor, not leisure-time rich.

In discretionary time, necessity is separated from choice, thus this measurement of time is superior to those that only measure how time is spent. As Goodin and colleagues (2008:84) explain, "time poverty, like money poverty…[should] be defined not in terms of actual expenditures, but instead in terms of necessary expenditures." A person who has little in their savings account after a year of extravagant cocktail party and fine-dining bills should not be considered poor (Goodin et al., 2008). Nor should a person who has little spare-time after a week of working late hours because they choose (not need) to work late be considered time-poor (Goodin et al., 2008:54).

Hochschild (2000), however, points out that choice in the number of hours a person works is often limited by social factors as well as need. In *Time Bind* she highlights the gendered and classed reasons many people work longer hours. For some it is a means of liberation from being a housewife. For others, working longer hours is part of a work culture that only takes executive employees seriously if they comply with working 40 or more hours each week. Szollos (2009) offers a further critique of the word “choice” here. He argues that being time pressured is never an individual choice. Instead, “time pressure is always an interaction between the person and the environment, and…individual variations and context always need to be taken into account” (Szollos, 2009:339).

Despite these limitations, Goodin et al.’s (2008) overall conceptualisation is still valuable. They emphasise not just time, but control over one’s time as a central factor in assessing a person’s welfare (Goodin et al., 2008). Just as having a sufficient household income and discretionary income are strongly linked with life satisfaction, having discretionary time is correlated with life satisfaction. Thus control over time matters more than time itself to a person’s social welfare (Goodin et al., 2008; Szollos, 2009). This is a necessary distinction for this study. There was a significant difference in the experiences of those carers who could and those who could not choose to become more or less busy to either distract themselves from their emotions or attend to their emotions.

This sociology of time literature helped to make sense of carers’ experiences in this research. Goodin and colleagues’ quantitative and political contribution and Davies’ feminist approach emphasise the value of looking at a person’s temporal autonomy as a whole. This pushed me to examine, not just how much time the carer spends caring, but how much time they spend in their other roles and how much control they have over their commitments. This understanding of time and temporal autonomy informed my placement of carers’ experiences into three categories: time-sovereign, time-poor and time-destitute carers (see figure 13).

Time-sovereign carers were those carers, like Fred and Jane, who (x) were looking after a spouse whose cancer and treatment were not debilitating and (y) did not have other substantial “claimants” on their time (Hassard, 1990:12). The majority, eight males and six females (44%), of the carers interviewed fell into this category. For these carers, caregiving responsibilities were largely social and emotional, not physical, and took up only a moderate amount of their time. Because they did not have paid work or other caring responsibilities they had control over their time.

Time-poor carers were those carers, like Joe, who (x) were looking after a spouse whose cancer and treatment were debilitating and (y) did not have other demands on their time. Of all interviewees, 12.5 percent fell into this category, three males and one female. These carers were providing many onerous personal care tasks such as bathing and lifting their spouses, in addition to giving social and emotional support. Often, this meant caregiving took place 24 hours, or close to it, each day. Like time-sovereign carers, these carers did not have paid work or other caring responsibilities, which allowed them to meet the numerous care needs of their spouses.

Time-destitute carers were those carers, like Anne and Sally, who (x) were looking after a spouse whose cancer and treatment were not debilitating and (y) had multiple claimants on their time. Three husbands and six wives, 28 percent of all interviewees, fell into this category. For these carers, like time-sovereign carers, their caregiving responsibilities to their spouses were largely social and emotional, not physical, and took up only a moderate amount of their time. The other demands on their time, including paid work, other caregiving responsibilities and childcare, left them with very little control over their time.

No interviewees fell into the category of (x) providing time-consuming physical, personal care, social and emotional support to their spouse as well as (y) juggling multiple responsibilities outside of caregiving. Perhaps no interviewees were in this category because providing care to a spouse who had become debilitated and fulfilling multiple commitments outside of this role would be impossible or, at the very least, it would be impossible for a person in this position to spare time to participate in an interview. Undoubtedly, if any carers’ experiences match this description, they too would be qualitatively categorised as time-destitute.

It is important to make the distinction that these qualitative concepts are not exclusive categories, but exist on two continuums (see figure 13). The x axis represents the time-demands of caregiving. Those providing social and emotional support are on the left, categorised as providing mild to moderate support. Those carers managing biomedical aspects of their spouses' treatment (administering or monitoring reactions to medication), providing personal and physical care (bathing, toileting or lifting) to their spouse, in addition to giving social and emotional support, would be categorised on the right as giving moderately to extremely demanding care.

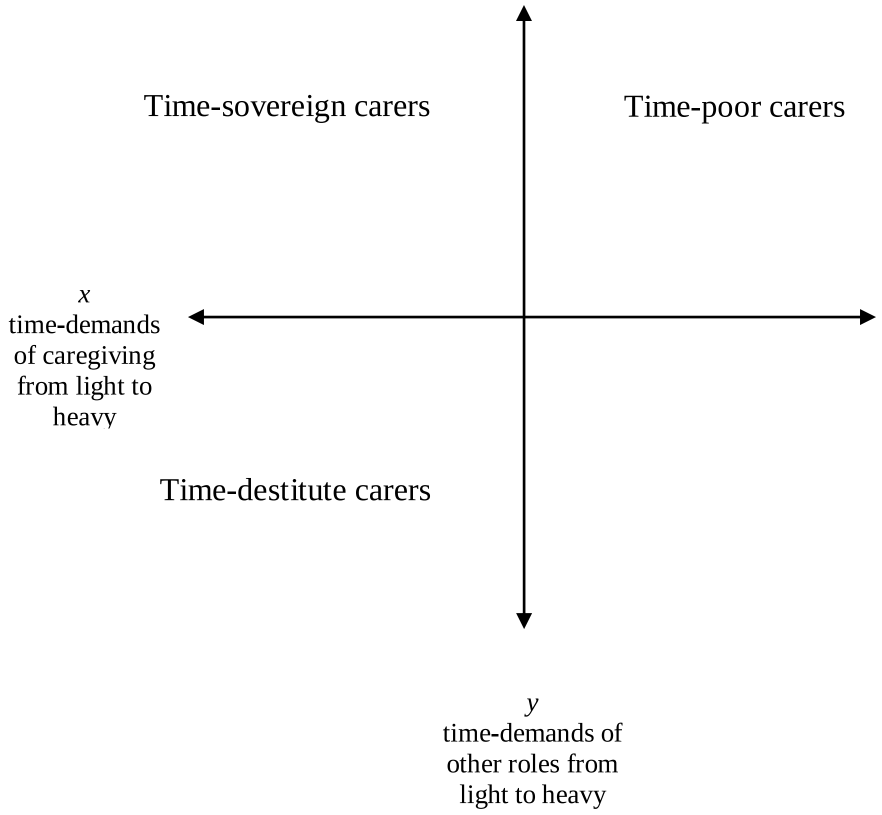

Figure 13 – Categorisation of carers autonomy based on (x) the time-demands of caregiving and (y) the time-demands of their other roles.

The y axis represents the number of other claimants on a carer's time and the time-consuming nature of these claimants. Those solely providing care to their spouse are at the top of the spectrum. Those involved in paid work and caregiving for their spouse would be in the middle. Those managing multiple responsibilities (childcare, caring for elderly relatives and paid work) would be at the bottom of the spectrum.

Viewing these categories along a continuum allows for the placement of the remaining five carers interviewed. These carers had experiences that might be categorised as somewhere in between time-sovereign and time-poor or time-poor and time-destitute. Bernard, for example, cared for his wife following a mastectomy and during chemotherapy treatments. Because she had severe pain following surgery, he provided more than social and emotional support. He managed her pain and monitored her reactions to chemotherapy, but did not need to help his wife with toileting or bathing. He performed much of this care work in the evenings and during weekends because he worked full-time during the weekdays. He was not, however, giving care to other adults or providing childcare, as time-destitute carers were. Thus, Bernard might be categorised as somewhere between time-poor and time-destitute.

Depicting these experiences in fluid categories is also useful in a longitudinal sense. Although most interviewees' experiences fell into the time-sovereign category on an ongoing basis, many experienced time-poverty or destitution on a temporary basis. Charlie, for example, was time-sovereign during our first interview, but by our second interview his wife's condition had deteriorated substantially. The metastasis to her brain caused her to vomit uncontrollably and repeatedly. This meant he was constantly cleaning up and thus, he had become time-poor. Viewing carers experiences on a temporal continuum allows for the conceptualisation of carers' experiences as not fixed but fluctuating with changes in the patient's wellbeing, mobility, reactions to treatment and changes in their family, financial, and employment situations.

It is important to note that these categories are based on qualitative conceptualisations of carers' experiences. Although "poverty" is often used as a political, economic and quantitative measurement, it can also be experienced subjectively. That is not to say, however, that the concepts developed here could not be adapted for use in future quantitative studies.

Time to Feel

Categorising carers experiences based on time-sovereignty uncovered a qualitative difference in carers' emotional experiences and showed that time and emotions are intimately linked. Studies of dementia carers and cancer carers show that a benefit of caregiving experienced by some carers is growing closer to the care-recipient (Grbich et al., 2001; Kramer, 1997b; McNamara, 2001; Thomas et al., 2002) (see chapter one).[29] Analysing carers' experiences based on the amounts of control they have over their time shows that this benefit is not experienced equally.

Time-sovereign carers, by definition had control over their time and thus, had time to feel. These carers had more time to experience a range of emotions related to caregiving and cancer. They had time to feel and reconnect with their spouse (see also chapter six).

Time-poor carers, who were managing one very demanding caregiving responsibility (caring for their spouse), also had enough time to share emotion-rich experiences with their spouses. Time-poor carers had little time to themselves. In order to keep on top of the housework, treatment management, appointments, coordination and caregiving, these carers often gave up personal time and sleep. A sense of obligation and desire to help their spouses as much as possible reduced their personal-time to dangerously low levels (see chapter seven). Yet, time-poor carers reported having some time to feel. They reported having enough control over their time to prioritise sharing emotions with their spouse and feel a reconnection or heightened sense of closeness with their spouse as a result of the cancer experience.

Those carers who were time-destitute had little control over their time due to the number and time-intensity of the multiple roles they were juggling. Consequently, these carers had little time to feel, as Anne and Sally's stories illustrate. Managing all of these commitments made it difficult for these carers to prioritise their own emotions. They had little time to themselves to sort through their emotions and little time to grow closer to their spouse.

---

[29] One carer postulated, however, that this benefit depends, for spouse cancer carers, on the quality of the relationship before diagnosis. "It just polarises things that are already on the ground" (*Leo*). If there is tension in the marriage before cancer, it may prompt divorce. If there is love and stability, cancer caregiving may help the relationship to grow stronger.

Charlie’s experience illustrates the importance of time in experiencing emotions. During our first interview, he told me he was constantly reflecting on his wife’s uncertain future and on his own sadness. Even cartoons would prompt the flow of tears. By our second interview, Charlie’s time-sovereignty had eroded. His wife’s wellness and mobility had decreased and her dependency on him had sharply increased. He was time-poor. Consequently, he had less time to reflect on his emotions. While he still prioritised connecting emotionally with his wife, when he was not interacting with his wife, he had so much to do that he “ran on remote control” instead of feeling.

Time for Support?

This finding indicates, not only that time and emotions are intimately linked, but that time and support are linked. This finding allowed me to understand the differences in carers’ opposing perceptions of telephone calls and emotional support. It answered the question that emerged when analysing cancer carers accounts in this research: why do some carers “need” phone calls and emotion focused support while others take the phone off the hook and prefer not to respond to voicemail messages? The reasons are twofold: time-sovereign carers (1) have more emotion-rich caring experiences that more often necessitate accessing emotional support and (2) they can afford the time to access this emotional support.

Time-destitute carers did not have time to feel, they did not seek out emotional support nor did they appreciate phone calls from friends and family offering emotional support. Their primary focus was finding enough time to manage their competing responsibilities. Like time-destitute carers, time-poor carers often avoided phone calls and did not seek emotional support. Time-sovereign carers had so much time to feel that many made an effort to distract themselves from their emotions. They appreciated emotional support and distractions from friends and family via the phone and in other formats. They more often sought out help in managing their emotions (see chapter six).

Time: Understanding Quantitative Research

A final insight provided from categorising carers’ experiences based on time-sovereignty was in better understanding the quantitative correlations established in past research between age, gender and even financial position. The findings presented here suggest that one reason older carers are less likely to have unmet needs is because they are more likely to be retired, with grown children, and thus more likely to have control over their time. Being retired is linked with having greater time-sovereignty. For many, retirement adds 40 or more hours a week to a person's discretionary time. The age of one's children is also significantly linked to temporal autonomy. Having young children, especially under the age of five, has been found to increase the amount of time required to meet basic needs in all three of Goodin et al.'s (2008) categories: income, household chores and personal care. In Australia, this decreased a person's discretionary time by 13 hours, making young children the most significant contributor to a person's lack of spare time (Goodin et al., 2008). Add cancer caregiving and attending hospital appointments to this (Firth, 2006) and it is clear why past research indicates that older carers tend to have fewer unmet needs than younger carers (in their 30s and 40s) with young children; older carers generally have more control of their time.[30] Older time-poor carers with an exceptionally taxing caring role, however, are an important exception.

Control over time also explains why gender has been a significant variable in statistical research on caregiving and unmet needs. Women, in general have less discretionary time than men by two hours each week because women "are responsible for juggling more roles inside and outside the family" (Goodin et al., 2008; Northouse et al., 2000:281). Women's time is far more centred around meeting the needs of "significant others" which restricts women's capacity to control their time (Davies, 2001:136). The people to whom women attend to are not limited to children. Women are also more likely to be carers (ABS, 1999; Allen et al., 1999). Adding paid work reduces women's spare time considerably (Davies, 2001). Working mothers have approximately 30 percent less spare time than stay at home mothers (Goodin et al., 2008). Conversely, male carers are more likely to have autonomy over their time because they are less likely to be looking after older relatives and children. Thus, time-sovereignty also provides insight into why statistical research reports that women tend to have more unmet needs.

---

[30] This link is also supported by statistical analysis of the experiences of carers of older adults with dementia (see Braithwaite, 1990).

A few quantitative studies have also linked financial troubles with unmet needs. Gibson et al. (1996) found that carers with unmet needs were significantly more likely to be experiencing economic or financial strain. Regarding cancer carers specifically, financial problems have been found to be a predictor of a negative caregiving experience and linked to high morbidity rates (Sharpe et al., 2005; Thomas et al., 2002). Under capitalism, time can be exchanged for money and money can be exchanged for time (Hassard, 1990). Class shapes how much time a person has. People with financial resources can "buy" time through purchasing time-saving technology or the labour of others (Adam, 2004; Holmes, 2002:51). Carers with access to money can retire from paid work or hire people to do time consuming housework reducing the number of hours spent in competing responsibilities and ultimately increasing their temporal autonomy.[31] Said another way, not having enough money "can really compromise your ability to look after someone" because of time commitments needed for an income (*Linda*). Thus, categorising and understanding carers' experiences using time-sovereignty as a framework helps to explain the higher rates of unmet need amongst younger, female and lower income carers of cancer patients.

Implications

These findings about the relationship between time and emotions in the qualitative experiences of carers of a spouse with cancer have strong implications for future research, theoretical exploration and policy developments. I suggest here that adding time-sovereignty to theoretical work within the sociology of emotions could be fruitful in exploring a possible link between time-destitution and marital instability. Gathering quantitative data on the link between time-sovereignty, unmet needs and relationship stability might provide confirmation and add to the growing literature on cancer carers' experiences. For service providers and policymakers, I suggest including a new approach to understanding the variation in carers' experiences based on temporal autonomy.

For the Sociology of Emotions

These findings point to a need to incorporate time more centrally into how we understand emotions. Time and emotions are intimately linked. Feeling is a time

---

[31] This finding is also supported by Braithwaite's (1990) quantitative study of dementia carers.

intensive activity. Some emotions, such as embarrassment or delight, occur in the moment as a flash or eruption of emotion. Others, like grief, dread, guilt or anger, may be of sudden onset but persistent or growing and require attention to interpret, confirm and manage. Sally, for instance, talked about how long it takes her to digest information and emotionally respond to it. "That processing takes quite awhile, especially when they are big nasty bits of information. Isn't that funny how…I have to run over it and run over it (laughs) to actually absorb it somehow."

These findings show that those carers with control over their time have plenty of time to feel and "absorb" these slow growing and at times confusing emotions surrounding their circumstances (see chapter six). They sought out distractions from their emotions in conversations with friends and family, in planning vacations and in joining community activities. Time-destitute carers, in contrast, have too little time to feel or reflect on their own emotions. These findings point to the potential benefits of incorporating time into the sociology of emotions.

Time might be added to theories on emotions, improving their explanatory capacity. On the whole sociologists of emotions, like most other sociologists, neglect time in their analyses (Adam, 2004; Lewis & Weigart, 1990). Hochschild and Szollos are two exceptions. In her study of flight attendants, Hochschild points to the importance of time to performing emotional labour. She writes, "when an industry speed up drastically shortens the time available for contact between flight attendants and passengers, it can become virtually impossible to deliver emotional labor" (Hochschild, 1983:121).[32] In her book *Time Bind*, Hochschild relays the experiences of one of her interviewees and alludes to a link between time and processing emotion in her study. She writes, "things [her emotional attachments] seemed strangely upside down to her – but who had time or the opportunity to sort it all out?" (Hochschild, 2000:113). This connection between time and emotion, needing time to feel, however, is not explicitly explored. Szollos (2009) also makes a connection between time and emotions. Feeling time pressured and "being rushed has a strong emotional dimension that includes anxiety, worry and frustration" (Szollos, 2009:345).

---

[32] My research raises similar questions about time and carers' abilities to manage their own and their spouses' emotions.

My contribution, however, is quite different. Szollos is showing that a person's subjective experience of time can cause them to feel specific emotions. I am arguing that being time pressured, as time-destitute carers in my study were, can cause a person to be so preoccupied with completing tasks related to their multiple roles that they have little time to unravel certain emotional responses. While they go on experiencing those emotions that occur in bursts, their temporally constrained circumstances limit the types of emotions they can experience and the extent to which they can digest, interpret and reflect on the emotions that may be simmering below the surface.

The phrase "time to feel" is used here to make that new contribution. The terms repression and denial have purposefully been avoided because they denote coping strategies of psychological origin and findings presented in chapter four suggest coping strategies are only employed by carers on a short term basis. Instead "time to feel" connotes the constraint on time posed by external and social roles, such as parenting, being a paid employee and carer. These constraints detract from a person's capacity to process their emotions. Future research in the sociology of emotions might focus on this link between time and processing emotions, not just in spouse cancer caring relationships, but also in work, friendship and the stability of relationships in general.

Determinist concepts of emotion like Collins' (2004) *Interactional Ritual Chains,* for instance, might benefit from the inclusion of time (see chapter one). Collins outlines how emotions shared with others can work to maintain a social structure. Building on Durkheim's theories of rituals as sacred celebrations of a society, and following Goffman's focus on interpersonal presentation and communication, Collins argues that emotions are both shaped by and work to perpetuate groups (Baehr, 2005; Collins, 2004). Collins (2004; Collins, 2008) explains that rituals make people feel a certain way, and the desire to maintain this positive emotion or withdraw from a negative experience is what shapes the social institution's future: continuation or abandonment. To elicit an emotional response, four "basic ingredients" are required (Baehr, 2005). First, there must be "co-presence" with two or more people together and aware that they are part of the group. Second, there must be "barriers to outsiders" (Collins, 2004; Turner & Stets, 2005:79). There must be a boundary, real or imagined, that separates insiders and outsiders, "lending participants a privileged sense of inclusiveness" (Baehr, 2005:2; Collins, 2004). Third, there must be a “mutual focus of attention” (Collins, 2004; Turner & Stets, 2005:79). Everyone must be doing the same thing. The group must focus on a shared activity or object, and individuals must be aware of others focusing on this activity or object. Fourth, participants must all feel the same mood (Baehr, 2005; Collins, 2004).

When all of these ingredients are combined, “emotional energy” results. That is, the group members feel a sense of solidarity, membership, excitement and pride (Baehr, 2005; Collins, 2008; Turner & Stets, 2005). But, emotional energy “varies with the degree that the people present become entrained in each other’s emotions and bodily rhythms, and caught up in a common focus of attention” (Collins, 2008:19). This interaction ritual process will either build a sense of validation in an individual, where the individual feels positive emotional energy in the presence of the group and its symbols, or this process will fail, and the individual will not feel valued and accepted and may withdraw from the group. If the individuals in a group do feel positive emotional energy and do feel accepted and validated, then the group will be maintained. Without positive emotional energy, people might not continue to participate in organisations and the group might weaken and crumble.

Joe’s experience exemplifies the group affirming, positive emotional energy that results from interaction ritual chains. Despite the onerous nature of his caregiving experience, he and his wife did, on occasions, have time to celebrate their marriage and love for each other. On Joe’s 60th birthday, his wife was eager to show Joe how much she appreciated him by having a party at their townhouse with their close friends. “Betsy was in a fairly advanced stage of her disease then, but she was determined to have a birthday party for me.” Joe really likes prawns so Betsy “colluded with one of her girlfriends” and placed an order with the local fish market. Betsy, however, was hemiplegic: one half of her body was paralysed as a result of the cancer metastasising to her brain. Thus, she was unable to peel prawns. Joe explained that, to overcome this setback, “Betsy bought a whole lot of tea towels which I have still…and we had clips and so these were bibs and the rule was that everyone had to peel some prawns for Betsy as well as their own (crying) so, we had a good party there.”

Joe’s story is an example of an interaction ritual. There were many guests seated at the table for the birthday dinner, aware that they were part of a group, focused on the same activity (conversing, peeling and eating prawns) and separated from others by the four walls of their townhouse. Joe’s tears in recounting this story are a testament to the potent emotional energy that resulted from this party.

The findings of my research, however, indicate that time is necessary to participate in interaction rituals. Time-destitute carers did not relay relationship experiences like Joe’s. Adding time to this theoretical approach to understanding group solidarity at a micro-sociological level could clarify why some individuals within marriages and families (small groups, but nonetheless central social institutions) grow closer and more cohesive when facing cancer while others do not. Hochschild (2000:50-1) has investigated the increasing amounts of emotion work that parents must engage in with their children as a result of decreasing and “taylorised” amounts of time, but this research suggests time-sovereignty and group solidarity as another fruitful area of investigation. If some members of the group lack time-sovereignty, then the group may have insufficient opportunities to engage in group interaction rituals. Without opportunities for sharing a mutual focus of attention or mood, the group might not experience the strengthening emotional energy so central to solidarity in Collins’ theory. Without ongoing rituals the group’s remembered emotional energy would eventually fade, further undermining their solidarity. Thus, I would argue that time is necessary to understanding interaction rituals, group solidarity and emotions. Quantitative research and further qualitative investigation into the time-bound nature of rituals could confirm this link.

For a Sociology of Cancer Caregiving

This distinction in carers’ experiences based on time-sovereignty indicates that time and emotions are intimately linked. Time-sovereign carers like Fred and Jane had to work to manage their emotions. They alternated between attending to and distracting themselves from their emotions, the two basic strategies to dealing with emotions (Maex & De Valck, 2006). Some time-sovereign carers managed their emotions by managing their time: attending TAFE (Technical and Further Education) classes and church committee meetings to distract themselves from their emotions. Intermittent distraction from one's emotions was, it seems, desirable for these carers.

Too much distraction, however, could be problematic as evidenced by the experiences of time-destitute carers presented here. As alluded to above, my findings suggest that not having time to feel and grow closer with one's spouse may result in martial breakdown. Future research might confirm this link. To my knowledge, past research has not explicitly explored the statistical relationship between low time-sovereignty and increased marital strain amongst carers of a spouse with cancer. Similar links have been made that support the probability of a statistical link. Both Fallowfield (1995) and Sherwood (2004), in their studies of cancer carers, found that carers who balance more than one role, such as work and caregiving, more often experience caregiving as problematic. Statistical analysis of all carers' needs also shows a link between reporting higher rates of unmet needs and reporting "negative effects on the [carer and care receiver] relationship" (Gibson et al., 1996:118). Said in another way, Gibson and colleagues (1996:118) indicate that low rates of unmet needs amongst carers are associated with carers feeling "closer" to the care recipient. It is shown in this chapter that those carers in categories statistically associated with unmet needs (young, female and financially insecure carers) are likely experiencing unmet need as a result of their lack of time-sovereignty. Thus, it is likely that time-destitute carers are at a higher risk of experiencing marital strain and burden.

One reason this might be so is a lack of time to engage in "interaction ritual chains." Another reason might be time-destitution leading to poor communication. Little and colleagues (1998) stress the importance of patient-carer communication about the uncertain future and emotions related to this uncertainty. If these fears and emotions are not shared they can work to block all communication between the patient and carer, damaging the relationship and leading to the development of depression in the patient (Buckman, 1996; Little et al., 2001; Ussher et al., 2006). Thus, not having time to feel or connect with a spouse experiencing cancer may be detrimental to the patient's and carer's wellbeing as well as their relationship.

For Social Welfare Research

My findings suggest another area for future research. There is reason to include emotions in temporal studies of social welfare. First, my research indicates that incorporating emotions within discretionary-time measures of social welfare might help to explain why people with limited time-sovereignty experience eroded social welfare. Emotions are central to how people understand themselves and how they interact and bond (Collins, 2008; Powell, 2008). As my study indicates, insufficient time to engage with emotions may undermine the cohesive effects of interaction ritual chains. Second, focusing on emotions within studies of time and welfare may help to identify people at higher risk of relationship breakdown and unmet psychosocial needs. Future investigations of welfare and time might yield richer findings by investigating the emotional elements of a person's deteriorating social welfare connected with having less discretionary time.

For Health and Support Professionals

In addition to the recommendation that future studies of emotions incorporate time into their conceptualisations and vice versa, there are also implications for health professionals and others assessing and addressing the needs of carers. Time-sovereignty provides them with a new yardstick. Instead of solely using a carer's age, gender and financial security to predict who is at the highest risk of unmet need amongst carers (as indicated by the dominance of these variables in the psycho-oncology literature), I propose that service-providers consider another significant variable. Assessing a carer's time-sovereignty based on the demands of their care work and the amount and intensity of their competing commitments will help service providers to more accurately judge and tailor psychosocial support recommendations. As I explain in chapter six, time-poor and time-destitute carers need practical support, while time-sovereign carers may need emotional support. As these categories are fluid, however, this means carers' situations need to be continuously reassessed. Medical and psychosocial support personnel armed with this new way of conceptualising carers' experiences and needs can personalise offers of assistance.

The demonstrated connections between time, emotional wellbeing and relationship stability also have implications for policymakers and service providers: carers, especially time-destitute carers, need help in taking a break and alleviating their time-poverty. Davies (2001), in her research with childcare workers, describes "pauses" within the workday as central to an employee's wellbeing. A source of rest and “reflection” she explains, is necessary for personal and professional growth (Davies, 2001:141). However, care work makes pausing difficult (Davies, 2001). The number of tasks that need to be accomplished and the “spatial” difficulty of leaving “those who cannot care for themselves” makes thought “digestion” and emotional introspection difficult for carers (Davies, 2001:143, 141). Thus, despite the difficulties of pausing, service providers and policies could encourage time-destitute carers to take breaks from their competing responsibilities or from their care work, for their emotional wellbeing and for the stability of their marriage. The efficacy of current policies at addressing time-destitute carers’ needs as well as a more in-depth explanation of how time shapes carers support service needs is discussed in the next chapter.

Chapter Six: Time for Support?

On a warm autumn afternoon I parked my car behind a Canberra church function room and approached a meeting room door. I had asked the support group facilitator a few weeks prior to stopping by if I could visit and talk to carers and cancer patients about my research. When I arrived the facilitator met me outside and explained that one patient was in the middle of giving his story. I walked in and quietly sat down and listened to Craig’s story. Craig had had an asbestos related cancer for over seven years. He was telling the group, made up of four (cancer patient and carer) couples, about his experience undergoing aggressive but unsuccessful chemotherapy treatment. “There is no cure” he explained. Because of this, he felt like he was waiting to die. Then his focus shifted from the present and future to the past and his life as a whole. He told the group of his travels abroad and career. He sat up a little taller in his chair, making it clear that he was proud as he told us of his life accomplishments. I was witness to Craig finding a place for cancer in his biography.

As one o’clock approached, the facilitator took over and suggested we come back to Craig’s story in the second half of the meeting after a brief recess. During the break a few people were looking at newspapers to check movie times, others used the toilets and refilled their tea. I got a cup of tea and sat quietly observing the interaction. While reflecting on my observations, something struck me as strange. I could not tell the difference between these participants. Who were the carers and who were the patients? I expected it to be obvious with patients looking noticeably frail and with scarves or bald heads as a result of post-chemotherapy hair loss. I expected patients to be expressing extreme emotions of anger and grief and I thought carers might be the one’s holding their hands. This was not the case. Further, it was clear that patients like Craig valued the support group as a helpful forum for addressing the biographical disruption of their illness, as past research suggests (Crouch & McKenzie, 2000; Davison et al., 2000; Harpham, 1994; Little et al., 1998; Ussher et al., 2006). But, what about the carers? What were carers getting out of this support group? What do they get from other support services?

Questionnaire responses show that carers (34/47) received formal support from at least one of the following: nurses, counsellors, government programs and NGOs such as Carers ACT, The Cancer Council ACT support group, Bosom Buddies, The Leukaemia Foundation House, OVCA, Look Good Feel Better, The Independent Living Centre and Meals on Wheels. Yet, little is understood about the value of support for carers of cancer patients (Harding & Higginson, 2003; Thomas & Morris, 2002).

Few studies have assessed the quality of support services for carers of cancer patients using a social lens (see chapter one). More often, support service efficacy is measured in limited and positivistic units that offer assessment in psychological terms such as burden relief (Askham, 1997; Boulton et al., 2001; Thomas & Morris, 2002). As a concept, however, burden is self-evidently limited because "it is unclear how much burden is clinically significant" and because examining burden underestimates an intervention's efficacy as it relates only to psychological stress (Sörensen et al., 2002; Thomas & Morris, 2002; Weitzner et al., 2000:273). Further, measuring burden relief does not explain what makes support services effective (Askham, 1997). Thus, it is unclear what support is helpful or unhelpful to carers and why.

