

# Caregiver Role Stress: When Families Become Providers

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**Background:** *In view of the large number of families engaged in caregiving, this study was initiated to describe informal cancer care provision from the perspective of the caregiver.*

**Methods:** *A professional data collection site was used to convene focus groups in four cities. Participants included 63 caregivers, 87% of whom were female, mean age of 56 years. Caregivers responded to an open-ended question regarding the challenges of providing care. The study utilized qualitative analysis of verbatim transcripts. Transcript coding with four independent raters, using an iterative process, achieved a high inter-rater reliability.*

**Results:** *The project elucidates self-reported concerns confronted in cancer caregiving. Five primary themes emerged: supportive care demands, emotional toll, impact on health status, coping strategies, and rewards and affirmation. Providing supportive care introduced a balancing act in caregivers' lives as they attempted to address complex and overlapping roles. They felt alone in their decisions, were under-prepared for tasks they assumed, and tried to shield the care recipient.*

**Conclusions:** *This qualitative approach confirmed past research while identifying novel concepts related to maintaining well-being and a sense of purpose despite caregiving hardships. Some aspects of caregiver suffering were identified. Caregiver self-regulation strategies revealed by this work suggest ideas for psychosocial interventions caregivers could use to protect themselves and the care recipient from impending distress.*

## Introduction

Almost all of the 10 million cancer survivors in the United States were assisted by an informal caregiver during part of the disease continuum. Healthcare delivery has become increasingly technical, community-based, and dependent on family engagement for care provision. In fact, approximately 80% of home care services are provided by families,<sup>1</sup> introducing a com-

elling rationale to better understand what they do, how they manage, and what should be done to assist them. Family caregivers frequently step into their new role with little understanding of the complex ways it will alter their lives. The caring role can impose difficult personal care tasks and care of long duration, usually without outside help. The work may grow in intensity over time, and in the case of cancer caregiving, tasks often spike at intervals through the disease continuum.<sup>2,3</sup> This study sought to explicate the cancer caregiver's perception of the impact of the acquired role, the physical and emotional responses to new responsibilities, lifestyle changes, difficulties encountered, and perceived desire for help.

Using qualitative methods, this study offers a real-world portrayal of daily life in the words of the participants. We found few studies of cancer caregivers that used qualitative methods (focus groups or interviews) with active caregivers, in preference to survey methods, and fewer still that included inter-rater reliability with multiple coders.<sup>4,8</sup> This approach has inherent advantages since qualitative data are by definition descriptive, relevant, often illuminating, and sometimes theory generating. Conversations among people with similar experiences offer valuable insights, and focus group interviews, in particular, stimulate participant

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dialog leading to rich description and expansion of key concepts.<sup>9,10</sup> The focus group method was deliberately selected to capture the dialog, the group confirmation of concepts, the relative importance of expressed ideas, and any consensus. Coding the conversation is a form of analysis leading to patterns within the conversation, referred to as themes.<sup>11</sup> The comments can enhance understanding of caregiving work and the strategies used by caregivers to manage within the context of their own family environment. We anticipated that documentation of caregiving events and the attributed meaning would help to build theory and facilitate the development of new supportive interventions.

## Methods

### Recruitment

Potential participants were identified through the database of a national cancer call center. The study participants had requested cancer-specific information during the initial contact and expressed willingness to be re-contacted. Eligibility criteria included caring for an adult cancer patient, a minimum of 16 hours per week devoted to caring, care tasks that included activities of daily living (ADL), and ability to speak English. Focus group attendees were paid a nominal incentive (\$25) to cover their travel expenses.

Focus groups were convened within four US cities (Atlanta, Minneapolis, Dallas, and Kansas City), with two groups in each location. This study was part of a larger research project to explore caregiver needs and examine caregiver self-assessment capability. The venues, designed for research data collection, were outfitted with observation rooms and audio recording capability. An interview guide was used to center the discussion. The focus group discussion asked the caregivers to “tell me about the things that you find most challenging in your caregiving experiences” with follow-up questions aimed at clarification or facilitation of further discussion. Sessions were tape recorded and verbatim transcripts were used for content analysis.

### Transcript Coding

Transcript codes were generated inductively from the data, as described by Strauss and Corbin.<sup>12</sup> Four investigators read the transcripts of the first four focus groups and independently applied initial coding crafted by the first author. The coding was subsequently discussed, compared, and modified for use in the analysis of the remaining transcripts. Using a consensus development process, the primary coding was agreed upon, and unique secondary coding was allowed for each coder. Inter-rater agreement was established for primary codes achieving 67%, 92%, and finally 100% agreement for primary codes; agreement was not required

for secondary coding. Content redundancy became evident by the seventh transcript with few new concepts raised in discussions for the eighth group, suggesting that saturation had been reached.

