

Caregiver Burden as a Mediator Between Emotional Distress and Concentration Problems in Patients With Cancer

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OBJECTIVES: To examine the longitudinal mediation effect of caregiver burden on the relationship between emotional distress and concentration among individuals with cancer.

SAMPLE & SETTING: 96 patients with cancer and their caregivers (96 dyads) were selected from a study conducted at Duke University.

METHODS & VARIABLES: A secondary analysis from a longitudinal study was used. Caregiver burden, as well as patients' emotional distress and concentration problems, were selected as variables and analyzed.

RESULTS: Caregiver burden acts as a mediator between emotional distress and concentration problems among patients with cancer. More severe caregiver burden is associated with more severe concentration problems for the patient. Dyads with higher patient emotional distress at one week (T1) also had higher caregiver burden at T1, which increased the concentration problems of patients at T1. When caregiver burden became more severe over time, patient concentration problems also increased.

IMPLICATIONS FOR NURSING: Healthcare providers should assess caregiver burden and identify factors that contribute to increased caregiver burden. Providing support for managing caregiver burden and patients' emotional distress will help improve patients' concentration capacity.

KEYWORDS caregiver burden; emotional distress; concentration capacity; patients with cancer

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Patients with cancer often need support from family members or friends (i.e., caregivers) to manage their diagnosis and cancer-related symptoms (Wagner, Tanmoy Das, Bigatti, & Storniolo, 2011). A caregiver, as the main support person for the patient, provides a wide variety of assistance, ranging from facilitating transportation to identifying, monitoring, and managing cancer-related symptoms (Wagner et al., 2011). Patients with cancer benefit from their care; however, caregivers may feel burdened by high caregiving demands. Burden placed on caregivers can affect their ability to care for patients, which, in turn, may affect patients' health outcomes (Milbury, Badr, Fossella, Pisters, & Carmack, 2013).

Changes in cognitive function have been described as a complex symptom resulting from cancer or its treatment (Janelins, Kesler, Ahles, & Morrow, 2014). Impairment in cognitive function may occur in one or more cognitive domains (Janelins et al., 2014). Difficulty in concentration is one of the most common symptoms reported by patients with cancer. Sixty-seven percent of patients have reported problems with concentration during their cancer treatments, and 58% still report issues at six months after treatment (Janelins et al., 2014; Kohli et al., 2007).

Concentration problems in patients with cancer are often associated with emotional distress (Pullens, De Vries, & Roukema, 2010). In the non-cancer population, this association can be explained by the mediation effect of caregiver burden on the relationship between patients' emotional distress and concentration. In neurocognitive studies, a patient's high emotional distress contributes to increased caregiver burden, and this increased burden negatively influences patient concentration (Barbe et al., 2016; Mohamed, Rosenheck, Lyketsos, & Schneider, 2010; Viatonou et al., 2009). However, the mediation effect

of caregiver burden within the context of cancer is unclear. Using the theory of unpleasant symptoms (TUS) as a guiding framework, this secondary analysis examined the longitudinal mediation effect of caregiver burden on the relationship between emotional distress and concentration among patients with cancer (Lenz, Pugh, Milligan, Gift, & Suppe, 1997).

Using the TUS framework, the authors incorporated three major concepts: influencing factors, symptoms, and caregiver burden (Lenz et al., 1997). Influencing factors included psychological (emotional distress) and physiologic (fatigue, sleep, and age) factors that may influence the symptom (concentration). Physiologic factors are treated as covariates for their confounding effects on concentration. Caregiver burden is the newly added variable of interest. The authors' hypothesis is that caregiver burden mediates the relationship between emotional distress and concentration. The statistical analysis for this study aimed to validate or refute this mediation effect.

Methods

Design and Participants

This secondary analysis involved data obtained from an intervention study that tested the effects of caregiver training on patient and caregiver outcomes (Hendrix, Landerman, & Abernethy, 2013). In the parent study, the only observed intervention effect was seen in caregiver self-efficacy. Study participants included patients and their caregivers. Eligibility criteria of patients were being aged 50 years or older and having been admitted to a hospital for chemotherapy administration for hematologic malignancies or for treatment of complications within seven days of receiving chemotherapy. Included patients received chemotherapy only. The parent study was conducted at Duke University Hospital, a National Cancer Institute–designated comprehensive cancer center and hospital that specializes in complex patients, usually with late stages of cancer. Caregiver participants were adults who lived in the same household and provided hands-on care to the patients after hospital discharge. Caregiver eligibility also included absence of neurocognitive illness, such as dementia. Eligible participants were recruited during the patient's hospitalization. A total of 96 patient–caregiver dyads were used for this analysis, with data collected by mail at one week (T1), two weeks (T2), and four weeks after discharge (T3). Although one patient had missing data on two variables and nine caregivers had missing data on one variable across three time points because of unstable patient health conditions, they were missing at random ($\chi^2 = 146.31$, $p = 0.55$) and, therefore, had no

negative effect on parameter estimation (Little & Rubin, 2002).

