

CARERS OF CANCER PATIENTS: UNDERSTANDING THEIR SUPPORT SERVICE NEEDS



Australian Government

Cancer Australia

A Report to Cancer Australia

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Contents

	Executive Summary	3
1	Background and Research Context	4
	1.1 Rationale	4
	1.2 Project aims	6
	1.3 Research design	6
	1.3.1 Questionnaires	6
	1.3.2 Interviews	8
	1.3.3 Focus Group	11
	1.3.4 Analysis	11
	1.4 National applicability	12
2	Findings Part I: Time, Emotions and Support	13
	2.1 Time: a central factor in carers' needs and experiences	13
	2.1.1 Contradictory emotion work	16
	2.2 Time: a central factor in carers' support preferences	17
	2.2.1 Emotional support: informal	17
	2.2.2 Emotional support: counselling	18
	2.2.3 Emotional support: support groups	19
	2.2.4 Practical support	20
	2.2.5 Practical support: respite	20
	2.2.6 Practical support: financial aid	21
	2.2.6.1 Financial aid: Centrelink	21
	2.2.6.2 Financial aid: IPTAAS	23
	2.3 Summary	23
3	Findings Part II: Medical Systems Rely on Carers	24
	3.1 Inconsistent and bureaucratic care	24
	3.2 Does this model of care exacerbate carers' ill health?	27
	3.3 Information distribution	29
	3.4 Summary	30
4	Implications	31
	4.1 Mixed modes of emotional support services	31
	4.2 Practical support guidance	33
	4.3 Improved information dissemination	33
	4.4 Summary	36
	4.5 Limitations	37
	Appendices	38
	Appendix 1 Questionnaire	38
	Appendix 2 Questionnaire Demographics	40
	Appendix 3 Interview Research Guide 1	41
	Appendix 4 Interview Research Guide 2	42
	Appendix 5 Focus Group Questions	43
	Reference List	44

Executive Summary

Using questionnaire, interview and focus group data, this project provides a sociological account of spouse cancer carers' needs and experiences. Research outcomes fill a gap in the literature and through the dissemination of this report will allow relevant organisations to take a more informed approach to support service delivery and policy development.

Study findings indicated that time is a central factor in carers' needs and experiences. Some cancer carers experienced little control over their time as they managed multiple roles - working, parenting, caring for elderly relatives and caring for their spouse. In particular, they had little time to experience or interpret their feelings. Carers who experienced more control over their time also had more time to feel, more time to reap the benefits of caregiving - growing closer to their spouse - and more time to experience the confusion associated with the contradictory roles of being a carer and spouse.

These differences in what can be called 'time sovereignty' explained much of the variation in carers' support preferences. *Time-sovereign* carers – those who had control over their time - tended to prefer emotion-focused support. *Time-destitute* and *time-poor* carers tended to prefer practical support. For them, the central problem was the accessibility and efficacy of financial aid and respite programs.

The findings also indicated that while carers are relied on at home they are also relied on within medical systems to coordinate care and advocate for patients. With medical system care experienced as inconsistent and bureaucratic, spouses felt compelled to oversee their spouse's care. At the same time the health care system implicitly depended on carers to perform these roles. However, medical personnel rarely recognise these spouses as carers in need of inclusion and information on treatment and psychosocial support. The accounts presented here suggest that this neglect is having a detrimental impact on carers' wellbeing.

Based on these findings, this report makes the following recommendations:

1. Make a variety of emotional support options known and/or available to support those time-sovereign carers who are confused about their emotions, but do not feel comfortable in support groups.
2. For time-poor carers, make practical support easier to obtain and more widely known as this would improve their ability to cope with their time poverty.
3. An institutional need is for cancer nurses within the medical system, following the successful model put forward by breast care nurses, to lessen the burden on carers and ensure carers are provided with relevant information and guidance.

1 Background and Research Context

1.1 Rationale

Friends or family members who provide physical and emotional support to a patient are informal carers or caregivers (Franks & Stephens, 1992; Laizner et al., 1993). Shorter in-patient stays have shifted care to the home. Consequently, informal carers have become the “central plank of service provision” (Allen, 2000:150) providing between 55 (Nijboer et al., 1998) and 80 percent (Lewis, 2006) of long-term care. The roughly 15% of the Australian population involved in caregiving provide care within the home without pay (Evandrou, 1996; Howe et al., 1997), saving the medical system roughly \$30.5 billion dollars each year (Carers Australia, 2007).

This role is usually performed by a close relative (Thompson, 2005): 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). 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).

Though carers are often overlooked by medical professionals and many researchers (Chambers et al., 2001) since they are not the patient, and thus not in need of aid, caregiving can be detrimental to a carer’s health. More specifically, it has been found to have an impact on a carer’s finances (ABS, 1999), physical health and mental health. In addition to pre-existing health problems (Thomas et al., 2002), carrying, transferring and physically supporting another adult can injure carers’ musculoskeletal health and take time away from beneficial physical exercise (Evandrou, 1996; Toseland et al., 1995). Caregiving can also be stressful, 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; Hodges et al., 2005; Kramer, 1997; Northouse et al., 2000; Toseland et al., 1990; Weitzner et al., 2000). Carers tend to have more distress, anxiety and unmet psychological needs than patients, reflecting their overlooked position within the medical system (Harrison et al., 1995; Soothill et al., 2001; Thomas et al., 2001).

These studies have sufficiently established that being an informal carer is stressful and burdensome. Attention now needs to focus on how to improve their experiences (Lindstöm & Eriksson, 2005; Zarit, 1989), especially for carers of cancer patients. Most research to date has focused on carers of dementia patients. The illness patterns and caregiving experiences for dementia and cancer though are quite different and the disease can make a significant difference to carers’ experiences. A degenerative

disease like dementia typically occurs in old age, can be slow in onset, long-term, and can 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 follow an uncertain trajectory that vacillates between sickness and health, dying and wellness (Little et al., 1998).

Few researchers, however, have examined cancer carers' needs and support preferences (Thomas et al., 2001:106). Considering that 322 per 100,000 men and 245 per 100,000 women in Australia are diagnosed with cancer each year (PHRC, 2002), that cancer is the leading cause of death in Australia (ABS, 2007; National Cancer Control Initiative, 2003), and the primary reason for "potential life years lost" (Duckett, 2004:41), it is surprising that cancer carer's experiences have not been more thoroughly examined. The need for research that specifically examines the experiences of carers of cancer patients is well documented in the caregiver and cancer literature (Askham, 1997; Ciambone & Allen, 2005; Herron, 2005; Thomas et al., 2001; Twigg & Atkin, 1994).

The few existing studies of cancer carers' needs are psychological, descriptive and narrowly focused (for exceptions, see Allen et al., 2004; Thomas et al., 2001). Research with a more social lens examining the needs of cancer carers has been described as "under-explored" (Thomas et al., 2001:21). A few quantitative studies have examined cancer carers' experiences, for example, and found statistical variation in carers' needs. Age and gender have been found to be noteworthy factors with younger female carers reporting more emotional and unmet needs (Allen et al., 1999; Ciambone & Allen, 2005; Druhan-McGinn & White, 2004; Evandrou, 1996; Harding & Higginson, 2003; Northouse et al., 2000; Pruchno & Resch, 1989; Sharpe et al., 2005; Thomas et al., 2002; Zarit et al., 1986). The reasons for this variation, however, are unclear (Burns et al., 2004; Laizner et al., 1993; Thomas et al., 2001; Thomas et al., 2002). Although these past studies have made significant contributions to understanding cancer carers' experiences, there is a need for qualitative research on cancer carers' experiences (Ciambone & Allen, 2005).

Qualitative research would allow for a cancer carer led conceptualisation of carers' needs, why they vary and would also inform improved targeting of social support services (Burns et al., 2004; Herron, 2005; Nathan, 1990; Thomas et al., 2001). Many studies on cancer carers and support services have studied the effectiveness of support, but they are often limited to measuring the extent to which psycho-social 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 (Askham, 1997; Herron, 2005).

