An evaluation of concerns, self-perceived needs, and supportive interventions, for informal cancer carers:
A comparative study of female and male carers

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Publications Arising from the Project

In Press Refereed Journal Articles


Published Articles


**Conference Papers**


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Executive Summary

This groundbreaking project, a collaboration between Gender, Culture and Health Research: PsyHealth, at UWS; Medical Psychology Research Unit, Sydney University; Westmead Hospital; Cancer Council New South Wales; and Carers New South Wales, had the following aims:

1. To explore the concerns, self-perceived needs, and psychological well-being of primary informal carers for a person with cancer (cancer carers) living in New South Wales, systematically comparing the experience of male and female carers, using a combination of qualitative and quantitative measures, across group comparisons, and individual case studies.
2. To examine the differential pathways to distress in male and female cancer carers.
3. Based on these findings, to develop a program of supportive interventions targeted at the needs of male and female cancer carers, and then to systematically evaluate their relative efficacy, within a controlled trial: 3 different modes of intervention were compared.
4. A systematic review of the existing literature evaluating interventions for cancer carers was conducted.

Summary of the Literature

There is a growing literature examining the psychological well-being and adjustment of informal cancer carers: the partners, family members or friends who provide emotional and physical care for people with cancer. It has been concluded that 20-30% of cancer carers are at high risk for psychiatric morbidity (Hagedoorn, Buunk, Kuijer, Wobbes, & Sanderman, 2000), with various studies reporting above normal levels of psychological distress in 40% (Janda, Steginga, Langbecker, Dunn, Walker, & Eakin, 2007), 50% (Haley, LaMonde, Han, Narramore, & Schonwetter, 2001), or 84% (Payne, Smith, & Dean, 1999) of carers. These levels of distress are significantly higher than those found in community samples of the same age, and in some studies, significantly higher than rates of distress found in people with cancer (Gilbar & Ben-Zur, 2002; Janda et al., 2007; Langer, Abrams, & Syrjala, 2003; Matthews, 2003; Nordin, Wasteson, Hoffman, Glimelius, & Sjoden, 2001).

There are a number of risk factors for distress in cancer carers, the most significant being female gender (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008). Women cancer carers report higher rates of depression and anxiety, and lower life satisfaction and quality of life ratings (Blanchard, Albrecht, & Ruckdeschel, 1997; Bookwala & Schulz, 2000; Gilbar, 1999; Hagedoorn et al., 2000; Payne et al., 1999; Pitceathly & Maguire, 2003), as well as greater personal loss and activity restriction (Matthews, Baker, & Spikers, 2003), than male carers. Women carers also report more unmet needs (Allen, 1994), and a greater burden of care (Lutsky & Knight, 1994), both recognised as a cause of distress (Grimm, Zawacki, Mock, Krumm, & Frink, 2000) and physical health problems (Soothill, Morris, Harman, Francis, Thomas, & McIllmurray, 2001) in cancer carers. However, despite these consistent findings, there is little understanding of the mechanisms underlying gender differences in cancer carer distress, no well articulated theoretical framework for interpreting research findings, and no empirical exploration of mediator or moderator variables (Hagedoorn et al., 2008, p1.). The aim of the current study is to address these significant gaps in the literature.
Design: Stage One and Two

Through triangulation of design and method, quantitative surveys and interviews were used to examine the experience of being a cancer caregiver, and pathways to distress, amongst a stratified sample of male and female primary informal carers for a person with cancer. The research design was carefully structured so that each stage generates a heuristic framework to inform the inquiry techniques in following stages. The battery of questionnaires was based on insights from the literature review, discussions with stakeholders, and a pilot study funded by a UWS partnership grant in conjunction with NSWCC. The interviews and focus groups gave an insight into the complexities of individual subjective experience, analysed through case studies and group comparisons.

Stage 1: An examination of gender differences in unmet needs, burden of care, self-silencing and psychological distress in cancer carers

Four hundred and eighty four informal cancer carers (329 women & 155 men) living in New South Wales (NSW), Australia, took part in the study. Three hundred and twenty four (67%) were currently caring for someone with cancer, for 33 (8%) the person they were caring for with cancer had died and 28 (6%) were in remission. 108 (23%) of the carers indicated that they themselves had a serious illness. The most common cancer type was breast cancer (20%), followed by colorectal/digestive cancers (15%) and haematological cancers (13%).

Men and women cancer carers were comparable in age, but women were looking after significantly older patients, with a more advanced cancer condition, or cancer that is still active, and caring for a broader range of patients (partner, siblings, parents, friends), whilst men primarily cared for their partners. There was no gender difference in number of hours spent caring, additional responsibilities, or amount of support received from family and friends.

Unmet Psychosocial Needs (PNI): Women reported significantly more unmet needs than men, in relation to emotional and spiritual needs, identity needs, practical needs, and support network needs. .

Information needs: One in three participants reported unmet information needs, with information about what to expect being the highest unmet need for both men (41%) and women (46%).

Health Professionals: One in four participants reported unmet needs in relation to health professionals, with easy and quick access to doctors the highest unmet need reported (38%). Women were more likely than men to report unmet needs associated with health professionals who listen to me (33% women, 24% men), and health professionals who treat me with respect (26% women, 17% men). Unmet support network needs were reported by one in four participants, with absence of someone to talk to being the highest unmet need for both women (31% and men (26%).

Emotional and spiritual needs: On average, one in three participants reported unmet emotional and spiritual needs, with the highest unmet needs for women being help in dealing with the unpredictability of the future (50% women, 32% men), and for men, hope for the future (38% men, 47% women). Women also reported high unmet needs in relation to dealing with sad feelings (41% women, 34% men), dealing with fears (44% women, 35% men), needing help with anger (39% women, 21% men), and needing time for myself (41% women, 30% of men).
Identity: Unmet needs associated with identity were reported by one in three participants, with help in maintaining control over my own life being the highest unmet need (44% women, 30% of men).

Practical: One in three participants reported practical unmet needs, with help dealing with any distressing symptoms being the highest rated (37% women, 27% men), followed by help with dealing with tiredness (38% women, 24% men) and help with financial matters (30% women, 31% men).

Anxiety and Depression (HADS): Psychological distress scores for the entire sample were moderate to high and comparable to a previous sample of cancer carers (Janda et al., 2007). Whilst not used to formally diagnose participants in this study, 25% ($N = 113$) and 45% ($N = 216$) of the sample met the criteria for borderline and abnormal anxiety caseness respectively (figure 7). On the depression scale, 58% of the sample scored in the normal range, with 19% ($N = 90$) and 23% ($N = 112$) meeting the cut-offs for borderline and abnormal caseness respectively. Women reported significantly more anxiety and depression than men.

Caregiver Burden: Women cancer carers reported significantly greater burden of care, in relation to disrupted schedule, health problems and lack of family support. Women carers reported that looking after someone with cancer had disrupted their schedule more than men; caring for someone with cancer was having more of a negative effect on their health; and they had less family support than men.

Generalised Self-efficacy (GSES): High levels of self-efficacy were reported, in comparison to previous population norms. There was no significant difference between the scores for men and women.

Optimism and Control Over the Future: Relatively high levels of optimism and feelings of control over the future were reported, compared to population norms, and there was no significant difference between the scores for men and women.

Silencing the Self (STSS): For both men and women, self-silencing scores were higher than those found in a previous study of men and women in a relationship. Men scored significantly higher than women on two facets of self silencing: putting the needs of others before the self (Care as Self Sacrifice), and not expressing their feelings when to do so would cause disagreement (Silencing the Self), a pattern also reported in previous research.

The relationship between self-silencing and psychological distress: For both men and women, STSS Global Self-Silencing scores were significantly positively associated with both anxiety and depression scores on the HADS, suggesting that higher self-silencing is associated with greater psychological distress.

Differences in psychological distress between bereaved and non-bereaved carers: Bereaved participants reported significantly higher levels of depression than non-bereaved participants. When we examined depression in men and women separately, the bereaved women were significantly more depressed than the non-bereaved women. There was no significant difference for men.

Mediation analysis - Which factors predict gender differences in psychological distress? The purpose of the mediation analysis was to examine which variables predict gender differences in psychological distress. Gender differences in anxiety and depression are fully
explained by the combination of: Disrupted Schedule (CRA), Health Problems (CRA), Emotional and Spiritual Unmet Needs (PNI), and Silencing the Self (STSS).

**Summary and conclusions**

Women cancer carers report significantly higher levels of depression and anxiety than men carers, confirming previous research. In order to explain this finding, we explored gender differences in a range of confounding variables. Women reported significantly greater burden of care, in relation to Disrupted Schedule, Health Problems, and Lack of Family Support (CRA); significantly more unmet needs, in relation to Emotional and spiritual unmet needs, Identity unmet needs, Practical unmet needs and Support network unmet needs (PNI). Men reported significantly higher levels of Silencing the Self (STSS). In the mediation analysis, gender differences in anxiety and depression were fully explained by the combination of: Disrupted Schedule, Health Problems, Emotional and Spiritual Unmet Needs, and Silencing the Self.

**Stage 2: An examination of gender differences in the subjective experience of carer caring: Interviews with informal cancer carers**

Fifty-three participants (34 women & 19 men) were selected for individual interview, representing a cross section of cancer types and stages, gender, and relationship with the person with cancer, as reflected in the larger study population. In addition, two focus groups were conducted, one with 3 partners of men with prostate cancer, and one with 9 carers of a person with cancer from the Chinese community, resulting in total interview population of 64.

Participants identified positive and negative experiences in relation to the self, the person with cancer, and others. These are summarised below under the headings: emotional reactions to cancer and caring; self-silencing of carer needs and concerns, difficult aspects of the caring role; and reward in the caring relationship. Changes specific to sexuality and experiences with health professionals are discussed in separate sections:

**Emotional Reactions to Cancer and Caring**
- Shock
- Depression
- Anxiety
- Anger and Frustration about the Situation
- Caring as Obligation
- Caring by Choice

**Self-silencing Carer Needs and Concerns**
- Prioritising the needs of the patient.
- Silencing feelings as a requisite for coping.
- Men don’t express vulnerability.
- Counter-Narrative: Open Expression of Carer Emotions
- Silencing anger to avoid conflict.

**Difficult Aspects of the Caring Role**
- Change in roles
- Taking on Quasi-Medical Tasks and Decisions
- Change in relationship dynamics
- Neglecting Self and Other Relationships
Physical Health Consequences
Loneliness-Isolation
Difficulties in Requesting or Accepting Help
Counter Narrative: The Importance of a Good Social Support Network
Financial Issues
Feelings of Helplessness and Loss of Control
Conflicting Thoughts between the Carer and Person with Cancer

Rewards in the Caring Relationship
Admiring Strength of the Person with Cancer
Improved Relationship
Discovering Personal Strength
Personal Growth
Relationship with Others
Changed perspectives on Living
Positive aspects of providing palliative care at home
Positive Meanings Ascribed to the Dying Process

Summary and conclusions

Men were more likely than women to report shock at the diagnosis, to describe themselves as self-silencing because they never express vulnerability, and to describe change in roles as a difficult aspect of the caring role. However, they were also more likely to describe an improved relationship following their taking on a caring role. Women were more likely to report anxiety, caring by choice and self-silencing as a requisite for coping. Difficult aspects of the caring role that were more likely to be reported by women include having to make medical decisions, a change in relationship dynamics with the person with cancer, neglecting self and other relationships, physical health consequences, loneliness-isolation, difficulties in requesting or accepting help, and feelings of helplessness and loss of control. Women were also more likely to report discovering person strength through caring.

This suggests that there are many aspects of the caring role that are experienced differently by women and men, with women experiencing caring as more burdensome, and as having more impact on their psychological and physical wellbeing. This confirms and complements the findings of the survey, where women reported higher burden of care and unmet needs, as well as higher depression and anxiety.

Positive and negative interactions with health professionals

The aim of this aspect of study was to examine how cancer carers subjectively position their experiences of interactions with health professionals. Drawing on the interviews conducted with 53 carers, the analysis was guided by the following questions: What do informal cancer carers position as positive or negative interactions with health professionals? What are the perceived consequences for carers of positive or negative interactions with health professionals?

Positive experiences with health professionals
Health professionals who are ‘warm’ and ‘genuine’
Health professionals who are accessible and approachable
Health professionals help carers feel comfortable and accepted
Allied health professionals provide a space for carers’ cathartic release
The consequences of positive experiences with health professionals: Feeling in control and empowered

Negative experiences with health professionals
A lack of empathic communication style
A lack of information provision
‘It’s just a maze’: Not knowing who to turn to for support

The consequences of negative experiences with health professionals:
‘Nobody gives a damn’ - disappointment with the health system

Summary and conclusions

Given that cancer care is increasingly being shifted from the hospital into the home, with the responsibility of caring typically placed upon informal carers, it is important that health professionals are supportive of carers’ needs in order to help them to provide care. As shown in many of the accounts in the present study, many health professionals are providing support to cancer carers to good effect. Recognition of carer needs, manifested through empathic communication and availability, are key aspects of this care, associated with reports of carers feeling in control and empowered. There were, however, many other accounts where such support was clearly lacking, related to poor communication style, lack of information, and carers not knowing where to go for support. As this was associated with carers’ ability to cope and provide care, it is thus critical that such lack of support is redressed, for the wellbeing of both carers and the people with cancer for whom they care. These findings suggest that the need for communication training is still imperative, particularly for medical professionals who were the object of the most severe criticism. In addition, for allied health professionals, there is an ongoing need to provide practical assistance and strategies to help carers provide care, as well as offer a space for carers to discuss their mental health issues in a non-judgemental forum.

Sexuality and intimacy post-cancer diagnosis: The experience of partner carers

There is a growing body of evidence to show that cancer can result in dramatic changes to sexuality, sexual functioning, relationships, and sense of self. These changes can be experienced as the most significant in the person with cancer’s life, and can lead to emotional distance between couples, as well as feelings of isolation, anxiety, depression or inadequacy.

Changes in sexuality and intimacy following cancer were examined using open ended questionnaire responses with 156 informal carers who were partners of a person with cancer, across both reproductive and non-reproductive cancer types. Interviews were conducted with a representative sample of 20 participants to examine changes in depth.

Impact of cancer on the sexual relationship: Seventy six per cent of partners of a person with ‘non-reproductive’ cancers reported an impact on the sexual relationship, as did 84% of partners caring for a person involving ‘reproductive’ sites, such as prostate, breast or gynaecological cancer. Reports of complete cessation of sex were more common for women than men, and very few women gave accounts of developing alternative sexual practices if intercourse was no longer possible.
**Psychological well-being and sexuality:** Those individuals who reported an impact of cancer on their sexual relationship reported higher levels of depression and burden of care than those who reported no impact.

**Cessation or decreased frequency of sex and intimacy** was reported by 59% of women and 79% of men, with renegotiation of sexuality and intimacy post-cancer, to include practices such as non-coital sex, hugging and cuddling, reported by only 19% of women and 14% of men.

**Subjective experience of changes to sexuality and intimacy:** Each of the 122 participants elaborated on the changes to their sexual relationship experienced post-cancer, in open-ended responses and, for 20 of the participants, in an individual interview. The responses given by participants are illustrated below under each of the following major themes:

**Disruptions to carers sexuality and their sexual relationship**
Cessation or decreased frequency of sex was reported by 59% of women and 79% of men.

**Reasons given for changes to sexuality**
- My partner with cancer has no desire: impact of cancer or cancer treatment
- Exhaustion resulting from the caring role
- Re-positioning of person with cancer as a patient
- Reluctance to initiate sexual activity

**Feelings about changes to the sexual relationship**
- Positive feelings: accepting the changed sexual relationship, and increased closeness and intimacy.
- Negative feelings: self-blame, rejection, sadness, anger, and lack of sexual fulfilment.

**Renegotiating sexuality**
- Exploring alternative sexual practices or not, including practices such as non-coital sex, hugging and cuddling, reported by only 19% of women and 14% of men.

**Couple communication and relationship context**

**Discussions of sexuality with health professionals**
- Only 20% of partners had discussed sexuality with a health professional, and only 37% of those were satisfied with the discussion.

**Summary and conclusions**

The majority of participants reported that the cancer experience had impacted on their sexual relationship, resulting in a cessation or reduction of sexual activity, with only a minority renegotiating sexual intimacy post-cancer. This supports previous research which demonstrated that the impact of cancer and cancer treatment extends beyond the person with cancer reinforcing the need for acknowledgement of the sexual and intimate needs of partners, as well as of people with cancer. Rather than restricting our sample to partners caring for a person with cancer affecting the reproductive areas of the body, we examined changes to sexuality post-cancer across a range of cancer types. The majority of participants who were providing support to a person with prostate, breast or gynaecological cancer cited an impact,
confirming previous research. However, the finding that a high proportion of partners of a person with ‘non-reproductive’ cancer also reported changes highlights the pressing need to acknowledge and attend to the sexual concerns and needs of all partners who care for a person with cancer.

Stage 3: Evaluating the efficacy of psycho-social interventions for informal carers of cancer patients

A systematic review of the research literature

Recognition that informal cancer carers experience unmet needs and psychological distress has led to the development of a range of psycho-social interventions. The efficacy of such interventions was examined through a systematic review of the research literature, following NHMRC and Cochrane Collaboration guidelines. Of 13 level II randomised controlled trials (RCT), only 8 showed significant differences across groups, with moderate effect size. This included improvement in caregiver experience or appraisal of care-giving following psycho-education (2 studies); improved sexual satisfaction, dyadic coping, relationship quality and communication, or reduced psychological distress, following couple counselling (4); reduced distress following family grief therapy (1); and reduction in distress in bereavement following home palliative care (1). Level III-IV studies were also reviewed, reporting positive effects of psycho-education (5), problem solving (3), an arts intervention (1) and a support group (1). However, methodological concerns limit the generalisability of findings of level III-IV studies. It is concluded that interventions should target those most in need of support; recognise specific needs of carers across cancer type and stage, gender, and relationship context; be theory based; and evaluations should utilise RCT designs with outcome measures appropriate to the specific aims of the intervention, rather than global measures of distress.

An evaluation of three supportive interventions for cancer carers

Three different support interventions for cancer carers were developed, and then evaluated within a controlled trial, using a patient preference design and pre-post intervention evaluations. 30 carers were allocated to each intervention on the basis of preference. 59 participants completed 3 month follow-up questionnaires and 37 completed 6 month follow-up.

The 3 interventions evaluated were: Self-help information pack for cancer carers (I&SHP); one to one meeting with a professional (a flexible number of sessions), in conjunction with the self-help pack (HCP); on-line support group (10 sessions), in conjunction with the self-help pack (Online).

Pre-post evaluation results

Caution must be used in interpreting the findings of this aspect of the study, due to the high attrition at 3 and 6 month follow-up, and the absence of statistical analysis. Many of the participants in this study also reported utilising more than one form of support, including palliative care, Relationships Australia counselling, self-help books, face to face and
telephone support groups, pastoral care, Cancer Council Helplines, counselling, social work and psychology services,

However, the results do suggest that the self-help information pack and the on-line programs were successful in achieving many of the aims of the intervention: increasing coping skills, knowledge and communication on the part of carers. In addition, the on-line program appeared to be associated with an improvement in psychological well-being. The health professional program was successful in reducing anxiety and in increasing confidence in relation to communication with health professionals. The absence of a structured element to the intervention may account for the absence of positive findings on the other variables.

These results confirm the findings of the systematic literature review, that a range of interventions can be effective in addressing carer needs and concerns, and that targeted interventions are most effective in achieving their aims.

In the present study, the participants who completed the intervention programs were positive about the experience, as is illustrated in the qualitative data below, collected from open ended questions on the follow-up questionnaire. In future research, it would be useful to follow up those participants who dropped out of interventions, and those who did not find interventions effective, as this may provide important information about efficacy and suitability of programs to support cancer carers.

**Benefits of taking part in the intervention:** On the open ended questions, participants reported a range of benefits of taking part in the intervention programs, with individual differences being evident in the aspect of the pack that was most useful. This suggests that self-help information needs to be comprehensive, to meet the needs of a wide range of carers. The majority of participants who completed follow-up questionnaires reported that they experienced increased coping and other positive changes post-intervention, including improved communication, increased knowledge about cancer and its treatment, and less feelings of isolation. The findings from the closed ended questions and questionnaire measuring psychological well-being are summarised below.

**Information and self-help pack:** Improvements over time were reported on: ability to manage stress, confidence in providing care, control over own life, and ability to manage independence. There was increased knowledge of finances, food and diet, and sex and intimacy. Confidence was increased in ability to express feelings to the person with cancer, family and friends, and health professionals. Confidence was also increased in ability to express needs to the person with cancer and health professionals.

**On-line intervention:** There were reductions in anxiety and depression over time. Improvements over time were reported on: ability to manage stress; confidence in providing, in strategies to help with their role as a carer and in ability to manage independence. There was increased knowledge of finances, food and diet, and sex and intimacy. Confidence was increased in ability to express feelings to the person with cancer, family and friends, and health professionals. Confidence was also increased in ability to express needs to the person with cancer, family and friends, and health professionals.

**Health professional intervention and self-help pack:** There were reductions in anxiety over time. Improvements over time were reported on: ability to manage emotions, ability to express feelings to health professionals and ability to express needs to health professionals.
Summary and conclusions

Participants reported subjective benefits of taking part in each of the interventions, with the greatest subjective benefit reported by those who took part in the on-line intervention, followed by the information and self-help pack. Participants in the self-help information pack and the on-line programs also reported increased coping skills, increased knowledge and improved communication, with the on-line program being associated with the greatest improvement in psychological well-being. There were no obvious gender differences across the 3 interventions. Whilst high attrition at follow-up suggests caution should be used in interpreting these results, there is evidence that interventions focused at addressing carer needs can be effective in improving coping.

Recommendations

1. The cancer carers who took part in this study experienced high levels of anxiety, and moderate levels of depression. This confirms previous research, and suggests a level of distress that needs to be acknowledged by service providers.

2. In addressing the needs and concerns of cancer carers, gender needs to be considered as a salient factor, and prevention and intervention programs targeted accordingly.
   a. Women are more likely to experience psychological distress, to have unmet needs, and to experience caring as burdensome, than men. This suggests a greater need for psycho-social support on the part of women.
   b. However, men may not articulate their needs because of self-silencing, suggesting that men’s needs may be overlooked.
   c. There are many aspects of the caring role that are experienced differently by women and men, with women experiencing caring as having more impact on their psychological and physical wellbeing. In developing support services this needs to be taken into account.

3. A number of participants in the study were bereaved carers, who reported significantly higher levels of depression than those who were not bereaved, and gave accounts of both positive and negative experiences associated with the caring role.
   a. Service providers need to recognise and acknowledge the needs of bereaved carers, who may still need support after the caring role has ended.
   b. There is a need for further research on the needs and experiences of bereaved carers, and evaluation of different forms of supportive intervention.
   c. As women who were bereaved reported higher levels of depression than women who were not bereaved, future research should also examine the gendered experience and needs of bereaved carers.

4. The need for communication training for health professionals is still imperative, particularly for medical professionals who were the object of the most severe criticism in this study. In addition, for allied health professionals, there is an ongoing need to provide practical assistance and strategies to help carers provide care, as well as offer a space for carers to discuss their mental health issues in a non-judgemental forum.

5. Sexuality and intimacy was identified as a significant unmet need in this study, which is not addressed by health professionals.
a. Health professionals and service providers should address issues of sexuality and intimacy with people with cancer and their partners, as this is an important aspect of quality of life.

b. There is a need for further research examining the experiences of people with cancer in relation to sexuality and intimacy, as the current study focussed only on carers.

c. There is also a need for further research to examine the perspectives of health professionals, in order to understand why so few discuss sexuality and intimacy with their patients, and to facilitate such communication in future.

6. Cancer carers rated a range of interventions as beneficial, with varying degrees of efficacy across intervention when assessed by standardised measures.

a. Our systematic review of interventions for carers has identified that couple interventions are the most likely to be effective. There should thus be more emphasis on couples interventions in future service provision.

b. A range of modalities of intervention can be effective for addressing carers needs. This should be directly targeted at the needs of specific populations of carers.

c. In research on carer interventions, evaluations should be based on specific needs, rather than using global indices of distress or well-being, which are less likely to change over a short time period in the context of cancer caring.
Section One
Background and Introduction to the Study

It is estimated that in 2010 114,990 new cases of cancer will be diagnosed in Australia (AIHW (Australian Institute of Health and Welfare), 2008), with approximately 40,000 new cases occurring in NSW. This will result in a significant number of family members or close friends taking up the challenging role of being a cancer carer, with potential risks to their own health. There is now consistent evidence that cancer carers experience high rates of anxiety and depression, with 20-30% of all carers believed to be at high risk for psychiatric morbidity (Hagedoorn, Buunk, Kuijer, Wobbes, & Sanderman, 2000). For example, Payne et al. (1999) reported that 84% of cancer carers reported above normal levels of psychological distress. Haley et al. (2001) reported that over 50% of spousal carers (mean age 74.8 years) showed clinical levels of depression, three times the level found in community samples of people the same age. Similarly, in a study of 1775 Australian women, Lee and Porteus (2002) reported that carers had poorer health than non-carers, were more likely to be hospitalised in the past year and had taken medication for ‘nerves’, scored lower on physical and mental functioning, had greater levels of stress, felt busy, rushed and pressured, and were more likely to smoke. Carter (2003) found that carers exhibit moderate to severe sleep problems, which tend to fluctuate over time. Fatigue is also a common symptom reported among cancer carers (Grbich, Maddocks, & Parker, 2001b; Thomas, Morris, & Harman, 2002), as is financial strain (Jo, Brazil, Lohfeld, & Willison, 2007), appetite disturbance (Aranda & Hayman-White, 2001), and subordination of their own emotional needs (Thomas & Morris, 2002).

These levels of distress are significantly higher than those found in community samples of the same age, and in some studies, significantly higher than rates of distress found in people with cancer (Gilbar & Ben-Zur, 2002; Janda, Steginga, Langbecker, Dunn, Walker, & Eakin, 2007; Langer, Abrams, & Syrjala, 2003; Matthews, 2003; Nordin, Wasteson, Hoffman, Glimelius, & Sjoden, 2001). For example, in a study conducted by the current project team in New South Wales, funded by the NSW Cancer Council (Ussher, 2003), which examined mental health and Quality of Life (QOL) in carers who were attendees at a cancer support group, 21% reported symptoms that would be categorised as clinical anxiety, compared to 10% of people with cancer. Twenty four percent of carers reported moderate to severe sleep problems, which tend to fluctuate over time. Fatigue is also a common symptom reported among cancer carers (Grbich, Maddocks, & Parker, 2001b; Thomas, Morris, & Harman, 2002), as is financial strain (Jo, Brazil, Lohfeld, & Willison, 2007), appetite disturbance (Aranda & Hayman-White, 2001), and subordination of their own emotional needs (Thomas & Morris, 2002).

The psychological and physical well-being of cancer carers is a significant issue, for a number of reasons. Outside of the medical management of problems, the burden of care for people with cancer invariably falls on informal carers, in particular family and close friends (Australian Institute of Health and Welfare [AIHW] and Australasian Association of Cancer Registries [AACR], 2000). Depression, anxiety and fatigue often renders the carer unable to provide the care needed (Christensen, 1999), resulting in greater burden on health and social services. The psychological and physical wellbeing of people with cancer is closely associated with the level of support and care they receive from informal carers (Brown & Stetz, 1999), with good support leading to positive outcomes. The psychological well-being of people with cancer is also closely associated with the well-being of their primary carer.
Thus caring for carers is an essential part of caring for people with cancer. This study addressed this important social and health issue, examining the concerns and needs of cancer carers in NSW.

**Gender as a Risk Factor for Negative Outcomes**

There are a number of risk factors for distress in cancer carers, the most significant being female gender (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008). Women cancer carers report higher rates of depression and anxiety, and lower life satisfaction and quality of life ratings (Blanchard, Albrecht, & Ruckdeschel, 1997; Bookwala & Schulz, 2000; Gilbar, 1999; Hagedoorn et al., 2000; Payne et al., 1999; Pitceathly & Maguire, 2003), as well as greater personal loss and activity restriction (Matthews et al., 2003), than male carers. Women carers also report more unmet needs (Allen, 1994), and a greater burden of care (Lutsky & Knight, 1994), both recognised as a cause of distress (Grimm et al., 2000) and physical health problems (Soothill, Morris, Harman, Francis, Thomas, & McIlmurray, 2001) in cancer carers. This is reflected in the fact that in 2003 the NSW Cancer Council helpline received calls from 3078 female carers, compared to 676 male carers. Women are more likely to be the sole care-giver, providing, on average, double the amount of hours of care, as well as more intensive and complex care, than male caregivers (Navaie-Waliser, Spriggs, & Feldman, 2002). However, despite these consistent findings, there is little understanding of the mechanisms underlying gender differences in cancer carer distress, no well articulated theoretical framework for interpreting research findings, and no empirical exploration of mediator or moderator variables (Hagedoorn et al., 2008, p1.). The aim of the current study was to address these significant gaps in the literature, through systematically comparing the experiences and needs of male and female cancer caregivers within an in-depth multi-method study. These findings were then used to develop appropriate and targeted prevention and intervention programs, and these intervention programs evaluated.

**Over-responsibility and self-policing**

There are a number of theoretical explanations for why women cancer carers experience high rates of distress, a finding also reported in other caring contexts (Brown, Andrews, Harris, & Adler, 1986; Fox, 1998; Lee & Porteous, 2002). The present study was informed by a constructivist theoretical framework. Firstly, caring is socially constructed as a central component of women’s gendered role, leading to women being positioned as unquestioned emotional nurturers of others with an expectation of self-renunciation (O’Grady, 2005; Seigfried, 1989). This can result in women engaging in compulsive caretaking, pleasing the other, and inhibition of self-expression in relationships, in an attempt to achieve intimacy and meet relational needs (Carr, Gilroy, & Sherman, 1996). Described as “self-silencing” (Jack, 1991), this is a pattern of behaviour put forward as explanation for the higher rates of depression reported by women in general community samples (see Kuehner, 2003; Nolen-Hoeksema, 2001). In a study of elderly women carers in Sweden, Forssen, Carlstedt and Morthberg (2005) described this as ‘compulsive sensitivity’, characterised by an inner demand to take responsibility and put the needs of others before the self, which can lead to distress, which is then blamed on the self.

In the context of cancer-caring, women’s self-silencing and over-responsibility may partly result from external factors, as women carers have higher expectations placed upon them than men (Soothill, Morris, Thomas, Harman, Francis, & McIlmurray, 2003), receiving less acknowledgment and less social support (Matthews et al., 2003). For women in full time
caring roles, there is often no respite, leading to depersonalisation, emotional exhaustion and perceived burnout (Bradley, 2000). Women have been reported to be more likely to be the sole care-giver, providing, on average, double the amount of hours of care, as well as more intensive and complex care, than men caregivers (Navaie-Waliser et al., 2002). However, meta-analytic research has found no significant gender difference in total involvement in care, and whilst women carers do report doing more household tasks and personal care than men, the effect size has been found to be “quite small” (Miller & Cafasso, 1992, p. 505).

Women’s over-responsibility may also be associated with self-policing practices wherein women internalise the notion of the ‘caring self’, setting high standards for themselves and judging themselves as failures if they cannot emulate this ideal (Ussher & Sandoval, 2008). Women cancer carers have been found to position themselves as all encompassing expert carers, leading to over-responsibility, self-sacrifice, and distress, in contrast to men carers who position caring as a competency task, leading to feelings of self-mastery (Ussher & Sandoval, 2008). Feelings of failure in relation to informal cancer care have also been found to be associated with distress in women, but not men (Hagedoorn, Sanderman, Buunk, & Wobbes, 2002). In this vein, it has been suggested that the higher rates of depression reported by women cancer carers could be explained by women having to live up to these internalised standards of caring, in contrast to men carers who perform a role which is not expected of them, and thus experience a greater sense of reward as a result (Hagedoorn et al., 2000).

There is also consistent evidence that women are more affected than men by the emotional well-being of others (Hagedoorn, Sanderman, Ranchor, Brilman, Kempen, & Ormel, 2001), or by life-events, such as cancer, which affect others (Taylor, 2006). Described as “network events” this results from women’s greater involvement in the lives of those around them (Kessler & McLeod, 1984), with women’s responsiveness representing a “cost of caring” (Kessler, McLeod, & Wethington, 1985) that can lead to elevated levels of depression.

Further theoretical explanation for gender differences in cancer carer distress is provided by relational-cultural theory, which posits that a woman’s sense of self is conceptualised as “being in relation” (Jordan, Kaplan, Miller, Stiver, & Surrey, 1991; Jordan & Hartling, 2002; Miller, 1986). Mutual connectedness is deemed to be central to women’s identity and well-being, and the absence of empathic connectedness experienced as a failure of the self that can result in depression (Kaplan, 1986). The majority of women cancer carers are caring for male patients, who have been shown to avoid disclosure, due to a lower perceived need for support, fear of stigmatisation, need to minimise the threat of the illness and a desire to avoid burdening others, in contrast to female patients who report a need to talk about the illness and to share their feelings (Gray, Fitch, Phillips, Labrecque, & Fergus, 2000; Kiss & Meryn, 2001). This absence of communication and resultant connectedness may be implicated in women carer’s distress, as couples who avoid talking about the cancer or its emotional impact are recognised to report higher levels of distress and lower marital satisfaction, as outlined in detail below (Badr, Acitelli, & Carmack Taylor, 2008; Kuijer, Ybema, Buunk, de Jong, Thijsboer, & Sanderman, 2000; Manne, Ostroff, Norton, Fox, Goldstein, & Grana, 2006; Ptacek, Ptacek, & Dodge, 1994; Skerrett, 1998; Zunkel, 2002). Bookwala & Schulz (2000) also found that women cancer carers also reported a higher frequency of behavioural problems in the men they were caring for, than did male carers of a woman with cancer, and female patients have been found to be better adjusted to the disease with respect to sexual, social and vocational functioning, compared to male patients (Fife, Kennedy, & Robinson, 1994). Previous research has also reported that female patients tend to access an wider social network to confide their concerns. Male patients are more likely to use only one confidante, invariably their carer (Harrison, Maguire, & Piteathly, 1995). This suggests that the gender of the person with cancer is a relevant issue to explore in examinations of cancer carer distress, one of the issues addressed in the present study.
Relational communication and self silencing

In a meta-analysis and critical review of studies that examined distress in couples coping with cancer, Hagedoorn, Sanderman, Bolks, Tuinstra and Coyne (2008) argued that the person with cancer and their partner are an “interdependent emotional system” in which distress is not only shared but could be “transmitted directly to the other partner, perhaps as a result of emotional contagion” (p.6). From this perspective, relational dynamics, intersubjective negotiation and communication about subjective needs between people with cancer and their carers or partners are important aspects of the cancer caring experience.

It is now widely recognised that the pattern of communication adopted by couples living with cancer directly influences coping and psychological well-being. Couples who are mutually responsive, attend to each others needs, and talk openly about their stress, are able to engage in effective emotion and problem focused coping (Zunkel, 2002), which allows them to find benefits in the cancer experience, such as personal growth and relationship closeness (Kayser, Watson, & Andrade, 2007; Manne, Ostroff, Winkel, Goldstein, Fox, & Grana, 2004b). This pattern of mutual communication has also been found to be associated with lower levels of distress for patients and partners, and higher levels of marital satisfaction (Badr et al., 2008; Manne et al., 2006; Ptacek et al., 1994). Conversely, many partners are over-protective towards the person with cancer, engaging in “protective buffering” in an attempt to prevent distress (Badr & Carmack Taylor, 2006; Kuijer et al., 2000), or “disengaged avoidance” (Kayser et al., 2007, p412), involving complete denial of cancer or its effects. Whilst this may appear to be functional in protecting against suffering, it does not allow the partner to engage in supporting the person with cancer (Kayser et al., 2007) and can alienate the patient (Badr & Carmack Taylor, 2006). Indeed, couples who avoid talking about the cancer or its emotional impact report higher levels of distress and lower marital satisfaction (Badr et al., 2008; Kuijer et al., 2000; Manne et al., 2006; Ptacek et al., 1994; Skerrett, 1998; Zunkel, 2002), as well as less supportive behaviour within the couple (Manne, Ostroff, Winkel, Grana, & Fox, 2005).

The protective buffering and avoidance of talking about feelings commonly found in couples coping with cancer, is analogous to the pattern of self-silencing initially identified by Dana Jack (1991) as an explanation for women’s greater susceptibility to depression, as noted above. This pattern of compulsive caretaking and inhibition of self-expression in relationships can lead to a self-division between an ‘outwardly conforming and compliant self’ and an ‘inner self who is angry and resentful’ (Jack, 1987, p177), described by Jack as ‘the core dynamic of female depression’ (1991, p169). This is because women believe that they are not loved for who they are, but for how well they meet the needs of others, with the resultant silencing of desires and feelings, and the use of external standards against which to judge the self, leading to feelings of worthlessness and hopelessness (Duarte & Thompson, 1999). A self-report questionnaire developed to assess the intensity of self-silencing cognitive schema, the Self-Silencing-Scale (STSS) (Jack & Dill, 1992), identified four distinct facets underpinning self-silencing behaviour, which make up four subscales. ‘Externalised Self-Perception’ reflects the tendency to judge the self by external standards; ‘Care as Self-Sacrifice’ assesses propensity to put needs of others before the self; ‘Silencing the Self’ involves the inhibition of thoughts, feelings and behaviours in order to avoid relationship conflict or loss; and ‘Divided Self’ assesses the tendency to behave in a compliant manner whilst feeling angry and resentful inside. This scale was used to examine self-silencing in cancer carers in the present study.

Self-silencing is not a pattern of behaviour unique to women. In a number of studies men have been found to report levels of self-silencing equal to those of women (Cowan, Bommersbach, & Curtis, 1995; Jack & Dill, 1992), or higher than women (Cramer & Thoms,
However, differences have been reported between women and men in patterns of self-silencing, and in the relationship between self-silencing and depression. For example, a factor analytic study found that the Divided Self subscale did not appear as a construct for men, whilst it did for women. Instead, a factor of Autonomy/Concealment emerged uniquely for men, described as “an intention to prioritize ones own needs and to maintain a feeling of self-sufficiency, combined with the motivation of hiding what is perceived to be a potentially undesirable aspect of oneself from one’s partner” (Remen, Chambless, & Rodebaugh, 2002, p.154). Another study reported that the Care as Self-Sacrifice and Divided Self Subscales were inter-correlated for women, but not for men, suggesting that women who prioritise the needs of others experience anger and a loss of self, whereas men do not (Duarte & Thompson, 1999, p159). Researchers have also reported that whilst men report significantly higher self-silencing than women, they also report lower depression (Duarte & Thompson, 1999; Whiffen et al., 2007). These findings have led to the conclusion that further exploration of the reasons why men and women self-silence, and the consequences of this for psychological well-being, is needed (Cramer & Thoms, 2003; Remen et al., 2002). There is also a need to explore the development and function of self-silencing in different relational and situational contexts, as much of the existing research on self-silencing has been conducted with student populations.

One of the aims of the present study was to thus to examine gender differences in patterns of self-silencing, the relationship between self-silencing and psychological distress, and reasons for self-silencing, in men and women cancer carers, using questionnaires and interviews. Whilst previous research has examined self-silencing and psychological well-being in women with breast cancer (Kayser, Sormanti, & Strainchamps, 1999), there is no published research, to date, that has examined self-silencing in informal cancer carers, or has examined gender differences in self-silencing in the cancer context. Researchers have reported that many cancer carers feel unable to express their own needs to the person for whom they are caring, and that they experience their own needs as being unacknowledged, or seen as unimportant, resulting in distress (Grande, Todd, & Barclay, 1997; Lee Walker, 1997). This has led to the suggestion that there are ‘competing needs for space’ (Morris & Thomas, 2001) which need to be acknowledged by carers and people with cancer, as well as by health professionals. Research into self-silencing in cancer carers will not only provide further insight into the relational context of coping with cancer, in particular the connection between avoidant patterns of communication and distress, but it will also address the call for further examination of reasons why self-silencing occurs in women and men, with broader implications for the understanding of self-silencing as a gendered phenomenon.

Relational change in the context of cancer

The diagnosis of cancer can change the relational dynamics between people with cancer and their family members, in particular their intimate partners, which can have an impact on their subjective well-being and ability to cope. For example, it has been reported that informal carers of people with cancer assume new roles in the household (Ben-Zur, Gilbar, & Lev, 2001), or take on more complex multifaceted tasks (Given et al., 2001), in addition to providing physical and emotional support. As a consequence, carers can feel burdened by feelings of over-responsibility (Ussher & Sandoval, 2008), resulting in psychological distress (Hagedoorn et al., 2000). Couples living with cancer have also reported communication problems (Zahlis & Shandis, 1991) or increased conflict (Badr & Carmack Taylor, 2006) and in some instances have attributed relationship breakdown to cancer (Kornblith, Anderson, & Cella, 1990). Conversely, it has been argued that couples living with cancer are no more likely to separate than couples in the general community (Schover, 2004). Indeed, cancer has
been reported to have had a positive influence on some couple relationships (Badr & Carmack Taylor, 2006), bringing people with cancer and their partners closer together (Dorval, Guay, Mondor, Masse, Falarseau, & Robidoux, 2005), through the experience of greater intimacy (Manne, Ostroff, Rini, Fox, Goldstein, & Grana, 2004a). These conflicting findings have led Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne (2008) to conclude, in their meta-analysis of distress in couples coping with cancer, that further research is needed on “just how much cancer intrudes upon and organizes the daily lives of couples confronted with the disease” (p.24). However, there is also a need to examine whether cancer affects other caring dyads, such as siblings, parent-child, or friends, as previous research in this field has primarily focussed on couples in an intimate relationship.

A further issue deserved of investigation is the gendered experience of relationship change in the context of cancer caring. This is for a number of reasons. Firstly, there has been a dearth of research into men’s experiences of caring roles, or experiences of changes in relationship dynamics following life changing events such as cancer (Chattoo & Ahmad, 2008). Secondly, changes in relationship dynamics may thus provide partial explanation for the consistent finding that women cancer carers, as well as women with cancer, report higher distress than men (Hagedoorn et al., 2008), because women’s sense of self is constructed as “being in relation” (Jordan & Hartling, 2002), with relationship change resulting in distress (Kaplan, 1986). At the same time, although men and women have been found to be equally likely to remember their own life events, men have been reported to be less likely than women to remember life events affecting significant others, leading to the suggestion that men may avoid depression through “blocking out,” or not attending to, network events, those affecting significant others (Nazroo, Edwards, & Brown, 1997; Turner & Avison, 1989), which may influence men’s relational experiences in the context of cancer. Thus a further aim of this study was to examine accounts of change in roles and interpersonal dynamics between the person with cancer and their primary carer, from the perspective of informal carers, across a range of cancer types, relationship dyads, and across gender.

**Mediators of Gender Differences in Carer Distress**

Researchers have identified a number of additional risk factors for depression and anxiety in cancer carers. These were systematically examined in the present study, to identify differential pathways to distress for men and women. This directly addresses the plea made by Hagedoorn et al (2008), in their meta-analysis of gender and distress in couples coping with cancer, for the examination of “a wide range of potential confounds as statistical controls and to identify and test alternative direct influences and mediators and moderators of distress” (p.24).

**Social support:**
Higher levels of social support received by the carer have been reported to result in higher levels of psychological and physical well-being (Haley, 2003; Nijboer, Templaar, Triemstra, Sanderman, & van den Bos, 2001; Rodrigue & Hoffmann III, 1994; Thielemann, 2002).

**Provision of information to carers and involvement in the decision making process:**
There is evidence that when carers are provided with information, and when their involvement in the cancer scenario is legitimatized by others, it is easier for them to attend to their own needs and those of the patient (Morris & Thomas, 2001).

**Self-efficacy:**
Carers reporting higher levels of self-efficacy experience higher levels of wellbeing (Flaskerud, Carter, & Lee, 2000; Keefe, Ahles, Porter, Sutton, McBride, Pope et al., 2003;
Nijboer et al., 2001), and more active engagement in supporting the patient (Kuijer et al., 2000).

**Optimism/Pessimism:**
Carer optimism is negatively associated with psychological symptoms, with higher levels of pessimism resulting in higher levels of distress (1995; 2003).

**Carers’ appraisal of the role:**
Carers who appraise the caring role as stressful, find little meaning in the role, report getting less satisfaction from the role or generally hold a negative perception of caregiving, have been found to report higher levels of depression, lower life satisfaction and poorer adjustment overall (Haley, 2003; Nijboer et al., 2001; Northouse, Laten, & Reddy, 1995; Oberst, Gass, & Ward, 1989).

**Stage of caregiving journey:**
Caregiving can be perceived as a dynamic, ongoing process for which there may be several trajectories, with increases in distress reported at particular points: the point of diagnosis and the early stages of the caregiving journey (Gilbar, 1999); recurrence of the disease (Hind, 1992; Northouse, Dorris, & Charron-Moore, 1995) and the advanced stage or palliative phase of the illness (Morse & Fife, 1998; Siegel, Karus, Raveis, Christ, & Mesagno, 1996). The needs of carers will thus vary at different stages of the caregiving journey (Brown & Stetz, 1999; Nijboer et al., 2001), with implications for the development and delivery of interventions. Previous research on gender differences in carer distress has been criticised for focusing on early stage cancer, or for small sample size preventing examination of stage of cancer as a moderator (Hagedoorn et al., 2008).

