

# Effect of Caregiver Perception of Preparedness on Burden in an Oncology Population

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**Purpose/Objectives:** To identify the level of lay caregiver burden and perception of preparedness that exists for the oncology population prior to and just after hospital discharge.

**Design:** Descriptive, correlational design using repeated measures.

**Setting:** Large, tertiary care, private medical center in the midwestern United States.

**Sample:** 59 lay caregivers of patients with cancer who were discharged from inpatient hospital status.

**Methods:** Caregivers completed Robinson's Caregiver Strain Index and Archbold's Preparedness Scale questionnaires immediately prior to discharge, 7–10 days postdischarge, and 28–30 days postdischarge.

**Main Research Variables:** Caregivers' perception of preparedness and burden.

**Findings:** Preparedness levels ranged from "somewhat" to "pretty well" prepared and were consistent over time. Burden levels were moderate and also consistent over time. Increased levels of preparedness were associated with decreased levels of burden, and that relationship was consistent over time.

**Conclusions:** Caregivers' levels of preparedness can be enhanced, although no significant differences were reported in the period from prehospital discharge to one month following discharge. Burden experiences of caregivers are real and not affected by the transition from hospital to home. Burden experiences can be influenced by perceptions of preparedness.

**Implications for Nursing:** Efforts to enhance the preparedness of lay caregivers can influence their burden experience.

## Key Points . . .

- ▶ The experience of caregiver burden for lay caregivers of patients with cancer is important to recognize as a quality-of-life factor.
- ▶ Further efforts to define and assess caregivers' perceptions of preparedness and burden are required.
- ▶ Caregivers' perceptions of preparedness and burden, as currently measured, reveal that neither variable is affected significantly by the transition from inpatient care to home.
- ▶ The relationship between caregiver perception of preparedness and burden offers nurses a significant and unique opportunity to have an impact on the lives of caregivers and patients.

sition from acute inpatient care to the homecare setting likely requires the involvement of family members or significant others in a caregiving model (Given & Given, 1996; Whedon, 1998). The provision of comprehensive nursing care requires that patients and their informal caregivers receive appropriate support and education as they move throughout the healthcare continuum. Nurses must have a thorough understanding of the phenomenon and degree of caregiver burden experienced by the caregivers of their patients.

The existence of caregiver burden has been recognized for many years. Beginning in the 1980s, various authors have identified caregiver burden as a consequence of providing for the healthcare needs of patients (George & Gwyther, 1986;

Cancer is one of many chronic diseases that may necessitate multiple interactions with healthcare providers, including repeated hospitalizations. The use of Diagnostic Related Groups, beginning in 1983, accompanied by increasing acceptance of prospective payment systems and other cost-control measures, have served to shorten hospital stays. One outcome of shorter hospital stays is that the pressure on lay caregivers to provide more intensive and advanced levels of care at home was escalated (Bull, 1990). The successful tran-

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Digital Object Identifier: 10.1188/02.ONF.E70-E76

Robinson, 1983). Recently, research has increased regarding the experience of caregivers of patients with cancer. The anecdotal experiences of nurses practicing in direct patient-care settings are rich with examples of caregiver burden and stress (Carey, Oberst, McCubbin, & Hughes, 1991). The current study's author's clinical practice further validates the reality of caregiver burden.

According to estimates, about 1 of 2 men and 1 of 3 women in the United States will develop cancer (American Cancer Society, 2002). As patients with cancer live longer because of more effective disease treatments and methods to manage symptoms and side effects, the needs for physical and psychosocial care have increased. In addition, the incidence of cancer increases with advancing age, and as the percentage of people older than 65 increases, so will the number of people with cancer (American Cancer Society). These epidemiologic trends indicate the strong likelihood that most people will be required to function as caregivers at some point, thus providing compelling motivation for exploration of caregiver burden.

Little is known about the impact of caregiver preparedness on the experience of caregiver burden. A review of healthcare literature revealed that limited attention has been paid to the phenomenon in the geriatric population (Archbold, Stewart, Greenlick, & Harvath, 1990; Rusinak & Murphy, 1995). Consideration of the phenomenon in the oncology population has not been described.

