

Qualitative Analysis of the Experience of Mental Fatigue of Family Caregivers of Patients With Cancer in Phase I Trials

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Purpose/Objectives: To examine family caregivers' experience of mental fatigue, identify strategies they use to manage it, and ascertain the kind of help they would like from healthcare professionals.

Research Approach: Descriptive, qualitative study that was part of a larger mixed-methods study.

Setting: Metropolitan comprehensive cancer center in the midwestern United States.

Participants: 79 family caregivers of patients with advanced cancer who were participating in phase I clinical trials.

Methodologic Approach: Caregivers completed a semistructured, open-ended questionnaire and demographic and health history forms.

Findings: Caregivers were able to define mental fatigue and give many examples of it. They reported that mental fatigue did not interfere with patient care, but that it did have a negative effect on their own self-care. They identified strategies to manage mental fatigue. They wanted more information and support from professionals.

Conclusions: The majority of caregivers experienced mental fatigue, which manifested as trouble concentrating, difficulty remembering things, and irritability. The majority worked outside of the home and had health problems of their own.

Interpretation: Healthcare professionals need to assess caregivers for mental fatigue and find ways to help them reduce mental fatigue and restore their attention. Nurses are in a prime position to mobilize resources for caregivers to effectively manage burden and reduce mental fatigue.

Despite the many advances in treating cancer, metastatic cancer remains an incurable disease and a major threat to the life of patients and the well-being of their family caregivers. For metastatic cancers, few treatment options exist. Some patients with advanced cancer seek phase I clinical trials as a means of finding hope. Phase I clinical trials are the initial step in the translation of research from the laboratory to the clinical arena. Patient benefit is not the intent of these studies, and they are typically offered to patients whose disease is refractory to standard therapies and who have few, if any, remaining treatment options (LoRusso, Boerner, & Seymour, 2010). Patients with cancer participating in phase I clinical trials are generally heavily pretreated, have a poorer prognosis, and undergo treatments that may cause serious side effects. However, many patients remain optimistic about tumor response.

The stress associated with providing care to seriously ill patients with advanced cancer can negatively affect family caregivers' quality of life (Given et al., 2004; Northouse et al., 2007). In addition, caregivers may also face a great

deal of uncertainty about outcomes of these investigational treatments. Caregiving for this unique group of patients requires juggling multiple and complex tasks and responsibilities. Family caregivers try to gather available information while also managing multiple clinic appointments and adhering to demanding treatment schedules. Major responsibilities of family caregivers include monitoring for treatment response, assessing for adverse reactions, and assisting with symptom management. The increased number and complexity of these tasks may lead to mental fatigue in caregivers.

Mental fatigue is the inability to prevent distractions from interfering with directed attention because of overuse of the neural inhibitory process (Berman, Jonides, & Kaplan, 2008; Kaplan & Berman, 2010). Although the negative effects of advanced cancer on family caregivers' quality of life have been well documented (Badr, Smith, Goldstein, Gomez, & Redd, 2015; Given et al., 2004; Vanderwerker, Laff, Kadan-Lottick, McColl, & Prigerson, 2005), very little research exists on caregivers' experience of mental fatigue. Most prior research has documented mental fatigue in patients and its negative effect on their quality of life (Cimprich & Ronis, 2003). However, family caregivers are also at risk for mental fatigue because of the multiple and complex demands they face, which compete for their attention and pose distractions. For example, caregivers of terminally ill patients demonstrated significant impairment in attention, including reduced monitoring of self-performance and concentration (Mackenzie, Smith, Hasher, Leach, & Behl, 2007). Other research findings have revealed that female caregivers of a disabled or ill spouse were at greater risk for having low cognitive functioning because of the stress of caregiving, as opposed to matched non-caregiving women (Lee, Kawachi, & Grodstein, 2004).

To concentrate and direct their attention to complex tasks, caregivers must resist distraction and redirect mental effort to the task at hand. In addition, for learning and appropriate human behavior to occur, directed attention is needed to process information into working and long-term memory. Directed attention functions as a gatekeeper for the limited capacity of human cognition and information processing, and it determines which items will occupy working memory. Executive function also requires a focus on relevant information while inhibiting irrelevant stimuli (Kaplan & Berman, 2010). The executive attention process is the active updating and manipulation of information in working memory—part of a multifaceted relationship between directed attention and working memory. Inability to avoid the pervasiveness of distractions leads to difficulty engaging in activities that require directed attention (Kaplan & Berman, 2010).