### Data Management

An audit trail, or systematic collection of focus group materials, was maintained to confirm findings and verify the trustworthiness of the data. Participants were assigned a numeric identifier, and all demographic data were recorded using this coding system. A frequency table of code use enabled data retrieval, comparison, and identification of code density while revealing secondary codes for the same statements. This analysis focused the primary findings, helped construct the themes, and made it possible to portray the relationships among the themes. The analysis of data was con-

Table. — Participant Demographics

Caregivers	No. of Participants	%*
<b>Gender</b>		
Women	55	87.0
Men	8	13.0
<b>Age</b>		
Mean: 56		
Range: 25–75		
<b>Race/Ethnicity</b>		
African American	21	33.3
Caucasian	41	65.1
Hispanic	1	1.6
<b>Income</b>		
Less than \$20,000	11	17.5
\$21,000–40,000	16	25.4
\$41,000–60,000	22	34.9
Over \$60,000	14	22.2
<b>Education</b>		
Grade school	2	3.2
High school	28	44.4
College	14	22.2
Professional/graduate	19	30.2
<b>Care Delivered</b>		
Duration of care:		
Range 3–60 weeks		
Majority 6–12 weeks		
Level of care intensity:		
1: Total care		19.0
2: Help with activities of daily living		12.7
3: Housework, shop		31.8
4/5: Errands/drive		36.5
Care recipients:		
Parent	17	26.9
Spouse	21	33.3
Sibling	9	14.3
Adult child	4	6.3
Other relative	3	4.8
Friend	9	14.3
Disease type:		
Prostate cancer	12	19.0
Lung cancer	11	17.5
Breast cancer	8	12.7
Colorectal cancer	7	11.1
Head/neck cancer	5	7.9
Other tumors	20	31.7

\* Not all categories equal 100%.

ducted using a manual method and confirmed with NVivo software (NVivo version 2.0. QSR International Pty Ltd. Doncaster, Victoria).

## Results

### Participants

The eight groups included 63 male and female active caregivers representing a broad demographic spectrum and site of cancer (Table). Most of the participants were women caring for a current or ex-spouse, a parent, or a sibling.

### Challenges of Caregiving Themes

The primary themes revealed in the focus groups were (1) supportive care demands, (2) emotional toll, (3) impact on health status, (4) coping strategies, and (5) rewards and affirmation (Figure)

**(1) Supportive Care Demands:** Caring demands found in this study confirm previously reported objective demands.<sup>13</sup> Physical demands are the efforts expended by the caregiver to maintain the functional capacity and physical comfort of the care recipient. Many caregivers felt unprepared to perform certain tasks and expressed discomfort with intimate care. Caregivers thought that caregiving transformed a part of their identity from “spouse” to “nurse.” Family relationships placed strain on the caregiver as other family members’ abdicated responsibility for helping. Role conflicts among family members were often related to differing opinions about how to help and assessments of need. Some conflicts shifted additional physical care demands to the primary caregiver.

Organizational demands were daunting to older caregivers who reported a lack of familiarity with community resources and difficulty getting everything done within time constraints. Younger participants, however, were conflicted over dual roles, such as employment and care provision. Some patients did not want to know the status of their disease or the

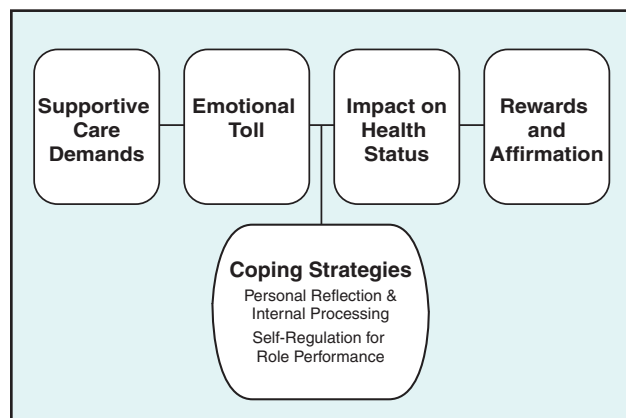


Figure. — Caregiver role: primary themes.

