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Patients' Experiences of Being a Burden on Family in Terminal Illness

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Abstract

Studies of persons with chronic and life-threatening illness have revealed a fear of being a burden on family. The purpose of this case study was to explore that concern in-depth in three persons with different terminal illnesses. Participants were part of a larger study of end-of-life decision making and were selected for this study because their illnesses are characterized by a steady decline in health (amyotrophic lateral sclerosis), a rapid decline (stage IV lung cancer), or an uncertain trajectory of decline (advanced heart failure). Content analysis of their interviews resulted in four themes: managing the burden, spirituality, supportive relationships, and planning for the future. Themes contained specific categories of thoughts, feelings, and actions related to fear of being a burden. These themes should be explored in greater depth in future larger studies of persons with terminal illness.

Keywords

cost of illness; end of life; family relationships; qualitative analysis; terminally ill

In many ways, burden and the end of life are inextricably linked. One of these links is the burden of caring for a terminally ill loved one. An under-recognized aspect of care burden at the end of life is how dying persons experience and manage the fear of being a burden on their families. This burden can have emotional, physical, social, and financial aspects. Patients with terminal illnesses face grief and fear not only for their own future but also for their families' future. These concerns over how their illness will affect their loved ones may influence how they seek care, what decisions they make about their care, and even how they experience dying. The purpose of this study was to further explore the concept of fear of being a burden on family from the perspective of the person in the terminal stage of illness.

REVIEW OF LITERATURE

How healthcare providers can best promote quality end-of-life (EOL) care and support EOL decision-making is currently a subject of intense interest. The American Geriatrics Society¹ demonstrated its belief in the importance of this issue by disseminating a list of quality domains they feel should be the focus in EOL care. These broad categories include physical and emotional symptoms, support of function and autonomy, advance care planning, family burden, and patient and family satisfaction. The Institute of Medicine (IOM)² built on this list to generate categories of outcomes that should be measured in assessments of the quality of EOL care. Two of these categories are patient perceptions of care and psychosocial well-being and functioning. The domains identified by the IOM and American Geriatrics Society do not explicitly mention burden as perceived by the patient, but it is likely to be a factor in some or all of them. Areas that burden is most likely to influence are emotional symptoms, quality of life, and patient satisfaction. The 1997 IOM report "Approaching Death: Improving Care at the End of Life" took a comprehensive look at the current state of the care system at the end of life and identified areas needing improvement and further research. Several federal agencies have created EOL research initiatives based on the IOM's recommendations, including the National Institute for Nursing Research, the National Institute on Aging, and Centers for Medicare and Medicaid Services.

Studies of persons with serious illnesses have revealed that being a burden on family is a significant concern about the end of life. In one study,³ persons in long-term care, patients receiving chronic dialysis, and patients with HIV-related illnesses expressed concern about the burden on others that their illnesses would cause. Specific areas with the potential for burden were physical care, witnessing their death, and substitute decision-making. A national-level survey⁴ asked several hundred Veterans Administration patients with advanced chronic illnesses, bereaved family members, and physicians and providers involved in EOL care to rate the importance of 44 attributes that defined a good death. Wanting to feel that they were not being a burden on family or society was one of the eight factors rated as important by most patients but not seen as important by most of the doctors. Canadian researchers interviewed hospitalized adults aged 55 years and older with a 50% probability of survival at 6 months along with their family members to find out what qualities mattered most to them in EOL care. Fifth highest on a list of 28 qualities was the wish to not be a physical or emotional burden on family, with 93% of respondents saying that this was very or extremely important to them. There were significant differences in ratings of importance of items among patient subgroups, which prompted the study's authors to recommend that EOL care be more customized to what matters to the individual patient and family.⁵ Not wanting to be a burden is a concern that patients with varying characteristics have expressed when asked about their EOL wishes.

Only one study⁶ thus far has conducted an in-depth exploration of the fear of being a burden among patients with serious illnesses. Open-ended interviews were conducted with patients who had advanced cancer and had expressed concern about being a burden on their caregivers. The investigators identified three categories of experiences related to self-perceived burden. The first category was "concern for others" and included actual burdens that patients worried about placing on loved ones. "Implications for self" comprised the emotional and psychological outcomes of being a burden, including guilt, sadness, and self-blame. The third category consisted of actions that ill persons took in hopes of "Minimizing the burden." These actions involved concealing difficulties, being active in their own care, making preparations for death and the aftermath, using avoidance, and even developing acceptance. This phenomenological project enabled the group to propose a new definition for self-perceived burden, which is "empathic concern engendered from the impact on others of one's illness and care needs, resulting in guilt, distress, feelings of responsibility, and diminished sense of self."^{6(p425)}

