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Author

Owensworth, Tamara, Henderson, Laura, Chambers, Suzanne K

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Social support buffers the impact of functional impairments on caregiver psychological well-being in the context of brain tumor and other cancers

Tamara Ownsworth¹, Laura Henderson¹, Suzanne Chambers^{1,2}

¹School of Psychology and Griffith Institute for Health and Medical Research, Griffith University, Brisbane

²Viertel Centre for Research in Cancer Control, The Cancer Council of Queensland, Brisbane

Contact for correspondence:

Tamara Ownsworth, PhD
School of Psychology
Griffith University
Mt Gravatt Campus
Nathan 4111
Australia

Ph: +61 73735 3368

Fax: +61 73735 3399

Email: t.ownsworth@griffith.edu.au

Abstract

Objective: This study investigated the association between functional impairments of individuals with cancer and caregiver psychological well-being, and examined the moderating effect of social support. *Methods:* Sixty-three caregivers (71% female) of individuals with brain **tumor** ($n = 27$) and other cancers ($n = 36$) were recruited from community services. Caregivers rated their psychological well-being on the World Health Organisation Quality of Life measure Brief version, social support on a brief version of the Social Support Questionnaire, and the individuals' functional impairments on the Patient Competency Rating Scale. *Results:* For caregivers of individuals with brain **tumor**, better psychological well-being was associated with lower functional impairment in all domains ($r_s = .33-.38, p < .05$) except for cognitive difficulties, and higher satisfaction with social support ($r = .67, p < .001$). For caregivers of individuals with other cancers, better psychological well-being was associated with lower functional impairment in all domains ($r_s = .30-.49, p < .05$), with the exception of activities of daily living, and higher satisfaction with social support ($r = .49, p < .01$). Caregivers supporting individuals with greater functional impairment had better psychological well-being if they were highly satisfied with their social support. *Conclusions:* Effective social support is particularly important for caregivers who support individuals with poorer functional status and this research highlights the need to evaluate caregiver social support interventions in the context of cancer.

Keywords: Cancer, oncology, brain tumor, caregiver, psychological well-being, functional impairment

Introduction

The diagnosis and treatment of cancer affects the individual's entire family and social network. Psychological distress is commonly reported by caregivers, who experience a range of stressors at different stages of the illness [1, 2]. In addition to physical impairments, caregivers are often faced with changes in the person's cognitive, emotional and behavioural functioning. Schumacher, Dodd and Paul [3] proposed that the functional status of the individual with cancer is a primary stressor impacting the psychological well-being of the caregiver and empirical research has identified that a greater level of physical impairment in the person with cancer is associated with poorer psychological well-being of caregivers at various stages of care [e.g., 1-3]. Schumacher et al. further hypothesized that the impact of the individuals' functional status on the caregiver's psychological well-being would vary according to their perceptions of social support. The present study investigated the association between functional impairment domains and caregiver psychological well-being and examined the potential moderating effects of social support.

The functional consequences of cancer and its treatment are considerable and include difficulties with activities of daily living (ADLs), cognitive function, interpersonal interaction and emotional regulation [4, 5]. **Marciniak and colleagues [6] found that patients with non-central nervous system (CNS) cancers reported more physical rehabilitation needs and those with CNS cancer reported more cognitive rehabilitation needs. However, both physical and cognitive impairments were commonly experienced regardless of the cancer location.** Emotional and behavioural changes are also commonly reported by individuals with cancer, including anxiety, depressed mood, anger, confusion, and social withdrawal [5]. Existing research [e.g., 1, 2] has focused on the impact of physical dependency (e.g., ADLs and self-care needs) in

cancer rather than a broader range of functional areas that are also likely to impact caregiver psychological adjustment.

