

CAREGIVERS OF CANCER SURVIVORS: THE STATE OF THE FIELD

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Abstract

Increasingly, researchers and clinicians are recognising the reverberating impact of a cancer diagnosis on patients' families. Upon diagnosis, families often find themselves grappling with intense emotions and existential concerns at the same time as they are providing support to patients, taking on novel care giving roles and responsibilities and attempting to remain afloat with other competing life events. In the midst of this whirlwind, patients and their caregivers may be struggling to find optimal coping strategies and adjust to potential disruptions in routines and activities. Despite efforts to manage care giving demands, these may inadvertently exceed caregivers' capabilities and result in them feeling burdened and exhausted. This paper reviews current evidence on the impact of a cancer diagnosis on families/caregivers, with a particular focus on the survivorship stage as well as Australian research initiatives. In addition, intervention research designed to assist families/caregivers with the demands of their roles will be reviewed. Last, limitations hampering caregiver research and priorities for future research will be discussed.

Within the last five years, studies documenting the short and long-term impacts of a cancer diagnosis on families/caregivers are increasing exponentially. Three main aspects of this literature will be reviewed, in turn: additional roles, responsibilities and skills required by caregivers; ensuring caregivers' needs for assistance and support and; caregivers' quality of life, with a focus on burden and psychological distress.

Caregivers roles and responsibilities: when is it too much?

Throughout the illness experience, families/caregivers provide valuable instrumental (eg. driving to medical appointments), informational (eg. searching treatment on the internet) and emotional support to patients with cancer.^{1,2,3} Such reliance on them is only expected to continue to grow,⁴ particularly as the course of cancer is changing from an acute to a chronic disease, and the setting for cancer care delivery is shifting from the hospital to the home.^{2,5,6} Care giving can extend for several years and roles/tasks can involve a considerable number of hours per week, which for some is comparable to a full-time job.³ According to patients' diagnosis and illness severity, care giving may require mastery of tasks typically performed by health care professionals, including symptom management, nutrition support, implementation of a treatment regimen, management of acute illness episodes and providing help with activities of daily living (eg. getting in and out of bed, feeding, getting dressed, bathing).³

In 2005, the Centre for Health Research and Psycho-oncology (CHeRP) embarked on a longitudinal study among a population-based sample (n=547) of partners and caregivers of cancer survivors with diverse cancer diagnoses to further examine the impact of care giving. This study aims to document physical, financial and psychosocial impacts of care giving six months, 12 months, two years, three and a half years and five years

post-diagnosis. Early results suggest that, at six months post-diagnosis, participants identified being mostly involved in: household tasks (daily 68.5%); emotional support (daily 39.9%) and; managing money (daily 22.7%). Interestingly, providing emotional support, liaising with doctors, making appointments and assessing for and managing medication were more associated with caregiver anxiety than other tasks. Similarly, a study by Bakas et al among caregivers of patients with lung cancer also found that one of the most time consuming tasks was providing emotional support, in addition to transportation and monitoring symptoms.¹ Moreover, these caregivers identified emotional support, behavioural management, monitoring symptoms and household tasks as the most difficult duties. These findings highlight that caregivers' tasks go beyond personal care or activities of daily living. Attention needs to be given not only to the frequency with which tasks are performed, but also the nature of these tasks and their perceived level of difficulty.

Taking on a care giving role also means that caregivers must develop a set of sophisticated skills and aptitudes, including monitoring, interpreting, making decisions, taking action, making adjustments, accessing resources, providing hands-on care, working together with the ill person and becoming an expert at navigating the healthcare system.³ Indisputably, care giving can become a daunting undertaking and involve many novelties for which caregivers, according to their previous knowledge and experience and physical and cognitive abilities, may require additional resources to cope. Healthcare professionals need to be aware of caregivers' tasks and roles and assess the extent to which they are apt and comfortable with these to be able to offer timely and fitting assistance. For instance, as emotional support appears to be one aspect of care giving that is difficult and anxiety-provoking, it may be effective for health care professionals to design communication interventions to enhance emotional support strategies such as active listening, reassurance and validation.¹ In addition, as care

giving responsibilities may negatively impact on carers' (and patients') illness experience, a better understanding of how caregivers acquire their skills and manage different tasks is a research avenue in need of more attention.⁵

Caregiver needs: what kind of help do caregivers require?