Fear of being a burden has emerged as a consideration for patients with chronic illness who wish to discontinue treatment. In a series of interviews⁷ with long-term dialysis patients who decided to stop receiving treatment, it was found that not wanting to be a burden on others was a major factor in their decision. In another study,⁸ surveys given to inpatients and outpatients nearing death revealed several psychiatric issues that were negatively correlated with the will to live. One of these issues was a feeling of being a burden on others. Some physical symptoms, such as pain and nausea, which are repeatedly emphasized in quality of EOL care, were not significantly associated with a lack of will to live. Patients may overestimate the amount of burden their illness causes. Sixty-nine patients with amyotrophic lateral sclerosis (ALS) and their corresponding family caregivers separately rated items on distress and burden using 10-point Likert scales. Patients estimated the burden experienced by their caregivers to be higher than the caregivers' ratings of their own burden (6.8 versus 5.0; $P < 0.05$).⁹

An aspect of the fear of being a burden that is not well understood is how persons with terminal illness view and manage being placed in the position of potentially being a burden on others. To address this deficiency, the purpose of this study was to explore the concept of being a burden on others in persons with terminal illness. This study differed from previous studies that queried individuals with serious—but not terminal—illness. Subjects were chosen regardless of whether they had mentioned the fear of being a burden in previous interviews. This was done in hopes of understanding how some individuals may successfully depend on others for assistance in their care without experiencing the fear of being a burden.

METHODOLOGY

Sample

The three-person case report study described in this article is part of a larger study of EOL decision-making in patients in the terminal stages of cancer, ALS, and heart failure.¹⁰ To be included in the main study, patients had to be at least 18 years of age and within 8 weeks of being diagnosed with ALS or advanced cancer or within 8 weeks of being hospitalized for class III-IV congestive heart failure (CHF). Cancer patients included those with nonresectable, non—small cell lung cancer or stage III or IV pancreatic or stage IV liver, colon, or gastric cancer. These three diseases were chosen because they represent three unique trajectories of illness. They are characterized by a rapid (advanced cancer), gradual (ALS), or unpredictable (CHF) decline in health to death.

Procedures

The study was approved by the Johns Hopkins Medicine Institutional Review Board. In the main study, patients were interviewed at baseline and every 3 months for 2 years or until death using quantitative surveys. A subset of patients was interviewed using open-ended qualitative interviews to provide context for the survey data. After several patients mentioned fear of being a burden on family during the quantitative surveys, authors selected one patient from each of the three disease groups for a one-time follow-up in-depth interview about fear of being a burden to explore this concept. This study reported on these three interviews. Because the interviews were conducted toward the end of the main study, all patients were at study time nine, which was 24 months after enrollment. Patients were selected to provide diversity in gender and race.

Interviews began with broad questions about the illness experience and then focused on role responsibilities and activities of daily living that the subject could no longer carry out independently because of illness. Subjects were asked whether anyone helped with or took over some of these activities and the extent to which the subject worried about no longer being able to do these things or being a burden on family. With the permission of the patient,

interviews were audio-taped and then transcribed by the interviewer. Authors read all three transcripts and used a qualitative description method described by Sandelowski to analyze the data.¹¹

Analysis

The first phase of analysis involved the use of content analysis using the constant comparison method,¹² which involves coding the text into categories with words or phrases used by the subjects. These categories were then combined under themes that extend across the cases. Sandelowski characterized qualitative description as a method that is more interpretive than quantitative description but less interpretive than other qualitative methods, such as phenomenology and grounded theory. In qualitative description, investigators remain close to the data and often choose words that subjects used to describe the phenomenon under study.

FINDINGS

Of the three subjects selected for interviews, one was an African American man with lung cancer, one was an African American woman with advanced heart failure, and one was a white woman with ALS. All three subjects were still able to walk short distances unassisted or with minimal assistance at the time of the interview. Although two of the three patients experienced shortness of breath on exertion, none of the subjects used oxygen. All three subjects had a family member caregiver who lived with them. Categories of the experience of being or anticipating being a burden on family are summarized in Table 1 under four themes: managing the transition, spirituality, supportive relationships, and planning for the future. Managing the transition referred to efforts used by the subjects to minimize the burden of their care and maintain a positive outlook as their health declined. Spirituality was the transcendental meaning that subjects attached to their illnesses. Supportive relationships were the ways their illness affected their personal relationships and how these relationships shaped their views on illness and its burden on others. Planning for the future was the way subjects worked to control and understand the course of illness and its effects on caregivers.

DISCUSSION AND IMPLICATIONS FOR FUTURE RESEARCH

Three categories occurred in all three subjects: being satisfied with healthcare providers, having a high level of emotional and social support from family, and accepting a move to a nursing home if necessary. The satisfaction with healthcare providers seemed to focus on the information and support that the physician and other team members provided from the time of diagnosis to the present. The white female subject was the only one who expressed a desire for more information regarding the prognosis of her illness. Other investigators have reported patients' desire for more information. In a study of patients with terminal illness, 23% of patients in the usual care group expressed a desire for more information about their condition from healthcare providers.¹³ It may be that this need for information, particularly on prognosis, is important for patients to be able to estimate when their care may become too burdensome for their family. Future studies should examine how patients' perceptions of their illness trajectory influence their fear of being a burden on the family.