Mental fatigue can be manifested in various ways. The inability to direct attention leads to reduced effectiveness and discomfort (Kaplan & Berman, 2010). The outcome of prolonged unrested mental energy is often seen in individuals who respond to the environment with irritability, frustration, impatience, and strained social relations (Kaplan, 2001). These cognitive manifestations of mental fatigue are related to the loss of concentration and the inability to manage distractions that interfere with the person's proper train of thought. Activities under executive control are also affected, including planning, setting goals, initiating or persevering in effortful activities, and the modification of behavior (Cimprich & Ronis, 2003). When caregivers experience mental fatigue, the important tasks they perform (e.g., assistance in symptom management, medication administration, effective communication with the patient and healthcare professionals, management of household tasks) may be compromised. These tasks are more complicated for family caregivers of individuals with cancer in phase I clinical trials because of the advanced cancer and the complex trial protocols that patients and their caregivers need to follow.

Although the high demands of caregiving for patients with advanced cancer have been documented (Badr et al., 2015; Given et al., 2004; Northouse et al., 2007), little research has been done on caregivers' experience of mental fatigue and how it affects their quality of life. The purpose of this study was to examine the experience of mental fatigue in caregivers of family members with cancer in phase I trials, identify strategies they use to manage their mental fatigue, and ascertain the kind of help they would like from healthcare professionals.

Methods

Design

Because little information is available on mental fatigue in family caregivers of patients with cancer, mixed methods were used to obtain a more complete understanding of caregivers' experience (Creswell, Klassen, Plano Clark, & Smith, 2011). A descriptive, qualitative design was used to meet study aims. A semistructured, open-ended questionnaire was used to obtain information from family caregivers of patients who were participating in a phase I clinical trial. Findings from these open-ended questions are reported in this study, and findings from other surveys completed by the caregivers will be reported separately.

Sample

The sample consisted of family caregivers of patients with advanced cancer who were in the phase

I cancer program at the Barbara Ann Karmanos Cancer Institute in Detroit, Michigan. The patients provided consent for the researchers to obtain health history data from their medical record (e.g., tumor type), but they were not interviewed for the study because the focus was on their family caregivers' experience of mental fatigue. Caregivers were eligible to take part in the study if they were aged 18 years or older, were identified by patients as their primary family caregiver (i.e., provider of emotional and/or physical care), were cognitively intact (score of greater than 24 on the Mini-Mental State Examination [MMSE]), and were able to speak English. The size of the sample for this study was determined by power analysis conducted to meet the aims of the quantitative portion of the mixed-methods study (Weiss, 2014).

Procedures and Data Collection

Study approval was obtained from the Human Investigation Committee at the cancer center and affiliated universities (Wayne State University in Detroit, Michigan, and the University of Michigan in Ann Arbor). Potential participants were identified by the phase I medical team. Eighty-five family caregivers were informed about the study, along with the patients. Seventy-nine caregivers agreed to participate in the larger mixed-methods study. Three patients declined participation, making their family caregiver ineligible for the study. Two caregivers declined because of their distance from the cancer center and work obligations, and one caregiver declined because the open-ended questionnaire looked too involved.

Written informed consent was obtained from family caregivers by a research assistant or the principal investigator. Following consent, a research assistant administered the MMSE to family caregivers to exclude those with preexisting cognitive dysfunction. The MMSE was performed in a quiet room in the clinic to minimize distractions. All 79 caregivers scored 24 or greater on the MMSE, indicating they had adequate cognitive function and were eligible for the study.

Eligible caregivers completed a survey collecting data on their demographics, health history, and caregiving experience. Next, they were asked to complete a semistructured, open-ended questionnaire that consisted of 10 questions designed to explore the caregivers' definition of mental fatigue, their experience of mental fatigue, and possible self-care strategies they used to manage mental fatigue. A self-report open-ended questionnaire was used (see Figure 1) rather than personal interviews because of the large number of caregivers (N = 79) in the original study and limited research resources. All 79 caregivers provided demographic information, and 75 provided

responses on the semistructured, open-ended questionnaire.