A social approach to understanding carer support services is needed to understand how programs are beneficial to carers and to identify why so few carers access them. For instance, while testimonies about support groups are largely positive, and many support groups are well attended, only a fraction of cancer carers and patients participate in them and few studies have investigated why this is so (Herron, 2005). Consequently, several researchers have suggested a re-examination of support services to allow for the documentation of more experience-driven carer and "social circumstance" based assessments of support (Boulton et al., 2001; Dunn et al., 2003; Thomas & Morris, 2002:181). For example, Askham (1997:4) calls for a more encompassing understanding of what carer's find supportive so that there can be a "conceptual refinement and redefinition" of carer support.

This research responds to that call. The findings presented in this chapter indicate that support services address carers' problems to do with emotion management, confusion and time poverty. I suggest that many carers of a spouse with cancer experience complex emotion management difficulties specific to the uncertain nature of the disease. To resolve the guilt and confusion that results from contradictory feeling roles, many carers speak to friends and family, seek counselling or join support groups. As explained in chapter five, time is a central factor in shaping carers' experiences. Time-sovereignty also shapes carers' support service preferences. Those who had time to feel accessed emotion-focused support such as counselling and support groups, and most assessed these services as helpful in addressing emotion management problems. Those who were time-poor or time-destitute primarily sought practical support, such as Centrelink or respite services. However, carers generally thought these services poorly addressed their time deficits.

Carers' Experiences of Emotion Work

Thomas et al.'s (2002) study of carers of cancer patients experiences is one of the first and few studies to use the sociology of emotions in studying cancer carers. They find that caring involves emotion work: shaping one's emotions to adhere to the feelings expected of carers. Adjusting to the informal carer role and expected "feeling rules" can be difficult (Fallowfield, 1995; Thomas et al., 2002). My research furthers Thomas et al.'s contribution by exploring the nature of the emotion work involved in caring for a spouse with cancer.

As a carer, emotion work starts with re-prioritisation and "readjustment" (*Blake*). With the diagnosis and onset of treatment, carers concentrated solely on the patient's wellbeing; their own emotions became less important. In Phyllis's words, "you [become] focused on looking after the person, making sure all their needs are met" and thus there is little room for one's own priorities. Put another way, the patient becomes the "prime focus" (*Fred*) and "you come last" (*Marian*). Past research provides corroboration. Carers tend to prioritise their own needs as second to patients' needs, if they recognise their needs at all (Boulton et al., 2001; Morris & Thomas, 2002; Thomas et al., 2002). Spouse carers, in particular, are the least likely to be concerned with their own health needs (Jansma et al., 2005).

Carers suppressed their emotions and needs. This involved being "the strong one" or the "rock of Gibraltar" for the patient and concealing feelings of disappointment or upset (*Jane*; *Sally*; *Fred*; *Anne*; *Colleen*). Sharon, for instance, worked hard to avoid becoming a "crying, bawling heap." Linda put on an "award-winning act" of hopefulness for her husband when she had to deliver bad news to him in the hospital. Male carers especially saw their own emotions as unimportant and even unhelpful. Patrick said, “Your partner is in a life threatening situation and you going to pieces ain’t going to help.” Carl said that even though his wife wished he was more emotional, he refuses because being emotional would hamper his ability to care. Like Thomas et al.’s (2002) study, this research found that both female and male carers concealed their own emotions for what they saw as their spouse’s benefit.

But this ongoing emotion management and maintenance of a brave face was also very tiring, because “you are not allowed to be weak” (*Sally*). Helping the patient to manage their emotions meant that the carer also had to manage their own emotions. Carers, however, received very little emotional support and had few outlets when the focus of their emotion management was their spouse, the very person they would normally turn to for support.

Thus, the emotion-work part of caring was said to be “demanding” (Thomas & Morris, 2002:180) and “the greater challenge” (*Rodney*) in caregiving. People found it tiring and confusing for two reasons: the uncertain border between carer and spouse; and the ambiguous nature of the patient’s future. On the first count, carers talked about the precarious balance or “fine line” (*Judy*) of the new caring roles after diagnosis within their marriages. Although they had entered into new roles of carer and patient after the diagnosis, they were still a married couple. During times of intense caregiving the required balance was clear. The patient was very sick and needed care, so the carer’s needs were a distant second priority. But, if the patient’s health improved and months or years devoted to caring were extended, the distinction between patient and spouse became less clear, and the imbalance between being a carer and spouse became more tiring and fraught with guilt. When the illness trajectory was uncertain, carers were not sure when their role ended. They wondered, “will it ever end?...Will our relationship ever be the same again?” (*Fiona*). They felt they could not suspend their own emotional needs indefinitely, but in turn felt selfish for wanting to give their own emotions and their own lives precedence. Millicent and Linda’s stories typify this experience.

Millicent’s emotion management involved an inward struggle typical of many carers. After caregiving for her husband with a haematological cancer intermittently for over 16 years, Millicent grew “resentful” and “sick of having to do everything.” She grew tired of rising repeatedly in the night to help her husband to the toilet and tired of him being home during the day requesting help. But, she said, “It is difficult to know how to handle it.” She sometimes lashed out at him when they disagreed, but then felt immediate guilt and remorse. Overall, her response was to withdraw. She said it was easier to approach caring like an emotionally detached nurse because this allowed her to shield her emotions and “stay in control.” But, she felt guilty about playing the nurse role instead of the wife role and sought reassurance asking me, “I don’t know if that happens with everyone or whether it is just me. Have you found this in your talks with people?” Later on in the interview she assessed her emotion management approach as inappropriate, saying, “I think I am really handling it the wrong way.” She thought she should ask a counsellor or social worker “how should I be doing this [managing my emotions] as a good wife?” Millicent’s requests for advice illustrate the emotional uncertainty and guilt that carers often feel, and show why many seek psychosocial support.

Linda’s story also illustrates the hazy boundary between being a spouse and carer and the corresponding complexity of emotion management. Although her husband was diagnosed as having a terminal cancer, he underwent radical surgery and has now improved so much that he is working again, though only six hours a week (see chapter three). When he was initially diagnosed as terminally ill, her emotion management priorities were obvious. But, as her husband’s wellbeing improved, her emotion management priorities have become unclear, particularly about how to respond when, in her words, he is “horrible” to her. Now that he is in remission, he is on a three monthly scan cycle to check for a recurrence. The scans cause him severe anxiety and to temporarily “lash-out” at her. Linda is angry and confused about how to respond. Because the role of marital partner and carer have such unclear boundaries, Linda feels so much guilt and bewilderment that she plans to seek advice from a marriage counsellor.

As time went on and patients became well enough to exhibit irritating idiosyncrasies and express criticisms (such as being “demanding and pushy” [*Frank*]), carers became angry and exasperated. But these spouse-appropriate feelings of resentment and anger were often followed by remorse for not maintaining carer-appropriate feelings of tolerance. Crucially, carer and spouse “feeling rules” are at odds (Hochschild, 1979:551). As Linda explained, it would be acceptable for her, as a wife, to feel anger towards her husband, but if a carer were to feel and act the same way, it would be construed as "bullying." Conversely, if a patient was angry or cruel to a carer, the carer would be expected to see these insults as the result of the patient's frustration and refrain from feeling upset. However, if a spouse were to hold back from responding to an insult, they would be viewed as a "doormat." Herein lies the emotion management difficulty and self-prioritisation complication: the ambiguity of the carer role parameters. Does patient-hood and thus carer-hood end? When is it appropriate for the carer to reprioritise their own wellbeing without neglecting the patient? To overcome this emotional uncertainty, many carers sought informal psychosocial support or formal support in the form of counselling and support groups.

Informal Support

All carers in this study sought the support of friends and family. In addition to traditional practical support, including chores, respite and medical advice, many carers reported seeking out conversations with friends or family to distract themselves from their emotions or to help them overcome their emotional confusion.

Sometimes, family and friends who lived close by took on some chores and responsibilities such as ironing, childcare, yard work and farm work. Neighbours, church friends and family often cooked for the carer and patient. One friend even replaced the patient's bedside flowers regularly. Doing these tasks allowed the carer more time to care or perhaps some time to be alone.

Periodically spending time with the patient was another way local friends and family helped the carer. It allowed the carer some respite from ongoing emotion management and assured the carer that a backup existed if required. Bernard's adult son, for example, would stop by in the afternoons to check on his mother. This helped Bernard to feel less anxious about his wife's health while he was at work. Conversely, losing a source of respite could be detrimental to a carer's psychological health. Andrew's son moved to another part of the country, provoking a surge in Andrew's anxiety until his sister-in-law came to visit. Overall, family and friends who were able to provide auxiliary caregiving reduced carers' anxiety and the burden of care. This finding was also made by Braithwaite in her study of carers of older people with dementia. Being a carer with no one else to rely on for help in caregiving was statistically related to having "poor mental health" (Braithwaite, 1990:113).

Carers also sought contact with friends and family to provide a diversion from their experience of the emotional burden of caring. Visits during periods of high anxiety in particular provided welcome distractions and companionship. For instance, Millicent said her daughters' company during her husband's final days helped the time to go by much faster. A dinner out with Andrew's sister-in-law helped him to temporarily forget his anxiety about his wife's surgery. Visits from friends and family provided welcome interruptions from loneliness and worried preoccupation.

Telephone conversations with friends and family, in particular, provided carers with a chance to voice emotions and concerns. This was especially appreciated by those carers who could not vent to their spouse because they were the patient. Judy, for example, did not want to upset her husband who was suffering from panic attacks, so she called her sisters when she wanted to have a cry.

Carers with friends or family in the medical system asked for medical advice from them regarding the best surgeon, best oncologist or treatment options. Carers sought out friends and family with cancer or counselling experience for help in interpreting and shaping their emotions and in maintaining the energy necessary to provide ongoing emotional support.

Patrick, whose wife had breast cancer, spoke with friends whose wives had breast cancer to gauge what to expect from the disease and how best to manage his own and his wife's emotions. He talked to workmates whose wives had cancer about "where they are at," which allowed him to compare and project his wife's illness trajectory. He talked with other husbands at breast cancer related functions and learned how they were dealing with their new awareness of mortality, allowing him to measure the normalcy and appropriateness of his own approach.

Fiona sought out her daughter's help in quieting her frustration, understanding her husband's feelings and rallying the energy to provide him with ongoing positive support. Her husband Mark had prostate cancer surgery that resulted in ongoing incontinence for 18 months. The incontinence left him very depressed, possibly even suicidal. Fiona saw her main role as emotionally "propping up" or "bringing up” her husband. When he was so “low” that it got her “down,” frustrated and ready to “switch off” she would call her daughter, who has a counselling diploma. She said their other two children were “supportive and very sympathetic” but she needed her daughter to “pull [her] a bit further than that,” to help her to see her husband’s side and give her emotional support so that she could continue to manage her own and subsequently, her husband’s emotions.

On the whole, support from friends and family reduced carers’ task, time and caring burdens. Informal emotional support, both in person and over the phone or internet, provided carers with a welcome distraction. Several carers talked with experienced family and friends about how to approach the future and how to provide ongoing emotion work.

However, as past research indicates (see chapter one) informal support was not an option for all carers, nor was it easy to access for others. Due to Canberra’s unique history as a planned capital city, many families move here for work, so few have their extended families on hand for support. Another consequence of being in Canberra is that several older carers said they did not have close friends in Canberra because this is not where they lived and worked in their twenties, the years they saw as fundamental to forming life-long friendships.

Gender was also a factor in how much informal support was on offer. Carers cited receiving informal support from females (75%) more often than males (33%). Female friends and family were generally assessed as more open to providing emotional support. This indicates that carers with few female friends may have fewer opportunities for informal support. Thus, informal support was not equally available to carers.

Even for those with friends and family nearby, accessing informal support was challenging. Friends feeling uncomfortable was one commonly expressed difficulty in accessing informal support. When I asked Leo if he gets emotional support from anyone he replied, “Not really…[I] have a few friends, but it is not the sort of thing that you can exactly access.” Many carers talked about having awkward conversations about cancer with friends and family. Not only was it difficult for friends to bring up the topic, but many were afraid of intruding. To overcome these hesitations, Mary took it upon herself to bring up cancer in conversations and encourage friends to “front up” to it. Both Mary and Marian said they learned that, as carers, they needed to ask for specific help from friends instead of waiting for friends to offer. Often friends want to help, they explained, but “people don’t know what to do, so if you ask them, you are doing them a favour and you are doing you a favour” (*Marian*). These carers also thought that asking for help relieved friends’ concerns about intruding.

Another problem in getting informal support was that some friends disappeared “off the map” after hearing of the diagnosis (*Charlie*). One carer thought this might have happened because those friends were uneducated and thought cancer was contagious. Other carers thought the reason was connected to people’s lack of assuredness in how to act around someone facing their own or their spouse’s mortality. Ian, for instance, said his friends did not ring him right away because they were “embarrassed.” Cindy’s friend just “can’t cope” and told Cindy to call her when she was better. Phyllis noted that “some friends just didn’t know how to deal with it…they don’t know what to say.”[33] For those carers with friends nearby, overcoming awkwardness, a lack of accepted scripts and the difficulty in organising help made accessing informal support burdensome.

One of the features of a cancer diagnosis is that it confronts people with death. Elias’s account of dying in the modern period is useful in explaining why cancer provokes such discomfort. Death, he explains, is regarded differently in the late twentieth century because life is more secure and expected than in centuries past. Today, citizens of industrialised countries do not often think about death because life-threatening events are less prevalent (Elias, 1985). Further, death is less often witnessed. “We no longer regard it as Sunday entertainment to see people hanged, quartered [or] broken on the wheel” (Elias, 1985:2). Nor do many westerners witness or manage the deaths of family. Instead, the aged and the dying are frequently institutionalised in hospitals, hospices, nursing homes and retirement communities. Thus, there are fewer opportunities to observe and model appropriate behaviour around the dying, which leaves many people feeling unsure of what to say or how to act around cancer patients and their carers.

---

[33] Perhaps future research could study the effectiveness of an advertising campaign to improve friends’ awareness of carers’ need for informal support, devoid of pity.

Help from family presented different obstacles. Although carers said help from family was more readily available than help from friends, family members often imposed on the carer for accommodation and hospitality. This added to the burden of caring rather than providing relief. Some family, especially in-laws, were described as "a nightmare" and a source of stress for the carer (*Phyllis*). Anne, for example, got so angry "I almost threw his mother up against a wall" when her mother-in-law stayed at their house for weeks to provide emotional support to the patient, but did not help with childcare, cooking or cleaning. Kyle too said that visits from family members were an imposition that created more cleaning, laundry, dishwashing and stress in his already time-intensive schedule.

Many carers reported practical and emotional informal support as essential to their ability to care. Others had either very little informal support available, or found accessing informal support onerous. Many carers who found informal support too difficult or insufficient at meeting their needs for emotional support sought the services of counsellors or support groups. The next section explores the experiences of those who sought out counselling.

Counselling

Past research (see chapter one) on counselling is ambivalent about its role. Some studies show counselling helps cancer patients to reduce their stress levels, but others have critiqued it as a source of conformity instead of adaptation and as too expensive and time-consuming. This study suggests that counselling has similar values and limitations for carers of spouses with cancer.

A third of the carers (half males and half females) in this study accessed counselling from various sources: Carers ACT, ACT Health, employee assistance counsellors, and the Canberra Hospital Psychologist. Those who did not access counselling cited several reasons. Some did not know counselling was available. Information on counselling was not made available to carers. Anne, for example, only found out about Carers ACT counselling by chance from a co-worker. Bernard did not find out that counselling was available until after he developed an anxiety related condition. Some, especially male carers, saw a stigma attached to seeking counselling. As Mary said of her husband, "women just think it's the normal thing to do. Guys just [think]: why on earth would you want to do that?"

The most frequently cited reason for not accessing formal psychological support, however, was because the patient and carer had enough informal support and did not feel like they needed it. These carers often said that just knowing the services were there if they needed them in the future was enough for the time being.

Carers who did seek counselling were having trouble managing their emotions or were unsure if they were managing them in the best way. From counsellors, they learned alternative emotion work strategies. The strategies counsellors recommended covered a vast range. Some were reassured that their emotions and emotion management techniques were “normal” and appropriate (*Rodney*). Others were warned that they needed to focus more on their own emotions. Bernard, for instance, was told to take time out for himself to ease the intensity of his emotions: “get out…go for walks…do something different.” He was also given information on “things you have got to watch out for” to keep from becoming depressed, clinically anxious or getting sick with a stress related illness. Some carers were taught meditation techniques during therapy, or were prescribed medication to alleviate anxiety and depression. A few were encouraged to change their orientation to the future (see chapter four). For example, Blake had started to drink more as a way of managing his depression. His psychologist said he was focusing too much on the future loss of his wife which was creating his “vicious cycle” of depression. To help him continue to provide care, his therapist recommended he look positively on the time they still had together in the present instead of anticipating his wife’s death. Overall, therapy provided carers initially with an emotion management assessment and consultation. Counsellors who considered carers’ coping strategies to be inadequate or inappropriate, supplied alternative techniques or approaches.

Counselling also improved role clarity. A few carers said counselling forced them to focus on themselves, their role and their emotions which helped them to clarify their feelings. Often carers’ feelings were complex and they were unsure of either what they were feeling or why they were feeling a certain way. Sally, for instance, recognised that she felt extreme anger towards her husband for smoking during his treatments, despite the specialist urging him to quit. She did not, however, understand why she was experiencing such intense emotion and perceived it as irrational. Counselling could help carers to sort through, label and connect these emotions to their carer roles and wider biography.

Carers also described counselling as a much needed rest, especially for those supplying intense emotion management to their spouse. For carers whose family was the source of their grief, stress or anger, counselling provided a safe environment to talk honestly about their feelings. Phyllis found that talking to a Carers ACT counsellor, who would not judge her, permitted her to stop acting for awhile (see chapter three). Talking to an outsider about emotions also gave their friends a break from the burden of listening.

Although many carers had helpful counselling experiences, some were not so positive about their experiences. A few carers felt they did not get any benefits from counselling. Joe said all he got out of it was a listener. He talked, the counsellor listened and that was it. Kyle was offended by his interaction with a psychologist. He was feeling extremely angry about the prognosis, his wife's pain and all of the frustrations he was experiencing in dealing with bureaucracies. He did not want to conform to expected emotions, so he found the counsellor's discussion on "this curve of emotion" to be lacking empathy and inappropriate.

Interviews

Some carers told me they felt they got similar benefits from my interviews as from counselling. Nine carers experienced the interview as a valuable occasion for organising their thoughts (Grbich et al. (2001) made a similar discovery), understanding their role and recognising how rich they were in informal support. This suggests the value of talking about emotions in a structured way, and also indicates that these conversations may not need to take place in therapy to give carers emotional relief.

Although it was not foreseen that these brief interviews would affect participants, during the first interview, several carers made positive remarks about the experience. Some said it made them feel good about themselves because it was an opportunity to help future cancer carers. Others made comments about the "cathartic" quality of being interviewed (*Leo*). A question about the impact of the interview experience was therefore included in all follow-up interviews to explore this line of discussion.

The responses provided some insight into the value of structured conversations. A few carers said that the interview was a rare opportunity to talk about their personal experiences instead of the patient's. This concentrated focus on *their* wellbeing had the effect of endorsing their feelings and distress. Carers said the interview provided them with an unusual chance to "reflect" and "articulate" their carer experience in a "very structured way" (*Linda*). The exchange allowed them to organise or give a "framework" to the nebulous thoughts and emotions that were "going on inside [their] mind" (*Linda*). They enjoyed the improved clarity in how they perceived their role. For Kyle - a self proclaimed recluse - talking about his experiences and emotions even had the effect of making the whole experience less sensitive. As he explained, discussing emotions "might ting a few nerves," but feelings should be talked about because "otherwise you are forever ticklish."

The discussions also shed light on the gender divide in how often emotions are discussed informally. Both men and women said the interview process was positive. More males than females, however, indicated that the interview provided them with a rare opportunity to discuss emotions. Leo, for example, said "you are the first person I have actually talked to specifically about this." Blake said, "I liked that…I don't really talk much." Rodney said it was "good to actually articulate" his feelings to someone, because he could not bring it up at the dinner table. It seems that for many men, such conversations are taboo among male friends and may be only acceptable with a professional or unknown academic researcher.

Support Groups

Past research suggests that support groups are an effective means of sharing information on the diagnosis of cancer and its impact on emotions. For patients, as Craig's experience relayed at the beginning of this chapter shows, support groups have been found to be a fertile environment for cancer patients to re-shape their life story to accommodate the interruption of the diagnosis. Few studies have investigated how carers, in particular, perceive and experience support groups. Specifically, few have investigated why so few carers attend them.

In the questionnaire component of this study, carers relayed positive impressions of support groups. Approximately 40 percent took part in support groups. Many said the value of support groups was in helping them feel less alone. They preferred support from other cancer carers because their shared experiences meant they knew what to say and do, avoiding the awkwardness so often experienced with others. Even respondents who had not accessed support services wrote that their value was in knowing they were there if needed in the future, providing an emotional safety net.

A third of the carers interviewed in this study reported going to support groups[34] including: the Cancer Council ACT Thursday afternoon support group for patients and carers, the Prostate Cancer support group, the Brain Tumour Australia support group, a support group for people affected by asbestos related diseases and their family, a breast cancer patient and carer support group, a support group arranged by psychosocial services at the Canberra hospital, a Carers ACT support group and a bereavement support group. Most of those interviewees who attended were women. The benefits from support groups were similar to those carers reported getting from counselling. Support groups were described as a place for carers to express their emotions honestly, learn about controlling emotions and more clearly understand their feelings. The differences reported between counselling and support groups was that carers could laugh, give back, observe how other couples manage, exchange practical information and make friends with other cancer carers.

Carers described support groups as a “very safe” place for emotional honesty. In support groups carers could take a break from their ongoing emotion management, talk about their feelings, cry or laugh. As Jane said of a support group for both carers and patients, “for two hours it was somebody else caring for him.” It also meant that other family members had respite from hearing about her feelings. An important element about this emotion-sharing was that it was devoid of pity, which carers said was essential. Carers often received pity from friends and family who had not experienced cancer or caring for a cancer patient. (Some even perceived it to be anger inspiring and condescending.) Support group discussions, however, did not evoke this response. As Sharon explained, “there is something about being able to talk with other people who have been there [and] done that, because you can talk about it [and it] doesn’t sound like you are trying

---

[34] Proportionally to the number of carers, only a small percentage use support groups. For this study, purposive sampling was used to ensure a balanced proportion of support service users and non-users were represented. This explains the unusually high representation of support group users in this study.

to go ‘oh, poor me.’” Carers found the pity-free and honest emotional interaction they received in support groups to be uplifting.

Unlike counselling, however, support groups were an opportunity to laugh. Carers found a balance between joy and sorrow in support groups. More experienced carers saw them as the opportunity to give back to the group and to help those who were new to cancer caring. Support groups were also a place where carers could debate the most appropriate approach to the future, often concluding that staying positive but realistic was best (see chapter four).

Learning practical information was another unique benefit of support groups. Carers learned about other support services and financial aid programs and how to access them. Other carers explained how to do practical tasks more easily, such as cutting pills with a pill cutter. Many learned about the likely illness trajectory. Especially when prognostic information from medical staff was hazy, carers appreciated the opportunity to prepare themselves for what to expect. Carers found support groups to be an empowering opportunity to compare notes on treatment, helping them to learn more about side effects and treatment alternatives that they might then discuss with their doctor.

Support groups also provided a place for carers to network. These monthly or fortnightly meetings provided a safe place for carers to know that they were not alone. Interactions in support groups often led to valuable informal friendships between carers outside of group meeting times. They provided an opportunity for carers going through similar experiences and emotions to speak honestly and enlarge carers’ emotional support options.

Generally, whether it is formally through a support group or informally through friends who met at the Leukaemia Foundation House or outside of support groups, talking about one’s experiences with others in a similar position provided a means of organising one’s thoughts, better understanding the carer role, seeing how others manage, receiving advice and clarifying cancer caring feeling rules.

Why do you Not Attend Support Groups?

The two-thirds of the carers in the study who did not go to support groups said they declined participation because of limits on their time or because they did not need support. Matthew’s wife, for instance, could not attend a support group for breast cancer patients because she worked at night and looked after their toddler-aged daughter during the day. Another carer said he did not have the time because of the intensity of his caring role. A few others said they could not go to the support group anymore because of full-time work commitments. Others said just knowing that support groups were there was enough for them at the moment. They had enough informal support from friends and family and did not feel any desire to talk about their situation or emotions with new people.

A further reason given for not attending support groups was not being told where to get this support or being advised against it. One carer said she would have liked to have gone to support groups but did not know about them. Another carer’s doctor told him about support groups, but recommended he avoid them.

Others went to one support group meeting, but declined further participation because of a lack of commonality with other participants. Phyllis attended a carers’ support group and did not return because she found she had little in common with carers of disabled children.

> They’d been looking after these young adults or kids for years and years and years…but they weren’t likely to die. And so it was different….In a way it was hard to relate to them because the issues and problems were totally different so I didn’t really find that helpful at all.

Blake’s wife had a similar experience. As a breast cancer patient, she joined a support group, but went only once because she felt that, as an Asian immigrant, she had little in common with the predominantly European Australian participants.

For some, support groups were not their preferred mode of support. A few carers, both male and female, said they preferred support that provided a distraction from thoughts on cancer instead of focusing on the cancer. They would favour networking opportunities like lunch groups. Male carers in particular said they would not go to support groups because they were not comfortable with the style of emotional support, specifically because they perceived them to be too emotional and feminine. Tyler, for example, said he thought support groups were too emotionally expressive and would undermine his resolve to be strong for his wife. Kyle thought support groups were too comforting and involved “pillows” and “daisy-chains,” whereas he was angry and wanted to “scream and shout.” Charlie called it “emotional gushy bloody rubbish.”

Two male carers tried going to a support group, but did not like what they experienced as excessive expressions of distress. Carl would not return because in a support group (set up by the Canberra hospital psychosocial services) one woman cried throughout the entire forum. For a man of (in his self-assessment) few emotions, this ongoing and uncontrolled expression of grief made him feel uncomfortable. Fred also found it “very trying” when he went to a support group facilitated by the Cancer Council and someone cried a lot. But he kept going and found that support groups actually provided a chance for him to laugh about the cancer at other times.

Like Fred, others initially thought they would be too emotional, but found this not to be the case after attending a few. Linda’s husband, for instance, perceived them to be a place where “everyone sat around with a tissue…[and got their] violins out.” After going to one, he changed his opinion.

> He came to one and I had to drag him away. It was well and truly finished…and he was still talking to people….He got so much out of it…because it was him actually realising too that you didn’t have to go because you needed a crutch, you went because you could help other people. And from that point he started to see himself as some who had a story to share to help others, not to have them feel sorry for him.…That’s what he didn’t want and that’s what I think he thought he was going to get but it wasn’t that at all.

Despite perceptions of support groups as full of tears and shared pity, this was not the experience of those who attended them regularly.

This largely gendered stigmatisation of support groups (and counselling), supported by past research (Druhan-McGinn & White, 2004; Shaw, 1997), paints a lonely depiction of male carers’ stoic masculinity. It seems most female carers feel comfortable seeking both informal and formal support to address their emotion management difficulties. Males, on the other hand, are less likely to access either informal or formal support. They are more likely to only have one confidant: their wife (Allen et al., 1999; Pruchno & Resch, 1989). When she can no longer perform the function when she becomes ill, the male carer is left with no one to talk with informally or formally. Questionnaire data reveals the extent of this phenomenon.

When asked “Who do you talk to about the emotional aspects of being a carer?” most females ticked boxes indicating that they have at least one (33%) or more than two (54%) people in whom they confide. Responses from men were far more evenly distributed: 39 percent indicated that they do not talk about their emotions, 17 percent specified one person and 39 percent pointed to having two or more people in whom they confide (the remaining 5% neglected to complete this section). Overall, carers most often reported talking about emotions to their family (43% of males and 46% of females), their friends (35% of males and 58% of females), and healthcare professionals (30% of males and 42% of females). Additionally, 13 percent of males and 38 percent of females reported talking about their emotions with a support group, 13 percent of females talked about their emotions with friends on the internet, one female spoke to a religious leader and one male and one female reported using the cancer council’s telephone support line to talk about their emotions. Three times as many males (39% of males and 13% of females) indicated that they do not talk about their emotions. Few females (17%), but a relatively high percentage of males (39%) indicated that they talk to the patient about the emotional side of caring. Considering the high proportion (72%) of questionnaire respondents caring for a spouse, this data exposes a problem, particularly regarding male carers. Because few cancer carers feel they can talk to their spouse about their emotions and males are more likely to confide solely in their spouse this suggests that there are many male carers of a spouse with cancer with no one to talk to about their emotions and anxieties.

Practical Support

Carers with little time to feel (see chapter five) preferred practical support in the form of respite or financial aid, but very little is known about the value and experiences of practical support for cancer carers. Policy was amended to provide support to carers in the form of respite and financial aid, but there has been little follow through. The practical support is merely *assumed* to be helpful (see chapter one). Here, I investigate that assumption by examining cancer carers’ experiences with practical support programs and exploring their efficacy.

Respite

Only two carers in this study accessed respite care. They were the carers with, arguably, the most physically demanding and time-intensive caring roles of all carers interviewed. Joe arranged with palliative care to have a volunteer come for two hours once a week. Although intended as a break, Joe used the two hours to run errands and buy groceries, as pushing a cart and his wife's wheelchair made shopping tricky.

Phyllis received four hours of respite from the hospice and two hours from Carers ACT on a weekly basis. As Phyllis's husband's neurological cancer altered his personality and mental capacity, Phyllis "desperately needed" the respite care. She was caring for him 24 hours a day and felt trapped at home because she was not receiving intellectual stimulation from her relationship with her husband. Like Joe, she spent most of her six hours running errands, going to the gym and only occasionally meeting with friends for a break. For two weeks, Phyllis's husband was put in a dementia unit, but she had to "fight" to get this respite. These accounts indicate that respite services, although accessed by those who need it, do not provide a long enough break to meet time-poor carers' needs for rest and personal reflection.

