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ORIGINAL ARTICLE

Impact of caregivers' negative response to cancer on long-term survivors' quality of life

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Abstract

Cancer survivors' quality of life (QoL) is consistently shown to be positively impacted by social support from family and friends, including informal caregivers. In contrast, a loved one's negative response to cancer can diminish survivors' QoL, and these negative responses can be more impactful than supportive behaviors. Nonetheless, negative caregiver response has not been extensively researched, and few studies have explored the potential interaction of negative caregiver response and perceived social support on survivors' QoL. Therefore, we examined direct effects of perceived negative caregiver response, and the potential moderating role of social support, on QoL in a population-based sample of cancer survivors ($N = 7543$) using generalized linear models. Findings indicate that survivors who rated their caregiver's response to their cancer diagnosis more negatively reported worse physical and mental health, even up to 10 years after their initial cancer diagnosis. Perceived social support was not significantly associated with physical health, but it was positively associated with mental health. However, social support was not shown to moderate the relationship between negative caregiver response and mental health. Findings suggest that positive support from others within a survivor's social network may not be enough to attenuate the negative effects of their primary caregiver's unsupportive behaviors. Accordingly, cancer survivorship research and practice must consider the critical role that negative caregiver responses have on survivors' QoL and develop strategies that focus on the survivor–caregiver dynamic.

Keywords Cancer survivors · Caregivers · Social support · Negative response to cancer · Quality of life

Introduction

The steady decline in cancer deaths in the USA over the past two decades can be largely attributed to reduction in cancer risk behaviors, earlier detection, and advancements in cancer treatment [1]. According to the most recent statistics presented by the American Cancer Society, the US cancer death rate decreased by 27% from 1991 to 2016 [1]. At the same time, the number of people living five or more years after a cancer diagnosis has risen sharply; there are now more than 15 million Americans living with a history of cancer, and this number is estimated to increase to more than 20 million by the year 2026 [2]. As such, efforts to improve the quality of life (QoL) of cancer survivors are of paramount importance. While physical factors, such as persistent side effects of cancer treatment, are often invoked when considering survivors' QoL, psychological and social factors have also been shown to play a critical role [3]. One such factor is social support, or the degree to which an individual feels supported by family, friends, and the community at large. Indeed, research shows that social support is consistently associated with better QoL among cancer survivors [4, 5]. In contrast, a loved one's *negative* response to cancer has been shown to diminish QoL [6–8]. In fact, negative response to cancer (e.g., emotional withdrawal, criticism, or open hostility) can be more impactful to a survivor's QoL than supportive responses [9].

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The term "caregiver" is operationalized in the present study as an individual's main source of support during cancer diagnosis and treatment. This person could be a friend, sibling, child, spouse, or other loved one identified by the patient as their primary care-taker. The support a survivor receives from family members and loved ones is an important determinant of QoL [9–11]. For example, one study found that positive caregiver support led to optimism and reduced sense of hopelessness among cancer patients [10]. Another more recent study conducted in Brazil found that social support was positively associated with multiple aspects of QoL among cancer survivors, including social, physical, and emotional well-being [12].

Conversely, research has found that problematic caregiver relationships and poor caregiver support can result in negative psychological outcomes among survivors, which may not be mitigated by positive helping relationship with others [13, 14]. Negative caregiver responses include expressions of excessive worry, pessimism, criticism of the patient's coping ability, underestimation of illness, and/or withdrawal [14]. These negative interactions can lead to feelings of abandonment, rejection, and increased psychological distress among cancer survivors [9, 14, 15]. A recent study found that social constraints and negative interactions with loved ones can impact sleep quality among cancer survivors [16]. Moreover, negative caregiver responses can have a stronger influence on cancer survivors' psychological health compared to positive or supportive responses [9].