### Box 1. — Supportive Care Demands

#### Skills

*“Well, my problem was trying to learn how to do all the things that needed to be done for him. I had the feeding tube and all that had to be cleaned and flushed out, and I had never done anything like that, so it was very difficult for me.” (female, spouse)*

#### Competence

*“I think that being prepared to take physical care of things that might be, that might require you to sort of go beyond the boundaries you have with that person before. And sort of just realize that’s what they need done.” (male, spouse)*

#### Time

*“I think my biggest challenge was trying to juggle a job, and run a home, and do this...” (male, son)*

*“And now I’m stuck in the middle between mom wanting to be a part of the family and being included and my kids saying ‘Does grandma have to go? Do we have to take grandma this time?’ They’re getting frustrated so it’s affecting relationships and that’s all related to punctuality.” (female, daughter)*

prognosis. Caregivers became keepers of “secrets,” such as information about the disease, the prognosis, finances, and other problems.

The caregiving role required the delivery of support to sustain the emotional well-being of the care recipient. This work was reported to be equally difficult to sustain as the physical tasks. Keeping peace and maintaining an upbeat atmosphere were widely noted to be essential to help the patient’s recovery or to maintain adherence to medical care. Examples of several components of the themes are reflected in the quotes that follow in Boxes 1–5. The quotes are attributed to the caregiver by gender and relationship to the care recipient (Box 1)

**(2) Emotional Toll:** Caregivers worried about the future and expressed feeling guilty, being overwhelmed, and experiencing strain, hardship, and a loss of control. Guilt arose as a sense of inadequacy, expressed as not being able to do enough or inability to attend to the entire family while providing care for one person. Some people felt guilty over hardships, conflicts, or financial concerns. Employed participants were torn between the desire to care and the need to provide the household income.

The job of caring for another person was universally consuming and overpowering. Participants were overwhelmed by the inability to finish tasks, and they experienced limited control over demands, time, and people. To alleviate frustration, caregivers frequently coped by lowering their expectations, although they still felt responsible to keep life orderly, often amid considerable chaos. Participants indicated that they provided emotional support to the care recipient but often received minimal personal reinforcement from other family members (Box 2).

## Box 2. — Emotional Toll

### Guilt

*"I've found myself thinking thoughts, you know, please let this cancer kill you. I'm sick of it. And then, I feel the natural guilt for having such horrible thoughts and occasionally I tell him how I think and how I feel." (female, spouse)*

*"When you don't feel like you are doing all that you should be." (female, spouse)*

### Overwhelmed

*"I was so overwhelmed. I had severe insomnia; I couldn't sleep because... you think about everything and you're worrying and stuff like that...you're always just running, running, running and it's just nonstop." (female, daughter)*

*"It was hard at first, I think, just because it felt I should be able to handle this myself and that part was difficult, and then finally, I just let her go because I just couldn't physically do it anymore, I was worn out." (male, spouse)*

### No Control

*"I feel so powerless to do anything for myself. And I know all this sounds really selfish but that's how I feel. I've had so much taken from me ...and I'm just scared." (female, spouse)*

**(3) Impact on Health Status:** The demands of caregiving had an impact on the health status of the primary caregiver. Caregivers described feeling exhausted, blaming the fatigue on sleep loss, and several reported that their own health was failing.<sup>13</sup> They raised concerns about their capacity to sustain the care they provided. These health status changes resulting from the caregiving experience have been reported elsewhere and constitute a known hazard of the family caregiving experience.<sup>13,14</sup>

**(4) Coping Strategies:** Two primary forms of coping were revealed in the study. One method was the use of personal reflection and internal processing of specific thoughts about the caregiving experience and its meaning or value. Another was the use of self-regulatory mechanisms to suppress feelings thought to be undesirable and to convey more positive messages during role performance.

Using the first method of coping, reflection and internal processing, caregivers remained optimistic and attempted to convey this hopefulness to the care recipient. They spoke about the importance of remaining positive and the belief that they could bear the responsibility and trust vested in them. They also described feeling deprived, a concept they tied to limited resources, a lack of support, or a loss of personal time and pleasure. They acknowledged that this sounded selfish, although it was counterbalanced by compassion, hope, patience, and a sense of responsibility.

Some important functions were canceled to make time for caregiving, thus generating a loss of joy and restricted freedom. Strained family relationships led to anger, frustration, and communication problems. Con-

tests for attention sometimes left the caregiver straddling problems from their own children as well as the care recipient. The combination of conflicted family relationships, caregiving demands, and a feeling of powerlessness led to eroded confidence and misery for the caregiver, situations interpreted as suffering.

People who discussed conflicts, frustration, and suffering suggested that their method of coping was to use internal dialog or personal thoughts to remind themselves that they were doing a good job. They told themselves to be patient, responsible, and tolerant of the infirmities of others. They spoke about "telling myself" some point of information or reassuring themselves. The internal dialog appeared to serve as a method to soothe frayed emotions and reinforce the determination to succeed (Box 3).