Financial Aid

For many couples, especially younger working couples, money and time were seen as two essential resources that are at odds with each other. Earning money took much needed time away from caring and managing other roles. Spending time with the patient took time away from paid work and hence reduced income that was more important than ever as a result of the loss of one earner and large medical bills. Supporting this qualitative finding, Braithwaite (1990) has also found that a lack of material resources is statistically linked with higher rates of psychiatric morbidity amongst informal carers of the elderly with dementia. Financial aid in the form of Centrelink payments and IPTAAS are programs currently in place to address this time-money tug-of-war (see chapter one).

The accounts below attest that these financial options are not widely known, readily accessible nor adequate. As one carer summed it up, cancer carers who are "at the weakest point of their lives are unable to deal with the financial side of things because they don't have the energy, they don't have the knowledge and they feel the system is against them" (*Linda*).

Centrelink

Although many time-destitute and lower SES (socioeconomic status) carers in this study were in financial need, few accessed the financial aid available to carers through Centrelink. Many carers had not heard of the carers' payment or carers' allowance. A few were told by social workers, but the rest either did not know or had researched the information on their own initiative. Of those who knew of the financial support available, many were dissuaded by the onerous application process and insignificant amounts of money (see chapter one). They found the process to be too stressful, too laborious, not cancer specific and contrary to some couple's emotion management approach. Some felt the structure of access to financial support seems designed to deter applicants as much as possible.

Those who found out about the carers payment and thought about applying were further deterred by the stressfulness of working with Centrelink. While caring, a person is "too emotionally and psychologically and mentally challenged to have to deal with the pressure of big financial decisions" (*Linda*). Dealing with Centrelink was just too much. Not only was dealing with the system difficult when they had so little time, but carers also felt they were treated with suspicion by these "big systems," as if they were trying to cheat Centrelink (*Kyle*). They concluded that it was better to avoid the stress of having to justify oneself to Centrelink. Carlie, for instance, said dealing with Centrelink left her "frazzled." After working all day and caring for her husband in the evenings, she had already had "enough mental, emotional things now without fighting Centrelink."

Anne's experience further illustrates the stressfulness of the process. She said they "wouldn't do anything." Anne is the mother of a toddler, carer for a husband with a very uncertain future and the breadwinner, working 6 days a week while her husband went through surgery and initial treatment. She was distraught and short of both time and money. She went to Centrelink for the first time in her life (as was the case for four fifths of the carers in this study) to access the Family Tax Benefit so that she could work fewer hours per week and spend more time caring for her husband and their daughter. But, because Centrelink wanted more people to receive the family tax benefit as a lump sum instead of weekly payments, they said she could only receive the support at the end of the financial year, 11 months from when she needed it. They did offer her more subsidised childcare, but this was not what she needed. She wanted to spend more time with her husband and daughter, not more time at work. Because they were unwilling to help her within the required timeframe, she was forced to work weekends, exacerbating her time poverty and stress. When I asked if she had considered applying for the carers payment she said she would not. Getting help with the application process took too long and was too "frustrating." She said, "I sat there for an hour and a half, just to get in to see someone and for them to turn around and say no." Her evaluation was that they would not do anything.

Anne also felt stigmatised and like a beggar after asking for financial aid. She said:

> I am not a [dole bludger], I have always been a workaholic…so to turn around and say to someone give me money or to go to Centrelink and ask for family tax benefit and then they say no, I felt…really bad, like I was begging for money. And then to be denied it in circumstances like this I felt even worse. I felt really cheap.

In addition to stress and stigma, Anne's story shows dealing with Centrelink imposed its own time demands. The forms were extremely long and many transactions had to occur in person. The forms were described as "appalling" (*Marian*) and "hard work" (*Millicent*). "Page after page after page you have got to fill out" (*Marian*). Linda described Centrelink's application approach as follows: "we are going to make it so hard for you to get this, at this probably worst time of your life, we are going to make you jump through all these hoops." Kyle echoed her assessment, saying "the thing I found really frustrating with Centrelink was the amount of repetition filling in forms, and I am sure they do it just to piss people off so they give up." This sentiment was also expressed by carers in others studies (Dow et al., 2004). The application's length and degree of detail, including listing all gifts received, was a deterrent for many carers, especially those who were already time-poor or time-destitute. Many who needed the financial assistance or could have experienced less financial strain as a result of receiving it did not apply or put off filling out and submitting the Centrelink forms. Carlie, a carer on a low income indicated the paperwork's exaggerated 15 cm thickness with her hands and said, "I looked at the papers…and I said no, no way! No, I couldn't be bothered." The amounts, $546.80AUD a fortnight for the asset/income-tested carer payment and up to $100.60AUD a fortnight for the carer allowance,[35] were insufficient to entice even some low income earners to wrestle with the daunting paperwork (Centrelink, 2008).

Another deterrent was the requirement that carers submit paperwork in person, "no matter how sick" the patient was (*Millicent*). For Joe, who was caring for a hemiplegic wife in a wheelchair this was no easy feat. He said,

> After filling [the forms] out…they wouldn't accept that they could just be posted in you had to take them in, in person….I couldn't just leave her here and go down there so I had to get Betsy out of bed, dress her, into the wheelchair, out to the car, into the car, put the wheelchair away, go down to Centrelink, get the wheelchair out, get Betsy in, go there. And then stand in a queue at Centrelink.

The forms also had apparently only limited applicability to cancer carers. They were geared more towards long term caring for a person with a mental or physical disability. Carlie said, because her husband "didn't have one leg and could walk," she was not sure that they would qualify and so she thought applying was a waste of time. Marian said, "It didn't fit me or our situation." She continued, saying cancer carers need support because it is more than a full-time commitment for most carers. "There is no way I could have done what I did and worked at the same time…but the form…assumed that if you [the patient] were okay physically…there was no need for the carer to do anything for them." Instead of recognising the limitations on cancer carers' employment and the multitude of tasks as well as emotional support carers perform, the forms focus on determining the extent of the care recipient's physical mobility limitations. Centrelink imposed a biomedical view of physical assistance which ignored carers' time and emotional commitments. The system seemed to assume that if that patient was mobile, the carer was doing nothing and thus deserved no compensation.

An additional deterrent for many carers was the "confronting" nature of Centrelink questions, in person and on the application (*Matt*). To receive financial aid, if the patient does not meet the physical limitation requirements, the carer and patient must emphasise that the patient has a terminal illness and hence a limited future. Following this path is "negating that positive approach" that some carers, like Marian, followed. She followed complementary and alternative medicine

---

[35] As Hughes (2007) points out, these amounts are significantly below minimum wage.

recommendations of believing that they could slow the cancer's spread by doing everything possible and truly believing that the patient would live (see chapter four). "Part of our mindset," she explained, "was: the only way we could beat this was by believing we could. So, getting a doctor to say we have only got three months was sort of negating that approach. So you can't have the both [optimism and Centrelink support]." This optimistic approach is the direct opposite to the approach bureaucratically imposed to qualify for support from Centrelink.

This method of distributing financial support meant that carers had to see their partner as terminal and get medical professionals to see them as terminal, which many doctors are reportedly unwilling to do. Millicent, for example, got a nurse instead of a doctor to fill out forms for a disabled parking sticker and carers' payment, because she was advised by nurses that doctors try to keep the patient positive and thus do not phrase the paperwork appropriately. So not only does this method of financial aid allocation negate some carers' emotional approaches to the future and only means of control over the situation, but it also contrary to many doctors' preferred way of communicating the patient's prognosis.

IPTAAS

IPTAAS (isolated patients travel and accommodation assistance scheme) is another program designed to provide financial assistance to patients and carers in remote and regional areas. Carers and patients who have to travel a minimum of 200 kilometres in New South Wales (NSW) (there is no minimum number of kilometres in the ACT) to access hospital services can apply for a per-kilometre fuel stipend and accommodation compensation (Parliament of Australia Senate, 2005). Of the six carers in this study who travelled for treatment or surgery, three of them accessed IPTAAS. But, like witnesses at a Senate inquiry into cancer care (Parliament of Australia Senate, 2005), these carers found IPTAAS to be a "farce" (*Tyler*), "onerous" (Millicent) and more bureaucracy than help. Millicent explained that,

> They make it so hard that people go, what is the use?...Each time we go just to see a doctor for a consultation in Canberra, you have got to fill in four pages of forms. You have to get the specialist himself to sign it – every time. And you feel badly when they have to do that because they are busy.

Tyler lived on the coast with his wife who required frequent Canberra hospitalisations. The four hour round trip, at 15 cents per kilometre equated to $55, but with the $40 administration fee for each claim, that left only $15 for the carer and patient. After completing the form, getting the specialist's signature and lodging the application, payment could take up to 4 months!

The Leukaemia Foundation House (LFH) however did provide carers and patients with haematological cancers accommodation. This saved them the cost of accommodation and the hassle of filling out IPTAAS forms, because the LFH claimed for them. Overall, Tyler and Millicent appreciated the free accommodation, but said they would have preferred more privacy, such as a small apartment with private amenities, instead of one shared toilet and kitchen between sometimes three or four families.

Questions for Future Research

Several researchers have argued that individual therapy is inappropriate in assisting cancer survivors with their experiences of liminality (see chapter one). This analysis of cancer carers' counselling experiences raised similar questions. For instance, Rodney said the "psychs" convinced him his feelings were "perfectly normal" and Millicent, sought advice from counsellors on how to feel, as "a good wife" and carer. These carers seemed to want psychological support not just to address their own emotional distress, but to ensure that they personally were adhering to social norms and thus were "normal." This finding raises a few questions for future research to explore.

First, does counselling for cancer carers promote conformity? Carers in this study either sought reassurance in their emotion's normalcy or sought assistance in reshaping their emotions to be "normal." In seeking the one "right" way to manage their emotions, carers were actively adhering to emotional norms. Rose (1989), following Foucault, describes this desire to be normal as the internalisation of state power, as people regulating their own behaviour to adhere to the norms of the clinical professional (see also Furedi, 2004; Powell, 2008). Psy-professionals share the job of enforcing those norms by encouraging their patients to manage their emotions to adhere to these norms. This raises questions for future research about the extent to which counselling allows carers autonomy in their emotions.

These findings raise a second question: does accessing psychotherapy redirect attention away from a social problem? In seeking individual counselling, carers may be overlooking the social and structural causes of their emotion management confusion. Rose (1989:xiii) has warned of the psy-professions tendency towards "reshaping subjectivity" which causes individuals to view problems of a social nature as individual psychological problems. This suggests that individual counselling perpetuates a user's misinformed belief that they are the point at which the problem begins and ends, when in fact, the problem may not be one of psychological disturbance, but of social and structural imbalance (a socially produced imbalance in access to time, for example).

There is a third question to come out of this finding: are carers becoming dependent on expensive counselling? Many carers, Millicent for instance, indicated their belief that professionals are gate-keepers of the "right-way" to manage emotions. This could be interpreted as a form of medicalisation of normal life events. Illich (1976) uses "medicalisation" to describe the increasing use of the medical profession as more and more parts of life are seen as medical problems requiring the consultation of medical professionals. Carers' accounts of seeking therapy to regulate their emotions might be called psychologicalisation, where social ailments are increasingly defined as psychological problems in need of costly counselling. The medical benefits scheme, however, only covers a limited number of psychological consults (Parliament of Australia Senate, 2005), thus ongoing dependence could result in compounding expenses at a time when a carers' income is typically compromised (ABS, 1999).

Implications

While there is a great deal of literature on the value of support services for cancer patients, there is comparatively little on how carers of cancer patients' value informal support, counselling, support groups and practical support. The research that has been conducted in this area typically emphasises the value of support services in measurements of stress or burden relief. This research, in taking a social approach to understanding carers' emotions, presents a new conceptualisation of the value of support services to carers: their value depends on a carers' time-sovereignty. Time-poor and time-destitute carers prefer practical support which gives them more time to juggle their competing roles or indeed, just time to feel.[36] Carers with time to feel prefer emotional support that helps them to organise, manage and validate their thoughts and emotions. As mentioned in chapter five, this categorisation of carers' experiences and subsequent support service preferences will aid support service providers and social workers by helping them to more accurately tailor their recommendations.

These findings fill another gap in the literature: understanding why so few carers access formal support. Carers who did not access counselling or support groups gave four reasons: sufficient informal support, lack of time, lack of knowledge or stigma. Those who did not access practical support gave similar reasons: lack of time, against their temporal orientation (see chapter four) and lack of knowledge. The most time-poor carers seem to be the least able to access support because of the time and energy required to apply, long waits and bureaucratic hurdles. For some, another deterrent is the requirement that they replace their optimistic approaches to the future with negative ones in order to access financial support. Finally, lack of knowledge of available support was a barrier to accessing both financial and practical support. The inaccessibility of respite, Centrelink and IPTAAS indicates that these time-impoverished carers are under-supported and may be most vulnerable to the negative mental and physical health consequences linked with caregiving (see chapters one and seven).

One implication from this finding is that financial support application processes should be improved. First, carers need an advocate and ally within the medical system to inform them of which financial and respite services they are eligible to receive. Second, the application processes should be made less onerous. The ally within the medical system might help carers in filling out this paperwork, but Centrelink could also improve its accessibility by allowing carers to make contact over the internet or telephone and by devising cancer-specific forms for carers. Third, payments could be increased, providing more substantial compensation for this role which often limits carers' capacity to earn an income.

---

[36] This explains past research that has found younger and female carers to be more likely to access practical support such as respite care (Gibson et al., 1996). It is because those younger and female carers are more likely to be time-destitute from working full-time and looking after children and elderly parents (see chapter five).

In September 2009 Carer Payment rates did increase by $30 and those receiving the Carer Payment may be eligible for a supplementary payment of $600. Those receiving the Carer Allowance may also be eligible for a supplementary $600 (Carers Australia 2009). Future research should determine if this rate increase is sufficient to entice more carers to complete the time-consuming application paperwork.

Another implication is that new forums are needed to make emotional support more attractive to male carers. More males than females in questionnaires and interviews, reported having no confidants. Few males in this study accessed support groups. Some found them to be too emotional. Information events with a strong emphasis on networking might be a way to facilitate informal connections for male carers, since formal discussions on emotions seem to be unappealing to many.

Information on both emotional and practical support is apparently poorly distributed. In the next chapter, the medical system's practices of including carers and disseminating information to carers are explored.

Chapter Seven: Relying on Carers at Home and in the Hospital

A limit to the efficacy of support services as a whole is restricted delivery of information within Canberra's medical system. This chapter relays carers' experiences of factory-like and inconsistent care within the Canberra medical system, of carers being relied upon to manage their spouse's medical system care and experiencing the negative effects of this model of care on their health. I argue *home at the hospital* explains the medical system's current dependence on carers to provide care in their homes *and* at the hospital. The exacerbating impact that this model of care has on carers' wellbeing is illustrated. Further, it is shown here that information on support services and how to provide medical care at home is not consistently disseminated to cancer carers within the medical system, despite the system's reliance on their care. Only breast cancer patients received medical and support service information. For patients and carers of other cancers, support service information delivery is inconsistent or is linked to an emergency. Not arming carers with methods of countering or preventing declining health until a crisis point has been reached is a breach of medical system ethics.

Carers' Hospital Experiences: Inconsistent and Bureaucratic

Judy and Frank's stories typify carers' experiences of uncoordinated, bureaucratic and at times faulty care within the medical systems. Judy's contact with both GPs and their oncologist was rife with mistakes and required her to do a lot of remedial work in caring for her husband. The first problem she had to overcome was consulting with one GP long enough to get a diagnosis. "We spent a year going from doctor to doctor before we got on to this [diagnosis]….The real problem was the nature of the GP practice….He was always seeing a different person so there was no one there with an overview." In the end, Judy had to "jump up and down" and present an ultimatum to get an appointment with a thoracic surgeon. She threatened to take her husband to Melbourne if she did not get a referral. After the surgeon made the diagnosis, they were referred to an oncologist. Although the oncologist was highly recommended, he made several mistakes which frustrated Judy and caused her to lose trust in him.

> Everyone else raves about him…I think he is absolutely ridiculous…. He ordered a prescription for Richard [her husband], the dosage was

> wrong and the drug was wrong. You only do three things on a script, the patient's name, the name of the drug and the dosage. He got two of them wrong…so I lost confidence in him [the oncologist].

During our second interview she told me she had lost even more confidence in this oncologist because he forgot to order a scan that was needed to determine if the chemotherapy had been effective. Overall, Judy felt that an overview was lacking. Each doctor did "his bit," but no one was coordinating. "We felt we were paddling in the dark with no one throwing a life line. No one with any overview." This was because medical staff only "pass you on from one to the other."

Frank too found his experience as a cancer patient to be confusing and uncoordinated. He was left to connect all the information for his various doctors.

> The problem I have is I have three doctors…an oncologist, a urologist and my normal GP….The urologist is doing his thing, the oncologist is doing his thing and the doctor, the GP, is doing his thing….But there's nothing, no coordination. And now I am becoming the coordinator….I hadn't been doing it because I assumed they were doing it.

Without a coordinator, Frank was unsure what direction to take. He wondered, "Does the other fellow know? And does he agree? Does my GP agree? It's becoming a mishmash of each one doing their own thing." Further, when he saw his GP, his appointment took longer and thus cost more, because he had to fill his GP in on information from specialists. He said, "It is frustrating…when I go to my GP…I have to basically tell him [what the urologist and oncologist have said]….It sort of extends my appointment somewhat. And so…last time, it cost me a $100 fee instead of a $56 fee because it was what's called a long interview." He concluded that "it needs to be coordinated better. It seems to me either one of the three [should] be nominated as the coordinator who then compiles the [patient information]."

These narratives represent most carers' experiences within Canberra's medical system. The current state of care[37] is one where medical staff have good intentions, but mistakes often occur, care is bureaucratic and carers are relied on to oversee patient care.

---

[37] 'Cancer care' refers to the "management of the total needs of a person with cancer, from the time of onset of symptoms of an underlying cancer or from the point of diagnosis of an asymptomatic cancer" (National Cancer Control Initiative, 2003:ix).

Respondents generally said that medical staff are diligent, friendly, mean well, and work hard. They phoned on weekends, gave out their mobile telephone numbers, made house calls without charging, stayed behind afterhours to ensure that they "acted immediately" to get the "process started" and postponed lunch to treat patients (*Charlie*). This is consistent with itemised accounts of doctors ten hour day schedules in the UK (Pritchard, 1992) and reports of many doctors working 80 hour weeks because of staff shortages (Parliament of Australia Senate, 2005). On the whole, carers perceived doctors, GPs, oncologists, surgeons and radio-oncologists to be overworked from doing everything they could for patients, with intermittent success.

Charlie felt included, for instance, when nurses explained the radiation treatment process to him and his wife: showing them the machines, explaining the procedure and leaving them with written information. Millicent, too, was thoroughly informed of her husband's status at the Canberra Hospital. Medical staff wrote the patient's blood count on the wall in plain view, helping her to stay informed and monitor his status.

However, mistakes were common. Medical staff forgot to give Sally's husband pain killers during a procedure to implant a stent. They forgot to get Matthew's wife anti-nausea medication after chemotherapy. Anne's husband was given the wrong anti-nausea medication. Tyler assessed the Canberra hospital system as working relatively well for such a big organisation, but not always and not without the carer's skilled input. Especially in emergency, many carers reported miscommunications, such as messages from oncologists and hospice staff being misplaced, hindering a carer's ability to get the patient access to medical attention.

This corresponds to national assessments of mistakes made in hospitals. Duckett's (2004) survey of the literature reports that between one-sixth and one-tenth of all hospital admissions in Australia result in iatrogenic injury, that is a "medical problem caused by the management of the disease rather than by the disease itself" (Bodenheimer & Grumbach, 2005:115). This type of injury ranges from minor to disastrous: from undesirable medication side-effects and longer than anticipated hospital stays, to operations on the wrong patient or body part (Davis & George, 1993; Duckett, 2004).

In addition to errors in physical treatment, most carers found that communication was inconsistent and found the Canberra hospital system to be bureaucratic (see also Parliament of Australia Senate, 2005:39). Carers and patients were treated as, in Petersen's (1994:101) words, "cases" instead of "human beings." Particularly in the public system, carers complained that service was compartmentalised, biomedical, slow, and matter-of-fact. They used words like "sausage factory" (*Charlie*) and "factory of drawers" (*Bernard*) to describe the organisation of care in certain departments, or "block of meat" (*Kyle*) and "number" (*Bernard*) to describe how patients were treated.

Radiation and emergency wards were often cited as being particularly unaccommodating, bureaucratic and slow. Charlie said there would often be a two-hour wait or longer after their scheduled appointment time in radiology before a technician could see them because the machines frequently broke down, but no one informed them that there would be a wait or told them how long.[38] He also said the receptionist gave out appointments "as if she was dealing out her own money" and the staff generally had a public servant attitude to their work: "oh it's 10 o'clock I have got to go and have my cup of tea now, it doesn't matter that eight people are in line waiting." Carers complained of long waits and unfriendly service in emergency as well. Tyler estimated that there was "invariably" a four-and-a-half-hour wait before being seen in emergency. He said it was "cold [and] impersonal…oh God it's a mess!"

Communication from and between hospital staff and GPs was also described as bureaucratic, hazy and ineffective. Skene (1990:66) explains that it is "professional medical etiquette" for specialists to report to GPs and have GPs explain diagnoses to patients or carers, but ideally both the GP and specialist would explain tests, side-effects and outcomes. If, however, a GP refers the patient to the specialist or an arbitrarily assigned group practice doctor "withdraws" from the patient's care, then it is the specialist's responsibility alone to provide patients and carers with medical information (Skene, 1990:225).

This contradictory informal protocol and tendency for "discontinuity" may have been counterbalanced in the past when GPs and patients had stronger, trusting and

---

[38] Pritchard (1992:89) describes making patients and carers wait as an "expression of power," but one that will be likely overlooked "if they know how long it is likely to be and an explanation is given."

long term relationships (Pritchard, 1992:80-1). Now patients increasingly use locum or short term care group practice GPs and the organisation of care is becoming more specialised and spread out across many different locations and personnel (Davis & George, 1993; Duckett, 2004; Pritchard, 1992; Turner, 2006; Wearing, 1996).

As a result, poor communication and a lack of continuity of care are common complaints in most bureaucratic medical systems (Duckett, 2004; Kiss & Sollner, 2006). In Tyler's assessment, when "you are dealing with a complex system…communication is just going to break down." This is especially the case in cancer care with patients being referred from a GP to a surgeon, to an oncologist, radiologist and other relevant specialists (National Cancer Control Initiative, 2003; Parliament of Australia Senate, 2005). As Frank's account illustrates, carers and patients are left to find their way through the system and coordinate with multiple players and wards. Frank's wife said she was certain that her doctors talked about her case at the hospital because her type of cancer was more interesting. She said, "If you get a few things that are rare, they [doctors] get all excited."[39] Other carers were either uncertain that the doctors were talking to each other, or certain that they were not, because the carer was relied on to communicate the information. Similar accounts from patients were made to a senate inquiry into cancer care (Parliament of Australia Senate, 2005) and a report by the National Cancer Control Initiative (2003). This practice of working solely within the confines of one's position has been described as "fragmentation" (Strauss et al. 1985:8; as cited by Allen et al., 2004:1010; Griffiths, 2003:160), where patients are "passed from specialist to specialist with no clear pathway of care," resulting in patients, and as this research shows carers, "feeling abandoned" and "lost" (Parliament of Australia Senate, 2005:30,8).

Carers whose spouses became classified as terminal felt this fragmentation most acutely. They said they were surprised that oncologists with whom they had worked and developed a rapport over so many months or years said there is "nothing more we can do for you" after a terminal prognosis was delivered (*Tyler*). The oncologists never sought out the patient or carer again, never offered

---

[39] In Becker et al.'s ([1961]1977) *Boys in White* interns were found to spend more time learning from patients with rare diseases as these uncommon experiences were found to impress their superiors.

any further information or support. Interaction was limited to the doctor's specialty, thus, it was bureaucratic and fragmented.[40]

Referrals provide another example. This step left patients and carers open to "unnecessary distress" because they were given little assistance in making referral decisions (National Cancer Control Initiative, 2003:x). Patients and carers were asked to select surgeons and oncologists, but with little background information on specialists, or, as Marian described it, on "who's who at the zoo." This may be because information on how many relevant surgeries a specialist has performed or his or her reputation are not given out by clinical colleges (Skene, 1990). Only informal information on specialists is available. Marian, for instance, was limited to asking her friends who worked in the hospital system who her husband should see. Thus, if a GP does not know who the most appropriate specialist is and if the patient and carer do not have friends inside the hospital system, their care will be left to chance. This has been described as a "cancer lottery," in which luck and not information shapes the referral process (Parliament of Australia Senate, 2005:7). (Patients treated under inexperienced surgeons have poorer chances of success (National Cancer Control Initiative, 2003; Parliament of Australia Senate, 2005).) This chance is not solely based on probability, but also based on socioeconomic status (SES), as individuals of higher SES are more likely to have medical personnel as acquaintances (Duckett, 2004; Petersen, 1994).

Relying on Carers

Carers eventually concluded that they could not leave the care of their spouse up to the medical system "lottery"; they must become the care coordinator. Fiona, for example, said to me and her husband,

> You were having transfusions and I could see the blood running out and bleeps going off and nothing happening so you run off to find someone and say, "Oi! I think you need to change the bag."…You think "oh god, I really need to be here 24 hours a day to make sure these things are happening."

---

[40] As McNamara (2001) points out, this may be because death is viewed as a failure by those within the medical system (see also Hockey, 1990).

Carers described their roles as connecting the “bits” of service provided by the different medical modalities and “put[ting] the pieces of the puzzle together” for their spouse (*Matthew*).

Tyler portrayed this medical system practice in a positive light. He was pleased that the hospital had changed over the past 40 years. When his wife was giving birth to their children in the 1960s he was banished to the waiting room to experience his fear and anxiety on his own. His experience with his wife in the hospital this time was less authoritative and more inclusive. Family are now allowed and even encouraged to visit the patient at all hours and be part of the treatment process. His comment alludes to a pendulum swing in how most hospital bureaucracies operate today. They have swung from a commanding and total care institution in the 1960s (see the introduction for a history of these changes) to a re-structured system today that more than allows family to participate. As these carer accounts show, the medical system now ***relies*** on family to provide care for patients.

Carers noticed this dependence and the necessity of their role. They described their role as navigating their spouse through the hospital system. They saw themselves as a combination of spouse and patient manager, a necessary player in patient care that provides more personalised care. Tyler, for example, said it was his job to “tickle” the system and tie up all the loose scheduling ends within the hospital system. He would often have to make arrangements with the renal ward and oncology ward to change conflicting chemotherapy and dialysis appointments. The hospital system, he said, “still needed somebody to wander around…[and] tie it all together…that last five percent.”

But most other carers saw themselves as more than just “tickling.” Instead, they interpreted their role as involving “case” or “project management” (*Linda, Tyler, Andrew*), administration (*Kyle*), appointment coordination (seven carers saw themselves as coordinators) and being a “patient advocate” (*Sharon*, *Phyllis*). Only a few carers with a long term and trusted GP relied on their physician to oversee their spouse’s care. Most carers saw themselves as essential to ensuring their spouse received accurate care: the right diagnosis and the right medication, at home and in the hospital. This involved recordkeeping, communicating with medical staff and actively persuading medical staff to change their treatment for the patient's benefit.

Keeping records of doctor-patient interactions was a primary task undertaken by almost all carers. Concerns about deference, communication and the subject matter often dominate patients' attention in medical interactions making recollection difficult (Davis & George, 1993; McNamara, 2001; Neuhauser, 2007). As Phyllis noted, "when you are really stressed you can't take it [information] in." Similarly, Millicent said her husband "is a bit hard of hearing…even if he hears he doesn't remember…[so] you [the carer] really need to be there as well because people do forget." Thus, carers took notes at doctor's office visits, collected scans, operation reports and prescriptions and then presented this overview to relevant medical professionals when needed.

However, carers who wanted to be more than passive information recipients often encountered difficulties. When diagnosis and treatment information were not communicated to carers, carers wanted to access it. Without a central point to which questions could be addressed, many carers had to wait hours for a specific doctor to return to get their questions answered or rely on the patient for information, despite the known limits of information absorption in patients experiencing post-diagnosis shock or treatment (Docherty, 2004). Phyllis, for instance, waited nine hours to speak to the Intensive Care Unit (ICU) doctor about her husband's prognosis because the nurse said she was not authorised to give that information. Mark and Fiona, who both had experiences as patients and carers, said "in every hospital, dreadful no one seems to know anything. 'So and so knows about that but she is at tea' and you think 'oh God, don't you write notes down?'" A lack of a central point of information made learning and recording information about a patient extraordinarily difficult.

Other than being a record keeper, a carer's involvement in communication with medical staff varied. Despite increasing recognition that medical care and communication should include the family (Breitbart, 2006; Firth, 2006; Surbone, 2006), some said that specialists "didn't really want to know the carer" (*Andrew*). Phyllis felt this way about her GP, so she sought out a new one who would include her as both a carer and a patient: positively reinforcing her care work, acknowledging her psychosocial distress and prescribing anti-anxiety medications.

A carer's involvement within the doctor-patient interaction ranged from an active role that almost excluded the patient to a passive or "back-seat" role limited to observation (*Matt*). Many argue that carer, patient and family should be treated as one unit, but that rarely happens because family therapy and communication is not part of medical culture or training (Breitbart, 2006; Fallowfield, 1988; Firth, 2006; Surbone, 2006). Others, however, argue that a carer's inclusion or exclusion from doctor-patient exchanges is related to the range of ways doctors interpret the patient's wishes and confidentiality laws (Arksey et al., 1998; Kearney et al., 2007). Canberra carers' accounts indicate that other factors also influence communication. They show a key aspect of this variation is the patient's wellbeing and the extent to which patients can be expected to make treatment decisions on their own. Another factor that Morris and Thomas (2002) also found influential is a doctor's perception of the carers' role.

When patients were very ill, some carers were so active in medical professional exchanges that they excluded the patient. When patients had "chemo fog" or lacked enough confidence to ask questions, their spouse carer was the automatic proxy in nurse and doctor interactions. In these instances, doctor-carer (not doctor-patient) interaction took place. One carer wanted to exclude the patient from prognosis information altogether because of his fragile psychological state; he was suffering from anxiety and depression. Carers in Thomas et al.'s (2002) study also tried to exclude patients from diagnostic information for emotion work purposes. Some carers even bypassed the patient to communicate with medical professionals, despite the patient's intact capacity. Carlie, for example, informed the doctor about her husband's leg pain which he thought was irrelevant, and it turned out to be deep vein thrombosis.