1.2 Project aims

This project aims to take a carer-led and sociological approach to understanding carers' emotions, their roles within the hospital system and evaluation of formal and informal support. In gaining a better understanding of their experiences and social circumstances, this project will fill a gap in the literature and provide information to relevant organisations in and beyond Canberra. The concepts that result will update support service providers on the reasons behind cancer carers' support service preferences and allow for informed targeting and reshaping of services. Support service providers often strategically plan their efforts to target as many individuals in the relevant population as possible with the most effective means of support. Understanding what impact demographic factors have on carers' needs and ability or desire to access support services is likely to help services in prioritising their efforts. It will also inform policy development on how public hospitals can better support these carers.

1.3 Research design

To meet these project aims, an examination of carers' accounts of interactions with medical and support services was required. A triangulation of methods was employed, involving multiple and longitudinal methods to increase the study's width, breadth and validity (Flick, 2002; Minichiello et al., 1995).

- Questionnaire data provided the platform on which interviews were based.
- Narrative and semi-structured longitudinal interviews were the main form of data collection, allowing for in depth exploration of carers' needs and experiences.
- A focus group with support personnel was used as a means of checking the validity of the results.

1.3.1 Questionnaires

Questionnaires were designed for this study (see Appendix 1). 917 were distributed through local support services in Canberra between September 2006 and March 2007 (see Appendix 2 for respondents' demographic information). Despite a 5% response rate (47/917), questionnaire data provided:

1. a necessary tool in accessing this population,
2. comparison with overseas data and
3. a basis for developing interview themes.

First, the questionnaires were an effective means of recruiting interview participants. Carers are a difficult population to study because they are dispersed and busy (Gray et al., 1997; Hunt & Mintz, 2002). Gaining access is a challenge, but 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. 28 out of 47 did so.

Second, the questionnaires allowed for comparison with quantitative data from overseas. The demographic characteristics of Thomas and colleagues’ (2001) questionnaire participants in the U.K. were compared with those in this study. The similarities in their make-up (in terms of carer-patient relationship, cancer type, age and employment status) indicate that participants in this study were not outliers (see figures 1-4).

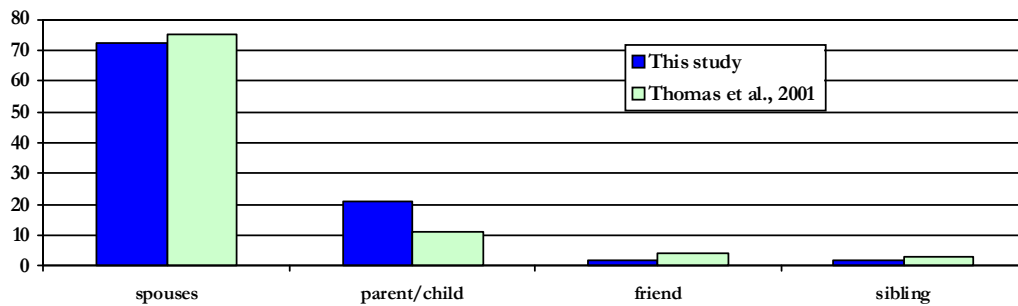


Figure 1 - A percentage comparison of carer-patient relationships in this study and in a U.K. study by Thomas and colleagues (2001).

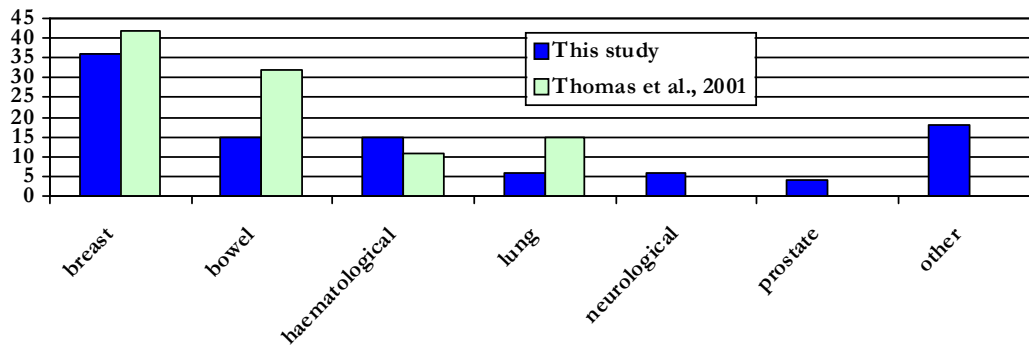


Figure 2 - A percentage comparison of cancer types affecting care recipients.

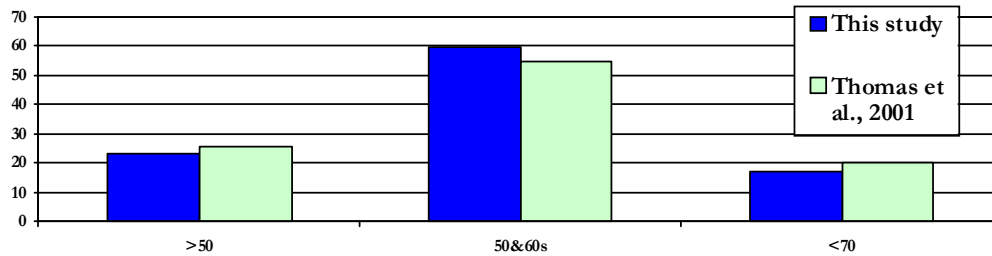


Figure 3 - A percentage comparison of respondents' ages.

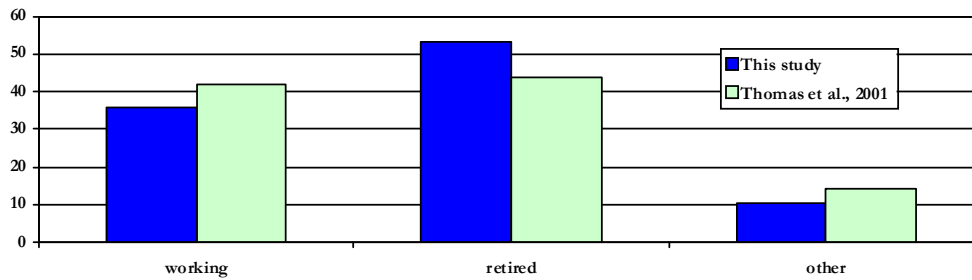


Figure 4 - A percentage comparison of questionnaire respondents' work categorisation.

Third, questionnaire data was essential to developing a grounded theory approach to data collection. A grounded theory approach is a systematic approach to research where data is collected and coded simultaneously so that the next step in the research is shaped by the themes that emerge from the previous step (Flick, 2002; Kellehear, 1993). It is adopted to avoid the imposition of research driven categories and to allow themes to emerge from the data. Leads and questions that arose from the analysis of the questionnaires informed the interview discussion guide.

1.3.2 Interviews

28 questionnaire respondents volunteered to participate in interviews. The scope of the study, however, was limited at this point to include only spouse cancer carers using the Canberra medical 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 marriage and go on caring even when it becomes too onerous (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. Past research suggests that age and gender are correlated with different levels of unmet need and stress (section 1.1). Therefore, 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.

Recruitment ended after 32 participants agreed to participate and patterns started to emerge from analysis. Qualitative research is more concerned with understanding the range, variation and relationships surrounding phenomena and less concerned with statistical generalisability (Becker, 1998). The 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. 19 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. 17 participants were employed in part-time or full-time paid work and 15 were retired from paid work (see figures 5-9).

Each participant was interviewed twice, roughly six months apart to allow for a longitudinal comparison, validation, clarification and exploration of themes that emerged from the analysis of first interviews (Flick, 2002; Minichiello et al., 1995). During the time between first and second interviews many carers' lives changed, slightly altering the study's demographics (see figures 5-9).

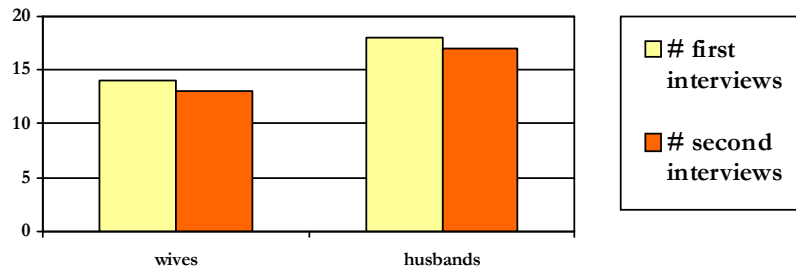


Figure 5 - The gender distribution of interviewees in whole numbers.

