4-2001

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Technological Caregiving: A Qualitative Perspective

Linda D. Scott, PhD, RN

Despite its importance, few studies have focused specifically on the informal technological caregiver. Therefore, this study explored the technological caregiving experience from the perspective of individuals assuming this role. Caregivers were asked to describe their experiences of caring for individuals dependent on inotropic infusion therapy for the management of their end-stage heart failure. Twenty themes reflecting the essence of the technological caregiving experience emerged from the qualitative narratives. Although technological caregiving was financially burdensome, socially confining, and psychologically distressing, caregivers still perceived it as a positive and rewarding experience.

Family caregivers have always had a significant role in the provision of health care in our society. Within the home, informal caregivers have met the health needs of family members with physical or cognitive limitations (Biegel, Sales, & Schulz, 1991). However, changing population demographics, increasing technological innovations, and spiraling health care costs have made the home environment an even more attractive arena for health care delivery. Patients are being discharged from hospitals quicker and sicker, transforming the home setting into a technological caregiving environment.

As spouses, parents, relatives, and significant others become the primary providers of technological care, it is important to ascertain individual reactions to care-

giving and evaluate people's preparation to assume caregiving roles. The determination of factors that facilitate effective family caregiving are pivotal to maximize positive health outcomes for both the caregiver and care recipient within the home environment. Nevertheless, limited research has been conducted that specifically focuses on technological family caregiving (Smith, 1995). Guided by Wilson and Cleary's (1995) health-related quality of life model and Smith's (1994, 1999) model of caregiving effectiveness, this study investigates how family caregivers define and manage the technological caregiving experience in the home.

RELATED LITERATURE

Individuals are considered technologically dependent when they require medical equipment to compensate for the loss of a vital physiologic function and need continuous care to avert death or disability (U.S. Congress, 1987). The complex, technological needs that fall under this rubric include home dialysis, external defibrillation, mechanical ventilation, and infusion therapies. Although these technologies were traditionally reserved for tertiary care settings, dissemination into the home environment has dramatically increased. Furthermore, the transfer of complex technology often requires a partial shift in the onus of responsibility from professional health care providers to family caregivers. Although the preponderance of technological diffusion research has focused on care recipients, increased

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Keywords: community-based inotropic infusions, family caregivers, home care, technological caregiving, technologically dependent population

Author's Note: This research was funded in part by Kappa Epsilon Chapter-At-Large, Sigma Theta Tau International, Grand Valley State University; Kirkhof School of Nursing, Grand Valley State University; and a Student Award Program grant from Blue Cross Blue Shield of Michigan Foundation.

attention, albeit sporadic, has been given to family caregivers of technologically dependent individuals.

Home dialysis. Caring for individuals dependent on home dialysis has been shown to have multiple effects on the family structure. Caregiving may mobilize families together (Flaherty & O'Brien, 1992) while enhancing the quality of the spousal relationship (Palmer, Canzona, & Wai, 1982). However, it may also precipitate serious psychiatric problems and major adjustment issues (Johnson et al., 1984). According to most caregivers, daily activities center around the technical needs of the care recipient (Maurin & Schenkel, 1976) and ultimately dictate the lives of family members (Palmer & Canzona, 1982). In addition to living a recipient-centered life, social and intimate activities are limited secondary to caregiver fatigue (Maurin & Schenkel, 1976), decreased leisure time, and increased caregiving responsibilities (Peterson, 1985). However, when family members perceive that home dialysis is a shared responsibility, families are better able to meet the needs of the technologically dependent family member (Palmer & Canzona, 1982).

External defibrillation. Automatic external defibrillator (AED) skill acquisition and retention has been examined among family caregivers of cardiac arrest survivors. Although caregivers are able to learn the necessary skills to perform external defibrillation, significant decreases in skill retention may occur within 6 weeks (Cummins et al., 1985; Moore et al., 1987), jeopardizing care recipient survival (Moore et al., 1987). In addition to the difficulties of skill retention, psychological aspects are associated with the use of AEDs in the home. The presence of an AED may enhance a sense of security for some family members yet exacerbate feelings of fear and distress in others. To reduce psychological stress and to cope with caring for a family member at risk for a repeated cardiac arrest, a caregiver may deny the seriousness of the care recipient's health status (Cummins et al., 1985).