## Literature Review

An evaluation of caregiver burden requires that caregivers be described and burden defined. The literature also uses "informal caregivers," ostensibly to differentiate between professional caregivers (i.e., healthcare workers) and lay individuals providing care because of pre-existing, interpersonal relationships with patients. In this article, the author used the word caregiver to describe informal caregivers. The definition of a caregiver provided by Miller & Keane (1992)—"a lay individual who assumes responsibility for the physical and emotional needs of another who is incapable of self care"—is used to describe the study population (p. 256).

Caregiver burden is a complex, multifaceted phenomenon. Identifying contributing factors, defining characteristics, and outcomes can be a circuitous endeavor. Because of the varied constructs that have been used by researchers and the highly individualistic nature of the caregiver experience, the current body of research-based knowledge reveals a diverse—and sometimes conflicting—picture. Caregiver burden is defined in this article as the caregiver's subjective experience that is perceived as stressful and is a consequence of caregiving.

## Caregiver Characteristics

A study of 30 spousal caregivers of patients with cancer found that previous experience with a spouse with chronic illness was associated with increased feelings of preparedness and coping skills that could be used to secure additional help (Rusinak & Murphy, 1995). When Archbold et al. (1990) studied 78 older people with a variety of needs and their caregivers after hospital discharge, preparedness was found to ameliorate some but not all aspects of role strain. Bucher et al. (2001) evaluated an educational intervention provided to patients with advanced cancer or family caregivers and found that participants had higher problem-solving scores after the program.

Caregiver attributes of poor health, lower socioeconomic status, and less education were found to be related to increased perceptions of harm or loss and threat, which, in turn, led to increased caregiver load (Oberst, Thomas, Gass, & Ward, 1989). Carey et al. (1991) stated that poor personal health of caregivers led to low family hardiness and negative appraisals of caregiving. Jensen and Given (1991) studied 248 caregivers of patients with cancer and found that 53% reported caregiver fatigue as moderate or severe, and fatigue was related to the impact of caregiving on daily schedules. Bull (1990) suggested that functional ability of caregivers was one of the best predictors of burden at two weeks and two months after discharge from the hospital in a study of 55 chronic illness patient-caregiver dyads. The high level of consistency in these studies suggests that a strong relationship exists between the physical health of caregivers and the degree of burden.

## Caregiver Burden

The phenomenon of caregiver burden is a perceptual and multidimensional experience. Several researchers have worked to identify, classify, and prioritize domains of caregiver burden through description and evaluation of caregiving tasks and caregivers' needs and concerns. Blank, Clark, Longman, and Atwood (1989) described caregiver needs according to types of stressors. Intrapersonal stressors included treatment uncertainty, worry, role conflict, fear of being alone, coping with the patients' situation, and guilt. Interpersonal stressors were associated with caregiver lack of support, relationships with patients, and lack of information. Lastly, transportation and finances were classified as extrapersonal stressors. The most pressing problems identified by 80 spousal caregivers of patients with cancer included fear of spouses dying (most frequent), uncertainty about the future, and spouses' emotional needs (Toseland, Blanchard, & McCallion, 1995). In the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment, which involved 2,129 interviews of families of seriously ill patients, 55% of those responding reported at least one severe caregiving or financial burden, including the need to make major life changes and the inability to function normally (Covinsky et al., 1994).

Different researchers have characterized various psychosocial concerns as either contributing to or outcomes of caregiver burden. An extensive review of the relevant literature revealed a lack of congruity in conceptualizing emotional aspects of caregiver burden. Depression and anxiety were found by Toseland et al. (1995) to be higher among spousal caregivers of patients with cancer than among the general population. Miaskowski, Zimmer, Barrett, Dibble, and Wallhagen (1997) reported that noncongruence of patient and caregiver pain ratings was associated with higher levels of caregiver strain, as manifested by increased tension, depression, confusion, and bodily pain, and less social activity, resulting in poorer mental and overall health. Similarly, Miaskowski, Kragness, Dibble, and Wallhagen (1997) found that caregivers had lower mental health scores than the general population. Also, George and Gwyther (1986) identified burden as being experienced primarily in the caregivers' mental health and social participation. In a study of 28 caregivers of patients with cancer, all reported a change in their emotional health as a result of caregiving, with 81% identifying fear and increased stress, 77% identifying anxiety and inability to cope, and 66% identifying emotional withdrawal (Perry & Roades de Meneses, 1989). Likewise, in

Hinds' (1985) study of 83 family members of patients with cancer, 53% reported psychological stressors and 19% reported that they needed assistance to deal with their fear.