Despite increased attention to documenting caregivers' needs, many of these reportedly remain unmet.^{7,8} Several research groups in Australia are examining the short and long-term, unmet supportive care needs of families/caregivers. For instance, Hodgkinson et al⁹ administered the Cancer Survivors' Partners Unmet Needs measure to partners (n=212) of a mixed group of cancer survivors (3.4 years on average post-cancer diagnosis and disease free for at least one year) and found that the top five unmet needs were: concerns about cancer recurrence; accessible hospital parking; reducing stress in the survivors' life; having an ongoing case manager and; up-to-date information.

In addition, in a study by Clavarino et al⁷ participating caregivers (n=19), living in rural and remote Queensland, identified needing most help with fears related to the patient's physical deterioration and the cancer returning, uncertainty concerning the future, changes to usual routine and lifestyle, concerns about their financial situation and monetary allowances for travel. Most patients participating in this study were within the first year following diagnosis. Carers and patients differed on the rank ordering of their highest unmet needs. Patients' needs were concerns about the worries of those close to them, fears regarding the cancer returning or spreading, having a staff member with whom they can talk about all aspects of the illness and monetary allowances for travel.⁷

The Supportive Care Needs Survey – Partners and Caregivers (SCNS-P&C) was developed jointly by CHERP and the Centre for Medical Psychology and Evidence-Based Decision Making, to facilitate identification of partners' and caregivers' unmet supportive care needs across the illness trajectory (available online at <http://www.newcastle.edu.au/research-centre/cherp/professional-resources/>). Administration of the SCNS-P&C to partners and caregivers participating in CHERP's longitudinal study (n=481) revealed the following as the highest unmet moderate or high needs: reducing stress for the patient; concerns about recurrence; understanding the patient experience; accessible hospital parking and; information on treatment for decision-making.¹⁰ Janda et al also administered the SCNS-P&C to 70 caregivers of patients with a brain tumour, recruited through the Queensland Cancer Fund* Brain Tumour Support Service, and found some overlap in unmet needs (moderate or high): addressing fears related to the patient's deterioration; impact of caring on working life; reducing stress in the life of the person with cancer; decision making in uncertainty, and; balancing caregiver and patient needs.⁸

Further research is required to document the needs of partners/caregivers, particularly regarding how these may vary as caregivers transition from the acute to the

survivorship phase of the illness and determining the most optimal strategies to address these.

Care giving outcomes

Throughout the past decade there has been a growing body of evidence documenting the negative physical, financial and psychosocial outcomes associated with care giving.¹¹⁻¹⁷ In a study by Kim and Schulz,³ 67.3% of caregivers (n=99) reported a moderate to high level of burden. In the same study, cancer caregivers had higher levels of financial hardship, physical strain and emotional stress than caregivers of individuals with diabetes and frail elderly caregivers. Nonetheless, burden levels reported by cancer caregivers were comparable to those caring for an individual with dementia,³ or AIDS,¹⁸ two other highly stress-inducing and challenging illnesses for caregivers.

In addition to higher burden, care giving has been associated with poorer quality of life.⁸ In comparison to population norms, Janda et al reported lower quality of life, as measured by the Functional Assessment of Cancer Therapy-General, among caregivers of brain tumour survivors (n=70) recruited from the brain tumour support service offered by Cancer Council Queensland.⁸ Most studies examining the quality of life of caregivers have focused on their levels of anxiety and depression.¹⁹ Typically, higher levels of anxiety are reported in comparison to depression,²⁰ with recent studies reporting anxiety levels ranging from 16% to 47% and depression levels ranging from 9.7% to 30% among caregivers of people with cancer.^{20,21,22} These rates are slightly to moderately higher than the prevalence of anxiety disorders (14.4%) and depressive episodes (4.1%) reported in the general Australian population.²³ Borderline or clinical levels of anxiety and depression appear to be more prevalent post-diagnosis or in the acute phase of the illness, however a certain percentage of caregivers continues to experience significant levels of anxiety and depression well into the medium and long-term survivorship stage of the illness.^{19,21,24}

