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Linda D. Scott
Grand Valley State University

Cynthia Arslanian-Engoren
University of Michigan - Ann Arbor

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The Decision to Care: A Life-Altering Experience

Linda D. Scott, PhD, RN
Cynthia Arslanian-Engoren, PhD, RN, CNS

The decision to care is often mandated by unavoidable alterations within the family, requiring a primary caregiver. One population that often requires complex community-based care is survivors of prolonged mechanical ventilation (PMV). This investigation explored the choices and challenges of eight family caregivers of PMV survivors. Using content analysis, several mutually exclusive themes emerged describing the caregiving experience as a physically exhausting, emotionally stressful decision that required a lifestyle change to actualize. Even with the burdensome challenges and overwhelming nature of the caregiving experience, participants identified positive rewards associated with the caregiving role. Home health care nurses are in a unique position to facilitate an effective transition to the caregiving role, serving as conduits for caregiver education and skill acquisition and advocating for the development of vital infrastructures that will provide resources, reassurance, and respite from burdensome caregiving challenges.

able alterations within the family or social structure that require an individual to assume a family caregiving career (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). Although not a new occurrence, an aging population, combined with technological innovation and spiraling health care costs, has influenced the complexity of the caregiving experience. Of the estimated 54 million Americans who are involved in some form of family caregiving (National Family Caregiver Association, 2000), 15% of these individuals provide direct care for a seriously ill or disabled family member (Family Caregiver Alliance, 2001). One population that often requires complex community-based care is survivors of prolonged mechanical ventilation (PMV; Engoren, Arslanian-Engoren, & Fenn Buderer, 2003).

The use of tracheostomy for PMV following a life-threatening event is a recognized treatment modality in chronic respiratory failure. Once these individuals have been successfully liberated from PMV, they frequently transition directly to the home environment, requiring a caregiver to assume responsibility for their physical, emotional, and technical health care needs. Yet little is known about the physical and psychological impact on

Typically, individuals have the opportunity to choose their professional careers. However, the decision to care is often mandated by unavoid-

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individuals who assume caregiving roles for this technically complex population.

An initial examination found that family caregivers of PMV survivors were able to manage the complexity of care. However, individuals who assumed caregiving roles perceived little preparation or forewarning for the role, experienced physical and mental challenges, and frequently made personal sacrifices to fulfill caregiving responsibilities (Scott & Arslanian-Engoren, 2002). In other technologically dependent populations, caregivers have reported frequent change, uncertainty, and unpredictability (O'Brien, 2001; Scott, 2001), as well as insufficient preparation for the role (Scott, 2000, 2001; Smith et al., 1998) and strained interpersonal relationships (O'Brien, 2001).

Furthermore, feelings of worry, anxiety, and fear concerning the care recipient's condition and ability to learn the intricate aspects of providing technological care have been identified as contributing factors to caregiver strain (Ferrario, Zotti, Zaccaria, & Donner, 2001; Scott, 2000, 2001; Smith et al., 1998). Despite perceptions that caring for technologically dependent care recipients is financially burdensome, socially confining, and psychologically distressing (Scott, 2001), family caregivers were still able to describe positive aspects of the role (Scott, 2001; Sevick et al., 1994), deriving personal gratification from caregiving (Scott & Arslanian-Engoren, 2002).

Assuming complex community-based caregiving may sacrifice the caregivers' mental and physical well-being. Before nurses can prepare individuals for newly acquired roles as family caregivers and implement strategies that will maximize positive outcomes for patients and family members, the nuances particular to the caregiving experience must be disentangled. Therefore, the purpose of this investigation was to explore the choices and challenges of family caregivers for PMV survivors from their personal experiences.

METHOD

Design

A large descriptive study was conducted to (a) examine functional health status outcomes and experiences of patients following tracheostomy for PMV (Engoren et al., 2003), (b) identify factors that contribute to successful liberation from PMV (Arslanian-Engoren & Scott, 2003), and (c) explore the family

caregiving experience for PMV survivors using triangulated methodology. These findings represent the qualitative results of family caregivers who had primary responsibility for the physical, emotional, and technical care of the recipient at the time of the study.