Although literature suggests that a loved one's negative response to cancer can have greater impact on a survivor's QoL compared to supportive responses, negative caregiver response to cancer has not been extensively researched and has garnered inconsistent conclusions [9, 14–17]. Furthermore, more research is needed to identify mechanisms by which negative caregiver response may be mitigated in order to inform strategies to enhance cancer survivors' QoL. Therefore, the goal of this study was to examine direct effects of perceived negative caregiver response, and the potential moderating role of social support, on physical and mental health-related QoL in a population-based sample of cancer survivors up to 10-year post diagnosis, adjusting for various socio-demographic and health-related characteristics.

Methods

Procedures

Study data were collected as part of the American Cancer Society's Study of Cancer Survivors-II (SCS-II), a nationwide, cross-sectional survey of psychosocial adjustment and quality of life among cancer survivors [18]. A full description of SCS-II's research design and methods are described elsewhere [19]. The SCS-II sample included three separate time-since-diagnosis cohorts (2-, 5-, and 10-year survivors). Study participants included survivors of seven different cancers: breast, prostate, colorectal, uterine, bladder, skin melanoma, and non-Hodgkin lymphoma. Other eligibility criteria for SCS-II included being age 18 years or older at the time of diagnosis, diagnosed with stage I–IV cancer, residence in one of SCS-II's target states at the time of diagnosis, and ability to read and write English or Spanish. Cancer survivors were identified and recruited through 14 state cancer registries and asked to complete either a mailed questionnaire or telephone interview survey. A total of 9170 survivors agreed to participate in the study, and most participants (89%) completed the mailed questionnaire. Approval for this study was obtained from the Institutional Review Board of Emory University. Additional approval was obtained from each of the 14 state cancer registries used to recruit SCS-II participants.

Study measures

The SCS-II survey includes a variety of scales and subscales that are well established, known to be valid and reliable, and have been widely used in cancer research [19]. The entire SCS-II survey was translated into Spanish by a certified translation specialist and then back-translated into English to ensure accuracy. Additionally, the Spanish version of the survey was pilot-tested with three Spanish-speaking focus groups to gather feedback and ensure accuracy of translation [19].

The primary independent variable, *negative caregiver response* to cancer, was assessed using seven items from the Criticism and Withdrawal subscale of the Partner Response to Cancer Inventory. This 14-item tool was designed to evaluate patient–caregiver interactions relevant to cancer treatment and has shown adequate reliability (Cronbach's alpha = 0.88) in previous research [20]. To minimize overall respondent burden, seven items were selected from the Criticism and Withdrawal subscale based on item loading in the original exploratory factor analysis [20], along with theoretical relevance to the study. Prior to responding to these items, participants were asked: *Who was the one person who you relied on to take care of you during your treatment for cancer?* After identifying a person (other than their medical provider) who they considered their primary informal caregiver during cancer treatment, participants responded to Criticism and Withdrawal items with that person in mind. For example, participants were asked how often their primary caregiver "criticized the way you handled your disease treatment" and "avoided being around you when you weren't feeling well." Items were measured on a 4-point Likert scale ranging from one (Never) to four (Often). Negative caregiver response was treated as a continuous variable in analyses, with higher scores indicating more negative perceptions of caregiver interactions.

Another independent variable assessed in this study, *perceived social support*, was assessed using the Multidimensional Scale of Perceived Social Support (MSPSS), which assesses perceived adequacy of social support [21]. This tool has shown adequate reliability (Cronbach's alpha = 0.88) in previous research [21]. The MSPSS contains 12 items measured using a 7-point Likert scale ranging from one (Very strongly disagree) to seven (Very strongly agree). Perceived social support was treated as a continuous variable in analyses, with higher scores indicating greater perceived social support.