The second method of coping involved the use of self-regulation for role performance. Caregivers were compassionate and protective; many resisted the temptation to put their own needs first and displayed restraint as they ministered to the care recipient. They contained feelings when performing difficult duties such as dressing changes. Over time, confidence in caregiving work increased, which reinforced the belief that they were doing a good job. Caregivers found novel ways to brace themselves emotionally for the role they played, sometimes developing an armor to protect themselves as they managed family conflicts. They suggested that it was essential to be contained in order to take things in stride and conceal their anxiety.

Some caregivers received little assistance for difficult tasks. Certain aspects were quite unappealing, forcing them to find innovative ways to meet the demand while shielding the patient from their personal reactions. They donned a "mask," pretending that things were easier when performing difficult tasks or "going

## Box 3. — Coping Strategies: Reflection and Internal Processing

### Being Responsible

*"If I have had just a little bit of time to get my thoughts and my emotions under control, I can usually bear it and I've learned to try and think before I speak." (female, spouse)*

### Handling Uncertainty

*"Not knowing what's next. What you need to panic over and what you don't." (male, son)*

### Suffering

*"Dealing with the pain and watching the person suffer for me was absolutely excruciating." (male, spouse)*

*"People tell me how well I'm doing, but I'm really not." (female, spouse)*

*"Everything bounces off me. If he's mad or he's angry, I hear the brunt of it. I may not have been the source, but I'm the main target." (female, spouse)*

incognito” for the sake of the patient when care tasks were repulsive. This effort shielded the patient from detecting the caregiver’s emotional conflict (Box 4).

**(5) Rewards and Affirmation:** The experience of caring for another person provided rewards and satisfaction. Some participants were surprised to be satisfied by caregiving and expressed pleasure with the opportunity to provide a valuable service. Their altruism led to an increased emotional closeness with the care recipient, and they reported feeling good about their role because it provided a chance to “pay back” another person. Some participants gained newly derived meaning and personal growth through the experience. A few thought the job of caring was a duty, but most viewed it as a special opportunity, noting the satisfaction of helping someone they loved.

The caregivers shared ideas for preserving time for personal leisure, reflection, and maintenance of health. They indicated that it was important to retain time alone and use it to exercise, prepare good food, and read or relax. They found that retaining some time for themselves helped to deal with uncertainty, to retain hope and patience with their role, and to keep themselves “looking good.” They agreed it was important to stop and regroup before approaching the next crisis or problem (Box 5).

**Box 4. — Coping Strategies: Self-Regulation for Role Performance**

**Developing Compassion**

*“I got to the point where after I went through the ‘nobody wants to help me’ stage, but down inside of me I knew, I’m doing everything I can here.” (female, daughter)*

*“I want to make sure that what I do is what she wants done.” (female, daughter)*

**Using Commitment**

*“You know, sometimes it just takes longer to do things. Well, I guess it’s a little hard, you know, I mean, because, you like to be on time and do things on time.” (female, daughter)*

**Developing Armor**

*“Learning to separate yourself from the patient. You get so emotionally involved.” (male, son)*

*“I’m doing everything I can here. I’m keeping him as strong as I can, I’m trying to motivate him as much as I can, motivate him and by being honest with him and with his diagnosis and letting him know that we can fight it together.” (male, son)*

**Using a Mask**

*“Not grossing out totally when you have to handle things you’ve never handled before. Finding that you have the grace to do it when you didn’t think you could.” (male, spouse)*

*“You have to put a barrier. I sort of just try to look at it as if it’s not my husband. So the cancer is different than my husband.” (female, spouse)*

*“You can’t be sad around them, you know, they’re going through a really hard time and you’re not ... and yet, it’s bothering you.” (female, sibling)*

## Discussion

Informal caregivers experience a myriad of strains associated with the complex physical and emotional demands involved in caring for another person. These strains can be due to the many aspects of life that are affected by cancer, including communication, nursing care, financial concerns, and emotional conflicts. In this qualitative study, we learned how caregiving affects the family and friends who provide the care for a loved one. We also learned that a common and prominent concern involved the lack of access to technologic information and skill development for caregiving. Caregivers wanted to do a good job but felt they had inadequate information and preparation. In response to the strains of caregiving, many caregivers used self-regulatory coping strategies to not only distance themselves from grueling and disturbing tasks, but also provide the most optimistic and supportive face for their loved one to see. The use of a therapeutic mask, armor, and internal dialog was prevalent across the geographic and sociodemographic characteristics of participants and seemed to be an effective approach to get them through the more difficult times. These concepts are similar to the idea of “concealment” of feelings reported by Sales.<sup>15</sup> Similar strategies are used by nurses in managing the day-to-day care of very ill patients (related in a conversation with C. E. F.; May 2005).