**Burden of Care and unmet needs:**
Higher levels of unmet needs predict higher rates of depression and anxiety. Informational and psychological needs are consistently ranked by carers as their primary priorities (Clumpus & Hill, 1999; Grimm et al., 2000; Harrington, Lackey, & Gates, 1996; Nikoletti, Kristjanson, Tataryn, McPhee, & Burt, 2003). Soothill et al (2001) in a study of 195 carers found that 43% reported at least 1 unmet need, whilst only 38% of participants reported being offered support services. Non-spousal carers, those with other responsibilities (such as children < 20 years old), carers who have few or no friends/relatives to call upon, and those caring for a patient in the palliative stage, are more likely to have unmet needs (Nikoletti et al., 2003; Soothill et al., 2001).

There is no Australian research, to date, examining the relative impact of these pathways to distress in a representative sample of cancer carers in NSW, comparing male and female carers. The present study addressed this aim.

**Positive Aspects of the Cancer Care-Giving Experience**

The focus on burden of care has acted to obscure the positive meanings many cancer carers construct in making sense of their caring experiences (Sinding, 2003). Indeed, as Addington-Hall and Ramirez (2006) contend, carers “resent suggestions that the experience is wholly negative or, indeed, negative at all” (p.56). It has thus been argued that positive aspects of informal cancer caring require attention in order to better understand the complexities of the caring experience (Hudson, Aranda, & Hayman-White, 2005).
There is now a significant body of research indicating that positive benefits occur for cancer survivors who “feel significantly altered by the experience, often for years after their treatment has ended” (Thornton, 2002, p153). These positive changes include altered life perspective (Nelson, 1996), improved interpersonal relationships (Sears, Stanton, & Danoff-Burg, 2003), and positive changes in the self (Fife, 1994). The small number of research studies examining benefit finding for informal cancer carers reveals similar conclusions. For example, in one study of 45 adult daughters of cancer patients, 93% of participants reported at least one positive change resulting from their parent’s cancer (Leedham & Meyerowitz, 1999), including positive changes in the relationship with the sick parent and with others, enjoying life more, and the development of inner strength. Similarly, in a study of 175 intimate partners of a person with cancer, Germino, Fife and Funk (1995) reported that re-evaluation of life and relationship priorities was a positive change experienced, with individuals searching for meaning in order to reduce the threat of cancer. Whilst palliative care is recognised to be particularly emotionally draining, in a study of 47 informal carers providing palliative care, Hudson (2004) reported that 60% of participants could identify positive aspects of the role, including closeness with the person with cancer, and experiencing caring as a privilege.

Benefit finding in the face of adverse events serves an important function in allowing individuals to incorporate difficult experiences into their worldview in a meaningful way, thus maintaining positive beliefs about the world (Thornton, 2002). Positive appraisal of a stressor, such as cancer or the care-giving role, allows people to enhance and maintain coping (Folkman, 1997). However, the extent to which these benefits act as a buffer for the negative aspects of the cancer caring role is debatable (Hudson, 2004). In a recent study of 896 informal cancer carers (Kim, Schulz, & Carver, 2007), whilst coming to accept what had happened and appreciating new relationships with others was associated with positive adjustment, becoming more empathic and reprioritising values was associated with greater symptoms of depression. There thus is a need for further research to examine positive aspects of informal cancer caring and benefits perceived to be experienced by carers (Coyle, 2004; Thornton, 2002), which may serve to provide insight into the question of why informal carers who find caring stressful continue to provide care, and what it is that keeps them there (Coyle, 2004). The present study addressed this aim, looking at gender differences in accounts of positive experiences of care.

**Aim of the Study**

The aim of the present study was firstly to examine the relationship between gender and distress in informal cancer carers, investigating the moderating and mediating role of burden of care, unmet needs, self-silencing, social support, self-efficacy, gender of the patient, and cancer stage, across a broad range of cancer types. The inclusion of a range of cancer types addresses the criticism that previous research in this area has focused on breast and prostate cancer, resulting in analysis of gender differences being confounded by the characteristics of the cancer (Hagedoorn et al., 2008).

We utilised the framework of self-silencing (Jack, 1991) and relational-cultural theory (Jordan & Hartling, 2002) to examine gender differences in distress, addressing the concerns of Miller and Cafasso (1992) and Hagedoorn et al (2008), who argued that rather than simply documenting gender differences in care-giving, we need to develop theoretically driven models of research, which pay more attention to gender-role explanations of the experience of caring.
Secondly, the study addressed the need for more qualitative research in this field (Hagedoorn et al., 2008), which can “excavate the contours of the lived experience of cancer care” (Thomas & Morris, 2002, p. 181), as the majority of research to date has been framed within a positivist research paradigm, focusing solely on measuring the impact of cancer or the caring role on carers’ psychological morbidity. In the present study, a mixed method design, conducted from a critical realist epistemological standpoint, was used, in order to examine the nature of gender differences in cancer caring, and provide insight into the mechanisms of effects, and to examine challenges and rewarding aspects of care. Critical Realism affirms the existence of reality (e.g. health, gender, economic factors), but recognises that our experience of reality is always mediated by culture, language and subjectivity (Bhaskar, 1989). Advocated as the way forward for research examining health in a socio-cultural context (Williams, 2003), a variety of methodological approaches, both qualitative and quantitative are valued equally and there is acceptance of the legitimacy of subjective experience, often marginalised or ignored in mainstream psychological research (Ussher, 1996).

Thirdly, despite the recognition of carer needs, there have been few comparative studies that have systematically examined effectiveness of cancer carer interventions. This project addressed this significant gap in the literature, through the evaluation of supportive cancer carer interventions, and in addition, through a systematic review of research literature on the effectiveness of psycho-social interventions for cancer carers.

**Design**

Through triangulation of design and method, quantitative surveys and interviews, were used to examine the experience of being a cancer caregiver, and pathways to distress, amongst a stratified sample of male and female primary informal carers for a person with cancer. The research design was carefully structured so that each stage generates a heuristic framework to inform the inquiry techniques in following stages. The battery of questionnaires was based on insights from the literature review, discussions with stakeholders, and a pilot study funded by a UWS partnership grant in conjunction with NSWCC. The interviews and focus groups gave an insight into the complexities of individual subjective experience, analysed through case studies and group comparisons.
Section Two

An Examination of Gender Differences in Unmet Needs, Burden of Care, Self-Silencing and Psychological Distress in Cancer Carers

Survey: Participants and Procedure

Four hundred and eighty four informal cancer carers (329 women & 155 men) living in New South Wales (NSW), Australia, took part in the study. ‘Informal carer’ is defined as the primary person providing emotional and/or physical support for the person with cancer. Using the HADS (Zigmond & Snaith, 1983), assuming a 25% prevalence of depression and anxiety in the female carer group, (as reported in our earlier study (Ussher, 2003), this sample size was sufficient to detect a 15% difference between men and women with significance = 5% and power = 80%. This size of gender difference has been reported in earlier studies of carers (Hagedoorn et al., 2000).

Participants were recruited via cancer support groups, media stories in local press, advertisements in cancer and carer specific newsletters, hospital clinics, and The Cancer Council NSW website and helpline. Participants who were interested in taking part contacted the research team by email or telephone and were sent an information sheet, consent form, survey, interview contact form, and reply paid envelope. Participants could also access the survey directly through a web address published in advertisements and complete the survey on-line. The majority of participants completed the survey in the hardcopy format (344) compared to the online format (140). Those completing the hard copy questionnaire were significantly older than those completing online ($M = 57$ years versus $49$ years, $t(468) = 6.61$, $p = .000$); were more likely to be male (80% of men versus 67% of women, $\chi^2 (1, 483) = 8.62$, $p = .003$); and reported lower depression ($M = 6.48$ versus $M = 8.19$), ($t(478) = -3.86$, $p = .000$) and anxiety ($M = 9.40$ versus $M = 11.28$), ($t(478) = -3.86$, $p = .000$). At the end of the survey participants were asked whether they would like to be considered to take part in a one hour interview, to discuss their caring experiences in more depth.

Two cancer carers nominated by a cancer consumer organisation ‘Cancer Voices’ acted as consultants on the project, commenting on the design, method and interpretation of results. Ethics approval was received from the University of Western Sydney Human Research Ethics Committee, and from 18 Area Health Authorities in NSW, from which participants were drawn. Demographic details of the survey sample are presented in Table 1.
Table 1: Characteristics for carer and person with cancer for the survey sample

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
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<th>Range</th>
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<tr>
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<td>18 - 93</td>
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<td>0.6 (1.8)</td>
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<td>*** p &lt; .001</td>
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<td></td>
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<tr>
<td>Respiratory</td>
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<td></td>
</tr>
<tr>
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<td>Intimate partner</td>
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<td>Child</td>
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<td></td>
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<td>Sibling</td>
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<td>9.2</td>
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<tr>
<td>Temporarily not working</td>
<td>44</td>
<td>9.2</td>
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<tr>
<td>Employed – Part-time</td>
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<tr>
<td>Unemployed</td>
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<tr>
<td>Full-time home duties</td>
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<tr>
<td>Retired</td>
<td>165</td>
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<tr>
<td>Student</td>
<td>8</td>
<td>1.7</td>
<td></td>
</tr>
<tr>
<td>Other</td>
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</tr>
<tr>
<td>Carer other responsibilities:</td>
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<tr>
<td>Dependent children</td>
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<tr>
<td>Household tasks</td>
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<td></td>
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<tr>
<td>Employment</td>
<td>188</td>
<td>39.1</td>
<td></td>
</tr>
<tr>
<td>Studies</td>
<td>83</td>
<td>17.3</td>
<td></td>
</tr>
</tbody>
</table>
Demographic details of the survey participants

Of the 484 people who took part in the study 324 (67%) were currently caring for someone with cancer, for 33 (8%) the person they were caring for with cancer had died and 28 (6%) were in remission. 108 (23%) of the carers indicated that they themselves had a serious illness. The cancer type of the person being cared for in the survey sample is illustrated in Figure 1.

The most common cancer type was breast cancer (20%), followed by colorectal/digestive cancers (15%) and haematological cancers (13%). These make up nearly a half of all the cancer types in the study sample.

The stage of cancer when first diagnosed is illustrated in figure 2. Forty eight per cent indicated the cancer was in an advanced stage when first diagnosed, 34% that it was early stage and 13% were not sure what stage the cancer was at.
The stage of cancer at the time the participants completed the survey is illustrated in figure 3. Thirty eight per cent reported that the cancer was in the advanced stage of the disease, 18% of cancers were no longer detectable, 9% were in the early stage and 5% of the people with cancer being cared for had died.

Participants reported that 63% of the individuals with cancer being cared for were currently receiving medical treatment, 20% reported that the treatment had been completed, with 1% reporting never having received treatment.

When asked how the cancer was affecting the daily living of the person for whom the participant cared, 29% reported that the person with cancer was able to care for most of their own needs, but required occasional care, 19% were able to care for themself, but unable to work or carry on other normal activities,16% needed considerable assistance and frequent care was required, with some self care possible,15% were fully mobile and 6% were disabled; requiring special care and assistance (see figure 4). Other than the cancer, 33% of the people being cared for in this cohort had another serious illness other than their cancer.
Measures

The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983), is a 14 item validated self report measure developed to measure anxiety and depression in non-psychiatric populations. Each sub-scale HADSA (anxiety) and HADSD (depression) has a maximum possible score of 21, with a score of between 8 and above recommended as the cut-off point for caseness, the cut-off for clinical diagnosis. A score of 8-10 is categorised borderline and a score of 11 and above categorised as abnormal in relation to caseness (Bjelland, Dahl, Haug, & Neckelmann, 2002).

The Psychosocial Needs Inventory (PNI) (Soothill et al., 2001) was used to assess unmet needs. Subscales include: Health Professional; Information; Support Network; Identity; Emotional and Spiritual; and Practical. A significant unmet need is one that is rated as important or very important and is rated as not at all, or not very, satisfied.

The Caregiver Reaction Assessment Scale (CRA) (Nijboer, 1999) was used to examine caregiver burden. Subscales include: Disrupted Schedule, Financial Problems, Lack of Family Support, Health Problems, and Self-esteem.

The Silencing the Self Scale (STSS) (Jack, 1991) is a standardised questionnaire consisting of 31 items measuring the extent to which individuals endorse self-silencing thoughts and actions, using a 5 point Likert scale. In addition to a Global score, the four subscales are: Care as Self-Sacrifice (e.g. Caring means putting the other person’s needs in front of my own), Silencing the Self (e.g. I don’t speak my feelings in an intimate relationship when I know they will cause disagreement), Externalised Self Perception (e.g. I tend to judge myself by how I think other people see me) and The Divided Self (e.g. Often I look happy enough on the outside, but inwardly I feel angry and rebellious).

Involvement in Care and Support Received: The total number of hours per day spent in direct care and companionship, and received in help, were assessed, as were the number of sources of help received and additional responsibilities (i.e., dependent children, household tasks, studies, employment, & other).

Social support was assessed using a validated one item social support scale (Blake, 1986); Self-Efficacy was examined using the General Self-Efficacy Scale (Schwarzer & Jerusalem, 1995), a 10-item psychometric scale that is designed to assess optimistic self-beliefs to cope with a variety of difficult demands in life.

The Optimism and Control Over the Future Sub-Scale is a four item factor by Rogers, Chamberlin, Ellison and Crean (1997), to measures empowerment, by looking at the sense of self worth and the extent to which the person has control over their life and the future.
Survey Results

Statistical Analysis

Univariate analyses were conducted to compare women and men on each of the socio-demographic variables of interest. For continuous variables, one-way ANOVA were conducted with gender as the grouping variable, and the chi square test for independence used for frequency data. Pearson’s correlations were used to assess associations between psychological distress variables and potential mediating variables for the entire sample. Independent sample t-test were used to assess gender differences in mean scores for all potential mediating variables. According to established criteria for mediation {Baron, 1986 #5471}, a mediating variable between gender and psychological distress is identified as one that shows evidence of both a significant association to the psychological distress variable and significant gender differences in mean scores. Finally, to test for the full or partial effect of any identified mediators, hierarchical linear regression analyses were conducted to establish whether covarying a variable with gender would reduce the relationship of gender to psychological distress. An alpha level of .05 was used for all statistical tests, and 95% confidence intervals (CI) are reported for effect sizes involving principal outcomes.

Demographic Data by Gender Groups

Table 2 presents the sample demographics by gender. For women and men carers, the mean age ($M = 53.9, SD = 13.8$; $M = 56.7, SD = 12.1$ respectively), years since patient diagnosis ($M = 8.7, SD = 21.3$; $M = 10.1, SD = 31.7$ respectively) and ethnicity profile (80.9% and 82.8% respectively for the cultural grouping Australian/While European) did not differ between the two groups. For patient age, the difference between women ($M = 60.3, SD = 14.1$) and men ($M = 55.6, SD = 11.6$) was significant, $t(368) = 10.35, p = .001$. The proportions for cancer type, stage of disease and relationship to patient differed between the gender groups, with exact proportions detailed in Table 1. The difference in proportions was significant for cancer type, $\chi^2 (12, N = 280) = 67.55, p < .001$, stage of disease, $\chi^2 (3, N = 361) = 12.67, p = .005$ and relationship to patient, $\chi^2 (6, N = 372) = 32.28, p < .001$.

Implications

Men and women cancer carers are comparable in age, but women are looking after significantly older patients, with a more advanced cancer condition, or cancer that is still active, and caring for a broader range of patients (partner, siblings, parents, friends). There was no gender difference in number of hours spent caring, additional responsibilities, or amount of support received from family and friends.
Table 2: Sample Demographics by Gender

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<th>Variable</th>
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<th></th>
<th></th>
<th>Men</th>
<th></th>
</tr>
</thead>
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<td></td>
<td>n</td>
<td>M (SD)</td>
<td>n</td>
<td>M (SD)</td>
<td></td>
</tr>
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<td>151</td>
<td>57.0 (11.9)</td>
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<tr>
<td>Patient age</td>
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<td>60.8 (14.1)</td>
<td>153</td>
<td>55.8 (11.9)</td>
<td></td>
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<tr>
<td>Years since first diagnosis</td>
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<td>3.0 (3.6)</td>
<td>151</td>
<td>3.4 (4.9)</td>
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<td>Ethnicity:</td>
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<td>124</td>
<td>80.5</td>
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<td>-</td>
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<tr>
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<tr>
<td>Has died</td>
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<td>10</td>
<td>7.0</td>
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<td>Relationship to patient:</td>
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<td>Partner</td>
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<td>141</td>
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<tr>
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<td>-</td>
<td>-</td>
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</tr>
</tbody>
</table>

Note a “Other” includes: Mesothelioma, Pancreatic, Bone, Melanoma, various, each less than 2%; b “Other” includes: paid carer or not specified.
Descriptive Data for Each Measure by Gender Groups

Psychosocial Needs Inventory

Overall there was a significant difference ($p=0.01$) in the unmet needs between men and women. Women (Mean 56) reported more unmet needs than men (Mean=53).

![Figure 5: Psychosocial Needs Inventory Totals](chart)

A t test looked at the differences in scores between men and women on each of the subscales of the PNI. Within each of the ‘need categories’ it can be seen that women had significantly more unmet psychological needs as informal carers than men for 4 of these categories. These categories were the PNI subscales ‘Emotional and spiritual unmet needs’, $t(483) = -3.19, p = .002$, ‘Identity unmet needs’, $t(483) = -3.47, p = .001$, ‘Practical unmet needs’ $t(483) = -2.24, p = .02$, and ‘Support network unmet needs $t(483) = -2.39, p = .02$.

![Figure 6: PNI Sub-Scales - Mean Scores](chart)

*Information needs:* One in three participants reported unmet information needs, with information about what to expect being the highest unmet need for both men (41%) and women (46%).
Health Professionals: One in four participants reported unmet needs in relation to health professionals, with easy and quick access to doctors the highest unmet need reported (38%). Women were more likely than men to report unmet needs associated with health professionals who listen to me (33% women, 24% men), and health professionals who treat me with respect (26% women, 17% men).

Support Network unmet needs were reported by one in four participants, with absence of someone to talk to being the highest unmet need for both women (31%) and men (26%).

Emotional and spiritual needs: On average, one in three participants reported unmet emotional and spiritual needs, with the highest unmet needs for women being help in dealing with the unpredictability of the future (50% women, 32% men), and for men, hope for the future (38% men, 47% women). Women also reported high unmet needs in relation to dealing with sad feelings (41% women, 34% men), dealing with fears (44% women, 35% men), needing help with anger (39% women, 21% men), and needing time for myself (41% women, 30% of men).

Identity: Unmet needs associated with identity were reported by one in three participants, with help in maintaining control over my own life being the highest unmet need (44% women, 30% of men).

Practical: One in three participants reported practical unmet needs, with help dealing with any distressing symptoms being the highest rated (37% women, 27% men), followed by help with dealing with tiredness (38% women, 24% men) and help with financial matters (30% women, 31% men).

Table 3 illustrates the percentage of unmet needs for both men and women for each individual item.
Table 3: Percentage of women and men who rated need items as significant unmet needs

<table>
<thead>
<tr>
<th>Unmet Need Item</th>
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<th>Female</th>
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<tbody>
<tr>
<td><strong>Information</strong></td>
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<tr>
<td>Information about medication and side effects</td>
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<td>33</td>
</tr>
<tr>
<td>Information about treatment plans</td>
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<td>30</td>
</tr>
<tr>
<td>Information about what to expect</td>
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<td>46</td>
</tr>
<tr>
<td>Access to other sources of information</td>
<td>31</td>
<td>34</td>
</tr>
<tr>
<td>Advice on what services and help are available</td>
<td>38</td>
<td>43</td>
</tr>
<tr>
<td>Opportunities to participate in choices around treatment</td>
<td>28</td>
<td>32</td>
</tr>
<tr>
<td><strong>Health Professionals</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Honest information</td>
<td>29</td>
<td>33</td>
</tr>
<tr>
<td>Confidence in the health professionals I meet</td>
<td>20</td>
<td>22</td>
</tr>
<tr>
<td>Information given sensitively</td>
<td>26</td>
<td>28</td>
</tr>
<tr>
<td>Health professionals who listen to me</td>
<td>24</td>
<td>33</td>
</tr>
<tr>
<td>Health professionals who have time discuss issues with me</td>
<td>29</td>
<td>34</td>
</tr>
<tr>
<td>Health professionals who treat me with respect</td>
<td>17</td>
<td>26</td>
</tr>
<tr>
<td>Easy and quick access to doctors</td>
<td>38</td>
<td>38</td>
</tr>
<tr>
<td>Easy and quick access to health professionals other than doctors</td>
<td>32</td>
<td>32</td>
</tr>
<tr>
<td><strong>Support Network</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support from the family</td>
<td>18</td>
<td>25</td>
</tr>
<tr>
<td>Support from the friends</td>
<td>14</td>
<td>20</td>
</tr>
<tr>
<td>Support from the neighbours</td>
<td>8</td>
<td>13</td>
</tr>
<tr>
<td>Support from the care professionals</td>
<td>22</td>
<td>29</td>
</tr>
<tr>
<td>Someone to talk to</td>
<td>26</td>
<td>31</td>
</tr>
<tr>
<td><strong>Emotional and spiritual</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help with finding a sense of purpose and meaning</td>
<td>37</td>
<td>38</td>
</tr>
<tr>
<td>Hope for the future</td>
<td>37</td>
<td>47</td>
</tr>
<tr>
<td>Opportunities for personal prayer</td>
<td>10</td>
<td>11</td>
</tr>
<tr>
<td>Support from people of my faith</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Support from a spiritual advisor</td>
<td>9</td>
<td>12</td>
</tr>
<tr>
<td>Help in dealing with unpredictability of the future</td>
<td>32</td>
<td>50</td>
</tr>
<tr>
<td>Help with any loneliness</td>
<td>28</td>
<td>31</td>
</tr>
<tr>
<td>Opportunities for meeting others who are in similar situation</td>
<td>21</td>
<td>32</td>
</tr>
<tr>
<td>Help with fears</td>
<td>35</td>
<td>44</td>
</tr>
<tr>
<td>Help with any sad feelings</td>
<td>34</td>
<td>41</td>
</tr>
<tr>
<td>Help with anger</td>
<td>21</td>
<td>39</td>
</tr>
<tr>
<td>Help with any feeling of guilt</td>
<td>18</td>
<td>31</td>
</tr>
<tr>
<td>Help in considering my sexual needs</td>
<td>16</td>
<td>15</td>
</tr>
<tr>
<td>Help in dealing with the feelings of others</td>
<td>20</td>
<td>32</td>
</tr>
<tr>
<td>Time for myself</td>
<td>30</td>
<td>41</td>
</tr>
<tr>
<td><strong>Identity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support with dealing with any changes in the way others see me</td>
<td>17</td>
<td>22</td>
</tr>
<tr>
<td>Help in maintaining a sense of control in my life</td>
<td>30</td>
<td>44</td>
</tr>
<tr>
<td>Support in dealing with changes in my body or the way I look</td>
<td>11</td>
<td>20</td>
</tr>
<tr>
<td>Support in dealing with the changes in my sense of who I am</td>
<td>15</td>
<td>31</td>
</tr>
<tr>
<td>Help in maintaining independence in the face of illness</td>
<td>26</td>
<td>35</td>
</tr>
</tbody>
</table>
Practical
Help with the housework 19 27
Help with transport 17 20
Help in dealing with any tiredness 24 38
Advice about food and diet 26 28
Help with financial matters 31 30
Help in filling our forms 11 16
Help with any distressing symptoms 27 37
Help with getting out and about socially 14 23
Help with child care 7 7

Anxiety and Depression (Hospital Anxiety and Depression Scale)

Psychological distress, measured by mean anxiety HADSA scores ($M = 9.94$, $SD = 4.46$) and depression HADSD ($M = 9.94$, $SD = 4.66$) scores for the entire sample were moderate to high and comparable to a previous sample of cancer carers (Janda et al., 2007). Whilst not used to formally diagnose participants in this study, 25% ($N = 113$) and 45% ($N = 216$) of the sample met the criteria for borderline and abnormal anxiety caseness respectively (Figure 7). On the depression scale, 58% of the sample scored in the normal range, with 19% ($N = 90$) and 23% ($N = 112$) meeting the cut-offs for borderline and abnormal caseness respectively (Figure 8).

Figure 7: Anxiety Scores

Figure 8: Depression Scores
**Differences in Psychological Distress between bereaved and non-bereaved participants**

Independent $t$ tests were conducted on HADSA and HADSD scores with bereaved status as the grouping variable with assumptions of normality and homogeneity of variance met in both instances. Bereaved participants reported significantly higher levels of depression than non-bereaved participants $t(462) = -2.85, p = .005$. The mean HADSD score was higher for bereaved ($M = 8.97, SD = 4.35$) than non-bereaved ($M = 6.78, SD = 4.45$). When we examined depression in men and women separately, the bereaved women were significantly more depressed ($M = 9.39, SD = 4.11$) than the non-bereaved women ($M = 7.02, SD = 4.52$), $t(314) = -2.57, p = .01$. There was no significant difference for men.

**Gender Differences in Psychological Distress**

Univariate analyses were used to compare women and men on the two psychological distress variables of interest (table 4). Independent $t$ tests were conducted on HADSA and HADSD scores with gender as the grouping variable with assumptions of normality and homogeneity of variance met in both instances. For anxiety scores, results indicated a statistically significant difference between women and men, $t(478) = -3.07, p = .002$. The mean HADSA score was higher for women ($M = 10.38, SD = 4.44$) than men ($M = 9.01, SD = 4.70$). For depression scores, results also indicated a statistically significant difference between women and men, $t(478) = -3.07, p = .002$. The mean HADSD score was higher for women ($M = 7.27, SD = 4.27$) than men ($M = 6.37, SD = 4.54$).

**Table 4: Means and Standard Deviations on the HADS for Women and Men**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Women ($n = 326$)</th>
<th>Men ($n = 154$)</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>HADS – Anxiety</td>
<td>$M$ 10.38, $SD$ 4.44</td>
<td>$M$ 9.01, $SD$ 4.70</td>
<td>.002</td>
</tr>
<tr>
<td>HADS – Depression</td>
<td>$M$ 7.27, $SD$ 4.27</td>
<td>$M$ 6.37, $SD$ 4.54</td>
<td>.040</td>
</tr>
</tbody>
</table>
Implications of findings

These findings suggest that participants were reporting levels of anxiety and depression higher than population norms for Australia (Australian Bureau of Statistics, 2008; Janda et al., 2007), adding to the now extensive body of research which has demonstrated that informal cancer carers experience high levels of anxiety and depression (Hagedoorn et al., 2000), with anxiety being found to be more prevalent than depression in the present study. Women carers reported higher levels of depression and anxiety than men, confirming previous research on gender differences in cancer carer distress (Hagedoorn et al., 2008). This is also in line with general population norms, where women consistently report higher rates of depression and anxiety than men (Bebbington, 1996; Kuehner, 2003).
**Caregiver Burden**

Caregiver burden was examined using the CRA, containing 5 subscales for measuring the positive and negative reaction to giving care to cancer patients. A t-test was used with each of the 5 subscales to determine whether there was a significant statistical difference between male and female scores. Of the 5 subscales, 3 demonstrated a significant statistical difference between genders: Disrupted Schedule, Health Problems, and Lack of Family Support. Below is a further breakdown of the results for each CRA subscale between men and women.

**Figure 11: Caregiver Reaction Assessment by Gender**

![Bar chart showing comparison between men and women for each subscale]

**Disrupted Schedule**

The total score possible for this subscale was 25. A t-test found there to be a significant difference in the scores for disrupted schedule between men (Mean=15.21, SD=5.46) and women (Mean=16.54, SD=5.54), (t(478)=-2.47, p=0.014). Women carers reported looking after someone with cancer had disrupted their schedule more than men.

**Figure 12: Disrupted Schedule subscale by Gender**

![Bar chart showing comparison between men and women for each subscale item marked with an asterisk]

(* represents a significant difference between men and women at 0.05)
Health Problems

The total score possible for this subscale was 20. An independent sample t-test found there to be a significant difference in the scores for health problems between men (Mean=10.38, SD=2.75) and women (Mean=11.21, SD=2.93), \( t(478)=-2.97, p=0.003 \). Female carers reported that caring for someone with cancer as having more of a negative effect on their health than men.

![Figure 13: Health Problems by Gender](image)

\( (*) \) represents a significant difference between men and women at 0.05

\( (**) \) represents a significant difference between men and women at 0.001

Lack of Family Support

The total possible score for this subscale was 25. A t-test found there to be a significant difference in the scores for lack of family support between men (M=9.41, SD=4.87) and women (M=10.43, SD=4.88), \( t(478)=-2.13, p=0.034 \). Female carers reported having less family support than men.

![Figure 14: Lack of Family Support by Gender](image)

\( (*) \) represents a significant difference between men and women at 0.05
Implications of findings
This study confirmed previous research findings that women cancer carers report greater personal loss and activity restriction than male carers (Matthews et al., 2003), and greater burden (Lutsky & Knight, 1994), in this context disrupted schedule, health problems and lack of family support.

Generalised Self-efficacy Scale
For the GSES there was no significant difference between the scores for men and women. The total score for this scale was 40, the mean score for men was 30.66 (SD 4.9) and the mean score for women was 30.68 (SD 5.02). This suggests high levels of self-efficacy, in comparison to previous population norms.

Optimism and Control Over the Future Sub-Scale
The total possible score for this sub-scale was 16. There was no significant difference between the scores for men and women. The mean score for men was 11.84 (SD 2.34) and the mean score for women was 11.5 (SD 2.38). These suggest relatively high levels of optimism and feelings of control over the future.

Silencing the Self Scale
The Silencing the Self Scale (STSS), is made up of four subscales that measure how carers create and maintain safe intimate relationships by silencing certain feelings, thoughts and actions. The total score for all four subscales making up the Silencing the Self Scale (STSS) is 155. In univariate analyses, men scored higher than women on STSS Global Self-Silencing \( F_{(1,478)} = 7.77, p = .006 \), Silencing the Self \( F_{(1,476)} = 13.08, p = .000 \) and Care as Self Sacrifice \( F_{(1,477)} = 36.32, p = .000 \) subscales, with no significant gender difference observed in mean subscale scores on Externalised Self-perception and Divided Self. For both men and women, scores were higher than those found in a previous study of men and women in a relationship (Cramer & Thoms, 2003) for Global Self-Silencing, Silencing the Self, and Care as Self-Sacrifice; Divided Self was higher for women only, and Externalised Self-Perception comparable for men (Table 5; Figure 14).

Table 5: Means and Standard Deviations on the STSS for Women and Men

<table>
<thead>
<tr>
<th>Variable</th>
<th>Women (n = 326)</th>
<th>Men (n = 154)</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td>P</td>
<td></td>
</tr>
<tr>
<td>Silencing the Self Scale (STSS)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Externalized Self-perception</td>
<td>16.41</td>
<td>5.81</td>
<td>15.46</td>
<td>5.35</td>
<td>.089</td>
<td></td>
</tr>
<tr>
<td>Silencing the Self</td>
<td>25.05</td>
<td>7.45</td>
<td>27.61</td>
<td>6.71</td>
<td>.000</td>
<td></td>
</tr>
<tr>
<td>Care as Self Sacrifice</td>
<td>27.39</td>
<td>6.61</td>
<td>31.35</td>
<td>6.89</td>
<td>.000</td>
<td></td>
</tr>
<tr>
<td>Divided Self</td>
<td>16.89</td>
<td>6.73</td>
<td>16.42</td>
<td>5.70</td>
<td>.451</td>
<td></td>
</tr>
<tr>
<td>Global Score</td>
<td>85.3</td>
<td>21.15</td>
<td>90.84</td>
<td>17.70</td>
<td>.006</td>
<td></td>
</tr>
</tbody>
</table>

Note. Statistical significance testing of differences in means conducted in one-way ANOVAs with gender as the grouping variable.
The total possible score for this subscale was 45. A t-test found there to be a significant difference in the scores for silencing the self between men (Mean=27.61, SD=6.71) and women (Mean=25.05, SD=7.45), (t=(327.8)=3.75, p=0.00). Men reported silencing the self more than women, meaning they reporting inhibiting their self-expression more than female carers and are taking action to avoid conflict with the person they are caring for.

(** represents a significant difference between men and women at 0.001)

Figure 15: Silencing the Self Scale

Silencing the Self subscale

Figure 16: Silencing the Self Scale by Gender

(* represents a significant difference between men and women at 0.05)
(** represents a significant difference between men and women at 0.001)
**Care as Self Sacrifice subscale**

The total possible score for this subscale was 45. A t-test found there to be a significant difference in the scores for care as self sacrifice between men (M=31.35, SD=6.89) and women (M=27.39, SD=6.61) \( t=(476)=6.03, p=0.00 \). Men reported putting the needs of others before themselves more than the women in the sample.

**Figure 17: Care as Self Sacrifice by Gender**

![Bar chart showing the difference in scores for care as self sacrifice between men and women.](chart)

(*) represents a significant difference between men and women at 0.05

(***) represents a significant difference between men and women at 0.001

**The relationship between self-silencing and psychological distress**

For women, significant positive inter-correlations were found between all STSS subscales. For men, there were significant correlations between all but the Care as Self Sacrifice and Divided Self subscales (see Table 6). Table 6 also presents the correlations among global and subscale STSS and subscale HADS scores for men and women. For both genders, STSS Global Self-Silencing scores were significantly positively associated with both anxiety and depression scores on the HADS. Regression analysis identified that for men, STSS Global scores accounted for 11% of the variance in HADSA and HADSD (\( R^2=.11 \) in both cases). For women, STSS Global scores accounted for 13% and 12% of the variance in HADSA and HADSD respectively (\( R^2=.13 \) and \( R^2=.12 \)). Externalised Self-perception and Divided Self were associated significantly and positively with HADS anxiety and depression score for both men and women. In contrast, Care as Self Sacrifice failed to reach significance with HADS subscales. A gender difference was observed on the correlations between the Silencing the Self and HADS subscales, with significant positive correlations found for women but not for men with respect to anxiety scores.
Table 6: Correlations between self-silencing and psychological distress

<table>
<thead>
<tr>
<th>Variable</th>
<th>Externalized Self-perception</th>
<th>Silencing the Self</th>
<th>Care as Self Sacrifice</th>
<th>Divided Self</th>
<th>Global Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HADS – Anxiety</td>
<td>.43**</td>
<td>.20**</td>
<td>.07</td>
<td>.40**</td>
<td>.34**</td>
</tr>
<tr>
<td>HADS – Depression</td>
<td>.33**</td>
<td>.23**</td>
<td>.10</td>
<td>.40**</td>
<td>.36**</td>
</tr>
<tr>
<td>Silencing the Self Scale (STSS)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Externalized Self-perception</td>
<td>.40**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Silencing the Self</td>
<td></td>
<td>.21**</td>
<td>.50**</td>
<td></td>
<td>.70**</td>
</tr>
<tr>
<td>Care as Self Sacrifice</td>
<td></td>
<td>.54**</td>
<td>.45**</td>
<td></td>
<td>.86**</td>
</tr>
<tr>
<td>Divided Self</td>
<td></td>
<td></td>
<td></td>
<td>.01</td>
<td>.66**</td>
</tr>
<tr>
<td>Men</td>
<td></td>
<td></td>
<td></td>
<td>.65**</td>
<td></td>
</tr>
<tr>
<td>HADS – Anxiety</td>
<td>.41**</td>
<td>.16</td>
<td>.06</td>
<td>.40**</td>
<td>.33**</td>
</tr>
<tr>
<td>HADS – Depression</td>
<td>.30**</td>
<td>.21**</td>
<td>.06</td>
<td>.42**</td>
<td>.33**</td>
</tr>
<tr>
<td>Silencing the Self Scale (STSS)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Externalized Self-perception</td>
<td>.46**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Silencing the Self</td>
<td></td>
<td>.58**</td>
<td></td>
<td></td>
<td>.75**</td>
</tr>
<tr>
<td>Care as Self Sacrifice</td>
<td></td>
<td>.62**</td>
<td></td>
<td></td>
<td>.86**</td>
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<tr>
<td>Divided Self</td>
<td></td>
<td></td>
<td></td>
<td>.67**</td>
<td></td>
</tr>
</tbody>
</table>

*Intercorrelations Between Scores on the STSS Subscales and HADS for Women and Men

** p < .01, two-tailed

Implications of findings

The association between self-silencing and depression found in both a cancer (Kayser et al., 1999) and non-cancer context (Duarte & Thompson, 1999; Gratch et al., 1995; Jack & Dill, 1992; Thompson, 1995; Uebelacker, Courtnagne, & Whisman, 2003; Whiffen et al., 2007) has been confirmed, and the association between self-silencing and anxiety established. However, whilst Global Self Silencing on the STSS was positively correlated with depression and anxiety, men scored higher than women on Global Self-Silencing, and on two facets of self silencing: putting the needs of others before the self (Care as Self Sacrifice), and not expressing their feelings when to do so would cause disagreement (Silencing the Self), a pattern also reported in previous research (Cramer & Thoms, 2003; Duarte & Thompson, 1999; Gratch et al., 1995; Page & Stevens, 1996; Thompson, 1995; Whiffen et al., 2007).

One explanation for this apparent paradox is that the aspects of self-silencing on which men rated highly were not strongly associated with depression and anxiety. In the present study, Care as Self Sacrifice was not correlated with depression or anxiety at all, which confirms the findings of Whiffen et al (2007), who examined self-silencing and marital conflict in a community sample of adult couples. The correlation between Silencing the Self and depression was also weaker than that found on the other subscales, as reported by previous research (Duarte & Thompson, 1999; Whiffen et al., 2007), with no association found with Silencing the Self and anxiety for men. Thus, men may report more self-silencing behaviours, but these behaviours are at best weakly associated with depression, and not associated with anxiety. There is also evidence that self-silencing may be functioning differently for men and
women, as is evidenced by the finding that the Care as Self-Sacrifice and Divided Self subscales were inter-correlated for women, but not for men, as previously reported by Duarte and Thompson (1999). This suggests that women who prioritise the needs of others are putting forward a compliant outer self, whilst their inner self grows angry and hostile, and as a result, experiencing a loss of self, a pattern not seen for men. The qualitative analysis of in-depth interviews (section four) acts to provide insight into these gender differences in self-silencing behaviour, in the specific context of caring for a person with cancer.

**Mediation Analysis: Which Factors Predict Gender Differences in Psychological Distress?**

The purpose of the mediation analysis was to examine which variables predict gender differences in psychological distress. As noted above, according to established criteria for mediation (Baron & Kenny, 1986), a mediating variable between gender and psychological distress is identified as one that shows evidence of both a significant association to the psychological distress variable and significant gender differences in mean scores.

A hierarchical linear regression analysis was conducted to test whether the identified variables were responsible for the full or partial mediation of the gender difference in anxiety. With HADSA scores as the dependent variable, gender was entered in the first block to predict anxiety. ‘Disrupted schedule’, ‘Health Problems’, ‘Silencing the self’, ‘Emotional and spiritual unmet needs’, ‘Identity unmet needs’ and ‘Social Network Unmet Needs’ were all entered in the second block. All variables were centred before entering. The entry of variables in step 2 of the model reduced the significant relationship of gender and anxiety in step 1 to non-significance (see Table 7). ‘Disrupted schedule’, ‘Health problems’, ‘Self-Silencing’ and ‘Emotional and spiritual unmet needs’ together fully mediate the gender difference in anxiety.

**Table 7: Hierarchical Linear Regression Analysis Predicting Anxiety Scores**

<table>
<thead>
<tr>
<th>Variable</th>
<th>( \Delta R^2 )</th>
<th>Final ( \beta )</th>
<th>Final 95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>.02***</td>
<td>.06</td>
<td>[-.18, 1.37]</td>
</tr>
<tr>
<td>Step 2</td>
<td>.32***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disrupted schedule (CRA)</td>
<td>.19***</td>
<td></td>
<td>[0.08, 0.24]</td>
</tr>
<tr>
<td>Health problems (CRA)</td>
<td>.19***</td>
<td></td>
<td>[0.16, 0.46]</td>
</tr>
<tr>
<td>Silencing the self (STSS)</td>
<td>.10**</td>
<td></td>
<td>[0.02, 0.11]</td>
</tr>
<tr>
<td>Emotional and spiritual unmet needs</td>
<td>.26***</td>
<td></td>
<td>[0.17, 0.44]</td>
</tr>
<tr>
<td>Identity unmet needs (PNI)</td>
<td>.07</td>
<td></td>
<td>[-.08, 0.49]</td>
</tr>
<tr>
<td>Social Network Unmet Needs (PNI)</td>
<td>.03</td>
<td></td>
<td>[-.08, 0.52]</td>
</tr>
<tr>
<td>Total Adj. ( R^2 )</td>
<td>.33***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>( N )</td>
<td>467</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Note.** *p < .05, **p < .01, ***p < .001.
A hierarchical linear regression analysis was conducted to test whether the identified variables were responsible for the full or partial mediation of the gender difference in depression. With HADSA scores as the dependent variable, gender was entered in the first block to predict anxiety. ‘Disrupted schedule’, ‘Health Problems’, ‘Silencing the self’, ‘Emotional and spiritual unmet needs’, ‘Identity unmet needs’ and ‘Social Network Unmet Needs’ were all entered in the second block. All variables were centred before entering. The entry of variables in step 2 of the model reduced the significant relationship of gender and depression in step 1 to non-significance (see Table 8). ‘Disrupted schedule’, ‘Health problems’, ‘Self-Silencing’ and ‘Emotional and spiritual unmet needs’ together fully mediate the gender difference in depression.

Table 8: Hierarchical Linear Regression Analysis Predicting Depression

<table>
<thead>
<tr>
<th>Variable</th>
<th>ΔR²</th>
<th>Final β</th>
<th>Final 95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>.01*</td>
<td>.02</td>
<td>[-.53, .92]</td>
</tr>
<tr>
<td>Step 2</td>
<td>.35***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disrupted schedule (CRA)</td>
<td></td>
<td>.23***</td>
<td>[0.11, 0.25]</td>
</tr>
<tr>
<td>Health problems (CRA)</td>
<td></td>
<td>.17***</td>
<td>[0.13, 0.40]</td>
</tr>
<tr>
<td>Silencing the self (STSS)</td>
<td></td>
<td>.14**</td>
<td>[0.04, 0.13]</td>
</tr>
<tr>
<td>Emotional and spiritual unmet Needs (PNI)</td>
<td></td>
<td>.24***</td>
<td>[0.14, 0.40]</td>
</tr>
<tr>
<td>Identity unmet needs (PNI)</td>
<td></td>
<td>.10</td>
<td>[-0.01, 0.54]</td>
</tr>
<tr>
<td>Support network (PNI)</td>
<td></td>
<td>.04</td>
<td>[-0.21, 0.45]</td>
</tr>
<tr>
<td>Total Adj. R²</td>
<td>.36***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>N</td>
<td>467</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note * p < .05. ** p < .01. *** p < .001.

Implications of findings

Gender differences in anxiety and depression are fully explained by the combination of: Disrupted Schedule (CRA), Health Problems (CRA), Emotional and Spiritual Unmet Needs (PNI), and Silencing the Self (STSS).
Summary and conclusions

Women cancer carers report significantly higher levels of depression and anxiety than men carers, confirming previous research. In order to explain this finding, we explored gender differences in a range of confounding variables. Women reported significantly greater burden of care, in relation to Disrupted Schedule, Health Problems, and Lack of Family Support (CRA); significantly more unmet needs, in relation to Emotional and spiritual unmet needs, Identity unmet needs, Practical unmet needs and Support network unmet needs (PNI). Men reported significantly higher levels of Silencing the Self (STSS). In the mediation analysis, gender differences in anxiety and depression were fully explained by the combination of: Disrupted Schedule, Health Problems, Emotional and Spiritual Unmet Needs, and Silencing the Self.
Section Four
An Examination of Gender Differences in the Subjective Experience of Carer Caring

Interviews: Participants and Procedure

One of the limitations of much of the previous research on cancer caring, is that it has used quantitative outcome measures, or content analysis of interviews, which does not facilitate examination of the richness of carers’ experiences of positive aspects of care (Hagedoorn et al., 2008; Ussher & Sandoval, 2008). There has thus been a plea for more interview based research, which can “excavate the contours of the lived experience of cancer care” (Thomas & Morris, 2002, p.181). In this context, the aim of the following section was to examine carers’ accounts of difficult and rewarding aspects of providing cancer care, using a qualitative methodology.

Fifty-three participants (34 women & 19 men) were selected for interview, representing a cross section of cancer types and stages, gender, and relationship with the person with cancer, as reflected in the larger study population. Whilst the mean length of time from diagnosis was statistically greater in the interview sample (see table 9) ($t(472) = -3.59, p = .000$), the median was more comparable (1.5 months survey sample, 5.2 months interview sample). In addition, two focus groups were conducted, one with 3 partners of men with prostate cancer, and one with 8 carers of a person with cancer from the Chinese community. There were a higher percentage of bereaved participants in the interview sample because a number of individuals selected for interview had become bereaved after having completed the questionnaire.

An open ended narrative interview conducted on a face-to-face basis, was used to examine the experience and construction of care, in the context of the broader caring relationship. The interviews were conducted at a venue convenient for the participants, including the University campus, Cancer Council NSW offices, or the participant’s home. Interviewees were offered $25 as a reimbursement for any travel expenses. The interview was audio-taped and lasted approximately 1 hour.