Mechanical ventilation. Family members have described positive and negative experiences associated with caring for an individual dependent on mechanical ventilation. Most caregivers express a desire to assume the primary caregiver role (Findeis, Larson, Gallo, & Shekleton, 1994), view it as a positive experience (Sevick et al., 1994), and are able to master the technical skills required to care for their loved one at home

(Findeis et al., 1994; Smith, Mayer, Parkhurst, Perkins, & Pingleton, 1991). Nevertheless, satisfaction with the caregiving role may significantly decrease over time as caregivers experience an overwhelming sense of responsibility to provide technical and emergent care (Smith, Mayer, et al., 1991). In addition, caregivers experience feelings of hopelessness and resentment (Smith, Mayer, et al., 1991), alienation and social isolation (Aday & Wegener, 1988; Hazlett, 1989), altered sleep patterns, financial hardships (Aday & Wegener, 1988; Hazlett, 1989; Quint, Chesterman, Crain, Winkleby, & Boyce, 1990), and difficulties in coordinating professional services (Hazlett, 1989), and they often perceive a lack of social support for the caregiving role (Aday & Wegener, 1988).

Infusion therapies. Caregivers who assist with the administration of total parenteral nutrition (TPN) verbalize a sense of pride and gratification associated with managing technological care in the home (Smith, Giefer, & Bieker, 1991). Despite these positive feelings, caregivers describe negative effects secondary to providing care, such as financial burden, anxiousness, and declining personal health (Smith, Giefer, & Bieker, 1991). In particular, caregivers report being "up day and night" to meet the physical needs of the recipient (Smith, Moushey, Ross, & Giefer, 1993). As a result, caregivers experience fatigue and exhaustion as well as negative psychological feelings such as depression and labile emotions. However, quality interactions between caregivers and care recipients in concert with caregiver preparation and esteem have been linked with effective technological caregiving processes. Furthermore, the enhancement of family coping, caregiver role adaptation, social support, and financial stability are identified as areas that can assist families caring for individuals dependent on nutritional therapy (Smith, 1994, 1999).

Inotropic infusions. A more recent addition to community-based infusion therapy is the administration of inotropic medications for the treatment of end-stage heart failure (HF). Inotropic medications are potent pharmacological agents that can be administered as either an intermittent or a continuous infusion for palliative measures or as a bridge to cardiac transplantation. Whereas their use had been limited to critical care units under the auspices of professional caregivers, the transfer of inotropic infusions into the home requires individuals to assume responsibility for complex

technology. As the technical needs, complexity, and acuity of individuals cared for within the home continues to rise, so does the need to understand the impact of technological caregiving on family members.

METHOD

These findings are the qualitative results of a larger descriptive study (Scott, 1999) that incorporated triangulated methodology. To obtain a better understanding of the technological caregiving experience, this investigation approached 6 primary caregivers of end-stage HF patients receiving community-based inotropic infusions in the Midwest region. Of the 6 caregivers, 5 agreed to participate in the qualitative interviews.

Once the caregivers agreed to participate, an informed-consent form was mailed to obtain permission to conduct and audiotape each interview to ensure accuracy and integrity of the data. One caregiver was interviewed in person, with the remaining interviews conducted by telephone. At the end of the interview, the caregiver participants were each mailed a \$5 honorarium. This research procedure was approved through a university institutional review board.

A multifaceted qualitative interview was conducted using a preestablished set of questions to guide the interview process and to establish consistency. Each participant was asked the following five questions: (a) What has it been like to care for someone with HF? (b) What factors have contributed to the decision to care? (c) What were the expectations, realities, rewards, and challenges associated with caregiving? (d) How did caregivers perceive their preparation to care? (e) If given the opportunity, what advice should be given to a new caregiver?

