

# The impact of coping strategies of cancer caregivers on psychophysiological outcomes: an integrative review

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**Purpose:** A growing number of studies have explored the psychosocial burden experienced by cancer caregivers, but less attention has been given to the psychophysiological impact of caregiving and the impact of caregivers' coping strategies on this association. This paper reviews existing research on the processes underlying distress experienced by cancer caregivers, with a specific focus on the role of coping strategies on psychophysiological correlates of burden.

**Methods:** A broad literature search was conducted in health-related databases namely MEDLINE, Science Citations Index Expanded, Scopus, and PsycINFO, using relevant search terms. All types of studies published in English were considered for inclusion.

**Results:** We found that cancer caregiving was related to increased blood pressure, dysregulation of autonomic nervous system, hypothalamic–pituitary–axis dysregulation, immune changes, and poor health-related behaviors. We also found that problem-focused coping was associated with decreased caregiver burden, decreased depression, and better adjustment, while emotion-focused coping was related to higher levels of posttraumatic growth and psychological distress. The way coping impacts psychophysiological correlates of burden, however, remains unexplored.

**Conclusion:** A better understanding of the psychophysiological elements of caregiver burden is needed. We propose a model that attends specifically to factors that may impact psychophysiological correlates of burden among cancer caregivers. Based on the proposed model, psychosocial interventions that specifically target caregivers' coping and emotion regulation skills, family functioning, and self-care are endemic to the preservation of the health and well-being of this vulnerable population.

**Keywords:** cancer, caregiver, burden, coping, psychophysiology

## Background

Throughout history, the provision of informal care by family members and friends has been a critical avenue for the protection of individuals with chronic health problems.<sup>1</sup> Caregivers have always held significant socioeconomic value in society, one that will likely increase exponentially in the future as the number of individuals with chronic medical illnesses continues to rise. For example, the annual economic value of informal caregiving (i.e., providing care to a loved one with a chronic medical illness without being compensated financially to do so) in the USA was recently estimated at \$375 billion.<sup>2</sup>

While the negative impact of caregiving has been widely documented, much less attention has been given to ways in which such negative outcomes may be avoided.<sup>3</sup> The objective of this review was to examine the role of coping strategies on dimensions

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of stress and negative health outcomes, with a specific focus on psychophysiological correlates of burden among cancer caregivers. Since psychological adjustment to cancer is a dynamic process that depends in part on the meaning attributed to the illness and coping strategies employed to face emotional exhaustion and perceived lack of control, a greater understanding of caregivers' coping strategies will directly inform the development of empirically supported interventions that attend to the unique psychological symptoms of burden experienced by cancer caregivers.<sup>3,4</sup>

## Caregiver burden

A large body of literature suggests that providing care to a chronically ill loved one has the potential to cause caregiver burden. Specifically, cancer has the potential to significantly and negatively impact patients and their informal caregivers, for whom the disease trajectory represents a significant source of distress and burden.<sup>5</sup> According to the Oncology Nursing Society,<sup>6</sup> caregiver burden encompasses the difficulties of the caregiver role and the associated alterations in caregivers' emotional and physical health that can occur when care demands exceed resources. Caregivers experience varying challenges during different phases of the cancer trajectory that can significantly impact their functioning and quality of life. Indeed, close to one-half of caregivers of patients with advanced cancer have some symptoms of distress (e.g., depression, anxiety, insomnia, and decreased quality of life).<sup>7</sup> Moreover, family members significantly involved in the patient's care, and who report a significant impact of caregiving on their daily activities, often report fatigue and burden associated with the patient's cognitive and physical dysfunction.<sup>8,9</sup> Additionally, in families of patients at end of life, caregivers face the dual challenge of providing care and beginning to process anticipatory grief. These concerns are well recognized by health organizations that consider the patient and family as a unit of care, and offer support during the disease trajectory, from diagnosis to bereavement.<sup>10–12</sup>

## Emotional burden

While rates of psychopathology are high among patients with cancer – higher than rates in the general population – new data suggest that the rates are even higher among their caregivers. For example, several reviews and meta-analyses have demonstrated a higher prevalence of psychiatric disorders, especially anxiety and depressive disorders, in caregivers when compared with individuals in the general population.<sup>13–17</sup> Depression, in particular, has emerged as a primary focus of research. A literature review found that an estimated

