

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

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 ^[1], with various studies reporting above normal levels of psychological distress in 40% ^[2], 50% ^[3], or 84% ^[4] 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 ^[2, 5-8].

There are a number of risk factors for distress in cancer carers, the most significant being female gender ^[9]. Women cancer carers report higher rates of depression and anxiety, and lower life satisfaction and quality of life ratings ^[1, 4, 10-13], as well as greater personal loss and activity restriction ^[14], than male carers. Women carers also report more unmet needs ^[15], and a greater burden of care ^[16], both recognised as a cause of distress ^[17] and physical health problems ^[18] 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 ^[9, 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^[2]. 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.

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Publications arising from the project:

1. Ussher, J.M., Perz, J, Butow, P., & Wain, G. Gender differences in cancer carer psychological distress: A moderation and mediation analysis. *European Journal of Cancer Care (under review)*
2. Gilbert, E., Ussher, J.M., Perz, J., Hobbs, K., & Kirsten L. (2010). Positive and negative interactions with health professionals: A qualitative investigation of the experiences of informal cancer carers. *Cancer Nursing: An International Journal for Cancer Care (in press, accepted Feb 2010)*
3. Ussher, J.M., Wong, W.K.T., & Perz, J. (2010). A qualitative analysis of changes in relationship dynamics and roles between people with cancer and their primary informal carer *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine (in press, accepted Feb 2010)*

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