The benefits of social support on caregivers' psychological well-being are well established in the literature for cancer and other chronic conditions [7, 8]. **Longitudinal cancer research by Nijboer and colleagues [9] found that perceptions of daily emotional support moderated the association between caregiver experiences and depression. Specifically, caregivers who perceived greater disruptions to their schedule and reported lower levels of daily emotional support were more likely to show increased levels of depression over time. However, recent research by Thielemann and Conner [10] identified that social support partially mediated the relationship between caregiver demands and caregiver depression. Similarly, Schumacher et al. [3] found that caregivers of individuals with cancer who had greater functional independence perceived that their social support was more adequate which, in turn, predicted lower depression.**

Overall, there are somewhat mixed views and findings concerning the role of social support in terms of its relationship to caregiver experiences and psychological adjustment [3, 9, 10]. Despite a lack of uniformity in the measurement of social support, **an approach that is commonly recommended in the literature** is to assess the level of satisfaction an individual has with their sources of support [11]. Satisfaction with social support has been found to be a better predictor of caregiver psychological well-being than the amount of support [8]. According to theory [12], supportive social interactions are purported to alleviate the negative impact of a stressor on an individual's well-being [see also 3]. Therefore, in the context of cancer, it is proposed that the stress associated with caring for an individual with greater functional impairment may be alleviated by caregivers having more satisfying social support.

To date, few studies have investigated the impact of functional impairment and satisfaction with social support on caregiver well-being in cancer. Given that functional decline is typically more marked following brain tumor than other cancers [4], this caregiver subgroup was of particular interest in the present study. The first aim was to determine whether level of functional impairment was associated with the psychological well-being of caregivers of individuals with brain tumor and other cancers. It was hypothesised that level of impairment on each functional domain (i.e., ADLs, cognitive, interpersonal and emotional) would be significantly related to poorer caregiver psychological well-being. The second aim was to investigate the potential moderating effect of satisfaction with social support on the relationship between functional impairment and caregiver psychological well-being. It was hypothesised that high satisfaction with social support would buffer the effect of greater functional impairment on caregiver psychological well-being.

Method

Participants

Ethical approval for the study was granted by the Griffith University Human Research Ethics Committee. Caregivers of individuals with cancer were recruited from a range of cancer-specific support groups including networks for people with brain, prostate, leukaemia, head and neck cancer. The inclusion criteria were that individuals were over the age of 18 and were currently the primary caregiver for an adult (18 years or older) with cancer. The total sample of 63 caregivers consisted of 27 caregivers of people with a primary brain tumor (43%) and 36 caregivers of people with other cancers (leukaemia = 19%, prostate = 19%, skin = 5%, multiple cancers = 5%, lung = 3%, breast, throat, mouth, oesophageal = 1.5% [each]). The majority of caregivers were female (71.4%) and the spouse or partner of the person with cancer (88.8%), and were on average 60.1 years old

($SD = 11.7$, range: 26 – 79 years). **For individuals with brain tumor, 52% had been diagnosed with a stage 1 or 2 tumor (benign) and 48% had been diagnosed with a stage 3 or 4 tumor (malignant). Two individuals with a malignant tumor had multiple brain tumors. In the general cancer sample, 3 individuals had received multiple cancer diagnoses (e.g., initial diagnosis of bowel cancer, remission of the bowel cancer and a subsequent diagnosis of leukaemia). Overall, information regarding the stage and/or recurrence of the individual's cancer was not available for the majority of participants.**

Of the individuals with cancer, 65% had undergone multiple treatments (e.g., chemotherapy, surgery and/or radiation). Surgery was the most common single treatment (17%), followed by chemotherapy (8%), radiation (6%), hormone therapy (2%), and cyber knife (2%). The average time since diagnosis was 4.24 years (range = 1 month to 38 years), **with 44% diagnosed up to 1 year ago, 29% diagnosed >1 year – 5 years ago, 19% diagnosed >5 - 10 years ago and 8% diagnosed over 10 year ago. The caregivers' employment status entailed 14% (n = 9) in full-time employment, 24% (n = 15) in part-time work and 62% not working (n = 39).**

Measures

Psychological well-being: Psychological well-being was assessed using the psychological domain of the World Health Organisation Quality of Life measure Brief version (WHOQOL-BREF [13]). The WHOQOL-BREF consists of 26 of the original 100 items of the WHOQOL-100, with items divided into four domains; physical health, psychological well-being, social relationships and environmental factors. The six items on the psychological well-being domain refer to self-esteem, positive and negative feelings and spirituality. Each item is rated on a 5-point Likert scale, with higher scores reflecting

better psychological well-being. Internal consistency of the psychological domain for the present sample was sound ($\alpha = .79$).