20%–73% of cancer caregivers experience depressive symptomatology, rates that are higher than those in the general population.<sup>18</sup> Importantly, depression has been found to be associated with specific factors, including caregivers demographic characteristics (i.e., younger age, female gender, and spousal relationship with care recipient), negative appraisals of caregiving demands, and inadequate support received by the cancer caregiver.<sup>5,19,20</sup> Moreover, the responsibility to fulfill roles in addition to cancer care, such as employment or childcare, may lead to greater emotional or psychological distress among caregivers.<sup>21</sup> Lack of time, financial burden, and reduced income are also apparent among family members providing care to patients with cancer.<sup>22–24</sup>

## Physical burden

While emotional aspects of caregiver burden have been thoroughly evaluated and documented, considerably less research has explored physical burden and psychophysiological correlates of such burden among caregivers. Caregivers are at risk of a range of physical health complications as a result of their role.<sup>25–27</sup> These include sleep difficulties,<sup>28–30</sup> fatigue,<sup>8,31</sup> cardiovascular disease,<sup>32,33</sup> poor immune functioning,<sup>34,35</sup> and increased mortality.<sup>36,37</sup> For example, Schulz and Beach<sup>36</sup> found that caregivers who reported burden had a 63% increased risk of mortality when compared with noncaregivers. In addition, these caregivers were much less likely to have time to rest when sick, time to exercise, or to secure adequate rest to allow for optimal caregiving capacity. Studies have also reported poor health-related behaviors, such as increased alcohol and tobacco use.<sup>38,39</sup> In fact, some studies indicate that caregivers are less likely to undertake preventive health behaviors and generally exhibit decreased health care service utilization.<sup>40</sup>

## Positive outcomes of caregiving

Although a majority of studies have highlighted the negative outcomes of caregiving, some positive outcomes of caregiving have also been reported. Recent systematic reviews have identified positive aspects in informal caregiving. These include improved mood, better relationship satisfaction, personal growth, competence and mastery, better subjective well-being, and even better cognitive functioning and lower mortality.<sup>41,42</sup> Using a diary methodology, Cheng et al<sup>43</sup> found that Alzheimer caregivers were capable of identifying several positive gains within this process, such as a sense of purpose, feelings of gratification, increased tolerance, or even cultivation of positive meanings. In the specific context of cancer, caregiving was also associated with positive experiences. In two recent systematic reviews, caregivers reported feelings

of being rewarded, personal growth, and finding meaning, personal satisfaction and discovery of personal strength, and improved their relationship, not only with the care-receiver, but also within other relationships.<sup>44,45</sup>

## This review

The purpose of this review was to provide an extensive overview of the state of literature in relation to the psychophysiological consequences of caregiving and the role of coping strategies on this association. To that end, we first review the status of the relationship between caregiving and psychophysiological stress responses, and the association between coping and psychophysiological correlates of burden. Based on our findings and on previous models, we propose a model to guide research within this field. We conclude by outlining potential lines of inquiry for future research.

## Methodology

A broad literature search on the processes underlying distress experienced by cancer caregivers, with a specific focus on the impact of coping strategies on psychophysiological correlates of burden was conducted using several databases,

namely MEDLINE, Science Citation Index Expanded, Scopus, and PsycINFO. To this end, keywords such as “cancer”, “oncology”, “caregiver”, “caregiving”, “carer”, “coping”, or “coping strategies”, “burden”, “physiology”, “distress” were used. All types of studies (e.g., quantitative, qualitative), published in English, assessing 1) psychophysiological stress responses in the context of caregiving and 2) the association between coping strategies and psychophysiological correlates of burden in samples of cancer caregivers were included.

## Results

A total of 30 articles were identified. From these, four articles exploring the link between caregiving and psychophysiological stress responses and five articles exploring the association between coping strategies and psychophysiological correlates were included in this review. Study characteristics and main results are presented in Tables 1 and 2. Given the lack of studies found, results from included studies were also related to studies from other caregiving contexts and from the broad psychophysiological literature to better understand the results obtained in the context of cancer caregiving.