Procedure

To elucidate the caregiving experience, this study sought to interview primary caregivers of individuals who had been liberated from PMV. Of the 15 family caregivers that participated in the quantitative phase of the study (Scott & Arslanian-Engoren, 2002), 8 agreed to participate in the qualitative interviews.

A consent form was mailed to each participant to obtain written permission to conduct and audiotape the interview to ensure accuracy and integrity of the data. All of the interviews were conducted by telephone. At the end of the interview, the caregiver participants were each mailed a certificate of participation and a \$10.00 honorarium. This research procedure was approved through a university institutional review board.

A preestablished set of questions was used to guide the interview process and to establish consistency. In particular, each participant was asked to respond to the following questions: (a) What was the caregiving experience like for you? (b) What were the expectations and realities of the caregiving experience? (c) What were the rewards and challenges associated with caregiving? and (d) If given the opportunity, what advice should be given to a new caregiver?

Content Analysis Procedure

The content analysis procedure described by Morse and Field (1995) was used to analyze the qualitative interviews. The collective experience of the eight caregivers composed the unit of analysis. The narrative descriptions were transcribed verbatim and read multiple times to identify major ideas, phrases, and statements. A coding scheme was developed to organize the data and to identify emerging themes. Once the initial themes were identified, supporting statements were reviewed to ensure that the derived themes reflected the essence of the caregivers' experiences.

Participants

All caregivers were females, ranging in age from 37 to 70 ($M = 54.12$, $SD = 10.5$). On average, the participants provided at least 9 hours of daily care to a PMV survivor (range = 1.50 to 24 hours) and often combined

TABLE 1
Participant Characteristics

Caregiver		Recipient		Daily Caregiving	
Age	Sex	Sex	Relationship	Hours	Employed
37	Female	Male	Grandfather	1.5	Yes
44	Female	Male	Fiancé	2.0	Yes
49	Female	Male	Son	8.0	Yes
54	Female	Male	Husband	10.5	Yes
57	Female	Male	Husband	8.0	Yes
60	Female	Female	Sister	24.0	Yes
62	Female	Male	Husband	12.0	No
70	Female	Male	Husband	8.0	No

caregiving with full-time employment ($n = 6$). Care provision spanned from 3 months to 3.5 years, with 71% providing care 8 months or less ($n = 5$). Participant characteristics are summarized in Table 1.

RESULTS

Several mutually exclusive themes emerged from the narrative descriptions of the participants. A summary of the interview questions and derived themes are presented in Table 2.

Caregiving Experience

Participants described the caregiving experience as a physically exhausting, emotionally stressful experience that required a lifestyle change to actualize. Caregivers reported being very exhausted while caregiving and that most of the time, they “don’t feel rested.” One participant indicated the caregiving experience had “taken its toll” on her, saying that “I think I have aged 40 years” since assuming the role. Additionally, participants described caregiving as a “lonely, lonely” experience that “took a toll on [them] emotionally.” One participant indicated that the experience “made me think more about do I want to do this the rest of my life?” Caregivers described feeling as if they wanted to cry and that they “worried that [they] might, the first few days, do something wrong” while providing care to their loved one. One participant indicated thinking that she had “adjusted okay . . . and some little thing happens and I think I can’t handle this anymore.”

Since assuming the caregiving role, participants reported missing their “footloose and fancy-free days” and having to “modify [their] behavior” to accommo-

TABLE 2
Summary of Caregiving Themes

Question	Themes
Caregiving experience	Physically exhausting Emotionally stressful Required lifestyle change
Expectations and realities	Similar to expectations Different from expectations
Rewards	Recovery Having loved one at home Gratifying experience
Challenges	Emotional toll of providing care Change in family dynamics
Advice to new caregivers	Need for adequate preparation Ask for help Lots of love Take one day at a time Treat person with dignity Take care of self

date the needs of their loved one. One participant said “I lived by myself [before this happened] and kind of came and went as I pleased . . . now I have to come [home] every night . . . my time is not my own anymore.” Similar sentiments were echoed by another participant who indicated “I think what bothers me more than anything is having to leave the house and going to all these doctors’ appointments and therapy. Just for a day, I want to stay home and do what I want to do.”