The primary outcome of interest, *health-related quality of life (QoL)*, was assessed using the Medical Outcome Study Short Form Health Survey (SF-36), which is a 36-item health status instrument that provides two summary indexes: physical health and mental health [22]. The physical health summary index contains 22 items evaluating self-reported physical functioning, pain, changes in role functioning due to physical health, and an assessment of general health status. The mental health summary index contains 14 items evaluating self-reported feelings of vitality, social functioning, changes in role functioning due to emotional difficulties, and general mental health. Both the physical and mental health summary indices of the SF-36 have shown adequate reliability among US adults (Cronbach's alpha = 0.93 and 0.88, respectively) [23]. Further, the SF-36 has been used widely in research to assess physical, mental, and social functioning in individuals with a wide range of chronic diseases, including cancer. Response options for both health-related QoL indices varied by item, and both indices were treated as continuous variables in analyses, with higher scores on both subscales indicate better QoL.

Various socio-demographic and health-related characteristics of study participants were assessed. Socio-demographic characteristics included participants' age, gender (coded as "male" or "female"), marital status (recoded as "married/partnered" and "single/divorced/widowed"), education level (recoded as "less than high school," "high school graduate," and "some college or more"), and race/ethnicity (recoded as "non-Hispanic White," "Non-Hispanic Black," "Non-Hispanic other," and "Hispanic"). Age and education level were treated as continuous variables in inferential statistical models, while other socio-demographic variables were treated as categorical in analyses. Health-related characteristics included cancer type (coded as "breast," "prostate," "colorectal," "uterine," "bladder," "skin melanoma," or "non-Hodgkin lymphoma"), time since diagnosis (coded as "2 years," "5 years," or "10 years"), stage at diagnosis (coded as "in situ," "localized," "regional," or "distant"), and primary caregiver during cancer experience (recoded as "spouse/partner," "other family member," "close friend," and "other caregiver"). Time since diagnosis and stage at diagnosis were treated as continuous variables in inferential statistical models, with increasing values indicating longer time since diagnosis and more advanced stage at diagnosis. Cancer type and primary caregiver were treated as categorical variables in analyses.

Participants' *spirituality* was also assessed due to its established association with increased perceptions of social support and better QoL among cancer patients and survivors [24–26]. Spirituality, defined broadly as one's transcendent beliefs, was assessed using the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale (FACIT-Sp) [27]. The FACIT-Sp is a 12-item measure of spiritual well-being for individuals with chronic disease, which assesses spirituality across three subscales: meaning, peace, and faith. Scores for these subscales can be combined to create a total spirituality score, which has shown adequate reliability (Cronbach's alpha = 0.87) in previous research [27]. Response options were measured on a 5-point Likert scale ranging from zero (Not at all) to four (Very much). Spirituality was treated as a continuous variable in analyses, with higher scores indicating greater levels of spirituality.

Data analysis

Study data were analyzed using IBM SPSS Statistics, version 24. Correlational analyses were conducted, and correlation coefficients were examined, which ruled out multicollinearity among study variables. Only study variables with less than 10% missing data were included in inferential analyses. The variable indicating primary caregiver's relationship to the survivor had 11.3% missing data and was therefore excluded from inferential analyses. However, caregiver's relationship to the survivor was included in correlation analyses and was not significantly associated with any study variable. Although each individual variable included in regression models had no more than 10% missing data, a total of 1627 participants were missing data for at least one key study variable and were excluded from analyses. The final analytic sample included 7543 participants. Descriptive statistics (i.e., frequencies, means, and standard deviations) were calculated to describe the sample. General linear models were used to test the relationship between negative caregiver response and QoL, adjusting for relevant socio-demographic and health-related characteristics. Since QoL was divided into two domains (physical and mental health), two separate models were constructed. Additionally, we tested the potential moderating role of perceived support from survivors' broader social network on the relationship between negative caregiver response and QoL. To test moderation, we examined the interaction effect between negative caregiver response and perceived social support in models predicting QoL.