Data Analysis

Caregivers' responses to the open-ended questions were deidentified and then copied into a Microsoft Excel® spreadsheet and imported into NVivo 10, an electronic qualitative data analysis package. The principal investigator reviewed the participants' responses repeatedly to become immersed in the data. Notes were made of the researcher's impressions of the text. Content analysis was used to group the data into patterned responses (Pope & Mays, 2006). Labels for codes were developed that represented more than one key context. Codes were sorted into categories based on associations among them. The developing categories were organized and arranged according to similar content (Hsieh & Shannon, 2005). Validity, or the accuracy of the interpretation of the data, was facilitated by coding the content based on the exact wording of family caregivers. Inter-rater reliability was obtained by having two PhD-prepared nurse researchers independently code responses. They verified the coding scheme and categories obtained by the principal investigator. Only a few discrepancies were found, and they were resolved through verification of the reported data and consensus among the raters. To strengthen the study's rigor, triangulation was applied by evaluating the results of the current study with those of the original study. In addition to the

FIGURE 1. Qualitative Questions Asked of Family Caregivers

- What does mental fatigue mean to you?
- Do you ever have trouble concentrating or remembering things? If so, can you give me an example of when this may have occurred?
- Is mental fatigue interfering with your caregiver activities?
- If so, how is mental fatigue interfering with your caregiver activities?
- How does mental fatigue interfere with your ability to care for yourself?
- Name a few distractions in your day-to-day life that may inhibit or get in the way of your ability to concentrate on activities that you want to do.
- How would you rate the quality of care you are providing?
 - Poor
 - Average
 - Above average
 - Excellent
- How do you manage mental fatigue if you are experiencing it?
- What kinds of things can the healthcare system do to decrease the mental fatigue in caregivers?
- Is there anything more that you would like to tell me about your experience as a caregiver?

qualitative analyses, SPSS®, version 21.0, and descriptive statistics were used to analyze demographic and disease data. Table 1 offers demographic information provided by the family caregivers.

TABLE 1. Sample Characteristics (N = 79)

Characteristic	\bar{X}	Range
Age (years) ^a	54.8	18–80
Characteristic	n	
Comorbidities		
None	32	
1	20	
2	13	
3	7	
4	4	
4 or more	1	
Missing	2	
Education		
High school	29	
College	32	
Graduate school	10	
Other	4	
Missing	4	
Employment		
Employed	37	
Retired	29	
Homemaker	7	
Other	4	
Missing	2	
Ethnicity		
Caucasian	65	
African American	8	
Asian	2	
Other	2	
Multiracial	1	
Missing	1	
Gender		
Female	50	
Male	29	
Income (\$)		
30,000 or less	13	
30,001–50,000	11	
50,001–75,000	16	
75,001 or greater	25	
Missing	14	
Most frequent comorbidities^b		
Hypertension	20	
Arthritis	17	
Hypercholesterolemia	10	
Diabetes	5	
Gastroesophageal reflux	5	
Hypothyroidism	5	
Relationship to patient		
Spouse	46	
Daughter or son	10	
Other relative	10	
Friend	7	
Sibling	6	

^a Two caregivers did not provide a response.

^b Participants (n = 45) could select more than one response to this question.

Results

Caregivers' Characterization of Mental Fatigue

Analysis of the 75 caregivers' descriptions of their mental fatigue resulted in four subcategories: (a) their definition of mental fatigue, (b) problems with memory and concentration, (c) effect on their caregiving role, and (d) interference with own self-care. Some caregivers gave more than one response to each of the open-ended questions. Specific quotes obtained from caregivers pertaining to each of these areas are shown in Figure 2.

When asked about their definition of mental fatigue, a majority of the caregivers (n = 72) provided a definition. Some of the more common definitions caregivers reported were feeling tired (n = 19), having difficulty concentrating (n = 17), and feeling overwhelmed by their circumstances (n = 10). The family caregivers were able to clearly describe what mental fatigue meant to them.

Another major subcategory that emerged from caregivers' characterization of mental fatigue was having difficulty thinking and remembering things. Thirty-four of the caregivers acknowledged difficulty in this area.

The caregivers were asked if mental fatigue hindered their caregiving or the quality of care they provided. A majority (n = 58) stated that mental fatigue did not interfere in their caregiver role, and 15 said that it did interfere. Fifty-seven caregivers rated their care as above average to excellent, whereas 15 described their quality of care as average. One caregiver said it was poor.