Functional Impairment: The Patient Competency Rating Scale – **Relative Version** (PCRS, [14]) is a 30-item measure that assesses functional difficulties experienced after brain injury **from the perspective of the caregiver**. The measure is divided into four domains (ADLs, cognitive, emotional and interpersonal) with a total score indicating overall level of functional impairment [14]. Caregivers were asked to rate the individual's abilities across each of the domains on a Likert scale ranging from 1 (*can't do*) to 5 (*can do with ease*). Lower PCRS scores indicate greater functional impairment. As examples, PCRS items relate to the person's **current** ability to drive, prepare meals, remember daily events, handle arguments, and manage negative emotions [14]. In the present study, internal consistency was found to be high for each PCRS domain and the total score ($\alpha = .83 - .95$).

Satisfaction with Social Support: For the present study, a briefer version of the Social Support Questionnaire (SSQ [11]) was developed and **utilised for the first time**. The Brief Social Support Questionnaire (BSSQ) focussed specifically on the support provided to the caregiver since the onset of their relative's illness, incorporating past support received and current sources of support. **For the initial question regarding sources of support**, participants list up to nine people or services that have provided them with support since the onset of their relative's cancer. **Then, for each source of support identified (up to a maximum of 9)**, they rate how satisfied they are with the support received from this source on a 6-point Likert scale from 1 (*very dissatisfied*) to 6 (*very satisfied*). These scores are averaged to derive a mean satisfaction with social support score, where higher scores reflected greater satisfaction.

Procedure

Following ethical clearance, the caregivers of individuals with brain tumor were recruited from brain tumor support group and a major neurosurgical clinic. The coordinators of the support service and clinic initially approached participants by telephone to discuss the study and then provided contact details of interested potential participants to the researchers. Of the total number of caregivers approached ($n = 45$), 56% consented to participate (note: details of non-respondents were not available). Recruitment of caregivers of individuals with other forms of cancer was initiated through meetings with support coordinators at The Cancer Council of Queensland. Researchers then attended a series of support meetings held at accommodation lodges, groups for the wives of men with prostate cancer and a group for people with head and neck cancer. Of the total number of caregivers of people with general cancer who were directly approached about the study ($n = 90$), 40% consented to participate (note: details of non-respondents were not available). All caregivers were asked to complete the WHOQOL-BREF, PCRS, BSSQ and a demographic and health survey which included questions regarding the person's cancer type, date of diagnosis, status of the cancer (if known) and treatment regime. All caregivers returned completed questionnaires to the researchers via a reply-paid envelope.

Data Analysis

Following data screening, the Pearson's product moment correlation was conducted to examine associations between each functional domain of the PCRS and caregiver psychological well-being on the WHOQOLBREF. Separate analyses were conducted for the caregivers of individuals with brain tumor ($n = 27$) and caregiver of individuals with other cancers ($n = 36$), as well as the total caregiver sample. To investigate the moderating

effect of satisfaction with social support on functional impairment and caregiver psychological well-being a moderated hierarchical regression was conducted. The significant moderating effect was probed using simple slopes analysis, **with cut-off scores involving upper (1 SD > M) and lower (1 SD < M) limits** [15].

Results

A descriptive summary of the caregivers' ratings on each measure is provided in Table 1. Overall, the scores on each measure were largely comparable between the two samples. However, caregivers of individuals with general cancer reported poorer psychological well-being than caregivers of individuals with brain tumor ($p < .05$). On the PCRS, the caregivers' responses indicated that the abilities of individuals with brain tumor typically ranged from the upper level of *Can do with some difficulty* to mid range of *Fairly easy to do* and *Can do with ease* (i.e., range: Emotional = 3.6–ADLs = 4.47). The item averages for the caregivers of individuals with general cancer were similar (range: Emotional = 3.7 – Interpersonal = 3.9), although these were significantly lower for ADLs (item average = 3.8) than those for the brain tumor sample ($p < .05$).