**Table 1** Study characteristics and main results of included studies for associations between caregiving and psychophysiological stress responses (N=4)

| Study references                         | Study design  | Results  |
|--|---|--|
| Weitzner et al, <sup>47</sup> 2000       | Review – caregiving among older cancer patients                                       | Caregiving was associated with lowered immune system functioning, increase in blood pressure, and altered lipid profiles.  |
| Lucini et al, <sup>48</sup> 2008         | Observational study with 58 cancer caregivers (vs. 60 controls)                       | Caregivers showed an autonomic imbalance, suggestive of sympathetic predominance at rest and of a reduction of vagal cardiac regulation.   |
| Teixeira and Pereira, <sup>49</sup> 2014 | Cross-sectional study with 78 cancer caregivers (vs. 78 controls)                     | Cancer caregivers showed higher cardiovascular (heart rate) and electrodermal reactivity (skin conductance) while visualizing standardized pictures with different emotional valences. |
| Luecken and Lemery, <sup>55</sup> 2004   | Review – early caregiving and pathways to dysregulated physiological stress responses | Different genetic, psychosocial, and cognitive-affective pathways to dysregulated physiological stress responses among caregivers were found.  |

**Table 2** Study characteristics and main results of included studies for associations between coping strategies and psychophysiological correlates (N=5)

| Study references                           | Study design   | Results   |
|--|--|---|
| Patrick and Hayden, <sup>60</sup> 1999     | Cross-sectional study with 596 women with an adult child with a chronic disability   | Coping strategies were associated with well-being.  |
| Elliott and Shewchuk, <sup>61</sup> 2003   | Cross-sectional study with 60 caregivers of patients with several physical disabilities  | Problem-focused coping was associated with depression, mental health, social functioning, and vitality.   |
| Fuemmeler et al, <sup>62</sup> 2005        | Cross-sectional study with 47 parents of childhood cancer survivors (vs. 31 parents of children with type I diabetes mellitus) | Lower levels of emotion-focused coping were associated with increased frequency of both posttraumatic stress symptoms and general psychological distress.       |
| Hoekstra-Weebers et al, <sup>63</sup> 2000 | Longitudinal study with parents of pediatric cancer patients   | Coping was associated with levels of distress and was a buffer for depression.  |
| Schumacher et al, <sup>64</sup> 1993       | Longitudinal study with 75 caregivers of persons receiving chemotherapy  | Coping strategies were associated with both strain and depression. Further analysis showed that coping mediated the relationship between strain and depression. |

## Caregiving and psychophysiological stress responses

Although certain physiological responses (e.g., increase in cardiovascular function and a release of adrenal catecholamines) are anticipated and considered adaptive during the initial reaction to an acute stressor<sup>46</sup> such as the diagnosis of cancer in oneself or a loved one,<sup>39</sup> a period of chronic stress – such as that experienced during the cancer caregiving trajectory – can lead to changes in cardiovascular and immune functioning that are no longer adaptive, but instead have the potential to compromise the physical well-being of the caregiver. In their review, Weitzner et al<sup>47</sup> found that when faced with demanding care situations, cancer caregivers present a lowered immune system functioning, an increase in blood pressure, and altered lipid profiles, leading to a state of enhanced psychological morbidity and burden. In another study, Lucini et al<sup>48</sup> evaluated the effects of caregiving as a risk factor for poor health in caregivers of cancer patients and noncaregivers. The study included the investigation of psychological and physiological (autonomic nervous system) measures. The results indicated that cancer caregivers showed dysregulation of the autonomic nervous system, which was attributed to stressors associated with caregiving. The experience of stress led to an activation of the hypothalamic–pituitary–axis (HPA) and immune changes, as well as behavioral alterations such as adoption of poor health-related behaviors. The results revealed that since cancer caregivers had higher levels of stress, and an obvious autonomic imbalance, there was a reduction in cardiac vagal regulation, which significantly compromised their health status. This result, as well as others reported by Teixeira and Pereira,<sup>49</sup> suggests the need to carry out preventive strategies to improve the autonomic profile of cancer caregivers. For example, decreased immune functioning may occur as a result of diminished cytokine production (considered mediators and regulators of innate immunity), eventually compromising the body in relation to the ability to cope with a disease.<sup>50,51</sup>