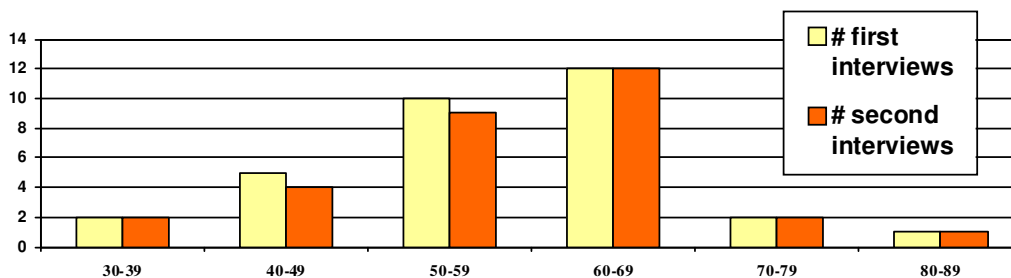


Figure 6 - The age range of interviewees in whole numbers.

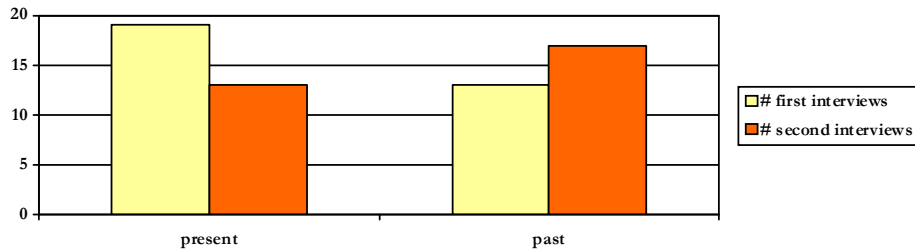


Figure 7 - The caring stages of interviewees in whole numbers: active/present or retired/past.

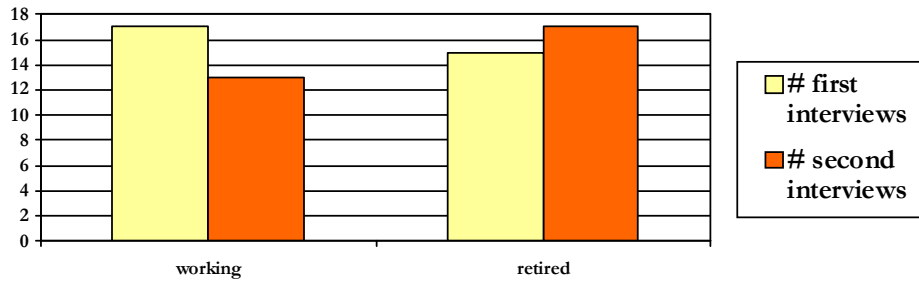


Figure 8 - The working category of interviewees in whole numbers.

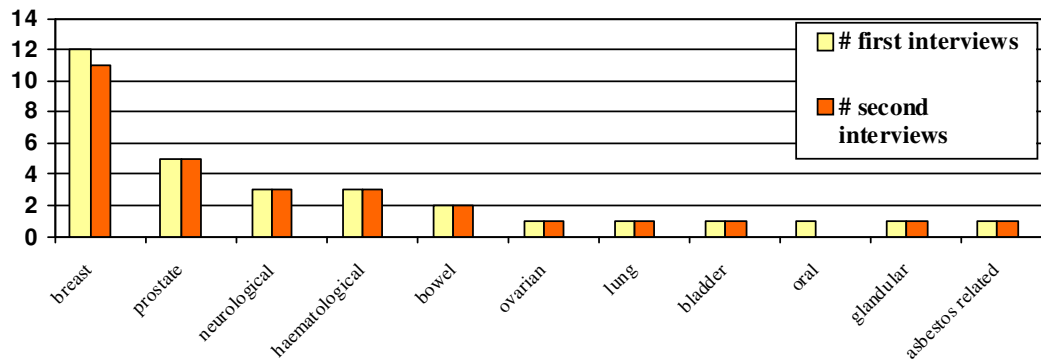


Figure 9 - The types of cancer affecting interviewees' spouses in whole numbers.

In the first interviews, questions were asked about the following:

1. each participants' caring role, the type of cancer, how long the interviewee had been caring, and the tasks involved in caring;
2. their story or overall experience of caregiving; and
3. thematic questions related to informal support, thoughts on support groups, carers' biggest needs, dealing with emotions and the roles medical and support services play in how carers deal with emotions.

A research guide was used to remind the researcher to address all of these topics during interviews (see Appendix 3).

Follow up interviews focused on validity and change. During the second interviews the researcher focused on:

1. ensuring the first interview discussion had been accurately interpreted;
2. assessing each carers' current feelings regarding their carer role;
3. repeating thematic questions from the first interviews to measure any change over time; and
4. asking about new themes that emerged from the analysis of the first interviews using a research guide (see Appendix 4).

All interviews were transcribed using noise cancellation and speed control software to improve accuracy.

1.3.3 Focus Group

A thirty minute presentation of findings and hour long focus group with Cancer Council ACT personnel, including support group facilitators, was also conducted. The group first discussed their reactions to the presentation, with facilitators and staff strongly identifying with research themes. This feedback supported the plausibility of these research findings. Second, the group responded to a list of questions (see Appendix 5). The resulting discussion evaluated different suggestions on overcoming challenges to support service delivery and linkages between medical systems and non-profit services linkages. This discussion has informed the implication sections of this report.

1.3.4 Analysis

This research used a grounded theory approach to analysis. 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). Thematic coding was undertaken to order participants' texts (Flick, 2002). *Nvivo*, a qualitative research software program, was used to help in categorising the 663 pages of text (Minichiello et al., 1995). When all transcripts had been coded, the themes of each category were summarised to allow for the examination of study wide themes (Flick, 2002).

Though efforts were made during analysis to highlight emic or the insiders' perspectives, it needs to be acknowledged that this research is not free from researcher input. Data collection, analysis and the production of knowledge are 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). Further, it should be kept in mind that the conclusions of this study are made from contact with a limited number of informants, and may not be

representative of every cancer carers' thoughts, emotions and experiences (Broom, 2005). Instead, these findings should be valued as realistic and plausible (Flick, 2002); they should be perceived, not as absolute, but as an insight into reality (Flick, 2002).

1.4 National applicability

Canberra is an outlier nationally because of its high socio-economic status and low rates of disadvantage (ABS, 2006). It is a hub of public servants living in an enclave within rural NSW. These characteristics of Canberra's social landscape, however, seem to have little bearing on its population's experiences of cancer. The demographic and experiential similarities between this study and Thomas et al.'s (2001) imply that this study's findings are widely applicable. Although collected data was restricted to carers of cancer patients using Australian Capital Territory (ACT) based medical systems, and focus groups were limited to ACT cancer carer facilitators, findings from this study are likely to have national applicability as respondents were drawn from varying income-levels, professions and locations (metropolitan, coastal and regional)¹.

¹ A few participants were New South Wales residents whose spouses used the Canberra hospital's radiation and oncology specialists in conjunction with smaller regional hospitals.

2 Findings Part I: Time, Emotions and Support

2.1 Time: a central factor in carers needs and experiences

Past research emphasises the statistical correlation between age, gender and higher rates of unmet need among cancer carers (see section 1.1). Quantitative studies have suggested inconclusive hypotheses as to the cause of this variation. This research introduces time as a central variable in understanding carers' experiences and the statistical outcomes of past research.

Questionnaire data showed that the amount of time spent caregiving varies widely. Of the 39 carers who completed this section of the survey 30% reported caring between zero and 29 hours each week, 31.5% reported caring between 30 and 120 hours per week, 18% provided care around the clock seven days a week (168 hours), and the remaining 20.5% said that it varies.

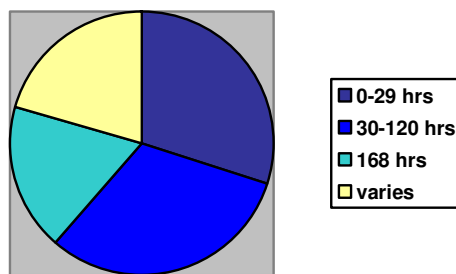


Figure 10 - percentage distribution of the number of hours spent caregiving, as reported by questionnaire respondents.