Participants were sent a list of the question areas one week prior to the interview. At the beginning of the interview, participants were told: “today is an opportunity for you to chat to me about your experience as a carer, and to talk a little more in depth about some of the things you said in the questionnaire. The areas we cover will be those mentioned in the letter you received recently”. The interviewer then asked about difficult and rewarding experiences; ability to take time out for self care; support received from family, friends and health professionals; emotional reactions to cancer and cancer caring; and communication of carer needs within the relationship, the focus of the present paper. In accordance with established protocols in qualitative research, sampling was discontinued when information redundancy was reached, and no additional information was forthcoming (Miles & Huberman, 1994).
Table 9: Characteristics for Carer and Person with Cancer, and Carer Characteristics for the Interview Sample

<table>
<thead>
<tr>
<th>Variable</th>
<th>Interview Sub-Sample</th>
<th></th>
<th>M (SD)</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>N</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Informal carer age</td>
<td>52</td>
<td>56.4(12.3)</td>
<td>29 - 85</td>
<td></td>
</tr>
<tr>
<td>Person with cancer age</td>
<td>51</td>
<td>57.0(14.1)</td>
<td>29 - 85</td>
<td></td>
</tr>
<tr>
<td>Years since first diagnosis</td>
<td>51</td>
<td>1.8(3.1)***</td>
<td>1mth – 12yrs</td>
<td></td>
</tr>
<tr>
<td></td>
<td>*** p &lt; .001</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>N</td>
<td>%</td>
<td></td>
</tr>
<tr>
<td>Ethnicity:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aust/White European</td>
<td>50</td>
<td>96.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>2</td>
<td>3.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aboriginal</td>
<td>-</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not stated</td>
<td>-</td>
<td>-</td>
<td></td>
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</tr>
<tr>
<td>Employment status:</td>
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<td></td>
<td></td>
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<tr>
<td>Employed fulltime/part time</td>
<td>22</td>
<td>42.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Temporarily not working</td>
<td>3</td>
<td>5.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>20</td>
<td>38.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home duties</td>
<td>2</td>
<td>3.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
<td>9.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer type:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brain</td>
<td>7</td>
<td>13.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>13</td>
<td>25</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Colorectal/Digestive</td>
<td>6</td>
<td>11.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gynaecological</td>
<td>3</td>
<td>5.8</td>
<td></td>
<td></td>
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<tr>
<td>Haematological</td>
<td>1</td>
<td>1.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Multiple Non-Sexual</td>
<td>1</td>
<td>1.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Multiple Sexual</td>
<td>3</td>
<td>5.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prostrate</td>
<td>6</td>
<td>11.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respiratory</td>
<td>7</td>
<td>13.5</td>
<td></td>
<td></td>
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<tr>
<td>Other</td>
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<td>5.8</td>
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<td></td>
</tr>
<tr>
<td>Missing</td>
<td>2</td>
<td>3.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage of disease:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No longer detectable</td>
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<td>19.2</td>
<td></td>
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</tr>
<tr>
<td>Early</td>
<td>6</td>
<td>11.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Advanced</td>
<td>14</td>
<td>26.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not sure/applicable</td>
<td>11</td>
<td>21.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bereaved</td>
<td>11</td>
<td>21.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationship with patient</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intimate partner</td>
<td>40</td>
<td>76.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child</td>
<td>2</td>
<td>3.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent</td>
<td>4</td>
<td>7.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friend</td>
<td>3</td>
<td>5.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sibling</td>
<td>2</td>
<td>3.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>1.9</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: *“Other” includes: unemployed, student and non-specified; b “Other” includes: Mesothelioma, Pancreatic, Bone, Melanoma, various, each less than 2%
Interview Results

Qualitative analysis

All of the interviews were transcribed verbatim. After transcription, the interviews were independently read by three members of the research team, in order to ascertain the major themes emerging, and to develop a coding frame, based on notions of consistency, commonality, and the function and effects of specific themes. The whole data set was then coded, line by line, by two of the researchers, after which a group meeting was held to discuss any new or unforeseen themes, and to re-evaluate the inclusion of themes which appeared with low frequency. The interpretation of these themes was conducted by a process of reading and re-reading, as well as reference to relevant literature, following established protocols for thematic analysis (Braun & Clarke, 2006). This process follows what Stenner (1993, p114) has termed a ‘thematic decomposition’, a close reading which attempts to separate a given text into coherent themes or narratives which reflect subject positions allocated to, or taken up by, a person (Davies & Harre, 1990). Participants identified positive and negative experiences in relation to the self, the person with cancer, and others. These will be discussed below under the headings: emotional reactions to cancer and caring; self-silencing of carer needs and concerns, difficult aspects of the caring role; and reward in the caring relationship. Changes specific to sexuality and experiences with health professionals are discussed in separate sections.

Emotional reactions to cancer and caring

Many participants gave accounts of difficulties in relation to emotional reactions associated with cancer, including the ‘shock’ they felt when their loved ones received a cancer diagnosis, as well as the depression and anxiety suffered as a result of having to come to terms with not only the diagnosis, but also the caring situation.

Shock

A number of carers (41% of women and 63% of men) said the cancer diagnosis was completely unexpected resulting in feelings of shock. For example, Kay, age 73, who cared for her husband with pancreatic cancer, said she “had no idea” or Jenny, age 37, who also cared for her husband who had brain cancer, said that she thought he had another health problem because “he had no headaches, he had no seizures” and it was only through routine testing that they found out “he had a brain tumour”. When the cancer diagnosis was given, carers spoke of the feelings of being “slightly numb” and “overwhelming” because of “it being such a shock” (Bella), or Andrew, age 55, who cared for his wife with colorectal cancer, said that the “huge shock” of the news required “a while for it to sink in”. Naomi, age 41, who cared for her husband with brain cancer, said she “didn’t know where to go [or] what to do”. It was, as Ed, age 54, who cared for his wife with brain cancer, stated “it [cancer] suddenly had taken my world and turned it upside down”. While these carers spoke of the dramatic and often profound change in their lives, other carers spoke of their need to have time to adjust to the diagnosis and to consider their next step. A female carer in a prostate cancer support group provided the following account.
I know when we got that first diagnosis, I burst into tears and I thought “Oh god, you know I can’t believe this” and he remained calm at that moment. But when we got home we both cried because we thought, you know, this is going to change his life. And you know, had to really think about it. And I got on the phone and started checking all these alternate people because the doctor, immediately right there and then said well we can book you in. And I said “Oh no, no, no do you want to do that straight away?” So it’s really just a matter of taking stock of things and seeing where do we go to next and it certainly is a big shock.

In contrast to the above account, some carers reported succumbing to the pressure exerted by others to make important decisions at a time when they were mentally and emotionally unprepared. Hilary, age 59, who cared for her husband with colorectal cancer, provided the following account:

It was July 2004 that he became ill and was diagnosed with stomach cancer. (We were) advised on a Thursday, had to race up to [suburb] on the Friday and then he was operated on on the Tuesday so we didn’t have much time to even think about it, talk about it, or anything. So it was a lack of information at that time which I, you know, regret.

Unsurprisingly, an aspect of the shock many carers spoke of related to the short amount of time before possible death and the speed of their loved ones’ deterioration. For example, Gary, age 61, who cared for his female partner with respiratory cancer, said she was “given six months to live (...) that was a major shock” or Adam, age 46, who cared for his wife with breast cancer, said “she just went downhill so fast it was amazing”. Perhaps what was most difficult and shocking for the carers was that there was nothing that could be done for their loved ones. For example, Gina, age 59, who cared for her husband with mesothelioma, said “realising there could be no assistance he could get for this type of cancer, I think, was just mind-blowing” or when Connie, age 70, who cared for her husband with prostate cancer, “realised that this was actually terminal and that they were going to do what they could but it was sort of towards the end of the end”, it was “traumatic”.

**Depression**

The upheaval caused by cancer in people’s lives was evident in carers’ accounts, and some (41% of women and 47% of men) spoke specifically about the depression they experienced because of this. For example, Donna, age 42, caring for her mother with gynaecological cancer, provided an account in which she described her depression as “situational” because she “wasn’t a depressed sort of character”. Similarly, a female carer in a prostate cancer support group said that she “had a bit of depression with all that had happened”. Interestingly, Denis, age 43, who cared for a female friend with gynaecological cancer, said that he “gone through depression without actually analysing it”, for he had “never been to a doctor and been diagnosed with depression” but acknowledged that he “just laid on the lounge and just couldn’t do nothing”
because of his emotional state. The constant worry experienced by carers was articulated by the wife of a man with pancreatic cancer in a support group specifically for Chinese carers.

> Well, if I can’t sleep, I cry and I feel very upset. Well, and that situation continues and that somehow affects my already stomach reflux. Well I feel so, perhaps this is the reason why my stomach is not in such a good condition so far. I can’t tackle this at night, there’s no one to talk to me at night time and even when I try, I try to suppress the sounds from my crying ’cause I don’t want to wake my husband. I know that all these together wears me down and I’m so down hearted.

Many carers spoke of the feeling of uncertainty with which they lived in their everyday lives, and this feeling of uncertainty was attributed to many concerns relating to possible health deterioration and death. Andrew offered the following account, which illustrated the emotions experienced by many carers.

> Well, you just sort of feel empty and desolate sort of thing. To think that this thing is happening to you or to your wife and the outcome could be death. You try not to think about that possibility but I mean it just keeps coming up and it comes back to you every now and then. In six months time your wife could be dead so when you think about those things occasionally obviously that’s pretty devastating and I felt quite despairing at times.

The absence of hope was a debilitating emotional experience particularly when treatment options were limited and the possibility of their loved ones recovering from cancer was remote. For example, Leslie, age 62, who cared for her husband with prostate cancer, said that “there wasn’t like anything to hope for”, or Judith, who also cared for her husband, recounted her experience of “being so helpless sitting there knowing that you can’t do anything is the worst feeling”. Similarly, Evelyn, age 65, who cared for her daughter with haematological cancer, spoke of the “nights when [she] cried and felt absolutely hopeless” because the cancer “was stronger than both of [them] and that it would win in the end”. It was thus not surprising that many carers mentioned that they used anti-depressant medication as a way of managing their emotional state, even if there was some hesitation about such medication. Paul, age 45, who cared for his wife with breast cancer, offered an account that illustrates this:

> I’ve always had slightly maudlin or depressive or negative tendencies so when this happened [cancer], I went and got some antidepressants but they take a few months to work and in the meantime they just kind of screw around with your head a bit more. They’re ok, I think they keep me relatively stable but I can’t sleep unless I take sleeping pills (...) I don’t really see myself coming off antidepressants (...) Yeah. I think they’re keeping me relatively normal. I think I’m only being held in place by medication.
Anxiety

The constant worry, the unpredictability of the cancer illness trajectory and the fear of their loved ones’ death, were also regarded by many carers as reasons for their anxiety (reported by 53% of women and 42% of men). For example, Kathryn, age 67, who cared for her husband with brain cancer, said that because caring for him was a “24 hour a day job”, the constant worry and demands meant that she “live[d] on [her] nerves”. Jessie, age 36, who cared for her female partner with breast cancer, said that because the situation was, at times, unclear and she did not know what was happening about her partner’s health, it was “the most stressful time”. Lesley, age 62, who cared for her husband with mesothelioma, offered an account in which she referred to the “anxious sessions” when she would “wake up at three o’clock in the morning or in the middle of the night” thus highlighting the prevalent anxiety when caring for a loved one with cancer. More troubling for carers were the fear and anxiety related to the possibility of their loved ones’ death. Jenny made clear that “it was completely stressful to try and deal with the fact that I might lose my husband”.

For some carers, the caring experience has left an indelible mark on their psychological health. For example, Tessa, age 30, provided a detailed account of the anxiety she suffered as a result of caring for her mother with breast cancer and the effects of anxiety and depression she continued to experience many years after her mother’s death.

I’ve actually had a lot of therapy as in seen a lot of psychologists to treat my anxiety because of this [caring for mother]. And I just have this pattern of having this horrible kind of anxiety on Sunday nights and eventually we worked out that it was me, because for four years every Sunday night was when I’d go back up there [to care for mother] and have this horrible anxiety (...) it’s been nearly ten years now, well eight or something years so, yeah, I’m still, I’m still on antidepressants. I have to stay on them for the rest of my life basically because I keep relapsing every time I stop taking them, keep having panic attacks again. And I’ve been seeing psychologists, psychiatrists, counsellors, since that time so it’s still something that I have to put effort into controlling (...) there was no family history of depression or anxiety or panic attacks. It seems to be a result of the experience which I know is certainly quite common.

Anger and frustration about the situation

Many carers (50% of women and 58% of men) reported feeling angry and frustrated about the impact of cancer on their lives. For example, Brian, age 57, who spoke of everything changing forever because of his wife’s haematological cancer, said he “hated” having to witness her “continual degeneration” and did not “think anyone can realise how much [he] hated it”. For other carers, the situation of their loved ones having cancer or having to care made them angry and distressed. For example, a female carer in a prostate cancer support group said that she was “angry at the type of diagnosis because [he] is such a good man…and [she] thought he doesn’t deserve
this” or Kay saying that she was “distressed” and “angry that [he] has got cancer” as “it’s altered our lives”. Donna was more circumspect in clarifying how she felt about the situation as is illustrated by the following account.

I think it’s probably, I had it, it was probably as good as it was going to get. Like it’s a hard situation so you can’t, I don’t think you can say, ok we’re going to do it, all of this, and you’ll be fine, it’d be easy, you’ll actually really enjoy ‘cause I don’t think you’re going to get that so there’s not going to be any situation where you’re going to say, well that’s fine if you just do this and this and this, it’ll be alright. So you’ve got to recognise, it’s tough.

Interestingly, Sean, age 64, spoke of the usefulness of targeting his anger directly at his wife’s breast cancer as it improved the quality of his relationship with his partner.

So we now tell the cancer and we’re very angry with the cancer and we express that and that’s very valuable. And, you know, we both get tired and we both get stressed and we don’t blame each other anymore. We used to blame each other to some extent but now, it’s not – it’s the cancer that we blame.

Implications of findings

These accounts confirm previous reports that cancer carers experience high rates of anxiety, anger and depression (Hagedoorn et al., 2000; Haley et al., 2001; Payne et al., 1999), and provide explanation for why this is so. This reinforces the need for psychological support for carers, to alleviate this emotional distress, and to support the person with cancer, as the psychological well-being of people with cancer is also closely associated with the well-being of their primary carer (Baider & Denour, 1999). Equally, the psychological and physical wellbeing of people with cancer is closely associated with the level of support and care they receive from informal carers (Brown & Stetz, 1999), with good support leading to positive outcomes. Carers who are depressed and anxious will find it more difficult to provide such support.

Recognition that caring has negative consequences for carers, and that depression and anxiety are common, has raised the question of why informal carers who find caring stressful continue to provide care, and what it is that keeps them there (Coyle, 2004). In our interviews participants provided two explanations for this: that caring was an obligation, or a choice.

Caring as obligation

Approximately one quarter of the interviewees (26% of women and 21% of men) offered accounts in which taking up the caring role was not positioned as altogether their choice. Cheryl, age 50, caring for her husband with haematological cancer, said she felt she was expected to care for her husband, for she was told “indirectly by another manager that I shouldn’t be at work, I should be at home staying with my husband”. Tessa spoke of her grandparents who expected her to care for her mother as
it was her “duty as the eldest child” and felt they “pushed me into it”. Although she was “pushed” into caring for her mother, she conceded that “it was the right thing for me to do but at the time, it didn’t feel like it was 100% my choice”. Similarly, Diana said that even though she “didn’t want to actually go down the road [caring]” for her husband, she did so because she said she could “never turn my back on him. Because there…who else is there?” Naomi said that the caring experience was “really horrible”, but she did not feel she had a choice. Maxine, age 67, who had cared for her husband who had multiple cancers, further emphasised this point in the following account.

*And I don’t think we really fully understand the difficulties that carers actually have caring for people. And carers, sometimes it’s not their choice, it is not their choice and they’re lumbered with this and where do they go?*

In this context, it is understandable that some carers (21% of women and 11% of men) had thoughts that appeared to be ambivalent and paradoxical with respect to their caring roles. For example, Sarah, age 57, spoke of the difficulties in caring for her husband who had pancreatic cancer, and said that at times she “wish[ed] it was over, and then other days you…you’re glad that you’ve got what you’ve got”. Sarah was not alone in this way of thinking, for Stephanie, age 56, who cared for her sister with breast cancer, spoke of “want[ing] this [caring] to end [because I] can’t deal with this anymore” and Alan, age 47, who cared for his mother with colorectal cancer, said that even though his mother’s death would be distressing, he was “looking forward to having [his] life back”.

It could also be interpreted from these accounts that there was an imperative to provide the necessary care, as has been suggested by previous research (Stajduhar, 2003). However, the sense of obligation to care is not as negative as it appears. Many participants in the present study experienced a sense of reward from “doing something good”, or meeting cultural expectations of the “right thing” to do, supporting previous findings of informal cancer carers finding satisfaction in being able to “fulfil social obligations” (Zapart, Kenny, Hall, Servis, & Wiley, 2007, p.105). At the same time, there were many accounts from carers that offered a positive perspective about taking up the caring role.

**Caring by choice**

Fifty percent of female carers and 16% of male carers gave accounts where caring was regarded as a positive choice. Notwithstanding the difficulties and challenges associated with caring, Adam, age 46, caring for his wife with breast cancer, said he had wanted to provide all the necessary care because she “was my wife and I wanted to do everything…even right at the end”. Similarly, Janice, age 68, who cared for her husband with brain cancer, confirmed that she was “quite happy to have him [her husband] here [at home], and look after him, and do everything with him”. For some carers, the decision to take up the caring role was motivated by not wanting their loved ones to be cared for in institutions. For example, Carol, age 64, said her mother who had haematological cancer “would have had to go somewhere to be cared for and [she] wasn’t prepared to let that happen”. For other carers, the decision to care was not an issue that required deliberation as the answer was obvious. Thus Denis, age 43, who cared for a female friend with gynaecological cancer, said that he did not “feel
obligated to help, you just help because you can”. Equally, while Anne, age 56, recognised the challenges she faced when caring for her husband with brain cancer, taking on this role was positioned as the “right way” as illustrated in the following account.

I’m saying how hard and difficult everything was, and it was but I wouldn’t have not done that…ever…you know, I would never have decided that wasn’t the best thing to do, for all of us. For our family, …it was definitely the right way for us, you know…to deal with all of this.

In a similar vein, Olivia, age 62, caring for a friend with multiple cancers, said she “couldn’t, could not possibly have done anything else, we could not have done anything else except do this for her because she was very special to us both.” Judith, age 57, caring for her husband with respiratory cancer, said that “you have to do it, you have to look after him, he’s been your husband for over 30 years, and I knew, I wanted to do that”. An account which highlighted the imperative nature of the healthy partner providing care was offered by John, age 31, who cared for his partner with breast cancer, when he said the following.

I’d never even considered myself as, like a carer, you know. You are that person’s partner and you know, in any situation, you look out for them. So it wasn’t really any different. …I guess because of that, I didn’t consider anything inconvenient, you know, taking time out for whatever…she is the most important, so it doesn’t matter what else was on, it’s just not inconvenient, it’s just something that you are happy to do.

Whilst carers such as John spoke of their willingness to care, factors such as the strength of their relationship, and their ability to talk to each other openly and effectively, complemented the carers’ willingness and thus enabled them to successfully care for their loved ones. Self-silencing of carer needs was thus a factor that could lead to distress, as is explored below.

**Self-silencing carer needs and concerns**

In the interviews, the majority of participants reported that they did not express their own needs and concerns to the person with cancer. These concerns were extensive, including depression, anxiety, shock, loneliness, exhaustion, physical health problems, feelings of over-responsibility, and sexual needs. This particular pattern of self-silencing was explained in a number of ways, outlined in the following sub-themes: prioritising the needs of the patient; silence as a requisite for coping; men don’t express vulnerability; and silencing anger to avoid conflict.

**Prioritising the needs of the patient**

The most common explanation, adopted equal numbers of women and men cancer carers, was that the needs and concerns of the person with cancer should be prioritised
and made the focus. As Ellen, age 63 told us about her relationship with her friend with multiple cancers “she didn’t need to hear anything about me, it was all about her at that point”. Or as Sally, age 60, said about her husband with haematological cancer “I tried to put all my feelings underground because I felt he needed to be the focus at that point so I really, I suppose I went into limbo land”. Implicit in these accounts was a comparison of the gravity or magnitude of the concerns of the person with cancer compared with those of the carer, with the carer always self-positioned as secondary. As Adam, age 46, commented about his wife with breast cancer, “My wife’s passing away, my wife’s dying, I mean, I don’t care about me”. He added that he could not “see a relevance” in even thinking about his own needs when his wife had breast cancer. In a similar vein, Jenny, age 29, said of her partner with brain cancer “I didn’t ever tell him (how bad I was coping) because I think for me I didn’t want to burden him, you know, he was dealing with the whole of his life flashing before his eyes”. Sean, age 62, gave a comparable account of his caring for his wife with breast cancer.

_The expressing needs and concerns, I meter everything I say to C. She’s going through an even more personal experience than I am. She’s facing her own death and I mean we all know that life’s a terminal disease but, you know, she doesn’t know how long she’s got to live and I don’t want to impose anymore on her with regard to my needs and concerns than is absolutely necessary._

These are accounts of a desire to protect the person with cancer from the ‘burden’ of carer concerns. In particular, carers didn’t want the person with cancer to be aware of the burden of care. As Donna, age 42, told us, with reference to her mother with gynaecological cancer, “I probably didn’t want her to worry at all about the fact that I was having a hard time doing it (caring)”. The majority of participants positioned this prioritising of the needs of the patient as a choice, a sacrifice which was made willingly as part of the caring role. As Ellen said, “I was so glad that I was able to do it. I’d never really questioned it… it was a gift to me to be able to do it”, or as Adam commented “she was my wife and I wanted to do everything”. However, this experience did exact an emotional cost for the carers, often resulting in feelings of isolation and loneliness, a major theme within the interviews. Bella’s (age 36), description of her loneliness in caring for her husband with prostrate cancer illustrates this.

_It was a harrowing, very lonely experience lying in bed with him at night knowing, well he’s a cancer patient, I’m his wife but I can’t talk to him about really how I feel because I wasn’t going to be here to dump all my stuff on him._

This pattern of self-silencing was often marked by significant self-sacrifice on the part of the carer, involving negation of their own physical and psychological needs, in order to put the needs of the patient first. Whilst this pattern of behaviour is comparable to Jack’s (1991) description of Care as Self-Sacrifice, in the present study does not appear to be primarily motivated by a desire to secure attachments, born out of feelings of insecurity, as Jack (1991) and others (Duarte & Thompson, 1999; Thompson, 1995) suggest. Rather, it is positioned by participants as a context specific choice to prioritise the needs of the person with cancer, a sacrifice that is made willingly as part of the cancer caring role. A socially sanctioned and valued justification was therefore provided for this self-sacrifice, which may account for this facet of self-silencing not being associated with depression. This is supported by
participant accounts of self-sacrifice being a privilege, confirming previous reports that cancer caring is experienced as a “gift” (Grbich, Parker, & Maddocks, 2001a, p.33), or an “honour” (Sinding, 2003, p.157). This particular form of self-sacrifice may also reflect patterns of behaviour which become normalised in long term relationships without negative psychological consequences, as is suggested by the findings of Whiffen et al (2007).

**Silencing feelings as a requisite for coping**

A second explanation for the self-silencing of carer needs was that it was a requisite for coping – an explanation much more common in female carers’ than in male carers’ account. These accounts described the suppression of carer needs as a necessity, partly because the caring role left no space for their concerns. As James, age 46, told us, with reference to caring for his wife with advanced breast cancer, “I can’t allow myself to get all stressed up over it. Because if I… who’s going to look after me, when I get crook (sick)” As a male participant, James was an exception, because the majority of accounts in this sub-theme were from women. There was a strong sense of obligation in these accounts, with self-silencing described as an inevitable aspect of the caring role. This is illustrated by Diana (age 44) and Jean (age 61), respectively, both caring for husbands with advanced prostate cancer, “I’m not allowed to show any sign of weakness”, “I had to continue, I didn’t have a choice… I’d sort of gloss over it (feelings), I mean so I was coping”. This silencing of their own needs was positioned as a normal aspect of the way they coped with life’s responsibilities. Jean said “I’m from the old school, you sort of… life went on no matter what, and you just had to”, and Diana said “being the strongest daughter and being the responsible one… No, Diana, you must be strong and you must carry on.” Again, this was described as difficult for the carer, as Olivia, age 62, told us when describing caring for her friend with respiratory and bowel cancer.

*The difficult part was having to help, having to control myself and help people cope. Right? So there were people that, you just had, you can’t just go around weeping and wailing and gnashing your teeth and all of that sort of stuff, that wasn’t the way M. was doing it, that meant it wasn’t the way I was doing it and I just had to help people cope.*

Similarly, Diana said “I just think the last four years have really taken their toll on me …I haven’t coped with this well and I… I’m very short-fused.” In many of the accounts of self-silencing in order to cope, participants talked of the importance of being seen to be coping by others, implicitly evoking external evaluation or judgement. Jenny’s account of being “brave” when caring for her husband with brain cancer exemplified this.

*things just started to build up and I think I tried to be so brave at work and I tried to be so brave in front of H. and in front of my friends….I was so determined to help H. and to look like I was doing a good job as a carer and a wife that, yeah, I took on way too much (laughs).*
At the same time, many participants talked of not receiving support from others, because of the assumption they were coping. As Diana told us “sometimes people don’t even stop and think, ‘Well, I wonder how poor Diana is actually coping?’ And bothering to ask”. Friends and family were also said to not look beneath the surface and see that the carer might need support. Hilary, age 59, who was caring for her husband with bowel cancer, described her grown up children thus: “They just think, ‘Oh, you know, everything’s all right. Dad’s got over this. Mum’s cooking for dad. Yeah, he’s eating. There’s nothing more’. That’s my impression”. Maintaining a façade of coping thus had further consequences, in terms of carer isolation and lack of support from others.

The finding that accounts of silencing feelings in order to cope, often associated with awareness of the evaluation of others, were much more common in women than in men, may reflect the “self-policing” (Foucault, 1979) which is central to women’s gendered role, linked to constructions of idealised femininity, in particular to the positioning of women as ‘natural’ carers (O’Grady, 2005; Seigfried, 1989), or better suited to the caring role than men (Collins & Jones, 1997). Michel Foucault (1979) described self-policing as the modern replacement for external, authoritarian, methods of surveillance and social control, where discipline is instilled within, and punishment, if we waver from the norm, self-induced. As Gordon (1980, p.155) comments: “There is no need for arms, physical violence, material constraints. Just a gaze. An inspecting gaze, a gaze which each individual under its weight will end by interiorising to the point that he is his own overseer, each individual thus exercising this surveillance over, and against, himself”. Indeed, it has been argued that self-policing practices are now so ingrained in the Western psyche that they are taken for granted, scarcely visible to conscious awareness, making them all the more effective as a means of social regulation (Foucault, 1979).

Gendered self-policing practices can lead to self-renunciation and over-responsibility on the part of women, as they attempt to emulate an idealised version of femininity (Strickling, 1988; Ussher, 2004). This is evidenced by previous women cancer carers in the present study positioning themselves as all encompassing expert carers, leading to over-responsibility and self-sacrifice, in contrast to men carers who positioned caring as a competency task, leading to feelings of self-mastery (Ussher & Sandoval, 2008). This gender difference in self-policing partly results from external factors, as women carers generally have higher expectations placed upon them (Soothill et al., 2003). However, it is also associated with women internalising the notion of the ‘caring self’, and judging themselves as failures if they cannot provide the level of care expected (O’Grady, 2005; Ussher, 2006). Forssen, Carlstedt and Mortberg (2005), in their research on elderly women carers in Sweden, have described this as ‘compulsive sensitivity’, an inner demand to take responsibility and put the needs of others before the self, which can lead to distress, which is then blamed on the self. It has been suggested that the higher rates of depression reported by women cancer carers could be explained by women having to live up to these high standards of caring and coping, in contrast to men carers who perform a role which is not expected of them, and thus experience a greater sense of reward as a result (Hagedoorn et al., 2000).

This is reflected in the present study in accounts of women positioning themselves as having ‘no option’ but to continue caring, regardless of the physical or psychological
cost to themselves, and in accounts of guilt or anger in response to feeling overwhelmed or wishing it was over, suggesting that even the thought of abnegating care was problematic for women carers, as has been previously reported in studies of women carers of dementia sufferers (Collins & Jones, 1997). It has also been reported that feelings of failure in relation to informal cancer care are associated with distress in women, but not men (Hagedoorn et al., 2002), providing some explanation for the higher rates of depression and anxiety reported by women carers in the present study.

Men don’t express vulnerability

The third explanation for the self-silencing of carer needs or concerns, given by a number of men participants, was that they never express their vulnerability, and why should they behave differently in the context of cancer caring. Gary, age 61, told us he had never expressed his feelings to his partner, who had recently died of respiratory cancer, either before or after her cancer diagnosis. Brian, age 57, caring for his wife with pancreatic cancer, told us that he “didn’t want to” discuss his feelings with her: “I couldn’t see any point in that. I mean, no, no, it didn’t even cross me mind”. He justified his behaviour by positioning it as normal for men. “No. I’m fella, I’m not a girl. It’s different for men, I mean it’s totally different for men”. Drawing on similar constructions of stoic masculinity, Paul, age 45, who was caring for his wife with advanced breast cancer, described talking about feelings, or asking for support, as “an admission of weakness”. Lawrence, age 63, was regretful that he didn’t have a more open pattern of communication with his sister, who had multiple cancers. He positioned their avoidance of “sloppy” conversation as “hard”, but somehow inevitable because they were siblings: “You try and bottle them up and don’t show them (emotions) but it’s one of them things.”

A number of men carers talked of not only silencing their own needs, but of also putting up a positive front in order to facilitate coping. This was partly explained as a habitual pattern, as is evidenced by Denis (age 43) who gave an account of “always smiling” when caring for his friend with gynaecological cancer: “I suppose when stuff like that happens then sadness creeps in and you don’t want it to, you try to keep it back at the door, stay away, if you see what I mean”. The other explanation given for putting up a positive front was to protect the person with cancer, rallying them round in the face of despair. As Ed, age 54, told us “you drag everything you can that’s positive … that was basically my major job, to keep her spirits up. And even when you didn’t feel like it you felt you had to convince her that cancer is just a word not a sentence”. In a similar vein, Adam, caring for his wife with breast cancer, said “I would always try and get a positive spin on things and I wouldn’t let her go to sleep at night time thinking negative.” He described his experience as a soccer coach as “training” for his caring role, saying “I’ve always managed to get a positive out of (things)”. Many of the women carers also talked of the male patient not being willing to discuss his feelings, and this being the reason for the absence of emotional communication in the relationship. Margaret, age 71, described her husband who had bowel, brain and lung cancer, as “not being a person to express his emotions very much, he wouldn’t say much about it, I think he felt much more about it than he ever said about it”. Similarly, Maxine, said she “would try to open up the conversation”, with her husband but he “was not that sort of person…he was not a person who would dwell
on what had happened to him, no. So I mean we didn’t have those (conversations)”. Maxine commented that the fact her husband “didn’t need to discuss things…was harder for me than for him”. Kay, age 73, tried to find out how her husband with pancreatic cancer was feeling, and he would simply say “‘oh I’m good’, and that’s the end of the conversation.” She described this as “a man thing”, concluding “I think men don’t like to think that they are no longer in charge, especially of their own body”. This reluctance of men patients to discuss emotions functioned to silence any discussion of carer needs and concerns. As Hilary told us:

*Interviewer:* Did he ever ask you how you were -- how you were doing?

*Hilary:* No. No. And through those early stages I didn’t know how he was feeling. He wouldn’t talk much. There was one night we actually did start to talk but he just broke down and he said, “Oh, don’t” -- I can’t remember what he said now. It was like, “Oh, don’t say that”, or something. I don’t know, I can’t remember. So I think after that I just -- I just clammed up and I was really frightened to bring anything up at all.

Accounts of male carers, or male patients, never expressing needs or feelings, suppressing vulnerability because it is unmanly, or putting up a positive front, draw on hegemonic discourses of masculinity, wherein emotional expression is positioned as weakness (Batty, 2006; Edley & Wetherell, 1995). Thus, boys are socialised to be strong and courageous, and to suppress emotion or vulnerability in the face of stress (Felsten, 1998), with self-silencing occurring in reaction these social norms (Duarte & Thompson, 1999). Men may also not develop the emotional vocabulary to communicate relational and emotional needs, and thus self-silencing becomes their default option (Gratch et al., 1995). This stands in contrast to women who generally do have the emotional vocabulary to express their needs, but self-silence to achieve connectedness with others (Kaplan, 1986), or to live up to culturally constructed ideals of coping and competent femininity (Ussher, 2004), as discussed above. This provides some explanation for the finding that the Care as Self-Sacrifice and Divided Self Subscales on the STSS were inter-correlated for women, but not for men in the present study, as self-silencing is normalised and expected for men, and thus does not lead to anger or loss of self. The discovery of an ‘Autonomy/Concealment’ factor on the STSS for men (Remen et al., 2002), reflecting a tendency for self-sufficiency and concealment of potentially undesirable aspects of the self from one’s partner, has resonance with men’s accounts of self-silencing to conceal vulnerability in the present study, and is a coping strategy also reported in previous research with men cancer carers (Lethborg, Kissane, & Burns, 2003).

**Silencing anger to avoid conflict**

The final sub-theme within accounts of carer self-silencing in relation to the person with cancer concerned the silencing of carer anger, reported by equal numbers of men and women. Participants gave accounts of feeling angry about a range of issues, including lack of support, lack of time for self-care, relationship conflicts, patient behaviour (such as refusal to eat food or accept external help), and decline in sexual activity within the relationship. The primary reason given for self-silencing in relation to anger was to avoid conflict in the relationship, or avoid upsetting the person with cancer, even if they were being “difficult”. As James said, “I feel very
angry. I feel like, to just explode, yeah. And really just lash out at her. But I know I can’t because that would just make it even worse. So I just hold my tongue and just… just cop the abuse from her.” Gary gave a similar account: “I can’t win, you know. I just have… All I can do is just be here, and you know, be a punching bag for a little while longer. You know what I mean?”

All of the carers said that this silencing of anger was a change in their normal pattern of responding to the person with cancer. For example, Kay described her inability to retaliate towards her husband as “frustrating”.

*He can flare up for no reason, well I don’t think it’s a reason. Well I have to walk away from that, I can’t retaliate. There’s absolutely no point, I mean he’s not responsible for what he’s saying and so there’s no point in me retaliating. Now that’s frustrating because you think you have every right to retaliate. And under normal circumstances you probably would.*

Acceptance that the person with cancer might be moody or angry because of their illness, and that tolerance on the part of the carer was required, was a frequent retort in the interviews. This is illustrated by the comments of Paul (age 45) and Cheryl (age 50), who cared for partners with breast and haematological cancer, respectively “Yeah well she takes it out on me and, which I think is pretty normal”; “When he got angry and that was okay because I thought well that’s normal”. The person with cancer was thus exonerated from behaviours which would normally not have been accepted. Melanie (age 52) described the “mood swings” of her husband with prostate cancer as analogous to a woman with premenstrual syndrome, which functioned to absolve him from responsibility, because he is “not really in control of it”. She told us that her husband would get angry at her for no reason, which meant that she had to “walk a fine line of when do you actually snap and get angry back or just think, just bite your tongue and don’t cause a big argument and that sort of thing”.

Melanie’s account suggests she didn’t always repress her anger. If she felt her husband had crossed a line and had become “abusive”, she did “snap and get angry back”. This suggests a conscious decision to stop self-silencing and let anger out. In other accounts, carers talked of expressing anger or irritation in a less controlled way, such as when Naomi described “losing patience” with her husband who had brain cancer. “You sort of try and be patient but then you lose patience. It was always over the children, all our issues were always over the children”. A number of carers told us they felt guilty if they failed to self-silence anger. Alan described his experience of caring for his mother thus. “So you get angry, you start to yell at her and at the same time, after a few minutes you realise, “why did I do that?” and you kind of like regret it… I felt guilty that I did it”. However, Alan went on to justify his behaviour by saying, “but at the same time I realised I shouldn’t have felt guilty cause I had to let go of my emotion”. Other carers talked of justifying their anger to the person with cancer in an attempt to assuage guilt, as is evidenced by the account of David, age 62, whose wife had breast cancer. “Sometimes when you become angry you tend to feel guilty and not really good afterwards …and just have to comfort her or to explain to her that I’m not really good the way I am and I’ve got my own feelings”.

A number of participants reported that when they openly expressed anger or irritation, the person with cancer would evoke feelings of guilt in an attempt to silence them. As
Paul told us “sometimes I say ‘you’re being unreasonable’. And then her attitude would be, ‘I’m being unreasonable, I’m the one with cancer, what’s your problem’”, or as Gay, age 54, described her husband with brain cancer:

*I still have to bear my husband’s bad temper. He always uses one thing to speak against me, “I have no time left, not much time left so...” Because of that response from him, I have to suppress whatever my feelings are I have inside me.*

The self-silencing of the carer was thus maintained within the relationship, through the comments of the person with cancer. These accounts of carers silencing anger towards the person with cancer to avoid conflict are analogous to Jack’s (1991; 2001) description of Silencing the Self. Both men and women carers described consciously suppressing anger which they would normally express because they positioned the person with cancer as vulnerable, with any difficult or argumentative behaviour attributed to the illness, which functioned to excuse it. As noted above, in the statistical analysis, Silencing the Self was significantly associated with depression, confirming previous research (Duarte & Thompson, 1999; Jack, 2001; Thompson, 1995) and participant accounts in the interviews bear testimony to the personal cost of silently bearing the brunt of patient anger or frustration, and of feeling guilty if they expressed anger. Accounts of the person with cancer eliciting guilt if the carer expressed anger demonstrate that self-silencing occurs in the context of a relational interaction, influenced by the responses of significant others. This also confirms that cancer is as Kayser et al (2007) described, a “we-disease”, a dyadic interaction with both parties in the carer-patient dyad acting to influence each others attempts to process and cope with the illness (Badr & Carmack Taylor, 2006).

The majority of participants who gave accounts of suppressed anger were partners of the person with cancer, who described positioning the person with cancer as a ‘patient’ rather than a partner. This shift in positioning in the context of cancer can have a significant impact on the relationship, leading to reductions in intimacy and sexuality (Gilbert, Ussher, & Perz, 2010; Hawkins, Ussher, Gilbert, Perz, Sandoval, & Sundquist, 2009), which in turn can lead to or exacerbate distress (Foy & Rose, 2001). Previous research has reported that the avoidance of communication results in lower relationship satisfaction for couples living with cancer (Manne et al., 2006; Ptacek, Pierce, & Ptacek, 2002). The shift to a carer-patient positioning may be one explanation for this finding. Whilst both women and men talked of expressing anger, it was an experience more commonly reported by men. This may be because anger is positioned as unacceptable for women within idealised constructions of femininity (Ussher, 2006), resulting in women carers being less likely to describe their emotional reactions in such a manner within an interview. Men were also more likely to give accounts of assuaging guilt through justifying their anger, which may reflect the positioning of anger as a normal or expected aspect of masculinity (Edley & Wetherell, 1995). However, a weakness of the present study was that anger was not assessed directly. This would be a fruitful avenue for exploration in future research.
Counter-narrative: Open expression of carer emotions

Self-silencing of carer needs or anger, accounts of guilt following the expression of anger, or patient refusal to listen to carer concerns, was not universally found across all of the interviews. A number of participants, 26% of the interview sample, gave accounts of openly expressing their feelings to the person with cancer, and of this being a positive experience within their relationship. For example, Coral, age 55, told us how she broke her self-silencing with her husband who had prostate cancer some years ago, which led to a pattern of open communication between the couple which they still enjoyed.

I remember a couple of years ago, hearing A. talking to one of the children on the phone and he said ‘Oh Coral’s fine, she’s coping wonderfully well’ and I never ever shout, I never swear but I came down the hall screaming at the top of my lungs ‘I am not bloody fine, I am falling apart. How dare you, how dare you tell the children I am coping fine.’ Well that’s the first he knew.

Some participants talked of having valued open communication in their relationship prior to cancer, which continued during their time as a carer, allowing their needs or concerns to be expressed. As June, age 42, said, of her relationship with her husband with prostate cancer “we just have a really good open communication… an ability to have really good open communication so nothing is taboo. We just say what’s on our minds and that’s worked out well for us. So it’s good in that respect”. Jenny, age 29, gave a similar account of her relationship with her husband with brain cancer “We always had really good communication before this happened and I think that’s been the main thing, that we’ve really made an effort to keep that going”. A number of participants positioned open communication as central to their ability to cope with cancer, as Marcus, age 47, told us of caring for his wife with breast cancer.

We could talk to each other. We’ve always had a very open sort of thing. One of the main factors of our marriage or relationship is that we can communicate, we’ve got excellent communication between us. And because of that we’ve had a very good marriage and because of the communication we were able to overcome all obstacles during her treatment and during her illness.

Conversely, there were accounts of couples having to learn to talk openly to each other since the advent of cancer, which was described as being of benefit to the relationship. As Myra, age 63, caring for her husband with lung cancer, told us, “after this illness we have more time to sit together to talk to each other and to share our feelings. So we listen to the other, we listen to each other. So actually our relationship becomes better”. Similarly Paul told us, “E and I, we’ve sorted out a few issues over the last month or six weeks or whatever. In some ways I feel closer to E…than I have been for some time”.

In a similar vein, many carers (18% of women and 37% of men) provided accounts which illustrated the importance of communication in resolving difficulties arising from cancer and caring. For example, as Marcus illustrated in the following account –
We could talk to each other. We’ve always had a very open sort of thing. One of the main factors of our marriage or relationship is that we can communicate. We’ve got excellent communication between us. And because of that we’ve had a very good marriage and because of the communication we were able to overcome all obstacles during her treatment and during her illness.

Some carers also noted how being open and honest facilitated a level of trust that was valuable in the caring context. For example, Olivia, who cared for her friend, said that they “had a communication level that didn’t necessarily require words and she would tolerate pushiness from me that she wouldn’t tolerate from anybody else”. Other carers, such as Adam, who cared for his wife, said that there was “just trust” between them in terms of what he needed to do for her. This was affirmed by Olga, age 54, who said she and her male partner with renal cancer “could talk about everything”, and perhaps it was due to their openness and honesty to each other, she was able to care for him because “there was total trust there”.

These accounts of carers continuing good communication, or experiencing improved communication following cancer, and of experiencing a closer relationship with the person with cancer as a result, stand as testimony to the importance of addressing self-silencing through psycho-social interventions in the field of cancer (Badr & Taylor, 2008). Previous researchers have also reported that open communication in the context of cancer can function to bring couples closer (Dorval et al., 2005), result in a more intimate relationship (Manne et al., 2004a), or emotional growth (Manne et al., 2004b). The present study suggests that this may also be the case for non-couple carer-patient dyads.

**Implications of findings**

All of the participants in the present study had positive intentions in suppressing their own emotional needs or anger – the desire to prioritise the needs of the person with cancer, or to protect them from burden or conflict, paralleling the findings of previous research on protective buffering or avoidance of emotional discussion in couples living with cancer (Badr & Carmack Taylor, 2006; Kayser et al., 2007). However, the significant association of self-silencing with depression and anxiety confirms that it is not an adaptive behaviour for the carer, supporting previous reports that avoidance of emotional discussion in couples living with cancer is detrimental to coping and to mental health (Kayser et al., 2007; Manne et al., 2006; Skerrett, 1998). As the well-being of informal carers has an impact on the wellbeing of people with cancer (Hodges, Humphris, & Macfarlane, 2005), this is also an issue for the person with cancer. One of the limitations of the present study is that the focus was only on carers, and thus self-silencing and psychological well-being on the part of the person with cancer, or the interaction between carer and patient communication, has not been assessed. Future research on self-silencing in the context of cancer should look at both partners in the carer-patient dyad, and examine a broader range of communication strategies in addition to self-silencing.
Difficult aspects of the caring role

Change in roles

Twenty four percent of women and 42% of men reported that one of the challenges of caring was the change in roles in their relationship with the person with cancer. The change in roles was often reported as having a negative impact on carers, a point Tessa, age 30, emphasised when she spoke of having to care for her mother with breast cancer.

It was me being frustrated that I was looking after this person who used to be so wonderful and such a good friend to me and such a good carer to me and then it took me so long to adjust to the fact that the roles were reversed.

The main issue identified was the need to take on additional tasks at home that were previously performed by the person with cancer, confirming previous research findings (Ben-Zur et al., 2001; Given et al., 2001). The types of tasks range from the mundane, for example, the responsibility of having to be the designated driver (“I was not a driver, he had driven me all these years…so I had to learn to drive again.” – Kathryn) to the more substantial, for example, Jenny having to be responsible for earning an income due to her husband not being able to work (“suddenly being the breadwinner when he couldn’t work”).

Interestingly, the additional tasks that carers spoke of were often across the gender divide. For example, voicing an issue raised by other female carers, Margaret spoke of having to manage house maintenance work, which was her husband’s job before his illness.

Primarily my role was to be [his] carer, if I did things and… and carer of the environment around us too, because I was playing the role that he, in the past, had always played. You know the fixing of leaking pipes, and mowing the acres of stuff that needs mowing, and um… you know, the things that happen around a… it’s not a property where we produce anything, but it’s quite a… it’s, you know, quite a big bit of area to look after.