In CHERP's longitudinal study, at six months post-diagnosis, 40% and 11% of partners/caregivers report anxiety or depression, respectively, with 15% reporting both anxiety and depression. Importantly, at one-year post-diagnosis, 30% of caregivers were still borderline/clinically anxious. Although some studies suggest that caregivers and patients have comparable levels of general quality of life and distress,^{21,25,26} others actually report lower quality of life⁶ and greater distress among caregivers (reaching clinical levels).^{27,28,19}

Variables influencing caregiver outcomes

The literature identifies myriad variables associated with or predictive of, psychosocial outcomes among cancer caregivers, including short and less satisfactory relationships with the patient,²⁹ having concerns apropos the patient's well-being²⁹ or job-related concerns,²⁹ being uncertain about the future,²⁹ high level of unmet needs,³⁰ feeling of burden,^{27,3,28} avoidance attachment orientation,²⁸ using avoidant coping strategies,³¹ and lower family and social support.^{6,32}

* Now called Cancer Council Queensland.

In addition, demographic and/or treatment/disease related variables increasing caregiver risk for distress include: lower education,^{3,29} lower income,⁶ being female,^{2,3,6} being unmarried,⁶ younger age,^{6,31} shorter-term marriages,²⁹ less well-adjusted marriages,^{28,29} patients with greater functional impairment,²⁷ and greater illness severity.³³⁻³⁵

Interestingly, several studies have found that cancer survivors' and caregivers' quality of life (or lack thereof) interact and have a mutual influence, positive or negative.^{6,36} A recent meta-analysis examining the relationship between the psychological distress of cancer patients and their caregivers further supported the positive association between patients' and caregivers' psychological distress ($r=.35$, $p<.00001$).³⁷ Furthermore, it appears that this relationship is directional and that partner anxiety seems to be more influential on patient anxiety, than patient anxiety on their partner's well-being. Overall, these findings emphasise the reciprocal influence of cancer caregivers' health on patients (and vice-versa) and argue for holistic interventions targeting couples or families.

Although most research identifies variables associated with a 'negative' care giving experience, recently studies have focused on predicting 'positive' change in caregivers' life philosophy, relationships and personal growth, which has also been coined as post-traumatic growth (PTG) or benefit finding. Thornton & Perez found that PTG among 67 wives of prostate cancer survivors was predicted by less education, being with a partner who was employed, higher avoidance symptoms of stress at pre-surgery and preferring positive reframing coping.³⁸ Noteworthy, both patients and caregivers were found to have comparable levels of PTG, further emphasising the distress associated with a loved one's cancer diagnosis.³⁸ In addition, Kim et al reported that caregivers of a mixed group of cancer survivors ($n=779$) were more likely to report benefit finding if they were less educated, engaged in religious coping and perceived the availability of social support.³⁹ Lower education has also been related to higher levels of distress, which might explain its relationship with PTG or benefit findings.³⁸ Findings on whether PTG or benefit finding positively influence psychosocial adjustment are equivocal and additional studies are warranted to further elucidate this relationship.