Studies have found that the level of optimism maintained by caregivers is the most important predictor of their mental health and reactions to caregiving, which includes the perceived impact on physical health and daily schedules (Given et al., 1993). An evaluation of 150 patient-caregiver dyads also suggested that the impact of caregiving on caregivers' health, schedules, and depression should be considered and that caregiver optimism is a strong predictor of reactions to the burden of caregiving (Kurtz, Kurtz, Given, & Given, 1995). Although the emotional health of caregivers is not identified consistently as an antecedent, manifestation, or outcome of caregiver burden, these studies provide compelling evidence of a strong symmetrical correlation between caregiver burden and psychosocial concerns of caregivers.

## Conceptual Framework

The current study's author defined caregiver burden as the subjective experience of the caregiver that is perceived as stressful and is a consequence of caregiving. Sources, attributes, and manifestations of caregiver burden are associated in multiple and often complex ways. Antecedents of caregiver burden can be categorized broadly into four groups: factors specific to patients, to caregivers, and to situations, and economic concerns. The prevalence of caregiver burden is significant and likely underrecognized. The specific framework that was utilized in development of this research is demonstrated in Figure 1.

## Purpose

The purposes of this study were to identify the level of caregiver burden and caregiver perception of preparedness prior to and after discharge from an inpatient setting; to determine what changes, if any, occur over time; and to determine the strength of the relationship between the level of caregiver burden and caregiver perception of preparedness.

## Methods

The researcher chose a descriptive, correlational design using repeated measures. Institutional review board approval was obtained from the university and medical center. The variables explored included patient and caregiver demographics, caregiver burden, and caregiver perception of preparedness to assume the caregiving role. The burden and preparedness variables were measured at three points in time: 24–48

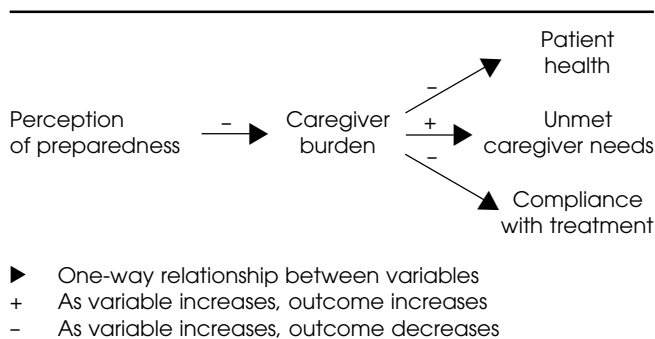


Figure 1. Conceptual Framework of Caregiver Burden

hours prior to anticipated hospital discharge, 7–10 days post-discharge, and 28–30 days postdischarge.

## Setting and Sample

A large, tertiary care, private medical center with a strong hematology and oncology practice in the midwestern United States was the setting for this study. Two specific inpatient units were used in the recruitment of study participants, a 17-bed oncology unit and a 21-bed hematology unit. Patients with cancer are admitted to both units, and both units have a staff that consists of mostly RNs, a small number of licensed practical nurses, and some patient-care assistants and secretarial support.

The population was caregivers of patients receiving inpatient care in either of the units. Sample inclusion criteria follow.

- Patients had to have any solid or hematologic malignancy.
- Patients had to be hospitalized for medical management of
  - their disease, including treatment with chemotherapy or radiation therapy
  - side effects of that disease
  - complications of the disease process or treatment.
 Patients admitted or dismissed for defined hospice care were excluded.
- Both patients and caregivers had to be older than 20.
- Both patients and caregivers had to speak English.
- Patients were not hospitalized at the institution previously during the study period.
- Patients must have had a single caregiver who met the study definition of caregiver.

## Instruments

Demographic information about caregivers and patients was obtained, including age, gender, duration and type of illness, relationship of patient and caregiver, living situation, duration of caretaking relationship, and length of current hospitalization. Data for patients were obtained from medical records; data for caregivers were obtained at the first data collection point.