Table 1 Sample socio-demographic and health-related characteristics ($N = 7543$)

Variables	$M \pm SD$	Number (%)*
Age	66.57 ± 11.82	–
Gender		
Female	–	4155 (55.1)
Male	–	3388 (44.9)
Education level		
< High school	–	900 (11.9)
High school graduate	–	1906 (25.3)
Some college or more	–	4737 (62.8)
Marital status		
Married/Partnered	–	5589 (74.1)
Single/Divorced/Widowed	–	1954 (25.9)
Race/Ethnicity		
Non-Hispanic White	–	5922 (78.5)
Non-Hispanic Black	–	719 (9.5)
Non-Hispanic Other	–	351 (4.7)
Hispanic	–	551 (7.3)
Cancer type		
Breast	–	2387 (31.6)
Prostate	–	1829 (24.2)
Colorectal	–	1564 (20.7)
Bladder	–	471 (6.2)
Uterine	–	594 (7.9)
Skin Melanoma	–	650 (8.6)
Non-Hodgkin lymphoma	–	48 (0.6)
Time since diagnosis		
2 years	–	2725 (36.1)
5 years	–	2663 (35.3)
10 years	–	2155 (28.6)
Stage at diagnosis		
In situ	–	206 (2.7)
Localized	–	5270 (69.9)
Regional	–	1920 (25.5)
Distant	–	147 (1.9)
Primary caregiver's relationship to survivor*		
Spouse/Partner	–	5064 (67.1)
Other family member	–	1454 (19.3)
Close friend	–	395 (5.2)
Other Caregiver	–	147 (1.9)

*Due to missing data, the percentages do not add up to 100

Results

Sample description

Table 1 displays socio-demographic and health-related characteristics of study participants ($N = 7543$). Participants ranged from 23 to 100 years of age ($M = 66.57 \pm 11.82$), with over half being female (55.1%). Most participants reported their race/ethnicity as non-Hispanic White (78.5%), and over 60% had at least some college education. Of the seven cancer types included in the study sample, nearly a third of participants had been diagnosed with breast cancer (31.6%), followed by prostate cancer (24.2%) and colorectal cancer (20.7%). Time since diagnosis (2, 5, or 10 years) was fairly evenly distributed across the sample, and most participants had been diagnosed with either localized (69.9%) or regional (25.5%) stage cancer. Over 67% of the sample reported their partner or spouse as their primary caregiver during their cancer experience, followed by another family member (19.3%) or close friend (5.2%).

Physical health component of QoL

The first model (Table 2) explained approximately 17% of the variance in the physical health component of QoL ($R^2 = 0.17$). Negative caregiver response was negatively associated with physical health [F (1, 7524) = 80.72, $p < 0.001$], and various health-related and socio-demographic co-variates were significant in this model. Spirituality was positively associated with physical health [F (1, 7524) = 334.08, $p < 0.001$], while perceived social support was not significant in this model. Therefore, an interaction effect between negative caregiver response and social support on the physical component of QoL was not tested.

Mental health component of QoL

The second model (Table 3) explained approximately 37% of the variance in the mental health component of QoL ($R^2 = 0.37$). Negative caregiver response was negatively associated with mental health [F (1, 7524) = 193.17, $p < 0.001$], and various health-related and socio-demographic co-variates were significant in this model as well. Spirituality [F (1, 7524) = 2595.33, $p < 0.001$] and perceived social support [F (1, 7524) = 12.11, $p < 0.01$] were both positively associated with mental health. Since perceived social support was associated with the mental health component of QoL, we tested the hypothesis that social support from others in a survivor's network may moderate the relationship between negative caregiver response and mental health. A significant interaction effect between negative caregiver response and social support was not detected, and thus, the interaction term was not retained in the final model.