The caregivers were also asked if mental fatigue interfered with self-care. The majority of caregivers who responded to this question (n = 25) reported that caregiving had an impact on caring for themselves, particularly with routine health activities. The kinds of routine self-care activities they described were feeling too tired to do things for themselves (n = 6), having no time for exercise (n = 6), paying less attention to grooming needs (n = 5), forgoing their own health care (n = 4), and making poor diet choices (n = 4). A small set of caregivers reported having less time to spend on social activities (n = 3) and being unable to feel motivated (n = 3).

Management of Mental Fatigue

A second major category of responses obtained from the qualitative data was how caregivers manage mental fatigue. The subcategories in this area were (a) self-care strategies and (b) support in the caregiving role.

One of the most frequently mentioned strategies was using sleep (n = 24) as a means to manage mental

fatigue. This strategy was followed by exercise (n = 17), talking concerns over with family or friends (n = 9), and reading (n = 8). Other less frequently noted strategies included self-medication (n = 5), watching television (n = 5), and engaging in other activities, such as knitting, lighting a candle, and praying.

The caregivers were asked to identify ways the healthcare system could assist them in managing mental fatigue. Fewer caregivers provided a response to this question (n = 49). Of those who did respond, the most common suggestion was to have more social support available (i.e., social worker, group, and individual

FIGURE 2. Mental Fatigue Characterization and Caregiver Quotes

MEANING OF MENTAL FATIGUE

- “Not being able to concentrate”
- “Not being able to make decisions easily”
- “Can’t think clearly”
- “Can’t focus on what you need to focus on”
- “Exhausted by trying to remember everything, do everything”
- “Being irritable and not having patience”
- “Feeling lethargic and uncomfortable”
- “Worry about what is happening and anger that I cannot change the process”
- “Feeling overwhelmed when something is added to an already full plate”
- “Making mistakes on everyday tasks”

EXAMPLES OF MENTAL FATIGUE

- “I will go to do something, and, on my way, I will forget.”
- “My short-term memory has become basically nonexistent.”
- “Not paying attention to the task at hand”
- “Turn pages in a book but don’t know what the words meant”
- “Last month, it took three weeks to remember to call a repairman.”
- “I have had trouble remembering to do basic things, like feed my dogs.”
- “I was so distracted and busy, I forgot an appointment I had made earlier for myself.”

HOW MENTAL FATIGUE INTERFERES WITH CAREGIVING

- “Trying hard to get all the jobs of the day done”
- “I forget that I said I would do something.”
- “I find I must double-check all appointments now.”
- “Just feel like there’s so much to take care of that’s so important, feel like I may not be doing my best”
- “When I feel tired and overwhelmed, it can make me short-tempered.”
- “I grind down and have less zeal.”
- “I don’t devote the amount of time to leisure-time activities with him that I should.”
- “Feeling paralyzed, unable to concentrate on anything else but cancer”

HOW MENTAL FATIGUE INTERFERES WITH SELF-CARE

- “Sometimes I’m too tired to enjoy activities.”
- “Often I am too tired to work out or eat regularly.”
- “Putting off things for yourself, like going to the dentist”
- “I don’t have the energy to stay in touch with others as I should.”
- “I feel uninterested in my health.”
- “No time or energy to take care of me”

“Personal care, clothes, grooming, etc.”

“I forget to take medication, not doing my exercises. I am diabetic and not following diet as close as I was before.”

DISTRACTIONS CONTRIBUTING TO MENTAL FATIGUE

- “Phone rings a lot”
- “I also watch two granddaughters age[d] 6 and 7. So I need to schedule my time carefully. After cleaning, I am the last one to get care.”
- “Constant bills, keeping our home running smoothly”
- “Internet, video”
- “The worry about what could happen to husband”
- “Frequent switches from one incomplete activity to another”
- “Right now, we are in the process of refinancing our home, being audited by the IRS, planning a wedding for one daughter [and] a mission trip for the other daughter, doing a clinical trial, working full-time.”
- “Phone calls to doctors, episodes of his pain, filling oxygen tanks, medication management”
- “Our 3-year-old son, housework, yard work, errands, doctor appointments, our son’s appointments”
- “My upcoming wedding, how my mom is feeling that day, upcoming doctor appointments, work, feeding my family”