After analysing interview data, it became clear that time is a central factor in conceptualising the range of carers' emotional experiences and needs. Carers' experiences greatly varied depending not just on how much time they spend caring, but on how much control they had 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 one of the benefits of caregiving: feeling closer to their spouse. Carers with little to moderate control over their time had more time to feel² and were more likely to describe the cancer as a source of enhanced closeness with their partner.

The following vignettes illustrate the importance of time in carers' differing experiences.

² The terms repression and denial have purposefully been avoided because they denote coping strategies of uncertain internal origin. 'Time to feel' connotes an external origin to this internal constraint, with one intensive or multiple roles detracting from carers' capacities to process their emotions.

Vignette 1: Time-destitute cancer carers

Anne³ is in her 30s. She is the mother of a toddler, a receptionist and carer to her husband who has a rare glandular cancer. Since his diagnosis, disfiguring surgery and radiation treatment, Anne has taken on the role of breadwinner in addition to her other roles. This means that Anne works 6 days a week.

Anne said she was physically and emotionally exhausted. She cried throughout the entire first interview and said she was drinking more at night to cope with her perceived lack of control over her life. Anne did not report 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.

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

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.

Sally saw her emotions as an indulgence for which she did not have time. "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)".

Sally, like Anne, is time-destitute. With so many people relying on them, these carers did not have time to feel.

Vignette 2: Time-poor cancer carer

Joe is in his 60s. He retired when his wife became disabled and fully dependent on him for care as a result of metastatic cancer. They had no children, so Joe alone took on the cooking, cleaning and communicating with family and friends, taking only a few hours respite each week to do the grocery shopping and run errands. He would wake up when she stirred at night to roll her over in bed, because she was no longer

³ Names have been changed to maintain participants' anonymity.

able to roll over herself. He existed on only a few hours of sleep each night, but said the experience 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 3: Time-sovereign carers

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. They had far more control over their time than Anne, Sally or Joe. They were retired from full-time work, their children were grown and their cancers were not physically debilitating. Thus, they had more 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 lifting his spirits.

Fred struggled with feelings of guilt, fear and uncertainty as a spouse 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”.

This conceptualisation of carers differing emotional experiences based on the amount of control they have over time explains a lot of the poorly understood variation in cancer carers’ experiences and support needs. It explains why age and gender are so often found to be statistical factors in understanding carers’ higher rates of unmet needs. Older carers are more likely to be retired, with grown children, and thus more likely to have control over their time. Women are more likely to be selected by relatives to be carers (ABS, 1999; Allen et al., 1999). Consequently, male carers are more likely to have autonomy over their time because they are less likely to be the primary carer for older relatives and young children.

These vignettes also show that more time-sovereign carers had more emotion-rich experiences with their spouses. Carers with time perceived caregiving to be beneficial, allowing them to feel closer to their spouse. For many, however, this time to feel also meant sorting through confusing and conflicting emotions related to the cancer caring role.

2.1.1 Contradictory emotion work

Being a carer involves reprioritisation. With the diagnosis and onset of treatment, carers concentrated solely on the patient's wellbeing and their own emotions became less important. This ongoing suppression of emotions and maintenance of a brave face was very tiring. Helping to shape a patient's emotions (often to be positive) meant that the carer also had to change their own emotions. This is called emotion work or emotion management: the efforts made to change one's own physical and cognitive emotions through externally presenting a different emotion and trying to change internal feelings (Hochschild, 1990). Carers, however, received very little emotional support in doing emotion work 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, many carers said the emotional aspect of caring was "the greater challenge". They 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" (*female bowel cancer carer in her 40s*) of the new caring roles after diagnosis within their marriages. Though 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 the 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 felt they could not suspend their own emotional needs indefinitely, but in turn felt selfish for wanting to give their own feelings and lives precedence.

Examining carers' experiences of anger show the contradictory nature of this reprioritisation. As time went on and patients became well enough to exhibit irritating idiosyncrasies and express criticisms, carers became exasperated. But these spouse-appropriate feelings of resentment were often followed by remorse for not maintaining carer-appropriate feelings of tolerance. Crucially, carer and spouse

‘feeling rules’⁴ (Hochschild, 1979; Turner & Stets, 2005) are at odds. For example, one carer explained that, as a wife, it would be acceptable for her 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” (*bowel cancer carer in her 40s*). Herein lies the feeling rule 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 emotional support from friends and family or formal support in the form of counselling and support groups.

2.2 Time: a central factor in carers support preferences

All carers sought support. On one side of the spectrum, time-sovereign carers had time to feel and consequently tended to seek emotional support to help them organise, interpret and manage their emotions (see sections 2.2.1-3). On the other side of the spectrum, time-poor and time-destitute carers had little time for their emotions. As a result of their time-consuming caring role or multiple roles, these carers reported accessing emotional support less frequently than time-sovereign carers. More often, time-poor carers sought practical support (see sections 2.2.4-6).

2.2.1 Emotional support: informal support

All carers in this study received support from friends and family. In addition to traditional practical support, including chores, respite and medical advice, many time-sovereign carers reported seeking out conversations with friends or family to distract them from their emotions or to help them overcome their emotional confusion. One carer, for example, described the “moral support” provided by friends in emails and phone conversations as essential to feeling included and distracted from his cancer-related worries (*lung cancer carer in his 70s*).

Time-sovereign carers also 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 to their spouses. A prostate cancer carer in her 60s, for example, spoke with her daughter who had trained as a counsellor to help “pull” her up enough to continue “propping up” her husband when he got “low”.

⁴ Feeling rules are culturally defined norms of how a person should feel in terms of intensity, direction (positive or negative) and duration.

However, 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 had moved 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. Thus, informal support was not equally available to all carers.

Even for those with friends and family nearby, accessing informal support was challenging. Many friends appeared to be uncomfortable around cancer patients. Carers said friends did not know what to say or do and seemed to be afraid of intruding. Some friends even stopped contacting the couple all together after hearing of the diagnosis. This made it hard for carers to access informal emotional support.

Time-sovereign 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 accessed counselling.

2.2.2 Emotional support: counselling

A third of the carers (half males and half females) in this study accessed counselling and psychiatric services from various sources: Carers ACT, ACT Health, employee assistance counsellors, and the Canberra Hospital Psychologist. These carers, mostly time-sovereign carers, were having trouble managing their emotions or were unsure if they were managing them in the best way. From counsellors, they:

- learned alternative coping strategies,
- developed a better understanding of their role and emotions, and
- took a break from emotion management.

Counsellors and psychiatrists recommended a vast range of methods to help carers cope. Some were reassured that their coping strategies were 'normal' and appropriate. Others were warned that they needed to focus more on their own emotions, respite and overall wellbeing. Psychological health professionals taught meditation techniques during therapy, or prescribed medication to alleviate anxiety and depression. A few carers were encouraged to change their orientation to the future, to look positively on the time they still had together instead of anticipating the loss.

Counselling also helped carers to achieve improved clarity about their role and emotions. A few carers said counselling forced them to focus on themselves, their role and their emotions which helped them to clarify their feelings. Often their feelings were complex and carers were unsure of either what they were feeling or why they

were feeling a certain way. Counselling helped some carers to sort through, label and connect these emotions to their carer role and other roles.

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. Talking to outsiders about emotions also gave their friends a break from the burden of listening.

Though many carers had helpful counselling experiences, some were not as positive about their experiences. A few carers felt they did not get any benefits from counselling. Joe (see vignette 2) said all he got out of it was a listener. Another carer 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 (*breast cancer carer in his 40s*).

2.2.3 Emotional support: support groups

A third of the carers interviewed in this study reported going to support groups 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 families, a breast cancer patient and carer support group, a support group arranged by psychosocial services at the Canberra hospital and a bereavement support group. Most of those interviewees who attended were female time-sovereign carers.

Carers reported getting similar benefits from support groups as from counselling. Support groups were described as a "safe" place for carers to express their emotions honestly, learn about controlling emotions and more clearly understand their feelings.

Unlike counselling, support groups also provided the following benefits:

- laughter and an opportunity to find balance between joy and sorrow;
- satisfaction from giving back and helping new cancer carers;
- reassurance in the most appropriate approach to the future;
- information on other support services, financial aid programs, the likely illness trajectory, treatment alternatives, and how to do practical tasks more easily, such as cutting pills with a pill cutter; and
- new friendships between carers in and outside of group meeting times, enlarging carers' emotional support options.