Insert Table 1 about here

Associations between Functional Impairment and Caregiver Psychological Well-being

As shown in Table 2, with the exception of the cognitive domain, level of functional impairment on each PCRS domain was significantly related to poorer psychological well-being for caregivers of individuals with brain tumor. For the other cancer caregiver subgroup, level of functional impairment on each domain (i.e., cognitive, interpersonal and emotional) was significantly related to caregiver psychological well-being, with the

exception of ADLs. For the total caregiver sample, psychological well-being was significantly correlated with overall functional impairment as well as level of impairment on each domain.

 Insert Table 2 about here

Moderating Effects of Satisfaction with Social Support

The suitability of moderation analyses was supported by inspection of bivariate correlations. Overall functional impairment was significantly correlated with caregiver psychological well-being (see Table 2) and satisfaction with social support was significantly correlated with caregiver psychological well-being ($r = -.40, p < .005$), but not with functional impairment ($r = .20, p > .05$). **Further, the preliminary analysis identified that there were no significant effects of age, time since diagnosis or employment status on psychological well-being ($p > .05$). However, males reported significantly higher levels of psychological well-being ($M = 23.89, SD = 2.32$) than females ($M = 20.32, SD = 3.87, t = -3.65, p = .001$). Further, as previously discussed, psychological well-being differed according to cancer type (brain tumor vs general cancer). However, partial correlations identified that the association between cancer type and psychological well-being was largely related to gender differences between the two samples (cancer type partial correlation = $-.10, p = .410$; gender partial correlation = $.33, p < .01$). Given the need to maximise the participant to variable ratio, gender was selected as the key potential confound to control for in the subsequent analysis.**

As shown in Table 3, the results of the moderated regression analyses indicated that after controlling for gender in Step 1 ($R^2 = .18, p < .001$), satisfaction with social support significantly moderated between functional impairment and caregiver psychological well-

being (Functional ability x Social support $B = -.05, p < .05$). A visual representation of this interaction is shown in Figure 1.

 Insert Table 3 about here

 Insert Figure 1 about here

The results of a simple slopes analysis indicated that while the slope of the relationship between functional impairment and psychological well-being was significant for low satisfaction with social support ($\beta = .571, p = .003$), it was not significant for high satisfaction with social support ($\beta = .026, p = .874$). Therefore, caregivers who reported high functional impairment (**1 SD > M**) in the person with cancer and low satisfaction with their social support displayed significantly poorer psychological well-being than caregivers reporting low functional impairment (**1 SD < M**) and low satisfaction with social support. Moreover, caregivers supporting individuals with high functional impairment had better psychological well-being if they were highly satisfied with their social support.

Discussion

Consistent with theoretical perspectives, a higher level of functional impairment experienced by individuals with cancer was associated with poorer caregiver psychological well-being. In contrast to previous research [1], the psychological well-being of caregivers of individuals with other cancer was not significantly related to difficulties with ADLs, but was instead associated with degree of cognitive, interpersonal and **emotional** difficulties. Interestingly, the psychological well-being of caregivers of

individuals with brain tumor was related to difficulties with ADLs, interpersonal and **emotional** function, but not cognitive impairment. **This finding was somewhat unexpected given that cognitive impairment is particularly common for individuals with brain tumor [6].**

The pattern of findings for both caregiver samples may be explained on the basis of caregiver mastery and preparedness [16, 17], which may vary according to different functional impairments. Previous research identified that caregiver mastery partially mediated the effect of behavioural disturbance following brain tumor on caregiver depressive symptoms [17]. **Further, Nijboer et al. [9] found that mastery moderated the relationship between caregiver experiences and depression.** Although caregiver mastery and preparedness were not assessed in the current study, it is proposed that caregivers' psychological well-being may in part be influenced by perceptions of their ability to cope with and manage different functional changes experienced in the context of cancer. The present study extends the literature by demonstrating that a range of functional impairments are related to caregiver psychological well-being, and particularly highlights the importance of considering the cognitive, interpersonal and emotional effects of cancer in addition to self-care dependency.