**Burden assessment:** Caregivers completed the **Caregiver Strain Index** as a measurement of burden. This instrument originally was developed for use as a screening tool to detect strain in a population of caregivers (Robinson, 1983). In evaluating the caregivers, the investigator anticipated that caregiver strain would be correlated with the caregivers' physical and psychological needs, along with their negative assessments of the impact of caregiving on their lifestyles, their perceptions of their major role as caretakers, and negative beliefs about the emotional domain of the caretaking relationship. The Caregiver Strain Index is a 13-item ordinal scale that measures family caregivers' strain in providing various degrees of care to patients at home. Each item is answered with a "yes" or "no" response. Scoring is accomplished through adding all affirmative responses to arrive at a total score; thus, a higher score implies a higher level of burden. Internal consistency with Cronbach's alpha was reported as 0.86, and construct validity was demonstrated in outpatient characteristics, subjective perceptions of the caretaking relationship by caregivers, and emotional health of caregivers (Robinson). A question was added to this research tool to assess for the utilization of any professional homecare services by patients or caregivers.

**Preparedness assessment:** Caregivers also completed the **Preparedness for Caregiving Scale of the Family Caregiving Inventory**. This instrument comes from the perspective of role theory, and the burden concept is based on an intrapersonal theoretical perspective. The current study's researcher utilized the perspective of domain-specific preparedness (i.e., physical needs, emotional needs, resources, and stress) in developing it, as well as a question regarding overall preparedness. The scale was a structured, self-report, written assessment questionnaire with eight items. A Likert scale was used to answer each question, with choices ranging from 1 (not at all prepared) to 5 (very well prepared). All responses from each survey were averaged to arrive at a preparedness score, ranging from 1–5. Reliability was assessed using Cronbach's alpha and ranged from 0.67–0.92 (P. Archbold, personal communication, November 30, 1998).

## Procedures

The nursing staff of the two units identified a convenience sample of potential research subjects upon hospital admission. The investigator determined whether patients met inclusion criteria through chart review. When patients were identified as potential study participants, the investigator met with patients and caregivers to explain the study purpose and commitment, identify the rights of each to decline, and ask for participation. On receipt of positive responses from both, caregivers provided written informed consent and received instructions for participation and estimated dismissal dates for patients were identified. At that time, the investigator completed patient demographic forms using information from medical records.

The first data collection took place on the day of discharge or just prior. It consisted of completion of the caregiver demographic sheet, Caregiver Strain Index, and Preparedness for Caregiving Scale, and the data were returned immediately. If caregivers were not available at the hospital, the first data collection took place via mail or telephone prior to or at the time of hospital discharge. The caregiver then was given or sent a packet with instructions, survey tools, and return-addressed, stamped envelopes, with instructions to complete the first set 7–10 days after discharge and the second set 28–30 days after discharge. Specific dates for completion also were identified. Both the Caregiver Strain Index and Preparedness for Caregiving Scale of the Family Caregiving Inventory were to be completed at the two subsequent data collection points and returned immediately after completion. Each set of instruments was coded to identify recipients with five-character codes, which were used to determine that subjects had returned their responses and for data analysis purposes. If responses were not received, reminder phone calls were placed to encourage continued involvement in the study.

## Data Analysis

Clerical data entry staff input data, and biostatistics staff at the medical center conducted statistical analysis. Analysis of variance testing was used to assess changes over time in measurements of caregiver burden and perception of preparedness. Responses were evaluated within and between groups; data for each subject were compared over time, and summary data for the total groups were evaluated. A mixed model technique that accounted for intraindividual correlation tested the

relationship between perception of preparedness and burden. This class of regression model analysis allowed for an examination of the relationship between the two variables and changes over time.

## Results

### Sample Characteristics

The study's sample size was 59. Fifty-seven responses were received at discharge, yielding a return rate of 97%. The percentage of one-week responses received was 83% (n = 49), with a mean time period of 9.2 days since discharge, and the percentage of one-month responses received was 75% (n = 44), with a mean time period of 31.4 days after discharge. Therefore, a full data set was available for 75% of participants.