Recent research has begun to identify mechanisms through which the caregiving experience impacts health outcomes. Previous reviews<sup>52</sup> have identified several potential mechanisms, including the ability to regulate psychophysiological responses to environmental challenges. For example, psychophysiological stress responses prepare the body to survive physical threats by mobilizing stored energy, increasing cardiac output, and suppressing nonessential digestive, immune, and reproductive functions.<sup>46</sup> At a psychophysiological level, research also suggests that the

combination of prolonged stress and physical demands of caregiving can compromise the physiological functioning of caregivers and increase the risk of health problems.<sup>53,54</sup> As Luecken and Lemery's study<sup>55</sup> suggests, caregiving may be associated, in the long term, with dysregulated physiological stress responses and, ultimately, disease outcomes. Beyond the genetic and the psychosocial pathways, Davies and Cummings reflect on a cognitive-affective pathway, suggesting that caregiving experiences influence the development of cognitive and emotional self-regulatory abilities and threat appraisals, which can then alter subsequent responses to stress. In fact, affective self-regulation has been linked with improved coping with daily stressors,<sup>56</sup> lower levels of aggression and hostility,<sup>57</sup> and improved health-related behaviors.<sup>58</sup> Therefore, the manner in which individuals make sense of situations has the potential to impact both behavioral and physiological responses.

## Coping and psychophysiological correlates of burden

Similar to the dearth of studies that systematically examine the impact of specific coping strategies on psychological outcomes, very little attention has been given to the impact of caregivers' coping strategies on psychophysiological correlates of burden.<sup>59</sup> For example, problem-focused coping has been associated with decreased caregiver burden,<sup>60</sup> while problem-solving ability of the caregiver of a physically disabled family member has been found to predict improved adjustment and decreased depression.<sup>61</sup> Additionally, emotion-focused coping has been associated with higher levels of posttraumatic stress disorder symptoms and general psychological distress in parents of children with cancer and diabetes.<sup>62</sup> When coping styles were investigated longitudinally among cancer caregivers, problem-focused coping was most effective at the time of diagnosis, a point which requires learning about the illness and exploring treatment options.<sup>63</sup> The same study also revealed that coping styles shifted as treatment progressed, and that previous coping styles did not necessarily impact later level of distress. There is also evidence that coping styles can act as a buffer for depression in cancer caregivers. For example, Schumacher et al<sup>64</sup> found that caregivers' perceptions of the efficacy of their coping strategies mediated the relationship between strain and depression. However, when compared with other dimensions of the cancer caregiving context such as stress or depression, coping has remained relatively unexplored.

## Discussion

Given the vast literature documenting caregiver burden and the multiply determined nature of such burden, the field of psychooncology is increasingly turning its attention to coping and how mental health professionals may help cancer caregivers to cope with the many demands they face. Indeed, the growing recognition of the critical role that informal caregivers play in our health care systems has been met with equal attention by researchers and government agencies alike on ways in which the health and well-being of cancer caregivers can be maintained.

This integrative review provides evidence of the lack of studies exploring the association between caregiving and psychophysiological outcomes and examining the role of coping on these associations. Yet, some evidence was gathered regarding the impact of caregiving on blood pressure, HPA function, immune function, and health-related behaviors. Moreover, coping strategies used by cancer caregivers seem to influence their psychosocial adaptation and, consequently, may affect their psychophysiological outcomes.

To better understand the experience of cancer caregivers, several models have been proposed (Table 3).<sup>65–67</sup>

In light of the literature reviewed here and the fact that the previous models<sup>22,40,69–71</sup> do not specifically attend to psychophysiological indicators of burden, we propose an explanatory model that accounts for this important element of the caregiving experience (Figure 1). Contextual factors (e.g., age, gender, family variables, and emotional development), cancer-related events of the caregiver (previous caregiving experiences and other stressors), and disease characteristics and treatments (i.e., nature of the cancer and treatments) may impact the way caregivers make sense of a situation in terms of demands, stressors, and goals (i.e., cognitive reappraisal) as well as the way they think about the presence or absence of internal and external resources to meet these demands,

stressors, and goals. This cognitive appraisal informs the experience of burden, as indicated via psychophysiological mechanisms. Specifically, such burden may manifest as an activation of the HPA axis and the sympathetic adrenomedullary system (i.e., reduction in cardiac vagal regulation and increased blood pressure), or neuroendocrine and immune changes, such as diminished cytokine production and elevated release of cortisol. These psychophysiological responses, however, can be modulated by caregivers' coping strategies and specific psychosocial variables. Some authors<sup>57,72,73</sup> have proposed that effectiveness of coping strategies and, specifically, cognitive appraisals, are linked to psychophysiological reactivity to stress, with negative appraisals being associated with increased cardiovascular reactivity.