Instruments and Variables

The Caregiver Quality of Life–Cancer (CQOLC) scale is a self-administered instrument that evaluates the quality of life of caregivers of patients with cancer (Duan et al., 2015). Of the four subscales of the CQOLC, burden (10 items, Cronbach alpha = 0.89) was chosen

TABLE 1. Baseline Patient Characteristics (N = 96)

Characteristic	\bar{X}	SD
Age (years)	65.3	7.6
Activities of daily living ^a	1.61	1.35
Characteristic	n	
Gender		
Male	69	
Female	26	
No response	1	
Education		
Less than high school	10	
High school diploma	31	
Technical or associate degree	15	
Associate of arts degree	6	
Bachelor's degree	22	
Postgraduate degree	9	
No response	3	
Race		
Caucasian	83	
African American	8	
Native American	2	
Other or no response	3	
Marital status		
Married	80	
Divorced	8	
Widowed	4	
Other or no response	4	
Comorbidities		
Depression, anxiety, or other emotional issues	31	
Epilepsy	3	
Memory problems	1	
None or no response	61	

^a Assessed using the Older Americans Resources and Services Multidimensional Functional Assessment Questionnaire, with possible responses of 1 (needs no help), 2 (needs some help), or 3 (unable to do)

for this analysis to assess perceived burden among caregivers of individuals with cancer. Scores ranged from 0 to 40, with higher scores denoting greater burden that caregivers perceived in their caregiving situation. The Memorial Symptom Assessment Scale (MSAS) (Portenoy et al., 1994) assesses the severity, frequency, and distress associated with 32 highly prevalent symptoms experienced by patients. Subscales assessing worry, irritability, nervousness, and sadness were chosen to represent patients' emotional distress (Cronbach alpha = 0.99). The MSAS subscale that assesses difficulty concentrating was chosen to represent concentration problems. Scores range from 3 to 13, with higher scores denoting greater emotional distress and greater concentration problems.

Data Analysis

Longitudinal parallel process (LPP) modeling was used for data analysis (Sousa, Kwok, Schmiede, & West, 2014). The LPP is a type of growth curve modeling that

combines multilevel modeling and structural equation modeling. This two-step approach allows examination of the relationships between two (or more) different longitudinal processes at the same time. This provides insight into how emotional distress, concentration, and caregiver-perceived burden change over time, and how these longitudinal changes relate to one another.

Because no observed effects of interventions were seen in patients' emotional distress and concentration and caregiver-perceived burden in the parent study, this secondary analysis merged the groups (control and intervention) into a single sample for analysis. In the first step of LPP modeling, the initial status at T1 (intercept) and the change over time (slope) of each variable (emotional distress, burden, and concentration problems) were estimated separately by using multilevel modeling with SAS® Proc Mixed. This approach helped address missing data. Structural equation modeling was then used to examine the mediation effect of emotional distress on concentration problems through caregiver-perceived burden using IBM SPSS Amos, version 25.0.

TABLE 2. Baseline Caregiver Characteristics (N = 96)		
Characteristic	\bar{X}	SD
Age (years)	59.3	12.8
Anxiety ^a	7.25	4.2
Depression ^a	4.2	3.21
Characteristic	n	
Gender		
Female	79	
Male	15	
No response	2	
Race		
Caucasian	83	
African American	6	
Asian	2	
Native American	1	
Other	4	
Relationship to patient		
Spouse or partner	69	
Parents	15	
Child	2	
Friend	2	
Sibling	1	
Other or no response	7	
^a Assessed using the Hospital Anxiety and Depression Scale, with scores ranging from 0–7 (normal), 8–10 (borderline abnormal), and 11–21 (abnormal)		

Results

Sample Characteristics

Characteristics of study participants and caregivers are summarized in Tables 1 and 2. The majority of patients were Caucasian, male, and married, and had obtained at least a high school diploma. Patients appeared to have capacity for independent activities of daily living. Thirty-five patients reported comorbidities, such as emotional problems (n = 31), epilepsy (n = 3), and memory problems (n = 1). The majority of caregivers were Caucasian, female, spouses or partners of the patients, and not working. The mean level of caregivers' depression was within normal range (\bar{X} = 4.2, SD = 3.21), while their anxiety level was mildly higher than the normal range (\bar{X} = 7.25, SD = 4.2).

Mediation Effect of Caregiver-Perceived Burden

The model fit indices showed a good model fit (χ^2 = 12.56, p = 0.083; goodness of fit [GFI] = 0.96, normed fit [NFI] = 0.98, incremental fit [IFI] = 0.99, relative fit [RFI] = 0.96, comparison fit [CFI] = 0.99, root mean square error of approximation [RMSEA] = 0.091). Patients' emotional distress had a direct relationship with concentration problems at T1 (β = 0.27, p < 0.001), but not over time (see Figure 1). Dyads with higher emotional distress for patients at T1 also had higher caregiver-perceived burden at T1 (β = 0.46, p < 0.001), which, in turn, was positively related to patients' concentration problems at T1 (β = 0.29, p < 0.01). This showed that patient emotional distress at T1 directly influenced

patient concentration problems at T1, but also indirectly influenced concentration problems via caregiver-perceived burden. There was a partial mediation effect at T1, and a full mediation effect over time. The speed of increase in caregiver-perceived burden was slower over time ($\beta = -0.38$, $p < 0.001$) when the caregiver cared for patients with higher emotional distress at T1 than those with lower emotional distress at T1. When caregiver-perceived burden became more severe over time, patient concentration became worse over time ($\beta = 0.26$, $p < 0.001$). This provides evidence that the relationship between emotional distress at T1 (intercept) and the change in concentration over time (slope) was fully mediated by the change over time (slope) of burden.