Expectations and Realities

Next, participants were asked if the reality of assuming the role was similar or different from what they expected. Three of the participants indicated that the role was “like I thought it would be,” whereas four of the participants indicated that it was “more overwhelming” than expected. One participant indicated that their loved one’s “recovery was slower than I had hoped for or expected,” whereas another said that assuming the role was “a big change . . . we don’t leave the house, only mostly for medical appointments . . . so I just sort of became a shut-in, too.”

Rewards and Challenges

When participants were asked to describe the rewards and challenges associated with providing care, three rewards and two challenges were described. The recovery of their loved one, having them at home, and a

sense of gratification were viewed as rewards, whereas the emotional toll of providing care and the change in family dynamics were identified as challenges.

"Watching her get better and better, that really was my own reward," said one participant. Others indicated that "just to see him come back from almost dying" was a rewarding aspect of providing care. Participants reported that having their loved one "back in the household again instead of being gone" was a "miracle." They were "grateful" for "just knowing he's there in the middle of the night." One participant described the experience as "very gratifying, fulfilling. . . . It was fun to do because I knew I was helping somebody." Similarly, others described feeling good about what they were doing, stating it felt "good to care for him."

Participants also described the challenges of caregiving as having to handle "the emotional end of it" and worrying "something else is going to happen." Participants expected their "life to be a bit more normal" than what they experienced while caregiving and that "that was an adjustment." Alterations in family dynamics that occurred as a result of their caregiving role included "not having the intimate relationship that I want" and having to "take over the [family] business." One participant described the challenge of maintaining the family business in addition to assuming caregiving responsibilities as "being self-employed people, it was like I had no choice but to try and step in and keep the business going because for 29 years, we had this business." Additional changes in family dynamics included changes in loved ones' behavior. "He used some really bad language . . . and the aggressiveness was real hard." Another participant described having to deal with her aunt who "means well . . . [when she gives advice on how to care for my grandfather]. She has my grandfather's best needs in her heart . . . too bad if it annoys me is basically her outlook."

Advice to New Caregivers

When participants were asked what advice they would offer to a new caregiver, six different themes emerged from the descriptive data: the need for adequate preparation, to ask for help, to take one day at a time, to have lots of love, to treat the person with dignity, and to take care of yourself. Participants believed that caregivers need to be well trained to assume the caregiving role and that it is essential for new caregivers to "get as much information as possible before you leave that hospital." Additionally, participants stated that new caregivers should not "be afraid to ask

[for help]" and that it was important for them to know "there is help available, they are not taking on something with no help." One participant believed that new caregivers should ask for spiritual help to care for their loved one and recommended that new caregivers "call on the Lord in heaven to help you and his blessed mother, because you can't do it alone."

Because "it is going to be rough," participants believed that it was necessary to "have a lot of love" and "to really care about the person to want to assume that kind of [caregiving] role." Additionally, participants advised new caregivers to "be prepared to work hard," to "be flexible," and to be "very patient with yourself and with whomever [you care for]." Participants expressed the importance of taking it "one day at a time" and remembering that it is "normal to feel frustrated" at times when caring for someone you love. Additionally, participants believed that it was important for new caregivers to treat the person they are caring for as an individual whom you must "fight for . . . because they can't fight for themselves."

The final piece of advice the participants offered new caregivers was to pace themselves so that they "don't get so exhausted they can't continue." Participants indicated that if new caregivers "need a break, make sure you make some time" for yourself, even if it means getting "somebody to help watch him for a day or whatever, just so you have some time to be able to do something for yourself."