Conversely, a number of the male carers provided accounts of increased domestic chores since their wives/women partners or siblings became ill. For example, Lawrence, age 63, who was living with and caring for his sister with multiple cancers, reported that not only had he continued to be responsible for the maintenance of the house and grounds, he was also “doing the shopping, (…) the washing, the real bugbear of ironing”. Other male carers spoke of cooking and cleaning chores they had to do, as well as ‘running’ the house, as illustrated by Paul, age 45, caring for his wife with breast cancer.

There’s the usual things, there’s cooking, there’s cleaning. We get all the help with meals from relatives and friends. There’s extra running around, there’s getting people motivated and organised in the morning and then there’s basically having to
skip out of work early or shoot off to go and pick kids up or take them to appointments, you know, take them to a dentist, whatever it happens to be. There’s also I feel I need to be more attentive to [my wife] but it’s hard to be more attentive to [her] and run the house, keep things ticking over, make sure the kids have done there homework. You know, it’s just the usual stuff, but it’s just very, very busy.

This suggests that insight into the gendered nature of the divisions in household labour (Sirianni & Negrey, 2000), and awareness of the confidence individuals have in taking on tasks which are positioned as outside of their gendered role, is central to supporting carers. Men had a greater tendency to report that additional household responsibilities were a challenging aspect of caring. This may reflect the fact that multiple caring responsibilities are socially constructed as a central component of women’s gendered role (O’Grady, 2005), with caring is positioned as “natural” for women (Hughes, KcKie, Hopkins, & Watson, 2005; Seigfried, 1989), leading women cancer carers to take on these responsibilities in an unquestioned way (Ussher & Sandoval, 2008). However, this is not necessarily positive for women, as gendered self-policing practices (Foucault, 1979) can lead to self-renunciation and over-responsibility, in the attempt to emulate an idealised version of femininity (Strickling, 1988; Ussher, 2004), as discussed above.

Taking on quasi-medical tasks and decisions

For some carers, approximately one quarter of men and women interviewed, the change in roles required them to act in a quasi-medical capacity when meeting their loved ones’ day-to-day medical needs. For example, carers talked about having to give injections (Sean), dress wounds (James), dispense medication (Sarah) and maintain the oleostomy bag (Margaret). Some carers, such as Donna, age 42, who cared for her mother with gynaecological cancer, found this role challenging, for “it’s not nice because if you do it [injection] incorrectly, you can cause pain and you just want to do it as quickly and easily as possible so that wasn’t particularly nice”. For others, such as Adam the quasi-medical role produced the desired outcome of enabling his wife with breast cancer to be relatively pain-free, which was a crucial aspect of his caring role:

*And I really felt that we got her medication down beautifully. I’ve talked to people since and they have trouble regulating pain control and them being coherent, that sort of stuff. (…) I think because we tried to follow the doctor’s orders because I’m always one that, it’s what I say, I don’t sort of think sideways, if that’s the way they want it, that’s the way I do it. And sometimes it works, sometimes it doesn’t. (…) I mean, the way it worked out, [she] was pain-free, she was coherent with everybody, she could understand and she could converse right up until the very last.*

While many carers encouraged the person with cancer to make their own medically related decisions, 44% of the women and 11% of the men, said these decisions were deferred to them. This decision making role was experienced by many carers as a
profound change in their relationship with the person with cancer. Olga, age 54, caring for her partner with renal cancer, talked about having “had a relationship where we didn’t make decisions for each other” but due to her partner’s declining health she “was making decisions for him”. For example, Hilary spoke of it being “all up to [her]” in ensuring that her husband receive the appropriate meals with “every bit of vitamin and nourishment and fat” he needed. Similarly, Lesley, age 63, caring for her husband with multiple cancers, also spoke of the responsibility of having to monitor her husband’s medical treatments, which she found “quite exhausting”, for she was “left with the responsibility of trying the new medications as per a quick instruction”. However, with appropriate support, some carers, such as Stephanie, age 56, said that the medical care she provided for her sister with breast cancer made her feel “very powerful, very empowered to be making these amazing judgements about the medical treatment of another human being”.

In contrast, making decisions was described as a “tremendous burden” for carers such as Maxine, age 67, caring for her husband with prostate and bladder cancer. She elaborated on this sense of burden by recounting the “guilty” feeling she experienced when she consented, based on medical advice, to her husband having radiation that resulted in him developing “frontal lobe dementia”, which led her to question whether or not she had made the ‘right’ decision for her husband. Similarly, Judith, age 57, provided an account in which she spoke of having to make the end-of-life decision for her husband who had colorectal cancer.

*I made the decision not to revive him. At first it was, “oh god how could I have made a decision like that”, but I was with the team and they explained, they could have revived him but he wouldn’t live more than 10 hours, even if they did that. I just, it was like, I didn’t want all that invasive intervention when it wasn’t going to do any good (…) I had enough help from the medical team but in hindsight I just wish they hadn’t have asked me that. I mean legally they have to ask you and I realise that but there was no hope so surely in cases like that they shouldn’t even have to ask.*

Other carers said they felt that their everyday lives were dominated by medical and health issues, which was challenging and unwelcome. For example, Naomi, age 41, caring for her husband with brain cancer, said that “all the medical things, the places you have to go, it’s just a whole different life, it’s a horrible life”. However, some carers, such as Stephanie, age 54, caring for her sister with breast cancer, felt “very powerful, very empowered to be making these amazing judgements about the medical treatment of another human being”. The need to provide medical care and make decisions could also affect how carers perceived the person for whom they were caring, impacting on their interpersonal dynamics. Cheryl, age 50, described changes in the way she felt about her husband who had haematological cancer:

*Because you see your husband as a patient and when they’re really sick it’s really hard to see them in the role of your husband … you’re doing things for them that you wouldn’t normally do, it changes. You’re viewing them in a different way. (…) That’s really hard because that’s your husband, but you’re doing the job that a doctor or a nurse would do, and it’s just really hard because it’s like you’ve met a new person.*
These reports of changes from an equal relationship to a patient-carer role suggest that a significant alteration in positioning is occurring in many relational contexts, with implications for the way in which individuals relate to each other. In particular, the threats to bodily integrity associated with these quasi-medical aspects of caring may be experienced as an infringement of autonomy (Giddens, 1998), requiring a renegotiation of roles and relationships in order to maintain interconnections (Chattoo & Ahmad, 2008). Although previous studies have found changes in responsibilities, such as managing the medications, have “empowered (cancer carers) in their caring role” (Anderson & Kralik, 2008, p.355), this study also illustrated how such changes in responsibilities and roles can affect the relational dynamics between people with cancer and their carers, outlined below.

**Change in relationship dynamics**

In addition to changes in roles, many participants talked about experiencing a change in the relationship dynamics between themselves and the person with cancer. Twenty-nine percent of the women carers and 11% of the men, primarily partners of the person with cancer, spoke of the considerable changes in the personalities and moods of their partner due to the cancer and associated treatments. For example, a man interviewed as part of a group said that “the most difficult part is to get used to the change in moods” of his wife. The changes were so great for Leslie, age 62, caring for her husband with prostate cancer that “I lost the husband that I married”. Similarly, Melanie, age 55, caring for her husband with prostate cancer said that “it’s almost as if his whole entire life that was, no longer exists and he’s now this person that he can’t even bear to be around most of the time, let alone anyone else be around him”.

Increased emotional unavailability on the part of their partner was the major concern of a number of participants. For example, Margaret said it was as though her husband “had gone away somewhere, but he was there, but part of him had gone away” and Sarah, age 57, described her husband who had pancreatic cancer as “not really there” because of the amount of medication he was taking.

However, in all of the interviews, there was acceptance that the person with cancer might have changed emotionally because of their illness, and that tolerance on the part of the carer was required. Cheryl, age 50, who cared for her husband with pancreatic cancer, illustrated this point by commenting that “when he got angry and that was okay because I thought well that’s normal”. The changed relationship, along with the burden of caring, was also described by some participants as the trigger for their own anger or emotional outbursts. For example, Alan, age 47, talked about the “bout of anger” he felt when caring for his mother who had colorectal cancer, which can result in him “yell[ing] at her”. Carol, age 64, who cared for her mother with haematological cancer, said “we had our blow ups but it was more the anger of everything that was going on”. Anger and conflict was not isolated to caring relationships between parents and children. Bella, age 36, who cared for her husband with prostate cancer, said because she was “so highly strung” and “getting strung out”, she would “turn [her] frustration on him”.

Women had a greater tendency to report that emotional or personality changes in the person with cancer were experienced as a source of difficulty, primarily referring to their men partners. Bookwala & Schulz (2000) found that women cancer carers reported a higher frequency of behavioural problems in the men they were caring for,
than did men caring for a woman with cancer, and women patients have been found to be better adjusted to the disease with respect to sexual, social and vocational functioning, compared to men (Fife et al., 1994). This suggests that the gender of the person with cancer is a relevant issue to systematically explore in future research on the relational context of cancer.

**Neglecting self and other relationships**

A significant number of interviewees reported that the time and demands involved in caring was a “24 hour a day job” that resulted in a focus on the relationship with the person with cancer to the exclusion of all others. This experience was reported by 41% of female carers and 21% of male carers. This constant vigilance was suggested by Brian, age 57, in his account when caring for his wife with pancreatic cancer indicated that caring was an ‘around the clock’ activity or as Kathryn, age 67, caring for her husband with brain cancer described it, “a 24 hour a day job”. Even when carers might not be physically caring at a particular moment, such as Stephanie, who cared for her sister, said, she would be “just always thinking about it, it’s always there with you all the time”, for “it’s a constant, always thinking about how you’re going to deal best with a situation”.

The dependency of the person with cancer on the carer was particularly evident when caring for loved ones in the advanced stages of cancer, where a metaphor of motherhood was commonly used, wherein caring for a person with cancer was positioned as analogous to caring for a baby. For example, Lesley said caring for her husband was “a bit like having a baby in the house”, or Sarah, age 57, who cared for husband with pancreatic cancer, said it was “like caring for like a child or having an adolescent in the house”.

This 24/7 care could result in the neglect of self or other relationships. For example, Olivia, age 62 said that she was not giving enough support to her husband because she “wanted to devote [herself] entirely” to caring for her friend with multiple cancers. Similarly, Naomi spoke of being unavailable to her children, for she was spending all her time with her husband when he was being cared for at the hospital, saying “I sort of lost four months of their lives because I wasn’t here [at home] at all”. Bob, age 66, caring for his wife with breast cancer, offered an insightful account of how and why he restricted his relationships with others:

I’d rather just, I’d spend a lot of time visiting [my wife] while she was in hospital and I tended to almost, not get resentful but shielded myself from phone calls with the answering machine because I wanted to be with her and just support her quietly.

Other participants, such as Margaret, talked about not having time for herself because “I just didn’t feel that my life is mine”. Similarly, Kay said that she “didn’t have a lot of feelings for [herself]” because her intention was to ensure her husband’s needs were met. As an illustration of how overwhelming this responsibility can be, Olga contrasted her own experience with that of her partner, describing how she was “actually jealous of him” for having the time and space to do things such as read the paper or watch TV, whilst she “never got to do those things because I was just so overwhelmed with things to do”. Participants who took time out from the caring role
often had to reconcile this with feelings of guilt. As Gay, age 54, caring for her husband with prostate cancer said “You become very self-sacrificed. But it’s difficult to find time just for you because you do that, you wind up feel guilty about it whole thing”. As a result, some carers spoke of forgoing their hobbies or interests. Gary said that attending football games “was a great enjoyment for me to go, and that was the point, I could never really get away”. For other carers, the organisation required in order for them to take time out would detract the enjoyment of it. Lesley, who cared for her husband, provided the following account to illustrate this point.

“Yes, the freedom to sort of jump in the car and go off and do something. Everything’s a big production – get this organised, get the other organised. You go together and then it’s never quite the same, you don’t have that little bit of freedom.”

In contrast, a number of carers provided accounts that highlighted the importance of taking time as respite from caring. For example, while James said he would “need that time out” to “get [his] battery recharged” in order to care for his wife, Ben (age 51) engaged in a group exercise activity as a “stress relief” from the care he was providing to his wife with breast cancer, and Jenny spoke of arranging her day “just to have some time to myself” as a way of looking after herself in caring for her husband.

Interestingly, Rose, aged 19, said she “didn’t feel as if it was a burden or anything having to stay home” to care for her mother with gynaecological cancer because when she had the opportunity, she “was still able to go out and still have a life”. The opportunity to “have a life” outside of the caring role is also important in terms of maintaining a separate identity as illustrated in the following account offered by a female carer in a prostate cancer support group.

“I do have a life of my own. (...) I belong to a [social group]. (...) I think it’s really important that you have a sense of identity, a carer has a sense of their own identity and doesn’t become absorbed by the other person, which is very easy to do.

These accounts illustrate the challenges to autonomous identity imposed by serious illness (Donchin, 2000), as well as the costs of caring (Kessler et al., 1985), which may be implicated in high levels of distress reported by cancer carers.

Physical health consequences

In addition to the psychological and emotional effects suffered, some carers (44% women and 11% men) also spoke of the physical effects that caring for their loved ones had on them. For example, in a cancer support group specifically for Chinese carers, the wife of man with cancer said that she “lost 7 kg in weight”, which she attributed to her being “a bit worried about [her] husband”. Evelyn, age 65, who cared for her daughter with haematological cancer, provided an account in which she talked about her being “absolutely burnt out”, her “hair fell out” and had “a problem with [her] thyroid”. Diana, age 44, caring for her husband with prostate cancer, provided a detailed account of the change in her physical wellbeing resulting from the caring she provided to her husband.
I haven’t had a spring in my step for a long, long time. You know, I get – I get very tired, um... very, sort of, fatigued. Um... you know, just general wellbeing, don’t – don’t sort feel fantastic, even though I’m eating very good, very good vegan diet and taking lots of multivitamins and everything. Um... I think I’m just a bit – bit worn out, um... emotionally and psychologically and probably physically.

The issue of looking after their own health was one that carers had divergent views. Some carers were clear about the need to look after themselves in order to care for their loved ones. For example, in a prostate cancer carer support group, a female carer said she thought it was “really important for a carer to keep mentally and physically fit”, and Diana, despite the deterioration in her general wellbeing, recognised that she had “to try and look after [her] own health [in order] to be strong, and to be able to support him and help him”. Conversely, other carers provided accounts in which they minimised the importance of their own health needs. For example, Lesley, while caring for her husband, was advised to “look after [her]self and things like that” but her response to this was “I know I’m tired, I don’t need to be told what I should do, I come second” (carers placing themselves “second” was also an idea noted earlier in not voicing their needs and issues). Similarly and more bluntly, Kathryn, who also cared for her husband, said that as a carer, she had to “forget” herself. Judith provided a more detailed account of neglecting her own health care needs “because [she was] so busy doing things for the person that’s sick, she just forget about [her]self”.

There were heaps of things that I forgot. I mean, I’d look at my diary, oh my god I was supposed to have my check-up, I was supposed to have my scan, I was supposed to have this, I was supposed to have my transfusion, I was supposed to have that and, yes, that was, and in the end I used to just get the doctor to ring me and say, get yourself in here, then I would remember to go.

Possibly as a consequence of the constant diminishing and neglecting of their own health care needs, many carers also spoke of the tiredness they frequently felt because of the unrelenting demands. For example, Carol spoke of the “exhaustion” she felt from caring for her mother, and Margaret recalled “feeling so exhausted” when recounting her experience of caring for her husband. Similarly, Gary, when describing the care he provided to his female partner, commented “You go to work the next morning, and you’re totally exhausted, and you know that when you come home that night, it will all be on again”.

When the level of demand and physical strain increased as the person with cancer became more unwell and dependent, some carers spoke of “running on pure adrenaline” (Fred) or to utilise professional services (Donna) as ways of dealing with the changed circumstances. For Maxine, her ability to care for her husband with brain cancer when the situation became even more demanding reflected a resolve she made when she became his carer.
Well in the end I was absolutely exhausted, absolutely exhausted. Physically, I just kept going because I think mentally I had made up my mind that this was what I wanted to do and, as I said to you, at one stage when I really felt… I just said to myself, what do I do to make this better? So I mean people used to say to me, I don’t know how you do it, but I did.

An aspect of the physical strain that many carers experienced was the poor sleeping pattern developed as a result of the caring demands. For example, Anne, age 56, who cared for her husband with brain cancer, attributed her poor sleeping pattern to the cancer experience, for “ever since [my husband] was diagnosed (…) I probably would get a good sleep once every ten days or so”. Gina spoke of her husband’s pattern of wanting to sleep during the day but not at night, “so you’d go to bed at night, and he just did not… he wanted to talk (…) so I was getting no sleep [and] he was getting his rest”. The carer’s sleeping pattern being dictated by the person with carer was reinforced by Alan whose mother had a “disturbed sleeping pattern, which did not allow [him] to sleep either”. Brian offered specific details as how the caring responsibilities for his wife affected his sleeping pattern.

You couldn’t sleep because when she had to go to the toilet you had to kind of, we had to get two single beds. I actually got a mattress on the floor and I got a single bed ‘cause it was easier for us… watching her, you’d be awake all night waiting for her to have to get up to go to the toilet because she couldn’t get out of bed by herself.

These findings confirm previous research conducted by Carter (2003), which reported that carers exhibit moderate to severe sleep problems, which tend to fluctuate over time. It also confirms reports that fatigue is commonly reported among carers (Grbich et al., 2001b; Thomas et al., 2002). This has serious implications for carers ability to cope and to provide care, and is also implicated in the psychological well-being of carers.

Loneliness - Isolation

In many instances, the imperative to care can create a sense of isolation for carers, manifested by participants feeling that the responsibility of care rested solely on them (41% of women and 26% of men). For example, Ben, age 51, caring for his wife with breast cancer, said that “at the end of the day, no-one was helping me deal with what [his wife] was going through”. Ben’s comment should not be taken to mean he lacked support or assistance, but rather that he felt he was solely responsible for his wife. This point was reiterated by Gary in the following account.

Friends would pop around during the day, and girls from the club would pop around through the day, you know, and friends, and all that kind of stuff. But when evening comes, it was just me and [her]. And that’s the way it felt, all the way through. Just me and [her], you know.
Some carers appeared to have created a sense of isolation because they did not want to burden others, or because they did not expect others to understand their experiences. As Paul said “I don’t know anybody who doesn’t have problems of some kind so I don’t feel inclined to go and burden them”. Tessa, who cared for her mother, provided the following account:

*I think that’s why I isolated myself as well because I didn’t want to burden anyone and I didn’t want to, I didn’t know anyone else who had been something like this so I didn’t feel like I could talk to people about it and try and share that experience if they hadn’t been through it.*

These comments were echoed by Naomi who did not feel there was anyone with whom she could share her experience of caring for her husband “because there’s no one that can understand what you go through, nobody”. Similarly, Bella said she felt “very lonely” because she did not know “who to turn to for any verbal support” as the person she would have talked to was her husband, but she was not prepared to “dump all [her] stuff on him” because he had cancer. Many carers talked of being the sort of person who doesn’t share feelings at the best of times, describing themselves as a “social isolate”, or someone who “ends to shut people out”. This made it hard to ask for help in the context of cancer, as it would mean changing normal patterns of behaviour.

Many of the carers told us that they did not access any emotional support, as they had no-one to express their feelings to. In some cases this was because of practical reasons, such as geography, meaning that there were no local support services. As Bella commented:

*I did ring someone like the Cancer Council. But I found it all just so, oh, you know, like I wished that I had had just somebody in an office at the Falls Village, you know, that I could have just gone and sat with for three hours and bled my heart out. But I didn’t have anyone.*

Participants also talked of not receiving support because other people didn’t ask how they were coping. As Diana told us “sometimes people don’t even stop and think, “Well, I wonder how poor Diana is actually coping?” And bothering to ask”. In many cases, friends and family did not look beneath the surface and see that the carer might need support, assuming that everything was alright. Hilary described her grown up children thus: “They just think, ‘Oh, you know, everything’s all right. Dad’s got over this. Mum’s cooking for dad. Yeah, he’s eating. There’s nothing more’. That’s my impression”. Other participants said that friends and family found the notion of cancer too difficult to cope with, resulting in their withdrawal. Carol described her friends as “absent pretty much most of the time because it was very, it was too confrontational (for them)”. Similarly, Sean said “Oh well cancer changes the relationships of everybody. We’ve had friends who can’t handle it and who’ve disappeared”.

**Difficulties in requesting or accepting help**

A number of carers (53% of women and 32% of men) provided accounts that indicated that, for a range of reasons, they were unable to ask for or accept assistance
offered by friends or relatives. For example, Adam said because he was a “very independent person” and even though he accepted some assistance, when “there was anything to be done with [his wife]”, he preferred to do it himself, for “she was [his] wife”. Brian offered a similar account about the acceptance of support or assistance, for he said he “didn’t like calling on anyone, didn’t like calling on help”, so even though help was available, he did not utilise it. Not calling on help was also voiced by female carers. For example, Kathryn did not draw on support that was available because she “couldn’t put [her husband] off to strangers”. Jenny simply stated that she was “not good at asking for help”, for she reasoned that “she can look after [her] husband and [she] can be a good wife”, a “big defensive thing” that stopped her from asking for help. Paul encapsulated this resistance to asking for help by saying he “kind of see it as an admission of weakness”.

Other carers were deliberate and selective about whom they would seek help from. For example, although Connie, age 71, caring for her husband with prostate cancer, said she had sons and daughters-in-law to call on, she did not “want to burden them any more than they need to be burdened” so she “probably will rely on friends more”. Despite the readiness of other carers to accept help and support, they were aware that this was a demand and thus were mindful of how much they accept the help available. Maxine offered the following account.

I mean people were very good to me. I mean you know, the fellow upstairs, he used to take [him] out for a drive. People were good. But you can’t, well, they were not people that you could ring up and say, “Look, come and sit with him”. Or you wouldn’t sort of – they possibly would have, but I didn’t feel that I could be using, in inverted commas, “using” people.

Some carers provided accounts that highlighted the limitations of when assistance was utilised. For example, Olga spoke of the professional home care assistance she utilised in caring for her male partner, and because different workers were involved, and even though “they were good at listening but it meant that we were continually trying to teach them” about his particular needs.

In some instances, the personalities of the carer and person with cancer precluded others from helping. For example, Hilary described her husband as a “very private person” and preferred the situation to be managed by them independently, for he “didn’t want to ask people to help”. Similarly, Alan said that because his mother “wasn’t keen to be with stranger or be left with someone she didn’t know”, which made him less inclined to seek assistance. For Donna, she said her mother’s preference was to call on her when necessary because “she could feel miserable or sit there and just go, “oh I feel like I need a sleep or can you turn the telly off” or blah, blah, whereas you can’t say that to some people who are looking after you”. Interestingly, Anne, age 56, caring for her husband with brain cancer, spoke of the negative effect that having help had on her. In her account, she talked about a relative whose assistance she found difficult to negotiate.

[This relative] lives nearby, like a block and a half away or something like that, and, um... how can I put this? She, um... she was doing her best to be helpful...and I actually found
that overwhelming and... and too much (...) it was sort of... she seemed to be here all the time.

These findings suggest that many carers lack the social support that facilitates coping and psychological well-being. This reinforces the need for family members and friends to be available to support cancer carers, and for health professionals or peer support groups to provide additional or alternative support. Cancer support groups, provide an opportunity to share feelings with others “in the same boat” (Mermelstein & Lesko, 1992; Ussher, Kirsten, Butow, & Sandoval, 2006), and are increasingly being recognised as an effective forum for providing this psycho-social support.

Attendance at a cancer support group has been associated with reductions in depression (Bultz, Speca, Brasher, Leggie, & Page, 2000; Fawzy, Cousins, Fawzy, Kemeny, Elashoff, & Morton, 1990; Telch & Telch, 1986) and anxiety (Hosaka, Sugiyama, Hirai, Okuyama, Sugawara, & Nakamura, 2001; Montazeri, Jarvandi, Haghhighat, Vahdani, Sajadian, Ebrahimi et al., 2001; Samarel, Fawcett, Krippendorf, Piacentino, Eliasof, Hughes et al., 1998; Targ & Levine, 2002); improvements in coping (Fawzy et al., 1990; Targ & Levine, 2002) and quality of life (Coward, 1998; Cunningham & Tocco, 1989; Katz, Koppie, Wu, Meng, Grossfeld, Sadesky et al., 2002); and increases in cancer related knowledge (Carlson & Strang, 1998; Coreil & Behal, 1999; Grahn & Danielson, 1996; Gray, Fitch, Davis, & Phillips, 1997a).

**Counter narrative: The importance of a good social support network**

At the same time, many carers (76% of women and 68% of men) talked about the importance of having people in their lives to whom they could turn when requiring both physical and emotional support in managing the caring situation. For example, Connie spoke of friends she could call on, and when she did so, she said “it’s just nice to know that people are going to be for you”. Indeed, she added that “it’s quite nice when people cry” with her because it showed her that “in fact they’re experiencing some of what I am going through”. This illustrated that sympathy and empathy were, for some carers, important aspects of the emotional support they sought. John’s account further developed this idea when he said that not only “it was just important knowing it [support] was out there and that you could talk about it [cancer]” but “just the getting it out was such a relief”. The opportunity to talk to friends about his experience of caring for his wife was, for him, “all that was really needed, just the fact that you can discuss it freely”. The ability to talk freely about cancer and their caring experiences enabled other carers, such as Kay, to say that they did not “feel alone”.

The above accounts underscored the importance of having support on which carers can rely in looking after their own emotional needs. The majority of carers talked about the support they received from family, friends and work colleagues. For example, Rose, age 19, who cared for her mother with gynaecological cancer, referred to her two aunts who “were always very supportive of me”, her sisters to whom she was “very close”, and “some really good friends, like they’re very supportive, like if there was ever a time [she] couldn’t go out or [she] needed to talk, they were fine, they totally understood”. Equally important was support some carers received from their work colleagues; this was particularly so for some carers who did not have “a lot of family” to call on. Colin, age 52, caring for his partner with brain cancer, for example, offered the following account.
We haven’t got a lot of family in Sydney, I come from [country] but [my wife] and the children come from [country] and [her] only sister lives here in Sydney, she’s been wonderful, I mean great support we’ve had there. We’ve got really good, just the community that we live in where we live, are very, very supportive. Because I only work in a small business a lot of the people I work with are aware that things haven’t been right because I wasn’t right and they all ask how [she] is and how it’s doing and we’ve just found that we’ve been overwhelmed with support and so it hasn’t been that bad really.

Similarly, Judith referred to a couple of her husband’s work colleagues as important support, and said the following.

One in particular, he was at the hospital with me when [he] died, he went right through everything with me and that was, him and his wife were just fantastic.

Furthermore, many carers referred to the practical help they received in meals preparation, house cleaning, household chores, transportation to and from medical appointments, and physical assistance in caring for the person with cancer. Significantly, as noted previously, just as some friendships did not survive the cancer experience, Sean said the support he received from some friends had made them “very close friends” while others had become “even closer”. However, negotiating how support was provided was also an issue for some carers as the support was, at times, troublesome for both the carer and person with cancer. For example, Naomi spoke of having to play the “big ogre wife” to their friends because when they visited her husband in the hospital “they’d just sit there talking and [he] was trying to carry on a conversation which he found really hard anyhow, so that was really hard because people wanted to see him” when “he didn’t want people to come and see him”.

Financial issues

Approximately one third of the carers spoke about financial pressure they experienced in caring for their loved ones. Evelyn described the financial demands on her when caring for her daughter as “like throwing a stone in pond isn’t it? The ripples spread out and you don’t know where they’re going to stop”. There were many costs carers referred when discussing the impact caring had on their finances. For example, Kathryn said because her husband was prescribed a medication that was a “trial thing, the government do (sic) not support this” and she said because “it’s not on the PBS [Pharmaceutical Benefits Scheme]”, they had to pay for the medication without government subsidy. The weight of financial cost involved in cancer caring was also reflected in commonplace occurrences. For example, Brian spoke of the mounting parking cost involved in meeting his wife’s medical needs:

I want some help with coming in [to the hospital] ’cause you have to pay the parking fee every time you come to hospital and that soon racks up when you’re going two and three or four, five, six times a week (...) I think it was five dollars a go and I mean when you’ve lost, when you’re down to one job and
you’re struggling I mean (...) it’s a very expensive little
episode that breaks you at the end.

Another issue Brian raised, which many carers echoed in their accounts, was the
financial worry due to change in their income. Janice spoke of “really having a battle
now, to live on one income” because of her husband’s inability to work, or Carol who
“drop[ped] from a corporate salary to a carer’s salary” and had to “learn to live on
such a little amount”. As a result of changes to their incomes, carers had to adjust and
adapt to different lifestyles as Lawrence, who cared for his sister, explained.

Yeah when you’re a pensioner it sort of knocks you around a
bit but that’s…you just rearrange where you spend your money
and you’ve got to really prioritise things and it makes you think
a little bit, probably a bit better on where you’re going to
spend your money and what you spend it on and just prioritise
and just make sure that things that have got to be spent on that
it’s spent on that and the frivolous things, well they can just
wait.

Some carers spoke specifically about the importance of the government financial
assistance received, which enabled them to care for their loved ones. For example,
Alan said that although the financial assistance he received was “not big money”, he
was “getting consistent money”. However, there were carers, such as Jean, who said
she was reluctant to utilise government financial assistance because “it was a little bit
of a sign of weakness”, for she felt she and her husband were people from the
generation who “have to do this on [their] own [and] don’t always take the help that’s
offered”. These findings suggest that financial support for carers may alleviate their
care-give burden, and facilitate coping.

Mourning previous relationship or life

The change in roles experienced by carers can be difficult as it represents not only a
change in their relationship with the person with cancer but also sadness or grief for
the loss of the relationship they previously had. Jenny articulated her experience by
lamenting that she “would love to go back to how our married life used to be, and it
never will”. Similarly, Sally described her experience as follows.

We’re just getting through day by day. I don’t feel greatly
depressed, I feel very sorrowful that the life that we thought we
were going to have won’t be there because we just can’t do, as
I said, we’re trying to form a new, well we’re having to form a
new relationship and so far it’s not offering what, enough for
me, whether it will I don’t know. But nor am I willing to give
up on forty years of marriage I suppose. And I couldn’t leave
him – the guilt would be too much. So, no, I can’t see any
golden thing, it’s just been a long, harrowing, emotionally
draining experience.

The sorrow felt because of the profound, and evidently negative, changes in their lives
was echoed by other carers. Brian said that his life was “never the same” and that
“everything at that point in time changes forever and I don’t think you’re prepared for that”. In the same way, when James was remembering life before cancer, he mourned that “those times have all gone”. Janice commented that “we had no future” because cancer had become a part of their lives. Lesley spoke of the profound changes and the sense of loss she felt for the life she had in tangible terms:

things have changed rapidly because you realise well this can go on, off and on, off and on with, you know, if that's the best outcome it will be like this until we're both gone and you decide you're not going to build a house, for instance, where we are. We’ve got a block of land with a fibro shack on it but we’re going to have to make do with living in the fibro shack. That’s kind of another part of your life that’s gone.

Women were more likely to describe themselves as mourning the relationship they previously shared with the person with cancer. This may reflect the importance of relational connectedness to women’s emotional well-being (Kaplan, 1986), or the finding that women are more affected than men by the emotional well-being of others (Hagedoorn et al., 2001), and by life-events, such as cancer, which affect others (Kessler & McLeod, 1984). However, it may also reflect a pattern of avoidance of emotional engagement on the part of men, a masculine coping strategy reported in previous research with men cancer carers (Lethborg et al., 2003). This may also result in the emotional needs of men who are cancer carers being overlooked, and of services being directed at women, who are more likely to express distress associated with burden of care (Thomas et al., 2002).

Feelings of helplessness and loss of control

Many carers (44% of women and 37% of men) gave accounts that the presence of cancer in their lives had made them feel impotent and out of control in relation to their situations. For example, Connie said she felt “there’s nothing [she] could do” for her husband with cancer, and John thought his wife’s breast cancer was like “any cancer situation [where] no one knows why you get it and there’s very little you can really do about it”. This lack of agency in overcoming the situation was elaborated on by Jean in the following account.

Everything’s out of your control, I’ve always been the sort of person that I like to be in control of my life, if I don’t like a situation where I’m in, I’ll either just get on with it then and think I won’t do that again, or I’ll get out of it, I won’t…that was the most difficult thing to cope with when he first got ill, your life was out of control, and you had no control over it, no control whatsoever, and we said…when he was first diagnosed, we said our lives will never be the same, and they never were.
Conflicting thoughts between the carer and person with cancer

The effects of cancer and possible consequences – remission or death - can affect carers and the person with cancer differently, which in turn can influence the way in which the situation is negotiated and managed. For example, Andrew, who cared for his wife for whom cancer treatment was effective, said she was “feeling guilty” because she survived while people she knew did not. This was a perplexing situation for Andrew, and in the following account, he illustrated how this affected their interactions.

_I used to think she was feeling a bit ungrateful, she should have been feeling on top of the world. Sometimes I’d get a bit short with her (...) I thought why are you feeling guilty if you’re surviving? I used to get a bit cranky when she’d raise that with me because I didn’t understand that was actually one of the things they do go through._

In a similar vein, Maxine described the negative effect of her husband not wanting to discuss the possibility of his death, when this was an important issue for her.

_I mean he was not interested which I found somewhat difficult because I used to try to talk to him about death and dying and he just used to say, I’m not going anywhere, I don’t wish to discuss it. I was trying to sort of say, well if you die what… He said “you know exactly, I am not having a funeral, you know my thoughts on funerals”, so there was no discussion and that I found extremely hard to cope with. My needs were not being met but he’d made up his mind and that was it, there was no discussion at all._

The accounts of Andrew and Maxine highlighted two issues – 1) in coping with the stress and distress caused by cancer, the experiences of the carer and the person with cancer can diverge in terms of how to manage the situation and 2) carers can often be in conflict with the person with cancer during the course of caring. This provides some explanation for why couple interventions which focus on facilitating relational coping and communication (e.g. Kayser, 2005; Scott, Halford, & Ward, 2004) are generally more effective than other types of intervention for reducing cancer carer distress (Ussher, Perz, Hawkins, & Brack, 2009).

Rewards in the caring relationship

The focus on burden of care has acted to obscure the positive meanings many carers construct in making sense of their caring experiences (Sinding, 2003). Indeed, as Addington-Hall and Ramirez (2006) contend, carers “resent suggestions that the experience is wholly negative or, indeed, negative at all” (p.56). It has thus been argued that positive aspects of informal cancer caring require attention in order to better understand the complexities of the caring experience (Hudson et al., 2005). Four main positive and rewarding aspects associated with caring were identified by participants in the present study, which were positioned as providing direct benefits
for the carer. These themes were: admiring the strength in the person with cancer; the strength they discovered in themselves as a result of having to provide the necessary care; the relationships they developed or relationships that were enriched with the person for whom they cared; and the personal growth they achieved resulting from their caring.

Admiring strength of the person with cancer

Over one third of men and women carers talked of admiring the strength of the person with cancer when confronting the physical and emotional ordeals resulting from their illness. For example, Keith, age 58, spoke of his wife’s “courage” in living with breast cancer and her attitude of “do[ing] whatever it takes” in dealing it. In particular, Bella specifically said that her husband did not “look to people for strength” but rather he found it “within himself and that’s really admirable”. Alternatively, John spoke of his wife’s “upbeat” and “happy” personality, which made him feel that he was not “hard done by or burdened” in his caring role. The admiration carers had for their loved ones was also evident in accounts of the person with cancer managing the situation in a way that allowed the carer to confront the difficulties. For example, Evelyn offered the following account that detailed her daughter’s perspective in how to she had to deal with cancer.

“look mum it’s like this, I could throw myself down on the ground and kick my heels up and scream and yell and have a tantrum but it’s not going to make it go away and what I’ve got to do is get on with it” and she’s had that attitude right from day one. I’ve never heard [her] say, why me? She’s just, it’s just the way she’s been I think.

A number of carers offered accounts which suggested that they drew strength from the person with cancer. For example, Keith said he needed “that strength of [his wife]” in order to negotiate the difficulties inherent in their situation. Likewise, Diana said that it was her husband’s “attitude” and his being “very, very brave”, which gave her the “tremendous strength” to believe he could survive cancer. Olga offered the following account that captured the ideas shared by many carers about the person for whom they cared.

I think this is a bit arrogant to think that you’re unique in any way but I think that the relationship that [he] and I had, and the sort of person he was, was very, very special. And it was a combination of who he was in terms of how he dealt with it, so he made it as easy as possible for me to care for him.

Olga’s comment about the quality of her relationship with her partner illustrated the importance of interpersonal dynamics in forging a successful caring relationship. Indeed, for many participants, cancer was reported to have deepened and enriched their relationship with the person for whom they cared.
**Improved relationship**

Many carers (46% of women and 68% of men) made reference to the quality of their relationship with the person with cancer as being an important positive aspect of their caring experiences. Feeling closer together was commonly reported as a reward of caring: “‘I am able to spend quality time with my grandmother’; ‘being able to be with my husband’; ‘being together’; ‘just being able to share these times’; ‘being there for him’. Some carers indicated that the knowledge of the person’s impending death encouraged them to value the time they spent together, which in turn enriched the relationship. This was illustrated by Donna in her account about the time she and her mother spent together.

> Like you don’t know, you probably don’t ask those questions until you know something’s going to happen or maybe some people know, like find out the history of their parents in a detail that you probably don’t think to ask a lot of the detail until you realise that they’re probably not going to be around forever. So, that was really fun (...) so you see facets of them that you wouldn’t have otherwise.

For others, the need to be present with the person for whom they were caring strengthened a closeness they already had, or led to a closeness that they had not previously experienced. Maxine provided an account that underscored the reward of caring for her husband, which required them to spend time together in a manner that was not previously available.

> What was really good about it? The fact that I was able to take him for drives and we were able to do things that we hadn’t done before like driving all around Sydney (...) just doing those things together that we hadn’t done. (...) Those were the nice things. I can honestly say though that we had had a very good life together. So that was something I guess. I can look back and say well, we’d had some lovely times (...) there was a togetherness and a closeness, because he’d always done his own thing...so I guess there was that sort of closeness that we hadn’t had before. So yes those were the pluses.

The “togetherness” and “closeness” developed from time spent together, as expressed by Maxine, also afforded the carers occasions through which to discover and appreciate the relationship in ways they had not previously experienced. Confronted by the changes, challenges and difficulties embedded in caring, Olga narrated an account that reflects an understanding of herself and her male partner she developed through the caring role.

> I think the biggest thing, I have to say that was a good time, was good that came out of it was him and me, about what we found out about ourselves, our level of resilience, resourcefulness, love, respect, liking, and finding out what we could actually do, a sense of humour.
Similarly, when Bob, age 66, spoke of his time of caring for his wife with breast cancer, he said “it certainly brings you closer”. Andrew, who also cared for his wife, said that the difficulties and challenges that cancer created only showed “how much you love each other and how much you need each other and how much you would miss each other if that relationship wasn’t there”. Indeed, in spite of the difficulties and challenges, Colin emphasised that there were many positive aspects in his caring experience, of which the most positive was noted in the following account.

There’s quite a lot of positive really. So yes, the most positive is the love for my wife and my family and the other is really, I think it’s given us the opportunity to do things together in the knowledge that maybe we’ll have to hurry up.

The enrichment of their relationships resulting from the intrusion of cancer into their lives, for some carers, was signified by the tasks they needed to perform, which were positioned as a demonstration of their love towards the person for whom they cared. Gina described the act of caring as not only a reward but also a way of ‘realising’ her love for her husband.

I think it was…it sounds funny, but I felt rewarded being able to help him. Um...I think...I didn’t realise how much I loved him...or, I knew that, but you don’t realise how much, until you have to do something. And, I would have... I did everything for him, from cleaning his bottom to doing everything....the lot.

This confirms findings from previous research (Germino, Fife, & Funk, 1995; Grbich et al., 2001a; Koop & Strang, 2003; Leedham & Meyerowitz, 1999), that the act of caring, or the likelihood of imminent death, can be a time when the relationships between the carer and the person with cancer is enriched and deepened. The deepening of the bond in the relationships from caring, and the ‘love’ between the carer and the person with cancer, was positioned by some participants as the most positive aspect of their caring experience (“…I didn’t realise how much I loved him…until you have to do something;” “Caring for the person I love is most important to allo of us”; “I love my mother-in-law so it has given me a chance to show my love”). From this perspective, in terms of performing necessary caring tasks, the carer role that participants had taken up not only enabled them to make sense of their “relational responsibilities” (O’Connor, 2007, p.169), but also highlighted the fact that caregiving relationships “often have love as a reference point” (Sinding, 2003, p.153). As Twigg and Atkin (1994) have argued, caring takes place in a relationship, and although caring relations are not always defined by love, they are often “associated with and energized by it” (p.8). In this regard, caring can be understood as an act that informal cancer carers undertake to show their love for the person with cancer.

Furthermore, some participants positioned the act of performing everyday caring tasks as a demonstration of their love for the person for whom they cared. In this context, it could be interpreted that these everyday tasks, demands and challenges, in some situations, cannot simply be constructed as difficulties that informal cancer carers need to overcome. Rather, they also could be interpreted as events that facilitated emotional expression, which, for some participants, were constructed as a
reward resulting from the caring, confirming Sinding’s (2003) finding that “even the literal shit work of caring (can be) rendered meaningful” (p.158).

**Discovering personal strength**

The majority of participants (44% women and 20% men) identified positive benefits which arose from being in a caring role, or from performing necessary caring tasks, positioning themselves as having possessed strength that they had not previously recognised. This is illustrated by Naomi who said “I look back on it now and I just think, my god how did I do it?” Many participants described developing strength through adversity’. Stephanie described being challenged by the demands of caring and experiencing emotional distress from witnessing her sister’s physical deterioration. However, in her account of the frustration associated with caring, she also conveyed the insight she gained about her own strength.

> So we brought her home and it was a very, very difficult, challenging, and I certainly learned a lot about myself and I think human limits (...) The experience for me as a person was huge and I think you learn how much inner strength you have as a person and sometimes how little you have when you lose it.
> (56 years old; cared for sister with breast cancer)

Discovering strength through adversity was a theme identified in other participants’ accounts, such as Tessa who constructed her caring as an experience that “taught [her] about being strong”. Needing to be strong was also echoed in the account offered by Anne, in which she not only stated that her caring experience was difficult but also identified the effect that it had on one of their children; however, she still positioned her caring experience as an experience that made her stronger.

> I think we... we all benefited from having him here at home with us. So that was probably the best way for us to go. And even though, you know, I sort of have thought at times maybe it was the wrong thing for [daughter], the one that found it difficult. I don’t think so either...hindsight being such a wonderful thing...but, you know, at the time I think that was...that was, you know...it was...it was a very difficult time for all of us, but at the same time, you know, if it doesn’t kill you, it makes you stronger, doesn’t it?

Some participants spoke of the strength they acquired through their acceptance of the situation, which enabled them to find ways to deal with the challenges and difficulties associated with caring. For example, Alan provided an account of acceptance of the difficulties as a way of negotiating the frustration and anger he experienced, which enabled him to find the strength needed in order to provide the necessary care.

> I think in certain part where you get angry and frustrated when everything becomes too much for her, she was always clingy and all that. But towards the end it kind of, towards the end, in a way I accepted the whole thing. As I say, the next day it would be another struggle so I kind of accepted that, it’s a new day so we’re going to be in this thing together.
Maxine indicated that she was able to reconcile the difficulties involved in caring when she accepted that her husband’s condition was not likely to change and that she needed to change her expectations in order to find strength in continuing to provide care.

Physically, I just kept going because I think mentally I had made up my mind that this was what I wanted to do (...) I just said to myself, what do I do to make this better? (...) So I just decided that right from day one this time, this was it. I mean we’d had all those other cancers, I’d lived through his bowel cancer which was a fairly horrendous operation and having his lung out was another horrendous operation, and I’d lived through all of those, so I just felt this time... (...) I just felt well, this is it, and I’m here for the long haul, so I was.

For other participants, the everyday difficult circumstances they encountered made it necessary for them to exercise strength in their attempts to produce a positive outcome for their loved ones. For example, Jean cared for her husband at home and described a number of difficulties associated with caring, including liaising with health professionals. She provided an account of a situation where she had to be strong and to “fight” for her husband.

I couldn’t get parking near the entrance to the hospital, so I pushed him up the hill in the wheelchair. It was a hot day, and I’m not that young myself, (to) get up to the ward after going through the admission sections, and I said to the girl, “oh, [husband] to be admitted”, and she said “oh, no, we haven’t got an admission in today”, and the other girl said “oh yes we have, oh yes we have, second door on the right”...left me on my own, so I go in there, the bed’s this high, couldn’t work out how to get it down, no pillow, no blankets, no towels, previous patient’s medication’s in the...the locker, and no wonder why you get frustrated, ’cause my husband could see I was getting upset, he said “don’t worry about it, don’t worry about it”, but you had this feeling that you must fight for them, they’re being treated badly, so you must fight for them.

In a similar vein, Gina made reference to an everyday task that she had to master in order to provide the care for her husband with respiratory cancer as an illustration of what she had to do out of necessity. Her husband was dependent on her in meeting many of his needs, which included daily injections for “acute diabetes” he had developed as a result of medications prescribed for cancer.

So then I had to do, um, the diabetic checks every day, and give him insulin and... which I never thought I’d be able to do in my life, but you do. You just do.