Gender distribution for patients and caregivers varied: 58% of patients were men, and 42% were women; 33% of caregivers were men, and 67% were women. Cancer diagnoses are summarized in Table 1. The age distribution of patients and caregivers is found in Table 2. Caregivers' relationships to patients most commonly were spouses (86%), then children (9%), then others (5%). The duration of the caregiving relationship, as identified by caregivers at the time of discharge, most frequently was less than six months (44%), more than three years (25%), 6–12 months (17%), and 1–3 years (14%). The time since diagnosis followed a similar distribution: 47% reported less than six months, 32% reported more than three years, 17.5% said 1–3 years, and 3.5% said 6–12 months. As expected, the vast majority of caregivers (91%) lived with the patients.

### Burden

The level of caregiver burden varied little with time, as shown in Table 3. Although people at each time period demonstrated minimal and maximal levels of burden, the mean burden score was moderate.

Data from all collection periods were combined to provide a profile of the nature and frequency of caregiver strain. A positive response to the question was tracked. Domains of burden are identified in Table 4.

### Preparedness

Perception of preparedness for caregiving showed little variability across the three data collection points. Similar to

**Table 1. Primary Cancer Diagnoses of Patients With Study Participant Caregivers**

Diagnosis	n	%
Non-Hodgkin's lymphoma	12	21
Lung cancer	5	9
Prostate cancer	4	7
Neuroendocrine tumor	4	7
Acute leukemia	3	5
Multiple myeloma	3	5
Ovarian cancer	3	5
Carcinoid tumor	3	5
Breast cancer	2	4
Uterine cancer	2	4
Germ cell tumor	2	4
Other (each < 2%)	14	25

N = 57

**Table 2. Age Distribution of Patients and Caregivers**

Age Range	Patients		Caregivers	
	n	%	n	%
Younger than 40	4	7	4	7
40-49	9	16	12	21
50-59	15	26	23	40
60-69	19	33	9	16
70 and older	10	18	9	16

N = 57

the burden scores, people at each point in time reported the highest to the lowest or almost lowest level of preparedness. Overall, these scores ranked on the scale between “somewhat well prepared” and “pretty well prepared.” Review of the responses for each of the eight individual preparedness questions revealed a consistent peak at the response “pretty well prepared.” These data are summarized in Table 5.

### Burden and Preparedness Changes Over Time

After applying generalized estimating equations techniques to the repeated measures data using a Poisson regression model (Diggle, Liang, & Zeger, 1994), the researcher found that the change over time of both burden and preparedness measurements was not significant (see Table 6).

### Relationship Between Preparedness and Burden

Again using generalized estimating equations, the researcher found a significant inverse relationship between the two measures. Specifically, for every one-unit increase in the preparedness score, the burden score decreased 0.853 units. In other words, burden was found to decline, on average, about 17% for every one-unit increase in preparedness. The relationship between burden and preparedness was constant across time (see Table 7).

## Discussion

The data that were obtained regarding the level of caregiver burden are consistent with what has been observed and recorded previously. The subjective nature of burden suggests that a great variability will exist in the measure of this experience. The sample in this study demonstrated this, with burden scores at all time frames ranging from 0 (no burden) to 12-13 (the highest levels of burden). The literature review identified significant variability in the antecedents, manifestations, and measurements of burden. For example, Given, Given, Helms, Stommel, and DeVoss (1997) observed that caregivers are largely affected by the objective

**Table 3. Distribution of Caregiver Burden Scores Over Three Data Collection Periods**

Time Period	n	$\bar{X}$	SD	Range
Before or at discharge	56	5.07	3.54	0-13
7-10 days after discharge	49	4.78	3.20	0-12
One month after discharge	44	5.00	3.69	0-13

**Table 4. Profile of Domains of Burden**

Domain	%
Work adjustments	55
Changing plans	53
Feeling completely overwhelmed	51
Confining	46
Family adjustments	41
Financial strain	41
Patient changes	37
Other time demands	36
Emotional adjustments	35
Disturbed sleep	34
Patient behavior upsetting	29
Inconvenient	24
Physical strain	16

demands of the situation, but Kurtz et al. (1995) reported that the reactions of caregivers are distinct and influenced by different variables, including caregiver optimism. Another perspective was provided by Siegel, Raveis, Houts, and Mor (1991), who described burden in the domains of financial, physical, time, social, and employment. Higher burden scores were found to be associated with an increased risk of unmet patient needs. Objective physical domain burden was reported least often by their subjects, similar to the current study's sample. Of the many references that were considered in this analysis of caregiver burden, no clear consensus exists as to how best to describe and quantify burden; therefore, no consistent measure of the experience exists. Applying these results is difficult given the disparity that currently exists in defining and measuring burden. However, caregiver burden is real, significant, and vital to consider.