DISCUSSION

The narrative descriptions obtained in this study provide a glimpse into the elusive world of complex family caregiving. Overall, the decision to engage in this role was one that was embraced as a result of an unexpected illness in a family member. Consequently, there was an overwhelming sense of responsibility to fulfill the caregiving role, even though the transition required individuals to restructure their lives and make personal sacrifices. As their loved one's caregiving needs became the focus of their lives, caregivers had no choice but to alter their previous lifestyles, acquire new skills, and attempt to balance competing demands. Living a recipient-centered life, making difficult decisions, and dealing with adversity, as well as multiple responsibilities, are consistent with other investigations of the caregiving experience (Aneshensel et al., 1995; Boland & Sims, 1996; Given & Given, 1991; Scott, 2001; Shyu, 2000).

Even though most individuals were able to express a sense of gratification from the caregiving experience, issues that may adversely affect their physical and mental well-being emanated from their descriptions. It was clear from the participants' narratives that anxiety, fear, and loneliness were constant threads throughout the caregiving experience. Furthermore, the perceived burden associated with complex caregiving was overwhelming for most of the participants. Perceptions of isolation, burden, and altered family dynamics appear to be inherent characteristics experienced by caregivers as they navigate their way through a solitary journey (Boland & Sims, 1996).

The level of physical and mental fatigue was apparent among the caregivers, with the experience taking a toll on their well-being. Inasmuch as six of the eight informants in this study were employed outside the home, work and caregiving demands, coupled with few hours for respite from these dual and often competing roles, precipitated their physical and mental fatigue, which in turn can adversely affect both caregiver performance and work productivity (Scharlach, 1994; Scott, 2001).

Given the burdensome challenges and overwhelming nature reflected in the caregiving experience, it was not surprising that participants provided recommendations to maximize caregiver self-preservation and the caregiver-care recipient relationship. Although the caregivers in this study had difficulty actualizing self-care strategies for themselves, they encouraged new caregivers to seek assistance and to acquire adequate preparation. Equally important to the caregiving-care receiving experience is the maintenance of a loving and patient relationship with their family member. Rewards from care provision, combined with the ability to find happiness and contentment within the caregiving role, have been noted to enhance family satisfaction and well-being (Carruth, Tate, Moffett, & Hill, 1997), caregiver esteem (Scott, 2001; Scott & Arslanian-Engoren, 2002), and family cohesiveness (Carruth et al. 1997).

IMPLICATIONS AND RECOMMENDATIONS

Findings from this study indicate that the decision to assume the caregiving role must be buttressed by adequate preparation, caring relationships, and external support. These elements are essential to maximize the emotional, psychological, and technical resources needed for complex caregiving and to ensure that fam-

ily members do not deplete their own physical and emotional reserves. Therefore, it is imperative that home health care nurses facilitate an effective transition to the caregiving role, serving as conduits for caregiver education and skill acquisition and advocating for the development of vital infrastructures that will provide resources, reassurance, and respite from burdensome caregiving challenges.

It is recognized that the limited number of participants in the study hinders the transferability of the findings to other caregiving populations. However, it is important to note that the descriptions of the caregiving experience among survivors of PMV are consistent with those in other technologically dependent populations (Ferrario et al., 2001; O'Brien, 2001; Scott, 2001; Smith et al., 1998). As these descriptions continue to converge, it suggests that the consistent themes are inherent in the complex caregiving experience and are not isolated occurrences specific to a given patient population.

In summary, evidence-based interventions are urgently needed that will augment the caregiving-care receiving experience for patients and families. It is hoped that this study will serve as a platform for the development and implementation of nursing interventions to improve caregiver preparation, mental and physical well-being, and quality caregiver-care recipient relationships.

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Linda D. Scott, PhD, RN, is an associate professor of nursing at Grand Valley State University in Grand Rapids, Michigan, where she teaches leadership, nursing administration, and research. The focus of her research is technological family caregiving and care receiving outcomes and quality of life.

Cynthia Arslanian-Engoren, PhD, MSN, RN, CNS, is an assistant professor of nursing at the University of Michigan. She has taught courses in adult health, advanced practice, and research methods. Her research interests include women's cardiovascular health, decision making, and health status outcomes using both quantitative and qualitative methods.