An important concern that emerged in our study was the general loss of time for caregivers to take care of themselves, to manage their own medical care, or to get respite from the daily strain of cancer caregiving. This concern has particular salience because these caregivers are at increased risk for health problems<sup>16-21</sup> due to increasing age, work overload, and inadequate emotional support.<sup>18,19,22,23</sup> These risks are exacerbated when demanding caregiving is sustained over long periods of time.<sup>24</sup> Although accessing outside formal resources for assistance would seem a reasonable solution to this problem, family caregivers seem to resist this option for care due to guilt, lack of awareness of

**Box 5. — Rewards and Affirmation**

**Satisfaction**

*“This gave me a second chance to [provide care]. She [an aunt] was almost like a mother to me; I’ve known her all of my life. And so, what I couldn’t do when my mother died then, I had another chance.” (female, niece)*

*“She is really, really failing. And my sister and I have the responsibility for caring for her. But it’s something that I really feel very good about doing.” (female, daughter)*

**Affirmation**

*“We’ve known each other for many, many years. But if anything, I would say this experience has brought us closer together.” (female, live-in friend)*

the options, or possibly lack of insight about how caregiving increases risk to their own health. A convincing reason to sustain caregiver health status is the increased possibility that one may not be able to continue care provision.

We hypothesize that caregivers cope more effectively when they have both the time and the ability to use reflection to find value in their experiences. The potential for decline in caregiver health is an important personal health risk and has recently been noted to be a growing public health concern.<sup>14</sup> The model we have constructed based on this work places the caregiver role as a latent variable, with personal reflection and self-regulation as mediators of the relationship between supportive care demands and effects on caregiver health. We plan to test the model through a self-assessment intervention to determine if improved self-regulatory methods affect caregiver health status.

Several limitations should be noted in the present work. First, the convenience sample was biased toward persons who had already sought information. It was not possible to achieve a representative sample when recruiting from the existing database. However, the study sample did include people from different geographic areas of the United States and thus provided some representation of cultural differences. Further, the cross-case approach for analysis strengthened the ability to generalize. Consistency of response was observed across the four sampled sites, and convergence of new information was obtained as the sample size increased. As with most qualitative studies, the interpretation of the transcripts may be biased by the experiences of the investigators. Consensus review and extensive discussion of thematic observations were attempts to guard against this, but another set of reviewers might interpret the data differently. Despite these limitations, interpretation of the study data is consistent with previously reported findings, thus enhancing our confidence that our conclusions are sound.

## Conclusions

Our research revealed several new topics that are potential areas for further investigation. Caregiver suffering is an undeveloped area of research, and published work on the topic usually focuses on existential issues.<sup>8</sup> Our findings suggest that caregivers suffer through the extensive role demands, role conflict, a loss of control, or feelings of being unappreciated, all of which contribute to psychic or emotional suffering. Caregiver suffering is clearly consistent with the concept reported by Cassell<sup>25</sup> whereby a “state of distress occurring when the integrity of the person is threatened, an affliction of the person not the body.” By elucidating the causes and reverberations of this suffering,

we hope to stimulate further clarification of these concepts for cancer caregivers.

A topic that merits focused research is the family’s approach to becoming either supportive or nonsupportive in the wake of caregiving requirements. This research would require an exploration of family dynamics, perhaps through group interviews, rather than a focus on the primary caregiver. Although we found these families wished to be supportive, they disagreed about who should provide certain types of care and how it might be accomplished. The primary caregiver reported feeling stressed by the competing opinions.

Another promising path of research is exploring in greater depth the concept of self-regulation. We found that role performance appeared to be affected by high personal expectations as well as expectations of the patient and family. The internal thought processes and the type of self-regulation or self control of the caregiver might have enabled some caregivers to function with less distress than others. Some types of internal dialogs might be more effective than others at helping caregivers regulate their emotional response. Does providing adequate training in medical or nursing skills mitigate the need for some of these coping strategies? Are these self-regulation strategies associated with hidden costs in terms of caregiver health status, family relationship strain, or greater experience of hardship? Could self-assessment tools help caregivers to identify topics and intervals that require greater insight? These and other questions could be productively explored in observational research. Development of future supportive interventions for family members depends on an accurate description of the challenges they face and their ideas about the help they desire.

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