On the other extreme, a few carers said they did not want to take any attention away from their spouse, the patient. Carers who said this were looking after a newly diagnosed spouse or one with few mental and physical hindrances, despite their diagnosis. These carers only wanted to ride in the "back-seat" (*Matt*) and observe or record their spouse's interactions with medical professionals. They viewed taking part in the doctor-patient interaction as an insult, robbing the patient of attention (Thomas et al., 2001 show similar findings).

A few carers were roughly equally included within the doctor-patient interaction, making it a doctor-patient and carer interaction, or "triad" (Kearney et al., 2007:21). This happened when doctors treated the couple as a "unit," as Phyllis's new GP did, and perceived the carer as also in need of emotional and physical support. Most often, however, carers were only perceived as co-consumers when they had reached a crisis-point in their own emotional wellbeing or health such as crying in front of medical staff, experiencing anxiety-induced Irritable Bowel Syndrome (IBS) or heart troubles. Although carers are "scribes" in formal appointments with doctors, any further involvement depended on the patient's wellbeing and the doctor's perceptions of the carer as either part of the care unit or more often, outside of the doctor-patient relationship.

Making a case to alter treatment or diagnosis was another aspect of carers' case management positions within hospital interactions. Just as the severity of a patient's diagnosis and the extent of their impairment was a central factor in the carer's placement within doctor-patient communication, it was also a factor in a carer's pushiness. As the patient's morbidity increased, in the short term because of treatment or in the long term because of progressing disease, many carers became active patient advocates. Carers advocated to ensure their spouse got the right diagnosis and treatment. They learned that they could not rely on the hospital system to thoroughly oversee his or her wellbeing and they learned that they did not get results by patiently waiting for someone else to notice the problem. Carers had to intervene, "push politely" (*Marian*), "become really assertive" (*Phyllis*) or even be "an absolute bitch" (*Linda*) to organise the care their spouse needed.[41] Their duty to their spouse overrode etiquette (Allen, 2000 made similar conclusions).

Requests of medical staff ranged from mundane, such as asking nurses for bedpans and meals, to challenging, such as arranging for a second opinion, getting a different doctor or even pushing medical staff to consider different assessment or treatment options. These "expert carers" (Allen, 2000) researched their spouse's disease, monitored their health, persuaded medical staff to perform

---

[41] Grbich et al. (2001:36) refer to this as "terrier-like persistence."

scans, arranged clinical trial participation or pressured staff to re-evaluate their initial diagnosis based on the carer's observations and research. Kyle, for instance, did research on available clinical trials, presented the information to their oncologist and asked if they were eligible to participate. Marian monitored her husband's neurological cancer-induced seizures, presented a graph of his seizures to the oncologist to show that the current prescription was not working and even suggested alternative medications.

Linda's story provides the most extreme example of a carer feeling compelled to be pushy. Linda urged medical staff to reconsider their first diagnosis for four months. They initially thought it was an abscess in his abdomen as a result of gangrenous appendicitis. The medical staff kept draining it without results and prescribing antibiotics. They thought he was improving after each course of antibiotics, but Linda had a contradicting long term perspective. She found that the antibiotics made a slight improvement in how he was feeling, but never eventuated in a full recovery; he was continuing to decline in the long term. If she had not pushed for a re-evaluation, they would have left the abdominal bulge *in situ* and he would have died soon after.

Doctors and medical staff, however, did not always respond favourably to carers requests. Allen (2000:151), citing Rosenthal et al. (1980), explains that nurses "seek to control the conditions of their work, whereas patients and their families seek to control the conditions of their hospital experience." The result is conflict, classification and sometimes subordination of carers. At hospitals, nurses categorised those carers who entertained the patient, kept their loved one comfortable and made occasional requests of nurses on the patient's behalf as non-threatening "visitors." Those categorised as "workers" alleviated the nursing staff's burden by doing jobs like bathing and toileting the patient (Allen, 2000:151-4). "Expert carers" or "established family carers" were also very involved in patient care, but unlike "workers" these carers undertook ongoing "advocacy work" that significantly interrupted nurses' work such as challenging the timing or method of a nurse's personal care: "he likes it better when you feed him like this" (Allen, 2000:150,154-7). Conflict resulted between nurses' concerns for the whole ward and expert carers' concerns for their ill family member (Allen, 2000:157). As in Allen's study, carers in this study said they had to be adamant, despite this resistance. Especially in emergency, Canberra carers found they had to pressure staff to get their spouse help in a reasonable amount of time.

Successes in bargaining with medical staff made carers feel reassured that their subjective and long term knowledge did provide them with an advantage in assessing their partner's health. These experiences encouraged carers to continue advocating for the patient, despite the opposition they often encountered from medical staff. A few carers found that they were treated disapprovingly for being meddlesome complainers until medical staff conceded and found that the carer was right. Then, they were treated like "fellow professional[s]" and given "credibility" (*Linda*). Others found the way they were regarded was unpredictable: they were perceived as credible lay-professionals by some doctors and as intruders by other doctors.

Thus, despite the "tension" (Allen, 2000:158) that surfaced between carers and medical staff from advocacy work, carers perceived themselves as essential players in a bureaucratic and inconsistent hospital system. They felt compelled to ensure their spouses' care was not the result of luck, but of measured decisions and coordination.

Home at the Hospital

Dependence on carers to fill in the many "cracks" within cancer care reflects the changes that have occurred politically and financially within Australia's and other countries' medical systems. As detailed in the introduction, care in the 1960s was institutional and paternalistic. During and after the 1970s and 1980s, there was an ethical and economic shift in medical care in Australia. On the ethical side, there was a desire for decreased institutionalisation, increased community participation, patient empowerment and equality in access to medical care. On the economic side, there was a need to restrict the increasing cost of healthcare. Biomedical and economic principles were used to do so, resulting in shorter hospital stays and more outpatient care. The combination of these forces resulted in care being outsourced to, first "care *in* the community" and then "care *by* the community" (my emphasis Allen, 2000:150). That is, these changes in the structure and funding of the Australian medical system have resulted in a 180 degree shift. Family were excluded from patients' bedsides during the mid-twentieth century.

Now, family carers are relied on to not only provide care at home, but care in the hospital as well.

Currently, patients are increasingly treated during the day and most acute care is provided in the home (Duckett, 2004; National Cancer Control Initiative, 2003). In place of long inpatient care, hospital staff or community medical staff visit patients in their home. This is done to either avoid admission to a hospital entirely or to provide safe "early discharge" (Duckett, 2004:138). This trend of shorter hospital stays, with the patient spending more of their time at home under the care of a nurse who visits the patient at home is referred to as "hospital in the home" (Duckett, 2004:138).

Hospital in the home or "care in the community" was gradually replaced by "hospital at home" and "care by the community" (Allen, 2000:150; White, 2006:105). These latter terms acknowledge those who have now become the biggest providers of patient care: not community medical staff, but the family. These conceptualisations explain that not only has the location of care moved to the home, but the primary care provider has changed. Now, most of the care that takes place on an outpatient basis is not provided by visiting medical professionals, but by family members, most often women (White, 2006).

This research shows that practices have shifted from one side of the gamut, to the other. Whereas 50 years ago patient care was almost wholly institutional, now, informal caregivers supply between 55 and 80 percent of patient care (Jansma et al., 2005; Lewis, 2006). Therefore, *home at the hospital* also reflects the experiences of carers of a spouse with cancer. In addition to providing care at home, carers are now relied on to manage patient care within the hospital. With bulk billing group practices replacing "the trusted family doctor," with medicine becoming increasingly specialised and with the relocation of care from the hospital to "many different centres" (Davis & George, 1993:163; Skene, 1990:1-2), carers are increasingly counted on to coordinate care for their sick relative within the hospital wards and other medical service centres.

This outcome may reflect the original goals of community participation: allowing the community to "take control" and "make decisions about their health" instead of relying on a paternalistic medical interaction (Petersen, 1994:110). It also, however, reflects the interests of “state power” (Petersen, 1994:122). As Petersen (1994:110) points out, “when it has been sponsored by governments, community participation has generally been about pursuing objectives other than power sharing or fundamental social change.” That objective is saving the government money, approximately $30.5 billion each year (Access Economics, 2005; Carers Australia, 2007; Hughes, 2007). This goal has been sustained because of the cost and meaning attached to caring. Few families can afford to pay for professional care and caring for family members at home is considered emotionally rewarding, moral and even obligatory for spouses because of “in sickness and in health” marital vows (Allen et al., 2004:1020; Weitzner et al., 2000). Thus, family carers are the pawns in a bureaucratic strategy to reduce medical spending. Although they gain more contact with their sick loved one, this allowance comes at a price to carers in their health.

Community participation strategies rely on the selfless nature of family care (Cahn, 2000). Altruism, love and family devotion certainly motivate family members to work hard as carers, harder than they would if they were caring for a stranger for financial gain, but, as is shown in the next section, it also means they are likely to work too hard (Cahn, 2000). Although carers can now participate more within medical interactions, they also have more responsibility, stress and consequently poorer health. This negative impact on carers has gone largely without acknowledgement from politicians, historical accounts of health care or medical professionals. This lack of recognition is exacerbating the negative impact on carers’ health, as Bernard’s story illustrates.

Relying on Carers Negatively Impacts on their Wellbeing

Bernard developed anxiety and IBS because his rising stress levels as a carer were perceived to be outside of doctor-patient interactions. When we first spoke, it had been approximately a month since his wife’s death and he had been reflecting on his carer experience in the hospital and hospice. While he and his wife were under the care of the hospital system, Bernard was relied on to administer medication and make decisions about his wife’s care at home after chemotherapy treatments. On several occasions, his wife had extreme reactions to chemotherapy. Although there was a phone number he could call 24 hours a day at the private hospital, when he called with an urgent concern, they did not have access to his wife’s records and could not provide any advice.[42] This left Bernard unsupported in making emergency medical decisions. Another source of stress was his ongoing effort to manage his wife's emotions by focusing on positive things happening in the present, at the expense of spending time on his own emotions. Yet another burden on his time and emotions was their financial need for him to continue paid work.

The stress and severe anxiety that he developed from this time, energy and emotionally consuming role caused his IBS. But, he said there were no words of caution in medical interactions, no pamphlets in hospital waiting rooms telling carers to take care of themselves so they could keep on caring for their partners. As Bernard surmised, "the medical system was focused on the patient [and] through the disease process missed the carer…it was just too many patients and not enough practitioners, and certainly the carers were not in the picture." It was only when he went to an Employee Assistance Counsellor after developing IBS that he found out about the relevant stress and mental health warning signs.

At the hospice, however, care was not biomedical or factory-like, but holistic. Upon their admittance into the hospice, Bernard and his wife were introduced to the chaplain and counsellor and made aware of the emotional, spiritual and physical support programs available to both the patient and family. There was continuity of care, the environment was relaxing and the staff treated them like people and not numbers. There were even volunteers who would sit with the patient for 30 minute intervals, allowing the carer to take a break, take a walk and take time, albeit a small amount, for self-care. Bernard wished that this type of service had also been part of the earlier stages of their cancer journey.[43] He was unsure if there was a counsellor, chaplain or social worker at the hospital because he had not been made aware of their existence.

---

[42] The Freedom of Information Act only extends to "Commonwealth-run health facilities," thus, it is not standard practice for private hospital nurses to access files and help over the phone (Skene, 1990:122). Jansma et al. (2005), however, highlight the importance of nurses being available on call after hours for carers of palliative cancer patients.

[43] There is well documented evidence of the success of the preventative measures taken in some palliative care facilities where "family-focused grief therapy" is used to recognise families in danger of psychosocial morbidity and identify productive coping strategies already in place to prevent further health decline (Kissane & Bloch, 2002).

Bernard's story highlights shortcomings of the current hospital system that are exacerbating carers' health problems.[44] Deficiencies do not stem from negligent or unfeeling medical professionals. Doctors and nurses were described as caring. The paradigms guiding hospital system assessment and patient care are to blame. In the hospice, the holistic and "very small investment that we make in palliative care has an enormous benefit for the health of the whole community" (Parliament of Australia Senate, 2005:119).[45] Conversely, the cost-cutting and restricted focus of hospital systems has a detrimental effect. First, economic principles used to justify cutbacks and community participation overlook the externalities of these strategies on carers' health. Second, the biomedical gaze excludes carers and psychosocial information dissemination as outside the scope of their practice.

The principles of economic rationalism charged with analysing and improving the hospital system's productivity leave carers out of analysis (Petersen, 1994). As an accountant, Bernard realised that hospitals follow a factory model that both excludes carers from medical care and relies on carers because it is the most cost effective way, "given the limited resources." He assessed that the focus on efficiency may not have a direct negative outcome on the patients' disease outcomes. It does, however, make a significant difference to the emotional, spiritual, mental and even physical health outcomes for carers and, by extension impacts on patient outcomes (Braithwaite, 1990; Hunt & Mintz, 2002; Kennedy & Lloyd-Williams, 2006; Thomas et al., 2001).

Bernard is alluding to the well documented shortfalls of using economic units of measurement in the medical system. Many have argued that equity, patient-autonomy and access to psychosocial services within medical systems are incompatible with shorter appointments, unregulated business models and a profit focus because all of these services require time, money and personnel beyond basic fee-for-service doctor-patient interactions (Davis & George, 1993; Duckett, 2004; Frankenberg, 1992; Hochschild, 1995; Kiss & Sollner, 2006; Little, 1995;

---

[44] Quantitative analysis supports this assertion. Feeling prepared for the caring role regarding what to do and what is expected were related to lower psychiatric morbidity in a study of dementia carers (Braithwaite, 1990:80).

[45] However, even in palliative care facilities, medical professionals are said to focus on the physical and not the emotional or spiritual side of health, leaving this focus to counsellors and chaplains (Kennedy & Lloyd-Williams, 2006).

Petersen, 1994; Pritchard, 1992).[46] Although economic rationalist principles have arguably been effective at limiting the growing cost of healthcare, these principles are ill-suited to solving medical system problems (Petersen, 1994).

I argue that in addition to the above shortfalls, economic assessments also exclude carers and their health. Because financial transactions are not made in the carer relationship, carers are excluded from economic assessments on healthcare spending (Duckett, 2004). That is, moving the hospital to the home and the home to the hospital looks prudent in monetary units. "False efficienc[ies]," however, are making the shift look economical (Cahn, 2000:43). Financial measurements of hospital productivity are "highly deceptive" because they do not factor in social costs (Cahn, 2000:43). This is done by simply changing the delineation of when the medical system's share of patient care begins and ends (Duckett, 2004). By dropping an increasing portion of patient care onto families and calling it productivity, hospitals appear to be containing costs. Instead, they are outsourcing costs and inflating costs.

Market principles assume that "the costs and benefits of both production and consumption fall in the same place" (Duckett, 2004:33). Reality, however, is rarely this clear cut. "Externalities," that is, ignored costs that take place beyond the exchange location, do result (Cahn, 2000; Duckett, 2004; National Cancer Control Initiative, 2003). The "externalities" reported by carers in this study include anxiety, high stress, eczema, heart trouble, poor gastrointestinal health, depression, increased alcohol consumption, sleep interruption and divorce. Some of these health problems can be linked to grief and coping (Stiefel & Razavi, 2006). These and similar health problems, however, such as heart disease and cancer, have also been linked with extreme, time-sensitive responsibilities such as caregiving (Dossey 1982; as cited by Adam, 1992). Overall, increased levels of carer burden are correlated with higher levels of morbidity (Sharpe et al., 2005) and carers who report being insufficiently supported are statistically more likely to report having worsened health problems (McNamara & Rosenwax, 2007). Thus, this research suggests that home at the hospital cost-cutting strategies are having an "inflationary impact" (White, 1978; as cited by Capra, 1982:368).

---

[46] The move from hospital to home has made economic calculations of hospital efficiency even more challenging for economists because many exchanges between patients and doctors occur outside of office walls (Duckett, 2004).

Davis and George (1993:366) explain this finding in economic terms: “crude cost-benefit analyses [of medical systems] might promise lower immediate costs, but generate higher long-term ones.” In other words the already emotional and stressful experience of accepting that one’s spouse has cancer, is made exponentially worse when cost-cutting strategies compel carers to navigate, advocate and coordinate patient care within a medical system without support. Eventually, carers’ health may buckle under the strain of having too much responsibility and anxiety and too little time, or a carer may leave the responsibility and the marriage (Boulton et al., 2001; Fallowfield, 1995).[47] Further, while these “externalities” create “false efficiencies” and make it look as though cost-cutting is taking place, it has the reverse impact: these external costs eventually take the form of sick carers and internal costs or unsupported patients requiring institutional care and internal costs (Braithwaite, 1990).[48]

There is a “need to widen the focus to include relationships with informal carers” within medical systems and support modalities, for (I argue) cost-control and moral reasons (Jaffee 2001; as cited by Griffiths, 2003:161). First, including carers within medical interactions could save the medical system “inflationary” costs later on (Bodenheimer & Grumbach, 2005:76; National Cancer Control Initiative, 2003:xiv). Second, if carers are going to be relied on, then medical systems have a “duty of care” to ensure carers’ already high rates of morbidity are not increasing.

Bernard saw support services as the solution to lessening the impact of these externalities: a necessary preventative or therapeutic measure to ensure that carers have somewhere to turn to if they become ill or start to become overwhelmed and want to abandon caregiving. A patient expressed a similar view at the senate inquiry into cancer care. She told the committee that “a diagnosis of cancer brings with it so many other practical problems and issues. Life on the home front had to go on. My marriage imploded, my children struggled to cope with the diagnosis…but regular psychotherapy helped me to keep my head above water” (Parliament of Australia Senate, 2005:8). Bernard argued that hospitals have a

---

[47] None of the carers in this study left their marriage, but several relayed accounts of friends and celebrities abandoning their spouses when caregiving became too emotionally burdensome. Bard (1997:46) explains that severe illness poses a challenge to marriages, especially those already experiencing problems.

[48] Capra (1982:352) refers to this as a lack of a “systems” approach, where health should be, but is not, viewed as an “ongoing process” in medicine.

duty of care to inform carers of available psychosocial support. Unpaid family members are relieving a big portion of the hospital's burden and they need help to continue to care. Informing carers of available psychosocial assistance, however, is beyond the biomedical scope of doctor-patient-carer interactions.

The contrast in Bernard's experiences between the hospice system and the hospital highlights another cause of carer neglect within the medical system: the biomedical model. The allopathic or biomedical model is the cornerstone of the medical profession, with roots beyond the nineteenth century, as far down as Descartes, Galileo and Newton (Capra, 1982; Turner, 2006). It is a paradigm focused solely on addressing the biological causes of disease (Capra, 1982; Davis & George, 1993). Prevention, health protection, a quality of life focus, communication, ethics, the psychosocial and incorporating both mind and body in concepts of health were lost with its introduction (Capra, 1982; Davis & George, 1993). Mark's assessment of hospital priorities reflects the biomedical model's limited focus: "the priority goes from when you are post-op and in intensive care for the first couple of hours until they know you are going to live or die. And once they know you are going to live they really lose all interest." Nurses are said to be more aware, but doctors do not typically recognise psychological problems or that carers need attention until they are physically unwell (Askham, 1997; National Cancer Control Initiative, 2003; Parliament of Australia Senate, 2005; Thomas et al., 2001). Thus, it is hard for patients and carers to access psychosocial services because prevention, emotions and carers are all beyond biomedical perceptions of care (Grbich et al., 2001; National Cancer Control Initiative, 2003; Parliament of Australia Senate, 2005).

A consequence of this paradigm is that carers tend to overlook *their own* need for emotional care. An iatrogenic side-effect of this biomedical model's neglect of emotions is that many carers, like Bernard, ignore their emotions and poor psychological health. By focusing only on physical ailments, providers show that psychosocial support for patients and carers is irrelevant (Maguire, 1985). Following the trusted reputations of medical professionals, carers and their informal social networks judge their stress and anxiety as trivial until it is too late and a crisis point has been reached. In short, both economic and biomedical paradigms worsen carer morbidity.

Information Distribution

If carers were guided through the myriad of information on available psychosocial services, this might counter the iatrogenic impact of excluding carers and emotions from medical system budgets and biomedical practices (Janda et al., 2006; Morris & Thomas, 2002; Sharpe et al., 2005; Sherwood et al., 2004). Understanding and using technical equipment (such as IVs and colostomy bags) associated with cancer care at home is another source of carer's anxiety (American Cancer Society, 2006). If carers were given explicit directions in how to provide technical care at home and provided with support in medical decision-making outside of the hospital, this might lessen the associated distress (Janda et al., 2006; Sherwood et al., 2004). The Canberra medical system's practical and psychosocial information dissemination[49] practices, however, are inconsistent. Many medical professionals miss the importance of certain types of information for carers (Haug et al., 1999; Morris & Thomas, 2002).

Carers reported a lack of information on how to perform coordination within the hospital and how to provide care at home. They felt unprepared and unqualified to manage their spouse's care. Even carers who had worked previously as medical professionals found that learning how the hospital hierarchy works, how to get the system to do what you want and how to perform minor medical tasks involved "a huge learning curve" (*Marian*). Carers had to educate themselves on the hospital language, accepted behaviours and hierarchy. Phyllis for instance said, "You are just thrown into the deep end" trying to figure out who everyone is and what they are doing or recommending. Jane and Fred, in comparing their experiences as both patients and carers, thought older males were especially unfamiliar with the hospital system, because they are less likely to have been in the hospital during the birthing process.

Carers were also ill-prepared to perform nursing tasks at home. This finding is consistent with Chambers et al.'s (2001) assessment that there is a scarcity of information on managing nursing tasks at home for family carers. In questionnaires, the item asking "Where do you get information about providing

---

[49] While doctors may be reluctant to disclose a prognosis to psychologically vulnerable patients or carers, no such hesitation should impede distribution of practical and psychosocial support information.

practical support, such as how to administer an IV?" elicited several enthusiastic notes in the margins describing poorly distributed information on how to perform nursing tasks and manage medications. One carer wrote, "I was not impressed" about health professionals. In interviews, a few carers said they were asked to give injections and change catheter bags at home with little instruction. In Phyllis's case, hospital nurses came to her home and said her husband needed regular injections, but gave her very little explanation on how to perform these injections. The nurse,

> marched down to the bedroom…and she said "now, you will do this, this, this, this" and she says to me "give him the injection everyday" and she virtually left. And I was thinking, "I was a nurse 30 years ago! I don't know. I have never used this. How do I use this?"…she hadn't bothered to show me whether it [the injection] was…under the skin or when you should give it.

She did not know how, but was expected to perform this medical procedure for her husband, exacerbating her anxiety. Similarly, Colleen was told to change her husband's catheter after his prostate cancer surgery, but was given little instruction. This caused her distress and her husband discomfort when she made an error. Even if carers were given some technical information from medical staff, this was not always enough to ensure carers provided competent care, without anxiety to them or pain to the patient.

Further, carers were unsupported in accessing psychosocial support. Just knowing about financial and psychosocial support, knowing "other people are there to support me when I need it" was a relief to carers (*Millicent*). A senate inquiry into cancer care made a similar assessment. "Cancer is not just a physical disease but has an emotional and practical impact on [patients], their family and carers and…referral to support services should be standard practice from the beginning of their cancer journey" (Parliament of Australia Senate, 2005:8). But, literature on support services was not distributed to all carers. "It wasn't part of the normal procedures" (*Marian*). Many "reported stumbling over information which should have been provided to them or readily available in a range of formats" (Parliament of Australia Senate, 2005:8). The same was true for carers in this study. Carers often complained that they did not know what support was available to them. While a few were offered support, allocation of information was inconsistent and followed a squeaky hinge principle.

A few carers relayed accounts of hospital staff offering help without the patient or carer having to ask for it. Carlie, a low-income earner relied on to be the breadwinner and carer for her husband with an oral cancer, was offered assistance by hospital administration in getting non-government organisation (NGO) help to cover their household bills. Cindy and Frank, a couple in their early seventies, recounted hospital personnel spontaneously assessing what equipment was needed in their home and offering tips on how to perform household tasks when the patient's mobility was reduced. Another carer was given information about financial support, but only when she was in the Melbourne Peter McCallum cancer hospital.

Other carers came across support service information by chance. Marian only received one pamphlet from a particularly attentive nurse, but saw breast cancer carers leaving the hospital with bags full of pamphlets. Phyllis thought that support group meetings were better disseminators of Centrelink financial support options than medical personnel. Anne heard about Carers ACT's free counselling through a friend who works there, not from medical staff. She said, "Information is just not given out. I don't know who is supposed to do it." Three carers concluded that they must have been among the unlucky few who fell through the cracks in the support service information delivery system. This led me to conclude that the problem was not cracks in an otherwise functioning system, but an at best precarious system.

Thus, dissemination of support service information either occurs haphazardly or following a critical care model (Dow et al., 2004; Fallowfield, 1988; Grbich et al., 2001; Harding & Higginson, 2003; Parliament of Australia Senate, 2005). Instead of support information being distributed to all carers on the basis of averting a crisis, allocation of information does not occur until the carer reaches an emotional crisis point. "It is very much who yells the loudest…which is not a very good way to allocate resources really" (*Phyllis*). Just as only the squeakiest of hinges receive oil, only the most desperate or loudest crying carer was introduced to psychosocial staff within the hospital.[50] For instance, only after Marian became upset with a doctor and burst into tears in the hospital did a social worker make

---

[50] Cahn highlights the inflexibility of allocating support in this way. It "tends to focus all funding on survival rather than capacity building. Once on that treadmill, it is almost impossible to get off; all energy is invested in simply staying where one is" (Cahn, 2000:95).

herself known to Marian. Only after a carer suffering from depression went "downhill quite a lot" was he referred to a psychologist (*Ian*).

It became apparent through discussions with male carers in particular that this method of allotting information increases the stigma attached to support services. Fiona alluded to this stigma when she assessed her husband and men in general as "not the best at asking for things" such as psychosocial help. Carers like Rodney also mentioned the stigma attached to visiting the "psychs." Only crazy or abnormal people saw them. If, however, psychosocial support was offered to everyone (not just those in crisis) this would convey a different message: that support services are a preventative measure taken by many carers to feel included, to protect their health and sustain their caring capabilities. If carers are not "squeaky" enough or do not receive information by chance, they are left to navigate the vast networks of non-profit support and hospital services on their own and many carers found that this left them inadequately informed.

Some carers were successful in researching what support is available, determining if they are eligible and making contact on their own. Judy contacted social workers, heard about a support group for asbestos-related diseases and found support. Few carers were as successful. As Fiona explained, many carers "wouldn't know where to start and even when they did start would find, what they would find to be incomprehensible and then I think they would be sort of lost." Others found out about services, but only after it was too late. Blake's wife, who emigrated to Australia years before the diagnosis, only discovered that she was eligible for a healthcare card after they started experiencing financial strain. Millicent was a pensioner caring off and on for 16 years without any social work support being offered. Without the assistance of a social worker, Millicent only discovered a few months before her husband's death (when a patient suggested it) that she was eligible to stay at the Leukaemia foundation house. Knowing about and staying at the Leukaemia foundation house when they travelled to the Canberra Hospital from a regional town for treatment would have saved her a decade of expenditure on accommodation. This inconsistent method of informing carers is likely to have a detrimental impact on carers, as having unmet needs has been found to be linked with higher rates of emotional and physical health problems especially exhaustion, depression, anger and stress (Gibson et al., 1996).

An exception to this pattern is that breast cancer carers in this study appeared to have few unmet psychosocial support needs because of the presence of breast care nurses. In interviews, most carers in contact with breast care nurses reported receiving both technical and psychosocial support information. Studies on breast care nurses in other Australian states support this finding (Eley et al., 2007; Victorian Centre for Nursing Practice Research, 2001). An inquiry into cancer care in Australia made a similar distinction. They concluded that breast cancer patients receive more information on their diagnosis, treatment and support service options than patients with other cancers (Parliament of Australia Senate, 2005).

The experiences of husband and wife Mark and Fiona illustrate this contrast. Mark was a carer for Fiona when she had breast cancer but said the information and attention from breast care nurses meant that virtually all the caring tasks were “taken care of from start to finish.” But when Fiona was caring for Mark as a prostate cancer patient she had to work much harder to find information on incontinence products and other relevant services. Many carers of a wife with breast cancer were provided with ample information, supplies and coordination because of breast care nurses. They give breast cancer patients and carers statistics, case studies, reconstructive surgery options, booklets, information on the hospital system and directories of non-profit services such as the wig service. For most, breast care nurses are available on an ongoing basis, ensuring that questions are answered and information is tailored to each couple’s specific situation. They supply the patient with a post-mastectomy cushion and drain-carry bag. They even coordinated appointments with other hospital departments such as physiotherapy.

Overall, breast care nurses have a positive impact. They provide information, support and an extra set of eyes watching out for patients, relieving much of these carers’ burden and anxiety. The breast cancer nurses lessened Mark’s research burden and his coordination burden. They included Mark, asking about his emotions and treating the couple as a unit. He described them as “extremely effective.” Mitch too was taken aback when a breast care nurse called on a weekend to check how his wife was coping at a time when she was depressed, alleviating his emotion management burden. He said that breast care nurses are “how people get well” emotionally and physically, and an instance of the medical system getting it right. The National Cancer Control Initiative (2003) supports his assertion, showing that breast care nurses improve survival outcomes. By including carers in their scope of care, breast care nurses may also be ameliorating carer morbidity and strengthening their caring capacity. Gibson and colleagues (1996) found that carers who are well informed of their technical and emotional role and potential health risks experience less anxiety, fewer health problems and are therefore better carers.

Breast care nurses, however, did not help every breast cancer patient and carer. They made mistakes, were not in contact with all breast cancer carers and, because of understaffing, could only do so much. Colleen, a breast cancer survivor, said her initial breast care nurse was more harm than help. The breast care nurse overloaded her with information when she was recovering from a mastectomy and did not explain who she was or what information was applicable. Not explaining what data was relevant caused Colleen undue anxiety. She later learned that this lapse in tailored information dissemination was because that breast care nurse was burnt out.

Not all carers of a spouse with breast cancer had contact with breast care nurses. Matthew, whose wife was undergoing chemotherapy for breast cancer, had not heard of breast care nurses. Patrick, whose wife was also going through chemotherapy for breast cancer, did not mention breast care nurses once during our two interviews.