Satisfaction with social support was found to moderate between functional impairment and caregiver psychological well-being, suggesting that when the individual with cancer experiences more marked functional difficulties the caregiver's satisfaction with his/her social support network is particularly important to enhance or maintain psychological well-being. **Such findings are similar to previous research by Nijboer and colleagues [9], who reported that level of daily emotional support modified the association between caregiver experiences and depression, although this study did not examine functional impairments.** Interestingly, other caregiver research [3, 10] **found that social support mediated rather than moderated between the stressor (i.e.,**

functional status or care demands) and caregiver depression. In contrast to previous research, social support in the present study was not found to be significantly affected by the proposed stressor (i.e., level of functional impairment). It should be noted, however, that the present study assessed caregivers' satisfaction with identified sources of social support, while previous research has examined the frequency of positive and negative social interactions [e.g., 10]. Thus, differences in the conceptualisation and measurement of social support may influence findings concerning its role or function with respect to caregiver psychological well-being.

Overall, due to the cross-sectional nature of existing research, including the present study, it is difficult to determine the direction of relationships between variables. Therefore, while the present findings suggest that supportive social interactions may buffer the stress associated with caring for an individual with greater functional impairments, longitudinal research is needed to investigate the apparent interactive relationships between factors impacting on caregiver psychological well-being at different stages of care.

Limitations in the present study include the heterogeneity of caregivers with respect to type of cancer and time since diagnosis. **Information regarding cancer status was not available for most participants and therefore could not be examined as a possible confound in the analysis. A further methodological issue relates to the reliance on caregiver ratings to assess the functioning of the individual with cancer as well as their own well-being. It is also feasible that bidirectional relationships exist between variables, particularly the caregiver ratings on the PCRS and their ratings of their own psychological well-being. To clarify this relationship in future research it is recommended that functional impairments be measured via an independent approach such as self-ratings of the individual with cancer, or collateral information provided by a treating health professional. The disproportionate number of female**

(72%) and spousal (89%) caregivers in this sample should also be taken into account when interpreting the findings, as the caregiver's gender and relationship to the individual with cancer are likely to impact on the caregiving experience. Finally, it is important to acknowledge that the source of participant recruitment involved support group networks for individuals with cancer and their caregivers. As information regarding non-responders could not be obtained it is possible that the findings were impacted by self-selection bias. Given that these issues may affect generalizability, the present findings should be considered exploratory.

In summary, the present findings indicate that a range of functional impairments are related to caregivers' psychological well-being in the context of cancer. High satisfaction with social support was found to buffer the effect of caring for an individual with greater functional impairment. Such findings support the need to monitor caregivers' perceptions of their social support to determine the need for specific assistance or resources to enhance their adjustment throughout the course of the illness. Evaluation of strategies for enhancing caregiver social support remains a key area for future research.

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Figure Caption

Figure 1. Moderating effect of satisfaction with social support on functional impairment and caregiver psychological well-being