Patients described several strategies to minimize the burden on their caregivers and maintain a positive attitude as their health declined. Accepting support from friends and sharing tasks with a spouse were two ways in which the male subject helped his wife with the burdens of his illness. Focusing on their remaining abilities and roles and reminiscing about the satisfaction with their former roles, such as parenting young children who were now grown, were ways in which the subjects strove to maintain a positive attitude about their limitations. These strategies to minimize burden and maintain a positive attitude were creative and satisfactory to the subjects. Interventions that incorporate these approaches should be developed and tested on a

larger population. The fact that all three subjects expressed a plan to be admitted to a nursing home despite reporting a high level of emotional and social support from family suggests that this is a strategy to avoid family burden. This finding is consistent with previous reports of patients at the EOL who wish to lessen their families' burden of caring for them.³⁻⁵

Three of the four categories that occurred with the two women subjects but not with the male subject involved the theme of supportive relationships. In two of these categories, the women described their illnesses as a learning opportunity for the family and one by which the family had become more closely united. In the third category, the women said their experiences in caring for other family members helped them accept being cared for by others. One patient commented that her daughter would care for her in the same way that she had cared for her mother. The fact that women are the caregivers for ill family members more often than men has been shown in other studies.¹⁴ The idea that women become caregivers by either observing or hearing about the caregiving provided by other women in the family is consistent with Bandura's Theory of Self-Efficacy.¹⁵ In this theory, an individual's self-efficacy or confidence in mastering a behavior (in this case, caregiving) is influenced by previous performance of the desired behavior or positive feedback from others that one can successfully perform the behavior. Perhaps the fear of being a burden on family is less intense in women who have been family caregivers themselves. They may see being cared for as a natural progression of life events or an opportunity to teach the next generation this important skill. Further study is needed to determine whether there are important differences between men and women in the way they perceive the burden their care places upon the family.

The two black subjects discussed spiritual issues related to their illnesses. Both said that faith in God and belief in salvation kept them from becoming distressed about their illness. The black man who had lung cancer and a long history of smoking explained that it was important to him to acknowledge that his lung cancer was caused by his smoking and was not an act of God. Other studies have demonstrated a high degree of religious coping when facing medical or psychiatric illness. This is especially true for older adults and African Americans.¹⁶ A patient's attribution of the illness may be an important factor in understanding the way in which he or she views the illness and the way of managing the burden that the illness causes within the family. Also, future study should explore the use of spiritual coping with the fear of being a burden on others to determine whether there are cultural differences by race in the use of this coping mechanism.

The subjects' access to healthcare may have influenced their attitudes about being a burden on their family. One of the female subjects explained that she was grateful that she was able to purchase long-term care insurance shortly after being diagnosed with her illness. She had feared being ineligible for such coverage but was able to take advantage of a one-time offer for this type of coverage without the requirement of a health examination. Future health policy initiatives should take into account the psychological distress caused by patients' concerns of being a burden on the family and the financial and psychological support that benefits such as long-term care insurance can provide to families.

CONCLUSION

Patients who have terminal illness with a rapid, gradual, or unpredictable rate of decline share common concerns about being a burden on their families. Nurses and other healthcare providers should assess terminally ill patients to determine how they manage the transition from being independent to relying on family for their care. Findings from this study have suggested that patients use various strategies to make this transition easier and manage the fear of burdening their families. Strategies included accepting the support of friends and willing caregivers, maintaining spiritual beliefs, and making plans for their future care needs. Further study is

needed to explore which strategies are most effective in decreasing patients' worries and fears about being a burden on their families.

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Table 1

Themes and Categories Surrounding the Experience of Being a Burden on Family

Themes and Categories	Black Male in 70s with Cancer	Black Female in 80s with CHF	White Female in 50s with ALS
Managing the Transition			
Accepting material support from friends	X		
Sharing tasks with spouse to maintain role	X		
Focusing on remaining abilities		X	X
Reflecting on roles fulfilled		X	
Focusing on emotional and social roles remaining			X
Maintaining satisfactory relationships with healthcare providers	X	X	X
Sustaining Spirituality			
Having faith in God and belief in salvation	X	X	
Attributing cause of illness to self rather than God	X		
Maintaining Supportive Relationships			
Receiving emotional and social support from family	X	X	X
Believing care is not a burden if giver is willing		X	
Viewing illness as learning opportunity for family		X	X
Having family cohesiveness before illness and at present	X	X	
Believing a family responsibility is to care for ill members			X
Seeing relationships grown closer since illness		X	X
Having experience of caring for ill family member(s)		X	X
Planning for the Future			
Accepting move to nursing facility	X	X	X
Having long-term care insurance			X
Needing more information on health trajectory from healthcare providers			X
Feeling that illness allows letting go of some future worries			X
Reflecting on own fears of being a burden			X