MANAGEMENT OF MENTAL FATIGUE

- “Just stopping and focusing on problems fully”
- “I just plug along and get through it.”
- “Walk my dog, light a candle, talk with someone”
- “Try to listen to soothing music, have a coffee break”
- “Alcohol”
- “Sleep, exercise, nap, talk it out”
- “Turning off my phone”
- “Delegate more at work”

HOW THE HEALTHCARE TEAM CAN HELP DECREASE MENTAL FATIGUE

- “Perhaps make a social worker available.”
- “More information”
- “Insurance claim processing”
- “Support groups online and in person; I think it would help to talk to others in the same place.”
- “Listen to the caregiver’s assessment of what is happening to the patient. Include us in the plans.”
- “Usual support groups, online support, nurse navigators, yoga or other ways to decrease stress while patient is getting treatment”
- “There is a lot of support offered, but it needs to be reoffered and often.”

resources) (n = 12), and only a few reported being satisfied with the support they received (n = 4). Support was followed closely by needing more information (n = 10), involving the caregiver in discussions (n = 5), and providing assistance with insurance forms (n = 5).

Discussion

The experience of mental fatigue can cause frustration to an already overloaded neural system. The majority of caregivers in this study often worked outside the home as well as helped support the patient with appointments while balancing their own medical needs. Caregivers were able to define mental fatigue, using key terms such as *difficulty concentrating* and *feeling tired*. Caregivers' definitions of mental fatigue were consistent with the definition in studies that explained mental fatigue as the waning ability to inhibit distraction from directed attention (Berman et al., 2008) because of multiple distractions competing for attention. Mental fatigue occurs when the individual is aware of the higher level of effort needed to pay attention, which is consistent with the statements made by caregivers in this study.

In this study, most caregivers reported that mental fatigue did not interfere with their ability to provide care, and the majority rated the care they provided as above average. Of particular interest is that most caregivers perceived their being able to provide excellent care in spite of having mental fatigue. The reports from these caregivers provide a distinctly different perspective from the quantitative findings by Mackenzie et al. (2007), who found, in their study of caregivers of patients receiving palliative care, that caregivers had lower scores on measures of directed attention when compared to noncaregiver controls. The current study suggests that, even while experiencing mental fatigue, caregivers perceive that they are providing quality care to the patients, even though their own quality of self-care suffers. Additional research is needed that compares caregivers' perceptions of fatigue, objective measures of mental fatigue, and quality-of-care indicators. In this study, caregivers gave higher priority to patients' needs than their own health needs, and they worked hard to provide high-quality care despite their own mental fatigue. However, caregivers in this study did experience symptoms of mental fatigue consistent with the caregivers of patients receiving palliative care in the study by Mackenzie et al. (2007). In addition, Mackenzie et al. (2007) found that caregivers experienced the symptoms of irritability and short temperament, which are characteristic of mental fatigue.

Although study participants did not view mental fatigue as interfering with caregiving, they did recognize that it interfered with self-care. This finding is similar to the results from a study by Beesley, Price, and Webb (2011), who examined health behavior change in caregivers of family members with ovarian cancer. More than half of the caregivers in that study reported a worsening in their self-care, less physical activity, weight gain, and poor food choices. In addition to less self-care, more than half of the caregivers of patients in the current study had at least one comorbid condition, and close to one-third had more than one. In addition, researchers have found that caregiving can lead to chronic stress in caregivers and negatively affect caregivers' mental and physical health outcomes (Schulz & Sherwood, 2008). These three factors—poorer self-care, comorbidities of their own, and chronic stress—all place family caregivers at risk for poorer health outcomes.

Caregivers were able to identify strategies to manage their mental fatigue. A large percentage of the caregivers used rest to manage mental fatigue. This may be beneficial if caregivers are fully able to take their minds away from what is inhibiting directed attention. Sleep may provide some recovery, but it is not all that is required. Other ways to conserve mental energy and to help combat mental fatigue exist. Barsevick et al. (2004) conducted a randomized clinical trial with patients with cancer receiving treatment who had complaints of fatigue. The information provided to these patients consisted of pacing activities, setting priorities with cognitive restructuring, engaging in active problem solving, and participating in patient and family education. Caregivers in the current study seldom reported using these types of strategies, suggesting that they might benefit from more education about them.