For this reason, we propose that the extent of psychophysiological dysregulation experienced by caregivers is impacted by the use of targeted coping strategies (problem-, emotion-, and meaning-focused) previously described, as well as caregivers' engagement in optimal emotion regulation strategies (vs. worry, rumination) and self-care (vs. poor health-related behaviors), the existence of family function (vs. dysfunction), and capacity to maintain a present focus (vs. becoming overwhelmed with the perception of the chronicity of the caregiving trajectory). These factors together will impact caregivers' appraisals of the situation (in terms of perceived harm and threat and capacity to overcome these limitations) and hence, the psychophysiological outcomes experienced.

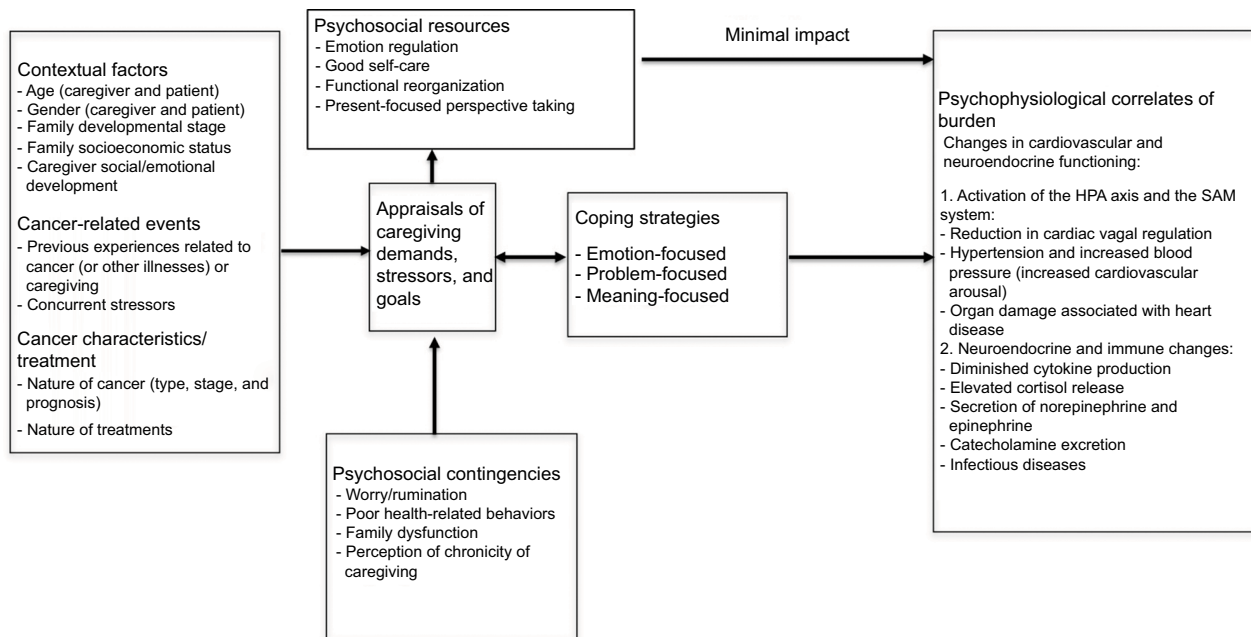
## Future directions

It is clear that psychosocial interventions that target the unique needs of cancer caregivers are needed. In particular, this review highlights the potential benefits of interventions that attend not only to symptoms of burden, but also the mechanisms underlying such symptom profiles. Importantly, our proposed model suggests multiple avenues for