These findings support previous research that reported that wives of men with prostate cancer experienced an increase in personal strength following their husbands’ cancer (Manne et al., 2004b). Personal strength was a benefit also reported in
previous research with adult daughters of a person with cancer (Leedham & Meyerowitz, 1999), and bereaved carers who had provided home based care (Koop & Strang, 2003). Positioning themselves as having the strength to negotiate caring demands could be interpreted as a way that enabled informal cancer carers to construct these demands as “difficult but not impossible to manage, and that drawing upon existing or acquirable skills offers a genuine prospect for mastery” (Lazarus, 1998, p.198). In this context, for some participants, the caring experience produced a situation of ‘self-discovery’ through which an insightful understanding of themselves, their abilities and the act of caring itself was developed. For them, this understanding was positive and rewarding in their effort to make sense of their caring experiences after the death of their loved ones.

**Personal growth**

For many participants, caring for someone with cancer, and facing the likelihood of their imminent death, was positioned as having facilitated personal changes and growth. As one participant commented on the open ended questionnaire “the wonderful spirit of people who are dying, whichever way it may be, i.e. in pain, with peace, or just railing. I have learnt so much about humanity that I did not know in my previous 60 years”. Two sub-themes pertaining to the sense of growth were identified in participants’ interview accounts: ‘Relationship with Others’ – the changes in their ways of relating to others; and ‘Perspectives on Living’ – the different perspectives participants took up in order to engage with life after the illness or death of their loved ones.

**Relationship with others**

A number of participants gave accounts of changes which occurred in broader family relationships as a result of the experience of caring for someone with cancer. This was often positioned as the result of a changed attitude to relationships, and a re-valuing of connectedness, resulting in past difficulties being resolved, as is illustrated by Ellen’s account.

… of course my friend was a huge part in that of my changing attitudes and the way I thought and the way I lived … it’s a confronting thing and it made me think, it made me go on my journey too to get myself in order and to repair damages that had been done with family and so on, even though my father had passed on, I could do that. And I’m just sorry he wasn’t here so I could talk to him, but I was able to repair a few issues as we all have with family, that was because I was attending her and I could see the sadness in her.

The awareness of mortality which comes from caring with someone with cancer, was positioned as central to this re-valuing of relationships, resulting in the expression of positive feelings, and relationships which were more caring, as Donna commented:

Look it probably changes you as a person. But I’m not sure how useful that is to you. You take on, and particularly if you’ve been, not properly exposed to illness before but it changes you because it makes you express your feelings to people where you might not
have said them before. I think it makes you a more caring and understanding person. And I am probably a nicer person as a result of it. ... You're more overt I think with showing people how much you care for them.

Tessa also spoke of the ‘growth’ in herself and the greater closeness in her relationships with others as a consequence of being the carer of her mother.

Maybe I just grew out of the experience into the way I am now. No, I think it’s definitely come out of that experience ... I can see a real kind of growth prior then through that experience and then beyond that so it’s, yeah, it’s certainly been kind of growth in that closeness, in that dependence on my friends.

As appreciating relationships with others has been found to be associated with better adjustment in informal cancer carers (Kim et al., 2007), this is an important finding.

*Changed perspectives on living*

As a consequence of experiencing the challenges and difficulties associated with caring, and having had to witness suffering the death of their loved ones with cancer, some participants provided accounts of changes in their perspectives on living, which they positioned as being positive and rewarding. Debbie, age 61, caring for her female partner with respiratory cancer, provided an account of change in how she is able to “experience the world” as a result of her caring role and subsequent bereavement. Debbie positioned this perspective to living as being “a gift” from her partner.

Sometimes I might come across something in the house, you know, like some little note that she wrote or something that I remember her needing or worrying about, and I think now look at you... you’re dead in the ground. I know that sounds callous, but she’s gone and all that worry for what, it’s irrelevant, and it really makes a difference to how I experience the world I think now. You know... it doesn’t actually matter in the end ... And actually you know you are going to end up dead in the ground and it won’t matter. So I feel that is a gift from her in a way.

Brian, who despite having “generally hated the whole thing” of caring for his wife due to the challenges and difficulties he experienced, constructed an account that illustrated changes in his life priorities resulting from his caring experience.

Yeah, well I used to, well when I was working seven days a week I didn’t have much time, but now I’ve done a lot of walking and get out and do things I want to do and I’m now looking at buying a motor home to go around Australia. Well her, me and my wife, we were always going to do it and now I’m going to do it....So it’s something I want to do and it was something we were going to do, so I’m going to do that.
Thus regardless of the difficulties and challenges associated with caring for a loved one with terminal cancer, when given the opportunity to reflect on the whole of their caring experiences, the majority of participants said that they now focused on the positive aspects of caring, allowing themselves to experience benefits from the caring experience. This is exemplified by Donna, who stated “But you, yeah, I think you come out of it thinking, oh you know, I really feel, I do feel quite privileged to have done it”.

This was positioned by some participants as a reflective process which could only take place in retrospect, after the caring was over. As Olga commented, “Because now, a lot of what I remember are the good things, which is how you want it to be. And I remember the good things rather than just how terrible it was”. Similarly, Gary said:

> I’ve sort of come through the whole... come through the whole process, and looked back on it, and go “mm, that was a good experience”, if you could say that.

These reports of a changed perspective on living confirm the finding of Leedham and Meyerowitz (1999) that informal cancer carers report living life every day, not letting little things bother them, and the finding of Germino, Fife, and Funk (1995) that cancer carers re-evaluate life priorities. In this context, it could be interpreted that the difficulties faced through caring and subsequent loss were constructed by participants as a “growth-promoting experience” (Manne et al., 2004b, p.43). However, what is interesting from the accounts of participants’ in the present study, made available by the qualitative research methodology, is the details of how this growth is constructed, in terms of changes in their relationships with others and changed perspectives on living. This is noteworthy, for it has been suggested that an “important task of resolving adversity is the development of an understanding of the hardship and its implications” (Pakenham, 2005, p.985). Therefore, it could be argued informal cancer carers construct and ascribe subjectively satisfying meanings to their caring as a strategy to make sense of the difficulties, and in doing so, not only achieve a sense of coherence but also find positive reasons to remain as a carer, or in the case of bereaved carers, deal with loss. This provides support for the view that interventions developed to support informal cancer carers need to enhance positive benefits of caring, as well as ameliorating difficulties (Hudson et al., 2005).

This supports the assertion of Davis, Nolen-Hoeksema, and Larson (1998) that the act of finding benefits in traumatic situations involves individuals learning something about themselves (e.g. strengths), about others (e.g. valuing relationships) or about the meaning of life (e.g. personal growth). These accounts of benefit finding in cancer caring could be interpreted as the carers’ ways of reconciling distress and difficulties through constructing subjectively meaningful interpretations of a challenging situation, and focusing on positive aspects of the experience. This is in line with the work of Neimeyer, Baldwin, and Gillies (2006), who argued that a significant loss, such as that of major illness or death, produces a profound disruption, which requires “active attempts to (a) make sense of the loss, (b) find some sort of “silver lining” or benefit in the experience, and (c) reorganize one’s identity as survivor” (Neimeyer et al., 2006, p.718).
Positive aspects of providing palliative care at home

Bereaved cancer carers are of particular interest in examining positive aspects of cancer care, because they are in a position to make sense of their caring experiences as a coherent whole. Gergen and Gergen (1993) argued that an individual’s experience in a given moment can be nonsensical unless it can be meaningfully related to the past and is placed in the context of preceding and subsequent events. It can thus be argued that bereaved carers’ accounts will not only reveal the way they “integrate and surmount difficult experiences” but also their construction of “benefit out of adverse events” (Monroe & Oliviere, 2007, p.2).

In the present study, 22 of the participants were bereaved at the point of interview. A number of themes emerged in relation to accounts of rewards being experienced as a result of providing palliative care at home. These included a sense of reward for doing something good; meeting the expressed needs of the patient; being able to continue with normal life as much as possible; improving the conditions of the relationship, and meeting cultural expectations of the right thing to do.

The personal reward resulting from doing something good was emphasised by many participants, as it evidenced by the account of Olivia who cared for her closest friend with respiratory cancer, “it was a privilege to do it, I could not possibly have done anything else”. Similarly, Ellen who cared for her friend with multiple types of cancer, commented “it was a gift to me to be able to do it”. Providing necessary care at home was also positioned as being “rewarding”. For example, Fred (57 years old) who cared for his wife with breast cancer offered the following account: “Yes, I suppose to some extent it was rewarding for me because I could do it and it meant that it kept her out of hospital”.

Satisfaction in meeting the expressed needs of the person with cancer was also central to caring being experienced as rewarding. For example, Gary emphasised the importance of being able to be with her at home throughout his partner’s illness.

*I’d have to say it was worthwhile towards the end, you know what I mean. That I helped her, I felt like I’d helped her all the way through. And that she appreciated, like, me being there. That was the point, you know.*

Similarly, Anne described the experience of caring for her husband as not only “rewarding to give him his wish to be at home” but also it was an “easier” situation than if he had been hospitalised due to other everyday tasks and demands.

*He died here at home where he wanted to be. Um...and, um...oh, I actually found that not just rewarding, it was actually easier. (...) My youngest...my kids were only nine at the time. And I believe that if they...if he was in hospital...you want to spend as much time as you can there. However, you know...on a hospital ward there’s no washing machines, there’s nowhere to cook your dinner and, you know...bath your*
**kids and...So, you know what I mean, you can sort of get on with your life and still be there with him as well.**

The importance of this sense of normality to “get on with your life” was also emphasised by Maxine, in caring for her husband with a brain tumour.

*And after all, if somebody remains in their own home they feel much more comfortable. They’re not institutionalised so their limited time is more normal. So I believe that whatever support can be given to keep that on a fairly even keel is very important.*

Maxine’s account emphasised the importance of external support from a local palliative care team in facilitating her ability to care for her husband at home. This was repeated by many other participants who described palliative care teams as “wonderful”, (Anne), “very nice and sensible” (Stephanie), “amazing” (Gina), and “really good” (Olga), in providing “a lot of help” (Adam). Other participants, such as Olivia and Jean, paid privately for home nursing, or received support from family members.

Caring for a person with terminal cancer at home was an experience some participants reported as having had a profound, and positive, change in the relationship with the person for whom they cared, which made the caring rewarding as a consequence. Carol provided an account which illustrated this.

*(…)* because I’d spent so much time with my mum, we talked a lot about other family members...and a lot of personal information. I mean it’s very confessional when you’re dying as well so it’s hard to hear these things...I disliked her for a really long time and then she sat down, when we talked for four years, I realised that...she’s a person who’d made mistakes in her life and we adored each other in the end.

In contrast, Jean gave an account of palliative home care as something which was expected of her, and which she positioned as positive because it was the “right thing” to do, avoiding the “dreadful” experience of her husband dying in a hospital.

*I don’t know whether I felt it was rewarding, but I just felt it was the right thing to do and I should’ve done it anyway (...) so I don’t look on it now as rewarding, I look at it as yes, I’m glad I’ve done that, and while it was tough at the time, that’s all in the past, so I...you know, I don’t have any regrets, I think some people that...I think to die in hospital would be just dreadful, (...) so yeah, I...I feel I’ve done the right thing.*
Positive Meanings ascribed to the dying process

Being present through the dying process was positioned as an important and rewarding aspect of providing informal palliative care. For the fifteen participants who cared for someone who died at home, the place of death was positioned as central to the provision of a “good death”. For example, the ability of a home death to provide an aesthetic experience for some individuals is highlighted by Carol’s account of her mother’s final night being “a beautiful moment”:

But having her in the house, and when my dad said “I’m going to go and sleep in the room with her”. You know, at first I thought oh jeez that’s taking it one step too far but you know what, I think it was a great way. And you know throughout the night we’d go into the room and visit her. And it was really a beautiful moment.

The way in which a home death can foster the inclusion of others, as well as being calming and comforting, was also emphasised by Adam who described a social event that involved friends visiting his wife at home when she was nearing death and the meaning he ascribed to this event with respect to the dying process.

(...) and people would just come in and they were reminiscing and laughing and, yes, it was just amazing. I said to her, “how good is this”. I said “look, when I die I’m going to be in a hospital room about ten rows back, no one will ever know that I’ve gone for three days” and she’s just, it was just so good. And I think it made her, well I think it calmed her a fair bit to know that she could actually say goodbye to her friends and she could sort of feel the love that everybody had for her.

The way Adam made sense of the event enabled him and his wife to confront her impending death in a constructive and positive manner, allowing his wife to “say goodbye to her friends” in her own home, which “calmed” her at a time when death was foreseeable. In a similar vein, Jean reflected on her husband’s death in the following way.

...so yeah, the end you could say it was good, was pretty good, he was very peaceful, so...and he died at home, which he wanted to, because he thought he was going to have to go back to hospital because my girlfriend spoke to him on the Sunday night, she said no, you’re not going back to hospital. (…) and the people that were there when he died could see that yes, he had a peaceful death.

The description of her husband’s death as being “good” and “peaceful” enabled Jean to make sense of her caring in a positive way, positioning her caring effort as having produced a valuable outcome for her, her husband and others. Many participants’ also narrated accounts of experiencing a ‘completion’ with respect to the cancer
experience because of being able to have their loved ones die at home. This was made explicit by Margaret:

(...) and [my husband] died here at home (...) it is something we both wanted (...) it sort of meant that the story had its beginning, and its middle, and its ending all here. Um...that was...you know, we really...it was hard. It was very hard, but um...yeah. No, it was wonderful that, that could happen.

Alan offered an account of his mother’s death at home, wherein the difficulties he experienced in providing palliative care were balanced with the positive meaning he constructed in making sense of the loss experienced subsequent to her death.

And her last days before she passed away, it was sad, but I felt, it was very spiritual. (...) And it happened to be at home. I didn’t take her to a nursing home. (...) It was very spiritual.

The similarities in the accounts provided by Adam, Margaret, Jean, and Alan suggested that the sadness associated with their loved ones’ death was balanced with the peacefulness, dignity and spirituality identified at the moment of death. Significantly, these accounts emphasised the value of the home environment when death occurred.

In contrast, seven of the participants cared for someone who died in hospital, as a result of the wishes of the person with cancer, or because of medical necessity. Whilst dying in hospital had been anticipated with some dread, all of the participants were able to construct the experience as positive, even though they still positioned it as not an ideal situation. This is illustrated by the experience of Judith, who had cared for her husband with colorectal/digestive cancer at home, until he “needed so much intervention and I couldn’t lift him”.

I think one thing that really frightened me was that if he was in hospital he wouldn’t be allowed to die peacefully but they just made it, they did everything so well. They made sure he had a private room for him and that we were by ourselves and that we had everything we wanted. It couldn’t have been better. In the end I think... I suppose I feel really disappointed that I wasn’t able to keep him at home.

Naomi gave a similar account, saying that it had been her partner’s wish to die in hospital, and she was able to be with him at the end, sleeping beside him for two nights.

The oncologist was talking about sending him home and I’m thinking, I can’t look after him at home. As much as I wanted him to come home, that’s all I wanted....he always said that he didn’t want to die at home, that was his one thing he said to me, he did not want me to have those memories of him dying at home and now I am so glad that he didn’t come home and die here because I think it would make it even worse now.
Naomi positioned hospital as a place of death positively, and indicated that it was helpful in her grieving process. However, she had to resist pressure from medical staff to “send him home”, illustrating the influence of the discourse of home as a place of a “good death”.

Implications of findings

Whilst difficulties associated with caring for someone with terminal cancer are now recognised, it has been argued that the positive meanings carers construct in making sense of their palliative caring experiences have often been obscured (Sinding, 2003). Kramer (1997) argued that a lack of attention to the positive aspects associated with caring not only “skews” our understanding of the caring experience but it also “limits our ability to enhance theory of caregiver adaptation” (p.218). In a recent study of 47 informal carers providing palliative care, Hudson (2004) reported that 60% of participants could identify positive aspects of the role, including closeness with the person with cancer, and experiencing caring as a privilege. It has also been reported that the relationship with the person with cancer was strengthened because of the uniqueness of the palliative caring experience (Koop & Strang, 2003), or the threat of imminent death (Andershed & Ternestedt, 1999). This has led to bereaved carers reflecting on the whole caring experience as an accomplishment (Koop & Strang, 2003), or as an opportunity to have spent quality time with the person for whom they cared (Grbich et al., 2001b). Equally, offering a home based death has been positioned as a positive way of preserving the dignity of the person with cancer (Koop & Strang, 2003) and allowing carers to achieve their goal of being able to offer a “good death” (Sinding, 2003). Caring is thus positioned as a “gift” (Grbich et al., 2001a, p.33), which offsets the resentments.

The way bereaved participants in the present study made sense of their experiences has implications for how they negotiated and reconciled these difficulties, challenges, and their loved ones’ death. In doing so, they were able to construct their experiences as being “worthwhile” and, perhaps more crucially, were able to produce positive interpretations of the palliative caring experience. In this context, the implication arising from this study is that an effective way of supporting informal cancer carers is to help them see the good with the bad, in order to reconcile the difficulties embedded in their caring experiences (Hudson et al., 2005), which may act to facilitate a “healthy bereavement” (Koop & Strang, 2003, p.139).

However, the ‘decision’ to care for someone at home is not always an option for carers, due to social-structural factors. Consistent with findings from previous research (Grunfeld, Coyle, Whelan, Clinch, Reyno, Earle et al., 2004), the ability of some participants to care at home was reduced when the health of the person for whom they were caring declined, requiring hospitalisation. Social support, time and economic issues are also important factors. In the present study, a number of the participants cut back on work hours, or gave up work altogether, with negative financial consequences. As Carol said, “Financially it was just huge, to drop from a corporate salary down to a carer’s salary of seven and a half thousand a year”. In contexts where there is no carer’s allowance, and no state funded professional support or hospital care, these social-structural factors may impede the ability of individuals to offer home cancer care (Parker, Grbich, & Maddocks, 2001; Wiles, 2003).
The implications of the place of death has been the focus of a number of research studies (Addington-Hall & Karlsen, 2000; Goodenough, Drew, Higgins, & Trethewie, 2004; Thomas, Morris, & Clark, 2004). Whilst previous research has indicated that the provision of palliative care at home can increase emotional distress for informal cancer carers (Kurtz, Kurtz, Given, & Given, 1997) and produce detrimental effect on their bereavement experiences (Addington-Hall & Karlsen, 2000), other research has indicated that palliative care at home can produce positive bereavement experiences (Koop & Strang, 2003). Indeed, in the context of palliative care, to die at home has been “considered ideal when defining a good death” (Stajduhar & Davies, 2005, p.21). This is confirmed by accounts of participants in the present study who described wanting to offer their loved ones a “good death” at home, which facilitated the process of saying goodbye, fostered the inclusion of others, provided closure, and was a spiritual experience. However, participants who experienced a hospital death also described it positively, suggesting that many of the rewarding aspects of a home death can be experienced in a hospital setting, if this is facilitated structurally, and if carers can construct the experience in a meaningful way. Health professionals need to recognise this, and not position the home as the only place to have a “good death”, as this may not meet the needs of carers, or the person with cancer.

**Summary and conclusions**

The employment of a qualitative research methodology allowed for detailed exploration of the aspects of informal cancer caring that participants regarded as difficult or as positive, complementing and extending previous research in this field. In particular, the findings presented in this section contribute to understanding gender differences in providing care. Men were more likely than women to report shock at the diagnosis, to describe themselves as self-silencing because they never express vulnerability, and to describe change in roles as a difficult aspect of the caring role. However, they were also more likely to describe an improved relationship following their taking on a caring role. Women were more likely to report anxiety, caring by choice and self-silencing as a requisite for coping. Difficult aspects of the caring role that were more likely to be reported by women include having to make medical decisions, a change in relationship dynamics with the person with cancer, neglecting self and other relationships, physical health consequences, loneliness-isolation, difficulties in requesting or accepting help, and feelings of helplessness and loss of control. Women were also more likely to report discovering person strength through caring.

This suggests that there are many aspects of the caring role that are experienced differently by women and men, with women experiencing caring as more burdensome, and as having more impact on their psychological and physical wellbeing. This confirms and complements the findings of the survey, where women reported higher burden of care and unmet needs, as well as higher depression and anxiety.

With reference to the bereaved carers, it was not possible to make explicit claims about how the caring experience could have affected their bereavement, as this issue was not specifically examined in this study. Equally, it is not possible to say whether
benefit construction was a retrospective activity, achieved as a way of making sense of caregiving and loss. It is therefore important that future research endeavours to specifically explore the relationship between the meaning making process in which informal cancer carers engage and both the caring and bereavement experience. There is presently no longitudinal research examining this issue over the course of caring through to bereavement; this would offer important insights into the nature and consequences of benefit finding for both cancer carers, and those who are bereaved.
Section Five
Positive and Negative Interactions with
Health Professionals: A Qualitative
Investigation of the Experiences of Informal
Cancer Carers

Background and Review of the Literature

Over the past few decades the shift from a purely biomedical to a more humanistic
approach to health care has emphasised empathy as a critical component for clinical
practice (MacLeod, 2000). Health professionals are required to not only provide
medical and health information to those receiving care, but to communicate this
information with sensitivity (Morris & Thomas, 2002). Indeed, research has shown
that empathy and support from health professionals is associated with patient
satisfaction (Acorn, 2008), wellbeing (Wilkinson, Roberts, & Aldridge, 1998),
psychological comfort, personal agency and hope (Thorne, Hislop, Armstrong, &
Oglov, 2008), as well as mutuality and trust (Halldorsdottir & Hamrin, 1997). Equally, a
lack of empathy and support is associated with dissatisfaction (Frankel, 1995), as well
as with medical complaints (Fallowfield, Jenkins, Farewell, Sual, Duffy, & Eves,
2002).

It is argued that empathic and competent care is particularly important in the context
of cancer, as diagnoses can be distressing and treatment choices are often complex
(Gysels, Richardson, & Higginson, 2004; Ong, De Haes, Hoos, & Lammes, 1995).
However, most of the existing research has found that many people with cancer report
that their interactions and experiences with health professionals are often perceived as
uncaring. Ineffective health professional communication – typically manifested as
indifference and insensitivity (Halldorsdottir & Hamrin, 1997; Thorne et al., 2008)
and a lack of information provision – typically manifested as incompetence and
neglect (Frankel, 1995; Ong et al., 1995) are the key issues that lead to patients
feeling uncared for (Ford, Fallowfield, & Lewis, 1996).

Since family members have become the primary source of informal care-giving to
people with cancer (Cameron, Shin, Williams, & Stewart, 2004; Docherty, Owens,
Asadi-Lari, Petchey, Williams, & Carter, 2008), often taking on responsibilities that
can be physically and emotionally challenging, there is also a need to examine how
informal carers experience interactions with health professionals and how these
interactions impact upon their own well-being (Jansma, Schure, & Meyboom de Jong,
2005; Thorne, Kuo, Armstrong, McPherson, Harris, & Hislop, 2005). However, there
is a critical void in the literature that examines these interactions and their impact
upon the subjective wellbeing of carers. This void may be due in part to the dominant
model of health care delivery that privileges the sanctity of the doctor-patient
relationship (Morris & Thomas, 2001), which can result in the information needs of
informal carers being subordinated to those of the person with cancer (Morris &
Thomas, 2002). There is, therefore, a need for research to redress this void as carers
require information and support from health professionals in order to adequately care, and to assist with their own psychological wellbeing (Clayton, Butow, & Tattersall, 2005a).

The limited amount of research that does examine informal cancer carers’ interactions with health professionals has tended to focus almost exclusively on the experiences of bereaved carers, or carers of people in the palliative or advanced stages of cancer. For example, the results of a survey of 156 bereaved cancer carers (Lecouturier, Jacoby, Bradshaw, Lovel, & Eccles, 1999) found that although 90% of carers felt that they had the opportunity to ask questions to health professionals about what was ‘wrong with the patient’, 62% felt that they had not been given adequate time to discuss matters fully with health professionals. Ninety percent reported not being given any written information about the illness and treatment, despite the fact that 60% would have found this information helpful (Lecouturier et al., 1999). Other research has shown that carers report lack of information about practical and medical tasks, their own health, their participation in the implementation of the patient’s care, and social support (Jansma et al., 2005) – issues that can lead to feeling unsupported by health professionals (Eriksson & Lauri, 2000; Leydon, Bynoe-Sutherland, & Coleman, 2003). Informal carers have also reported that the control of pain and other distressing symptoms by health professionals is inadequate (Sykes, Pearson, & Chell, 1992), that health professional communication is often poor (Higginson, Wade, & McCarthy, 1990), that the provision of nursing care and equipment is lacking (Addington-Hall, MacDonald, & Anderson, 1991), that more information is needed about what to expect during this phase (Clayton, Butow, Arnold, & Tattersall, 2005b; Clayton et al., 2005a), and that emotional support is lacking for the family of the person with cancer (Lecouturier et al., 1999).

It is important to recognise that the needs of carers are not static and change according to whether the person they are caring for is in the early, middle, or terminal phase of cancer (Morris & Thomas, 2002). For example, carers of people who are undergoing early stages of treatment for cancer have to manage the shock of a cancer diagnosis, as well as learn to provide physical and emotional supporting, issues that those caring for a person with advanced cancer may have become more adept at managing (Cameron et al., 2004; Hodges et al., 2005). Similarly, Harrington, Lackey and Gates (1996) reported that carers of people receiving treatment for cancer wanted information about treatment side effects, as well as the type and extent of the illness, whereas greater physical care needs, desire for equipment to help with care, and information about the type of symptoms to expect, were reported during the palliative care stage. Further research which seeks to explore how cancer carers, across a range of cancer stages, experience and position interactions with health professionals is needed to explore these issues more fully.

The aim of this aspect of present study was to examine how informal cancer carers across a range of cancer types and stages subjectively position their experiences of interactions with health professionals. Drawing on the interviews conducted with 53 carers, the analysis was guided by the following questions: What do informal cancer carers position as positive or negative interactions with health professionals? What are the perceived consequences for carers of positive or negative interactions with health professionals? The analysis will focus on interactions with health professionals that were positioned as positive or negative by informal carers, and accounts of the
consequences of such interactions. Demographic information is provided for longer quotes, which are omitted to enhance readability from shorter quotes.

Results

Positive experiences with health professionals

Health professionals who are ‘warm’ and ‘genuine’

In the majority of accounts of positive experiences, health professionals were positioned as ‘warm’ and ‘genuine’ in their approach, suggesting that the characteristics of the individuals concerned contributed largely to the positive interaction. For example, when discussing his interactions with his wife’s surgeons, John (31 years old who cared for 30 year old wife with breast cancer in remission) said, ‘I thought they were genuine people and were genuinely interested, and it wasn’t just another number and cancer victim 457 or whatever’. Adam (46 year old bereaved carer of his wife with breast cancer) talked about having ‘so much admiration’ for the oncologists, doctors and nurses who were caring for his wife: ‘They’re just so compassionate and all of them are beautiful people. (…) Yes my word. They were just amazing people. Nothing was too much trouble’. Similarly, as Keith said, his wife’s surgeon was ‘just phenomenal’, and was ‘one of those freaks you see on TV that actually care about people’. Other carers elaborated on the individual traits of these supportive professionals, giving accounts that were rich in hyperbole especially when talking about medics, describing them as ‘genius people’; ‘awesome’; ‘amazing’; ‘magnificent’; ‘brilliant’; ‘lovely’; ‘absolutely splendid’; and ‘absolutely tremendous’.

Some carers positioned particular groups of health professionals, primarily nurses and palliative care staff, as ‘caring’, which was a core aspect of their positive experience. For example, Margaret said that the nurses ‘were just so good’ and ‘gave us such a sense of caring about the patient and the carer’. Similarly, although Gary (61 year old bereaved carer of female partner with lung cancer) reported having less than ideal experiences with the oncologists treating his partner, he said of the nurses:

The nurses are very into how everybody is, and they’re absolutely tremendous, because they really counsel people. They give you support. And the nurses at oncology... or chemotherapy, were absolutely wonderful. Because they’d talk o you, and (ask) how are you coping?

Similarly, Adam (46 year old bereaved carer of his wife with breast cancer) reported that the palliative care workers are ‘wonderful’ insofar as they ‘don’t just treat you like a number, I mean you really care to them’. He went on to say that ‘the one thing I always tried to do was to keep her dignity and I think that those people helped me do that’. Practical support from palliative care staff was also positioned as important, with participants reporting ‘really good help’ from the workers which included the loan of equipment and ‘advice about how to do things’.
Health professionals who are accessible and approachable: they ‘really listen’

When carers reported having a positive experience with health professionals this was also related, in large part, to the professional’s perceived accessibility and approachability. For example, Kathryn (67 years old caring for husband with brain cancer) described her husband’s doctor as ‘marvellous’, and said that although ‘she’s a very busy woman’, ‘she’s accessible and that’s the main thing. I could ring her and ask her and she will find time to ring me.’ Similarly, Olga (54 year old bereaved carer of partner with renal cancer) said that she and her male partner ‘had an absolutely phenomenal GP who actually made house calls and he came in the last weeks and never charged’ for his visits.

In particular, being able to contact a health professional and ‘get an answer’ to a medical question was positioned as important. This was firstly because talking to a professional when the person with cancer was in physical pain usually provided a solution for how to alleviate that pain. Secondly, alleviating this physical pain was described as providing an almost immediate decrease in carer distress. As Judith (57 year old bereaved carer of husband with colorectal cancer) said, ‘I found I could ring one of them (nurses) and talk to them and just feel better after I’d spoken to them’.

Other carers discussed the importance of an accessible and supportive palliative care team. Gina (59 year old bereaved carer of husband with advanced mesothelioma) said ‘the palliative care that were up there was absolutely amazing. They could be contacted at any hour of the day, and were very responsive’. A key aspect of this type of accessibility and approachability was that health professionals ‘really listened’ to and heard carers’ needs and concerns. For example, when discussing her experiences with her husband’s haematologist, Cheryl (50 years old caring for husband with haematological cancer) said: ‘he was just so good (...) he treated you as a person. He knew that you’d have a lot of questions’ and ‘he really listens’.

Health professionals help carers feel comfortable and accepted

Feeling accepted and being made to feel comfortable within a clinical context was positioned as another key aspect of positive experiences with health professionals. Connie (70 years old caring for husband with advanced prostate cancer) provided an example of this – saying that throughout the course of her husband’s treatment she started to feel like ‘part of the family’: ‘you know he’s really really nice, he’s a terrific doctor. And everyone in the Centre they’re lovely… It makes you feel really comfortable to go there’. Similarly, Melanie talked about being included in the cancer treatment and decision making process by her husband’s oncologist who ‘made a point of it being a team thing and that we were together with it all’. Being accepted by health professionals was positioned as a particularly important issue for Jessie (aged 36), a lesbian carer for her 38 year old female partner with breast cancer. Although Jessie had been in a relationship with her partner for over twenty years, she had never ‘come out as a lesbian’ until her partner was diagnosed with cancer. The surgeon treating Jessie’s partner was ‘very good and you know accepting of me as her partner’ – a situation that was described as having made the coming out process easier.
Allied health professionals provide a space for carers’ cathartic release

Throughout the cancer journey carers often have an ongoing relationship with allied health professionals such as social workers and psychologists. For many participants, social workers in particular were described as providing practical assistance and strategies enabling more effective coping with the caring role. Evelyn reported that the social worker she was seeing was ‘great’, and that the social worker her mother was seeing provided ‘really good stuff’ for her - including relaxation techniques and aromatherapy - techniques that Evelyn experienced as making her role as a carer easier. Many of the carers also talked about how social workers provided them with ‘mental support’ – and that although, as Sally mentioned, medical doctors were ‘good to talk to’, they often focused more specifically on the needs of the patient - ‘most of the talk was always about the patient’. James felt that he needed, and considered he received, ‘a lot of support’ with his wife Nancy, who has breast and bone cancer, ‘because she’s very depressed and she has these really big mood swings’ that ‘upset the dynamics of the home greatly’.  This kind of support was also mentioned by carers in relation to their interactions with psychologists. As Gary said: ‘having someone to actually bounce off of and swear and say, “This is not fair, and I can’t handle it,” and have a few cries and a tear (...) helped me a great deal’.

The consequences of positive experiences with health professionals: Feeling in control and empowered

When carers constructed their interactions with health professional as positive, they reported feeling valued and recognised: ‘they made you feel good’ (Margaret) and ‘he treated you as a person’ (Cheryl); comforted: ‘really reassured’ (John); emotionally supported: ‘they saved my sanity’ (Ellen); and practically supported: ‘We got all the support that we needed’ (Fred); and less isolated: ‘I’ve realised I’m not alone’ (Diana). These feelings were positioned by many carers as leading to an increased sense of control over the cancer journey and their caring responsibilities. This increased sense of control was associated with reports of feeling empowered – key in terms of the perceived manageability of the caring role. For example, Evelyn (29 years old caring for mother with haematological cancer) found it ‘quite empowering’ and ‘felt as though I wasn’t quite as hopeless as I had been’ because the nursing staff treating her mother were ‘wonderful’ and ‘forthcoming’ with information. For Keith, feelings of empowerment were positioned as stemming from the information provided by health professionals. As he told us, ‘what you really need is information, that’s something you’ve got to hold onto’ because it ‘gives you some empowerment - you’re in the hands of the Gods but the information was great’.

Negative experiences with health professionals

‘Not a very good bedside manner’: A lack of empathic communication style

Many carers who reported negative experiences with health professionals were primarily concerned with communication style, in particular, lack of empathy. Carers positioned some health professionals as having ‘no humanity’, ‘no rapport’, as ‘bastards’, ‘cold’, ‘shockers’, ‘uncaring’, ‘Mr Bigs’, or as not having a ‘very good bedside manner’. In the majority of these cases, they were referring to medics. Poor
communication skills when delivering medical results or ‘bad news’ were positioned as particularly problematic. For example, Gary recounted the story of his female partner’s diagnosis of lung cancer: ‘After the first time, when she went with her son, and he (the oncologist) said, ‘You’ve got six to eight months. That’s it.” Every time we went, he was professional and cold’. Similarly, Gavin (67 years old caring for female friend with respiratory cancer) described the issue ‘that needs to be improved’ as doctors being ‘a bit more reassuring’ about delivering ‘news’ or medical results, ‘rather than simply send people away more or less saying, well you better go and make whoopee if you like while you’re still alive.’ Naomi (41 year old carer for husband with a brain tumour), told us that ‘as much as’ she ‘respects’ her husband’s surgeon his ‘bedside manners are unbelievable,’. When talking about the way in which her husband’s medical results were communicated, she said ‘It’s just the way they sort of tell you and deal with it, it’s just like you’re another piece of cattle type thing’. In a similar vein, Margaret reported that when she asked questions of her husband’s oncologist, she felt that she ‘might as well have been Eric’s jumper or his coat or something for all the notice the man took of me’. This reinforces the need for health professionals to take time to explain diagnosis and treatment, and to develop positive communication skills for use in their interactions with carers, as well as patients.

A lack of information provision

Lack of information about the possible progression of cancer, how best to care for the person with cancer, and who to turn to for additional support was one of the most common accounts of a negative health professional experience. Diana (44 year old caring for husband with prostate cancer), said that although she ‘doesn’t want to speak ill of the medical world’, ‘the top surgeon’ in their area ‘did not educate us on anything’, and ‘nothing was really explained’ to her and her husband ‘in any depth, in anyway whatsoever’. Hilary (59 years old caring for husband in remission from colorectal cancer) also felt that her husband’s doctor ‘didn’t really explain well enough’ to her about the decline in her husband’s physical stature as a result of his stomach cancer. She said it would have been helpful if the doctor had said: ‘well you’re going to have a shadow of a husband from hereafter because of losing your stomach and not being able to hold nutrition’.

For Marcus (47 years old cared for wife in remission from breast cancer), having information or some guidance about ‘the symptoms, the after effects which we were supposed to look for, what the patient goes through but what the carer has to look for or the best way to give help to the patient’ would ‘have helped out’, ‘made the picture a lot clearer’ and allowed him to make more informed decisions. Others gave accounts of not being given adequate information about the administration of medication. As Lesley (62 years old caring for husband with respiratory cancer) commented, ‘just keeping track of, was he taking the right medicines and whether the medicine was the right thing for him’ was difficult. Lesley’s was an experience shared by other carers, including Judith whose statement that - ‘you were really conscious that you might be overdosing him or what if this is wrong’. This highlights the important need for information provision around the practical and often medical tasks, carried out by carers.
Not being provided with information about support groups and palliative care services was also positioned as a problem by many carers. Bella (36 years old caring for husband with prostate cancer) reported that she “was really, really angry for a long time with the actual surgeon because I just don’t feel that we were given, or I was given as the partner, any follow up support network, nothing”. She went on to say that, ‘if I’d just been given a bloody pamphlet by that surgeon to say that in your regional area, there is a cancer support nurse or there’s a cancer counselling service’ she would have felt a lot less ‘frustration and loneliness’. For Jean (61 years old caring for husband with prostate and bone cancer), who ‘didn’t know about palliative care, no one had told me what was available to me as a service’, coming across information about palliative care services was by chance – ‘I overheard somebody in the bed next to us talking to the doctors about care at home and I thought oh, what’s this about?

‘It’s just a maze’: Not knowing who to turn to for support

A number of carers reported that a major problem they encountered was a systemic one - namely the lack of coordination of services within the health system. This was described as leading to confusion about the appropriate person or agency to approach for their particular needs. As Jean said, ‘there was no overall umbrella that you can come under for cancer patients’. For Andrew, who had experience working in the health system, managing different professionals and agencies in the health sphere was described as ‘just a maze’ for the many carers who ‘don’t understand the system’, leaving carers with ‘no idea of where to go’. Maxine (67 years old bereaved carer of her husband with advanced prostate, bowel, lung and brain cancer), talked about the difficulties she faced arranging palliative care services for her husband. What Maxine ‘would like to have seen was a proper coordination of the services by somebody other than myself’ which may have prevented the ‘wheels falling off’.

The consequences of negative experiences with health professionals: ‘Nobody gives a damn’ - disappointment with the health system

The feeling that ‘nobody gives a damn’ (Brian) was commonly reported by carers who described negative experiences with health professionals. In many of the carers’ accounts there was a sense that they had been neglected, and that the system and those working within it had ‘let them down’. For Brian, this general feeling of being neglected was apparent in his interactions with oncologists, social workers, and surgeons – all of whom were ‘no help’ and led to disappointment with the health system. Brian’s feeling was echoed by Hilary, who said that she felt that ‘nobody’s helping me, nobody’s guiding me here’, leading to feelings of isolation. Similarly, Naomi (41 year old bereaved carer of husband with brain cancer) described her experience as ‘just horrible,’ when talking about the hospital medical staff treating her husband, saying: “They just left us then. I remember Tony saying after, and we were four floors up he said, I could have jumped out the window for all they cared, they just told us and just sort of walked out and you know deal with it by yourself”.

Feeling a sense of neglect and of having been let down by the health system was described as having disrupted many carers’ ability to cope with the cancer journey. As the accounts above highlight, for some carers this manifested as distress: ‘it had me worried and upset’ (Hilary); as anger - ‘I had this huge shouting match and crying
with the doctors and the nurses and it was just awful’ (Stephanie); resentment – ‘sometimes I feel enormous resentment towards the medical professions’ (Maxine); as ‘sheer utter frustration’ (Bella); and as loneliness – ‘it’s very hard, because you’re completely alone’ (Diana). These reported feelings of distress, anger, resentment, loneliness, and frustration are diametrically opposed to the feelings of control and empowerment that were reported by carers who had positive experiences with health professionals.

**Implications of findings**

The findings from this aspect of the study contribute to the significant gap in research on the construction of informal cancer carers’ interactions with health professionals, in particular, examining the factors positioned by carers as positive and negative in these interactions. Positive interactions were characterised as those involving health professionals who were experienced as warm and genuine, who made carers feel accepted and comfortable, and who were accessible, approachable and really listened. This finding is consistent with existing research which has shown that health professional accessibility is positively associated with carers’ well-being (Jansma et al., 2005), and that emotional support from health professionals is associated with carer satisfaction (Rhodes, Mitchell, Miller, Connor, & Teno, 2008). One of the defining features of positive interactions with health professionals in the present study was that carers’ felt recognised and valued – they were made to feel as though they ‘really mattered’. Interactions with health professionals were described by carers not simply as a series of clinical ‘appointments’, but as meaningful relational interactions based on mutuality.

The need to feel recognised and valued by health professionals has been discussed by previous researchers in the context of health professional and cancer patient interactions (e.g. Frankel, 1995; Thorne et al., 2005). Such research has shown that when health professionals make some form of human connection, and recognise patients as human beings rather than merely bearers of a diseased organ or ill body, people with cancer report increased feelings of wellbeing (Thorne et al., 2005). Our findings indicate that feeling recognised and valued by health professionals is also associated with carers feeling valued, comforted, emotionally and practically supported, and less isolated – feelings that are associated with increased feelings of control over, and empowerment within, their caring role (Docherty et al., 2008). As carers often feel out of control and disempowered (Flaskerud et al., 2000), particularly in relation to ‘expert’ health professionals and medical knowledge (Ong et al., 1995), the positioning of positive health profession interactions as facilitating control is an important finding.

Negative experiences with health professionals were positioned as involving poor communication, lack of provision of information, and absence of guidance about additional support. Poor communication on the part of health professionals is an issue that has been widely documented in previous research examining the field of oncology, primarily focusing on doctor-patient interactions (Fallowfield et al., 2002). The present study provides further insight into the aspects of communication that carers position as problematic. One of the key issues raised in this study was that the communication style of some health care professionals was lacking in empathy and
sensitivity. When we examine the assumptions underpinning medicine, including the values of detachment, distance (Frankel, 1995) and an objective focus on the diagnosis and treatment of physical dysfunction (Gysels et al., 2004), it is perhaps not surprising that some medics and nurses lack good communication skills. Despite this, empathic and compassionate communication training for health professionals such as medics and nurses has been demonstrated to be effective (Gysels et al., 2004), and these communication skills can be sustained and incorporated successfully into their practice (Fallowfield, Jenkins, Farewell, & Solis-Trapala, 2003). The present study suggests that such training should include communication with carers as well as communication with patients. Equally, whilst health professionals may believe that they are utilising positive and effective communication skills, carers and patients may not experience the interaction in the same way, positioning professionalism as coldness or lack of interest. This suggests that health professionals need to be sensitive to the needs and reactions of individual carers and patients, and to ensure that information has been accurately received and understood. Repetition of information across consultations, and provision of information in both verbal and written form, may assist with this process.

There is also a need to avoid seeing carers as a homogenous group sharing the same needs regardless of the stage of the cancer journey. This was illustrated in our finding that participants caring for a person undergoing early stage treatment would have liked more information about the administration of medicine and medical tasks, whilst participants caring for a person in the later and palliative stages would have liked more information about support groups, palliative care services and equipment. Although there is evidence that a lack of information provision can be related to carers’ own uncertainty and anxiety about contacting ‘busy’ health professionals for fear of being labelled as ‘demanding’ or ‘difficult’ (Hudson, Aranda, & Kristjanson, 2004; Leydon et al., 2003; Worth, Boyd, Kendall, Heaney, Macleod, Cormie et al., 2006), our findings show that lack of information was positioned by carers as the ‘fault’ of the health professional whom carers expected to provide medical information about the cancer as well as information about how best to provide care. Being provided with such information is positioned by carers as allowing them to make informed decisions, alleviating fear and confusion surrounding the administration of medicine, and preventing the situation whereby they are left not knowing who to turn to for additional support, and feeling as though the health system is a maze (Morris & Thomas, 2001). This reinforces the need for health professionals to address psycho-social aspects of cancer and cancer caring in their interactions with carers, along side medical aspects of the illness. The issue for health professionals to negotiate is when to provide information and how much of it to provide in order to prevent carers feeling as though they are being neglected. As carers may not be receptive to certain types of information at particular stages in the cancer journey, such as support group information in the early stages, this again suggests that repetition of information may be necessary to ensure that needs are met when they arise.

Another noteworthy finding was that the most extreme and polarised language was used by carers in relation to their positioning of medics. Carers positioned medics, such as surgeons and other doctors, as ‘arrogant pigs’, ‘bastards’ and ‘inhumane’, or in contrast, as ‘magnificent’, ‘genius people’ and ‘brilliant’- a polarisation not ascribed to other health professionals, such as nurses, social workers and
psychologists. The dominant socio-medical construction of medics as humane and competent experts with the power to heal, means that they take up, and are assigned to by others, a position at the top of the health professional hierarchy (Foucault, 1989). This positioning creates an expectation that medics should provide the most expert and competent care. When medics are perceived by carers to be providing such care, they are deified in a way that other health professionals who are not subject to the same socio-medical construction are not. When medics are perceived by carers as failing to live up to expectations, they become subject to extreme condemnation and are repositioned by carers as behaving in a way which is antithetical to the socio-medical construction of humane experts. This reinforces the particular need for medics to ‘get it right’ in their interactions with carers and patients, and emphasises the importance of good communication skills and training for both new and established medical professionals.