Others described the impact of breast care nurses as limited. When making emergency decisions about his wife’s care, Bernard said “there is that breast care nurse…the trouble is that it only goes as far as the things they know about and can do and they are already stretched…beyond the limit probably.” Colleen, too, now has contact with breast care nurses, but says they are too busy to be of immediate help. She said that they “are very good except it’s very hard to get onto them because not only do they answer their phone, they go around hospitals visiting patients.” Despite these systemic problems, those who had ongoing contact with breast care nurses benefited.

Breast nurses cannot resolve all of the problems stemming from economic efficiency imperatives, biomedical blinders and an increasingly complex and fragmented medical system. They cannot fill every gap in the medical system, but overall, they seem to alleviate much of carers' confusion related to navigating and coordinating care within the medical system and external support centres, when their services are not stretched too thin. Further, they provide carers with relevant technical instructions over the phone, support service details and an ally within medical systems. They provide a much needed holistic and carer inclusive approach to cancer care.

All carers need medical personnel to provide this information to them because carers are not in an ideal position to research how to change a catheter or how to identify the warning signs of severe anxiety (Dow et al., 2004; Thomas et al., 2002). The reasons are threefold. First, many carers do not identify themselves as carers, thus they do not "take actions that protect their own physical and mental health and financial security" (Hoffman, 2002:2; Hunt & Mintz, 2002) (see chapter three). Although participants in this study recognised their title as carer,[51] most saw it as secondary to their primary role: spouse. Carers need to be informed first that they are carers and then guided appropriately. Second, even if carers do identify with the role, it is still very difficult for them to know where to look. Need is partly determined by "what people know to be available" (Gibson et al., 1996:5). Without knowing what their needs are and where to look, carers would be ill-prepared to research the medical information and psychosocial support services. Further, most carers and cancer patients have not previously accessed agencies like Centrelink, palliative care, the Cancer Council or the "array"[52] of other services, so they do not know what is available or how to look for what is available (Parliament of Australia Senate, 2005:50-1). Third, many carers do not have the time to prioritise their own emotions (see chapter five), nor are they encouraged to make time for their emotions in doctor-patient-carer interactions guided by the biomedical model. Thus, carers need to be included, guided and supported within the medical system.

Further, there is a moral imperative to support carers. Currently, "there is a social welfare responsibility" that is being neglected by inconsistently supporting cancer carers (*Linda*). Not providing practical and emotional care resources to all carers

---

[51] It would be reasonable to assume that those who did not see themselves as informal carers would not have participated in this research.

[52] For example, in 1997 there were over 2,000 Home and Community Care funded organisations in Australia (Duckett, 2004).

is a breach of law and ethics.[53] It could be interpreted as a tort: “a wrongful act or injury done wilfully or negligently” by medical professionals (Bodenheimer & Grumbach, 2005:125; Braithwaite, 1990). The medical system may be breaking the law by not acting to counter the poor health externalities that it is causing. It is also a breach of two central pillars of medical ethics since Hippocrates: beneficence and non-maleficence (Bodenheimer & Grumbach, 2005; Braithwaite, 1990; Duckett, 2004; Little, 1995). Beneficence is the “obligation of healthcare providers to help people in need” and non-maleficence is “the duty of healthcare providers to do no harm” (Bodenheimer & Grumbach, 2005:129).

Strategic changes need to be made in the short term and long term if medical systems are to continue to rely on carers and weather the surge in cancer care that has been predicted over the coming decade (Burns et al., 2004; Parliament of Australia Senate, 2005). Little (1995) goes as far as to argue that changes towards a more personal and holistic approach need to be made within the medical system as a whole if medicine is to hold on to its trusted position within society. Further, with people living longer, life should not be the benchmark of medical success. Instead, satisfaction with psychosocial, emotional and personalised medical care should become the new benchmarks. But, how should policymakers go about addressing the holistic care and information dissemination deficits and breach of ethics identified in this chapter? Recommendations for addressing these systematic hurtles is the focus of chapter eight.

---

[53] Similarly, Grbich et al. (2001) argue that insufficiently supporting carers is a breach of palliative care standards.

Chapter Eight: Recommendations to Improve Carer Support

In chapter seven, I describe the negative impact that *home at the hospital* practices (hospital system practices of relying on spouses to provide care for cancer patients at home and in the hospital) are having on carers of cancer patients' wellbeing. In this chapter, I make recommendations on how policy and hospital practice might be amended, based on carers' experiences and a review of the literature.

One option is reverting back to total institutions, but this would be politically unacceptable. Thirty-one of the thirty-two carers interviewed expressed strong desires to be involved in providing personal care for their spouse, not banished to waiting rooms. Total institution care would also be unpopular with governments and tax-payers, as removing carers from the care dynamic would dramatically increase hospital costs.

Enlisting the often presumed "untapped resources" of the non-market world (i.e. more family-carers or volunteers) would also be unlikely to succeed (Cahn, 2000:51). People only have so much time and "everywhere one turns…the market economy are crying out for more and more help from the non-market economy" (Cahn, 2000:115). Further, the emotionally charged nature of volunteering with cancer services means most do not volunteer on a long term basis. Phyllis, for example, started volunteering with cancer support organisations a few months after her husband's death, but has since asked to be taken off their mailing lists so that she can put the experience behind her. A staff member at a local cancer support service found this to be a common occurrence. Further still, people expect this kind of help to come from medical systems, not the non-market world (McNamara, 2001; McNamara & Rosenwax, 2007).

Instead of impersonal and costly institutional care or relying on volunteers who are unlikely to eventuate or last long, implementing a patient care coordinator role is a more feasible solution. Often carers made comments to the effect that "it would be nice to deal with one person who just advocated for you and coordinated everything" (*Phyllis*). Some thought GPs should be the ones to advocate, coordinate and disseminate information to patients and carers. Others thought a new care coordinator position should be implemented within the hospital system.

Similarly, two frequent and feasible recommendations on how to improve waning trust and decreasing personal care (Little, 1995) within cancer care and wider medical industry literature are (1) educating doctors on the benefits of holistic care and having GPs play the care coordinator role or (2) expanding the breast cancer care role to include all cancer patients and their carers. I argue that the latter approach is likely to be more effective.

Changing Medical School Curriculum

Inquiry committees (Parliament of Australia Senate, 2005), ethicists (Little, 1995) and other researchers (Fallowfield & Jenkins, 2006; Haug et al., 1999; Kearney et al., 2007; Maguire, 1985; National Cancer Control Initiative, 2003; Stiefel et al., 2006; Wearing, 1996) have all suggested that GPs and specialists should be educated and trained to provide more holistic, coordinated and even more "time-empathetic" care (Pritchard, 1992:91). There is also a push to require current medical professionals to undergo communication skills training (CST)[54] to improve clinicians' flexibility in interactions and ability to elicit emotional information from patients (Fallowfield & Jenkins, 2006; Stiefel et al., 2006).

As education is a key means of socialising students into their respective professions and limiting students' foci to a specific paradigm, it has been rationalised that changing the curriculum will encourage GPs to provide more holistic and emotion-focused care (Davis & George, 1993; Little, 1995; Petersen, 1994). Currently, doctors are barriers to information (Allen et al., 2004; Broom, 2005; Burns et al., 2004; Hutchinson et al., 2006). This is because recruitment of students is based on academic achievement, not interpersonal skills and medical science training only prepares doctors in an objective stance, not the empathetic subjectivity required in holistic care and effective communication (Davis & George, 1993; Goldstein et al., 1988; Maex & De Valck, 2006). New curriculum, it has been suggested, should include "empathetic, fluent and intelligible communication with patients" as its central aim, and courses on literature and the humanities to teach medical students of the "tensions of their professional pain and loss and suffering" (Little, 1995:165, 173).

---

[54] Communication training is already a requirement for medical school accreditation in Australia (Skene, 1990).

This solution seems to directly confront the problem of a waning trust in the medical system and science that is evidenced in the increasing use of complementary and alternative therapies, complaints, litigation and media coverage of medical professionals' "greed," "coldness" and "businesslike" approach (Allsop & Mulcahy, 1998; Fallowfield & Jenkins, 2006:106; Little, 1995:2, 160, 174; Parliament of Australia Senate, 2005; Stewart et al., 1999; Turner, 2006). This problem is part of a wider lag in medicine. As infectious diseases become less threatening with pharmaceutical advances and chronic illness becomes the stuff of most medical interactions, life expectancy "as a measure of achievement" has become inappropriate (Guillemin, 1997; Little, 1995:8; Turner, 2006). Patients do not just want to have their lives' saved (Little, 1995). They also want holistic care, delivered with compassion and clear communication, that improves their quality of life (Breitbart, 2006; Little, 1995; National Cancer Control Initiative, 2003). Thus, incorporating humanities and the social elements of health into medical school curriculum and training current GPs in communication is thought to result in more quality of life-focused care and a new definition of "progress" and "success" (Little, 1995:170, 177, 74, 12, 81).

A direct approach, however, may not be the most effective. Although, medical curriculum does have paradigm shifting and behaviour changing potential, "'magic bullets' are hard to come by" (Bodenheimer & Grumbach, 2005:187; Petersen, 1994). On a micro level, a focus on educating doctors indicates that doctors alone are at fault. This might be construed as a personal attack against doctors, which can lead to fear and cover-ups amongst medical professionals instead of improvement (Bodenheimer & Grumbach, 2005). On a macro level, curriculum changes are not likely to be successful in improving carer inclusion and psychosocial support within medical interactions unless the many systemic obstructions are also addressed (Fallowfield & Jenkins, 2006).

An understanding of the hurdles at macro, meso and micro levels is required in assessing the merit of medical system change strategies (Duckett, 2004; Griffiths, 2003; National Cancer Control Initiative, 2003; Straus, 1990). Implementing curriculum changes is unlikely to be an effective solution to carers' problems of holistic inclusion and receiving information because it overlooks the many systematic barriers to change.[55] These barriers include (1) doctors' biomedical socialisation during internships, (2) the challenge to medical dominance posed by holistic care, (3) time constraints in medical interactions, (4) patients' and carers' expectations, and (5) the decreasing prevalence of life-long GPs.

First, doctors' socialisation into their professions has more impact than their education, rendering curriculum changes ineffective. In their famous study *Boys in White*, Becker and colleagues ([1961] 1977) found that medical students' priorities are shaped less by their education and more by the priorities they adopt during internships and practice. Most medical students begin their academic careers with strong ideals of caring for others, but slowly adopt new priorities. In order to succeed as interns they must learn new skills and gain experience with rare afflictions. Eventually, career advancement overrides holistic care as their main priority (see also Coombs & Powers, 1976). Recent assessments of doctor communication training show that this is still the case. Fallowfield and Jenkins assert that "there is little point in equipping junior staff in better skills if they then enter the same old system that has consummately failed to provide excellent communicators" (2006:110-1). New medical school curriculum is not likely to have an impact unless changes are made in hospital priorities and supervisors' values.

Moreover, even if GPs are trained in social models of health, the predominance of their biomedical training is likely to prevail. This is because doctors are equipped primarily with biomedical tools in treating illness, not social ones. They are trained to reshape problems of a social origin into biological problems that can be treated with medication (Grbich, 1996). Thus, doctors are poorly placed to combat psychosocial illness. Without a therapy background, doctors are unlikely to begin to feel confident in addressing patients' and carers' psychosocial needs (Firth, 2006; Grbich et al., 2001; Hutchinson et al., 2006). Thus, GPs and specialists are likely to continue neglecting carers and emotional facets of ill-health despite curriculum changes (see Capra, 1982).

---

[55] The senate inquiry into cancer care also list several barriers to change within the medical system: "attitudes and resistance to change of medical practitioners; funding model; the medical benefits scheme and differences in private and public systems; [and] lack of time, resources and clinical staff" (Parliament of Australia Senate, 2005:36-7).

Second, doctors, like most professionals, are not receptive to changes which might undermine their positions of dominance (Broom, 2005; Petersen, 1994; Willis, 1983). Doctors' interests are not purely mercenary, but reflect "vested interests" in maintaining their status (Little, 1995:4). Providing holistic and empathetic care undermines their status. Medicine's dominance, doctors' positions of authority within the medical system, their higher income and higher prestige are all legitimated by a doctor's superior knowledge and connection to positivist, quantified and objective science (Capra, 1982; Davis & George, 1993; Petersen, 1994; Turner, 2006; Wearing, 1996; Willis, 1983). An overt focus on psychosocial and quality of life care circumvents this link to positivism and superiority. Despite the centrality of interpersonal skills to the quality of care delivered by a doctor, performing emotion work is generally viewed as below the "status shield" of doctors (Small, 1996:270; Turner, 2006). Thus, to maintain their superior positions, it is in GPs' best interests to emphasise the objective and scientific elements of their jobs.

Medical systems, as bureaucracies, help doctors to defend this dominance. Bureaucracies are strong structures resistant to change (Petersen, 1994). Their tendency towards "minimalist services," rigidity, Taylorism, dominance-reinforcement and rational thought make bureaucracies especially resistant to curriculum changes (Grbich, 1996; Petersen, 1994:90-7). If changes were introduced, psychosocial care would only be "grafted on to the dominant biomedical, physical system" (Petersen, 1994:105).

Third, this research shows that time, as well as biomedical training are preventing doctors from treating carers as co-consumers. Medical Benefit Scheme incentives, pressure from peers and management, staff shortages and the overarching drive for more efficient medical care have shortened doctor-patient (and carer) interactions to under ten minutes on average (Allen, 2000; Bodenheimer & Grumbach, 2005; Davis & George, 1993; Duckett, 2004; Fallowfield & Jenkins, 2006; Little, 1995; Pritchard, 1992; Surbone, 2006). There is little time to explain procedures and risks let alone time for holistic care (Allsop & Mulcahy, 1998; Kennedy & Lloyd-Williams, 2006). Before holistic care can be prioritised, time constraints need to be addressed (see Addington-Hall et al., 1992).

Conversely, before holistic care can be requested, time constraints need to be addressed. As users are required to pay the difference between what Medicare covers and what the doctor charges, carers are unlikely to push for more time for psychosocial support-rich interactions (Bodenheimer & Grumbach, 2005; Davis & George, 1993). Further, carers are unlikely to take any time from patients' in doctor's appointments, let alone request psychosocial support (Mellon et al., 2006; Northouse et al., 2000). The extreme time constraints result in patients' and carers' autonomy being compromised and GPs' priorities being constrained to only the most pressing physical concerns (Fallowfield & Jenkins, 2006; Pritchard, 1992).

The emphasis on efficiency also means that doctors have very little time for debriefing or unpacking their own emotions.[56] Complaints and interacting with dying patients have been shown to have potent emotional impacts on medical practitioners (Allsop & Mulcahy, 1998; Guillemin, 1997; Kuhl, 2002). Some doctors act removed or hide behind statistical information to protect themselves from emotional exchanges with patients and families (Bard, 1997; Maguire, 1985; Small, 1996; Surbone, 2003). As interviews with carers of cancer patients show (see chapter five), time is centrally linked to emotions. To interpret and cope, time devoted to emotional introspection is required. Thus, doctors are unlikely to be emotionally receptive and more likely to avoid emotionally charged patient or carer interactions without time for their own emotions.

Fourth, carers and patients expect doctors to be distant, objective and rushed. Irvine (1996:197) explains that doctors' are expected to be "objective and emotionally detached." Expectations are culturally shaped and change in the health system can only occur when the culture has changed (Capra, 1982; Payer, 1988). Thus, educating medical students is unlikely to directly effect patients' and carers' expectations.

---

[56] The characters in the novel *House of God* describe doctors as unable to connect with patients because they are not given time or not allowed to experience emotions themselves. The author, a medical doctor himself, writes, "lethal, this becoming and being a doctor! Denying hope and fear, ritualized defenses pulled up around ears like turtlenecks" (Shem, 1978:324). And in another passage he writes, "how can we care for patients if'n nobody cares for us?" (Shem, 1978:359)

Fifth, many theorists have argued that GPs' roles are changing or may even cease to exist within the next twenty years (Davis & George, 1993; Marceau & McKinlay, 2008; Turner, 2006; White, 2000). The life long family GP is a less common occurrence and use of locum services is increasing (Duckett, 2004). More "minute-clinics" are opening their doors to faceless streams of patients in need of prescriptions or sick certificates (Marceau & McKinlay, 2008). This bureaucratic, impersonal and "consumerist medicine" approach to health care, where patients contact an arbitrary doctor when required, means fewer GPs are providing ongoing care (Davis & George, 1993:370). If few GPs are in a position to provide an overview or support carers in the long term, then implementing holistic medical school curriculum will not counter this. Thus, solutions should not be focused on GPs.

Cancer Nurses

Changes in medical school curriculum may intervene directly at the level within the power structure where the problem occurs, but there are many obstacles to success and it will take a long time for these changes to make an impact (Straus, 1990:27). As Capra (1982:359) points out, "integrat[ing] physical and psychological therapies will amount to a major revolution in healthcare." Those who are in positions to gain from the continuation of the biomedical paradigm are likely to resist this revolution forcefully. Thus, indirect systemic change, making changes at a level other than where the problem occurs, is more likely to be effective.

Systemic change or taking a "systems management approach" was interviewee Andrew's proposed solution. Focusing on communication, he assessed the system to be *ad hoc*, inconsistent and full of "cracks." He thought consistent communication could be ensured if a patient care coordinator role was created. This position would involve coordinators advocating for patients (and carers) in hospital decisions and providing an overview of each patient's care to both medical staff and families. He foresaw the patient coordinator creating a tick box approach for doctors - clicking a box on a computer program when they had communicated the relevant information to the listed required parties. This, he thought, would prevent time consuming system breakdowns. In addition to the communication checklist, he thought details of a patient's history, diagnosis and treatment plan could be uploaded to a database, allowing other doctors and nurses in the hospital to review the patient's "total picture" and allowing other medical staff to give the information to the patient or family members at a central information point within the hospital.

Andrew was not alone in making this suggestion. Researchers (Dow et al., 2004) and other carers pointed out the need for a patient coordinator to liaise between families, the medical team and available psychosocial support. Jane suggested the implementation of a cancer specific position between the GP and the specialist, someone to "take the fear out" of the process and tell carers and patients what to expect, emotionally and physically. She said booklets are insufficient because carers and patients are often too stunned before they are rushed to treatment to be able to focus on digesting any written material. Matthew thought there was a need for a person at the hospital to distribute information to patients and carers on their financial options at Centrelink and going back to work. Phyllis wished there was one person a carer could talk to enquire about relevant support services in Canberra. Bernard said that having a community cancer nurse on call to help with the initial post-chemotherapy nausea would provide a reaction model for carers and decrease their worrying.

Providing all oncology carers and patients with a cancer nurse would address this need for systemic change and care coordination. As Capra (1982:368) points out "compassion and wisdom" are more important in delivery of holistic care than advanced certification in science, so the role should not be limited to doctors. Skene (1990:227) writes, "it does not matter who gives it" as long as the patient and carer are well informed. In fact, it is best if the coordinator is not a doctor. Matthew's experience shows why. Matthew's oncologist told him to call her day or night if they needed anything, but he felt he could not because he knew how busy she was. Deference to doctors makes them unapproachable and ill-suited to the provision of time-consuming psychosocial information. This highlights the need for a non-doctor coordinator within the hospital system that patients and carers feel they can contact without imposing.

Nurses are best suited to undertake this role (Chambers et al., 2001). Unlike doctors, nurses are not as immersed in the biomedical model, nor do they rely on it to maintain a position of medical dominance. The medical benefits scheme does not dictate the length of their consultations and, unlike predictions about GPs, nurses are likely to continue as a central part of cancer care in the future. The number of nurse practitioners, for instance, is predicted to double by 2015 (Cooper et al. 1998; as cited by Bodenheimer & Grumbach, 2005). Further, (1) nurses are a less costly solution, (2) they have a demonstrated beneficial impact, (3) holistic care is in line with carers' and patients' expectations of nursing work, (4) cancer care nurses would increase patient autonomy and (5) prevent conflict between nurses and carers.

First, having cancer nurses provide holistic care and coordination is more cost-effective. In terms of salary, employing nurses is irrefutably less expensive than GPs. On average, nurses earn approximately half as much as GPs and one third as much as specialists (ABS 2002; as cited by Duckett, 2004). Thus, as a cost to the government, nurses' time is much less expensive. Doctors are paid higher salaries for their advanced scientific and specialist knowledge, so it makes more fiscal sense to limit their role to that area of specialisation and have nurses perform the more time consuming role of providing holistic care.

Second, it is unclear if medical school curriculum changes will have the desired effect, but past research, patient accounts and the accounts of carers provided in this thesis demonstrate the value of breast care nurses (Docherty, 2004; National Cancer Control Initiative, 2003; Parliament of Australia Senate, 2005; Sardell et al., 2000). It is reasonable to assume that cancer nurses would be similarly effective. Sally, in her experience with cancer support nurses at the Peter McCallum Cancer Treatment Centre in Melbourne found this to be true. Further, Addington-Hall et al. (1992) found that coordination of cancer care has a positive impact on patients' side-effects and carers' feelings of bereavement anger (though no impact was found on carers' physical health). Having cancer nurses specialise in certain types and ranges of cancer (such as prostate, haematological or rare cancers) might also ensure that they are well informed of the specific needs of patients and carers with certain cancer.

Third, carers and patients expect emotion-oriented and holistic care from nurses. Carers, like Judy, did not want doctors to provide emotional support, but welcomingly received emotional support from nurses. Linda spoke of the reassurance she experienced when she asked a nurse educator about the appropriateness of her emotional framework. While patients and carers expect doctors to be removed and objective, they expect nurses to provide empathetic care, to clarify information and be accessible (Haug et al., 1999; Kennedy & Lloyd-Williams, 2006; Skene, 1990; Small, 1996; Wearing, 1996). Much of these expectations are shaped by the fact that almost all nurses are women (Davis & George, 1993; Wearing, 1996). Although using cancer nurses to provide holistic and emotional support may perpetuate the gendered and unequal division of labour within the medical system, it may also provide these nurses with more autonomy. Nurse specialists feel more in control of their work, more respected in their role and more satisfied in their work (Davis & George, 1993). They also tend to make fewer mistakes and experience burnout less often (Chernomas & Chernomas 1989, Hall 1989, Karasek 1989; as cited by Davis & George, 1993). To counter the detrimental "psychological health consequences of gendered division in emotion work," debriefing and support mechanisms should be put in place to prevent cancer care nurse burnout (Davies, 2001; Strazdins & Broom, 2004:59).

Fourth, the cancer care nurse position would improve patient autonomy. Adding another player to the "game" provides carers and patients with more autonomy in doctor-patient decisions. In Allen et al.'s (2004) analysis of family caregivers and patient "care trajectories" in multidisciplinary care, Elias's game theory (1978) is used to understand the multi-causal and complex forces propelling patient care outcomes (see chapter three). One of the conclusions is that as "the alliances between health and social care players [strengthen] the relative power of the patient and their carers is weakened and this is likely to have an adverse effect on patient choice" (Allen et al., 2004:1026). Conversely, strengthening the alliance between carers, patients and a cancer care coordinator could strengthen carers' and patients' relative power and autonomy, providing them with an ally in "care trajectory" decision making.

Fifth, the cancer care nurse position would decrease conflict between nurses and carers by strengthening the relationship between carers, patients and cancer nurses. Carers in this study and Allen's (2000) found that they could not advocate for patients without being perceived as rude because busy nurses rarely asked carers for their input and thus rarely provided carers with an opportunity to unobtrusively contribute. Having a cancer nurse coordinator would provide a forum where carers can request help for themselves and, more effectively and less offensively advocate for their spouses (Sharpe et al., 2005).

Not only are cancer nurses in a better position than GPs to provide coordination and overcome structural barriers to holistic and carer inclusive services, but the role of cancer nurse also has the potential to systematise psychosocial and emotional support for carers and medical personnel. Cancer nurses could standardise psychosocial support by providing triage-based psychosocial referrals to patients and carers and, in their role as liaison, facilitate emotional support for medical staff.

Cancer nurses could provide more personalised psychosocial support recommendations to patients and carers. Cancer nurses are well positioned to “assess” and address carers needs (Chambers et al., 2001:99). Carers and patients have been found to have a variety of needs (Harding & Higginson, 2003; Sörensen et al., 2002). This research shows that much of that variety can be explained based on time-sovereignty, but cancer type and phase as well as gender are also factors that shape carers varying needs. Cancer nurses could tailor information distribution to match patients’ and carers’ perceived or predicted needs. Simply disseminating information is insufficient. Too much information can be overwhelming to carers and patients (Krishnasamy et al. 2001; as cited by Morris & Thomas, 2002). A tailored or “triage” approach where both carers and patients are regularly assessed by cancer nurses and then methodically supplied information on services related to their needs would be most effective (Hutchinson et al., 2006:542). This “systematic discharge strategy” would help to overcome those challenges for carers, such as self-identification and lack of familiarity with support services, listed in chapter seven (Chambers et al., 2001:104).

It is important to highlight, however, that carers would need to be a central focus of cancer nurses (Sharpe et al., 2005). Too often they are an afterthought in policy and service provision. Carers, however, have higher unmet needs than patients (see chapter one) and their wellbeing has a direct impact on their ability to care and the patients’ wellbeing (see chapter seven). Thus, carers’ treatment as both “co-client” and “co-worker” should be central to the cancer nursing role (Thomas & Morris, 2002:180).

Cancer nurses could also be the linchpins connecting community, hospital and family care workers, improving system-wide communication and facilitating emotional support. Each side of the medical system is poorly informed of the "needs, limitations and pressures" of the other (Payne et al., 2002; Pearson, 2006:10). Improving coordination with the cancer nurse position could result in higher service quality in all areas (Pearson, 2006). In their role as liaison of the multidisciplinary care team cancer nurses could also arrange emotional debriefing for medical staff working with cancer patients. As mentioned in chapters five and seven, time is a central factor in giving space to interpret emotions. Recognising this, counsellors have regular meetings with other counsellors to get feedback and prevent "emotional burnout" (Fallowfield, 1988:728). Hospice nurses also meet formally and informally to debrief and re-enforce the value system that gives meaning to their work and helps them cope (McNamara, 2001; McNamara et al., 1995). Doctors and nurses working in cancer should have this kind of support too (Maguire, 1985). In their role as liaison, cancer nurses could facilitate meetings that also act as emotional support outlets for medical staff. Having an outlet to express and interpret their emotions could help in preventing cancer care burnout and encourage cancer care personnel to become less emotionally distant from patients and family. It might improve medical professionals' empathy for the value of support groups. It may also help to counter the biomedical precedence within medical systems that prioritises physical care work above emotional labour (McNamara, 2001).

In sum, strategically implementing cancer nurses into oncology care is likely to ameliorate much of carers' ill-health that is being exacerbated by the current model of care. In this current model, factory-like and fragmented care cause carers of a spouse with cancer to take on a care coordinator role for their spouses at home and at the hospital. The stressful responsibility of managing patient information, advocating for the patient and simultaneously managing their spouses and their own peaked emotions has a detrimental effect on carers' health. Adequately supporting carers with practical, technical and psychosocial support would, it has been suggested by carers here, lessen the harmful impact of this model of care. Nurses, as cancer care coordinators, are in an ideal position to provide this support, to provide more systematic psychosocial support to carers and patients and, as a liaison between levels of care within the medical system, they would have the potential to decrease emotional burn out amongst oncology staff.

Conclusion

In this thesis I have argued that caring for a spouse with cancer often involves indefinite grief, a sense of confusion about complex emotions and contradictory emotion work, but little time to reflect on these emotions. These experiences are, in part, a product of a medical system which simultaneously relies on carers – thus increasing their burden – and excludes carers from important information, leaving them under-resourced to deal with their partners' needs and their own emotions. In analysing the emotional and systematic struggles of carers of spouse with cancer, I have made contributions to the emerging sociology of cancer caregiving, to the sociology of emotions and the sociology of time.

This thesis highlighted that little is known about carers of cancer patients' overall experiences, emotions and needs relative to what is known about cancer patients. The many contradictions and gaps within the literature informed the four areas of focus in this thesis and my overarching research question: *what are the experiences and support service needs of carers looking after a spouse with cancer?* The first of those four areas for inquiry was about carers' illness experiences. While much attention has been paid to cancer patients' experiences of liminality, meaning and identity re-creation, little has been paid to carers of cancer patients' illness stories. Thus, I asked: do carers experience the biographical disruption of illness in the same way cancer patients do? The second focus was on carers' emotions and cancer patients' needs. The psycho-oncology literature that dominates this area has argued that cancer carers typically employ coping strategies, especially denial, to overcome the emotional challenges inherent to their role. But, a carer's denial has been found to suffocate cancer patients' attempts at identity re-creation. So, I asked: are carers in denial and if not, what are their emotional experiences? The third focus was cancer carers' high rates of unmet need, particularly amongst younger female carers. In quantitative research, why does this demographic group consistently show higher rates of stress and burden? The fourth focus was support services. This is an area where there is an abundance of literature on cancer patients' experiences, but a paucity of research on the experiences and value of these services for carers. I asked: why do some carers prefer emotional support and others prefer practical support and why do so few carers access formal support services?

These questions were central to informing the data collection and analysis process. To expand on the largely quantitative and psycho-oncology based contributions made by past research, I used a qualitative approach to research, based in the symbolic interactionist tradition. This approach values highly the participants' understanding of their social world. To this end, a triangulation of methods was used and a quasi-grounded theory approach to analysis was adopted. As such, participant observation of support groups was performed first, to inform the design of the questionnaire. Data from completed questionnaires allowed for comparison of a sample of the Canberra cancer caregiving population with one overseas and provided a necessary means of recruiting participants. Longitudinal interviews with 32 carers of a spouse with cancer provided the most in depth data. As part of an action-based imperative, a focus group with a local not-for-profit and support group facilitators provided both a means of giving feedback to local change agents and a means of checking the study's accuracy. A report of relevant findings was also submitted to Cancer Australia in 2009 to provide more detailed feedback to the federal organisation responsible for policy change in this area.