Generally, talking about experiences with others in a similar position provided carers with a means of organising their thoughts and better understanding their carer role, after seeing how others managed and discussing cancer caring emotions.

Two-thirds of the carers in the study did not go to support groups. Some declined participation because they felt they did not need support. They had enough informal support from friends and family. Some carers wanted to join, but work, childcare or demanding caring roles kept them from attending.

For others, 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. Several male carers 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. One thought emotionally expressive support groups would undermine his resolve to be strong for his wife (*haematological cancer carer in his 60s*). Another thought support groups were too comforting, involving “pillows” and “daisy-chains”, whereas he was angry and wanted to “scream and shout” (*breast cancer carer in his 40s*).

2.2.4 Practical support

Overall, carers with time to feel more often accessed emotional support. Carers with little time to feel 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 (Pearson, 2006). Thus, cancer carers’ experiences with practical support programs and their efficacy are examined here.

2.2.5 Practical support: 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 those interviewed. Joe (see vignette 2) arranged with palliative care to have a volunteer come for two hours once a week. Though intended as a break, he used the two hours to run errands and buy groceries, as pushing a shopping trolley and his wife’s wheelchair made shopping tricky.

Another carer received four hours of respite from the hospice and two hours from Carers ACT on a weekly basis. This carer of a husband with neurological cancer said she “desperately needed” the respite care. She was caring 24 hours a day for her husband, whose mental capacity diminished as a result of the cancer and she felt trapped at home. She also spent most of her six respite hours running errands, going to the gym and only occasionally meeting with friends for a break. These accounts

indicate that respite services, although accessed by carers who need it, do not provide a long enough break to meet time-poor carers' needs for rest and personal reflection.

2.2.6 Practical support: financial aid

For many couples, especially younger working (and thus time-destitute) 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 their income when it was more important than ever as a result of the loss of one earner and large medical bills. Financial aid in the form of Centrelink payments and IPTAAS (Isolated Patients Travel and Accommodation Assistance Scheme) are programs currently in place to address this time-money tug-of-war⁵.

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” (*bowel cancer carer in her 40s*).

2.2.6.1 Practical support: Centrelink

Though many time-destitute and lower 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. Some felt the structure of access to financial support seems designed to deter applicants as much as possible.

Of those who found out about the carers payment many were deterred by:

- the stress of interacting with Centrelink;
- the time demands of applying;
- the limited applicability of the forms to cancer carers; and
- the pessimistic nature of the questions asked.

Dealing with Centrelink was too stressful. While caring, a person is “too emotionally and psychologically and mentally challenged to have to deal with the pressure of big financial decisions” (*bowel cancer carer in her 40s*). Carers often felt they were treated with suspicion by these “big systems” (*breast cancer carer in his 40s*), as if

⁵ Only one other financial aid program was mentioned by carers during interviews. A low income earner mentioned the Eden Monaro Cancer Support organisation for helping her to pay a utility bill.

they were trying to cheat Centrelink. They concluded that it was better to avoid the stress of having to justify oneself to Centrelink.

In addition to stress, 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” (*neurological cancer carer in her 50s*) and “hard work” (*haematological cancer carer in her 60s*). The form’s length and degree of detail was a deterrent for many carers. Many who needed the financial assistance did not apply or put off filling out and submitting the Centrelink forms. During interviews, one oral cancer carer in her 50s on a low income used her thumb and pointer finger to indicate the paperwork’s exaggerated 15 cm thickness 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 (Centrelink, 2008), were not sufficient to entice even low income earners to wrestle with the daunting paperwork.

Another deterrent was the requirement that carers submit the paperwork in person, “no matter how sick” the patient was (*haematological cancer carer in her 60s*). For Joe (see vignette 2), whose wife was 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 limited applicability to cancer carers. They were geared more towards long-term caring for a person with a mental or physical disability. One carer said that because her husband “didn’t have one leg and could walk,” she wasn’t sure that they would qualify and so she thought applying was a waste of time (*oral cancer carer in her 50s*). Another said, “It didn’t fit me or our situation” (*neurological cancer carer in her 50s*). Instead of recognising the limitations on cancer carers’ employment, the forms focused on determining the extent of the care recipient’s physical mobility limitations, ignoring carers’ time and emotional commitments.

An additional deterrent for many carers was the “confronting” nature of Centrelink questions, in person and on the application (*breast cancer carer in his 40s*). 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 follow (*neurological cancer carer in her 50s*). This positive approach involved believing that they could slow the cancer’s spread by doing everything possible and truly believing that the patient would live. This optimistic approach is the direct

opposite to the approach bureaucratically imposed to qualify for support from Centrelink.

This method of defining financial support meant that carers had to see their partner as terminally ill and get medical professionals to see them as terminally ill, which many doctors were reportedly unwilling to do. So not only does this method of financial aid allocation negate some carers' approaches and only means of control over the situation, but it is also contrary to many doctors preferred way of communicating the patient's prognosis.

2.2.6.2 Practical support: IPTAAS

IPTAAS is another program designed to provide financial assistance to patients and carers in remote and regional areas. Carers and patients who have to travel to access hospital services can apply for a per kilometre fuel stipend and accommodation compensation. Requirements vary from state to state. For example, NSW patients must live a minimum of 200km from the specialist to qualify, but there is no minimum for ACT residents (Parliament of Australia Senate, 2005:66).

Of the six carers in this study who travelled for treatment or surgery, three of them accessed IPTAAS. These carers found IPTAAS to be a "farce" and more bureaucracy than help (*haematological cancer carer in his 60s*). "They make it so hard that people go, what is the use?" (*haematological cancer carer in her 60s*). One carer lived on the coast with his wife who required frequent Canberra hospitalisations. The four hour round trip, at 15 cents per kilometre equated to roughly \$60, but with the \$40 per claim administration fee for NSW residents that left only \$20 for the carer and patient. Further, the forms required carers to get signatures from specialists, when they already felt indebted to these specialists. After all that, when an application was lodged payment could take up to 4 months.

2.3 Summary

Overall, carers of cancer patients need support. For many carers, informal support is unavailable or does not sufficiently address their emotional and practical support needs. Time-sovereign carers need emotional support. These carers have time to feel. As a result, many grew closer with their spouses. They also had time to experience the contradictory and confusing emotions inherent in being a spouse and carer. Thus, these carers sought counselling and support group interactions to help in understanding and managing their own and their spouse's emotions. Time-poor and time-destitute carers need practical support. These carers sought time, in the form of respite, or monetary support from Centrelink and IPTAAS. Carers' accounts raise question about the efficacy of these programs.

In section four, the implications of these findings are developed further. First, findings on carers' placement and experiences within medical systems will be explored.

3 Findings Part II: Medical Systems Rely on Carers

A limit to the efficacy of support services as a whole is restricted delivery of information within Canberra's medical system. This section relays carers' experiences of factory-like and inconsistent care within medical systems, 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 wellbeing. 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.

3.1 Inconsistent and bureaucratic care

The following vignettes typify carers' experiences of uncoordinated, bureaucratic and at times faulty care within the medical systems.

Vignette 4: Frank

Frank found his experience as a prostate cancer patient in his 60s 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". 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]".

Vignette 5: Judy

Judy's (asbestos related cancer carer in her 60s) contact with both general practitioners (GPs) and their oncologist was rife with mistakes and required her to do a lot of remedial work. 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. Though 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, 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 [the oncologist].

Overall, Judy, like Frank, 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.”

These narratives represent most carers' experiences within Canberra's medical system. The current state of care is one where medical personnel have good intentions. Respondents generally said that doctors and nurses are diligent, friendly, meant well, and worked hard. However, mistakes often occur, care is bureaucratic, communication is inconsistent and carers are relied on to oversee patient care.

Mistakes were common, as is the case nationally (Duckett, 2004). Interviewees reported several medication blunders and miscommunications between staff, especially in Emergency.

Care was bureaucratic. Carers and patients complained that service was compartmentalised, slow, and matter-of-fact. They used words like “sausage factory” and “factory of drawers” to describe the organisation of care in certain departments, or “block of meat” and “number” to describe how patients were treated.