When carers positioned their interactions with health professionals as negative, we found that they also reported feeling neglected, let down by the health system, distressed, angry, frustrated, as though ‘nobody gives a damn about them’, or as though they are ‘another piece of cattle’. These carers clearly did not feel valued or recognised. According to Jessica Benjamin, the recognition of ‘the other’ as ‘another subject’ rather than simply as an object (a jumper or a coat in the case of one carer - Margaret), is necessary for the self to ‘fully experience his or her subjectivity in the other’s presence’ (Benjamin, 1990). Recognition begins with the other providing a confirming response, which in ‘the enjoyment of the others’ confirming response’ provides a mutual recognition that we ‘recognise him or her in return’ (Benjamin, 1990). For this mutuality to occur the carer requires a response and recognition from the health professional, and the health professional’s communication and interactions are dependent, to some degree, on a response and recognition from the carer. According to Benjamin, this mutual recognition is one of the key moments of transformation through which there is the recognition that ‘this other can share my feeling’ (Benjamin, 1990). It is in the space where health professionals recognise the feelings of carers - a recognition that can manifest, for example, as a caring or empathic response - that then allows carers to feel empowered or in control of their caring role. In contrast, the lack of recognition by health professionals that led to carers feeling neglected and distressed in our study is an example of the ‘crisis’ that can occur intersubjectively - the tension between asserting the self and recognising the needs of the other. This crisis, according to Benjamin, can be seen in part as stemming from Hegel’s idea of the self’s wish for absolute independence and the self’s need for recognition. That is, in trying to establish oneself as a self independent from others, the self must also recognise the other as a subject like itself in order to be recognised by it. Herein lies the paradox, in the very moment of realising our own independent will, we are dependent on another to recognise it. In this crisis, each self wants to be recognised and yet maintain its absolute identity. We could perhaps argue that health professionals who do not recognise or value the other (in this instance carers) are in this phase of crisis – unwilling to give up their own ‘mental omnipotence’ and denying everything outside themselves, so that a recognition of the reality of another cannot exist. The problem, of course, is that if health professionals fail to recognise the other, the emotional wellbeing of carers is affected, as is their ability to provide care, as the carer can feel positioned as an object, rather than an active subject, and as such, as someone who does not exist in the eyes of the health professional.
Summary and conclusions

Given that cancer care is increasingly being shifted from the hospital into the home (Aranda & Hayman-White, 2001), with the responsibility of caring typically placed upon informal carers (Morris & Thomas, 2002), it is important that health professionals are supportive of carers’ needs in order to help them to provide care (Harrington et al., 1996). The results yielded from this study – highlighting aspects of health professional interactions that carers position as positive or negative - point towards some of the ways that health professionals can support carers through the cancer journey. Most significantly, it is important that health professionals communicate with carers in an empathetic and professional way. A key part of this communication involves providing adequate information to carers that is relevant for their particular stage of the cancer journey, in a positive and empathic manner. Carers also need health professionals to be approachable and accessible, and to feel as though they are in a relationship of mutuality with a person who recognises and values their needs and concerns. The fact that many carers in the present study did not experience health professional interactions as such, suggests that the need for communication training is still imperative, particularly for medical professionals who were the object of the most severe criticism. In addition, for allied health professionals, there is an ongoing need to provide practical assistance and strategies to help carers provide care, as well as offer a space for carers to discuss their mental health issues in a non-judgemental forum. This underlines the benefits of multi-disciplinary team work, and of the way in which allied health professionals can meet many of the psycho-social needs of carers, allowing medical and nursing professionals to focus on other aspects of care.

Future research in this area could address some of the issues not addressed in the present study. It would be useful to include health professionals in the sample to examine the interactional dynamics of health professional–cancer carers’ experiences, allowing for an exploration of the way health professionals position the needs and concerns of cancer carers, as well as carer reactions or receptivity to information. It would also be useful to examine the positioning of health professional interactions in carer-patient dyads, to see whether the constructions of the carer were similar or different to those of the patient, and the ways in which the meaning of specific interactions is negotiated by both. The sample in the present study was comprised largely of Anglo-Australian carers. Future studies could usefully include carers from a diverse range of cultural backgrounds, as carers’ expectations and experiences of interactions with health professionals are likely to be shaped by cultural identity (Thorne et al., 2005).

In conclusion, as shown in many of the accounts in the present study, many health professionals are providing support to cancer carers to good effect. Recognition of carer needs, manifested through empathic communication and availability, are key aspects of this care, associated with reports of carers feeling in control and empowered. There were, however, many other accounts where such support was clearly lacking, related to poor communication style, lack of information, and carers not knowing where to go for support. As this was associated with carers ability to cope and provide care, it is thus critical that such lack of support is redressed, for the wellbeing of both carers and the people with cancer for whom they care.
Section Six
Sexuality and Intimacy Post-Cancer Diagnosis: The Experience of Partner Carers

Background and Review of the Literature

Sexuality and intimacy are important aspects of quality of life (World Health Organisation, 1995) and there is a growing body of evidence to show that cancer can result in dramatic changes to sexuality, sexual functioning, relationships, and sense of self (Gurevich, Bishop, Bower, Malka, & Nyhof-Yonhg, 2004; Juraskova, Butow, Robertson, Sharpe, McLeod, & Hacker, 2003; Maughan, Heyman, & Matthews, 2002). These changes can be experienced as the most significant in the person with cancer’s life (Anderson & Golden-Kreutz, 2000), and can lead to emotional distance between couples (Rolland, 1994), as well as feelings of isolation, anxiety, depression (Germino et al., 1995), or inadequacy (Anillo, 2000). Conversely, sexuality and physical intimacy has been found to make the experience of cancer more manageable, assist in the recovery process (Schultz & Van de Wiel, 2003), or be central to couple closeness and quality of life in palliative care (Lemieux, Kaiser, Pereira, & Meadows, 2004).

Whilst the experiences of partners are often neglected in research on sexuality and intimacy post-cancer (Reichers, 2004), there is growing acknowledgement of their unmet needs in this area (De Groot, Mah, Fyles, Winton, Greenwood, & De Petrillo, 2005; Perez, Skinner, & Meyerowitz, 2002). Reported disruptions include decreases in their own sex drive; fear of initiating sex with their partner; difficulty regaining a level of ‘normality’ within the sexual relationship; and feeling unwanted and unattractive because of cessation of sex (Harden, Schafanack, Northouse, Mood, Pienta, Hussain et al., 2002; Maughan et al., 2002; Sanders, Pedro, Bantum, & Galbraith, 2006). It has also been argued that when sexual intercourse ceases in the context of illness, touching and other forms of affectionate physical contact also diminish (Kuyper & Wester, 1998) because of a perception amongst some couples that these forms of affection necessarily lead to sexual intercourse which is either not possible or deemed inappropriate (Hughes, 2000). These kinds of disruptions to sexuality and sexual relationships are frequently identified as problematic for partners of a person with cancer (Kuyper & Wester, 1998; Perez et al., 2002; Reichers, 2004; Soothill et al., 2003; Thomas et al., 2002), are associated with poor emotional and physical health, as well as being ‘highly associated with negative experiences in sexual relationships and overall well-being’ (Schober, 2004, p. 54).

There is also evidence to show that negotiation within the couple relationship about sexual matters is often difficult (De Groot et al., 2005; Foy & Rose, 2001; Germino et al., 1995; Holmberg, Scott, Alexy, & Fife, 2001; Zahlen & Shands, 1993), though the specific issues of whether, and in what ways, intimate partners “renegotiate” their sexual relationship if coitus is no longer physiologically possible or desirable in the
context of cancer has been under-researched. Fortunately, there is a body of research that has explored how couples renegotiate their sexual relationship in the context of physical disability, spinal cord injury, and most notably, erectile dysfunction (ED)—an issue that couples facing cancer often have to negotiate. For example, in the area of ED, a study by Warkentin, Gray, and Wassersug (2006) examined how dildos could be used as an alternative to erectile dysfunction treatments for men and found that, in time, the dildo became a normal erotic part of sexual life, with a key factor in the sexual satisfaction within the relationship being that the couple were working together to explore sexual activities. In a similar vein, Potts (2006) reported that when it was difficult for individuals to engage in coitus because of ED, sexual repertoires can become more varied. One of the possibilities to emerge was the experience that sex is not confined to the organic body and that the “sex” can be deepened to include sexual feelings produced without physical touching. This has resulted in the development of “flexibility” in couples’ sexual repertoires, becoming a central aspect of interventions conducted by sex therapists (Barsky, Friedman, & Rosen, 2008; Schover, Evans, & von Eschenbach, 1987).

The few studies that have examined sexual renegotiation in the context of cancer have shown that for the most part couples are unable to renegotiate sexuality and intimacy. This inability is reportedly associated with difficulties in communicating about sexual matters (Arrington, 2003; Foy & Rose, 2001; Holmberg, Scott, Alexy, & Fife, 2001), for fear of creating feelings of guilt in the person with cancer (Kuyper & Wester, 1998). In addition, for intimate partners who are also the carer of a person with cancer, renegotiating a sexual relationship may be particularly problematic given the discursive construction of the “good carer,” who should subordinate their own needs, put the person with cancer first, and engage in the “emotion work” of managing their own feelings and the feelings of others (Hodges et al., 2005; see also Thomas, Morris, & Harman, 2002). It has also been reported that partner carers subordinate their own sexual needs in the light of what is considered “the proper thing to do” when in a caring role—including not initiating sex, not pressuring their partner to be sexually intimate, and not being sexually demanding (Gilbert, Ussher, & Hawkins, 2010; Hawkins, Ussher, Perz, Gilbert, & Sandoval, 2009). Carers may come to consider the person with cancer purely as a “patient,” and as such, dependent upon them for their basic needs—needs that are often antithetical to the expression of sexuality within the relationship (Gilbert et al., 2010; Hawkins et al., 2009; Parker, 1990; Pope, 1999). For example, Manderson (2005) found that people with a stoma and their partners find it difficult to sexualise a body on which there is now attached a bag containing in a very visual way “abject” urinary fluid and defecation. Similarly, partners who provide a great deal of intimate physical care to the person with cancer (such as helping with toileting or feeding) can experience difficulties in continuing to see them as a sexual person (D’Ardenne, 2004; Kelly, 1992; Pope, 1999).

Equally, when an individual is diagnosed with cancer and comes to be seen as “ill,” a different set of norms emerge for acceptable behavior within their illness state (Wellard, 1998), including the notion that people with cancer have either limited sexual needs or are asexual (D’Ardenne, 2004). According to Schildrick (2005), people with a disability or serious illness are disqualified from normative discourses of sexuality, as “proper” sexuality is associated only with able bodied, healthy, and usually young individuals, which “legitimates a denial of sexual desire and pleasure” (p., 334) for those falling outside these discourses. This disqualification and denial is
also associated with the prominence of the “coital imperative” in medical, social, and legal discourse (Gavey, McPhillips, & Braun, 1999). The coital imperative positions intercourse as “real sex,” as a sign of a healthy and normal relationship, and positions those who cannot perform it properly as dysfunctional (Tiefer, 1996, 2001). It is thus not surprising that intercourse has been found to be strongly connected with feelings of acceptance, intimacy, and love, and absence of intercourse with feelings of self-doubt (Gavey et al., 1999).

One of the limitations of research in the area of cancer and sexuality is the focus on experiences of sexuality following cancer that affects the reproductive organs (e.g. Harden et al., 2002; Maughan et al., 2002; Sanders et al., 2006). There is a need for research examining the experiences of partners across a range of cancer types, as cancers that do not involve parts of the body designated as ‘sexual’ or ‘reproductive’ may also impact on sexuality (Reichers, 2004). In this chapter we examine subjective experience of changes to sexuality and intimacy following the diagnosis and treatment of cancer for partners of a person with cancer, across a range of cancer types, using qualitative methods. We will look specifically at the following issues: How do partners of a person with cancer account for changes in their sexual relationship post-cancer?; How do constructions of the caring role and sexuality impact on partners’ experiences of their sexual relationship post-cancer?; and How do carers who are the intimate partner of a person with cancer renegotiate their sexual relationship following the onset of cancer and the caring role?

**Participants and Procedure**

One hundred and fifty six informal carers (55 men, 101 women), were selected from their participation in the larger mixed methods study, on the basis of being the intimate partner of a person with cancer. Demographic details of the sample in this aspect of the study are presented below in Table 10.

Of the 46% of partner carers who indicated a willingness to be interviewed about sexuality, 20 were selected for interview, on the basis of reporting changes to sexuality since the diagnosis of their partner’s cancer, with the sample stratified by gender, cancer stage and type. The interview sample was comprised of thirteen women – eleven of whom were heterosexual and two were lesbian, and seven heterosexual men. The participants’ ages ranged from 29 to 76 years, with an average age of 53 years. The average age of the person for whom they care/d was 56. Eight of the participants were currently caring for a person with cancer and 12 participants had cared in the past. Of the 12 participants who had cared in the past, 5 were caring for a person who had survived cancer and were in remission at the time of interview and the remaining 7 participants were bereaved. In terms of cultural background, 18 of the participants were either Anglo-Australian or Anglo-Saxon, one participant was Filipina, and one was Italian. Of the 20 participants, 3 were caring for people with brain cancer, 4 for people with prostate cancer, 2 for people with lung cancer, 7 for people with breast cancer, 1 for a person with pancreatic cancer, 1 for a person with mesothelioma, and 2 were caring for people with a combination of bowel, liver, lung, prostate, and brain cancer.
Table 10: Sample characteristics for partner carer and person with cancer

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>Mean</th>
<th>Median</th>
<th>S.D.</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Partner carer age</td>
<td>153</td>
<td>57</td>
<td>59</td>
<td>10.63</td>
<td>28 - 79</td>
</tr>
<tr>
<td>Person with cancer age</td>
<td>154</td>
<td>59</td>
<td>59</td>
<td>11.83</td>
<td>29 - 93</td>
</tr>
<tr>
<td>Years since first diagnosis</td>
<td>153</td>
<td>3.48</td>
<td>2.00</td>
<td>4.36</td>
<td>2mths – 23yrs</td>
</tr>
</tbody>
</table>

| Sexual orientation:             |     |      |        |        |         |
| Heterosexual                    | 149 | 95.5 |
| Lesbian / Gay                   | 7   | 4.5  |

| Ethnicity:                      |     |      |        |        |         |
| White European /Aust            | 141 | 90.4 |
| Asian                           | 3   | 1.3  |
| Not stated                      | 12  | 7.7  |

| Cancer type:                    |     |      |        |        |         |
| Colorectal/Digestive            | 24  | 15.4 |
| Breast                          | 23  | 14.7 |
| Haematological                  | 22  | 14.1 |
| Multiple Non-Sexual              | 15  | 9.6  |
| Multiple Sexual                  | 10  | 6.4  |
| Prostate                         | 10  | 6.4  |
| Other*                          | 52  | 33.4 |

| Stage of disease:               |     |      |        |        |         |
| No longer detectable            | 29  | 18.6 |
| Early                           | 10  | 6.4  |
| Advanced                        | 56  | 35   |
| Not sure/applicable             | 61  | 39   |

* “Other” includes: Respiratory, Gynaecological, Brain, Mesothelioma, Pancreatic and missing.

Measures

Questions on sexuality were developed for the study, in consultation with the study’s steering advisory committee. Three fixed choice questions (no, yes), asked participants: if they were in a sexual relationship with a person with cancer; if there had been changes to their sexual relationship post-cancer; and if issues about sexuality had been discussed with a health care provider. The two open-ended questionnaire items concerning changes in sexuality post-cancer were: please describe the changes to your sexual relationship; and, if your role as carer has made any difference to your sexual relationship, please describe this difference.

A semi-structured interview, audio-recorded and conducted on a face-to-face or telephone basis, lasting approximately 1 hour, was used to examine in depth partners’ experiences of sexuality post-cancer. The interview discussion focused on: changes to partners’ intimate/sexual relationship; feelings about their intimate/sexual relationship; communication with the person with cancer about intimacy; and experiences with health care professionals. In accordance with established protocols in qualitative
research, sampling was discontinued when information redundancy was reached, and no additional information was forthcoming (Miles & Huberman, 1994).

All of the interviews were transcribed verbatim, and thematic analysis was used to analyse the data (Braun & Clarke, 2006). After transcription, the interviews and open-ended questionnaire responses were independently read by two researchers, in order to ascertain the major themes, and to develop a coding frame. Following discussion between the researchers, and other members of the research team, the coding system was used to organise the data into conceptual categories which were based on participants’ stories and responses. The research was, therefore, largely inductive, where the concepts and categories came from the data, rather than being deductive or informed by existing preconceptions about cancer caring and sexuality (Janesick, 1994). The interpretation of the data was conducted from within the framework of positioning theory (Davies & Harre, 1990), where it is assumed that narratives do not simply mirror a world ‘out there’, but that they are constructions which reflect subject positions taken up or given to individuals, which provide the context for the negotiation of experience. The interviews and responses were then coded thematically by two of the researchers, using consensus discussion, with a third researcher available to discuss any disagreements. NVivo software, a program which allows for qualitative data to be organised thematically, as well as across demographic, or other key variables, was used to organise the coded data. Discussion and competing explanations between the two researchers during the coding process, as well as discussions with the broader team, allowed the coding frame to be refined (Barbour, 2001). Responses from the questionnaire were also tabulated and counted to identify frequency and patterning within and across groups, specifically gender and cancer type.

**Survey Results**

Of the 176 carers whose partner had cancer, 159 indicated that they had been in a sexual relationship with them. In response to the question regarding whether cancer had impacted on the sexual relationship (yes/no), when we examined the rate across all cancer types, 77% (44 men, 77 women) answered that it had. When we examined the cancers previously associated with changes to sexuality post-cancer, the rate was 93% for partners of men with prostate cancer and 72% for partners of women with breast cancer. The means and variance statistics for the HADS subscales and CRA subscales for the carers who responded that their partner’s cancer had either made an impact or no impact to their sexual relationship, are presented in Table 11.
Table 11: Descriptive statistics for HADS subscales and CRA subscales for carers who reported an ‘impact’ or ‘no impact’ on their sexual relationships.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Reported Impact</th>
<th>N</th>
<th>Mean (SD)</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>HADS – Anxiety</td>
<td>Yes</td>
<td>120</td>
<td>10.83 (4.41)</td>
<td>2-20</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>32</td>
<td>9.47 (4.76)</td>
<td>1-18</td>
</tr>
<tr>
<td>HADS - Depression</td>
<td>Yes</td>
<td>119</td>
<td>7.77 (4.08)</td>
<td>0-20</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>32</td>
<td>6.22 (3.77)</td>
<td>0-14</td>
</tr>
<tr>
<td>CRA – Disrupted schedule</td>
<td>Yes</td>
<td>120</td>
<td>18.14 (4.33)</td>
<td>7-25</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>33</td>
<td>14.64 (5.51)</td>
<td>0-25</td>
</tr>
<tr>
<td>CRA – Health problems</td>
<td>Yes</td>
<td>119</td>
<td>12.15 (2.32)</td>
<td>6-16</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>34</td>
<td>10.88 (2.53)</td>
<td>5-15</td>
</tr>
<tr>
<td>CRA – Lack of family support</td>
<td>Yes</td>
<td>120</td>
<td>9.97 (5.46)</td>
<td>0-25</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>34</td>
<td>6.91 (3.73)</td>
<td>0-17</td>
</tr>
<tr>
<td>CRA – Financial problems</td>
<td>Yes</td>
<td>120</td>
<td>8.11 (3.95)</td>
<td>0-15</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>34</td>
<td>6.50 (3.38)</td>
<td>0-14</td>
</tr>
<tr>
<td>CRA – Self esteem</td>
<td>Yes</td>
<td>118</td>
<td>27.81 (4.35)</td>
<td>15-35</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>32</td>
<td>28.00 (5.38)</td>
<td>5-34</td>
</tr>
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The independent-samples t-tests revealed that whilst there was no significant difference between the average anxiety scores on the HADS for the impact (M = 10.83, SD = 4.41) and no impact (M = 9.47, SD = 4.76) groups, \( t(150) = 1.52, p = .130 \), the difference between the average depression scores on the HADS between the two groups was approaching significance, \( t(149) = 1.94, p = .054 \), with the impact group (M = 7.77, SD = 4.08) having a higher mean than the no impact group (M = 6.22, SD = 3.77). The average depression score of 7.77 for the impact group was approaching the borderline cut-off score of 8.

In relation to burden of care, the average CRA score for the subscale of disrupted schedule of the impact group (M = 18.14, SD = 4.33) was higher than the average score for the no impact group (M = 14.64, SD = 5.51). There was a significant difference between these two conditions, \( t(151) = 3.87, p = .000 \). A significant difference was also found between the impact and no impact groups for the average CRA scores for the health problems subscale, \( t(151) = 2.76, p = .007 \). The average score on this subscale for the impact group (M = 12.15, SD = 2.32) was higher than that of the no impact group (M = 10.88, SD = 2.53). For the CRA subscale of lack of family support, the average score of the impact group (M = 9.97, SD = 5.46) was higher than the average for the no impact group (M = 6.91, SD = 3.73). The result of the \( t \)-test showed that this was also a significant difference, \( t(152) = 3.06, p = .003 \). The average score for the CRA subscale of financial problems for the impact group (M = 8.11, SD = 3.95) was higher than the average score on this subscale for the no impact group (M = 6.50, SD = 3.38). This was also a significant difference, \( t(152) = 2.16, p = .033 \). For the final CRA subscale of self-esteem, the average score of the impact group (M = 27.81, SD = 4.35) was lower than the average score for the no impact group (M = 28.00, SD = 5.38). A higher score on this final subscale, unlike the previous four subscales, indicates that the impact has been perceived as a positive one. The difference between the average scores for the two groups was not, however, significant, \( t(148) = .21, p = .833 \).
Implications of findings

The finding that carers who reported changes in sexuality post-cancer reported significantly higher levels of depression and burden of care than those who reported no sexual changes, adds support to the notion that sexuality is associated with cancer carers’ quality of life and psychological well-being (Foy & Rose, 2001). Depression and burden of care may be a cause, or a consequence, of changes in sexuality post-cancer; further research is needed to examine this issue in more depth, looking at the factors which may moderate and mediate changes to the sexual relationship in cancer carers and their partners, as well as the consequences of such changes for the couple.

Results of Open Ended Questions and Interviews

One hundred and twenty-two participants (43 men, 79 women), or 78% of this sub-sample reported that the onset of cancer had negatively impacted upon their sexuality and their sexual relationship. When we examined the type of cancers associated with changes to sexuality post-cancer, the rate was 90% for partners of men with prostate cancer, 71% for partners of women with gynaecological cancer, and 78% for partners of women with breast cancer. Overall, the percentage of partner carers of people with ‘non-reproductive’ cancers who reported an impact on the sexual relationship was 76%, and the percentage of those caring for people with cancers involving ‘reproductive’ sites was 84%.

Each of the 122 participants elaborated on the changes to their sexual relationship experienced post-cancer, in open-ended responses and, for 20 of the participants, in an individual interview. The responses given by participants are illustrated below under each of the following major themes: Disruptions to carers sexuality and their sexual relationship (cessation or decreased frequency of sex); Reasons given for changes to sexuality (impact of cancer or cancer treatment: caring role; re-positioning of person with cancer as a patient); Feelings about such changes (positive and negative); Renegotiating sexuality (exploring alternative sexual practices or not); Couple communication and relationship context; and Discussions of sexuality with health professionals. Percentages cited refer to the open ended questionnaire responses.

Disruptions to carers’ sexuality and their sexual relationship

Cessation or decreased frequency of sex and intimacy

A complete cessation of sex, or a marked decrease in the frequency of sex, was reported by 59% of women and 79% of men (Figure 18). For those who experienced a complete cessation of sex, the ‘end’ of the sexual relationship was reported as a sudden event: “Our sex life disappeared overnight”; “Gone from fantastic sex life to none”. For other participants, it was a gradual change: “Initially we found other ways to be intimate, however over time our sex life has ceased”. The impact of both the cessation of sex, and the loss of intimacy, is evident in the following interview extract:
A big... big chunk of your life is lost, and I don’t just mean the physical aspects of it... I mean that’s... you can live with that or you can... or go without, but... the whole package is gone and I think that’s hard that, you’re a widow with somebody that’s still around.
(Sarah, age 57 year caring for her husband with brain cancer)

Of the participants who reported decreased sexual frequency, rather than a complete cessation, many positioned their sexual relationship in ways that indicated that they had previously enjoyed an active sex life: “We had a very strong physical relationship up until the cancer was discovered and after it, it just faded away”; “Very poor, we use to have sex 5 times a week, now maybe once in 3 or 4 months”. Others simply described a change in frequency: “Virtually non-existent”; “This aspect of our marriage has nearly stopped”. Many of the participants who reported cessation or decreased frequency of sex also reported decreased closeness and intimacy. Responses included: “…I couldn’t cuddle like we used to” and, “Often feel frustrated that it doesn’t happen like it used to – he is not as romantic either”.

**Figure 18: Partners reporting cessation or decreased sex**

![Bar chart showing percentage of men and women reporting cessation or decreased sex](image)

**Reasons given for changes in sexual relationships**

*My partner with cancer has no desire: The impact of cancer treatment*

Cancer treatments were positioned as the primary reason for changes to the sexual relationship. The effects of the treatments meant that there were now physical barriers to sex which were reported by 30% of men and 33% of women (figure 19) . For example: “Hormonal treatment has the effect of chemical castration, i.e. my husband has no sexual function”; “her poor body has been so cut and chemo has affected her so much that sex is not even possible”; “…non-existent due mainly to the chronic pain syndrome and a less than full confidence in colostomy bags!” For others, cessation or reduction in sex was due to overall bodily restrictions: “… He is physically unable to position himself for sex now”.
In June an epidural catheter was inserted into my husband’s chest and commenced on morphine 30 mgs three times a day. Not only was there no energy or inclination, because of the pain and reduced energy, there was now a ‘physical barrier’ to our relationship as well as all the side effects of morphine.

(Betsy, age 59, who cared for her husband with mesothelioma)

Many of the participants also described side effects of the treatment such as pain, fatigue, and exhaustion. As one woman participant said about pain, “When he is unwell because of treatment I tend to be very careful in touching him in case it causes further pain/discomfort”. Descriptions of fatigue being given as a reason for changes to the sexual relationship included: “As a result of treatment (chemotherapy) my wife is tired more of the time and her libido is reduced”; “He was just too exhausted”. The impact of cancer treatment on the self-esteem and self-image of their partner was also identified as a reason for changes to the sexual relationship in a number of cases. For example, one partner commented that:

As her health declined she had very low self esteem caused by loss of hair and muscle tone. When I did have sex at the beginning she would accuse me of not treating her the same as I did in the past and get depressed.

(Gary, age 61, who care for his partner with lung cancer, bereaved)

Many of the male and the lesbian participants talked about the ways in which the ‘sweats’, general sickness, ‘feeling unwell’, and changes in mood caused a decrease in the level of sexual arousal and desire in their female partner. An issue that was most often raised by the male participants and the two lesbian participants was that the pain that resulted from surgery or radiotherapy meant that certain areas of their partners’ body became ‘off limits’ to intimate physical touching. This was particularly the case for those caring for a female partner who had breast cancer. In addition, for some of these participants the physical restrictions that result from surgery and treatments were often difficult to negotiate. For example, Ed, who is 54 years old, a ‘househusband’ and caring for his 52 year old wife who has breast cancer, points out, ‘it puts a damper on the free flow because part of your brain is always [thinking], we’ve got a port-a-cath, I can’t go near her on this side and we’ve got a sore and
sensitive area so you can’t sort of suddenly give her a big cuddle’. The negotiation of
these physical restrictions, accompanied with an increased awareness of the pain
associated with particular areas of the body that were ‘off limits’, meant that it was
difficult for sexual intimacy to be as spontaneous as it had been prior to the onset of
cancer. Sexual intimacy now meant for many participants an increasing mindfulness
and anxiety about the sexual positions they adopted, the areas of their partners’ body
they could and could not touch, and the potential pain they could unintentionally
cause to their partner during sex.

Exhaustion resulting from the caring role

Exhaustion resulting from the caring role was positioned as the cause of changes to
their sexual relationship by 16% of the women and 9% of the men (figure 20). The
responses included: “We don’t really have any intimacy anymore for reasons
including his health and my exhaustion”; “Exhaustion, brain still ticking about things
to be organised”; “Even if he was still interested in the sexual side of our marriage I
think I would have been too exhausted to have taken part”. Participants also
commented on a revised prioritisation that centred on coping and survival, leaving no
time for sex or intimacy.

The sexual issue is really not a priority as all our energy seems to be focussed
on trying to find a way to beat the cancer.
(Julie, age 44 years, caring for her husband with prostate cancer)

Figure 20: Exhaustion as the reason for change

Percentage reporting exhaustion as a reason for change

Some of the interview participants described how their desire for sexual activity
decreased in the initial stages of the cancer diagnosis, as their concern for the health
and well-being of their partner outweighed their interest in sex. For example, John
stated, ‘I wasn’t even thinking about, you know, doing the business during that whole
initial sort of period’. Similarly, Jessie, who is 36 years old, self-employed, and who
cared for her female partner who is now in remission from breast cancer, pointed out
that her sexual desire had diminished ‘in the beginning [pause] because you know
you’re concerned and you’re not interested in sex’. Other participants described their
libido as having decreased more significantly in the later stages of their partner’s cancer journey, after they had been performing caring tasks for years, and had assumed more caring responsibilities. For these participants, ‘taking care’ of their partner meant accompanying them to medical appointments for chemo- or radiation therapy, washing, cleaning, preparing meals, medicating, managing personal finances, and managing the health care system – caring tasks that were associated with an emotional and physical exhaustion not conducive to the expression of sexuality. Thus Margaret said that she became ‘just too tired to be very interested’ in sex and that she would often fall asleep and ‘didn’t really compensate in any sort of personal private sense, you know, masturbation’. Diana who is 44 years old, and caring for her husband with prostate cancer, commented that her tiredness and stress discouraged her from ‘making the effort’ to be sexually or physically intimate. However, both Margaret and Diana discussed the importance of sexual intimacy to their sense of self, and both were disappointed that an important aspect of their lives had been negatively disrupted. When reflecting on her time caring for her husband, Margaret mentioned that she was regretful that she did not explore her own ways of achieving sexual pleasure through acts such as self masturbation. It was clear that, upon reflection, Margaret would have done things differently in order to have maintained her sense of sexual self. For Diana, the disruption to her sexual relationship and her own sexuality was an issue she had given much consideration to. During her interview she discussed having ‘entertained’ the idea of ‘having an affair, purely for sexual gratification’, but stated that morally she could not reconcile doing so whilst still caring for her husband with cancer.

**I see my partner with cancer as a child, or an asexual ‘sick’ patient**

For 28% of women and 47% (figure 21) of men caring for a partner with cancer, the caring role was reported to have resulted in a re-positioning of the person with cancer as a sick patient, or as a child - both positions rendering their partner asexual. For some interview participants helping their partner with bathing, assisting them in the bathroom, and shaving them, meant that they no longer saw their partner as sexual, or as Melanie, a 52 year old carer for her husband with early stage prostate cancer, involving chemotherapy and hormone treatment says:

‘they’re not the person that they were (...) they’re now this person that you care for (...) it feels as if we’re just sharing a life and that it could be my brother or whatever, because I don’t have any physical attraction towards him whatsoever.'
Similarly, Gary reported being in a ‘very physical relationship’ with his partner prior to the onset of lung cancer, but mentioned how the abjectification of her ill body impacted upon sexual activity. Although their sexual relationship continued after his partner’s diagnosis, Gary talked about some of the difficulties surrounding his attraction towards her, which stemmed partly from the fact that she lost control of her bladder, which ‘sort of affects the way you react to the body, not smelling nice or whatever’, and partly from the fact he sees his partner as dying. As Gary said, the thought that ‘she’s going to die, you know what I mean, I’m making love to a dead body type of thing’ kept ‘coming through to my mind’. Gina, who is 59 years old, and who cared for her 69 year old husband who recently died of mesothelioma, also positioned sickness as antithetical to sexuality, saying, ‘one time when I think he wanted to make love to me, and I thought, “You can’t. You’re too sick. How can you move?”’.

In some cases the positioning of the partner as an asexual sick patient also stemmed from the position participants took up vis-à-vis their caring role. To give some examples: “My role as a carer has overridden my role as a wife…”; “Having to spend more time on house/garden chores and be carer/nurse, one feels more like a housekeeper than a lover”.

When you are a carer it’s hard to be a lover, for either party, when dealing with incontinence of both bowel and bladder infections, along with the daily grind of showering, dressing, shaving, etc, then transferring from bed to wheelchair and return.

(Daisy, 59 years old, caring for male partner with haematological cancer)

This was especially the case for female participants who described taking up a ‘new clinical role’ (Melanie), and positioning themselves as a ‘nurse’ in relation to the sick patient. Melanie discussed how her new caring role makes her feel sexually ‘detached’ from her husband:

Melanie: (...) This probably sounds weird, but you’re not sort of in the role that you were before, and I guess that is more like a clinical, like now you’re the nursemaid, you’ve got a lot more to do because they can’t.
Interviewer: Mm, mm
Melanie: (...) He’s feeling that I’m not as affectionate, as hands on. But at the same time I can’t, I just don’t feel that way.

Other carers of both genders described the way in which the caring role and the kinds of care provided led them to see their partner as childlike, and their needs as akin to those of a child. For example, Gary described how he saw his partner as a ‘baby’ and that it was difficult to engage sexually with her because, as he said, ‘you know, like the baby’s okay, but you just don’t want to hurt it’. Similarly, Sarah stated that her sexual relationship has been redefined from that of an adult sexual relationship to one that she would have with her children. When asked if she still sees her husband as a sexual person, Sarah went to say:

Sarah: No. There’s no [pause] that feeling has all gone.
Interviewer: Yeah.
Sarah: Yeah, I [sigh] it’s a different person and... there’s nothing... nothing there. (...) that’s why I said it’s like looking after you know, one of your children now. That’s the feelings that you have, you know, you don’t have any, um... sexual feelings for your children......
(Sarah, 57 years old caring for husband with brain cancer)

The repositioning of her husband as an asexual child was a particularly important and complex feature of Sarah’s sexual relationship. Unlike the other interview participants in this study whose partners had not experienced changes to their cognitive functioning, Sarah’s husband’s advanced brain cancer caused him to have severely reduced cognitive functioning and memory loss. For Sarah, the full-time physical and intimate care she provided for her husband, in conjunction with the lack of ability to have and sustain a conversation with him, meant that sexual intimacy was simply ‘not an issue’. The daily ‘issues’ for Sarah centred around trying to help her husband communicate his everyday needs to her, trying to find time some spare time for herself, and trying to manage the relationship conflicts that often ensued as a result of her partner’s memory loss.

I’m reluctant to initiate sexual activity

Many participants indicated an awareness of what constitutes ‘appropriate’ sexual conduct in the light of the repositioning of their partner, and their own caring role. For these participants, appropriate sexual conduct was largely based on the idea that they should subordinate their own sexual needs to the everyday and health needs of their partner. Reluctance to initiate sexual activity with their partner was reported by participants of both genders. Participants talked about the fact that they ‘wouldn’t sort of initiate sex’ (Gary), or ‘force an encounter’ (John), deciding instead to ‘hang back’ (Jessie) and wait for their partner to initiate sex. In her response below, we can see that Jenny is concerned about ‘pressuring’ her husband into sex and fears being sexually ‘demanding’:

Jenny: I wouldn’t be being a good wife to him if I was demanding anything of him that he couldn’t follow through with and I wouldn’t be fair on him if I was pressuring him. So I would like more, I’ll be very honest, but it wouldn’t be fair on him to make him feel even worse than he does to say well, why
can’t it be like before, ‘cause reality is it won’t be at the moment.  
(Jenny, 29 years old caring for husband with brain cancer)

Jenny’s point that it would be ‘unfair’ of her to make her male partner feel ‘even worse’ by expressing her sexual needs, was also commonly raised by other heterosexual female carers whose partners were no longer able to get and sustain an erection due either to prostate surgery and treatment, or treatments for other types of cancer. Many of these female carers suggested that considering their own sexual needs ‘wouldn’t have been appropriate’ as Maxine stated. Indeed, as Diana pointed out, considering her own sexual needs was inappropriate because, ‘I don’t want him to feel [pause] well, he can’t satisfy me anymore’.

A number of male participants also reported feeling guilty about wanting to initiate sexual activity. For example, Paul, who is 45 years old, and caring for his wife with breast cancer, reported feeling guilty for even thinking about initiating sex with his wife because he explained that he ‘should be able to just deal with it, you know, just stop acting like an animal’ because ‘she’s a sick woman’. Paul mentions that the guilt he feels extends beyond his sexual relationship with his wife to include his own expressions of sexuality:

> I hate the idea of basically skulking away in the office and going to bigtits.com or whatever and just jerking off, it sort of makes me feel like I’m just a grotty 16 year old again, I should just be over it.  
(Paul, 45 years old caring for wife with breast cancer)

Picking up on a point raised earlier in relation to sexual spontaneity, for some of the participants, their reluctance to initiate sex also stemmed from a fear that sex could physically hurt their partner. Participants reported fears of holding their partner ‘too tight in case they broke’, and were cautious about touching tender areas on their partner’s body - as Bob who is 69 years old, and who cared for his wife now in remission from breast cancer stated, ‘Oh I didn’t even dream of touching her breast you know from the operation’. Similarly, Diana mentioned, ‘I worry myself sick thinking every time he moves, is he in pain?’

**Feelings about changes to the sexual relationship**

A number of the participants gave accounts of the emotions they experienced in response to the changes in their sexual relationship post-cancer, with accounts evenly divided between positive and negative feelings.

**Positive feelings**

Accounts of positive feelings were provided by 17% of women and 16% of men (figure 22). Many participants described feelings of understanding or acceptance of the effects of cancer or caring on their sexual relationship. Accounts included:

> Treatment makes my partner feel sick and makes me worry about him so this means we don’t feel up to sex... This is not an issue – just a fact/reality of current situation.  
(Kelly, 39 year old, caring for partner with lung cancer)
He is not up to performing and he has talked to me about it several times, but I assure him that I understand.
(Veronika, 66 year old, caring for husband with colon cancer)

**Figure 22: Positive feelings about changes**

![Bar chart showing percentage reporting positive feelings](chart)

A number of participants also reported feelings of affection and companionate devotion:

*Sexual urge had gone but my husband made me feel the most loved and cared for woman on this earth by his loving actions, his consideration, his caring attitude and the advice I sought even up till 12 hours before he died. I loved this man totally and he me.*
(Lucy, 68 year old, caring for husband with brain cancer, bereaved)

*[husband] has multiple brain tumours, lung tumours and clots plus multiple liver tumours so I just hug and reassure that I am here for the ‘long haul’ come what may.*
(Laura, 66 year old, who cared for husband with colon cancer)

The cancer experience was positioned as having brought the couple closer together by some participants, with one man saying he “probably has a more affectionate relationship at this point in our lives, and marriage” than prior to the onset of cancer, and another commenting “with the exclusion of sex, our intimacy is closer probably than it’s been for a long time”. Increased emotional closeness, despite absence of sex, was also evident in a number of the women participants’ interviews:

*We are so much closer now than we were....we wouldn’t be as close now and we wouldn’t be able to talk about absolutely anything now...Just seeing him at night, just makes my heart just go hshshsh.... Whereas before I don’t think we appreciated that about each other.*
(Jenny, 29 year old woman caring for husband with brain cancer)
Negative feelings

Accounts of negative feelings in response to changes to sexuality were reported by 13% of women and 21% of men (figure 23). These feelings included sadness that their sexual relationship was ‘lost’: “There is just an enormous sadness that we can no longer have this intimacy…”; “Still this whole traumatic experience has left me feeling very upset”. A number of participants reported also reported with self-blame, “No sex for 12 months – more my fault”, or rejection by their partners; “I felt excluded and unwanted. Sex became a chore and mechanical”; “She has absolutely no sexual interest in me whatsoever”.

*I don’t feel the desire to have a physical relationship with my husband. It almost makes me feel ill to even contemplate it. His whole physical appearance repels me.*

*(Melanie, 52 year old, caring for 55 year old husband with prostate cancer)*

Figure 23: Negative feelings about changes

A lack of fulfilment in relation to sex was another common feeling: “Not able to relax and enjoy”; “Often feel frustrated that it doesn’t happen like it used to”; “At times, I have considered having an affair purely for sexual gratification”; “leaves me less satisfied”. Some participants mentioned feelings of perceived obligation. For men, it was usually in relation to feeling that their partner felt obliged to provide sex.

Examples included: “On the infrequent occasions we now have sex she wants it over and done with as quickly as possible”; “She became less interested in sex and only accommodated me as if it was a wifey duty”. For women participants, obligation was positioned in terms of themselves feeling obliged to engage in sex.

*At the early stages of the diagnosis I felt that I couldn’t say no to him which put a lot of pressure on me. I had to make sure that I could respond to him and not give him any chance of feeling that I didn’t want to make love to him.*

*(Heather, 59 years old, caring for husband with gastric adenocarcinoma)*

A small number of women participants shared negative feelings regarding family planning and fertility. Changes to sexuality had particular implications for the younger female participants’ ability to fulfil their life aspirations – including not being
able to have children ‘naturally’ or not having someone to ‘look after’ them in their later years.

Prostate cancer has required removal of the sac that produces sperm. I am 36 and had always taken for granted I would fall pregnant in the most natural and intimate way. Once my partner is stronger, we will seek advice from an IVF Clinic regarding artificial insemination (hence my partner has secured enough in the sperm bank!). Still this whole traumatic experience has left me feeling very upset.
(Bella, 36 years old, caring for husband with prostate cancer)

Diana also reported that ‘it makes me very sad, because we can’t have children’, saying that:

(…) and knowing I will never have children and I may not have a family left, and I’ve got to worry about what will happen to me in later years. You know who will look after me?
(Diana, 44 years old caring for husband with prostate cancer)

Renegotiating sexuality and the sexual relationship

A renegotiation of their sexual relationship, to include non-coital sexual practices, or the development of non-sexual intimacy, was reported by 19% of women and 14% of men (figure 24). Men (12%) were more likely than women (1%) to report having developed alternative sexual behaviours to those practiced prior to the cancer. These behaviours consisted of changed sexual positions when attempting intercourse: “I am obviously more careful, having adjusted positions”; as well as the development of “workable alternatives to achieve partner satisfaction... within restrictions caused by the treatments”, including oral sex, massage, manual stimulation, mutual or self masturbation, or the use of a vibrator.

Figure 24: Renegotiating the sexual relationship
For example, during the interview when asked to describe the changes to her sexual relationship since the onset of cancer, Jenny talked about the increased importance of mutual masturbation in her sexual relationship:

Jenny: And then he started to get better, that’s when we just take the opportunity when it came up and that’s when, if I was feeling like it he would masturbate me or he would do something else so that he could still please me and likewise, you know, I would do anything to help him along (…)
Interviewer: (…) are you able to sort of give yourself pleasure like if he wasn’t there that’s still ok?
Jenny: Yeah, that’s fine and he understands. (…) Yeah, and I mean we probably wouldn’t have masturbated each other anywhere near as often as we do now…..

For the male participants, masturbation was seen as a way of being sexually intimate with their partner without the fear of physically hurting her by engaging in the type of “physical” penetrative sex they had engaged in prior to the onset of cancer. For example, Gary described how:

(…) when making love before it was pretty physical, and it was enjoyable, you know, like, just basically straight sex and all that, but it was very physical, and afterwards when she would feel pain or something, “Oh my god,” you know, like, it’s “No, I can’t do this.”

Similarly, there was one participant, Ed, who, when talking about the “alternatives” to penetrative sex, said that he and his wife were exploring both oral sex and the use of vibrators:

We’re trying to explore oral. (…) That’s both ways, it’s not just her on me, it’s both ways. She has the biggest problem with me on her. We’ve explored the use of vibrators, not greatly at the moment (…) we did a couple of times during chemo, but you’ve got to be very careful because if you over-sensitize something there are other reactions.
(Ed, 54 year old carer for wife with breast cancer)

Although he initially thought his sexual relationship would not “return to what it used to be, but return to the best we can get,” in the extract below Ed described how he and his wife could “maybe even make it better,” through the exploration of alternatives.

If we continue to explore alternatives, then maybe some will work and we can come out of it and put together a reasonable physical relationship again. Maybe even a better one.

Women (18%) were more likely than men (5%) to report that re-negotiation involved non-sexual intimacy, such as hugging and cuddling: “I’d put my legs up on his lap, and he’d put his arms around me, and I’d cuddle into him, and we’d watch TV”.

The last week of my husband’s life, he wanted to make love, but physically could not due to his illness. We talked this over as we always did and he knew
that hugs, cuddles and closeness were far more important than the actual act of making love.
(Cindy, 64 year old woman who cared for husband with pancreatic cancer, bereaved)

The importance of closeness to the well-being both of the partner and the person with cancer was emphasized by many of the interviewees. In the excerpt below, one partner describes how important it was to maintain physical closeness with her husband, despite the significant physical barriers that could have served to restrict the expression of intimacy.

We deliberately had kept the double bed. And then, when he got sick, and they needed a more supportive bed, I brought my single bed in, and we got this special height, set at the same height, so that he was always next to me. ... I remember the morning he died, I remember cuddling him all night. (…) Just to have your… to have your arm around him was just so, so good.
(Gina, 59 year old woman who cared for husband with mesothelioma, bereaved)

For many of the participants, this renegotiated intimacy was positioned as having brought them closer together, as John said, he “probably has a more affectionate relationship at this point in our lives, and marriage” than prior to the onset of cancer. Ed also said, “these cancers either blow the relationship apart or they pull you closer together.” For Bella, who says that she and her husband are “a very affectionate couple,” there is “still the same level of intimacy regardless of the sex there between us.” In fact, when referring to her sexually intimate relationship, Bella said that “maybe the cancer thing has brought us closer together,” and went on to say that: “I mean we didn’t need to do acrobatic flip-flops or anything to feel that we are closer together because our relationship is rock solid (...)