Analysis of interview data allowed me to explore carers' illness experiences. I found that, unlike cancer patients, carers do not seek to find meaning in their illness narratives. This is possibly because carers' identities are not altered to the same extent. While the literature shows that cancer patients reconstruct their identity to accommodate for the impact of the illness on their life story, I found that most carers of a spouse with cancer see themselves, still, as primarily spouses. Only when their spouse became too sick to respond, had a change in personality or became fully dependent on them for mobility and personal care would they change the way they saw their relationship and role. As such, carers' illness narratives were not about recreating their identities. Instead, they were stories of grief. Their grief, however, is poorly conceptualised in the loss and mourning literature. Thus, I offered the terms *indefinite loss* and *indefinite grief* to describe their uncertain and vacillating anticipatory mourning and consequently limited ability to plan for the future.

This concept makes the contribution of bearing witness to cancer carers' unique experiences of grief, providing validation and potentially helping carers to feel less alone. The term also arms support and psychosocial personnel with a clearer means of communicating about carers of a spouse with cancers' illness experiences. It adds to the literature on anticipatory grief and suggests a way forward for this contradictory field of inquiry. The findings presented in chapter three also build on the carer identification literature by identifying why it is that spouse carers rarely identify with the title; as long as some reciprocity in the relationship is maintained, carers of a spouse with cancer tend to see themselves as husbands or wives. This finding could be useful to support services in guiding how they phrase or market support services. Further, these findings add to the literature on caregiving trajectories. Carers' accounts indicate that reciprocity may also be central to understanding why some carers go on caring in the home, while others seek institutional support.

Although grief was central to these carers' experiences, grief is not the whole of carers' emotional experiences. Carers also use coping strategies and emotion work. In contrast to the findings in psycho-oncology studies that focus on denial and carers' coping strategies, findings presented in this thesis suggest that carers of a spouse with cancer are typically not in denial and use different coping strategies at different times. Carers primarily coped in three ways: distraction, compartmentalising and escapism. Further, interviewees' accounts show that cancer carers' use of coping strategies is typically only short term. To explore how cancer carers managed their own and their spouses' emotions, I employed Hochschild's concept of emotion work. Carers managed patients' emotions to help them to be "good patients," that is, to be positive and stoic. They did this by distracting them, giving pep talks, listening, acting and lying and blocking undesired communication. Helping the patient to be positive was thought to, possibly, improve immune system health and the patients' ability to overcome the cancer, help carers to feel a sense of control over the process and make it easier for the patient to receive informal support and support from medical staff.

Viewing emotions as an ongoing and social process, allowed me to understand the patterns around temporal orientation in carers' and patients' emotion work. The diagnosis and consequent uncertainty about the future causes carers to experience what I call *temporal anomie*. To overcome this lost sense of direction towards the future, carers either altered their temporal orientation or managed their emotions to maintain their current orientation. Most carers, in line with advice from medical professionals, managed their own and their spouses' emotions to be positive but realistic: to alter their focus from planning for a future together to enjoying life in the present. Others maintained a focus on the future by doing cognitive emotion work, either believing they would overcome the cancer or believing that nothing had changed, that their futures were never guaranteed. How doctors framed the diagnosis was central to the patient and carers' subsequent temporal orientation.

These findings support the socio-historical critique of denial as over diagnosed, individualistic and often mistaken for interaction norms where discussions or a focus on death are categorised as taboo. They also highlight the temporal distinction between the concepts of coping strategies and emotion work. As I suggested above, coping strategies, such as distraction and escapism, are used in the short term. In the long term (as well as in the short term) emotion work is performed to help carers and patients conform to a specific orientation. These findings also support the literature that shows being future-oriented is the norm. I showed that when this temporal orientation is challenged people do emotion work. Overall, these findings show the need to incorporate time into conceptualisations of, not just carers', but everyone's experiences of emotion and emotion work.

These findings also add to the patient-hood and prognostication literature. The finding that patient-hood was uncomfortable for men who could not work supports Rasmussen and Elversdam's conclusion that work is the antithesis to patient-hood. The finding that the delivery of the prognosis is central to the couple's temporal orientation supports critical medical sociology theories on prognostication and interactionist theories on doctor-patient behaviour. The doctor has power, being the one to frame, in terms of temporal orientation, how carers' and patients' perceive the future. But, how they frame this future is based on their perception of the cancer and patient. If doctors perceive the patient or carer as in denial, they may encourage a positive but realistic temporal orientation. If they perceive the prognosis as "good" and relatively certain, they may be more inclined to encourage the couple to do emotion work towards believing that nothing has changed, their lives were always uncertain and they should continue planning for the future. This finding, that *temporal anomie* is central to prognostication, also makes a contribution to the clinical narratives literature. I suggest that *temporal anomie* and *temporal orientation* should replace the ambiguous term "hope" currently used in this field.

On the whole, solely examining coping strategies is insufficient. I demonstrate that widening the scope to examine the influences of CAM, medical interactions and social support in understanding carers' emotions provides a more accurate picture of carers' emotions and doing so in future studies will help to decrease the misdiagnosis of denial and improve the quality of researchers' recommendations about how to support cancer carers.

The focus turned subsequently to the social impacts on cancer carers' emotional experiences. While the literature stresses gender and age as important factors in predicting carers' levels of stress, burden and unmet need, my findings suggest that time-sovereignty is the underlying cause behind this variation in carers' needs and experiences. Thus, I categorised carers' experiences based on time-sovereignty. I introduced the fluid categories of time-sovereign, time-poor and time-destitute as indicators of carers varying emotional experiences and thus varying needs. Those carers who had few demands on their time as a consequence of their caregiving role being less onerous and as a consequence of having few other responsibilities outside of caregiving, were categorised as time-sovereign. Carers, whose spouse required substantial help, as a result of impairment to their mobility for instance, were categorised as time-poor. I categorised those carers who had many demands on their time as a consequence of juggling multiple roles, such as parenting, caregiving and breadwinning, as time-destitute. This categorisation allowed me to discern an overall qualitative difference in carers' experiences. Those carers who were time-destitute had little time to process, absorb and reflect on their emotions. In short, unlike more time-sovereign carers, who tended to grow closer to their spouse, these carers had little time to feel.

Once again, time is shown to be central to understanding emotions. Time-destitute carers' experiences show that free time is necessary to processing and reflecting on one's feelings. Just as distraction is used in the short term to take a break from one's emotions, if a person is continually distracted from their emotions they will continually be unable to be introspective and ask themselves what they are feeling and why they are feeling a certain way. This finding contributes to the sociologies of time and emotions. It underscores interactionist interpretations of emotions as visceral and culturally shaped. I add that, before emotions can be modified to adhere to cultural feeling rules, time is a necessary factor in this process. A person must first assess and infer their visceral response before they can shape their emotions.

This finding also highlights several areas for future research. First is the necessity of including time-sovereignty in exploring emotions. The implications of these findings is that time is missing form the sociology of emotions. This research demonstrates that they are intimately linked and thus time should be more centrally included into future studies on emotions such as Collins' theory on interaction ritual chains. Time-sovereignty is necessary before anyone can engage in solidarity enhancing activities such as interaction rituals with others in their community or even others in their family. Second, this finding underscores the value of including emotions in measures of a person's discretionary time and social welfare (such as Goodin et al.'s recent work). Third, within the sociology of cancer caregiving, these findings suggest future researchers investigate the link implied by my findings – that time-destitution is related to marital breakdown amongst cancer patients and spouse carers and time-sovereignty is related to increased solidarity between patients and spouse carers who had a close relationship before the diagnosis. Further, this finding might also be useful to health and support service providers. In looking out for carers at higher risk of unmet needs and personalising support recommendations, time-sovereignty provides a new measurement for assessing carer wellbeing. And, for policymakers, this finding highlights the difficulties that these time-destitute and time-poor carers have in taking a break and their need for more accessible respite.

A brief digression is called for here to make a case for the value of these findings. Some have argued that these types of findings can have a normalising and self-policing effect. Hutton (1988:135), for example, argues that "the self is an abstract construction, one continually being redesigned in an ongoing discourse gendered by the imperatives of the policing process" (as cited by Frank, 1993:49). He, as a Foucauldian, is arguing that individuals seek information on what is normal and either monitor themselves or are monitored by others to conform to this definition. This conformity to the expectations of institutions and other bodies of power helps to maintain their functionality.

Others have argued that the human sciences are paramount in this process (Furedi, 2004; Powell, 2008; Rose, 1989). As Frank (1993:49) explains, psychologists and sociologists provide “types.” “‘Types’ then becomes ‘stages,’ and stage theories become institutionally enforced expectations.” Using the example of Kübler-Ross’s (1969) work with the dying, Frank shows how many human scientists seek to give “voices” to different groups, but unintentionally propagate their regulation when the findings are “appropriated in clinical settings to routinize how the ill are heard by staff, and even to label those who fail to confirm to the ‘appropriate’ stages” (Frank, 1993:49). Thus, findings related to grief and emotions often become scales of normality for institutional and individual “policing.”

Consequently, and for good reason, a person might conclude that conducting a study such as the one offered in this thesis is pointless as it will only result in self or clinical regulation. I argue, however, that for several reasons that would be an example of the old German proverb, throwing out the baby with the bath water: discarding something valuable just because of one flaw.

First, these findings have the beneficial effect of “giving a voice to the ‘other’” (Frank, 1993:50), bearing “‘witness’ to the suffering” (Kleinman 1988; as cited by Bury, 2001:282) and prompting action. Although Bury and Frank are referring to the suffering of patients, carers’ experiences may need witnessing even more so than patients, as they are often forgotten and in need of recognition by the media, by families (see the introduction) and, as this research shows, by medical staff. In fact, this was one of the reasons many carers participated. One carer said, “It appears that carers become invisible” and later, “I am just hoping that someone will do something to make life better” (*Frank*). In my field notes I wrote that following my first interview with Anne, she said “thank you for doing this research. I just hope that it helps other carers to avoid what I went through.”

Anne’s gratitude also speaks to a second value of these findings: legitimation (Bury, 1991). Compiling an overview of carers’ grief, coping and emotion work gives credibility to their experiences. Reading accounts of other carers’ emotional struggles can have the comforting effect of preparing others and decreasing their sense of stigma (Frank, 1993). Said in another way, people want to know that they their experiences are shared by others (Gregory, 2005). A degree of self-policing is to some extent necessary because we are embedded social beings. This was certainly true of the carers in my study. A few asked if other carers had gone through the same contradictory emotions. Those who went to support groups cited learning that others had gone through similar emotional experiences as a relief and a source of validation. Learning about the range of emotions carers experience can help carers to stop asking "what is wrong with me?" or "why am I feeling this way?" – questions explicitly and implicitly expressed by carers in many interviews.

Describing the values of his illness narrative, Frank (1994:16-7) says this yet another way.

> My illness narrative tells a reader nothing more than what she has already experienced herself: why is it still of value?...[because] The illness narrative addresses the desire to tell stories told many times before, precisely because they have already been experienced….They should listen also for the desire to recognize and be recognized by others that these texts signify.

The terminology I offer aids in this process of recognising and being recognised. Terms like indefinite grief, temporal anomie, and time-destitute will be helpful to support service providers and carers looking for ways of identifying and communicating their emotional experiences. Support group facilitators, during my focus group, supported this assessment.

Third, although studies on emotions run the risk of being fodder for regulatory and normalising efforts, recognising this risk helps to counter it. Warning human scientists and clinicians of the normalising potential that their practices hold may help to moderate their impact. For carers, acknowledging this normalising impact and the compulsion to conform may be empowering, by helping carers to recognise the constraints attached to their experiences (see Frank, 1993). Further, this research shows the variety of carers' experiences, as opposed to a description of *the* normal caregiving experiences. Highlighting the variation in carers' experiences may also help to counter the tendency towards self-policing and policing within medical interactions.

Fourth, by using a sociological gaze, these findings highlight the external influences and constraints on carers' emotions, moving the implied action away from clinical regulation and self-monitoring. They have the potential to inform support services personnel of the structural constraints, such as time and money, on a carer's ability to process and reflect upon their emotions. They also have the potential to make both carers and medical professionals more aware of the interactionist nature of carers' long term emotion work. It is a product of communication with the patient, doctors, nurses, counsellors, other carers and sometimes the CAM literature.

In sum, although the findings from the first half of this thesis risk having a normalising effect, they also have beneficial impacts. (1) They "give a voice" to cancer carers' often neglected experiences. (2) They help carers of a spouse with cancer to feel legitimated and prepared for the complex emotions and emotion work that lay ahead. (3) They inform professionals and carers of the normalising potential of this information. (4) They highlight the interactionist and external constraints on carers' emotions.

In the second half of the thesis, the focus moved away from micro-analysis of carers' emotions, towards the psychosocial programs available to carers of cancer patients and the structural constraints they face in accessing them. I applied the findings presented on time-sovereignty to studying the value of support services to cancer carers. First, the uncertain nature of carers of a spouse with carers' emotion work was revealed. This adds to Thomas et al.'s (2001) initial study by expanding on the understanding of the emotion work done by carers of a spouse with cancer. It involved reprioritising their own needs and concealing their emotions to manage their spouses', which was often tiring and perceived to be hard work. It was shown that these carers experience guilt and confusion because the boundaries between their roles as carer and spouse are unclear. Carers were unsure of how long they would be a carer because of the ambiguity of the disease's trajectory. Thus, they were uncertain about the longevity of their caregiving and in some instances uncertain about how they should feel.

To overcome this confusion, many carers sought emotional support informally from friends and family. Informal support, while it can be helpful can also be limited and problematic – not everyone has a local support network, those who do may not feel comfortable asking friends for help and, offering hospitality to family from out of town often exacerbated a carers' burden. Thus, many of those carers who found informal support inaccessible, burdensome or insufficient sought out formal support services. From counsellors, carers received emotion work advice, an opportunity to clarify for themselves how they were feeling and a break from emotion work. From support groups, carers received the same, as well as an opportunity to expand their support network, laugh about the cancer and share practical advice.

However, it is these time-sovereign carers who both have time to process and question their emotions and have time to seek formal support. Those carers who lacked time to feel more often sought practical support in the form of respite or financial aid. It is these services, however, that are the most stressful and time consuming to access. Carers found them to be under-effective, not widely known, inaccessible or inadequate. Centrelink in particular was found to be stressful, embarrassing, time-consuming, confronting and against some carers (and doctors') optimistic approaches to the future. This creates a deterrent for time-poor and time-destitute carers, those who could benefit most from accessing these services.

These findings contribute to the psychosocial support services literature by indicating why so few carers access counselling and support groups – many have sufficient informal support, others do not have time, some do not know about them and others feel they are stigmatising. Further, these findings underscore the gendered assessments of past research. Males have fewer opportunities to talk about cancer, formally or informally (see Allen et al., 1999; see Druhan-McGinn & White, 2004; Pruchno & Resch, 1989). They add to the limited existing research on practical support for carers and indicate that the inaccessibility of practical support may be causing time-destitute carers, those carers most vulnerable to the negative mental and physical health consequences linked with caregiving (see chapter one), to be under-supported. For support service providers, these findings indicate that information events, with informal emotional support and networking, may be more attractive to male carers. Future research should go into assessing the adequacy of the amounts received in carers' payments and investigating less onerous modes of applying and distributing practical support.

Medical staff have also been posed as deterrents in past research. Thus, my next focus was on cancer carers' experiences with the medical system. I found that the medical system is not only a barrier to accessing support services, but it is also a cause of added time-poverty for many carers. Medical personnel were diligent and meant well, but they were overworked and understaffed. As a result, care was fragmented, not coordinated by medical staff, bureaucratic, inconsistent and thus, mistakes and miscommunications were common. The bureaucratic and fragmented patient care that carers experience within the medical system compels them to become case managers for their spouses. Carers felt relied on to manage their spouse's care by advocating for their spouses to ensure information was coordinated between medical staff and systems, to ensure appointments did not conflict and medication was administered. *Home at the hospital* was offered as a new term to recognise this care work, coordination and patient advocacy that carers perform at home and in the hospital.

These findings add to the literature on carers' inclusion in doctor-patient exchanges. While past research emphasises the patient's wishes and confidentiality laws in determining carers' inclusion, accounts from my interviews indicate that the medical professionals' perceptions of carers as co-consumer or family, the interpretation of the patient's wellbeing and the extent to which the patient could be expected to make treatment decisions were also central factors in carer inclusion.

I also found that carers are treated like inexhaustible resources instead of co-consumers in need of support. I argue, however, that there are external costs to both relying on carers and treating carers as outside of doctor-patient interactions and carers bear these external cost in the erosion of their emotional and physical wellbeing. I argue that economic principles and the biomedical scope of care are to blame. Economic assessments exclude carers and their health and so, having the home at the hospital appears to be saving medical systems money, when it is actually creating externalities and increased costs in their negative impact on carers' wellbeing. The biomedical model also excludes carers and their psychosocial health from the scope of care, restricting the information carers receive on psychosocial support services and unintentionally trivialising psychological morbidity. To ameliorate the negative impact that the home at the hospital practice is having on carers, information on providing medical care at home, coordinating in the hospital and psychosocial support needs to be more consistently disseminated and personalised. Currently, information is consistently distributed to breast cancer patients and carers. For all others, information is only given to those carers who have reached a crisis point. Under-supporting carers as they take on a significant portion of the patient care, saving the medical system billions of dollars, is a breach of medical ethics that needs to be addressed.

This finding has implications for Australian policymaking. The ethical principles of non-malevolence and beneficence are being compromised by transferring health system costs onto carers who pay in their time and wellbeing. Equity in access to healthcare, an Australian imperative, is also being undermined by a restriction of information on support services to already informed and time-rich carers.

To improve the consistency, holistic focus and information dissemination practices of the medical system to overcome these breaches in ethics changes need to occur. Implementing a patient care coordinator is the recommendation made by carers in this study and by others. Some argue medical school curriculum should be changed to encourage GPs to adopt this role. I argue, however, that regardless of medical school training, GPs will be unlikely to become holistic and carer inclusive patient care coordinators because of the systemic barriers currently in place: their biomedical socialisation, the challenges these changes pose to their medical dominance, the growing time-constraints on medical interactions, consumers' expectations that doctors be distant and objective and the uncertain future of the life-long family GP.

Instead, cancer nurses would address this need for systemic change and care coordination. Cancer nurses should be incorporated into hospital systems to address this cancer care fragmentation and lack of psychosocial support dissemination. They could facilitate patients' treatment within multiple wards and centres, disseminate information related to the disease and available psychosocial support and liaise between community, hospital and family care. Further, they have the additional benefits of being less costly to the medical system, having a demonstrated efficacy and having the capacity to liaise within multi-disciplinary care teams to facilitate discussion and help oncology staff give time and space to their emotions. Fallowfield (1995) supports my argument and highlights the urgent imperative of implementing cancer nurses, to improve the accessibility of support for families and by extension, improve the quality of care that cancer patients receive.

More research, however, is needed. This study is merely the second brick (Thomas and colleagues (2001) provided the first) of many needed to build a sociology of cancer caregiving and improve policy and practice for this under-resourced and under-recognised army of carers, stoically carrying their families and, by extension, the Australian medical system on their shoulders. Further research should explore the role of reciprocity in caregiving trajectories, confirm the prevalence of indefinite grief (see chapter three), verify that time-destitution has a detrimental impact on the relationship between the caregiver and care-receiver (see chapter four) and corroborate the feasibility of the recommendation made in chapter eight: implementing cancer nurses into the medical system. This recommendation is primarily based on carers' accounts. Future studies should measure this solution against interlinking meso- and macro-level investigations within medical hierarchies, policy ethnography and budget analysis restrictions (Griffiths, 2003; Pearson, 2006). The strengths and value of the sociological analysis presented here and of carers of cancer patients' extended and multilevel insight of into medical systems, however, should not be downplayed (Frankenberg, 1992; Griffiths, 2003).

Reference List

ABS (1999), 'Disability, Ageing and Carers, Australia: Summary of Findings, 1998', Canberra, The Australian Bureau of Statistics.

ABS (2006), 'Research Paper: Analysis of the Regional Distribution of Relatively Disadvantaged Areas Using 2001 SEIFA', Canberra, The Australian Bureau of Statistics.

ABS (2007), '2005: Causes of Death', Canberra, The Australian Bureau of Statistics.

Abu-Lughod, L. and Lutz, C.A. (1990), 'Introduction: Emotion, Discourse, and the Politics of Everyday Life', *in* Lutz, C.A. and Abu-Lughod, L. (eds.), *Language and the Politics of Emotion*, Sydney, Cambridge University Press.

Access Economics (2005), 'The Economic Value of Informal Care', Canberra, Report by Access Economics for Carers Australia.

Adam, B. (1992), 'Time and Health Implicated: a Conceptual Critique', *in* Frankenberg, R. (ed.), *Time, Health and Medicine*, London, Sage.

Adam, B. (2004), *Time*, Cambridge, Polity Press.

Addington-Hall, J.M., MacDonald, L.D., Anderson, H.R., Chamberlain, J., Freeling, P., Bland, J.M. and Raftery, J. (1992), 'Randomised Controlled Trial of Effects of Coordinating Care for Terminally Ill Cancer Patients', *British Medical Journal*, 305, 1317-1322.

Allen, D. (2000), 'Negotiating the Role of Expert Carers on an Adult Hospital Ward', *Sociology of Health and Illness*, 22, 2, 149-171.

Allen, D., Griffiths, L. and Lyne, P. (2004), 'Understanding Complex Trajectories in Health and Social Care Provision', *Sociology of Health & Illness*, 26, 7, 1008-1030.

Allen, S., Goldscheider, F. and Ciambrone, D. (1999), 'Gender Roles, Marital Intimacy, and Nomination of Spouse as Primary Caregiver', *The Gerontologist*, 39, 2, 150-159.

Allsop, J. and Mulcahy, L. (1998), 'Maintaining Professional Identity: Doctors' Response to Complaints', *Sociology of Health & Illness*, 20, 6, 802-824.

American Cancer Society (2006), 'Family Caregivers Often Neglect Their Own Mental Health', *CA: Cancer Journal for Clinicians*, 56, 5-6.

Anderson, G.F. and Hussey, P.S. (2000), 'Population Aging: a Comparison Among Industrialized Countries', *Health Affairs*, 19, 3, 191-203.

Arksey, H., Heaton, J. and Sloper, P. (1998), 'Carers Tell it Like it is', *Health Service Journal*, 22, 32-33.

Askham, J. (1997), 'Supporting Caregivers of Older People: an Overview of Problems and Priorities', *1997 World Congress of Gerontology, Ageing Beyond 2000: One World One Future*, Adelaide, SA.

Baehr, P. (2005), 'Review Forum: The Sociology of Almost Everything, Four Questions to Randall Collins about *Interaction Ritual Chains*', *Canadian Journal of Sociology Online*.

Bar-Tal, Y., Barnoy, S. and Zisser, B. (2005), 'Whose Informational Needs are Considered? A Comparison Between Cancer Patients and Their Spouses' Perceptions of Their Own and Their Partners' Knowledge and Informational Needs', *Social Science & Medicine*, 60, 1459-1465.

Barbalet, J. (2002), 'Introduction: Why Emotions are Crucial', *in* Barbalet, J. (ed.), *Emotions and Sociology*, Oxford, Blackwell Publishing, The Sociological Review.

Barbalet, J.M. (1998), *Emotion, Social Theory, and Social Structure: A Macrosociological Approach*, Melbourne, Cambridge University Press.

Bard, M. (1997), 'The Price of Survival for Cancer Victims', *in* Wiener, C.L. and Strauss, A.L. (eds.), *Where Medicine Fails* (5th Edition), London, Transaction Publishers.

Bauman, Z. (1998), 'Postmodern Adventures of Life and Death', *in* Scambler, G. and Higgs, P. (eds.), *Modernity, Medicine and Health: Medical Sociology Towards 2000*, New York, Routledge.

Baxandall, S. and Reddy, P. (1993), *The Courage to Care: The Impact of Cancer on the Family*, Melbourne, David Lovell Publishing.

Becker, H. (1998), *Tricks of the Trade: How to Think about Your Research While You're Doing It*, Chicago, The University of Chicago Press.

Becker, H.S., Geer, B., Hughes, E.C. and Strauss, A.L. ([1961] 1977), *Boys in White: Student Culture in Medical School*, New Brunswick, Transaction Publishers.

Benzein, E. and Saveman, B.I. (1998), 'Nurses' Perception of Hope in Patients With Cancer: a Palliative Care Perspective', *Cancer Nursing*, 21, 1, 10-16.

Bodenheimer, T.S. and Grumbach, K. (2005), *Understanding Health Policy: A Clinical Approach* (4th Edition), New York, Lange Medical Books, McGraw-Hill.

Booth, R.J. and Pennebaker, J.W. (2000), 'Emotions and Immunity', *in* Lewis, M. and Haviland-Jones, J.M. (eds.), *Handbook on Emotions*, New York, The Guilford Press.

Boss, P. (1999), *Ambiguous Loss: Learning to Live with Unresolved Grief*, Cambridge, MA, Harvard University Press.

Boudioni, M., Mossman, J., Boulton, M., Ramirez, A., Moynihan, C. and Leydon, G. (2000), 'An Evaluation of a Cancer Counselling Service', *European Journal of Cancer Care*, 9, 212-220.

Boulton, M., Boudioni, M., Mossman, J., Moynihan, C., Leydon, G. and Ramirez, A. (2001), ''Dividing the Desolation': Clients Views on the Benefits of a Cancer Counselling Service', *Psycho-Oncology*, 10, 124-136.

Braithwaite, V. (1990), *Bound to Care*, Sydney, Allen & Unwin.

Breitbart, W. (2006), 'Foward: Communication as the Bridge to Hope and Healing in Cancer Care', *in* Stiefel, F. (ed.), *Communication in Cancer Care*, Berlin, Springer.

Breitbart, W., Rosenfeld, B., Pessin, H., Kaim, M., Funesti-Esch, J., Galietta, M., Nelson, C.J. and Brescia, R. (2000), 'Depression, Hopelessness, and Desire for Hastened Death in Terminally Ill Patients with Cancer', *The Journal of the American Medical Association*, 284, 22, 2907-2911.

Broom, A. (2005), 'The eMale: Prostate Cancer, Masculinity and Online Support as a Challenge to Medical Expertise', *Journal of Sociology*, 41, 1, 87-104.

Bryan, J. and Lyall, J. (1987), *Living with Cancer*, London, Penguin Books Ltd.

Bryant, M. and Cox, J.W. (2006), 'The Expression of Suppression: Loss and Emotional Labour in Narratives of Organisational Change', *Journal of Management and Organization*, 12, 2, 116-130.

Buckman, R. (1996), *"I Don't Know What to Say..." How to Help and Support Someone Who is Dying*, London, Pan Books.

Bultz, B.D., Speca, M., Brasher, P.M., Geggie, P.H.S. and Page, S.A. (2000), 'A Randomized Controlled Trial of a Brief Psychoeducational Support Group for Partners of Early Stage Breast Cancer Patients', *Psycho-Oncology*, 9, 303-313.

Burdess, N. (1996), 'Class and Health', *in* Grbich, C. (ed.), *Health in Australia: Sociological Concepts and Issues*, Sydney, Prentice Hall.

Burns, C.M., Craft, P.S. and Roder, D.M. (2005), 'Does Emotional Support Influence Survival? Findings From a Longitudinal Study of Patients with Advanced Cancer', *Supportive Care in Cancer*, 13, 5, 295-302.

Burns, C.M., Dixon, T., Broom, D., Smith, W.T. and Craft, P.S. (2003), 'Family Caregiver Knowledge of Treatment Intent in a Longitudinal Study of Patients with Advanced Cancer', *Supportive Care in Cancer*, 11, 10, 629-637.

Burns, C.M., Dixon, T., Smith, W.T. and Craft, P.S. (2004), 'Patients with Advanced Cancer and Family Caregivers' Knowledge of Health and Community Services: a Longitudinal Study', *Health and Social Care in the Community*, 12, 6, 488-503.

Bury, M. (1982), 'Chronic Illness as Biographical Disruption', *Sociology of Health and Illness*, 4, 2, 167-182.

Bury, M. (1991), 'The Sociology of Chronic Illness: A Review of Research and Prospects', *Sociology of Health and Illness*, 13, 4, 451-468.

Bury, M. (2001), 'Illness Narrative: Fact or Fiction?' *Sociology of Health and Illness*, 23, 3, 263-285.

Cahn, E.S. (2000), *No More Throw-Away People: The Co-Production Imperative*, Washington, Essential Books.

Cancer Council ACT (2007), 'General Information', Canberra, Cancer Council ACT.

Cancer Council Australia (2003), 'Cancer Council Australia. Profile and Annual Report', Cancer Council Australia.

Capra, F. (1982), *The Turning Point: Science, Society, and the Rising Culture*, London, Flamingo.

Carers Australia (2007), 'Supporting Family Carers', *How you Can Support Carers*, Carers Australia.

Carpenter, E.H. and Miller, B.H. (2005), 'Psychosocial Challenges and Rewards Experienced by Caregiving Men: A Review of the Literature and an Empirical Case Example', *in* Kramer, B.J. and Thompson, E.H.J. (eds.), *Men as Caregivers*, Amherst, NY, Prometheus Books.

Centrelink (2008), 'Disability and Carer Payment Rates', Canberra, Centrelink Australia.

Chambers, M., Ryan, A. and Connor, S.L. (2001), 'Exploring the Emotional Support Needs and Coping Strategies of Family Carers', *Journal of Psychiatric and Mental Health Nursing*, 8, 2, 99-106.

Chapman, K. and Pepler, C. (1998), 'Coping, Hope, and Anticipatory Grief in Family Members in Palliative Home Care', *Cancer Nursing*, 21, 4, 226-234.

Chattoo, S. (2002), 'The Moral Economy of Selfhood and Caring: A Case Study of Cancer', *Second Annual Sociology of Cancer Conference*, University of Warwick.

Cheek, J. and Rudge, T. (1996), 'Health for All? The Gendered Construction of Health and Health Care Practices', *in* Grbich, C. (ed.), *Health in Australia: Sociological Concepts and Issues*, Sydney, Prentice Hall.

Ciambrone, D. and Allen, S.M. (2005), 'Husbands Caring for Wives with Cancer', *in* Kramer, B.J. and Thompson, E.H.J. (eds.), *Men as Caregivers*, Amherst, NY, Prometheus Books.