Discussion

The results demonstrate a partial mediation effect of caregiver-perceived burden at T1. The authors' primary finding is supported by previous research demonstrating that a patient's emotional distress increases caregiver-perceived burden, which, in turn, affects patient concentration. Caregivers also reported little increase (i.e., slower speed of increase) in their perceived burden over time when they cared for patients with initially high emotional distress. These small increases in the level of perceived burden can be attributed to high levels of perceived burden at baseline, leaving little room for additional increase. The authors also observed that caregiver-perceived burden increased over time in tandem with increased patient concentration problems, demonstrating a full

KNOWLEDGE TRANSLATION

- Caregiver-perceived burden mediates the relationship between emotional distress and concentration among patients with cancer.
- More severe caregiver-perceived burden is associated with more severe patient concentration problems.
- Given the mediating effect of caregiver-perceived burden, assess and manage caregiver burden early to promote patients' concentration capacity.

mediation effect of caregiver-perceived burden on patient concentration problems.

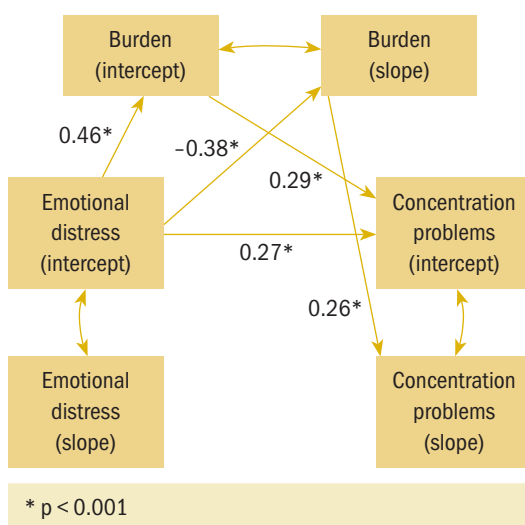
The change of patients' emotional distress over time (slope) showed no relationship to either caregiver-perceived burden or patient concentration problems. It is possible that patients sustained high levels of initial distress during the four weeks without showing changes and, therefore, failed to establish a relationship with either caregiver-perceived burden or concentration. Future studies should evaluate how a patient's emotional distress changes over time and how this change relates to caregiver-perceived burden and patient concentration. The authors also controlled for covariates (e.g., patient's fatigue, sleep, age) known to have confounding effects on concentration problems in the first step of LPP modeling. Although the TUS model provided a useful framework for understanding the relationships between physiologic and psychological factors and symptoms, future studies will need to consider additional situational factors and consequences in the framework. In this study, caregiver-perceived burden is an important variable that contributes toward concentration difficulties in patients with cancer.

Limitations

This secondary data analysis was limited to a one-item measure of subjective cognitive function that assessed severity, distress, and frequency dimensions of concentration. This subscale may not have fully captured patients' concentration capacity. Caregivers were mostly female, and women have been reported in the literature to carry higher caregiving burden (Friedemann & Buckwalter, 2014). However, this may be compensated by the fact that this study conducted a longitudinal data analytic approach.

Lastly, data within the parent study were collected during four weeks, which might be too brief of a timeframe to capture the trajectories of caregiver-perceived burden and patient emotional distress and concentration problems.

FIGURE 1. Longitudinal Parallel Process Model for the Mediating Impact of Caregiver Burden



Implications for Nursing

Findings from this study could be foundational to developing anticipatory guidance and intervention for management of cognitive problems at cancer clinics. Study findings suggest that concentration difficulties among patients with cancer can be affected by caregiver burden. In addition, emotional distress among individuals with cancer can lead to concentration problems. Results from this study emphasize the need for healthcare professionals to conduct early assessment to identify caregiver burden. By lowering burden, caregiver quality of life may be maintained, which may promote patient concentration capacity.

This study also informs the need for considering patients and their caregivers (dyads) when establishing management strategies for patients with cognitive challenges, such as impaired concentration. This dyadic intervention may help patients during aggressive medical treatments while also supporting their caregivers.

Conclusion

Caregiver-perceived burden acts as a mediator between emotional distress and concentration among patients with cancer. Additional research is needed to provide more insight into the role of caregiver-perceived burden on the patient's cognitive function to include several domains, such as concentration, memory, and thought processing.

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Yang, Pan, and Hendrix contributed to the conceptualization and design and provided analysis. Yang and Hendrix completed the data collection. Yang and Pan provided statistical support. All authors contributed to the manuscript preparation.

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