In contrast, the participants who had not re-negotiated sexuality in the context of cancer gave accounts which were in accordance with the coital imperative. For example, when asked if she and her husband were intimate, Connie (age 70, caring for her 81 year old husband with advanced prostate cancer) said that they had not had “full sex” for many years. “Full sex” according to Connie was penetrative vaginal/penis intercourse and was “real sex.” Any other practice of sex or intimacy was discounted in Connie’s account. Other women whose partners were no longer able to get and sustain an erection due either to prostate surgery and treatment, or treatments for other cancer types, commonly reported that considering their own sexual needs “wouldn’t have been appropriate” (Maxine). Although suppression of their sexual needs was described as distressing by these women, their own sexual needs were positioned as secondary to the risk of their partners’ feeling inadequate about their masculinity.

The complexity of this issue is illustrated by Melanie, (age 52, caring for her husband with prostate cancer) who talked about the importance of an erection to a man’s sense of identity.
Melanie: Oh well, there’s no erection (...) And I just think well why get yourself all stimulated if you can’t do anything anyway. I mean he’ll get frustrated. He is already frustrated enough knowing that he’s not what he was, and I think me trying to make him even be aroused or be intimate is going to frustrate him more. So better to leave that one alone.

Interviewer: Yeah, yeah.

Melanie: If we don’t even go there then we don’t have to deal with the fallout of you can’t do it, I’m left in mid air. And I’ve spoken to different ones about it and like just fellows that have had prostate cancer and of course the first thing they always say to Derek is you know, is it still working and whatever, because it’s a male thing. I don’t think every woman would put so much emphasis on it as the males do. It’s just the be all and end all, and when it’s not there it’s, they’re just so crushed and they don’t feel as if they’re a man anymore, and oh my God, their life’s, it’s just not worth living anymore if they can’t do it.

Melanie questioned the constructed centrality of an erection to masculinity, “I don’t think every woman would put so much emphasis on it as the males do,” while at the same time implicitly suggesting that because “there’s no erection” her sexual needs can no longer be met by her husband and as a result she’ll be “left in mid air.” Melanie thus appears, paradoxically, both to be complicit in discourses surrounding hetero-normative sexuality, and resistant to them. Her comment, “they're just so crushed and they don’t feel as if they’re a man anymore,” provides an explanation for her lack of initiative in attempting to renegotiate sexuality in the context of cancer: her fear of the effect on her husband’s masculine identity if the issue of sexuality were raised.

Couple communication and relationship context

The predominant explanation given by participants for their ability to renegotiate the sexual relationship in the context of cancer was positive communication and a good relationship context. Participants who gave accounts of renegotiation described being able to communicate about their sexual needs and concerns with the person with cancer, as well as having positive experiences within the relationship more generally. Although it was not necessarily comfortable or “easy” for these participants to express their own sexual needs and concerns to the person with cancer, “making the effort” to communicate was described as rewarding both for their sexual relationship, and the couple relationship more generally. For example, when asked if she felt she could express her concerns about the changes to their sexual relationship, Jenny stated that she and her husband “always promised to always have really good communication before this happened” and they have both “really made an effort to keep that going” throughout the cancer journey. Jenny continued that although it is often difficult to negotiate, she and her husband continue to invest time and effort in maintaining their sexually intimate relationship:

We went away last weekend, we met his mum in [name of town] for Mother’s Day so we made a weekend of it and so, you know, he surprised me with booking a double spa, like things like that. We knew where we were going and we knew the hotel and I knew the hotel but he, you know, rung up and said I
want to upgrade to a double spa. So, like he knows how to make me feel special and he hasn’t lost that. So I think that’s good.

Similarly, Ed noted that he and his wife “have had a number of discussions over, say the last six months” about the changes to their sexual relationship. These discussions “sometimes” made Ed “feel very bad” because he feels as though he is “talking to her about something which, in a sense she is the cause, and she’s already got enough on her plate.” However, Ed thinks these discussions are “something that has had to be done.” When asked how he wife has responded to these discussions, Ed said that:

*Her response has been quite understanding. She admits to the fact that even now her own desires are down low, lower than she’d like them to be, but it’s just something we, it’s got to be worked on and resolved as a couple not as a single person.*

Like Ed, Bella indicated that although it made her “feel guilty” to talk about her sexual needs and concerns, because her husband “didn’t need to hear all that” as “he was the victim,” she reported that communication was important to maintaining their “rock solid” relationship. The two lesbian participants also reported being in relationships where they could openly communicate about their sexual needs, with Jessie (36 year old carer for 38 year old female partner in remission from early stage breast cancer) saying “we discussed it a lot” and Debbie saying that “if there was a need for something else (sexually) then one or the other would say so.”

These accounts stand in contrast to the accounts of those who did not renegotiate sexuality or intimacy in the context of cancer, who reported having negative sexual experiences within the couple relationship more broadly, and being unable to communicate about their sexual needs and concerns with their partner. For example, Ben (51 year old carer for his 45 year old wife in remission from breast cancer) talked about how he felt “more serviced (sexually) through most of the relationship,” resulting in his feeling “emotionally abused.” Ben reported that their sexual relationship “was never brilliant.” When asked to think back to a particular time when, post-cancer diagnosis, he asked his wife to explore masturbation as a way of being intimate, Ben recounted that his wife wanted him “to hurry up” and that he “could feel from her hand that she was not that interested.” Ben said that his experience of his wife’s lack of interest in masturbating him made him feel like he was asking her to do a “chore,” as well as making him feel “rejected, or not wanted, or not being good enough.”

Melanie also indicated that it was often difficult for her to express her feelings and sexual needs to her husband, a concern shared by Margaret who said that she was “used to having a virtually non-existent, lousy sex life for over [pause], for some many years prior to cancer.” Margaret suggested that the lack of discussion within her relationship about sex was “perhaps a lot to do with the fact that we are products of the ’50s” and because “he was brought up in an atmosphere of ‘you don’t talk about it’.” Similarly, Sean (age 64, caring for his wife with breast cancer) said that the sexual communication within his relationship was “not perfect,” and that one of the “problems” within his relationship, both pre-cancer and during the cancer journey, has been his wife’s low libido. Although Sean sees his and his wife’s incompatible libidos
as problematic, he is “not talking to her about it” because he does not “want to put that stress on her,” and has “resisted imposing that on her.”

**Discussions of sexuality with health professionals**

In response to a survey question regarding whether a health professional had discussed sexuality with them, 20% of participants indicated that they had. The rate of discussion differed across cancer types, ranging from 50% of prostate cancer partner carers, to 0% of respiratory cancer. The rates across the other main cancer types were: 33% brain; 33% pancreatic; 30% breast; 29% gynaecological; 20% multiple – sexual; 17% colorectal/digestive; 17% mesothelioma; 15% multiple – non sexual; 15% other; and 9% haematological (figure 25). Of those who had discussed sexuality with health care providers, only 37% indicated that they were satisfied or very satisfied.

**Figure 25: Discussions with health professionals**

![Percentage, across cancer types, who had discussions with health professionals](image)

In the interviews, a number of the partners commented on their discussions with health professionals, in many cases giving a critical account. When they asked about sexual matters, participants reported being told, “Oh you don’t need to know that and things like that”, or told that they were “irresponsible to be thinking about having children” in raising fertility as a concern. The majority, however, gave accounts of sexuality not being discussed at all: “I haven’t got a lot of medical advice about how we should continue to conduct our intimate relationship”; “they did not educate us on anything… at all”.

*It’s not properly addressed by the medical profession, it is just completely glossed over. And I can remember, you know, we were sitting when the diagnosis came through and the guy said well, you know, you’ll get these hormone pills and we’ll give you an injection into your stomach and of course that will be the end of your sex life; and we’re just sitting there (...) That was the end of the discussion.*

*(Maxine, age 67 years, cared for husband with prostate, bowel, and lung cancer, bereaved.)*
Implication of findings

In this section we report on the changes to sexuality following the diagnosis and treatment of cancer for informal carers who were the partner of a person with cancer. The majority of participants reported that the cancer experience had impacted on their sexual relationship, resulting in a cessation or reduction of sexual activity, with only a minority renegotiating sexual intimacy post-cancer. This supports previous research which demonstrated that the impact of cancer and cancer treatment extends beyond the person with cancer (Gurevich et al., 2004; Juraskova et al., 2003; Maughan et al., 2002; Rolland, 1994; Walsh, Manuel, & Avis, 2005), reinforcing the need for acknowledgement of the sexual and intimate needs of partners, as well as of people with cancer. Rather than restricting our sample to partners caring for a person with cancer affecting the reproductive areas of the body, we examined changes to sexuality post-cancer across a range of cancer types. The majority of participants who were providing support to a person with prostate, breast or gynaecological cancer cited an impact, confirming previous research (Harden et al., 2002; Maughan et al., 2002; Sanders et al., 2006). However, the finding that a high proportion of partners of a person with ‘non-reproductive’ cancer also reported changes highlights the pressing need to acknowledge and attend to the sexual concerns and needs of all partners who care for a person with cancer.

There were some gender differences in the accounts of the nature of changes to the sexual relationship post-cancer. Reports of complete cessation of sex were more common for women than men, and very few women gave accounts of developing alternative sexual practices if intercourse was no longer possible. This could be attributed to women being more likely to assume that they should subordinate their own needs to the needs of their partner (O’Grady, 2005), and to cultural constructions of normative heterosexuality which expect men to initiate sex (Ussher, 1997). Previous research has found that partners are reluctant to initiate sexual intimacy if the person with cancer does not initiate (Maughan et al., 2002), and that heterosexual women partners do not wish to initiate sex, or discuss alternatives to coital sex, for fear of emasculating their partner if he can not ‘perform’ through sexual intercourse (Boehmer & Clarke, 2001). This is consistent with research that has demonstrated that sexual performance is positioned as central to heterosexual constructions of ‘manhood’, with failure having negative consequences in terms of a man’s sense of self (Tiefer, 1994). Equally, the ‘male sex drive discourse’ which positions men as ‘needing’ sex (Hollway, 1989; Potts, 2002), may result in the sexual needs of male partners being classified by either or both members of the couple as being ‘important enough’ for sex to continue post-cancer, or for alternative sexual practices to be developed, in contrast to women partners who were more likely to report that renegotiated intimacy was non-sexual. The phallocentric bias evident in the research and clinical literature on cancer and sexuality (Hyde, 2006), which serves to reinforce the notion that ‘normal’ sex equals coitus, and emphasises sexual ‘functioning’ with little attention to alternative practices, needs to be challenged, as this potentially plays a significant role in the construction of truths about sexuality which people with cancer and their partners take up, limiting their exploration of alternatives to coitus post-cancer. However, in the present study, four of the six lesbian partners all reported complete cessation of sex, suggesting that even couples positioned outside of a heterosexual matrix (Butler, 1990) can experience changes to sexuality post-cancer.
Whilst previous research has attributed changes in sexuality and intimacy post-cancer to the physiological effects of cancer or cancer treatment, a finding confirmed by many of the accounts in the present study, our findings also showed that the caring role had an impact on the sexual relationship. Participants associated sexual changes with stress, fatigue and exhaustion, revised prioritisation centred on coping and survival, and a redefined status as carer rather than lover. Past research that has explored carers’ experiences of stress and exhaustion primarily focuses on the impact upon carers’ general health and well-being. For example, Brown and Stetz (1999, p. 186) found that the initial period of ‘becoming a caregiver’ is particularly stressful, as carers are focused not only on their new role, but also have to ‘face the present’, negotiate their choice/or lack thereof to care, develop competency around their caring tasks, and evaluate their future. It is important to further investigate how the stresses involved in being a caregiver impact upon a carer’s sexuality, and how this may in turn impact on quality of life.

For a proportion of the participants, the disruptions meant that they no longer shared any sexual intimacy and were unable to negotiate other ways of being sexually intimate when penetrative sexual intercourse was no longer physiologically possible or desirable, again confirming previous reports (Kuyper & Wester, 1998; Pope, 1999). However, a number of the participants were able to renegotiate sexuality in the context of cancer, and their accounts of this experience provide us with insight into the reasons couples report difficulties in this arena, as well as providing indicators as to how the renegotiation process might be facilitated by health professionals. This is an issue that has been not been examined in previous research in the area of cancer caring and sexuality.

Furthermore, the impact of the re-positioning of the person with cancer as ‘patient’ or ‘child’, rather than as ‘lover’, is an important issue which requires further investigation. The finding that the physical symptoms of cancer, or the physical tasks associated with cancer caring, makes it difficult for many carers to continue to see their partner as a sexual person, confirms patterns found in other spheres of health care (Pope, 1999). This assignment of individuals with cancer with a ‘sick’ or ‘childlike’ identity, which is antithetical to an identity as a person with sexual desires and needs, can significantly impact on the sexual and intimate relationship of a couple facing cancer (Kelly & Field, 1996). Sex can be positioned as ‘inappropriate’, or as a ‘frivolous activity’ (Holmberg et al., 2001), resulting in carers experiencing guilt in the face of their own sexual needs or desires, and the avoidance of any discussion or renegotiation of sexual practices, as was reported in the present study. This could be seen as one aspect of a broader practice of self-silencing in cancer carers, where the needs of the carer are repressed, because the person with cancer has to be put first (Ussher & Sandoval, 2008). However, it is also associated with cultural discourses which position people with cancer as having limited sexual needs, or as asexual (D'Ardenne, 2004; Schildrick, 2005), resulting in a different set of norms being applied to what is acceptable behaviour (Wellard, 1998). The finding that male partners were more likely to report an impact of re-positioning the person with cancer as a patient may result from the role of carer being a more unfamiliar position for men to take up, given the congruence between femininity and the caring role (O'Grady, 2005). It may thus be more difficult for men to eroticize a partner with cancer who is in need of care. This matter is worthy of further investigation in future research.
Participants who reported actively renegotiating their experiences of sexual intimacy to include practices that had previously been marginalized to penetrative sex—including mutual masturbation, self masturbation, manual stimulation, oral sex, massage, the use of vibrators, kissing, and hugging—were able to resist the coital imperative and redefine their experience of sexual intimacy. For a number of participants sexual practices that may have initially been positioned as “alternatives,” and for some were positioned as less satisfying than intercourse, over time came to be reconceptualised as the norm. Indeed, for these participants, maintaining close physical contact was reported to be fundamental to the overall wellbeing of their relationship, and in most cases, participants stated that the onset of cancer had brought them and their partner closer together, confirming previous research (Rolland, 1994; Walsh, Manuel, & Avis, 2005), as well as evidence of benefit finding following cancer (Tomich & Helgeson, 2004).

Given our finding that some participants are able to actively renegotiate their sexual relationship, we would argue that the onset of cancer can actually open up for people with cancer and their partners a space to transgress and call into question the taken for granted nature of heterosex. In fact, in his examination of human corporeality as a site of transgression, Williams (1998) raised an issue similar to that being argued here, that of “dys-appearing” bodies—the idea that we only know our body when it is dysfunctional. For both people with cancer and their partner, it appears that the onset of illness, where pain, fatigue, and physiological disruption make the normalised idea of penetrative sexual intercourse impossible, is a turning point that allows them to transgress the norm of heterosex and to explore “alternatives” to this norm, as has previously been reported in the context of erectile dysfunction (Potts, 2006; Warkentin et al., 2006). It appears that discourses of intimacy become more salient than discourses of heterosex for couples during the cancer journey.

The sexual relationship context in which participants find themselves was crucial to their ability to openly negotiate “alternative” sexual practices. Willingness on the part of the participants to “make the effort” to maintain intimacy, and to openly communicate with their partner about their own sexual needs and concerns, were central to the sexual renegotiation process. Although many of these participants found it difficult or uncomfortable to talk about their own sexual needs to their partner, because they did not want to “burden” the person with cancer they persisted with the discussion, and were able to reach an understanding about the kinds of sexual practices and activities that would work for themselves and the person with cancer (see also Lemieux et al., 2004). In contrast, many of the participants who have not renegotiated their sexual relationship reported poor levels of communication, and avoiding communication with their partner.

As the majority of partners positioned these changes to their sexual relationship as problematic, confirming previous research (Kuyper & Wester, 1998; Perez et al., 2002; Reichers, 2004; Soothill et al., 2003), this suggests that education and information about sexuality post-cancer which challenges myths and provides a framework for re-negotiation of sexual relationships, needs to be included in advice and supportive interventions for partner carers. However, whilst it has been recognised that health professionals need to discuss issues of sexuality and intimacy with patients in cancer and palliative care (National Breast Cancer Centre and National Cancer Control Initiative, 2003), and can play a vital role in providing
‘permission’ for sexual intimacy between couples after the onset of cancer by legitimating such discussions (Schwartz & Plawecki, 2002), the findings of the present study confirm previous research which found that these discussions are not taking place for the majority of people with cancer or their partners (Stead, Brown, Fallowfield, & Selby, 2002), particularly for those outside the sphere of prostate cancer.

Even when sexuality was discussed, this was not at a level which was satisfactory to the majority of participants in the present study. This confirms recent Australian research which reported mis-matched expectations and unmet needs in relation to communication about sexuality between health professionals and individuals with cancer (Hordern & Street, 2007a; Hordern & Street, 2007b), suggesting that further education and training of health professionals is required, in order that they will be able to advise couples affected by cancer on issues of sexuality and intimacy, and address their unmet needs in this arena (Rees, Bath, & Lloyd-Williams, 1998). Whilst specific interventions have been developed to address sexuality issues in relation to cancer, (Hodgkinson, 2008) models of intervention which have been developed for disabled (Christopherson, Moore, Foley, & Warren, 2006; Simpson, Anwar, Wilson, & Bertapelle, 2006) or older aged (Fisher, Swingen, & O’Donohue, 1997; Sorocco, Kasl-Godley, & Zeiss, 2002) individuals can also be used to facilitate communication about sexuality between couples facing cancer, so that they understand and feel confident about trying ‘alternative’ modes of sexual behaviour, such as intimate touching or oral sex, without feelings of guilt or inadequacy. More specifically, couples can benefit from encouragement and permission to raise concerns about sexual functioning, allowing them to ask for and be provided with information, within a supportive environment that fosters open communication with health care professionals (Hodgkinson, 2008). Strategies that can be employed include using normalising statements to show that discussing sexual issues comprises standard and routine care; adopting a positive attitude towards such discussions; embedding individualised information in other aspects of care; and eliciting basic understanding of concerns and of the individual’s motivation to address the issue, in order to offer specific suggestions (Hodgkinson, 2008).

**Summary and conclusions**

In conclusion, sexuality and intimacy are central aspects of quality of life that have often been neglected in examinations of the well-being of partners of a person with cancer, particularly for “non-reproductive” cancers. The findings presented in this chapter add further support to the suggestion that sex should not be positioned as ‘inappropriate’ or ‘trivial’ in the context of cancer care, but rather be recognised as an aspect of couple relationships which is associated with well-being (Cort, Monroe, & Oliviere, 2004). Having health care professionals legitimate sexuality by ‘giving permission’ for couples to be sexually active or physically intimate when undergoing and recovering from treatment for cancer is one of the key strategies that could assist in this repositioning (Schwartz & Plawecki, 2002). The positive consequences of this may include increased feelings of well-being on the part of the partner carer, and closeness between the couple, which will have positive consequences for the physical and psychological well-being of the person with cancer (Hodges et al., 2005), the central aim of professional cancer care. There is thus no justification for sexuality and
intimacy being ignored or dismissed: partner cancer carers are telling us that it is important, it is time for health professionals to recognise this need and to act accordingly.
Section Seven
Evaluating the Efficacy of Psycho-Social Interventions for Informal Carers of Cancer Patients

A Systematic Review of the Research Literature

The psycho-social needs of people with cancer have long been recognised, leading to the development of an extensive range of supportive interventions (Newell, Sanson-Fisher, & Savolainen, 2002). The growing recognition of the needs of informal cancer carers has resulted in the development of a range of supportive psycho-social interventions, which aim to improve coping and psychological well-being, reduce distress and provide information. Recognising that a single approach will not be acceptable, or meet the broad range of carers’ needs across cancer stage and type, these interventions incorporate a variety of modalities and approaches, primarily within a psycho-educational, psychological, or practical domain. These include: professional home visits and professional care (Couldrick, 1992; Ingleton, 1999; Jones, 1993); Internet support (Monnier, Laken, & Cartr, 2002); Group psycho-educational sessions (Bradley, 2000; Gilbar, 1997); home based educational module kits (Ferrell, Grant, Chan, Ahn, & Ferrell, 1995; Pickett, Barg, & Lynch, 2001); support groups (Bradley, 2000; Giarelli, McCorkle, & Monturo, 2003; Robinson, 1998; Todd, Roberts, & Black, 2002); one-to-one counselling (Northouse, Walker, Schafanacker, Mood, Mellon, Galvin et al., 2002; Toseland, Blanchard, & McCallion, 1995); telephone support (Wells, Hepworth, Murphy, Wujcik, & Johnson, 2003). Common to most interventions are the following: information provision; support; validation of needs of carer; attention to self-efficacy and coping; problem solving.

However, knowing which interventions are effective, and the extent of their impact in meeting carers’ needs, is a central question which has not been fully addressed (Harding & Higginson, 2003). This knowledge is crucial to the cost-effective development and allocation of services (Coyne & Lepore, 2006) and the targeting of interventions to meet the needs of specific groups of cancer carers (Carlson, Bultz, Speca, & St-Pierre, 2000). The paucity of rigorous research in this area led Harding & Higginson (2003), in a review of the literature prior to 2001, to conclude that “the current evidence contributes more to feasibility and acceptability than to effectiveness” (p.63). However, a substantial amount of research has been published since the Harding and Higginson review, allowing firmer conclusions about effectiveness of certain interventions to now be drawn. The purpose of this section of the study was firstly to systematically examine the efficacy of psycho-social interventions for reducing distress and improving coping in informal cancer carers and to outline the implications of the findings for future research and theory in this field, as well as for the provision of supportive interventions.
**Method**

Data base searches were undertaken in September 2006, and updated in October 2008. These were supplemented by hand searches of contents of journals, and reviews of reference lists of identified papers. The search engine used was EBSCOHost, which accesses a range of data bases, including Medline, PsychInfo, CancerLit, and a range of others from nursing, health and psychology. Keywords used for the searches were cancer carer(s)/caregiver(s) intervention/support, cancer couple intervention/support. Papers which reported evaluations of supportive psycho-social interventions for informal carers of a person with cancer, or for couples where one person had cancer, were included. Psycho-social interventions under three broad categories were identified: psycho-educational (both general and specific problem solving), psychological (psychotherapeutic, problem solving psychological, and support groups), and practical, or a combination of these approaches. Couple or family interventions which only reported on the outcomes for the patient, did not distinguish patient from carer outcomes, only provided data on baseline, or post intervention satisfaction, or where sample size precluded statistical analysis, were not included in the review.

There are a number of recognised frameworks for making evidence based treatment recommendations, which propose a hierarchical ranking of evidence (National Health and Medical Research Council (NHMRC), 1999; Ropka & Spencer-Cisek, 2001). In the present review, all studies were rated following the NHMRC guidelines (see Table 1). Most highly valued (level I) are systematic reviews of multiple, high quality, randomised controlled trials (RCTs) – either a qualitative integrative review, or a quantitative meta-analyses. The next level (II) includes at least one well designed randomised control trial; followed by a well designed trial without randomisation (level III-1); comparative studies with concurrent controls and allocation not randomised (cohort studies), case-control studies, or interrupted time series with a control group are rated level III-2; comparative studies with historical control, two or more single-arm studies, or interrupted time series without a parallel control group are rated level III-3; and case series, either post-test or pre-test and post-test are rated level IV.

Meta-analysis was considered, but deemed inappropriate (see Mohr, Judd, & Terry, 1998), because of the variable nature and quality of the existing studies including lack of consistency in interventions and outcomes, differences in participant eligibility criteria and length of follow-up periods, and availability of sufficient detailed information in trials results (see also Newell et al., 2002). Instead, a systematic qualitative review of level II studies, high quality RCTs, was conducted (Hunt & McKibbon, 1998) (Table 12). In order to provide a broad picture of the current research knowledge in relation to psycho-social interventions for informal cancer carers, an evaluation of studies which would be rated as level III-IV using the NHMRC guidelines was also included (Table 13). This follows Barsevick, Sweeney, Haney and Chung (2002), who included level III-IV studies in their systematic qualitative analysis of psycho-educational interventions for people with cancer, in order to provide “additional support” (p75) for the evaluation of level II studies.

In addition to each study being rated for level of evidence (Table 12 and Table 13), the methodological quality of each of the randomized controlled trials was also
evaluated, using the guidelines recommended by the Cochrane Collaboration (Mulrow & Oxman, 1997). Following Newell, Sanson-Fisher, & Savolainen (2002), each trial was awarded 3 points for fulfilling each of ten criteria: adequate concealment of allocation; participants randomly selected; participants blinded to treatment group; care-providers blinded to treatment group; except trial intervention, other treatments equivalent; care-providers adherence monitored; detailed loss to follow-up information provided; percentage of participants not in the analysis; and outcomes measured blind. The quality of a trial was considered good if it had a score of more than 20 points; fair if it had 11-20 points, and poor if it had less than 11 points (Newell et al., 2002). Effect size was also calculated for the RCTs which had a significant positive outcome, and where sufficient statistical detail was provided, in order to provide an assessment of clinical importance of the results.
**Table 12: Design and study characteristics, interventions and findings by type of outcome for Level II randomised control trial studies**

<table>
<thead>
<tr>
<th>Study and quality score‡</th>
<th>Design and study characteristics</th>
<th>Interventions</th>
<th>Psychological constructs</th>
<th>Caregiver efficacy findings§</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Christensen, 1983)</td>
<td>Design: T0, T1. I: n = 10; C: n = 10</td>
<td>Counselling: structured couples program; 4 weekly sessions., C: unspecified</td>
<td>Psychological disturbance; Marital adjustment; Sexual satisfaction; Depression; Self-esteem; Helplessness; Anxiety</td>
<td>Improved: sexual satisfaction* (d = .51); emotional discomfort* (d = .87)</td>
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<tr>
<td>23</td>
<td>% male: 100</td>
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<td></td>
<td>Caregiver mean age: 39.5 years</td>
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<tr>
<td></td>
<td>Type: breast</td>
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<td></td>
<td>Stage: post mastectomy</td>
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<td></td>
<td>Eligibility: Patient’s cancer arrested and non-metastatic; surgery completed not &lt; 2 months and not &gt; 3 months prior to study; absence of current mitigating crisis or major emotional disturbance.</td>
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<tr>
<td>(Kissane, McKenzie, Bloch, Moskowitz, McKenzie, &amp; O'Neill, 2006)</td>
<td>Design: T0, T2 (6 &amp; 13mths post-bereavement). I: n = 180; C: n = 102</td>
<td>Psychotherapy: family focused grief therapy; 4-8 sessions C: usual care</td>
<td>Family functioning; Psychological morbidity and distress; Depression; Social functioning; Grief</td>
<td>Improved: psychological distress* at T2 6 &amp;13mths; depression * at T2 6 &amp; 13mths for the ‘most distressed’ caregivers at baseline.</td>
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<tr>
<td>23</td>
<td>% male: I: 47; C: 49</td>
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<tr>
<td></td>
<td>Caregiver mean age: I:37; C:36</td>
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<tr>
<td></td>
<td>Type: mixed</td>
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<td>Stage: advanced</td>
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<tr>
<td></td>
<td>Eligibility: Patient prognosis of 6 months age 35 and 70 years; 1 or more children &gt; 12 years</td>
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<tr>
<td>(Blanchard, Toseland, &amp; McCallion, 1996)</td>
<td>Design: T2 (6mths) to Toseland (see below)</td>
<td>See below</td>
<td>See below</td>
<td>NS</td>
</tr>
</tbody>
</table>
| (Bultz et al., 2000) | Design: T0, T1, T2 (3mths)  
I: n = 15; C: n = 19  
% male: 100  
Caregiver mean age: 51  
Type breast; Stage: early  
Eligibility: Patient diagnosis within 12 mth.  
Psychoeducational: short-term problem-solving; 6 sessions.  
C: wait list, usual care | Perceived health status; Depression; Anxiety; Marital adjustment; Coping behaviour | NS |
|---|---|---|---|
| (Walsh, Jones, Tookman, Mason, McLoughlin, Blizard et al., 2007)  
21 | Design: T0, T2 (4, 9, 12 wks)  
I: n = 137; C: n = 134  
% male: 21  
Caregiver mean age: I: 56.4; C: 56.1  
Type: mixed; Stage: advanced  
Eligibility: Score > 5/6 on the GHQ-28  
Education/support: advice and support; 6 weekly sessions.  
C: usual care | Psychological morbidity and distress; Strain; Quality of life; Grief | NS |
| (Toseland et al., 1995)  
Level II  
20 | Design: T0, T2 (2mths)  
I: n = 40; C: n = 38  
% male: 50  
Caregiver mean age: I: 56; C: 51  
Type: mixed; Stage: varied  
Eligibility: Exclusion if patient diagnosis <3mths or terminal phase; received other counselling in <6mths  
Psychosocial counselling: problem solving and coping; 6 sessions.  
C: usual care | Depression; Anxiety; Marital satisfaction; Satisfaction with support; Perceived health status; Burden; Help-seeking behaviour; Coping; Pressing problems; Personal change | NS |
<p>| Improved: physical, role and social functioning* (for highly distressed caregivers only); ability to cope with pressing problems* (for moderately burdened caregivers only). |</p>
<table>
<thead>
<tr>
<th>Design: T0, T2 (3 and 6mths)</th>
<th>Education/Support: Family-focused program; 5 sessions and 2 booster.</th>
<th>Appraisal; Uncertainty; Hopelessness; Coping: Quality of life</th>
<th>Improved: Negative appraisal* at T2 3mths, ((d = 0.37)); hopelessness** at T2 3mths, ((d = 0.54))</th>
</tr>
</thead>
<tbody>
<tr>
<td>I: n = 69; C: n = 65)</td>
<td></td>
<td>C: usual care</td>
<td></td>
</tr>
<tr>
<td>% male: not specified Caregiver mean age: 52 Type: breast; Stage of cancer: III and IV Eligibility: Patient life expectancy at least 6mths; family members</td>
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<tr>
<td>(Northouse, Kershaw, Mood, &amp; Schafenacker, 2005)</td>
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<tr>
<td>Design: T0, T1, T2 (6 and 12mths)</td>
<td>Psychotherapy: Couple-coping training; 3 sessions.</td>
<td>Couple communication; Coping; Psychological distress</td>
<td>Improved: Couple coping* and ( d = 1.23 ) between I and MI; withdrawal* at T2 6mths; coping effort* at T2 12mths and ( d = .64 ) between I and MI</td>
</tr>
<tr>
<td>N = 94</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>% male: 100 Caregiver mean age: 53 Type: breast and gynaecological Stage: early Eligibility: Patient about to commence treatment; committed relationship &gt;1 year.</td>
<td></td>
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<tr>
<td>(Scott et al., 2004)</td>
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<tr>
<td>Design: T0, T1, T2 (8wks post-bereavement)</td>
<td>Psychoeducation: Information-focused intervention; 2 sessions and 1 follow-up.</td>
<td>Preparedness for care-giving; Caregiver competence; Self-efficacy; Rewards Anxiety</td>
<td>Improved: rewards** at T1 ((d = .68)) and at T2* ((d = .66)).</td>
</tr>
<tr>
<td>I: n = 54; C: n = 52</td>
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<tr>
<td>% male: 34.9 Caregiver mean age: 60.78 Type: not specified Stage: advanced Eligibility: Residing with patient receiving home-based palliative care services.</td>
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<td>(Hudson et al., 2005)</td>
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<tr>
<td>(Kozachik, Given, Given, Pierce, Azzouz, Rawl et al., 2001)</td>
<td>Design: T0, T1 (9 wks post entry), T2 (24 wks post entry) I: n = 61; C: n = 59 % male: 50 Caregiver mean age: 52.44 years Type: mixed; Stage: varied. Eligibility: Patient to be newly diagnosed; eligible to receive chemotherapy; &lt; 56 days of initiating chemotherapy.</td>
<td>Education/support: Supportive nursing intervention; 9 contacts. C: usual care</td>
<td>Depression</td>
</tr>
<tr>
<td>(Goldberg, 1985)</td>
<td>Design: T0, T1 (6wks after diagnosis), T2 (3-4mths after diagnosis) I: n = 27; C: n = 21 % male: I: 15; C: 19 Caregiver mean age: I: 47; C: 53 Type: lung Stage: newly diagnosed</td>
<td>Psychosocial: Social support counselling; 12 sessions. C: usual care</td>
<td>Emotional, social and physical functioning</td>
</tr>
<tr>
<td>(Kuijer, Buunk, de Jong, Ybema, &amp; Sanderman, 2004)</td>
<td>Design: T0, T1, T2 I: n = 20; C: n = 19. % male: I: 70%; C: 68% Caregiver mean age: I: 49; C: 50 Type: mixed; Stage: varied Eligibility: Married or cohabitating; patient life expectancy at least 6mths</td>
<td>Counselling: Cognitive-behaviourally oriented couple counselling; 5 sessions. C: wait-list, usual care</td>
<td>Perceptions of inequity; Relationship quality; Psychological distress</td>
</tr>
</tbody>
</table>
| (Kayser, 2005) | Design: T0, T1, T2  
N: 50  
% male: 98  
Caregiver mean age: 49  
Type: breast; Stage: early  
Eligibility: Patient currently receiving treatment; married or in intimate relationship. | Psychosocial: Couple intervention; 9 sessions.  
Control: usual care | Individual well-being; Relationship functioning | Improved: stress communication coping at T2* |
|---|---|---|---|---|
| (McCorkle, Robinson, Nuamah, Lev, & Benoliel, 1998) | Design: Spousal data collected 5 x 6wk intervals, starting at 2 months after diagnosis.  
N: 46  
% male: I: 10; C: 40  
Caregiver mean age: 58  
Type: lung  
Stage: advanced | Support/Education: Specialised oncology home care.  
C: standard home care program (SHC); office care program, (OC). | Psychological distress | Improved: depression*; paranoid ideation* . |

§ = only statistically significant results representing improvements (ie. caregiver intervention group was statistically better than the caregiver control group)  
† = level of evidence (ref); ‡ = methodologic quality rating (Newell et al 2002); T0 = before/pre-test; T1 = post-test; T3 = follow-up; I = intervention; C = control; Type = type of cancer; Stage = stage of cancer; * < .05; ** < .01; d = calculated effect size when all relevant statistics were provided (Zimmerman 2007); NS = no significant caregiver outcomes between I and C.
<table>
<thead>
<tr>
<th>Study and level of evidence†</th>
<th>Design and study characteristics</th>
<th>Intervention</th>
<th>Psychological constructs</th>
<th>Caregiver efficacy findings§</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Heinrich &amp; Schag, 1985)</td>
<td>Design: T0, T1, T2 I: n = 12; C: n = 13 Caregiver mean age: not specified Type: mixed; Stage: varied</td>
<td>Psychoeducation: Group stress and activity management program; 6 sessions. C: usual care</td>
<td>Cancer information Psychosocial adjustment to illness; Quality of life; Daily activities; Psychological distress; Satisfaction with care received</td>
<td>Improved: information* at T2; recreational activity* at T2; satisfaction with care* at T2</td>
</tr>
<tr>
<td>III-1</td>
<td></td>
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<tr>
<td>(Gagnon, Charbonneau, Allard, Soulard, Dumont, &amp; Fillon, 2002)</td>
<td>Design: T0, T1 I: n = 66; C: n = 58 % male: 18 Caregiver mean age: I:54.6; C:53.3 Type: not specified; Stage: advanced</td>
<td>Psychoeducation: Written information C: usual care</td>
<td>Delirium knowledge; Perceived competence; Attitude towards delirium; Mood</td>
<td>Improved: knowledge of delirium frequency*; medication* competency in decision making **</td>
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<td>III-2</td>
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<tr>
<td>(Sabo, Brown, &amp; Smith, 1986)</td>
<td>Design: T0, T1 I: n = 6; C: n = 17 % male: 100 Caregiver mean age: not specified Type: breast; Stage: post-mastectomy</td>
<td>Support: Facilitated men’s support group; multisession. C: non-participants</td>
<td>Gender expectations; Self-esteem; Depression; Sexual compatibility; Verbal communication about mastectomy; Supportive attitude towards wife; Marital happiness</td>
<td>Improved: verbal communication about mastectomy**</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Education</td>
<td>Confidence in ability to provide care; Information about community resources; Problem-solving ability</td>
<td>Improved: information about community resources* caregiver problem-solving*</td>
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<tr>
<td>Bucher, Loscalzo, Zabora, Houts, Hooker, &amp; Brintzenhofeszoom, 2001</td>
<td>T0, T2; within-subjects</td>
<td>Individualised problem-solving educational session program for patients and caregivers</td>
<td></td>
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<tr>
<td>IV</td>
<td>N: 49</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>% male: 26</td>
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<tr>
<td></td>
<td>Caregiver mean age: 48</td>
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<td></td>
<td>Type: not specified; Stage: advanced</td>
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<tr>
<td>Cameron et al., 2004</td>
<td>T0, T1; within-subjects</td>
<td>Psychotherapy: Brief problem-solving intervention; 1 session</td>
<td>Amount of caregiving assistance provided; Confidence in caregiving; Emotional well-being; Problem-solving ability;</td>
<td>Improved: emotional tension*</td>
</tr>
<tr>
<td>IV</td>
<td>N: 34</td>
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<tr>
<td></td>
<td>% male: 32</td>
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<td></td>
<td>Caregiver mean age: 53.6</td>
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<tr>
<td></td>
<td>Type: mixed; Stage: advanced</td>
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<tr>
<td>Ferrell et al., 1995</td>
<td>T0, T1, T2; within-subjects</td>
<td>Psychoeducation: Pain education program for patients and family caregivers; 8 sessions.</td>
<td>Quality of life; Knowledge and attitudes about pain; Caregiver burden;</td>
<td>Improved: quality of life* at T1; knowledge* and experience* regarding pain</td>
</tr>
<tr>
<td>IV</td>
<td>N: 50</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>% male: 24</td>
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<tr>
<td></td>
<td>Caregiver mean age: 60.5</td>
<td></td>
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<tr>
<td></td>
<td>Type: mixed; Stage: varied</td>
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<tr>
<td>Lewis, Cochrane, Fletcher, Zahlis, Shands, Gralow et al., 2008</td>
<td>T0, T1; within-subjects</td>
<td>Education / Counselling: Skills and confidence focus; 5 sessions</td>
<td>Depression; Anxiety; Marital adjustment; Self-efficacy; Communication skills; Interpersonal support; Interview</td>
<td>Improved: depressed mood** anxiety** self-efficacy** spouse behavioural skills** Interview results reflected strengthening of relationship.</td>
</tr>
<tr>
<td>IV</td>
<td>N: 20</td>
<td></td>
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<tr>
<td></td>
<td>% male: 100</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Caregiver mean age: 53</td>
<td></td>
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<td></td>
<td>Type: breast; Stage: varied</td>
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<tr>
<td>Study</td>
<td>Design</td>
<td>N</td>
<td>% Male</td>
<td>Caregiver Mean Age</td>
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</tr>
<tr>
<td>Walsh, Martin, &amp; Schmidt, 2004</td>
<td>T0, T1; within-subjects</td>
<td>40</td>
<td>25%</td>
<td>51.43</td>
</tr>
<tr>
<td>Pasacreta, Barg, Nuamah, &amp; McCorkle, 2000</td>
<td>T0, T2; within-subjects</td>
<td>187</td>
<td>17%</td>
<td>not specified</td>
</tr>
</tbody>
</table>

§ = only statistically significant results representing improvements (ie. caregiver intervention group was statistically better than the caregiver control group or within group difference where no control group); † = level of evidence; III-1 = psuedorandomised controlled trial; III-2 = comparative study with concurrent controls; III-3 = comparative study without concurrent controls; VI = case series; T0 = before/pre-test; T1 = post-test; T3 = follow-up; I = intervention; C = control; Type = type of cancer; Stage = stage of cancer; * < .05; ** < .
Overview of findings and discussion

Of 13 level II randomised controlled trials (RCT) reviewed, 5 showed no significant difference across treatment groups and 8 showed significant effects, with moderate effect size. However, if we accept the contention that only high quality randomised controlled trials be considered in assessments of efficacy of psycho-social interventions in oncology (Manne & Andrykowski, 2006), the present review would base its conclusions on the five RCTs which received a good-quality rating (21 and over) using the Cochrane criteria. This would result in the conclusion that there is very little evidence for the efficacy of psycho-social interventions in reducing distress and improving coping in informal cancer carers.

Three studies showed no significant difference across treatment groups, following problem solving (Blanchard et al., 1996), or supportive psycho-education interventions (Bultz et al., 2000; Walsh et al., 2007). Two studies showed minimal impact, reporting increases in sexual satisfaction following couple counselling (Christensen, 1983) and reductions in general distress following family focussed grief therapy (Kissane et al., 2006). Of the eight other studies which would also be classified level II in the NHMRC ranking, and which received a fair-quality rating (11-20), two showed no significant effect following supportive counselling (Goldberg, 1985; Kozachik et al., 2001).

Modest positive effects were reported from three couple focused interventions, in relation to improvements in dyadic coping (Kayser, 2005), ratings of relationship quality (Kuijer et al., 2000), and supportive communication, sexual adjustment, coping effort and psychological distress (Scott et al., 2004). Supportive psycho-education interventions were reported to result in a more positive caregiver experience (Hudson et al., 2005), and less negative appraisal of care-giving (Northouse et al., 2005), and home nursing palliative care was found to reduce psychological distress in bereavement (McCorkle et al., 1998).

The present review also considered twelve non-RCT level III-IV studies, which did report positive results, across a range of domains. Psycho-education was reported to result in increased knowledge (Ferrell et al., 1995; Gagnon et al., 2002; Heinrich & Schag, 1985), improved self-efficacy in relation to coping (Lewis et al., 2008) or decision making (Gagnon et al., 2002), improved psychological well-being (Ferrell et al., 1995; Lewis et al., 2008), and reduction in caregiver burden (Pasacreta et al., 2000). Problem solving interventions were reported to increase knowledge and problem solving ability (Bucher et al., 2001), and to reduce emotional tension (Cameron et al., 2004). An arts intervention was reported to improve psychological well-being (Walsh et al., 2004), and a support group improved marital communication (Sabo et al., 1986).

Positive results from level III-IV studies cannot be accepted without caution however, as few of these studies demonstrate methodological rigor. Limitations include the absence of standardised measures, no pre-post outcome measures or absence of follow-up, no comparison or control groups, no information about attrition rates and absence of information about participant eligibility. However, RCTs are also not immune from methodological criticism. Small sample size is the norm in all studies,
level II-IV, increasing the likelihood of type II errors. The Kissane et al (2006) and Walsh (2007). RCTs are the only studies which met the recommended benchmark for evidence evaluation of over 100 participants per group (Hardorn, Baker, Hodges, & Hicks, 1996). Whilst 100 participants per group may be unrealistic in many research contexts, power calculations can be conducted, allowing estimates of the number of participants needed to have a 0.70 likelihood of detecting a moderate effect size. Few of the studies achieved this. The majority of the reviewed studies also employed a relatively short follow-up period, which prevents assessment of the long term effectiveness of interventions, and in some studies participants in the control condition accessed psychological support as part of usual care (e.g. Toseland et al., 1995), compromising the rigour of the controlled trial design. The emphasis on positive results recorded on a single outcome measure, in studies that used a range of measures, must also be viewed with caution, as this precludes standard interpretation of significance levels and increases the likelihood of a Type I error occurring.

There are a number of explanations for the paucity of significant findings in relation to psycho-social interventions reducing distress and improving coping in informal cancer carers. Whilst a number of informal carers experience elevated levels of distress associated with the presence of cancer, many participants in cancer carer interventions are described as highly-functioning, and do not show elevated levels of depression, stress or burden (e.g. Christensen, 1983; Goldberg & Wool, 1985). This confirms the suggestion that carers are not under stress when they access interventions, rather that they are doing so to collect information in order to prevent future problems (Toseland & Rossiter, 1989). This can result in a ceiling effect in relation to changes in psychological well-being. It has been suggested that those who decline participation may be those most in need of support (Goldberg & Wool, 1985). This appears to be borne out by the findings of Kissane et al (2006), who reported that the 66% of eligible families who declined to take part in their family focused grief therapy could be described as predominantly “chaotic/alientated” (p. 1216).

In recent reviews of the efficacy of psycho-social interventions for people with cancer (Andrykowski & Manne, 2006; Barsevick et al., 2002), it was concluded that when interventions are delivered to those with elevated levels of distress, the positive effect of such interventions is more evident. Two studies contained in the present review reported similar findings, suggesting that this may also be the case for informal cancer carers. Kissane et al (2006) reported that only families with high baseline depression scores reported significant reductions in depression following their family focused grief intervention. Similarly, Toseland et al (1995) only found significant effects of their problem solving intervention for those who scored one standard deviation below the mean on the Dyadic Adjustment Scale. This leads to the conclusion that psycho-social interventions which aim to reduce psychological distress should be targeted at those carers who have the most difficulty coping (Carlson et al., 2000).