The sample in the current study reported a moderate level of burden, and the degree of change was not significant from predischarge to one month after discharge. Many people tend to minimize their distress, so the strain experienced by the sample more likely was underreported, not overreported. Identifying an acceptable or desired level of burden would be unwise. Rather, a prudent approach requires that healthcare teams recognize the highly individual reality of burden, then modify endeavors to manage it accordingly.

On examination of data from the 13 questions that evaluated burden at all three points in time, 11 of the areas were experienced as strains 25% or more of the time, three of which were identified as stressful more than 50% of the time. Specifically, adjusting work (55%), needing to change personal plans (53%), and feeling completely overwhelmed (51%) were reported as stressful. The people who reported these answers were notably stressed in these domains, at

**Table 5. Caregiver Perception of Preparedness Score Distribution**

Time Period	n	$\bar{X}$	SD	Range
Before or at discharge	57	3.53	0.72	1.0-4.88
7-10 days after discharge	49	3.49	0.89	1.63-4.88
One month after discharge	44	3.53	0.86	1.5-5.0

**Table 6. Burden and Preparedness Scores Over Time, Analyzed With Generalized Estimating Equations Method**

Variable	$\bar{X}$	Test Statistic	Degrees of Freedom	p
<b>Burden</b>				
Discharge	5.07	$\chi^2 = 0.5310$	2	0.7668
One week	4.78			
One month	5.00			
<b>Preparedness</b>				
Discharge	3.53	Analysis of variance	2	0.0596
One week	3.49			
One month	3.53			

least temporarily. This finding aligns with information reported by Oberst et al. (1989), who found that caregivers reported that the most time was spent in transport, emotional support, and extra household tasks, and information reported by Jensen and Given (1991) regarding the significant role played by caregiver fatigue.

The study sample in this article appraised themselves as “somewhat” to “pretty well” prepared, with little change over time. Although limited, the previous research on preparedness revealed comparable results. Rusinak and Murphy (1995) presented data about elderly spousal caregivers who reported a moderate level of preparation in relation to the needs of their spouses recently diagnosed with cancer. Similar results were provided by Archbold et al. (1990) in an evaluation of preparedness and mutuality; caregivers identified that their level of preparedness at six weeks after hospitalization was above the midpoint. Would it not be the goal of healthcare teams that caregivers feel very well prepared at most, if not all, times? The lack of reported information about the preparedness experience of caregivers is strong testimony to the fact that inadequate attention has been paid to the concept.

The most exciting finding of this study is that the relationship between preparedness and burden is significant and relatively constant over time. This might be assumed based on the belief that having knowledge about what to expect (i.e., being prepared) would diminish caregivers’ level of stress (i.e., burden). Although previous work addressing this variable has been limited, this study’s results were consistent with those reported by Rusinak and Murphy (1995), who revealed that previous experience with an ill spouse was associated with higher levels of preparedness and coping skills. The work of Archbold et al. (1990) also supported this finding when they stated that preparedness could alleviate some, but not all, aspects of role strain. The reported level of significance of the finding in this study suggests that preparedness cannot be ignored in any consideration of caregiver burden.

## Limitations

Among the limitations of this study are its small sample size and singular geographic location. If preparedness is a function, at least in part, of healthcare teams’ efforts, then the level of preparedness experienced in this sample may differ from that which might be found in a sample receiving health care elsewhere. Also, repeated hospitalizations experienced by some patients may have influenced the preparedness and burden experiences of their caregivers. The burden experience may be different for groups receiving care elsewhere, and this study did not evaluate or control for other caregiver characteristics that may have affected preparedness and burden (e.g., age, personal health, gender, educational preparation). These limitations, however, do not change the fact that a relationship between burden and preparedness exists.