Communication was inconsistent, as Frank's account (see vignette 5) illustrates. Medical care involved multiple specialists, but 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. This is called care ‘fragmentation’, the practice of doctors working solely within the confines of their position (Allen et al., 2004; Griffiths, 2003; Parliament of Australia Senate, 2005).

The medical system relies on family to provide care for patients. Carers concluded that they could not leave the care of their spouse up to the medical system ‘lottery’ (Parliament of Australia Senate, 2005:7); they must become the care coordinator at home and in the hospital. They used the words “case” or “project management”⁶, coordinators⁷ and “patient advocate”⁸ to describe their role. This involved connecting

⁶ Three carers specifically used these words.

⁷ Seven carers specifically used these words.

the ‘bits’ of service provided by the different medical modalities and “put[ting] the pieces of the puzzle together” for their spouse (*breast cancer carer in his 40s*). Only a few carers with a long-term and trusted GP relied on their physician to oversee their spouse’s care. All others saw themselves as essential to ensuring their spouse received accurate care: the right diagnosis and medication, at home and in the hospital.

Coordinating patient care within medical systems involved the responsibilities listed below.

1. Recordkeeping, taking notes during doctors’ appointments, collecting scans, operation reports and prescriptions and then presenting this overview to relevant medical professionals when needed, was one job. Gathering information, however, could be difficult because medical information was often communicated to the patient alone. Patients, however, in a state of post-diagnosis shock (Docherty, 2004) or “chemo fog” (*breast cancer carer in his 50s*) do not thoroughly absorb information. This left many carers with the time-demanding task of seeking out information from medical professionals. One carer waited nine hours to speak to the Intensive Care Unit (ICU) doctor about her husband’s prognosis (*neurological cancer carer in her 50s*).

2. Communicating with medical staff was another care coordinator responsibility. When the patient became too ill or lacked the confidence to ask questions, carers were the automatic proxy in nurse and doctor interactions. Most carers, however, wanted to be consistently included in conversations with medical staff. Further, they wanted to be treated as both allies in the patient’s treatment and as ‘co-consumers’ 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 or physical wellbeing such as crying in front of medical staff, experiencing anxiety-induced Irritable Bowel Syndrome (IBS) or heart troubles.

3. Persuading medical staff to change their treatment or diagnosis was the patient advocacy aspect of a carer’s role. When the patient’s morbidity increased, 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 their spouse’s wellbeing and that they did not get results by waiting for someone else to notice problems. Requests of medical staff ranged from getting second opinions to suggesting different treatment options to pushing medical staff to consider a different diagnosis.

Pushing medical staff, however, could be very distressing for carers. Doctors and medical staff did not always respond favourably to carers’ requests. The result was often tension and conflict between the carer and medical staff (see Allen, 2000).

⁸ Two carers specifically used these words.

3.2 Does this model of care exacerbate carers' ill health?

Does relying on carers to provide a significant portion of patient care and coordination have an inflationary impact on carers' well documented poor health (see section 1.1)? Bernard's story suggests that this may be so.

Vignette 6: Bernard

Bernard (*breast cancer carer in his 50s*) developed anxiety and IBS (irritable bowel syndrome) because his rising stress levels as a carer were perceived to be outside of doctor-patient interactions. He was relied on to administer medication and make decisions about his wife's care at home after chemotherapy treatments, which was, at times, very distressing. On several occasions, his wife had extreme reactions to chemotherapy. Although there was a phone number he could call at the private hospital, when he called with an urgent concern, they didn't have access to his wife's records and couldn't provide any advice⁹. 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.

The stress and severe anxiety that he experienced 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.

Only when he went to an Employee Assistance Counsellor after developing IBS did he learn about the relevant stress and mental health warning signs.

Bernard's story highlights shortcomings of the current hospital system that are exacerbating carers' health problems. Deficiencies do not stem from negligent or unfeeling medical professionals. Doctors and nurses were described as caring. The paradigms guiding hospital system practice and patient care are to blame. First, economic principles overlook the externalities of this system on carers' health. Second, the biomedical model excludes carers and psychosocial information dissemination as outside the scope of medical practice.

⁹ 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.

1. The principles of economic rationalism charged with analysing and improving the hospital system's productivity (Petersen, 1994:97) leave carers out of analysis. 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, 2000:44; Duckett, 2004:33; National Cancer Control Initiative, 2003:xi).

The 'externalities' reported by carers in this study include anxiety, high stress, heart trouble, poor gastrointestinal health, depression, increased alcohol consumption, sleep interruption and divorce. As increased levels of carer burden are correlated with higher levels of morbidity (Sharpe et al., 2005), these carers accounts suggest that the current model of care, where medical systems rely on carers to coordinate the majority of patient care may be increasing carers sense of stress, anxiety, burden and, consequently, their overall morbidity.

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)¹⁰.

2. The biomedical model is also at fault for exacerbating carers' poor health. It is the dominant way of approaching problems within the medical profession. The focus is solely on addressing the biological causes of disease (Capra, 1982:352; Davis & George, 1993:402). Health protection, quality of life, communication, and the psychosocial are beyond its scope (Davis & George, 1993:178,385). Thus, it is hard for patients and carers to access psychosocial services (National Cancer Control Initiative, 2003:19; Parliament of Australia Senate, 2005:50) because prevention, emotions and carers are all beyond biomedical perceptions of care.

A consequence of this paradigm is that both doctors and carers tend to overlook carers needs for emotional care. Not only do doctors neglect to inform carers of available psychosocial support, but their example encourages many carers, like Bernard, to 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 may 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.

¹⁰ 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.

3.3 Information Distribution

If carers were guided through the myriad of information on available psychosocial services, this might counter the inflationary 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, 2006:6). 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 dissemination¹¹ practices, however, are inconsistent. Many medical professionals miss the importance of certain types of information for carers (Morris & Thomas, 2002:186).

Carers reported a lack of information on several topics central to their caring role.

- They were poorly guided on **how to coordinate care within the hospital**. Learning about the hospital hierarchy and how to get the system to work was “a huge learning curve” (*neurological cancer carer in her 50s*). Carers had to educate themselves on accepted hospital language and behaviours.
- Carers were ill-prepared to **perform nursing tasks at home**. Carers in this and other studies felt inadequately instructed on how to, for example, give injections and change catheter bags (Chambers et al., 2001). Even if carers were given some technical information from medical staff, it was not always enough to ensure carers provided competent care, without anxiety to themselves or pain to the patient.
- They were unsupported in **accessing psychosocial support**. Carers often complained that they did not know what support was available to them. Allocation of information was either haphazard or it followed a critical care model (Fallowfield, 1988; Harding & Higginson, 2003; Parliament of Australia Senate, 2005:57,53) where information was not given until the carer had reached an emotional crisis point. For example, one haematological cancer carer who had been caring off and on for twelve years 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

¹¹ While doctors may be reluctant to disclose a prognosis to some patients or carers, no such hesitation should impede distribution of practical and psychosocial support information.

Canberra Hospital from a regional town for treatment would have saved her a decade of expenditure on accommodation.

Breast cancer carers were an exception to this pattern. They appeared to have few unmet psychosocial support needs because of the presence of breast care nurses (see Parliament of Australia Senate, 2005:8). In interviews, breast care nurses were said to provide technical and psychosocial support information, supplies, coordination, statistics, case studies, reconstructive surgery options, booklets and information.

The experiences of husband and wife Mark and Fiona illustrate the positive impact of breast cancer nurses. 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”. In contrast, 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.

For most breast cancer patients and carers, breast care nurses were available on an ongoing basis, ensuring that questions were answered and information was tailored to each couple’s specific situation. Breast care nurses, however, did not help every breast cancer patient and carer. A few mistakes were reported and because of understaffing, two carers described their support as limited.

Though, breast nurses cannot resolve all of the problems in the medical system negatively shaping carers’ experiences, they do seem to alleviate much of carers’ confusion related to coordinating care, when their services are not stretched too thin. They provide a much needed holistic and carer inclusive approach to cancer care. Further, they provide carers with relevant technical instructions over the phone, support service details and an ally within medical systems. 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 (1996:119) 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.

3.4 Summary

This section shows that inconsistent care within medical systems compels carers to coordinate care and advocate for the patient. This added burden, without support, may be exacerbating carers’ poor health. 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., 2004:501; Parliament of Australia Senate, 2005:47). Recommendations on how policymakers should go about addressing this holistic care and information dissemination deficit are the focus of the next section.