Supportive care intervention research

While psychosocial interventions have been shown to improve quality of life among cancer survivors,⁴⁰ few studies have examined the potential of psychosocial interventions to ease burden and optimise adjustment outcomes among caregivers. Few Australian research groups have initiated intervention research among caregivers in the acute illness phase,⁴¹ and no published studies have been found for caregivers of cancer survivors. However, a tiered model of psychosocial care, developed by Queensland researchers to guide the design and implementation of supportive care services among patients with cancer and their caregivers, may provide some guidance in prioritising scarce resources according to patient and caregiver needs.⁴²

Internationally, few intervention studies have been undertaken with caregivers of cancer survivors. For instance, Canada et al implemented a sexual rehabilitation intervention among prostate cancer survivors and their caregivers ($n=51$), which led to an increase in sexual function for both patients and their caregivers three months post-intervention.⁴³ However, overall, intervention studies among caregivers of cancer survivors are scarce. Future research is needed to determine which aspects of the care giving experience warrant psychosocial intervention and might most contribute to enhancing the caregiver and patient cancer experience. The literature reviewed suggests that intervention research should ideally target both patients and caregivers and focus on such aspects of care as information sharing, communication among patients and caregivers and the treatment team, emotional support strategies, promotion of patient and caregiver empowerment and self-identification of needs, continuity and planning of care, and peer support.

Limitations of current studies

Although much attention has been directed at understanding the impact of a cancer diagnosis on partners/caregivers, these studies are typically cross-sectional, many include partners/caregivers of women with breast cancer or men with prostate cancer, and have a limited sample size (less than 100). Consequently, studies often report correlational analyses and little can be concluded regarding predictors of the care giving experience.

Future research priorities

Recently, Breast Cancer Network Australia published a summary report of the National Survivorship Think Tank meeting.⁴⁴ Among the different research priority areas discussed, appropriate measures of carer distress, considering the needs of families and caregivers, and implementing interventions to help families manage the impact of the cancer diagnosis were identified and echo the salient issues reviewed in this paper. Determining the extent to which providing care to cancer survivors contributes to burden, the unique challenges of being a caregiver in the survivorship stage and the way in which these can be addressed, are undoubtedly key research areas if we are to develop appropriate supportive services, optimise the care giving experience and maintain partners'/caregivers' ability to support patients throughout the illness trajectory.³ These empirical foundations are required to provide the basis upon which to design robust intervention studies. Particularly, research examining the interaction between the quality of life of cancer survivors and their families/caregivers during the long-term survivor phase and the factors predictive of both survivors' and family caregivers' quality of life, seems to be a promising avenue for research.^{6,45} In addition, findings from the aforementioned studies indicate that caregivers may require guidance in fulfilling some roles, however few studies have examined how care giving skills are acquired and developed over time among partners/caregivers of individuals with cancer.⁵ Finally, future research examining reasons and factors contributing to whether families/

caregivers have a positive (eg. benefit finding) or negative experience, may contribute to better understanding caregivers' ability to care for patients, which in turn may impact on their quality of life.