A second important limitation is that this sample represented the most willing and least burdened caregivers. Selective exclusion of caregivers who were under known stress, along with the self-selection that occurred as caregivers volunteered to participate, means that this sample represents only those people who, at least apparently, are less burdened. The conundrum of collecting data from people who are burdened *about their burden* is not resolved easily.

Another consideration is the time-limited nature of this study. With no baseline data, the researcher did not know how much burden this sample may have experienced prior to the specific hospitalization involved. Similarly, data about the time period beyond one month postdischarge were not collected.

## Implications for Practice, Theory, and Research

The most significant outcome of this study is the validation provided to the concept that caregivers must be prepared adequately for their responsibilities as a means of controlling burden. As efforts continue to control healthcare costs, this relationship between preparedness and burden mandates the development of programs and systems to ensure that caregivers are receiving the information and support they need to function successfully in their caregiving roles. A one-size-fits-all approach likely will not yield the desired outcomes. Therefore, healthcare teams should be able to address this issue in an individualized manner. This falls within the purview of nursing care, and nursing should take the initiative to operationalize this effort.

Nurses should consider several endeavors. A comprehensive approach to the caregiver burden experience requires that healthcare policy makers consider the ramifications of decisions that require more and more of lay people. Nurses are well positioned to provide lawmakers with concrete examples and data about this. Further efforts to define and describe the

**Table 7. Relationship Between Caregiver Preparedness and Burden**

Time Period	$\bar{X}$ Preparedness Score	$\bar{X}$ Burden Score	Coefficient Estimate	Empirical Standard Error	95% Confidence Limits	p
Discharge	3.53	5.07	-0.1587	0.0703	Between -0.2966 and -0.0209	0.0240
One week	3.49	4.58				
One month	3.53	5.00				

concept of caregiver burden would be useful. The literature reviewed has revealed that various researchers have conceptualized, defined, described, and measured burden with significant variability. Although caregiver burden remains a subjective and unique experience, room exists for further clarity in how it is characterized and quantified. Potential means to accomplish this could include the utilization of a burden-screening tool for caregivers to obtain baseline data about the actual incidence of burden and to identify levels at which either they or their patients are at risk.

Replication of this study with a larger and more diverse population is indicated. This may include patients and caregivers from multiple healthcare settings. Specifically, more research on this topic is needed as related to cancer as the chronic course of this disease becomes more recognized. Also, the impact of the aging population in the United States must be considered, both in terms of aging patients and aging caregivers. This was addressed by Schulz and Beach (1999), whose research with 819 spousal caregivers from ages 66–95 revealed that strained caregivers were 63% more likely to die than spouses not providing care. Additionally, those caregivers who are the most burdened, such as those who are not able to participate in studies, must be included in such efforts so that the full spectrum of the population can be considered. Lastly, outcome evaluation must occur as

programs and projects to address preparedness are developed and implemented.

## Summary

The complexity of the burden of caregiving is significant and manifested in a multitude of ways. The level of burden in this study's sample was moderate, and the level of perception of preparedness to assume caregiving responsibilities was less than 100%. The data revealed an inverse relationship between these experiences, with increased levels of preparedness corresponding with decreased levels of burden. This relationship is consistent from before discharge to one month postdischarge. This finding had not been reported previously in the oncology literature. The provision of comprehensive nursing care requires that attention be paid to the preparation level of caregivers, with the recognition of the potential impact of this variable on the burden experience of those individuals.

*The author extends appreciation to Dan Nicholls, EdD, RN, of Winona State University, chairman of this thesis committee.*