Discussion

This study examined direct effects of perceived negative caregiver response, and the potential moderating role of social support, on health-related among cancer survivors. Results

Table 2 Factors associated with physical health among cancer survivors ($N = 7543$)

Variable	B	Standard error, $R^2 = 0.17$	t value
Cancer type			
Breast	Ref	Ref	Ref
Prostate	2.43	0.50	4.84***
Colorectal	1.37	0.39	3.47**
Bladder	0.43	0.60	0.71
Uterine	− 0.84	0.46	− 1.84
Skin melanoma	1.83	0.49	3.76***
Non-Hodgkin lymphoma	0.57	1.47	0.40
Time since diagnosis	− 0.09	0.15	− 0.59
Stage at diagnosis	− 1.15	0.24	− 6.35***
Age	− 0.28	0.01	− 25.15***
Gender			
Female	Ref	Ref	Ref
Male	0.68	0.39	1.71
Education level	1.45	0.17	8.59***
Marital status			
Married/Partnered	Ref	Ref	Ref
Single/Divorced/Widowed	− 1.08	0.28	− 3.82***
Race/Ethnicity			
Non-Hispanic White	Ref	Ref	Ref
Non-Hispanic Black	− 3.00	0.40	− 7.45***
Non-Hispanic Other	0.14	0.55	0.25
Hispanic	− 1.06	0.45	− 2.35*
Spirituality	0.27	0.02	18.28***
Perceived social support	− 0.00	0.01	− 0.21
Negative caregiver response	− 0.34	0.04	− 8.98***

*$p < .05$; **$p < .01$; ***$p < .001$

indicate that survivors who rated their caregiver's actions more negatively reported worse physical and mental health, even up to 10 years after their initial cancer diagnosis, and this pattern held true after adjusting for various socio-demographic and health-related characteristics. Moreover, there were no differences in cancer survivors' reporting of negative caregiver response by time since diagnosis, which may indicate that perceptions about caregivers' actions during cancer treatment remain relatively stable over time. Perceived social support was not directly associated with physical health, but it was positively associated with mental health. This finding coincides with existing literature in which various indicators of social support have been correlated with positive psychological outcomes among cancer patients and survivors [12, 14]. Additionally, cancer survivors in our study who were married or in committed relationships reported better physical health compared to those who were single, divorced, or widowed. This further demonstrates the importance of social support in cancer survivorship, as having a committed spouse/partner may be an important component of one's social network.

Study findings also indicate that perceived social support did not moderate the relationship between negative caregiver response and mental health among cancer survivors. This suggests that positive support from others within a survivor's social network may not be enough to attenuate the negative effects of their primary caregiver's unsupportive behaviors. This finding deviates from some previous research. For example, Manne and colleagues [14] found that women coping with breast cancer who had strong social support networks were less severely impacted by their partners' unsupportive behaviors compared to women with less support from social networks. Nevertheless, our findings reinforce studies demonstrating that the inverse association between negative caregiver response and survivors' mental health is not always mitigated by social support from others [13]. The primary caregiver, who is most often a spouse or intimate partner, is likely to spend more time with the survivor relative to others in the survivor's social network, which may help explain the importance of the caregiver–survivor dynamic.

Table 3 Factors associated with mental health among cancer survivors ($N = 7543$)

Variable	B	Standard error, $R^2 = 0.37$	t value
Cancer type			
Breast	Ref	Ref	Ref
Prostate	0.63	0.39	1.63
Colorectal	0.09	0.30	0.29
Bladder	− 0.63	0.46	− 1.36
Uterine	0.73	0.35	2.08*
Skin melanoma	0.57	0.37	1.53
Non-Hodgkin lymphoma	− 0.02	1.12	− 0.02
Time since diagnosis	0.09	0.11	0.82
Stage at diagnosis	− 0.34	0.18	− 1.87
Age	0.80	0.01	9.35***
Gender			
Female	Ref	Ref	Ref
Male	1.11	0.30	3.66***
Education level	0.86	0.13	6.66***
Marital status			
Married/Partnered	Ref	Ref	Ref
Single/Divorced/Widowed	− 0.27	0.22	− 1.26
Race/Ethnicity			
Non-Hispanic White	Ref	Ref	Ref
Non-Hispanic Black	− 1.90	0.31	− 6.14***
Non-Hispanic Other	− 1.10	0.42	− 2.63**
Hispanic	− 2.48	0.35	− 7.20***
Spirituality	0.57	0.01	50.94***
Perceived social support	0.03	0.01	3.48*
Negative caregiver response	− 0.40	0.03	− 13.90***