References

- Bakas T, Lewis RR, Parsons JE. Caregiving tasks among family caregivers of patients with lung cancer. *ONF*. 2001;28:847-54.
- Hagedoorn M, Sanderman R, Bolks HN, Tuinstra J, Coyne JC. Distress in couples coping with cancer: a meta-analysis and critical review of role and gender effects. 2008. *Psychol Bull*;134:1-30.
- Kim Y, Schulz R. Family caregivers' strains comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. *J Aging Health*. 2009; doi:10.1177/0898264308317533.
- Dubenske LL, Wen K-Y, David GH, et al. Caregivers' differing needs across key experiences of the advanced cancer disease trajectory. *Palliat Support Care*. 2008;6:265-72.
- Schumacher KL, Beidler SM, Beeber AS, Gambino P. A transactional model of cancer family caregiving skill. *ANS Adv Nurs Sci*. 2006;29:271-86.
- Mellon S, Northouse LL, Weiss LK. A population-based study of the quality of life of cancer survivors and their family caregivers. *Cancer Nurs*. 2006;29:120-31.
- Clavarino AM, Lowe JB, Carmont S-A, Balanda K. The needs of cancer patients and their families from rural and remote areas of Queensland. *Aust J Rural Health*. 2002;10:188-95.
- Janda M, Steginga S, Dunn J, Langbecker D, Walker D, Eakin E. Unmet supportive care needs and interest in services among patients with a brain tumour and their carers. *Patient Educ Couns*. 2008;71:251-58.
- Hodgkinson K, Butow P, Hobbs KM, Hunt GE, Lo SK, Wain G. Assessing unmet supportive care needs in partners of cancer survivors: the development and evaluation of the Cancer Survivors' Partners Unmet Needs measure (CaSPUN). *J Clin Oncol*. 2007;16:805-13.
- Girgis A, Lambert S, Lecathelinais C. The supportive care needs survey for partners and caregivers of cancer survivors: development and psychometric evaluation. *Psychooncology*. Under editorial review.
- Kurtz ME, Given B, Kurtz JC, Given CW. The interaction of age, symptoms, and survival status on physical and mental health of patients with cancer and their families. *Cancer*. 1994;74:2071-78.
- Kurtz ME, Kurtz JC, Given CW, Given B. Relationship of caregiver reactions and depression to cancer patients' symptoms, functional states and depression – a longitudinal view. *Soc Sci Med*. 1995;40:837-46.
- Given B, Wyatt G, Given C, Sherwood P, Gift A, DeVoss D, Rahbar M. Burden and depression among caregivers of patients with cancer at the end of life. *Oncol Nurs Forum*. 1994;31:1105-17.
- Nijboer C, Tempelaar R, Sanderman R, Triemstra M, Spruijt RJ, Van Den Bos GAM. Cancer and caregiving: the impact on the caregiver's health. *Psychooncology*. 1998;7:3-13. Morse SR, Fife B, Coping with a partner's cancer: adjustment at four stages of the illness trajectory. *Oncol Nurs Forum*. 1998;25:751-60.
- Kershaw T, Northouse L, Kritpracha C, Schafenacker A, Mood D. Coping strategies and quality of life in women with advanced breast cancer and their family caregivers. *Psychol Health*. 2004;19:139-55.
- Haley WE, LaMonde LA, Han B, Narramore S, Schonwetter R. Family caregiving in hospice: effects on psychological and health functioning among spousal caregivers of hospice patients with lung cancer or dementia. *Hosp J*. 2001;15:1-18.
- Jepson C, McCorkle R, Adler D, Nuamah I, Lusk E. Effects of home care on caregivers' psychosocial status. *J Nurs Scholarsh*. 1999;31:115-20.
- Stetz KM, Brown M-A. Physical and psychosocial health in family caregiving: a comparison of AIDS and cancer caregivers. *Public Health Nurs*. 2004;21:533-40.
- Kim Y, Given BA. Quality of life of family caregivers of cancer survivors. *Cancer*. 2008 Jun 1;112(11 Suppl):2556-68.
- Grov EK, Dahl AA, Moum T, Fossha SD. Anxiety, depression, and quality of life in caregivers of patients with cancer in late palliative phase. *Ann Oncol*. 2005;16:1185-91.
- Jenewein J, Zwahlen RA, Zwahlen D, Drabe N, Moergeli H, Buchi S. Quality of life and dyadic adjustment in oral cancer patients and their female partners. *Eur J Cancer Care (Engl)*. 2008;17:127-35.
- Burridge LH, Barnett AG, Clavarino AM. The impact of perceived stage of cancer on carers' anxiety and depression during the patients' final year of life. *Psychooncology*. 2009;18:615-23.