Clark, E. (1990a), 'Intervention for Cancer Patients: A Clinical Sociology Approach to Program Planning', *in* Clark, E., Fritz, J.M., Rieker, P.P., Kutscher, A.H. and Bendiksen, R.A. (eds.), *Clincical Sociology Perspectives on Illness and Loss: The Linkage of Theory and Practice*, Philadelphia, The Charles Press, Publishers.

Clark, E. (1990b), 'Overview of Sociology's Contribution to Intervention in Life-Threatening Illness, Dying, Loss and Grief', *in* Clark, E., Fritz, J.M., Rieker, P.P., Kutscher, A.H. and Bendiksen, R.A. (eds.), *Clincical Sociology Perspectives on Illness and Loss: The Linkage of Theory and Practice*, Philadelphia, The Charles Press, Publishers.

Clarke, J.N. (1990), 'The Causes of Cancer: Women Talking', *in* Clark, E., Fritz, J.M., Rieker, P.P., Kutscher, A.H. and Bendiksen, R.A. (eds.), *Clincical Sociology Perspectives on Illness and Loss: The Linkage of Theory and Practice*, Philadelphia, The Charles Press, Publishers.

Cobb, S. (1976), 'Psychosomatic Medicine', *Social Support as a Moderator of Life Stress*, 38, 5, 300-314.

Collins, R. (1990), 'Stratification, Emotional Energy, and the Transient Emotions', *in* Kemper, T.D. (ed.), *Research Agendas in The Sociology of Emotions*, Albany, NY, State University of New York Press.

Collins, R. (2004), *Interaction Ritual Chains*, Princeton, Princeton University Press.

Collins, R. (2008), *Violence: A Micro-Sociological Theory*, Princeton, Princeton University Press.

Coombs, R.H. and Powers, P.S. (1976), 'Socialization for Death: The Physician’s Role', *in* Lofland, L.H. (ed.), *Toward A Sociology of Death and Dying*, London, Sage Publications.

Coser, L. and Coser, R. (1990), 'Time Perspective and Social Structure', *in* Hassard, J. (ed.), *The Sociology of Time*, London, Macmillan.

Cox, G. and Fundis, R.J. (1990), 'Teaching the Sociology of Dying and Death', *in* Clark, E., Fritz, J.M., Rieker, P.P., Kutscher, A.H. and Bendiksen, R.A. (eds.), *Clincical Sociology Perspectives on Illness and Loss: The Linkage of Theory and Practice*, Philadelphia, The Charles Press, Publishers.

Craft, P.S., Burns, C.M., Smith, W.T. and Broom, D.H. (2005), 'Knowledge of Treatment Intent Among Patients with Advanced Cancer: a Longitudinal Study', *European Journal of Cancer Care*, 14, 417-425.

Crouch, M. and McKenzie, H. (2000), 'Social Realities of Loss and Suffering Following Mastectomy', *Health*, 4, 2, 196-215.

Crow, G. and Heath, S. (2002), 'Introduction', *in* Crow, G. and Heath, S. (eds.), *Social Conceptions of Time: Structure and Process in Work and Everyday Life*, New York, Palgrave Macmillan.

Davies, K. (2001), 'Responsibility and Daily Life: Reflections Over Timespace', *in* May, J. and Thrift, N. (eds.), *Timespace: Geographies of Temporality*, London, Routledge.

Davis, A. and George, J. (1993), *States of Health: Health and Illness in Australia*, Pymble, NSW, Harper Educational.

Davis, C., Cohen, R.S. and Apolinsky, F. (2005), 'Providing Social Support to Cancer Patients: A look at Alternative Methods', *Journal of Psychosocial Oncology*, 23, 1, 75-85.

Davison, K., Pennebaker, J.W. and Dickerson, S.S. (2000), 'Who Talks? The Social Psychology of Illness Support Groups', *American Psychologist*, 55, 2, 205-217.

Denzin, N.K. (1999), 'Book Review: Emotion, Social Theory, and Social Structure: A Macrosociological Approach by J. M. Barbalet', *The American Journal of Sociology*, 104, 5, 1530-1532.

Denzin, N.K. and Lincoln, Y.S. (2005), 'The Discipline and Practice of Qualitative Research', *in* Denzin, N.K. and Lincoln, Y.S. (eds.), *The SAGE Handbook of Qualitative Research* (3rd Edition), Thousan Oaks, Sage Publications.

DeVries, H.M., Hamilton, D.W., Lovett, S. and Gallagher-Thompson, D. (1997), 'Patterns of Coping Preferences for Male and Female Caregivers of Frail Older Adults', *Psychology and Aging*, 12, 2, 263-267.

Dixon-Woods, M. (2008), 'Future Thinking: The Next 40 years of Medical Sociology', *BSA Medical Sociology Group 40th Annual Conference*, University of Sussex, Brighton, UK.

Docherty, A. (2004), 'Experience, Functions and Benefits of a Cancer Support Group', *Patient Education and Counseling*, 55, 87-93.

Dow, B., Haralambous, B., Giummarra, M. and Vrantsidis, F. (2004), 'What Carers Value: Review of Carer Literature and Practice', Melbourne, Department of Human Services and National Ageing Research Institute.

Druhan-McGinn, N. and White, K. (2004), 'Toward Best Practice in Supportive Care Service in the ACT', Cancer Council ACT and ACT Department of Health and Community Care.

Duckett, S.J. (2004), *The Australian Health Care System* (2nd Edition), South Melbourne, Oxford University Press.

Dufault, K. and Martocchio, B.C. (1985), 'Symposium on Compassionate Care and the Dying Experience. Hope: its Spheres and Dimensions', *The Nursing Clinics of North America*, 20, 2, 379-391.

Duke, S. (1998), 'An Exploration of Anticipatory Grief: The Lived Experience of People During their Spouses' Terminal Illness and in Bereavement', *Journal of Advanced Nursing*, 28, 4, 829-839.

Dumont, R.G. and Foss, D.C. (1972), *The American View of Death: Acceptance or Denial?*, Cambridge, MA, Schenkman Publishing Company, Inc.

Dunn, J., Steginga, S.K., Rosoman, N. and Millichap, D. (2003), 'A Review of Peer Support in the Context of Cancer', *Journal of Psychosocial Oncology*, 21, 2, 55-67.

Eley, R., Rogers-Clark, C. and Knight, C. (2007), 'Supporting Rural Women with Breast Cancer Project: Evaluation of the Role of Breast Care Nurse at Toowoomba Base Hospital', Toowoomba, QLD, Centre for Rural and Remote Area Health University of Southern Queensland, The Universities of Queensland and Southern Queensland.

Elias, N. (1978), *What is Sociology?*, London, Hutchinson.

Elias, N. (1985), *The Loneliness of the Dying*, New York, Basil Blackwell.

Elias, N. (1997), *Time: An Essay*, Oxford, Blackwell.

Evandrou, M. (1996), 'Unpaid Work, Carers and Health', *in* Blane, D., Brunner, E. and Wilkinson, R. (eds.), *Health and Social Organization: Towards a Health Policy for the Twenty-First Century*, New York, Routledge.

Eysenbach, G. (2003), 'The Impact of the Internet on Cancer Outcomes', *A Cancer Journal for Clinicians*, 53, 356-371.

Fallowfield, L. (1995), 'Helping the Relatives of Patients with Cancer', *European Journal of Cancer*, 31A, 11, 1731-1732.

Fallowfield, L. and Jenkins, V. (2006), 'Current Concepts of Communication Skills Training in Oncology', *in* Stiefel, F. (ed.), *Communication in Cancer Care*, Berlin, Springer.

Fallowfield, L.J. (1988), 'Counselling for Patients with Cancer', *British Medical Journal*, 297, 727-728.

Faull, C. (1998), 'The History and Principles of Palliative Care', *in* Faull, C., Carter, Y. and Woof, R. (eds.), *Handbook of Palliative Care*, Carlton, VIC, Blackwell Science, Ltd.

Femiano, S. and Coonerty-Femiano, A. (2005), 'Principles and Interventions for Working Therapeutically with Caregiving Men: Responding to Challenges', *in* Kramer, B.J. and Thompson, E.H.J. (eds.), *Men as Caregivers*, Amherst, NY, Prometheus Books.

Field, D. and Copp, G. (1999), 'Communication and Awareness about Dying in the 1990s', *Palliative Medicine*, 13, 6, 459-468.

Firth, P. (2006), 'Patients and Their Families', *in* Stiefel, F. (ed.), *Communication in Cancer Care*, Berlin, Springer.

Fitzgerald Miller, J. (2007), 'Hope: A Construct Central to Nursing', *Nursing Forum*, 42, 1, 12-19.

Fleisher, L., Bass, S., Ruzek, S.B. and McKeown-Conn, N. (2002), 'Relationships Among Internet Health Information Use, Patient Behavior and Self Efficacy in Newly Diagnosed Cancer Patients who Contact the National Center Institute's NCI Atlantic Region Cancer Information Service (CIS)', *Proceedings of the AMIA Annual Fall Symposium*, 260-264.

Flick, U. (2002), *An Introduction to Qualitative Research* (2nd Edition), London, Sage Publications.

Folkman, S. and Lazarus, R.S. (1980), 'An Analysis of Coping in a Middle-Aged Community Sample', *Journal of Health and Social Behavior*, 21, 3, 219-239.

Frank, A.W. (1993), 'The Rhetoric of Self-Change: Illness Experience as Narrative', *Sociological Quarterly*, 34, 1, 39-52.

Frank, A.W. (1994), 'Reclaiming an Orphan Genre: The First-Person Narrative of Illness', *Literature and Medicine*, 13, 1, 1-21.

Frank, A.W. (1995), *The Wounded Storyteller: Body, Illness, and Ethics*, Chicago, University of Chicago Press.

Frankenberg, R. (1992), ''Your Time or Mine': Temporal Contradictions of Biomedical Practice', *in* Frankenberg, R. (ed.), *Time, Health and Medicine*, London, Sage.

Franks, M. and Stephens, M.A.P. (1992), 'Multiple Roles of Middle-Generation Caregivers: Contextual Effect and Psychological Mechanisms', *Journal of Gerontology*, 47, 3, S123-129.

Frijda, N.H. (2000), 'The Psychologists' Point of View', *in* Lewis, M. and Haviland-Jones, J.M. (eds.), *Handbook of Emotions* (2nd Edition), New York, The Guilford Press.

Fritz, J.M. (1990), 'The Uses of Sociology in Clinical Settings', *in* Clark, E., Fritz, J.M., Rieker, P.P., Kutscher, A.H. and Bendiksen, R.A. (eds.), *Clincical Sociology Perspectives on Illness and Loss: The Linkage of Theory and Practice*, Philadelphia, The Charles Press, Publishers.

Fulton, G., Madden, C. and Minichiello, V. (1996), 'The Social Construction of Anticipatory Grief', *Social Science and Medicine*, 43, 9, 1349-1358.

Fulton, R. and Fulton, J. (1980), 'A Psychosocial Aspect of Terminal Care: Anticipatory Grief', *in* Kalish, R.A. (ed.), *Caring Relationships: The Dying and the Bereaved*, Farmingdale, NY, Baywood Publishing Company.

Funnell, R. (1998), 'For Better or Worse: Caregiving Husbands of Wives with Multiple Sclerosis', *School of Sociology, Politics and Anthropology*, Bundoora, VIC, La Trobe University.

Furedi, F. (2004), *Therapy Culture: Cultivating Vulnerability in an Uncertain Age,* Abingdon, Oxon, Routledge.

Galasiński, D. (2004), *Men and the Language of Emotions*, New York, Palgrave Macmillan.

Gawler, I. (2007), *You Can Conquer Cancer*, Melourne, Michelle Anderson Publishing.

Gear, E. and Haney, C.A. (1990), 'The Cancer Patient After Diagnosis: Hospitalization and Treatment', *in* Clark, E., Fritz, J.M., Rieker, P.P., Kutscher, A.H. and Bendiksen, R.A. (eds.), *Clinicical Sociology Perspectives on Illness and Loss: The Linkage of Theory and Practice*, Philadelphia, The Charles Press, Publishers.

Geertz, C. (2007), 'Person, Time, and Conduct in Bali', *in* Wulff, H. (ed.), *The Emotions: A Cultural Reader*, Oxford, Berg.

Gershuny, J. (2002), 'Service Regimes and the Political Economy of Time', *in* Crow, G. and Heath, S. (eds.), *Social Conceptions of Time: Structure and Process in Work and Everyday Life*, New York, Palgrave Macmillan.

Gibson, D., Butkus, E., Jenkins, A., Mather, S. and Liu, Z. (1996), *The Respite Care Needs of Australians*, Canberra, Australian Institute of Health and Welfare.

Gilhooly, M.L.M., Sweeting, H.N., Whittick, J.E. and McKee, K. (1994), 'Family Care of the Dementing Elderly', *International Review of Psychiatry*, 6, 29-40.

Gilliland, G. and Fleming, S. (1998), 'A Comparison of Spousal Anticipatory Grief and Conventional Grief', *Death Studies*, 22, 6, 541-569.

Glaser, B.G. and Strauss, A.L. (1967), *The Discovery of Grounded Theory: Strategies for Qualitative Research*, Hawthorne, NY, Aldine de Gruyter.

Gleick, J. (1999), *Faster: The Acceleration of Just About Everything*, New York, Pantheon Books.

Goffman, E. (1968a), *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*, Camberwell, VIC, Penguin.

Goffman, E. (1968b), *Stigma: Notes on the Management of Spoiled Identity*, Ringwood, VIC, Penguin Books.

Goldie, P. (2002), 'Emotions, Feeling and Intentionality', *Phenomenology and the Cognitive Sciences*, 1, 235-254.

Goldstein, M.S., Sutherland, C., Jaffe, D.T. and Wilson, J. (1988), 'Holistic Physicians and Family Practitioners: Similarities, Differences and Implications for Health Policy', *Social Science and Medicine*, 26, 8, 853-861.

Goodin, R.E., Rice, J.M., Parpo, A. and Eriksson, L. (2008), *Discretionary Time: A New Measure of Freedom*, Melbourne, Cambridge University Press.

Gould, S.J. (1995), 'The Median isn't the Message', *Adam's Navel and Other Essays*, London, Penguin Books.

Gray, R., Fitch, M., Davis, C. and Phillips, C. (1997), 'A Qualitative Study of Breast Cancer Self-Help Groups', *Psycho-Oncology*, 6, 279-289.

Grbich, C. (1996), 'Theoretical Perspectives in Health Sociology', *in* Grbich, C. (ed.), *Health in Australia: Sociological Concepts and Issues*, Sydney, Prentice Hall.

Grbich, C. (1999), *Qualitative Research in Health: An Introduction*, London, Sage Publications.

Grbich, C. (2007), *Qualitative Data Analysis: An Introduction*, Los Angeles, Sage.

Grbich, C., Parker, D. and Maddocks, I. (2001), 'The Emotions and Coping Strategies of Caregivers of Family Members with a Terminal Cancer', *Journal of Palliative Care*, 17, 1, 30-36.

Gregory, S. (2005), 'Living with Chronic Illness in the Family Setting', *Sociology of Health and Illness*, 27, 3, 372-392.

Griffiths, L. (2003), 'Making Connections: Studies of the Social Organisation of Healthcare', *Sociology of Health & Illness*, 25, 171.

Guillemin, J. (1997), 'Planning to Die', *in* Wiener, C.L. and Strauss, A.L. (eds.), *Where Medicine Fails* (5th Edition), London, Transaction Publishers.

Gurvitch, G. (1990), 'The Problem of Time', *in* Hassard, J. (ed.), *The Sociology of Time*, London, Macmillan.

Haar, J.M. (2006), 'The Downside of Coping: Work-Family Conflict, Employee Burnout and the Moderating Effects of Coping Strategies', *Journal of Management and Organization*, 12, 2, 146-159.

Halvorson-Boyd, G. and Hunter, L.K. (1995), *Dancing in Limbo: Making Sense of Life after Cancer*, San Francisco, Jossey-Bass Inc.

Hamilton, C. and Denniss, R. (2005), *Affluenza: When Too Much is Never Enough*, Crows Nest, NSW, Allen & Unwin.

Harden, J. (2005), 'Parenting a Young Person with Mental Health Problems: Temporal Disruption and Reconstruction', *Sociology of Health and Illness*, 27, 3, 351-371.

Hardey, M. (1999), 'Doctor in the House: The Internet as a Source of Lay Health Knowledge and the Challenge to Expertise', *Sociology of Health & Illness*, 21, 6, 820-835.

Harding, R. and Higginson, I. (2003), 'What is the Best Way to Help Caregivers in Cancer and Palliative Care? A Systematic Literature Review of Interventions and their Effectiveness', *Palliative Medicine*, 17, 63-74.

Harpham, W.S. (1994), *After Cancer: A Guide to Your New Life*, New York, DoubleDay.

Harris, P.B. (2005), 'The Voices of Husbands and Sons Caring for a Family Member with Dementia', *in* Kramer, B.J. and Thompson, E.H.J. (eds.), *Men as Caregivers*, Amherst, NY, Prometheus Books.

Harrison, J., Haddad, P. and Maguire, P. (1995), 'The Impact of Cancer on Key Relatives: A Comparison of Relative and Patient', *European Journal of Cancer*, 31, 11, 1736-1740.

Hassard, J. (1990), 'Introduction: The Sociological Study of Time', *in* Hassard, J. (ed.), *The Sociology of Time*, London, Macmillan.

Haug, M.R., Ford, A.B., Stange, K.C., Noelker, L.S. and Gaines, A.D. (1999), 'Effect of Giving Care on Caregivers' Health', *Research on Aging*, 21, 4, 515-538.

Heise, D.R. and O'Brien, J. (1993), 'Emotion Expression in Groups', *in* Lewis, M. and Haviland, J.M. (eds.), *Handbook on Emotions*, New York, Guilford Press.

Heise, D.R. and Weir, B. (1999), 'A Test of Symbolic Interactionist Predictions about Emotions in Imagined Situations', *Symbolic Interaction*, 22, 2, 139-161.

Herron, L.-M. (2005), 'Building Effective Cancer Support Groups: Report to the Department of Health and Ageing', The Cancer Council Australia.

Herth, K. (1993), 'Hope in the Family Caregiver of Terminally Ill People', *Journal of Advanced Nursing*, 18, 4, 538-548.

Hochschild, A.R. (1979), 'Emotion Work, Feeling Rules, and Social Structure', *The American Journal of Sociology*, 85, 3, 551-575.

Hochschild, A.R. (1983), *The Managed Heart*, Berkeley, CA, University of California Press.

Hochschild, A.R. (1990), 'Ideology and Emotion Management: A Perspective and Path for Future Research', *in* Kemper, T.D. (ed.), *Research Agendas in The Sociology of Emotions*, Albany, NY, State University of New York Press.

Hochschild, A.R. (1995), 'The Culture of Politics: Traditional, Post-modern, Cold Modern and Warm Modern Ideals of Care', *Social Politics: International Studies in Gender, State and Society*, 2, 3, 331-346.

Hochschild, A.R. (2000), *The Time Bind: When Work Becomes Home and Home Becomes Work*, New York, Henry Holt and Company.

Hockey, J.L. (1990), *Experiences of Death: An Anthropological Account*, Edinburgh, Edinburgh University Press.

Hodges, L.J., Humphries, G. and Macfarlane, G. (2005), 'A Meta-Analytic Investigation of the Relationship Between the Psychological Distress of Cancer Patients and Their Carers', *Social Science & Medicine*, 60, 1, 1-12.

Hoffman, M.K. (2002), 'Self-Awareness in Family Caregiving', *The Family Caregiver Self-Awareness and Empowerment Project*, Kensington, MD, National Family Caregiver Association and National Alliance for Caregiving.

Holmes, M. (2002), 'Politicizing Time: Temporal Issues for Second-Wave Feminists', *in* Crow, G. and Heath, S. (eds.), *Social Conceptions of Time: Structure and Process in Work and Everyday Life*, New York, Palgrave Macmillan.

Howe, A., Schofield, H. and Herrman, H. (1997), 'Caregiving: A Common or Uncommon Experience?' *Social Science & Medicine*, 45, 7, 1017-1029.

Hughes, J. (2007), 'Caring for Carers: The Financial Strain of Caring', *Family Matters*, 76, 32-33.

Hunt, G. and Mintz, S. (2002), 'Caregiver Needs and Preferences', *Family Caregiving: Sharing Strategies, Celebrating Progress*, Washington, DC, National Health Council.

Hunt, M. (1991), 'The Identification and Provision of Care for the Terminally Ill at Home by ‘Family’ Members', *Sociology of Health & Illness*, 13, 3, 375-395.

Hutchinson, S.D., Steginga, S.K. and Dunn, J. (2006), 'The Tiered Model of Psychosocial Intervention in Cancer: A Community Based Approach', *Psycho-Oncology*, 15, 541-546.

Illich, I. (1976), *Limits to Medicine: Medical Nemesis, the Expropriation of Health*, London, Marian Boyars.

Irvine, R. (1996), 'Losing Patients: Health Care Consumers, Power and Sociocultural Change', *in* Grbich, C. (ed.), *Health in Australia: Sociological Concepts and Issues*, Sydney, Prentice Hall.

Jackson, C.O. (1980), 'Death Shall Have No Dominion: The Passing of the World of the Dead in America', *in* Kalish, R.A. (ed.), *Death and Dying: View from Many Cultures*, Farmingdale, NY, Baywood Publishing Company.

Jalland, P. (2006), *Changing Ways of Death in Twentieth Century Australia: War, Medicine and the Funeral Business*, Sydney, University of New South Wales Press.

Janda, M., Eakin, E.G., Bailey, L., Walker, D. and Troy, K. (2006), 'Supportive Care Needs of People with Brain Tumours and their Carers', *Support Care Cancer*, 14, 1094-1103.

Jansma, F.F.I., Schure, L.M. and Meyboom de Jong, B. (2005), 'Support Requirements for Caregivers of Patients with Palliative Cancer', *Patient Education and Counseling*, 58, 182-186.

Jaques, E. (1990), 'The Enigma of Time', *in* Hassard, J. (ed.), *The Sociology of Time*, London, Macmillan.

Jones, R.V., Hansford, J. and Fiske, J. (1993), 'Death from Cancer at Home: The Carers' Perspective', *British Medical Journal*, 306, 249-251.

Kearney, N., Hubbard, G., Forbat, L. and Knighting, K. (2007), 'Developing Cancer Services: Patient and Carer Experiences', Stirling, Cancer Care Research Centre, University of Stirling.

Keat, R. and Urry, J. (1982), *Social Theory as Science* (2nd Edition), London, Routledge & Kegan Paul.

Kellehear, A. (1984), 'Are We A Death-Denying Society? A Sociological Review', *Social Science and Medicine*, 18, 9, 713-723.

Kellehear, A. (1993), *The Unobtrusive Researcher: A Guide to Methods*, St. Leonards, NSW, Allen & Unwin.

Kellehear, A. (2007), *A Social History of Dying*, Cambridge, Cambridge University Press.

Kennedy, V. and Lloyd-Williams, M. (2006), 'Maintaining Hope: Communication in Palliative Care', *in* Stiefel, F. (ed.), *Communication in Cancer Care*, Berlin, Springer.

Kiss, A. and Sollner, W. (2006), 'Communication and Communication Skills Training in Oncology: Open Questions and Future Tasks', *in* Stiefel, F. (ed.), *Communication in Cancer Care*, Berlin, Springer.

Kissane, D.W. and Bloch, S. (2002), *Family Focused Grief Therapy: A Model of Family-Centred Care During Palliative Care and Bereavement*, New York, Open University Press.

Kleinman, S. (1991), 'Field-Workers' Feelings: What We Feel, Who We Are, How We Analyze', *in* Shaffir, W.B. and Stebbins, R.A. (eds.), *Experiencing Fieldwork: An Inside View of Qualitative Research*, New Delhi, Sage Publications.

Knight, R.G., Devereux, R.C. and Godfrey, H.P.D. (1997), 'Psychosocial Consequences of Caring for a Spouse with Multiple Sclerosis', *Journal of Clinical and Experimental Neuropsychology*, 19, 1, 7-19.

Koffman, J., Higginson, I.J., Edmonds, P. and Morgan, M. (2004), 'The Role of Religion in Coping with Advanced Cancer Among Black Caribbean and Native-Born White UK Patients', *3rd Annual Sociology of Cancer Study Group Conference: Cancer and Collectivities*, University of Warwick.

Kramer, B.J. (1997a), 'Differential Predictors of Strain and Gain Among Husbands Caring for Wives with Dementia', *The Gerontologist*, 37, 2, 239-249.

Kramer, B.J. (1997b), 'Gain in the Caregiving Experience: Where are We? What Next?' *The Gerontologist*, 37, 2, 218-232.

Kramer, B.J. and Lambert, J.D. (1999), 'Caregiving as a Life Course Transition Among Older Husbands: A Prospective Study', *The Gerontologist*, 39, 6, 658-667.

Kübler-Ross, E. (1969), *On Death and Dying*, New York, Macmillian Publishing Company.

Kuhl, D. (2002), *What Dying People Want: Practical Wisdom for the End of Life*, Sydney, ABC Books.

Laizner, A.M., Yost, L.M.S., Barg, F.K. and McCorkle, R. (1993), 'Needs of Family Caregivers of Persons with Cancer: A Review', *Seminars in Oncology Nursing*, 9, 2, 114-120.

Lavery, J.F. and Clarke, V.A. (1999), 'Prostate Cancer: Patients' and Spouses' Coping and Marital Adjustment', *Psychology, Health & Medicine*, 4, 3, 289-302.

Leventhal, H. and Patrick-Miller, L. (2000), 'Emotions and Physical Illness: Causes and Indicators of Vulnerability', *in* Lewis, M. and Haviland-Jones, J.M. (eds.), *Handbook of Emotions*, New York, The Guilford Press.

Lewis, J.D. and Weigart, A.J. (1990), 'The Structures and Meanings of Social-Time', *in* Hassard, J. (ed.), *The Sociology of Time*, London, Macmillan.

Lewis, S. (2006), 'Caregiving', *Women's Health Seminar Series*, Bethesda, MD.

Lindemann, E. (1944), 'Symptomatology and Management of Acute Grief', *American Journal of Psychiatry*, 101, 141-148.

Lindstöm, B. and Eriksson, M. (2005), 'Professor Aaron Antonovsky (1923-1994): The Father of Salutogenesis', *Journal of Epidemiology and Community Health*, 59, 511.

Little, M. (1995), *Humane Medicine*, Cambridge, Cambridge University Press.

Little, M., Jordens, C., Paul, K., Montgomery, K. and Philpson, B. (1998), 'Liminality: A Major Category of the Experience of Cancer Illness', *Social Science and Medicine*, 47, 10, 1485-1494.

Little, M., Jordens, C., Paul, K. and Sayers, E.-J. (2001), *Surviving Survival: Life After Cancer*, Marrickville, NSW, Choice Books.

Lutz, C. (1995), 'Martha C. Nussbaum: Emotions and Women's Capabilities', *in* Nussbaum, M.C. and Glover, J. (eds.), *Women, Culture, and Development: A Study of Human Capabilities*, Oxford, Clarendon Press.

Maex, E. and De Valck, C. (2006), 'Key Elements of Communication in Cancer Care', *in* Stiefel, F. (ed.), *Communication in Cancer Care*, Berlin, Springer.

Maguire, P. (1985), 'Barriers to Psychological Care of the Dying', *British Medical Journal*, 291, 1711-1713.

Mamo, L. (1999), 'Death and Dying: Confluences of Emotion and Awareness', *Sociology of Health & Illness*, 21, 1, 13-36.

Marceau, L.D. and McKinlay, J.B. (2008), 'Reasons for the Likely Disappearance of Primary Care Doctors in the 21st Century', *BSA Medical Sociology Group 40th Annual Conference*, University of Sussex, Brighton.

Mathews, H.F. (2000), 'Negotiating Cultural Consensus in a Breast Cancer Self-Help Group', *Medical Anthropology Quarterly*, 14, 3, 394-413.

McKinnon, M. and Janicki, M. (2001), 'Caregiver Advocacy', *in* The Lewin Group (ed.), *The U.S. Administration on Aging Conference*, Washington, DC.

McNamara, B. (2000), 'Dying of Cancer', *in* Kellehear, A. (ed.), *Death and Dying in Australia*, South Melbourne, Oxford University Press.

McNamara, B. (2001), *Fragile Lives: Death, Dying and Care*, Buckingham, Open University Press

McNamara, B. and Rosenwax, L. (2007), 'The Mismanagement of Dying', *Health Sociology Review*, 16, 5, 373-383.

McNamara, B., Waddell, C. and Colvin, M. (1995), 'Threats to the Good Death: The Cultural Context of Stress and Coping Among Hospice Nurses', *Sociology of Health and Illness*, 17, 2, 222-244.

Mead, G.H. (2000), 'Mind, Self and Society', *in* Farganis, J. (ed.), *Readings in Social Theory: The Classic Tradition to Post-Modernism*, Boston, McGraw-Hill.

Mellon, S., Northouse, L.L. and Weiss, L.K. (2006), 'A Population-Based Study of the Quality of Life of Cancer Survivors and Their Family Caregivers', *Cancer Nursing*, 29, 2, 120-131.

Merton, R.K. and Sztompka, P. (1996), *On Social Structure and Science*, Chicago, The University of Chicago Press.

Meuser, T.M. and Marwit, S.J. (2001), 'A Comprehensive, Stage-Sensitive Model of Grief in Dementia Caregiving', *The Gerontologist*, 41, 5, 658-670.

Miller, S.M. and Schnoll, R.A. (2000), 'When Seeing is Feeling: A Cognitive-Emotional Approach to Coping and Health Stress', *in* Lewis, M. and Haviland-Jones, J.M. (eds.), *Handbook on Emotions*, New York, Guilford Press.

Minichiello, V., Aroni, R., Timewell, E. and Alexander, L. (1995), *In-depth Interviewing: Principles, Techniques, Analysis* (2nd Edition), Melbourne, Longman Australia Pty Ltd.

Morris, S. and Thomas, C. (2002), 'The Need to Know: Informal Carers and Information', *European Journal of Cancer Care*, 11, 183-187.

Morris, S.M. and Thomas, C. (2001), 'The Carer's Place in the Cancer Situation: Where Does the Carer Stand in the Medical Setting', *European Journal of Cancer Care*, 10, 2, 87-95.

Nash, M.L. (1980), 'Dignity of Person in the Final Phase of Life: An Exploratory Study', *in* Kalish, R.A. (ed.), *Caring Relationships: The Dying and the Bereaved*, Farmingdale, NY, Baywood Publishing Company.