Research on caregivers indicates that obtaining information is one of their needs (Stenberg, Ruland, & Miaskowski, 2010). Caregivers felt responsible for obtaining information on their own in addition to the information that they received in the clinic. When an unexpected event occurred, it prompted caregivers to seek and gather information. This process of obtaining information was described as beneficial and an integral element of providing care to be better prepared for the caregiver role. Healthcare professionals need to be more aware of caregivers' need for information and provide this information in an easy-to-understand manner because of caregivers' difficulty with concentration and memory.

Another need expressed by caregivers was for support. Caregivers reported that they wanted more opportunities for social support from professionals and from peers. Caregivers are forced to adjust to illness progression, impending loss, decreased intimacy,

Knowledge Translation

- Family caregivers of patients with advanced cancer are able to describe mental fatigue and report its symptoms, including irritability and difficulty concentrating.
- Mental fatigue can have a negative effect on caregivers' self-care and health.
- Clinicians need to be aware of symptoms of mental fatigue in caregivers and provide them with information and support to help them manage mental fatigue.

the accumulation of losses, and revised expectations that may lead to sadness, anger, disappointment, and hopelessness (Given et al., 2004). Directing attention to these emotions leaves less attentional capacity for the individual to attend to the task at hand (Baddeley, 2007). Therefore, preoccupation with worry and potential threat may manifest as mental fatigue (Stark & Cimprich, 2003). Obtaining support from professionals, as well as from peers who are undergoing similar experiences, may serve to mediate some of the stress that caregivers are experiencing.

Limitations

This study used a convenience sample and, because of the qualitative nature of the study, findings cannot be generalized. Another limitation was that most caregivers were Caucasian, college-educated, and middle-aged female spouses. Even so, this qualitative study was conducted with a fairly large sample of caregivers of patients with advanced cancer, resulting in rich data that can be used to further understand the mental fatigue experienced by family caregivers of patients with cancer in a phase I clinical trial. Reports of mental fatigue among family caregivers reflect the caregivers' subjective perceptions of their caregiving experience. Additional research is needed to compare subjective and objective indicators of mental fatigue. Although caregivers perceived that their caregiving was above average, more research is needed to determine if their perceptions are associated with objective indicators of high-quality care in the home.

Implications for Practice

Although caregivers experienced mental fatigue, they perceived little interference with their ability to provide care. Despite the presence of mental fatigue, caregivers reported that they performed above average in their role but often compromised their own health to provide high-quality care. This finding suggests a need for healthcare professionals to give attention to the healthcare needs of family caregivers. In ad-

dition to assessing the needs of the patient, healthcare professionals need to assess the health practices of caregivers and encourage them to attend to their own health so that they can continue to provide care to the patient.

Caregivers also wanted more information and social support from healthcare professionals. Healthcare professionals need to provide information to caregivers about the nature of the patient's illness and its treatments and inform them about resources where they can obtain support. Although many caregivers may not be able to attend support groups, providing them with reliable websites or community resources may be alternative ways for them to obtain support. Because caregivers may have difficulty processing large amounts of information at one time, healthcare professionals need to provide tailored information to address the unique needs of particular caregivers at the individual level over a more extended period of time.

Healthcare professionals can help caregivers manage mental fatigue in a number of ways. Some research indicates that using restorative activities and attending to conservation of attention can help reduce mental fatigue. For example, Cimprich and Ronis (2003) found that newly diagnosed patients with breast cancer who participated in an environmental intervention (e.g., spending time in nature) had higher scores on measures of attention than patients in the control group who did not receive the intervention. Caregivers also can be encouraged to try to conserve their directed attention by minimizing excess noise and distractions in their environment, decreasing time constraints, streamlining large tasks into smaller objectives, and providing structure to daily routines. These are some of the strategies that healthcare professionals can use in clinical practice to help caregivers manage mental fatigue. Future research needs to examine the efficacy of interventions to reduce mental fatigue in family caregivers.

Conclusion

The current study provided evidence that caregivers experience mental fatigue. This fatigue may affect the quality of life of patients with cancer and their family caregivers. Although caregivers reported a number of ways they try to manage mental fatigue, healthcare professionals need to attend more to the multiple demands on family caregivers and assist them in managing mental fatigue.

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