Participants

Although 5 family caregivers agreed to participate, only 4 were included in the final analysis. One care recipient expired 4 weeks prior to the scheduled interview, so this narrative was excluded because it was considered reflective.

Three of the 4 participants were female and all were elderly (mean age = 71.25 years, $SD = 7.68$). All participants were married and residing with their spouses. The participants provided at least 4 hours of care each day (range = 4 to 24 hours) to an elderly care recipient (mean age = 72.50 years, $SD = 5.00$). Of the 4, 2 were caregivers of individuals who were receiving inotropic

infusions in an ambulatory setting, whereas the other 2 were caregivers of individuals who were receiving home infusion therapy. A summary of the characteristics of the participants is presented in Table 1.

Content Analysis Procedure

The qualitative interviews were analyzed following the content analytic technique described by Morse and Field (1995). The four interviews of the caregivers comprised 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. Furthermore, the data were reviewed by experts in qualitative methods and caregiving research for theme verification, accuracy, and analytic completeness.

Content validity and verifiability of the 19 extracted themes was established through consensus. Interrater reliability analysis was conducted with 85.7% agreement obtained on the coding of the narrative statements. All discrepancies were discussed and resolved with 100% agreement. The reliability analysis for the theme extraction was 95%, with one additional theme added to more fully capture the technological caregiving experience. The 20 derived themes are presented in Table 2.

RESULTS

Caregiving Among Individuals With Heart Failure

When asked to describe what it was like to care for someone with end-stage HF receiving inotropic infusions, all of the caregivers described at least one positive aspect associated with providing care. Caregiving was perceived as a positive and gratifying experience, described as "a pleasure" and "really not too bad." In addition, receiving community-based inotropic infusion therapy was perceived to be "much easier" because "it beats the dickens out of going to the hospital" and having to "just sit there for 8 hours."

Although the participants were able to identify positive aspects of caregiving, they expressed more negative than positive aspects. The participants were "very nervous" and "very apprehensive" about how their

TABLE 1
Participant Characteristics

<i>Caregiver Age</i>	<i>Caregiver Sex</i>	<i>Recipient Age</i>	<i>Recipient Sex</i>	<i>Caregiving Hours</i>	<i>HF Diagnosis (years)</i>	<i>Inotropic Infusion (weeks)</i>	<i>Infusion Location</i>
62	Female	66	Male	4	3	52.14	Home
70	Female	72	Male	24	MD	38.57	Home
75	Female	78	Male	4	5	34.29	Ambulatory
80	Male	74	Female	5	4	102.86	Ambulatory

NOTE: MD = Missing data.

actions as a technological caregiver may harm their loved one. One caregiver was so worried and anxious about “not being a nurse” that she developed “hives the first few times” that she initiated the inotropic infusion. According to this caregiver, “it was traumatic not knowing if I was going to hurt him.” Similar concerns were echoed by another participant who said, “What if I did something wrong? I am not a nurse. I never even wanted to be a nurse.”

Along with anxiety and apprehension, burden was associated with the negative aspects of caregiving. The participants described caregiving as “a job” that requires you to be “prepared” and “on call all the time because you never know what’s going to happen.” Whereas specific caregiving challenges emerged in more detail throughout the interviews, the burdensome nature of the caregiving experience was consistent in the narrative descriptions. Caregiving was viewed as “not an easy road to go” and an experience that precipitates dramatic lifestyle “change,” heightened “responsibility,” and a belief that they “really don’t have a life of [their] own.”

Decision to Care

Despite the negative aspects of caring for someone with HF, the theme of social commitment/obligation to the caregiving role resonated throughout the narratives. When asked about the factors that contributed to their decision to care, caregivers believed that the commitment to care “is something . . . you should have if you live with somebody” and that you “owe” it to that person to accept the responsibility. According to the participants, we should demonstrate “loyalty” to our loved ones by not “putting people away [in a nursing home]” and by assuming the caregiver role.

Furthermore, the caregivers believed that “we all should [care for our spouses]” “because it comes along with the marriage.” As a component of the marriage,

spouses did not view the decision to become a caregiver as a “conscious” one. Spouses saw themselves as “the logical one” to provide technological care because “it just had to be done.” Participants believed that their spouses “would do the same” for them because their marriage was “for better or worse.”