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## References

- American Cancer Society. (2002). *Cancer facts and figures*. Atlanta: Author.
- Archbold, P.G., Stewart, B.J., Greenlick, M.R., & Harvath, T. (1990). Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing and Health, 13*, 375–384.
- Blank, J.J., Clark, L., Longman, A.J., & Atwood, J.R. (1989). Perceived home care needs of cancer patients and their caregivers. *Cancer Nursing, 12*, 78–84.
- Bucher, J.A., Loscalzo, M., Zabora, J., Houts, P.S., Hooker, C., & BrintzenhofeSzoc, K. (2001). Problem-solving cancer care education for patients and caregivers. *Cancer Practice, 9*, 66–70.
- Bull, M.J. (1990). Factors influencing family caregiver burden and health. *Western Journal of Nursing Research, 12*, 758–776.
- Carey, P.J., Oberst, M.T., McCubbin, M.A., & Hughes, S.H. (1991). Appraisal and caregiving burden in family members caring for patients receiving chemotherapy. *Oncology Nursing Forum, 18*, 1341–1348.
- Covinsky, K.E., Goldman, L., Cook, E.F., Oye, R., Desbiens, N., Reding, D., et al. (1994). The impact of serious illness on patients' families. SUPPORT investigators. Study to understand prognoses and preferences for outcomes and risks of treatment. *JAMA, 272*, 1839–1844.
- Diggle, P.J., Liang, K.Y., & Zeger, S.L. (1994). *Analysis of longitudinal data*. Oxford, England: Oxford University Press.
- George, L.K., & Gwyther, L.P. (1986). Caregiver well-being: A multi-dimensional examination of family caregivers of demented adults. *Gerontologist, 26*, 253–259.
- Given, B., & Given, C. (1996). Family caregiver burden from cancer care. In R. McCorkle, M. Grant, M. Frank-Stromborg, & S. Baird (Eds.), *Cancer nursing* (pp. 93–109). Philadelphia: Saunders.
- Given, B.A., Given, C.W., Helms, E., Stommel, M., & DeVoss, D.N. (1997). Determinants of family care giver reaction. New and recurrent cancer. *Cancer Practice, 5*, 17–24.
- Given, C.W., Stommel, M., Given, B., Osuch, J., Kurtz, M.E., & Kurtz, J.C. (1993). The influence of cancer patients' symptoms and functional states on patients' depression and family caregivers' reaction and depression. *Health Psychology, 12*, 277–285.
- Hinds, C. (1985). The needs of families who care for patients with cancer at home: Are we meeting them? *Journal of Advanced Nursing, 10*, 575–581.
- Jensen, S., & Given, B.A. (1991). Fatigue affecting family caregivers of cancer patients. *Cancer Nursing, 14*, 181–187.
- Kurtz, M.E., Kurtz, J.C., Given, C.W., & Given, B. (1995). Relationship of caregiver reactions and depression to cancer patients' symptoms, functional states, and depression—A longitudinal view. *Social Science and Medicine, 40*, 837–846.
- Miaskowski, C., Kragness, L., Dibble, S., & Wallhagen, M. (1997). Differences in mood states, health status, and caregiver strain between family caregivers of oncology outpatients with and without cancer-related pain. *Journal of Pain and Symptom Management, 13*, 138–147.
- Miaskowski, C., Zimmer, E.F., Barrett, K.M., Dibble, S.L., & Wallhagen, M. (1997). Differences in patients' and family caregivers' perceptions of the pain experience influence patient and caregiver outcomes. *Pain, 72*, 217–226.
- Miller, B.F., & Keane, C.B. (1992). *Encyclopedia and dictionary of medicine, nursing, and allied health* (5th ed.). Philadelphia: Saunders.
- Oberst, M.T., Thomas, S.E., Gass, K.A., & Ward, S.E. (1989). Caregiving demands and appraisal of stress among family members. *Cancer Nursing, 12*, 209–215.
- Perry, G.P., & Roades de Meneses, M. (1989). Cancer patients at home: Needs and coping styles of primary caregivers. *Home Healthcare Nurse, 7*(6), 27–30.
- Robinson, B.C. (1983). Validation of a Caregiver Strain Index. *Journal of Gerontology, 38*, 344–348.
- Rusinak, R.L., & Murphy, J.F. (1995). Elderly spousal caregivers: Knowledge of cancer care, perceptions of preparedness, and coping strategies. *Journal of Gerontological Nursing, 21*(3), 33–41.
- Schulz, R., & Beach, S.R. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *JAMA, 282*, 2215–2219.
- Siegel, K., Raveis, V.H., Houts, P., & Mor, V. (1991). Caregiver burden and unmet patient needs. *Cancer, 68*, 1131–1140.
- Toseland, R.W., Blanchard, C.G., & McCallion, P. (1995). A problem solving intervention for caregivers of cancer patients. *Social Science and Medicine, 40*, 517–528.
- Whedon, M.B. (1998). Quality of life of family caregivers in cancer care. *Quality of Life, 6*(5), 53–55.