*$p < .05$; **$p < .01$; ***$p < .001$

This study highlights the need for cancer survivorship interventions that target or are inclusive of caregivers. A cancer diagnosis not only affects the patient but it can impact their loved ones as well [28], and these loved ones often assume the role of caregiver with no formal training and limited resources to carry out this new role [29]. There is an abundance of research highlighting the social, economic, emotional, and physical burden that caregiving can place on a survivors' primary caregiver [30]. Therefore, caregiver burden may help explain why some cancer survivors in the present study perceived negative responses from their caregivers. Caregivers may struggle to effectively communicate with their loved one about their illness, which could lead to survivors perceiving criticism, blaming, and/or withdrawal from their caregiver. Accordingly, survivorship interventions should help facilitate effective communication between survivors and their caregivers, and resources should make caregivers proactively aware of how their actions may affect the survivor, as this may not be easily recognizable. Caregiver-focused interventions require a two-pronged approach, as caregivers may need resources to (1) help them effectively *support their loved one* through cancer diagnosis and treatment and (2) obtain *support for themselves* as they cope with their loved one's diagnosis and their new role. Additionally, interventions and resources targeting the survivor should incorporate strategies for coping with negative caregiver interactions.

Limitations

Findings from this research must be considered within the context of certain limitations. In particular, participants' responses may have been affected by recall bias given that participants were not in active treatment for cancer and were asked to recall experiences from 2, 5, or 10 years prior. Therefore, participants may have either overestimated or underestimated their caregivers' negative responses during their cancer diagnosis and treatment. However, there were no differences in ratings of negative caregiver response across time-since-diagnosis cohorts, suggesting that any recall bias was randomly distributed in the sample. Additionally, we are limited by the cross-sectional nature of study data which does not allow us to determine causality, but rather the associations among study variables. Finally, the majority of cancer survivors represented in this study were non-Hispanic White and had at least some college education, limiting the ability to generalize findings to more diverse populations. In particular, future research should explore the relationship between socioeconomic status and negative caregiver response. Caregiver burden may be compounded by socioeconomic factors (e.g., inadequate housing, financial worry) in underserved populations, potentially increasing the prevalence of negative caregiver response.

Literature suggests that survivors diagnosed with cancers that can be closely linked to individual behavior tend to perceive stigma and/or blame from others for their illness [31]. Specifically, researchers indicate that survivors diagnosed with lung and human papillomavirus (HPV)-related cancers (e.g., cervical, head and neck) often report feeling like others blame them for developing cancer due to associations with smoking and sexual behavior, respectively [31]. Consequently, lung and HPV-related cancer survivors may perceive a high level of negative caregiver response; however, the SCS-II dataset used for the present study did not include these cancer types. Thus, there are opportunities to advance this line of research by including patients diagnosed with lung and HPV-related cancers. This could provide an opportunity to compare findings for potentially stigmatized cancers with cancers that traditionally elicit less perceived stigma and blame (e.g., breast, prostate, colorectal).

Conclusions

The support cancer survivors receive from their loved ones is critical to their QoL. This study provides evidence that perceived negative responses from a survivor's primary caregiver can diminish their overall QoL. Although having a broader social network may help survivors cope with the negative responses from their primary caregiver, the caregiver–survivor dynamic remains essential to the mental and emotional well-being of cancer survivors. Thus, it is critical that future cancer survivorship research and practice efforts appropriately identify primary caregivers, adequately assess the caregiver–survivor dynamic, and integrate strategies that enhance interactions between survivors and their primary caregiver.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest. The corresponding author does not have full control of primary data analyzed in this manuscript. The data are owned by the American Cancer Society and were made available through a Collaborative Agreement between the American Cancer Society and the University of South Florida. If necessary, the journal may make a request to the American Cancer Society to review the primary data.

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