4 Implications & Recommendations

In this section the key areas of concern raised by participants are examined in more depth. Inferences are translated into recommended improvements in support service delivery, medical system practice and practical support processes. Key areas for improvement include:

1. prioritising the availability of a range of emotional support services to accommodate differing support service preferences,
2. improving the accessibility of practical support, and
3. implementing cancer nurses within all cancer multidisciplinary care teams to disseminate information to patients and carers, liaise between medical, community and support services, and alleviate much of the burden currently placed on carers.

4.1 Mixed modes of emotional support services

Interview data indicated a largely gendered stigmatisation of support groups (and to a lesser extent counselling) with males often finding formal psychosocial support too feminine or emotion-focused. Males are less likely to access either informal or formal support. They are also 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, many male carers are left with few people to talk with informally or formally about emotions. Questionnaire data reveals the extent of this phenomenon.

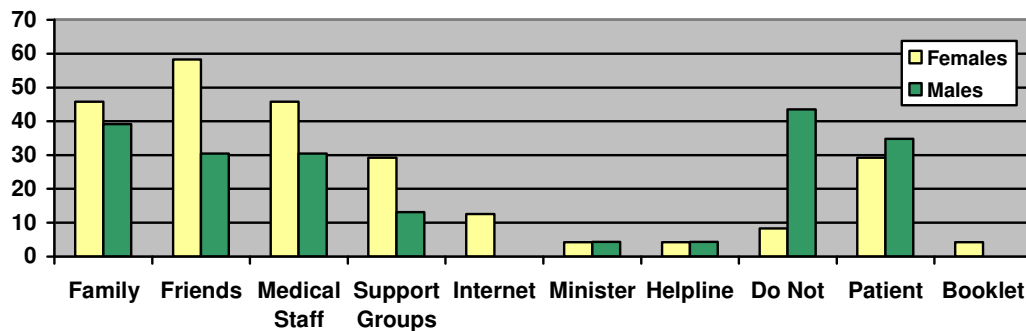


Figure 11 Questionnaire responses, by gender, to question: 'Who do you talk to about the emotional aspects of being a carer?'

When asked 'Who do you talk to about the emotional aspects of being a carer', male carers (43.5%) far more often than female carers (8.3%) reported that they do not talk about the emotional aspects of caring. Females (58.3%) were nearly twice as likely to confide in friends as males (30.4%) (see Appendix 2 for questionnaire respondents' demographic details). This data suggests that male carers may be at a higher risk of emotional isolation.

Offering a variety of emotional support services, including those listed below, may help to counter this emotional support disparity.

Support groups were described as an important source of emotional support by those participants who attended them. In addition to the benefits listed here (see section 2.2.3), research with carers of patients with dementia and multiple sclerosis have found them effective at helping the carer to go on caring (Knight et al., 1997) and at decreasing patients' symptoms (Sørensen et al., 2002). Further, they are a cost effective means of supporting carers (Harding & Higginson, 2003)¹². Thus, these findings suggest support groups should continue to be positioned as a primary emotional support option. Not all carers felt comfortable in support groups.

Information and networking forums could be another central emotional support option. Some carers preferred a distraction from their emotions and a chance to meet other carers informally. Providing information sessions more regularly could facilitate these carers' preferences for more informal emotional support. Sessions could be structured with several intermissions, during which networking between carers and patients could be facilitated.

Counselling could be positioned as an auxiliary emotional support option. The accounts presented here (see section 2.2.3) indicate that support groups are more effective at providing carers with alternative emotional support options, information, laughter and reassurance in their emotion management strategies. Further, the cost to the medical system (Harding & Higginson, 2003) and carer (Parliament of Australia Senate, 2005) makes it difficult for counselling to be offered as a primary emotional support option. However, for those carers whose other commitments make it difficult for them to attend support groups and for those carers experiencing acute psychological distress, anxiety and depression, counselling is an important option that should remain available (Harding & Higginson, 2003; Toseland et al., 1990).

Online support groups could be another auxiliary option. Studies with cancer patients suggests that they have similar benefits to support groups (Winzelberg et al., 2003) and their anonymity is ideal for those seeking emotional support related to embarrassing questions (Broom, 2005). They may be the only option for carers who become housebound with a very dependent care recipient (Herron, 2005).

Making carers aware of the range of emotional support services may help to prevent emotional isolation and provide suitable options for even housebound carers or those who find support groups stigmatising.

¹² They are generally free to participants and their cost to providers is limited to the price of renting the venue and compensating facilitators for their time.

4.2 Practical support guidance

The accounts of time-poor and time-destitute carers imply that they need guidance in accessing practical support. For example, the stressful, time-consuming and onerous nature of applying for financial aid acted as a deterrent for time-destitute carers. This indicates that Centrelink could implement the following changes to encourage more carers in need of support to apply.

1. Implementing a cancer carer application that assesses the extent to which emotional and physical aspects of caring limit a carer's capacity to work (not just the patient's physical mobility, prognosis and mental sharpness) would signify to carers that their specific needs are recognised and that completing the application is worth their time.
2. Making more services available online and over the telephone would make completing paperwork more accessible to housebound and time-destitute carers.
3. Countering any blatant or implied suspicious or judgemental treatment of applicants might also encourage those who are too embarrassed to apply.

The need to make information on all practical support more readily accessible is also implicated. Adding a carer information page to the Cancer Council ACT website, with links and guidance on how to access respite, IPTAAS and Centrelink, is a forthcoming outcome of the project.

4.3 Improved information dissemination

Section three relays accounts of carers being relied on to coordinate patient care within hospitals, their community and home. The detrimental impact of this stressful role on carers' wellbeing was also presented. Exclusion from medical interactions and a consequent lack of guidance on how to perform nursing tasks or access psychosocial support is to blame. Thus, these findings imply the following.

1. Carers need to be included within medical interactions and treated as both 'co-client' and 'co-worker' (Thomas & Morris, 2002).
2. Carers need medical personnel to provide them with information (Thomas et al., 2002) because carers are not in an ideal position to research nursing tasks, care coordination or available psychosocial support. There are many reasons for this.
 - a. Many carers do not identify themselves as carers (Hunt & Mintz, 2002:23), thus they do not "take actions that protect their own physical and mental health and financial security" (Hoffman, 2002:2). Though

participants in this study recognised their title as carer¹³, most saw it as secondary to their primary role: spouse.

- b. Even if carers do identify with the role, it is still very difficult for them to know where to look for information. Most carers do not have medical training and might find terms on nursing instructions incomprehensible. Further, most carers and cancer patients have not previously accessed agencies like Centrelink, palliative care, the Cancer Council or the “array”¹⁴ 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).
 - c. Many carers do not have the time to prioritise their own emotions (see section 2), nor are they encouraged to make time for their emotions in doctor-patient-carer interactions. Thus, carers may need prompting from medical professionals before they seek psychosocial support.
3. Carers need to be guided through relevant support services and assisted in accessing relevant services. Too often, carers and patients spoke of either being given little to no information or being bombarded with booklets about cancer, treatment and support services. Carers did not just want to be supplied information; they wanted to be guided through the information that applies to their situation and they wanted to ask a trustworthy person questions.

Many researchers (Fallowfield & Jenkins, 2006:105; Kearney et al., 2007:xiii; Little, 1995; Maguire, 1985; National Cancer Control Initiative, 2003; Parliament of Australia Senate, 2005; Stiefel et al., 2006; Wearing, 1996:218) have recommended that medical school curricula be changed to encourage GPs to provide more information, coordination and holistic care that includes carers. However, implementing cancer nurses into multidisciplinary care teams is likely to be more effective at addressing these recommendations. This is because curriculum changes are not likely to be successful in improving carer inclusion and information dissemination within doctor-patient interactions unless the many systemic obstructions are also addressed (Fallowfield & Jenkins, 2006:105). Two of these barriers include:

1. time constraints in medical interactions; and
2. the decreasing prevalence of having one GP for a person’s whole life.

¹³ Identifying as a carer was a pre-requisite to filling out a questionnaire. Thus, it would be reasonable to assume that those who did not see themselves as informal carers would not have participated in this research.

¹⁴ For example, in 1997 there were over 2000 HACC-funded small community care organisations in Australia (Duckett, 2004:224).