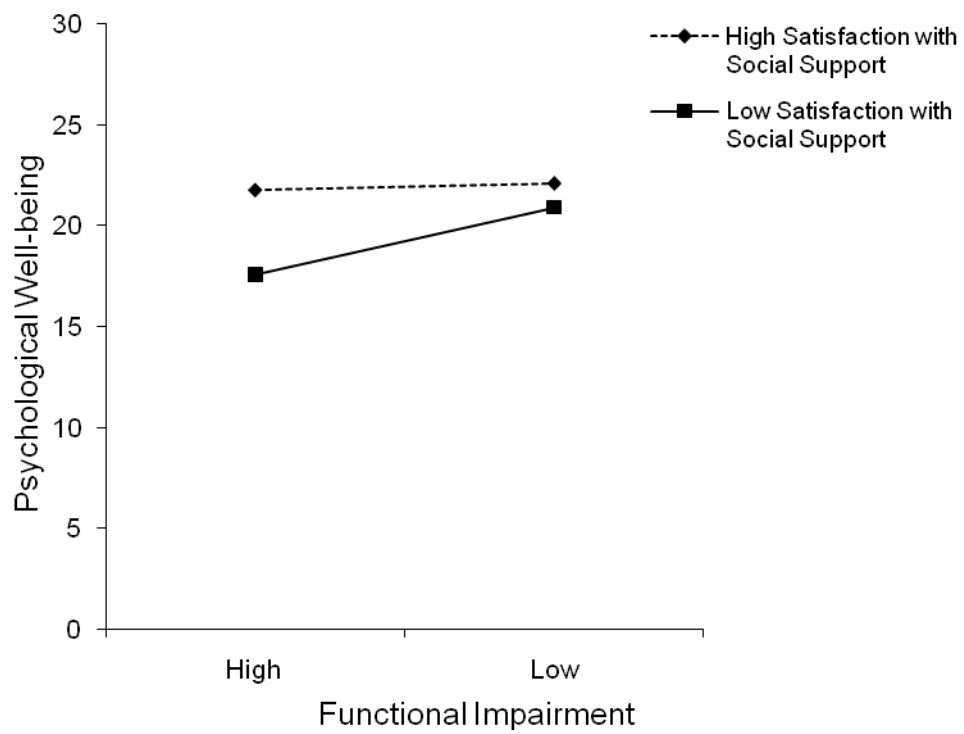


Table 1.*Descriptive Statistics for the Brain Tumor and General Cancer Caregiver Samples*

Measures (possible range)	Mean (SD) (Range)		Total
	Brain tumor	General cancer	
N ^o . social support (BSSQ, 1-9)	6.11 (2.04) (3-9)	5.17 (2.23) (1-9)	5.58 (2.19) (1-9)
Average satisfaction (BSSQ, 1-6)	4.73 (.91) (2.67-6)	5.26 (.78) (3.83-6)	5.03 (.87) (2.67-6)
Functional Ability (PCRS total, 30-150)	120.24 (18.90) (82-146)	112.36 (23.14) (66-144)	115.74 (21.63) (66-146)
ADLs (PCRS, 8-40)	35.76 (4.58) (24-40)	30.08 (8.11) (14-40)	32.52 (7.35) (14-40)
Cognitive (PCRS, 8-40)	31.82 (6.32) (16-40)	30.42 (6.81) (17-40)	31.02 (6.59) (16-40)
Emotional (PCRS, 7-35)	25.28 (5.26) (16-34)	26.00 (5.60) (12-35)	25.69 (5.42) (12-35)
Interpersonal (PCRS, 7-35)	27.50 (5.29) (18-35)	27.52 (5.40) (12-35)	27.51 (5.31) (15-35)
Psychological QoL (WHOQOL-BREF, 5-30)	22.67 (2.66) (16-27)	20.35 (4.30) (10-28)	21.34 (3.84) (10-28)

Note. ADLs = activities of daily living; BSSQ = Brief Social Support Questionnaire; PCRS = Patient Competency Rating Scale; WHOQOL-BREF = World Health Organisation Quality Of Life measure Brief version.

Table 2.

Correlations between Functional Impairment and Caregiver Psychological Well-Being

	Total caregiver sample ($n = 63$)	Brain tumor sample ($n = 27$)	Other cancer sample ($n = 36$)
	Psychological well-being		
Overall functional impairment	.34**	.33*	.30*
ADLs	.26*	.35*	.12
Cognitive	.38**	.15	.46**
Interpersonal	.43**	.38*	.49**
Emotion	.28*	.34*	.31*

* $p < .05$ ** $p < .005$, one-tailed test

Table 3*Moderated Regression on Caregiver Quality of Life*

Variables	<i>B</i>	<i>SE B</i>	<i>R</i>²	ΔR^2	<i>F/t</i>	<i>p</i>
Step 1						
Gender	3.62	.98	.184	.184	13.57	<.001
Step 2			.359	.175	7.90	.001
Functional impairment	.028	.02			1.42	.162
Satisfaction with social support	1.58	.48			3.34	.001
Step 3			.402	.043	4.10	.048
Functional impairment	.033	.02			1.70	.096
Satisfaction with social support	1.58	.46			3.42	.001
Functional impairment x satisfaction with social support	-.05	.02			-2.02	.048