**Table 3** Models for understanding the experience of cancer caregivers

|                            | <b>The caregiver stress model<br/>(Pearlin et al<sup>40</sup>)</b>  | <b>The theory of stress and coping<br/>(Lazarus and Folkman<sup>68</sup>)</b> |
|----------------------------|---|---|
| Background and the context | SES, caregiving history, family and network composition, program availability   | Personal and situational factors  |
| The stressors              | Primary stressors:<br>1) Objective indicators – cognitive status, problematic behaviors, IADL, dependences<br>2) Subjective indicators – overload, relational deprivation | Acute or chronic stressors and their appraisal (primary and secondary)        |
| The mediators              | Coping, social support  | Coping (emotional-focused, problem-solving, meaning-focused)                  |
| The outcomes               | Depression, anxiety, irascibility, cognitive disturbance, physical health, yielding of role   | Health and well-being   |

**Abbreviations:** IADL, instrumental activities of daily living; SES, socioeconomic status.



**Figure 1** A proposed model of the impact of coping strategies of cancer caregivers on psychophysiological indicators of burden.

**Abbreviations:** HPA, hypothalamic–pituitary–axis; SAM, sympathetic adrenomedullary.

intervention, including the facilitation of improved coping strategies, improved emotion regulation skills, self-care, and family functioning.

The present review suggests that, since coping strategies can be learned, interventions that target and provide psychoeducation about coping and adaptive strategies can be useful in preventing and/or decreasing burden, both as measured via subjective rating scales and physiological measurement tools. Drawing on the work of Lazarus and Folkman<sup>68</sup> and Folkman,<sup>74</sup> interventions that help caregivers to identify elements of the current caregiving-related challenges that are controllable or uncontrollable, and that teach problem-focused, emotion-focused, and meaning-focused skills have the potential to promote resilience and buffer distress and burden. Indeed, two systematic reviews of psychosocial interventions for cancer caregivers<sup>75,76</sup> highlighted the significant benefits of problem-solving and skills building interventions in assisting caregivers with carrying out their responsibilities and cultivating a sense of mastery and control. These reviews – in addition to the earlier reviews of Northouse et al<sup>77,78</sup> – also emphasized a dearth of interventions that target specific domains of caregiver needs, such as existential distress and insomnia.

Interventions that attend to caregivers' emotion regulation skills and ability to manage negative emotions in a healthful way are also critical in light of the expected emergence of negative emotions across the caregiving trajectory. One such

intervention, Emotion Regulation Therapy (ERT), originally developed by Mennin and Fresco<sup>79</sup> to address worry and rumination in individuals in the general population is currently being adapted to address the processes that underlie anxiety and mood symptoms among cancer caregivers (Emotion Regulation Therapy for Cancer Caregivers; ERT-C). Preliminary analyses have demonstrated strong effects of the ERT-C on rumination, worry, intolerance of uncertainty, and anxious and depressive symptomatology among cancer caregivers.<sup>80,81</sup>

Importantly, longitudinal studies that examine the experience of caregivers across the caregiving trajectory, from diagnosis to bereavement, and through survivorship, are needed to provide a clearer understanding of the progress of psychological well-being and coping processes of caregivers. Such studies have the potential to highlight critical points, such as diagnosis or relapse, at which distress among caregivers is likely to increase, and in so doing, clearly define critical time points for optimal psychotherapeutic intervention. Studies that examine the unique needs of caregivers of patients with specific types of cancer (e.g., brain tumors) or undergoing specific treatment regimens (e.g., hematopoietic stem-cell transplantation) are also needed so that interventions may target the unique burden experienced by these groups. Work is already underway<sup>82</sup> to develop such interventions for hematopoietic-stem-cell-transplant caregivers. Additionally, studies that examine the impact of life and developmental

stage on the caregiving experience will allow for a greater understanding of the context of burden among caregivers.<sup>83,84</sup> This, in turn, may highlight variable approaches to coping that are particularly consonant with certain stages in life.

Most critically, systematic study of the psychophysiological correlates of burden is needed in order to understand the broad impact of caregiving on the caregiver. As cancer caregivers themselves represent a population at risk of cancer and other chronic medical illnesses, such attention is critical in order to mitigate the impact of caregiving stress on this vulnerable population.

## Disclosure

The authors report no conflicts of interest in this work.

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