Nathan, L.E. (1990), 'Coping with Uncertainty: Family Members Adaptions During Cancer Remission', *in* Clark, E., Fritz, J.M., Rieker, P.P., Kutscher, A.H. and Bendiksen, R.A. (eds.), *Clinical Sociology Perspectives on Illness and Loss: The Linkage of Theory and Practice*, Philadelphia, The Charles Press, Publishers.

National Cancer Control Initiative (2003), 'Optimising Cancer Care in Australia', Clinical Oncological Society of Australia, The Cancer Council Australia and National Cancer Control Initiative.

Neary, M. and Rikowski, G. (2002), 'Time and Speed in the Social Universe of Capital', *in* Crow, G. and Heath, S. (eds.), *Social Conceptions of Time: Structure and Process in Work and Everyday Life*, New York, Palgrave Macmillan.

Neimeyer, R.A., Prigerson, H.G. and Davies, B. (2002), 'Mourning and Meaning', *American Behavioral Scientist*, 46, 235-251.

Neuhauser, L. (2007), 'Leveraging the Power of Health Communication', *National Centre for Epidemiology and Population Health Seminar Series*, Canberra, National Centre for Epidemiology and Population Health.

Nijboer, C., Tempelaar, R., Sanderman, R., Triemstra, M., Spruijt, R.J. and Van Den Bos, G.A.M. (1998), 'Cancer and Caregiving: The Impact on the Caregiver's Health', *Psycho-Oncology*, 7, 1, 3-13.

Northouse, L.L., Mood, D., Templin, T., Mellon, S. and George, T. (2000), 'Couples' Patterns of Adjustment to Colon Cancer', *Social Science & Medicine*, 50, 271-284.

Nyland, C. (1990), 'Capitalism and the History of Work-time Thought', *in* Hassard, J. (ed.), *The Sociology of Time*, London, Macmillan.

Oakley, A. (1985), *Sex, Gender and Society,* Hants, England, Gower.

Opie, A. (1992), *There's Nobody There: Community Care of Confused Older People*, Auckland, Oxford University Press.

Owen, D.C. (1989), 'Nurses' Perspectives on the Meaning of Hope in Patients with Cancer: A Qualitative Study', *Oncology Nursing Forum*, 16, 1, 75-79.

Parliament of Australia Senate (2005), 'The Cancer Journey: Informing Choice', *in* Community Affairs Committee (ed.), Commonwealth of Australia.

Payer, L. (1988), *Medicine & Culture: Notions of Health and Sickness in Britain, the U.S., France and West Germany*, London, Victor Gollancz Ltd.

Payne, S., Kerr, C., Hawker, S., Hardey, M. and Powell, J. (2002), 'The Communication of Information About Older People Between Health and Social Care Practitioners', *Age and Ageing*, 31, 2, 107-117.

Pearson, A. (2006), 'A Strategic Development Plan to Improve Supportive Care for People Living with Cancer', Adelaide, Joanna Briggs Institute.

Pennebaker, J.W. (1997), *Opening Up: The Healing Power of Expressing Emotions*, New York, Guilford Press.

Petersen, A. (2004), *Engendering Emotions*, New York, Palgrave Macmillan.

Petersen, A.R. (1994), *In a Critical Condition: Health and Power Relations in Australia*, St. Leonards, NSW, Allen & Unwin.

Phillips, K.-A., Osborne, R.H., Giles, G.G., Dite, G.S., Apicella, C., Hopper, J.L. and Milne, R.L. (2008), 'Psychosocial Factors and Survival of Young Women With Breast Cancer: A Population-Based Prospective Cohort Study', *Journal of Clinical Oncology*, 26, 28, 4666-4671.

PHRC (2002), 'Cancer in the Australian Capital Territory 1994-1998', Population Health Research Centre; ACT Department of Health and Community Care.

Pine, V.R. (1980), 'Social Organization and Death', *in* Kalish, R.A. (ed.), *Death, Dying, Transcending*, Farmingdale, NY, Baywood Publishing Company, Inc.

Powell, J.L. (2008), 'Social Theory and Emotion: Sociological Excursions', *International Journal of Sociology and Social Policy*, 28, 9/10, 394-407.

Pritchard, P. (1992), 'Doctors, Patients and Time', *in* Frankenberg, R. (ed.), *Time, Health and Medicine*, London, Sage.

Pruchno, R. and Resch, N. (1989), 'Husbands and Wives as Caregivers: Antecedents of Depression and Burden', *The Gerontologist*, 29, 2, 159-165.

Radley, A. (1999), 'The Aesthetics of Illness: Narrative, Horror and the Sublime', *Sociology of Health and Illness*, 21, 6, 778-796.

Rando, T. (1988), 'Anticipatory Grief: The Term is a Misnomer but the Phenomenon Exists', *Journal of Palliative Care*, 4, 70-73.

Rasmussen, D.M. and Elverdam, B. (2008), 'Cancer Survivors' Classification of Health Before, During and After Their Illness', *BSA Medical Sociology Group 40th Annual Conference*, University of Sussex, Brighton.

Remennick, L. (1998a), 'Introduction: The Cancer Problem in Medical Sociology and Demography', *Current Sociology*, 46, 1, 1-9.

Remennick, L. (1998b), 'Living with Cancer: A Patient Perspective', *Current Sociology*, 46, 1, 115-127.

Remennick, L. (1998c), 'Psychosocial Factors in Cancer Causation', *Current Sociology*, 46, 1, 39-42.

Roberts, K. (2002), 'Are Long or Unsocial Hours of Work Bad for Leisure?' *in* Crow, G. and Heath, S. (eds.), *Social Conceptions of Time: Structure and Process in Work and Everyday Life*, New York, Palgrave Macmillan.

Rose, K.E., Webb, C. and Waters, K. (1997), 'Coping Strategies Employed by Informal Carers of Terminally Ill Cancer Patients', *Journal of Cancer Nursing*, 1, 3, 126-133.

Rose, N. (1989), *Governing the Soul: The Shaping of the Private Self*, London, Routledge.

Roth, J.A. (1963), *Timetables: Structuring the Passage of Time in Hospital Treatment and Other Careers*, New York, Bobbs-Merrill Company, Inc.

Saad, K., Hartman, J., Ballard, C., Kurian, M., Graham, C. and Wilcock, G. (1995), 'Coping by the Carers of Dementia Sufferers', *Age and Ageing*, 24, 495-498.

Sabo, D. (1990), 'Men, Death Anxiety, and Denial: Critical Feminist Interpretations of Adjustment to Mastectomy', *in* Clark, E., Fritz, J.M., Rieker, P.P., Kutscher, A.H. and Bendiksen, R.A. (eds.), *Clinical Sociology Perspectives on Illness and Loss: The Linkage of Theory and Practice*, Philadelphia, The Charles Press, Publishers.

Sardell, S., Sharpe, G., Ashley, S., Guerrero, D. and Brada, M. (2000), 'Evaluation of a Nurse-Led Telephone Clinic in the Follow-Up of Patients with Malignant Glioma', *Clinical Oncology*, 12, 1, 36-41.

Sayer, A. (1984), *Method in Social Science: A Realist Approach*, Sydney, Hutchinson.

Scheff, T.J. (1997), *Emotions, the Social Bond, and Human Reality: Part/Whole Analysis*, Paris, Cambridge University Press.

Schwersenka, G. and Burt, C. (2001), 'Supplemental Services', *in* The Lewin Group (ed.), *The U.S. Administration on Aging Conference*, Washington, DC.

Shaffir, W.B. (1991), 'Managing a Convincing Self-Presentation: Some Personal Reflections on Entering the Field', *in* Shaffir, W.B. and Stebbins, R.A. (eds.), *Experiencing Fieldwork: An Inside View of Qualitative Research*, New Delhi, Sage Publications.

Shapiro, D.E., Boggs, S.R., Melamed, B.G. and Graham-Pole, J. (1992), 'The Effect of Varied Physician Affect on Recall, Anxiety, and Perception in Women at Risk for Breast Cancer: An Analogue Study', *Health Psychology*, 11, 1, 61-66.

Sharpe, L., Butow, P., Smith, C., McConnell, D. and Clarke, S. (2005), 'The Relationship Between Available Support, Unmet Needs and Caregiver Burden in Patients with Advanced Cancer and Their Carers', *Psycho-Oncology*, 14, 102-114.

Shaw, J. (1997), 'Even if I Videoed This, No-One Would Believe Me', Bendigo, Bendigo Health Care Group and Department of Health Services.

Shekelle, R.B., Raynor, W.J., Ostfeld, A.M., Garron, D.C., Bieliauskas, L.A., Liu, S.C., Maliza, C. and Paul, O. (1981), 'Psychological Depression and 17-Year Risk of Death from Cancer', *Psychosomatic Medicine*, 43, 2, 117-125.

Shem, S. (1978), *The House of God: A Novel*, New York, Richard Marek Publishers.

Sherwood, P.R., Given, B.A., Doorenbos, A.Z. and Given, C.W. (2004), 'Forgotten Voices: Lessons from Bereaved Caregivers of Persons with a Brain Tumour', *International Journal of Palliative Nursing*, 10, 2, 76-83.

Short, S.D., Sharman, E. and Speedy, S. (1993), *Sociology for Nurses: An Australian Introduction*, Crows Nest, NSW, Macmillan Education Australia.

Skene, L. (1990), *You, Your Doctor and the Law*, Melbourne, Oxford University Press.

Small, W. (1996), 'Emotion Work', *in* Grbich, C. (ed.), *Health in Australia: Sociological Concepts and Issues*, Sydney, Prentice Hall.

Sontag, S. (1991), *Illness as Metaphor and AIDS and Its Metaphors*, London, Penguin Books.

Soothill, K., Morris, S., Harman, J., Francis, B., Thomas, C. and McIllmurray, M. (2001), 'Informal Carers of Cancer Patients: What are their Unmet Psychosocial Needs?' *Health & Social Care in the Community*, 9, 6, 464-475.

Sörensen, S., Pinquart, M. and Duberstein, P. (2002), 'How Effective are Interventions with Caregivers? An Updated Meta-Analysis', *The Gerontologist*, 42, 3, 356-372.

Sourkes, B.M. (1982), *The Deepening Shade: Psychological Aspects of Life-Threatening Illness*, Pittsburgh, University of Pittsburgh Press.

Spacapan, S. (1988), 'Social Psychology and Health', *in* Spacapan, S. and Oskamp, S. (eds.), *The Social Psychology of Health*, London, Sage Publications.

Stacey, J. (1997), *Teratologies: A Cultural Study of Cancer*, London, Routledge.

Stansfeld, S.A. (1999), 'Social Support and Social Cohesion', *in* Marmot, M. and Wilkinson, R.G. (eds.), *Social Determinants of Health*, Melbourne, Oxford University Press.

Stewart, M., Brown, J.B., Boon, H., Galajda, J., Meredith, L. and Sangster, M. (1999), 'Evidence on Patient-Doctor Communication', *Cancer Prevention Control*, 3, 1, 30.

Stiefel, F., Favre, N. and Despland, J.N. (2006), 'Communication Skills Training in Oncology: It Works!' *in* Stiefel, F. (ed.), *Communication in Cancer Care*, Berlin, Springer.

Stiefel, F. and Razavi, D. (2006), 'Informing About Diagnosis, Relapse and Progression of Disease - Communication with the Terminally Ill Cancer Patient', *in* Stiefel, F. (ed.), *Communication in Cancer Care*, Berlin, Springer.

Stocker, M. and Hegeman, E. (1996), *Valuing Emotions*, Melbourne, Cambridge University Press.

Straus, R.A. (1990), 'Changing the Definition of the Situation: Toward a Theory of Sociological Intervention', *in* Clark, E., Fritz, J.M., Rieker, P.P., Kutscher, A.H. and Bendiksen, R.A. (eds.), *Clincical Sociology Perspectives on Illness and Loss: The Linkage of Theory and Practice*, Philadelphia, The Charles Press, Publishers.

Strauss, A.L., Fagerhaugh, S., Suczeck, B. and Wiener, C. (1985), *Social Organization of Medical Work*, Chicago, University of Chicago Press.

Strazdins, L. and Broom, D.H. (2004), 'Acts of Love (and Work): Gender Imbalance in Emotional Work and Women's Psychological Distress', *Journal of Family Issues*, 25, 3, 356-378.

Sudnow, D. (1967), *Passing On: The Social Organization of Dying*, Englewood Cliffs, NJ, Prentice-Hall, Inc.

Surbone, A. (2003), 'The Difficult Task of Family Caregiving in Oncology: Exactly Which Roles do Autonomy and Gender Play?' *Support Care Cancer*, 11, 617-619.

Surbone, A. (2006), 'Cultural Aspects of Communication in Cancer Care', *in* Stiefel, F. (ed.), *Communication in Cancer Care*, Berlin, Springer.

Sweeting, H.N. and Gilhooly, M.L. (1990), 'Anticipatory Grief: A Review', *Social Science and Medicine*, 30, 10, 1073-1080.

Szollos, A. (2009), 'Toward a Psychology of Chronic Time Pressure: Conceptual and Methodological Review', *Time and Society*, 18, 332-350.

Taylor, S.E. and Dakof, G.A. (1988), 'Social Support and the Cancer Patient', *in* Spacapan, S. and Oskamp, S. (eds.), *The Social Psychology of Health*, London, Sage Publications.

Thomas, C. and Morris, S. (2002), 'Informal Carers in Cancer Contexts', *European Journal of Cancer Care*, 11, 178-182.

Thomas, C., Morris, S., Soothill, K., McIllmurray, M., Francis, B. and Harman, J. (2001), 'What are the Psychosocial Needs of Cancer Patients and Their Main Carers? A Study of User Experiences of Cancer Services with Particular Reference to Psychosocial Need', Lancaster, The Institute for Health Research, Lancaster University.

Thomas, C., Morris, S.M. and Harman, J.C. (2002), 'Companions Through Cancer: The Care Given by Informal Carers in Cancer Contexts', *Social Science & Medicine*, 54, 529-544.

Thompson, E.H. (2005), 'What's Unique About Men's Caregiving?' *in* Kramer, B.J. and Thompson, E.H.J. (eds.), *Men as Caregivers*, Amherst, NY, Prometheus Books.

Thompson, E.H., Futterman, A.M., Gallagher-Thompson, D., Rose, J.M. and Lovett, S.B. (1993), 'Social Support and Caregiving Burden in Family Caregivers of Frail Elders', *Journal of Gerontology*, 48, 5, S245-S254.

Thrift, N. (1990), 'The Making of Capitalist Time Consciousness', *in* Hassard, J. (ed.), *The Sociology of Time*, London, Macmillan.

Toseland, R., Blanchard, C. and McCallion, P. (1995), 'A Problem Solving Intervention for Caregivers of Cancer Patients', *Social Science & Medicine*, 40, 4, 517-528.

Toseland, R. and Durham, L. (2001), 'Caregiver Training, Support Groups, and Counseling', *in* The Lewin Group (ed.), *The U.S. Administration of Aging Conference*, Washington, DC.

Toseland, R., Rossiter, C., Peak, T. and Smith, G. (1990), 'Comparative Effectiveness of Individual and Group Interventions to Support Family Caregivers', *Social Work*, 35, 3, 209-217.

Turner, B.S. (2006), 'Hospital', *Theory, Culture & Society*, 23, 573-9.

Turner, J.H. and Stets, J.E. (2005), *The Sociology of Emotions*, New York, University of Cambridge.

Twigg, J. and Atkin, K. (1994), *Carers Perceived: Policy and Practice in Informal Care*, Buckingham, Open University Press.

Ussher, J., Kirsten, L., Butow, P. and Sandoval, M. (2006), 'What do Cancer Support Groups Provide Which Other Supportive Relationships do not? The Experience of Peer Support Groups for People with Cancer', *Social Science & Medicine*, 62, 2565-2576.

Van Krieken, R., Habibis, D., Smith, P., Hutchins, B., Haralambos, M. and Holborn, M. (2006), *Sociology Themes and Perspectives* (3rd Edition), Frenchs Forest, NSW, Pearson Education Australia.

Victorian Centre for Nursing Practice Research (2001), 'Breast Care Nurses in Victoria: A Workforce Study of Practice and Factors Influencing Practice', Melbourne, The University of Melbourne, BreastCare Victoria Coordination Unit, Victorian Department of Human Services.

Wearing, M. (1996), 'Medical Dominance and the Division of Labour in the Health Professions', *in* Grbich, C. (ed.), *Health in Australia: Sociological Concepts and Issues*, Sydney, Prentice Hall.

Weitzner, M.A., Haley, W.E. and Chen, H. (2000), 'The Family Caregiver of the Older Cancer Patient', *Hematology/oncology Clinics of North America*, 14, 1, 269-281.

White, K. (2000), 'The State of the Market and General Practice: The Australian Case', *International Journal of Health Services*, 30, 2, 285-308.

White, K. (2006), *Sage Dictionary of Health and Society*, London, Sage Publications.

Whiting, P. and James, E. (2006), 'Bearing Witness to the Story: Narrative Reconstruction in Grief Counseling', American Counseling Association, Alexandria, VA.

Wiener, C.L. (1997), 'Introduction to the Fifth Edition', *in* Wiener, C.L. and Strauss, A.L. (eds.), *Where Medicine Fails* (5th Edition), London, Transaction Publishers.

Wilkie, P. (1998), 'The Person, the Patient and their Carers', *in* Faull, C., Carter, Y. and Woof, R. (eds.), *Handbook of Palliative Care*, Carlton, VIC, Blackwell Science, Ltd.

Wilkinson, A. (2006), 'Caregiving', *Women's Health Seminar Series*, Bethesda, MD.

Willis, E. (1983), *Medical Dominance: The Division of Labour in Australian Health Care*, Sydney, George Allen & Unwin.

Wiseman, J.P. (1970), *Stations of the Lost: The Treatment of Skid Row Alcoholics*, Englewood Cliffs, NJ, Prentice-Hall, Inc.

Woof, R. and Nyatanga, B. (1998), 'Adapting to Death, Dying, and Bereavement', *in* Faull, C., Carter, Y. and Woof, R. (eds.), *Handbook of Palliative Care*, Carlton, VIC, Blackwell Science, Ltd.

Zarit, S. (1989), 'Do we Need Another “Stress and Caregiving” Study?' *The Gerontologist*, 29, 2, 147-148.

Zarit, S., Todd, P. and Zarit, J. (1986), 'Subjective Burden of Husbands and Wives as Caregivers: A Longitudinal Study', *The Gerontologist*, 26, 3, 260-266.

Zerubavel, E. (1990), 'Private-time and Public-time', *in* Hassard, J. (ed.), *The Sociology of Time*, London, Macmillan.

Zimmerman, C. (2007), 'Death Denial: Obstacle or Instrument for Palliative Care? An Analysis of Clinical Literature', *Sociology of Health and Illness*, 29, 2, 297-314.

Zmuda, R.A. (2006), 'Caregivers Out of the Closet', *Caring for the Caregivers*, Matria Healthcare.

Appendix A: The Questionnaire

Demographic Information

Age: ____

Gender: ____ Female ____ Male

Highest level of education completed:
____ Secondary (high school)
____ Tertiary (undergraduate)
____ Postgraduate (masters / doctorate)

What is your primary source of income?
____
____
____

Being a Carer

What type of cancer does the person you are caring for have?
____
____
____
____

How many months has it been since diagnosis? ___________________

What is your relationship to the person you care for?

____ Husband, Wife or Partner
____ Friend
____ Parent
____ Child
____ Other, please specify:______________________

How many hours each week do you spend providing care? __________

In what ways do you provide care?
____
____
____
____
____
____

Where do you access information about the illness that the person you care for has? Please tick all that apply.

____Healthcare professionals
____Internet
____Helpline
____Support group
____Friend(s)
____The person being cared for
____Other, please specify ____________________
____I do not access information about the illness

Where do you get information about providing practical support, such as how to administer an IV? Please tick all that apply.

____Healthcare professionals
____Internet
____Helpline
____Support group
____Friend(s)
____The person being cared for
____Other, please specify ____________________
____I do not access information on practical support

Who do you talk with about the emotional aspects of being a carer, such as how to address feelings of fear and anxiety? Please tick all that apply.

____Healthcare professionals
____Internet friends (in a chat room for example)
____Helpline
____Support group
____Friend(s)
____Family
____The person being cared for
____Other, please specify ____________________
____I do not talk about emotional aspects of being a carer

What actions / behaviours of others do you find supportive? Why?
____
____
____
____
____

What programs do you find supportive? Why?

Have you found support programs or support from friends to be accessible and effective? Why or Why not?

Comments:

Would you like to be more involved in this study? If so, please write your contact details below so the researcher can phone you to set up a time and place for an interview. Interviews will focus on carers' thoughts and opinions on being a carer and supportive services.

First name[57]: ____________________

Phone number: __________________

Best time to call: _________________

- Thank you -

---

[57] Please note that all personal information will be kept confidential to the extent that the law allows. Contact details will be destroyed after the research has concluded. Should information obtained during an interview be used in published materials, names will be changed to maintain participants' privacy.

Appendix B: Consent Forms

INFORMATION FORM FOR CARER INTERVIEW PARTICIPANTS

Rebecca Olson, a Ph.D. candidate in the School of Social Sciences in the Faculty of Arts at the Australian National University, is conducting a study on the supportive service needs of carers of cancer patients.

Purpose & Method: The purpose of this study is to improve understanding of the supportive service needs of carers in the ACT. As part of this study, the researcher will be conducting recorded interviews with carers of cancer patients.

Time, Risks & Inconvenience: Participation in this research will take approximately 60 minutes. It is not anticipated that this research will involve any risks or inconveniences to participants, beyond the giving of their time.

Voluntary Participation: Participation is an informed and voluntary process. Be assured that declining participation will not impact on your relationship with the hosting institution. Further, after agreeing to participate, should you wish to withdraw from the study, you have the right to do so without giving a reason. Participants also have the right to ask questions at any time. As long as they do not involve a breach of another's confidentiality, questions will be answered.

Impact and Outcomes of Research: It is not anticipated that involvement in interviews will have any impact on participants. It is anticipated that the study as a whole, however, will have a positive impact on carers of cancer patients in the ACT because it will allow for a better understanding of the needs of carers and how better to meet those needs through supportive services. The results of this study will be made available in public documents, possibly including an academic journal or dissertation, but in such a way that no information identifying participants will be published. All possible precautions have been taken to protect identities and the security of the information participants provide, to the extent that this is permissible by law.

Contact Details

Researcher:	Rebecca Olson PhD Candidate School of Social Sciences Building 22, Haydon-Allen The Australian National University, ACT 0200 Phone 6125.2787 or Email Rebecca.olson@anu.edu.au
Supervisor:	Dr. Kevin White School of Social Sciences Building 22, Haydon-Allen The Australian National University, ACT 0200 Phone 6125.4561 or email Kevin.White@anu.edu.au

Should you have any problems or queries about the way in which the study was conducted and do not feel comfortable contacting the researcher or the aforementioned supervisor, you may contact the Human Research Ethics Committee Secretary: Ms. Yolanda Shave, Human Ethics Officer, Research Services Office, The Australian National University, ACT 0200. Phone 6125.7945.

(*For participants to keep*)

CONSENT FORM FOR CARER INTERVIEW PARTICIPATION

I understand that this study is being conducted by Rebecca Olson, a Ph.D. candidate in the School of Social Sciences in the Faculty of Arts at the Australian National University.

Purpose & Method: I understand that the purpose of this study is to improve understanding of the supportive service needs of carers in the ACT. I understand that as part of this study, the researcher will be conducting recorded interviews with carers of cancer patients. I understand that this interview will be audio-recorded, although I can request that the interviewer use note-taking as the only formal record. I have been informed that I can switch the recorder off at anytime or ask for any part of the tape to be erased.

Time, Risks & Inconvenience: I understand that I will be participating in an interview, approximately 60 minutes long, where I will be asked questions related to my opinions and experiences as a carer. I understand that it is not anticipated that this research will involve any risks or inconveniences to me, beyond the giving of my time.

Voluntary Participation: I understand that, should I agree to participate, I will be required to sign this consent form. I understand that participation is completely voluntary. Further, after agreeing to participate, should I wish to withdraw from the study, I understand that I have the right to do so without giving a reason. I also understand that I can ask questions at any time during the interview and that as long as these questions do not involve a breach of another's confidentiality, they will be answered. Conversely, I understand that I have the right to decline to answer any question.

Impact and Outcomes of Research: I understand that it is not anticipated that involvement in interviews will have any impact on participants. I understand the results of this study will be made available in public documents, including academic journals, but in such a way that no information identifying me will be published. I understand that all possible precautions have been taken to protect identities and the security of the information participants provide, to the extent that this is permissible by law.

I understand that the supervisors of this research will act as advisors or consultants on the research process and findings. They all have considerable expertise on the topic. They are Drs Dorothy Broom and Kevin White.

Should I have any problems or queries about the way in which the study was conducted and I do not feel comfortable contacting the aforementioned researcher or supervisors, I am aware that I may contact:

Ms. Yolanda Shave, Human Ethics Officer, Research Services Office, The Australian National University, ACT 0200. Phone number: 02 6125.7945.

I am satisfied that I have been made aware of the issues covered by the consent form.

……………………………………… (Signed by interview participant)

……………………………………… Date

(*To be returned to researcher*)

Appendix C: Interview Guide One

Themes & Suggested Questions

Narrative / carer's story

1. What type of cancer does your partner have?
2. How long have you been providing support for him/her?
3. What role do you see yourself playing in his or her care?
4. Starting from the beginning and in as much detail as possible, tell me about your experiences or overall story of being a carer (narrative).
5. What would ideal support be? What would the ideal service provider do?
6. OR – What kind of care would you have liked? What kind of support do you wish you had gotten that you did not get?
7. What do you think and feel about your experiences as a carer?

Probing Questions

8. Who supports you and how? (formal services/informal)
9. What do you think about support groups?
10. How did you deal with the emotional side of being a carer?
11. What role did medical and support service personnel play in how you dealt with the emotional side of being a carer?
12. What would you say your biggest needs are?

Appendix D: Interview Guide Two

Narrative Update

1. Last time we talked you told me…[summarise main points of their story]. Is there anything new to add?
2. How are you feeling about this now?

Repeat Questions

3. Who supports you and how?
4. What do you think about support groups?
5. What would you say your biggest needs are?
6. How do you deal with the emotional side of being a carer?

Emotions

7. Did/do you feel uncertain about what emotions you should be feeling as a carer and spouse?
    a. If not, what guided your assurance?
    b. If yes, do you feel more certain now? What has helped you to feel more certain?
8. Do you ever self censor? Do you ever feel that because your partner is sick that you shouldn’t have your own needs?
    a. Does your distress count? Are there times when you feel you can't say how you really feel?
9. Do/did you feel appreciated/valued as a husband/wife carer? How so?
    a. For the patient: how does/did your spouse help you?

Time & End

10. What role does/did time play in your experience as a carer?
11. Did you feel our discussion last time made any difference to how you think or feel about being a carer/spouse for someone with cancer?
12. Did you find the booklets helpful?
13. What has changed over the past 6 months?

Appendix E: Focus Group Questions

1. Have you found carers' emotion management to be the result of a learned process?
2. Would you agree that counselling and support groups are places where carers are encouraged in their current approach or encouraged to learn a new emotion management strategy?
3. Is the finding that some male carers might prefer less direct support, that is, the facilitation of networking and informal support consistent with your observations?
4. Have you found that breast cancer patients and carers are more consistently informed of available services?
5. Have you found that for other carers, information distribution follows a chance or emergency basis in the medical system?
6. What solutions might you offer to overcome the presented support service information distribution hurdles?

Appendix F: Summary of Participants

Carer's name	Gender	Spouse's name	past/present[58]	Carer's age	cancer type	location[59]	time[60] between interviews
Andrew	M	Martha	present	60s	breast	Suburb	6
Anne	F	James	present	30s	glandular	Suburb	6
Bernard	M	Sue	past	50s	breast	Suburb	6
Blake	M	Diana	present-past	40s	breast	Suburb	6.75
Carl	M	Kristen	present	70s	lung	Suburb	5.75
Carlie	F	Warren	present	50s	oral	Suburb	n/a
Charlie	M	Marsha	present	50s	breast	Suburb	6
Cindy	F	Frank	present	60s	prostate	Suburb	6
Colleen	F	Harold	past	60s	prostate	Suburb	6.25
Fiona	F	Mark	past	60s	prostate	Suburb	6.75
Frank	M	Cindy	past	70s	haematological cancer	Suburb	6
Fred	M	Jane	past	60s	melanoma	Suburb	6
Ian	M	Sonya	past	50s	breast	Suburb	6
Jane	F	Fred	past	60s	prostate	Suburb	6
Joe	M	Betsy	past	60s	ovarian	Suburb	5.75
Judy	F	Richard	present	60s	asbestos related cancer	Suburb	4
Kyle	M	Carol	past	40s	breast	Suburb	6.5
Leo	M	Winifred	present	60s	breast	Suburb	6
Linda	F	Michael	present-past	40s	bowel	Suburb	6.25
Marian	F	Steven	past	50s	neurological	Suburb	5.75
Mark	M	Fiona	past	60s	breast	Suburb	6.75
Mary	F	Leon	present	50s	prostate	Suburb	8
Matthew	M	Sherry	present	30s	breast	Suburb	n/a
Millicent	F	Charles	present-past	60s	haematological cancer	Regional	6
Mitch	M	Melanie	present	50s	breast	Suburb	5
Patrick	M	Phillipa	present	50s	breast	Suburb	6.75
Phyllis	F	John	past	50s	neurological	Regional-Suburb	6
Rodney	M	Chloe	present-past	30s	breast	Suburb	5.75
Sally	F	Greg	present-past	40s	bladder	Suburb	5.75
Seamus	M	Wilhelmina	past	80s	bowel	Suburb	6.25
Sharon	F	Sam	present	50s	neurological	Suburb	6.5
Tyler	M	Megan	present-past	60s	haematological cancer	Regional	6

---

[58] "Present-past" denotes a change in the carer's status from the first to second interview.
[59] "Regional-Suburb" indicates that the carer moved while they were caregiving.
[60] Time is measured here in months. "N/a" or not applicable indicates that this carer withdrew from the study.