- Slade T, Johnston A, Teesson M, Whiteford H, Burgess P, Pirkis J, et al. The mental health of Australians 2. Report on the 2007 national survey of mental health and wellbeing. Canberra: Department of Health and Ageing, 2009.
- Zwahlen D, Hagenbuch N, Carley MI, Recklitis CJ, Buchi S. Screening cancer patients' families with the distress thermometer (DDT): a validation study. *Psychooncology*. 2008;17:959-66.
- Eton DT, Lepore SJ, Helgeson VS. Psychological distress in spouses of men treated for early-stage prostate carcinoma. *Cancer*. 2005 Jun 1;103:2412-18.
- Vickery LE, Latchford G, Hewison J, Bellew M, Feber T. The impact of head and neck cancer and facial disfigurement on the quality of life of patients and their partners. *Head Neck*. 2003;25:289-96.
- Grunfeld E, Coyle D, Whelan T, Clinch J, Reyno L, Earle CC, et al. Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. *Can Med Assoc J*. 2004;170:1795-801.
- Braun M, Mikulincer M, Rydall A, Walsh A, Rodin G. Hidden morbidity in cancer: spouse caregivers. *J Clin Oncol*. 2007 Oct 20;25:4829-34.
- Lewis FM, Fletcher KA, Cochrane BB, Fann JR. Predictors of depressed mood in spouses of women with breast cancer. *J Clin Oncol*. 2008 Mar 10;26:1289-95.
- Matthews BA, Baker F, Spillers RL. Family caregivers and indicators of cancer-related distress. *Psychol Health Med*. 2003;8:46-56.
- Dalton WT, Nelson DV, Brobst JB, Lindsay JE, Friedman LC. Psychosocial variables associated with husbands' adjustment three months following wives' diagnosis of breast cancer. *J Cancer Educ*. 2007;22:245-49.
- Siefert ML, Williams A-L, Dowd MF, Chappel-Aiken L, McCorkle R. The caregiving experience in a racially diverse sample of cancer family caregivers. *Cancer Nurs*. 2008;31:399-407.
- Northouse LL, Mood D, Kershaw T, Ann Schafenacker A, Suzanne Mellon S, Julie Walker J, et al. Quality of life of women with recurrent breast cancer and their family members. *J Clin Oncol*. 2002;20:4050-64.
- Morse SR, Fife B. Coping with a partner's cancer: adjustment at four stages of the illness trajectory. *Oncol Nurs Forum*. 1998;25:751-60.
- Given BA, Given CW, Helms E, Stommel M, and DeVoss DN. Determinants of family caregiver reaction: new and recurrent cancer. *Cancer Pract*. 1997;5:17-24.
- Segrin C, Badger T, Dorros SM, Meek P, Lopez AM. Interdependent anxiety and psychological distress in women with breast cancer and their partners. *Psychooncology* 2007;16:634-643.
- Hodges LJ, Humphris G M, Macfarlane G. A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers. *Soc Sci Med*. 2005;60:1-12.
- Thornton AA, Perez MA. Posttraumatic growth in prostate cancer survivors and their partners. *Psychooncology*. 2006;15:285-96.
- Kim Y, Wellisch DK, Spiller RL, Crammer C. Psychological distress of female cancer caregivers: effects of type of cancer and caregivers' spirituality. *Support Care Cancer*. 2007;15:1367-74.
- Rehse B, Pukrop R. Effects of psychosocial interventions on quality of life in adult cancer patients: meta analysis of 37 published controlled outcome studies. *Patient Educ Couns*. 2003;50:179-86.
- Chambers SK, Schover L, Halford K, Clutton S, Ferguson M, Gordon L, et al. ProCan for couples: randomised controlled trial of a couples-based sexuality intervention for men with localised prostate cancer who receive radical prostatectomy. *BMC Cancer*. 2008;8: doi:10.1186/1471-2407-8-226.
- Hutchison SD, Steginga SK, Dunn J. The tiered model of psychosocial intervention in cancer: a community based approach. *Psychooncology*. 2006;15:541-6.
- Canada AL, Neese LE, Sui D, Schover LR. Pilot intervention to enhance sexual rehabilitation for couples after treatment for localised prostate carcinoma. *Cancer*. 2005 Dec 15;104:2689-700.
- Breast Cancer Network Australia. National survivorship think tank: summary report. 2009 Apr 16. Available from: http://www.bcna.org.au/images/stories/policy/microsoft_word_-_bcna_think_tank_report_final_160409.pdf [accessed 5/8/09].
- Kim Y, Kashy DA, Wellisch DK, Spillers RL, Kaw CK, Smith TG. Quality of Life of couples dealing with cancer: dyadic and individual adjustment among breast and prostate cancer survivors and their spousal caregivers. *Ann Behav Med*. 2008;35:230-8.