First, curriculum changes are unlikely to have an impact on care coordination or the dissemination of tailored psychosocial information to carers when appointments and conversations with doctors are so brief. Medical Benefit Scheme incentives (Davis & George, 1993:368; Duckett, 2004:214), pressure from peers and management (Fallowfield & Jenkins, 2006:108; Surbone, 2006:101), staff shortages (Allen, 2000:168; Bodenheimer & Grumbach, 2005:185) and the overarching drive for more efficient medical care have shortened doctor-patient (and carer) interactions to under ten minutes on average (Davis & George, 1993:269; Little, 1995:10; Pritchard, 1992:75). There is little time to explain procedures and risks (Allsop & Mulcahy, 1998:815) let alone time for holistic care (Kennedy & Lloyd-Williams, 2006:57).

Second, many theorists have argued that GPs' roles are changing (Davis & George, 1993:370; Turner, 2006:576; White, 2000) or may even cease to exist within the next twenty years (Marceau & McKinlay, 2008). Use of "minute-clinics" is increasing which means fewer GPs are providing ongoing care (Duckett, 2004:214; Marceau & McKinlay, 2008). 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 current medical system care deficits. Thus, solutions should not be focused on GPs.

Providing all oncology patients and carers with a cancer nurse would address this need for information-rich, carer inclusive and coordinated care (Chambers et al., 2001). Unlike doctors, the medical benefits scheme does not dictate the length of nurses' 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 example, is predicted to double by 2015 (Cooper et al., 1998; as cited by Bodenheimer & Grumbach, 2005). Further:

1. nurses are a less costly solution; and
2. they have a demonstrated beneficial impact.

First, having cancer nurses provide this more holistic care is more cost-effective. Based on salary, employing nurses is irrefutably less expensive than GPs. On average, nurses earn roughly 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 roles of coordination and support service guidance for patients and carers.

Second, past research (National Cancer Control Initiative, 2003:41), patient accounts (Docherty, 2004; Parliament of Australia Senate, 2005:47; Sardell et al., 2000) and the accounts provided here demonstrate the value of breast care nurses. It is

reasonable to assume that cancer nurses would be similarly effective. 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 those patients and their carers.

Part of the cancer nurse role could be providing triage-based psychosocial referrals to patients and carers (Hutchinson et al., 2006:542). They could use the insight presented here, that much of carers' needs and support service preferences are based on their time-sovereignty, and the insight provided in other studies that emphasise age and gender as predictors of unmet needs (see section 1.1). Based on this understanding of the variation in carers' needs and support preferences and on their own personal interactions with carers, cancer nurses could make assessments and then guide carers through relevant psychosocial support information. This methodical approach (Chambers et al., 2001) would help to overcome the challenges carers face in accessing information, such as lack of self-identification as a carer, familiarity with support services and knowledge of medical jargon.

Another part of the cancer nurse role could be connecting community, hospital and family care workers, because each side is poorly informed of the "needs, limitations and pressures" of the other (Payne et al., 2002; Pearson, 2006:10). This improved coordination could result in higher service quality in all areas (Pearson, 2006:23), a decreased reliance on carers within medical systems and, subsequently, lower levels of carer burden and subsequent poor health.

It is important to highlight, however, that carers should be a central focus for cancer nurses (Sharpe et al., 2005). Their needs should be "recognised and legitimised" (Morris & Thomas, 2001:87). Too often they are an afterthought in policy and service provision. Carers, however, have higher unmet needs than patients (Thomas et al., 2001) and their wellbeing has a direct impact on their ability to care (Boulton et al., 2001; Fallowfield, 1995).

4.4 Summary

In sum, the outcomes of this study imply that changes should be focused on the following areas:

1. encouraging support services to provide a variety of emotional support options including: support groups, information seminars, referrals to counselling and online support groups;
2. improving the cancer carer relevance of financial aid and overall accessibility of practical support; and

3. positioning cancer nurses as patient care coordinators to ameliorate the impact of the current model of care on carers' health and provide carers with guidance in accessing practical, technical and psychosocial support.

4.5 Limitations

It should be cautioned that these recommendations are primarily based on carers' accounts. The feasibility of this recommendation should be measured against further investigations within medical hierarchies, policy ethnography (Griffiths, 2003:163,165) and budget analysis restrictions (Pearson, 2006:16). The strengths of sociological analysis (Griffiths, 2003:157) and carers of cancer patients' extended and multilevel insight of into medical systems (Frankenberg, 1992:10), however, should not be downplayed.

Appendix 1 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?

Supportive Services

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 name¹⁵: _____

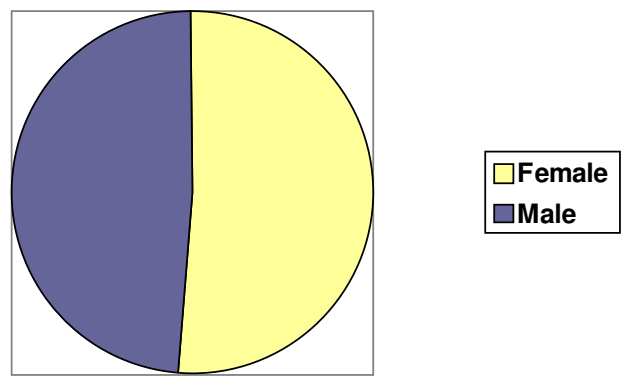
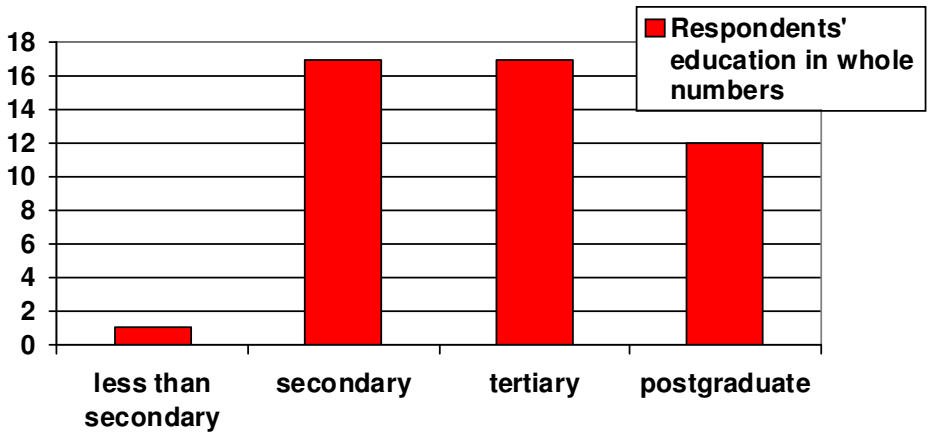
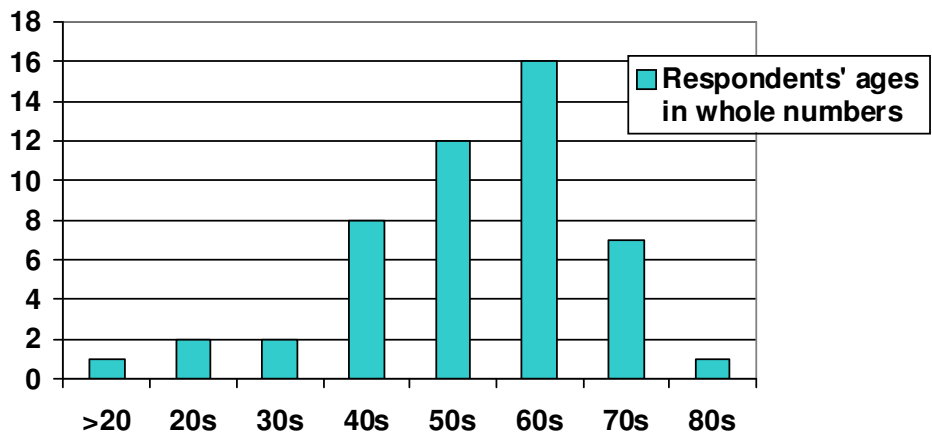
Phone number: _____

Best time to call: _____

- Thank you -

¹⁵Please 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 2 Questionnaire Demographics



Respondents' gender in percentages (51% female, 49% male, n=47).

Appendix 3 Interview Guide 1

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 4 Interview Guide 2

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

10. What role does/did time play in your experience as a carer?

End

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 5 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?

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