The importance of establishing exactly what interventions can be expected to accomplish, and tailoring outcome measures accordingly, is also paramount. It has been argued that outcome measures currently used in cancer carer intervention research are measuring more global indices of burden, stress or depression (Harding & Higginson, 2003; Toseland & Rossiter, 1989), or measuring trait rather than state characteristics (Kissane et al., 2006), both of which would not be expected to change over short periods of time. In many instances, care-giving demands increase over the
course of the cancer journey (Pasacreta et al., 2000), particularly for individuals providing end of life care (Walsh & Weiss, 2003), which could also confound any prospective evaluation of psychological distress pre-post intervention. Rather than focusing on global indices of distress, it may be more applicable to adopt a range of measures appropriate to the specific aims of the intervention under investigation, such as increased knowledge or appraisal of care-giving following psycho-education, or relationship communication and satisfaction following a couple intervention. These were the constructs which showed significant positive change in the present review, with moderate effect size, in contrast to measures of psychological distress which largely showed no change. It has also been suggested that that psycho-social interventions with informal cancer carers should focus on maintaining quality of life (Northouse et al., 2005), on increasing positive emotions which can act as a buffer against stress (Hudson et al., 2005), or on developing skills for managing and dealing with specific illness related concerns in concrete gender-sensitive ways (Cochrane & Lewis, 2005), rather than on reducing psychological distress.

One factor which needs to be considered in evaluating psycho-social interventions for cancer carers is the way in which participants are recruited for studies. It has been suggested that ‘gate-keeping’ of cancer carer access to interventions occurs via organisations, patients, and health professionals (Hudson et al., 2005), resulting in the exclusion of those who might benefit the most. Participants are primarily made up of those contacted through the person with cancer, who may decline involvement (Cochrane & Lewis, 2005), or those who volunteer to take part in response to a direct approach, with low take-up reported, 20-30% on average (e.g. Blanchard et al., 1996; Bultz et al., 2000; Goldberg, 1985; Goldstein, Alter, & Axelrod, 1996; Keefe, Ahles, Sutton, Dalton, Baucom, Pope et al., 2005; Ostroff, Ross, Steinglas, Ronis-Tobin, & Singh, 2004; Sabo et al., 1986). One reason for low participation may be the use of the term ‘care-giver’, or ‘carer’ in recruitment for studies, as many partners of a person with cancer, or those primarily providing emotional rather than physical support, may not identify with the term ‘carer’ (Hagedoorn et al., 2008). The corollary to this is that participants who take part in interventions on the basis of being the partner or first degree relative of a person with cancer may not be a ‘carer’ (Hagedoorn et al., 2008), and thus may have different concerns and needs to those who are in a caring role.

Reasons for non-participation in psycho-social interventions include carers feeling that they do not need support, belief that they are coping well with managing the illness, only wanting the intervention focus to be on the needs of the patient, and concerns about leaving the patient alone (Harding & Higginson, 2003). This parallels findings of research on cancer support group non-attendance more broadly (Bui, Last, Bradley, Law, Maier, & Smith, 2002; Ussher, Kirsten, Butow, & Sandoval, 2007; Winefield, Coventry, Lewis, & Harvey, 2003), and suggests that it should not be assumed that cancer carers will want to avail themselves of interventions that are offered, and that this should be respected. Many carers adapt well to the illness and the caring role without having undertaken any psychological intervention (Goldberg, 1985; Weisman & Worden, 1977). Equally, cancer carers consistently report that self-reliance and independence are important values (Grande et al., 1997), and the reports of negative effects of interventions in a proportion of studies (Jepson, McCorkle, Adler, Nuamah, & Lusk, 1999; Skilbeck, Payne, Ingleton, Nolan, Carey, & Hansen, 2005) suggests that interventions are not for everyone.
However, many informal cancer carers position their own needs or concerns as irrelevant or insignificant in comparison to those of the person with cancer (Ussher & Sandoval, 2008). Their perception of the severity of their own distress may be underestimated, leading to low motivation to attend to their own needs or to seek help, as predicted by the Health Belief Model (Janz & Becker, 1984). The provision of information about the emotional and physical costs of caring, and about the buffering effects of engaging in self-care or social support, may increase carer engagement with interventions. Equally, the high expectations placed on carers by health professionals and other family members (Soothill et al., 2003), may serve to create both a subjective and group norm which delegitimizes carers articulating their own needs, seeking help, or engaging in self-care. Reducing the costs of engagement with interventions, and greater social acknowledgment of carers needs, may overcome such barriers.

It is important to note that regardless of the mode of intervention, participants in psycho-social interventions report a high level of satisfaction (Bucher, Houts, Nezu, & Nezu, 1999; Gilbar, 1997; Ostroff et al., 2004; Walsh et al., 2007), rating interventions positively in terms of their usefulness (Bultz et al., 2000; Feldman, 1993; Goldstein et al., 1996), their impact on experience of the rewards of caring (Hudson et al., 2005; Manne et al., 2004b), and on improvements in communication and subjective wellbeing (Plant, Richardson, Stubbs, Lynch, Ellwood, & Slevin, 1987). The inclusion of qualitative evaluations of subjective experience of intervention efficacy and process, alongside standardised instruments, would be a valuable addition to future research, as qualitative research can identify both mechanisms of change, and previously neglected variables for consideration in quantitative studies (Hagedoorn et al., 2008). It is notable that two studies which adopted a qualitative methodology reported improvements in psychological wellbeing (Grahn & Danielson, 1996; McLane, Jones, Lydiatt, Lydiatt, & Richards, 2003), suggesting that there may be a disparity between subjective evaluation of intervention efficacy, and changes recorded on standardised instruments.

A number of further recommendations can be made for future research in this field. The importance of targeting interventions to the needs of cancer carers has been emphasised by many researchers (Goldberg, 1985; Harding & Higginson, 2003; Hudson et al., 2005; Kissane et al., 2006). However, many research studies include both carers and people with cancer, with no attempt to tailor support to their different needs, and in some instances, little or no differentiation between them (e.g. Bucher et al., 1999; Feldman, 1993; Ussher et al., 2006; Wells et al., 2003), or an overt focus on the needs of the patient (e.g. Keefe et al., 2005). There has been little attempt to recognise the range of relationship types present in the informal cancer carer population – which include spousal, friendship, parental, sibling and other family relationships. The gender balance of carers participating in interventions has also received little attention. It is now well established that women cancer carers report higher rates of depression and anxiety, and lower life satisfaction and quality of life ratings, compared to men carers (Hagedoorn et al., 2008). Women have also been found to construct and experience the caring experience differently from men, leading to different patterns of coping (Ussher & Sandoval, 2008). However, no interventions, to date, have targeted gender specific needs, and none have examined gender differences in the experience or efficacy of interventions. Such research is long overdue.
Equally, few studies include participants from a variety of cultural groups, those with poor literacy skills, or English as a second language, limiting generalisability of findings to such groups (Hudson et al., 2005). The intervention needs and barriers to participation of carers in rural and remote areas has also been overlooked, despite the evidence that rural family caregivers experience greater burden, due to isolation and limited resources (Conley & Burman, 1997). There are many areas of cancer carer needs not incorporated in current interventions studies. One example is sexuality and intimacy issues, which are frequently identified as problematic for cancer carers (Hawkins et al., 2009), with negotiation of sexual matters within the couple relationship often reported to be difficult (De Groot et al., 2005). This can have a significant impact on the well-being of the carer and the person with cancer (Schober, 2004). Yet, to date, there has been no systematic evaluation of interventions to address cancer carer psycho-sexual needs, and there is a general neglect of relationship issues in the majority of cancer carer interventions (Cochrane & Lewis, 2005). Another issue that needs consideration is the absence of research into the caregiving experience for partners in same sex relationships, as health care practices may not be attuned to the specific dynamics of gay and lesbian relationships, or to other social issues which may impact upon care (Kayser, 2005). Only one study reviewed in the present paper reported attempting to include same sex couples in their sample (Bultz et al., 2000), but they were not successful in doing so.

The relative efficacy of interventions for carers across different stages and types of cancer, or the merits of focusing on single types of cancer versus mixed types, has also been neglected. The needs and concerns of cancer carers will vary depending on the stage of cancer and prognosis, ranging from dealing with the shock of diagnosis in early stages, to anticipatory grieving in palliative care. However, many carer intervention studies do not specify cancer stage, and interventions are rarely targeted to meet the needs of carers at particular stages. Stage of cancer may also be a factor in recruitment, with some studies reporting higher take-up in carers of a person with newly diagnosed or early stage cancer, in comparison to those at later stages or remission (Carlson & Strang, 1996). Equally, whilst many of the studies fail to describe the breakdown of cancer types of the participants, those which do have predominantly focussed on breast, lung and prostate cancer. For people with cancer, interventions which focus on a single type of cancer (breast cancer) have been found to be more effective than those that include a range of cancer types, and the training of the health professionals offering the intervention has also been found to influence effectiveness (Zimmerman, Heinrichs, & Baucom, 2007). Future research should systematically compare the experience of carer interventions across cancer type and stage, and the mediators and moderators of effectiveness, including the professional background of the service deliverer, in order to inform health professionals as to the most effective time, modality and content of delivery for these difference groups. Examination of the influence of other potential moderating factors, such as level of carer burden (Lutsky & Knight, 1994), activity restriction (Matthews et al., 2003), and unmet needs (Allen, 1994), could also provide useful insight into the reasons why interventions may be effective for some carers, but not for others.

Interventions should also be based on a clear theoretical framework and a prior needs analysis; this is not the case for the majority at present (Cochrane & Lewis, 2005). Hagedoorn et al (2008), in their recent meta-analysis of distress in couples coping.
with cancer, suggest that research on stress in marital relations, on mutuality of relationships, and on gender differences in coping in relationships, can be usefully applied to understand distress in couples coping with cancer. The positive effects of couple interventions on relationship and sexual satisfaction, as well as on couple communication and coping (Christensen, 1983; Kayser, 2005; Kuijer et al., 2000; Scott et al., 2004) suggests that this is an area deserved of further investigation. Conceptualising cancer as a relational experience, using a model of dyadic coping (Kayser et al., 2007), provides explanation for the finding that interventions targeting couples appear to be more effective than interventions focusing solely on the carer. This model draws on systemic-transactional theory (Bodenmann, 2005), to conceptualise coping as an interaction between the stress signals and communication style of one partner and the coping responses of the other. Supporting this model, couples who are mutually responsive, attend to each others needs, and talk openly about their stress, have been reported to be able to engage in effective emotion and problem focused coping in relation to cancer (Zunkel, 2002). This allows them to find benefits in the cancer experience, such as personal growth and relationship closeness (Kayser et al., 2007; Manne et al., 2004b). This pattern of mutual communication has also been found to be associated with lower levels of distress for people with cancer and their partners, and higher levels of marital satisfaction (Badr et al., 2008; Manne et al., 2006; Ptacek et al., 1994). Conversely, many partners are over-protective towards the person with cancer, engaging in “protective buffering” in an attempt to prevent distress (Badr & Carmack Taylor, 2006; Kuijer et al., 2000), or “disengaged avoidance” (Kayser et al., 2007, p412), involving complete denial of cancer or its effects. This is associated with higher levels of distress and lower marital satisfaction (Badr et al., 2008; Kuijer et al., 2000; Manne et al., 2006; Ptacek et al., 1994; Skerrett, 1998; Zunkel, 2002), as well as less supportive behaviour within the couple (Manne et al., 2005). Longer term follow-up of participants in couple interventions may thus produce findings of reduced distress, associated with improved communication, coping and marital satisfaction.

However, not all informal carers are spouses. More broadly, Wuest’s (1997, 2000, 2001) work on patterns of carer coping, and how these shift and develop across the course of the caring relationship, could provide a theoretical framework for tailored interventions across different stages of the cancer journey. Wuest (1997) argues that the initial caring stages are characterised by ‘fraying connections’, involving daily struggles, altered prospects, and ambivalent feelings. For those carers who develop adaptive methods of coping, this is followed by a stage of ‘precarious ordering’, involving setting boundaries, negotiating, and ‘re-patterning’ care – including strategies such as anticipating, setting ground rules, juggling time, relinquishing and replenishing (Wuest, 2000, 2001). In a recent qualitative study of men and women cancer carers, the majority of women gave accounts which could be characterised as ‘fraying connections’, regardless of cancer stage, in contrast to the men carers who gave accounts of strategies of ‘re-patterned care’, and reported higher levels of psychological well-being and coping (Ussher & Sandoval, 2008). There is also evidence that women are more affected than men by the emotional well-being of others (Hagedoorn et al., 2001), or by life-events, such as cancer, which affect others (Kessler & McLeod, 1984; Taylor, 2006). This is because a woman’s sense of self is conceptualised as “being in relation” (Jordan et al., 1991; Miller, 1986), with mutual connectedness and the well-being of significant others being central to identity. This reinforces the need for interventions to be tailored to the specific needs of men and
women carers, across stage of the caring experience, as well as being based on a clear theoretical framework.

**Summary and conclusions**

In conclusion, this absence of consistent positive findings, accompanied by methodological problems, and moderate clinical impact, does not provide the body of evidence to make reliable clinical recommendations to guide practice (NHMRC, 2000) in relation to the provision of psycho-social interventions to reduce distress and improve coping for informal cancer cares. This parallels the conclusions of recent reviews of psycho-social interventions for people with cancer (Coyne, Lepore, & Palmer, 2006; Newell et al., 2002), or partners of a woman with breast cancer (Cochrane & Lewis, 2005). Isolated studies which appear to reduce distress do not provide sufficient evidence for the overall efficacy of this type of intervention, and consideration needs to be given to possible adverse effects and the other costs of such interventions (Coyne & Lepore, 2006). However, there is evidence that targeted psycho-social interventions can be effective in facilitating change in areas such as increased knowledge, relationship satisfaction or communication, appraisal of caregiver experience, and distress following bereavement. Equally, carers subjectively report benefit from engagement in interventions. Further rigorous research using a RCT design with adequate sample size is needed to evaluate which interventions are likely to work for which carers, across types of cancer, stage of illness, gender, cultural group, level of distress, and relationship with the person with cancer. Interventions need to be based on a clear theoretical framework, with outcome measures tailored specifically to the mode of intervention, rather than global measures of distress. Without this research evidence, there is not a strong case to be made for the development of specialised interventions which differ from the information and support that characterises ‘usual care’.
Section Eight
An Evaluation of Three Supportive Interventions for Cancer Carers

It has been argued that alternatives to randomised controlled trials (RCT) should be considered in evaluations of palliative care (Grande, Todd, Barclay, & Farquhar, 2000) and cancer carer research (Harding & Higginson, 2003), due to ethical issues about exclusions from intervention, and control groups, meaning that the ideal RCT is seriously compromised. Observational and quasi-experimental studies have been advocated, offering reliability as great as an RCT (Concato, 2000). Harding and Higginson (2003) conclude that a range of interventions should be developed, as no one model will meet the needs of all carers; interventions should be theory based; they should focus specifically on the needs of carers, rather than being a generic care service; have clear and achievable aims; and ensure that these aims are addressed using rigorous evaluation methods (using repeated measures from baseline and employing comparison groups). This project accomplished these aims, developing and rigorously evaluating a range of interventions, based on the perceived needs, concerns, and pathways to distress, of a broad spectrum of cancer carers in NSW.

Evaluation Method

Three different support interventions for cancer carers were developed, and then evaluated within a controlled trial, using a patient preference design and pre-post intervention evaluations. 90 cancer carers who took part in stage one, who agreed to take part in stage three of the study, were offered a range of supportive interventions and asked to indicate their preferences. 30 carers were allocated to each intervention on the basis of preference.

The 3 interventions evaluated were: Self-help information pack for cancer carers (I&SHP); one to one meeting with a professional (a flexible number of sessions), in conjunction with the self-help pack (HCP); on-line support group (10 sessions), in conjunction with the self-help pack (Online). The 3 interventions are modes commonly advocated in the research literature (Harding & Higginson, 2003) and adhere to best practice guidelines for carer’s support programs (Rose, 1997). The content of the interventions drew on the needs assessment conducted in stage one of the project, and previous research. This included information provision; support; validation of needs of carer; attention to self-efficacy and coping; problem solving, targeted specifically for the needs of men and women carers in NSW.

Pre-post evaluation measures

The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983), is a 14 item validated self report measure developed to measure anxiety and depression in non-psychiatric populations. Each sub-scale HADSA (anxiety) and HADSD (depression) has a maximum possible score of 21, with a score of between 8 and above recommended as the cut-off point for caseness, the cut-off for clinical
diagnosis. A score of 8-10 is categorised borderline and a score of 11 and above categorised as abnormal in relation to caseness (Bjelland et al., 2002).

**Coping with the demands of the caring role** was evaluated using 6 closed ended statements, developed for the present study.

**Knowledge and Information** was evaluated using 3 closed ended statements, developed for the present study.

**Communication of concerns and needs** was evaluated using 3 closed ended statements, developed for the present study.

**Coping strategies and changes following the intervention** were evaluated using open ended questions.

## The Interventions

### Aim of the interventions

The aim of each of the interventions was to raise carers’ awareness of their own needs, the importance of maintaining their emotional and physical well-being, and assist them to develop coping strategies when caring for people with cancer. After engaging in the interventions, it was hoped they will be able to:

- Describe how cancer and its treatments can impact on the relationship they have with the person for whom they are caring
- Assess their caring workload
- Identify signs of burn-out and stress.
- Identify the impact of their own wellbeing on the person for whom they are caring.
- Use practical strategies to improve or maintain their own physical wellbeing.
- Use practical strategies to improve or maintain their own emotional wellbeing.
- Identify and use sources of practical and emotional support networks in the community
- Gain access to more information about their own needs and those of the person for whom they are caring.

### Descriptions of the interventions

**Self-Help and Information pack**

The self-help booklet contained the following sections:

**Information & introduction**

- Who is a cancer carer
- What do carers do
- How to reduce & cope with stress
- About this pack
Dealing with issues facing you & the person you’re caring for: some practicalities

- Introduction
- Preparing for a doctor’s visit
- Communicating symptoms to your doctor
- Recording medical information
- Dealing with paperwork
- Financial information
- Cancer, food & diet
- Communicating with the person you’re caring for
- Safety at home
- Safe lifting
- Summary

Caring for the carer: the rewards, the difficulties

- Introduction
- The rewarding aspects of caring
- The stress of caring: what is stress?
- Self-silencing
- The emotional side of caring

Caring for the carer: dealing with emotional stress

- Introduction
- Keeping a diary
- Support groups
- Changing the way you think

Caring for the carer: how to communicate your needs

- Introduction
- Communication
- Being assertive
- Asking for & accepting help
- Dealing with family members

Caring for the carer: managing stress by learning how to relax

- Introduction
- Relaxation
- Time out for you
- Keeping a sense of who you are

Caring for the carer: looking after your own physical needs

- Introduction
- Visiting your GP
- Sleeping
- Exercise
• Diet

**Intimacy**

- Introduction
- The positive impact of caring on intimacy
- When caring affects intimacy

**Appendices**

- Recording medications

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**On-line intervention**

Participants in this program received a copy of the self-help booklet, and also engaged in an on-line group intervention. The on-line program duration was 6 hours divided into 4 x 1.5 hour sessions. Sessions were run one week apart. The program format was small group work guided by an expert facilitator, who had a knowledge of group dynamics, carers’ issues and oncology.

The on-line intervention program outline consisted of:

**Session 1 – Cancer Overview**

- Facts about cancer specific to the group (including cancer incidence and mortality)
- Cultural issues (gender issues and cultural beliefs about cancer and its causes)
- Cancer carers facts and issues
- How can I help?

**Session 2 – The Cancer Journey**

- Talking to health professionals
- Treatment (pain and symptom management)
- When the cancer won’t go away

**Session 3 – Support**

- Managing treatment and care
- Managing your family and friends
- Asking for help
- Looking after yourself
- End of life issues

**Session 4 – Summary and Conclusion**

- Support Networks
- Local Support Programs
- Ongoing support
- How to find help

*Health Care Professional Consultations*
Participants in this program received a copy of the self-help booklet, and also engaged in consultations with a health professional, in order to discuss their person needs and concerns associated with caring. Up to six sessions with the health care professional were available.

**Results**

**Sample characteristics**

90 participants completed and returned a pre-intervention questionnaire and a self select form choosing the intervention they wished to be part off. 3 months after being allocated into one of the three intervention groups they were asked to complete a post questionnaire. 59 participants completed this questionnaire. Finally 6 months after being allocated into an intervention group a 6 month questionnaire was sent to participants, 37 follow up questionnaires were returned at the 6 month follow up (Table 14).

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During each of the time periods nearly 2/3 of the sample was female, with no change at all in the gender ratio in the two follow up periods (Figure 26).

**Figure 26: Gender Profile**

- **Pre-intervention**: 29% Male, 71% Female
- **At 3 month follow up**: 32% Male, 68% Female
- **At 6 month follow up**: 32% Male, 68% Female
Descriptive analyses

Due to the level of attrition across time, it was not possible to conduct statistical analysis on the results. Descriptive data comparing each of the conditions on each of the outcome variables is presented below.

**Psychological Distress**

As in Stage 1 participants completed the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) to assess the carers’ levels of anxiety and depression. Total scores were calculated for, anxiety and depression. The maximum score possible for both subscales was a total of 21. A score between 0-7 indicates a score within the normal range, a score between 8-10 would indicate the person is within the borderline range, and a score between 11-21 would indicate being within the range for abnormal anxiety or depression levels.

![Figure 27: Psychological distress over time](image)

Over all three time periods the average anxiety score was within the borderline range, with anxiety levels very slightly decreasing over the 6 months (figure 27). The average score for depression over all three time periods participants was within the normal range, with a slight increase in depression scores at the 3 month follow up.

![Figure 28: Between group difference in anxiety over time](image)

Participants in the Information and Self Help Pack (I&SHP) intervention were the only group where anxiety scores increased over all the time periods, but the level of anxiety reported remained with the borderline range over the 6 months. With the Online intervention, anxiety levels peaked at the 3 month follow up where the score
for anxiety levels creeps into the abnormal range. This score decreases to below the pre intervention at the 6 month follow up and back to borderline range for anxiety. Only participants in the Health Care Professional (HCP) intervention saw a decrease in anxiety scores over all the time periods. The mean score for anxiety levels at the 6 month follow up just falls into the normal range (figure 28).

**Figure 29: Between group difference in depression over time**

Overall the online group scored the highest levels of depression, with levels of depression peaking at the 3 month follow up (figure 29). At the 6 month follow up the levels of depression have reduced from being within the borderline range to a score that falls just within the normal range for depression. Both of the other interventions have a slight decrease in depression scores from the pre intervention at the 3 month follow up, with an increase in depression scores at the 6 month follow up. For both these intervention groups the level of depression stays just within the normal score for depression over all 3 time periods.

*Coping with demands of the caring role*

Each of the six graphs in this section represents participant’s responses to six statements looking at how carers cope with the demands of the caring role. Participants were asked to indicate whether they disagreed, neither agreed nor disagreed or agreed with the statement. These questions were asked to all participants in all intervention groups, at each of the three time periods, with percentage rates reported, per group, at each time phase.
The proportion of participants across all intervention groups who agreed with the statement increased over time. The proportion of participants who neither agreed nor disagreed with this statement decreased over time.

The participants in the HCP intervention group agreed more strongly with the statement that they were able to manage stress in their caring role than those in the other intervention groups at the pre intervention stage. Agreement with the statement then decreased at the 3 month follow up to then increase slightly by the 6 month follow up. A proportion of participants in the HCP intervention only disagreed with this statement at the 3 month follow up and at no other time period. In both the Online and the I&SHP intervention group the proportion of participants over time agreeing with this statement increased. This suggests that the online and self-help pack intervention were associated with greater self-efficacy in coping with the demands of the caring role over time, whereas the health professional intervention was associated with reduced self-efficacy in relation to stress management.
The proportion of participants across all intervention groups who agreed with the statement “I have confidence in the level of care I provide: increased over time, with participants disagreeing with this statement decreasing over time.

Agreement with this statement increased over time with the Online intervention group. The opposite happened with the HCP intervention group where agreement with the statement decreased over time. For the I&SHP intervention group agreement with the statement was at its highest at the 3 month follow up, but agreement with the statement was still higher at the 6 month follow up than it was pre intervention stage.
Figure 33: Role as carer over time

I have strategies to help me cope with my role as a carer

The proportion of participants across all intervention groups who agreed with the statement “I have strategies to help me cope with my role as a carer” increased over time with participants disagreeing with this statement decreasing over time.

Figure 34: Between group difference in role as carer over time

I have strategies to help me cope with my role as a carer

The Online intervention group is the only intervention group where at the 6 month follow up agreement with the statement had increased from the pre intervention stage. Disagreement for this statement for the Online group was higher than those agreeing during the first two time periods. For both the I&SHP intervention group and the HCP intervention group agreement with this statement had decreased by the 6 month follow up.
The proportion of participants across all intervention groups who agreed with the statement “I’m able to manage my emotions” increased over time with participants disagreeing with this statement decreasing over time.

The HCP intervention group saw agreement to this statement increasing over time. For the I&SHP intervention group agreement with this statement decreasing over time. With the Online intervention group agreement with the statement had increased from the pre intervention stage, but a higher proportion of this group disagreed with this statement over time.
The proportion of participants across all intervention groups who disagreed with the statement “I do not have a sense of control in my life” increased over time with participants disagreeing with this statement decreasing over time.

The I&SHP intervention group agreement with the statement was higher at the 6 month follow up than at the beginning. For both the HCP intervention group and the Online intervention group disagreement with this statement was higher at the 6 month follow up than agreement with the statement.
The proportion of participants who agree with the statement “I’m able to manage my independence” increases at the 3 month follow up and then decreases at the 6 month follow up. At six months more people disagree with this statement than agree.

The I&SHP intervention group saw agreement with this statement increase over time. For the HCP intervention group, agreement with this statement decreased over time. In the Online intervention group a higher proportion of participants disagreed with this statement, this did decrease over time. Although a smaller proportion of this group agreed with the statement, agreement is higher at the 6 month follow up than at the beginning.
Knowledge and information

Each of the six graphs in this section represents participants’ responses to three statements looking at knowledge and information. Participants were asked to indicate whether they disagreed, neither agreed nor disagreed, or agreed with the statement. These questions were asked to all participants in all intervention groups, at each of the separate time periods.

Figure 41: Financial information over time

I have knowledge about important issues in relation to my caring role such as - financial information

More than half of the participants across all intervention groups agreed with the statement “I have knowledge about important issues in relation to my caring role, such as financial information”, with agreement peaking at the 3 month follow up. Participants disagreeing with this statement decreased over time.

Figure 42: Between group difference in financial information over time

I have knowledge about important issues in relation to my caring role such as - financial information

Agreement for this statement increased over time for the proportion of participants in the Online intervention group. For participants in the HCP intervention group agreement for this statement decreased over time. The proportion of participants who agreed with this statement in the I&SHP intervention group increased greatly from the pre intervention to the 3 month follow up.
The proportion of participants across all intervention groups agreed with the statement “I have knowledge about important issues in relation to my caring role, such as food and diet”, with agreement peaking at the 3-month follow up.

The proportion of participants across all intervention groups agreed with the statement “I have knowledge about important issues in relation to my caring role, such as food and diet”, with agreement peaking at the 3-month follow up.

Agreement with the statement increased over time for the Online intervention group, and the proportion of participants from this group who disagreed with the statement over time decreased. For the I&SHP intervention group the proportion of participants who agreed decreased over time. By the 6 month follow up in the HCP intervention group the proportion of participants who agreed with the statement had decreased since the pre intervention. However, this group had a higher proportion agreeing with the statement than the other 2 intervention groups.
Figure 45: Knowledge about sex and intimacy over time

I have knowledge about important issues in relation to my caring role such as - knowledge about sex and intimacy issues

The proportion of participants across all intervention groups who agreed with the statement “I have knowledge about important issues in relation to my caring role, such as knowledge about sexual and intimacy issues”, increased over time. The proportion of participants who disagreed with this statement decreased over time.

Figure 46. Between group difference in sex and intimacy over time

I have knowledge about important issues in relation to my caring role such as knowledge about - sex and intimacy issues

Both the Online intervention group and the I&SHP intervention group, the proportion of participants who agreed with this statement was greater at the 6 month follow up than at the start. For the HCP intervention group the proportion of participants who agreed decreased over time. The Online intervention and the I&SHP intervention group saw a decrease in the proportion of participant disagreeing with the statement.
Communication of concerns and needs

Each of the six graphs in this section represents participant’s responses to six statements looking at communication of carer concerns and needs. Participants were asked to indicate whether they disagreed, neither agreed nor disagreed or agreed with the statement. These questions were asked to all participants in all intervention groups, at each of the three time periods, with percentage rates reported, per group, at each time phase.

**Figure 47: Expressing feelings towards the person I care for over time**

I'm able to express my concerns and feelings to - the person I care for

The proportion of participants across all intervention groups who agreed with the statement “I’m able to express my concerns and feelings to – the person I care for” increased over time. The proportion of participants who disagreed with this statement decreased over time.

**Figure 48: Between group difference in expressing feelings towards the person I care for over time**

I'm able to express my concerns and feelings to the person I care for
In the HCP intervention group there was no change over time with the proportion of participants who agreed with this statement, however the number of participants who disagreed with this statement increased over time. The proportion of participants from the I&SHP intervention group who agreed with the statement increased over time. In the Online group agreement with the statement had increased from the pre intervention to the 6 month follow up, the agreement with the statement was at its highest level at the 3 month follow up.

**Figure 49: Expressing feelings towards family and friends over time**

I’m able to express my concerns and feelings to - family and friends

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The proportion of participants across all intervention groups who agreed with the statement ‘I’m able to express my concerns and feelings to – family and friends’ increased over time. The proportion of participants who disagreed with this statement decreased over time.

**Figure 50: Between group difference in expressing feelings towards family and friends over time**

I’m able to express my concerns and feelings to family and friends

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The HCP intervention group saw the proportion of participants who agreed with this statement decrease over time, and the proportion who disagreed increase, at a lower level. The I&SHP intervention group and the online intervention group both had a
A greater proportion who agreed with the statement at the 6 month follow than at the pre intervention time period with a decrease occurring at the 3 month follow up.

**Figure 51: Expressing feelings to health professionals over time**

I’m able to express my concerns and feelings to - health care professionals

![Bar chart showing the proportion of participants who agreed, neither agree nor disagree, or disagreed with the statement over time.](chart)

The proportion of participants across all intervention groups who agreed with the statement ‘I’m able to express my concerns and feelings to - health care professionals’ increased over time. The proportion of participants who disagreed with this statement decreased over time.

**Figure 52: Between group difference in expressing feelings to health professionals over time**

I’m able to express my concerns and feelings to health care professionals

![Bar chart showing the proportion of participants who agreed, neither agree nor disagree, or disagreed with the statement over time, across different intervention groups.](chart)

Both for the Online intervention group and the HCP intervention group the proportion of participants who agreed with the statement increased over time. The Online intervention group saw a higher number of participants disagreeing with this statement at the pre intervention stage, but this decreased at both the 3 and 6 month follow up to see a greater number from this group agreeing with the statement than disagreeing. The I&SHP intervention group saw a slight drop in the proportion of participants who agreed with this statement at the 6 month follow up.
The proportion of participants across all intervention groups who agreed with the statement increased over time. The proportion of participants who disagreed with this statement decreased over time.

The I&SHP intervention group the proportion of participants who agreed with the statement “I’m able to express my needs to the person I care for” increased over time. The proportion of the Online intervention group who agreed with the statement did increase over time, but agreement was higher at the 3 month follow up than it was at the 6 month follow up. For the HCP intervention group there was a decrease in agreement with this statement over time and an increase in disagreement with this statement.
The proportion of participants across all intervention groups who agreed with the statement “I’m able to express my needs to family and friends” increased over time. The proportion of participants who disagreed with this statement decreased over time.

The Online intervention group the proportion of participants who agreed with the statement increased over time and the proportion of participant who disagreed with the statement decreased over time. At the 6 month follow up more participants in the Online group agreed with the statement than disagreed. In the HCP intervention group the proportion of participants who agreed with the statement decreased over time and the proportion of participant who disagreed with the statement decreased over time. At the 6 month follow up there was no difference in the proportion of participants who agreed or disagreed with the statement. The I&SHP intervention group saw a slight increase in the proportion of participants who agreed with the statement over time, with a decrease in agreement happening at the 3 month follow up.
Figure 57: Expressing needs to health professionals over time

The proportion of participants across all intervention groups who agreed with the statement “I’m able to express my needs to health professionals” increased over time. The proportion of participants who disagreed with this statement decreased over time.

Figure 58 Between group difference in expressing needs to health professionals over time

For the Online intervention group and the HCP intervention group the proportion of participants who agreed with the statement increased over time. For the HCP intervention group there was a sharp increase in the number of participants who agreed with the statement at the 6 month follow up. For the Online intervention group at the pre intervention stage a higher number of participants disagreed than agreed with the statement. The I&SHP intervention group saw an increase in the proportion of participants who agreed with the statement although this number did fall slightly at the 6 month follow up, but the number remained higher than at the pre intervention stage. The number of participants in this group that neither agreed nor disagreed was higher than the proportion who agreed at the 6 month follow up.
Qualitative Results: Cancer carer perceptions of intervention efficacity

Coping strategies learnt following the intervention

Participants were asked what coping strategies they developed following the intervention. These are presented in tabular form below, taking each program in turn.

Table 15: Coping Strategies report after self-help and information pack

<table>
<thead>
<tr>
<th>Keeping a diary</th>
<th>Assertiveness</th>
<th>Intimacy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reinforced need to maintain own health and to continue positive self talk</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asking for help rather than attempting to do it all myself</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stop being “Mr Fix it” and listen</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relaxation techniques to help me sleep – meditation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>To be able to cope with what my wife was going through</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Used as a reminder of skills used before</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stop negative thoughts and change the way I think – out of the apparent “bad” things that happen – look at and focus on the positives – there is always one somewhere (a positive).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have made a small amount of time for self</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Just having the information made it easier.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Importance of self-care/support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How to manage stress</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trying to be more patient with my husband! I have learnt this is the hardest thing I have and will ever do! Realise my husband is not himself due to all the chemicals and medications pumped into his body and try and walk away from arguments.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self appraisal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Learnt to accept the condition. Conditioned myself to accept that Elinor was dying and I could not do anything to help her accept to be there and to support her</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No new ones but confirmed the understanding I had gained about possible strategies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Better communication</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Better self-care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Confirmation of my thoughts, activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Made me feel less alone</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 16: Coping Strategies report after on-line intervention

| How to ask for help. How to make time for me! |
| Variety of issues from different perspectives |
| Inadequate access, but I am still pursuing regular access as I feel this is a lot to gain |
| Able to discuss problems and ask questions. Able to receive varied suggestions and coping ideals. |
| Knowing that what I am feeling and dealing with is normal. |
| Unfortunately my issue now is grief rather than being a carer. |
| Accepting that I can’t be on top of everything like I used to be |
| The pack is useful for basic information. The best learning tool is to talk to other people going through similar experiences and issues. |
| Basically letting him deal with the illness in his own way and allowing myself to think positive. |

Table 17: Coping Strategies report after health care professional and self-help pack intervention
Getting to sleep. Learning to relax.
I believe I was much more settled following counselling, which for me came at the right time.
The booklet reinforced many of the coping strategies that I have been using.

Shall refer back to it when and if my husband’s condition and our situation worsens

Learnt and learning how to take time to help myself to get stronger so my problems can be addressed as being a carer can mean that conflicts are not resolved while dealing with another loved ones needs. Unresolved issues aren’t addressed until feeling stronger

Asking for and accepting help. Being more assertive/communicating more effectively

Really just confirmed that I have been doing the right things generally

Taking care of oneself

Better degree of understanding about myself, my reactions to the situation and possible solutions and by extension about my partner.

Ability to study my feelings and to accept them

Ability to recognise negative feelings in myself and acknowledge them

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**What has changed for you following the intervention?**

**Table 18: Positive benefits of self-help and information pack**

<table>
<thead>
<tr>
<th>Benefit</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am more relaxed/ I have a more open and better understanding of my husband’s needs, and also my own needs</td>
<td></td>
</tr>
<tr>
<td>Putting less pressure on myself – it’s okay not to do everything (e.g. housework, etc)</td>
<td></td>
</tr>
<tr>
<td>I feel much more capable than before to help and comfort my wife – especially because I feel more in control of my own feelings and recognise that its not a failure to ask for help sometimes.</td>
<td></td>
</tr>
<tr>
<td>The importance of looking after myself. My wife helped me greatly by insisting on me having time out.</td>
<td></td>
</tr>
<tr>
<td>Confidence that how I feel and some of the ways I act and things I do are a natural part of my behaviour given the circumstances of dealing with advanced cancer.</td>
<td></td>
</tr>
<tr>
<td>I have made a small amount of time for self</td>
<td></td>
</tr>
<tr>
<td>I knew there were more people out there feeling the way my husband felt and also more people like me trying to cope.</td>
<td></td>
</tr>
<tr>
<td>Know that there are others in same position</td>
<td></td>
</tr>
<tr>
<td>Know that there are support groups etc out there</td>
<td></td>
</tr>
<tr>
<td>How to deal with the lack of intimacy, but I have learnt that there are ways and means to overcome.</td>
<td></td>
</tr>
<tr>
<td>Realise that personal anger is normal. I now calm and pace my actions</td>
<td></td>
</tr>
<tr>
<td>More of an understanding of the ongoing effects of cancer and its treatment</td>
<td></td>
</tr>
<tr>
<td>More acceptance of the reality of life as the partner of someone with cancer – especially the unpredictability</td>
<td></td>
</tr>
<tr>
<td>Recognising the privilege of being a carer. I am more resilient, patient and less resentful.</td>
<td></td>
</tr>
<tr>
<td>The only thing that changed me significantly is going through this crisis “on my own”. I had to look after and really care for my husband, our 2 young girls and be teacher, taxi, cook, accountant, cleaner, maid, nurse and so much more as well as coping with working 20hrs pw.</td>
<td></td>
</tr>
<tr>
<td>It gives permission to care for self. I can always refer to the book if I need to</td>
<td></td>
</tr>
<tr>
<td>One significant difference has been, for me, the acknowledgement that many others shared the same anxieties, stresses, emotions etc that I did. This has made me empathetic with others that have had a similar journey.</td>
<td></td>
</tr>
</tbody>
</table>

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**Table 19: Positive benefits of on-line intervention**
Knowing that it's okay to have certain feelings without having to feel guilty
Knowing there is help when needed
Caring is worthwhile for what it is and I can be less concerned about what I have to forgo especially in other voluntary roles, I felt a loss and guilt to some extent about pulling out from things I have had a long term commitment to. More acceptances from others would be nice.
Use of forums. Asking for ideas and suggestions. Seeing how other carers cope with problems I have and adapting their strategies.
reading was good as it just clarified I was on the right track
Mainly I have met some very nice people via the forums.
Not feeling so isolated
More positive thinking.
I looked forward to Monday mornings. I wonder what the other carer's are up to. I felt I had support even though some friends made me feel inadequate to care for my husband.
The fact that you were speaking with other carers who also felt the same feelings of anger, guilt, frustration etc. as you did.
I have certainly benefited from the experience and realise I’m coping and don’t feel alone in my negative responses I sometimes feel.
Listening to others and interacting with them made me feel that I’m coping quite well.

Table 20: Positive benefits of health care professional and self-help pack

<table>
<thead>
<tr>
<th>Benefit</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>I felt more positive in my approach as a carer, feeling that I was doing the right thing for my wife during her illness</td>
<td>The distinction between ‘carer’ and simply being in a position of looking after a loved one as a natural outcome of life was raised for the first time in my experience. Was good to know my feeling was shared by others and acknowledged by professionals. Able to address suppressed issues surrounding relationships</td>
</tr>
<tr>
<td>That I am not alone! There is help and support out there!</td>
<td>Feeling connected, not isolated is very reassuring. One can feel very much alone when faced with a life threatening disease, it didn’t take long to realise there was a whole mass of help out there waiting</td>
</tr>
<tr>
<td>Feel more confident in my ability to cope with the situation</td>
<td>How badly I want something determines how successful. If effort is missing a wish does not turn into something wanted. May mean that it is not wanted? More confident in my abilities to accept my feelings and emotional behaviours</td>
</tr>
<tr>
<td>More appreciation of partner’s growth and development through the cancer journey</td>
<td></td>
</tr>
</tbody>
</table>

Table 21: What part of the pack did you find most useful? (all groups)

<table>
<thead>
<tr>
<th>Benefit</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asking for and accepting help</td>
<td>The book was very easy to read. The phone link up with the psychologist was excellent. Being able to speak freely was very reassuring. The cancer council is a brilliant organisation that can’t do enough to help.</td>
</tr>
<tr>
<td>Preparing for doctor’s visit. Caring and emotions.</td>
<td>Sleep, exercise and diet</td>
</tr>
<tr>
<td>The book was very easy to read. The phone link up with the psychologist was excellent. Being able to speak freely was very reassuring. The cancer council is a brilliant organisation that can’t do enough to help.</td>
<td>Managing emotional stress (asking for help) and managing stress (time for you)</td>
</tr>
<tr>
<td>Understanding what my wife was going through. Being able to support her through the hard times, cmo, etc</td>
<td>Managing self and documents</td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>Safety section – this is something I hadn’t considered and the info in the booklet regarding this issue has made me more aware of this important issue.</th>
</tr>
</thead>
<tbody>
<tr>
<td>That we could get diet advice</td>
</tr>
<tr>
<td>Reinforcement of need to care for self.</td>
</tr>
<tr>
<td>Knowing where to go for assistance was most helpful</td>
</tr>
<tr>
<td>Recording medications.</td>
</tr>
<tr>
<td>Tips on intimacy</td>
</tr>
<tr>
<td>The booklet on chemotherapy – what reactions to expect to the chemo. Keep an eye on infections. Side effects and things to do to help with them. foods to help with nausea.</td>
</tr>
<tr>
<td>My own thoughts reviewed as a carer</td>
</tr>
<tr>
<td>Types of support available</td>
</tr>
<tr>
<td>Types of cancers</td>
</tr>
<tr>
<td>Anxiety and depression ideas to help me</td>
</tr>
<tr>
<td>Chapter 5. Reading quotes from other carers</td>
</tr>
<tr>
<td>The book I likes was “When a parent has cancer how to talk to your kids”. The social worker also gave us a story to read to the kids. It was about cancer cells and the chemo shark that ate all the bad cells and sometimes the good cells too. The kids really benefited from that.</td>
</tr>
<tr>
<td>Financial information</td>
</tr>
<tr>
<td>Communicating with the person I care for</td>
</tr>
<tr>
<td>Dealing with family</td>
</tr>
<tr>
<td>I thought the package was excellent and was pleased that I was already partaking in things suggested</td>
</tr>
<tr>
<td>Keeping a sense of who I am</td>
</tr>
<tr>
<td>The part(s) that reflect on the personal role involvement by the carer in the treatment process. I always considered this supportive role to be very important and felt personally saddened by patients that didn’t have family or friends to offer this supportive structure.</td>
</tr>
</tbody>
</table>

### Summary of findings

On the open ended questions, participants reported a range of benefits of taking part in the intervention programs, with individual differences being evident in the aspect of the pack that was most useful. This suggests that self-help information needs to be comprehensive, to meet the needs of a wide range of carers. The majority of participants who completed follow-up questionnaires reported that they experienced increased coping and other positive changes post-intervention, including improved communication, increased knowledge about cancer and its treatment, and less feelings of isolation. The findings from the closed ended questions and questionnaire measuring psychological well-being are summarised below.

#### Information and self-help pack

Improvements over time were reported on: ability to manage stress, confidence in providing care, control over own life, and ability to manage independence. There was increased knowledge of finances, food and diet, and sex and intimacy. Confidence was increased in ability to express feelings to the person with cancer, family and friends, and health professionals. Confidence was also increased in ability to express needs to the person with cancer and health professionals.

#### On line intervention

There were reductions in anxiety and depression over time. Improvements over time were reported on: ability to manage stress; confidence in providing, in strategies to
help with their role as a carer and in ability to manage independence. There was increased knowledge of finances, food and diet, and sex and intimacy. Confidence was increased in ability to express feelings to the person with cancer, family and friends, and health professionals. Confidence was also increased in ability to express needs to the person with cancer, family and friends, and health professionals.

*Health Professional intervention and self-help pack*

There were reductions in anxiety over time. Improvements over time were reported on: ability to manage emotions, ability to express feelings to health professionals and ability to express needs to health professionals.

*Implications of pre-post intervention results*

Caution must be used in interpreting the findings of this aspect of the study, due to the high attrition at 3 and 6 month follow-up, and the absence of statistical analysis. Many of the participants in this study also reported utilising more than one form of support, including palliative care, Relationships Australia counselling, self-help books, face to face and telephone support groups, pastoral care, Cancer Council Helplines, counselling, social work and psychology services.

However, the results do suggest that the self-help information pack and the on-line programs were successful in achieving many of the aims of the intervention: increasing coping skills, knowledge and communication on the part of carers. In addition, the on-line program appeared to be associated with an improvement in psychological well-being. The health professional program was successful in reducing anxiety and in increasing confidence in relation to communication with health professionals. The absence of a structured element to the intervention may account for the absence of positive findings on the other variables.

These results confirm the findings of the systematic literature review, that a range of interventions can be effective in addressing carer needs and concerns, and that targeted interventions are most effective in achieving their aims.

In the present study, the participants who completed the intervention programs were positive about the experience, as is illustrated in the qualitative data collected from open ended questions on the follow-up questionnaire. In future research, it would be useful to follow up those participants who dropped out of interventions, and those who did not find interventions effective, as this may provide important information about efficacy and suitability of programs to support cancer carers.
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