Expectations and Realities of Caregiving

During the interviews, the caregivers were asked to discuss their thoughts, expectations, and realities of providing technological care. A total of five themes emerged from the caregivers’ narratives. Fear of the unknown and responsibilities of the role emerged as two separate themes reflecting the caregivers’ thoughts and expectations, whereas the realities of caregiving included the themes of confinement, facing the inevitable, and lifestyle changes.

Thoughts and expectations. Fear of the unknown permeated throughout the caregivers’ narratives. “Not knowing what to expect” was perceived as a pivotal stressor contributing to their daily fears. In particular, living with the uncertainty of “not knowing what tomorrow will bring” was reported by one caregiver as what stressed her the most. In addition, participants were afraid of the technology and responsibilities associated with the role. The caregivers stated that “not being nurses” yet having to use “syringes, heparin, and saline” was “the hardest part” of the caregiver role. Moreover, learning to “do the nursing care” while “keeping the priorities straight” was perceived as a formidable undertaking. “Fear,” “apprehension,” and anxiety forced the caregivers to assume personal responsibility for learning the intricate aspects of providing technological care. Participants believed that “you gotta learn; you have no choice” so not to “kill the person.”

TABLE 2
Caregiving Themes

<i>Topic</i>	<i>Caregiving Theme</i>
Caring for someone with heart failure	Positive aspects of caregiving Negative aspects of caregiving
Decision to care	Social commitment/obligation
Thoughts and expectations about caregiving	Responsibilities of the role Fear of the unknown
Caregiving realities	Confinement Facing the inevitable Lifestyle changes
Rewards of caregiving	One more day Caregiver esteem Normalcy
Challenges of caregiving	Financial challenges Psychological challenges Behavioral challenges Self-Care challenges
Preparation to care	Providing the technical aspects of care Obtaining problem-solving skills
Advice to new caregivers	Self-confidence Self-care Cherish the relationship

In addition to being a time-consuming and “stressful” process, the caregivers perceived that caregiving was a responsibility not equally shared with other family members. Although some family members did not “want to know how” to provide care, some caregivers did not “like to ask for help.” These caregivers viewed technological care as their sole responsibility and did not “want anyone else touching” the infusion.

Realities of caregiving. Three themes emerged that described the realities of caring for someone with HF: confinement, lifestyle changes, and facing the inevitable. Inasmuch as the care recipients were “homebound except for going to the doctor,” the caregivers perceived that they too were confined to home, resulting in social isolation. Whereas some caregivers did not “go anywhere” at all, others left the house only when it was “an absolute necessity.” Because of “time constraints,” there was not “time to do a whole lot of shopping or browsing,” especially if it was time to get “the medicine out.”

In addition to the confinement associated with technological care, the caregivers experienced lifestyle changes. For example, one caregiver described assuming household duties and chores previously performed by the care recipient. Having to “run the sweeper,” “make the bed,” and cook “breakfast” were among the many “change[s]” this caregiver described. Although the role reversal was unsettling, the caregiver was grateful to be “in good enough health to handle it.”

Yet one of the most disturbing realities of caregiving for the participants was facing the inevitable death of their spouse. All of the caregivers reported being aware that there was no cure for congestive HF, that the care recipients were “much worse than before,” and that HF was terminal. One caregiver expressed her concern “about leaving him for any reason at all because the doctor . . . said that it can be at anytime.” Another caregiver said, “that’s my concern to wake up some night [and my spouse will be dead]. Sooner or later, it’s going to happen.”

Rewards and Challenges of Caregiving

The caregivers were able to describe rewards as well as challenges to caregiving. The narrative descriptions further illuminated the positive and negatives aspects of the technological caregiving process.

Rewards of caregiving. Three themes emerged that reflected the rewards of providing care: one more day, caregiver esteem, and normalcy. Because caregivers had to face the inevitability of the recipients’ death, each additional day that their loved one was “still here” was one of their greatest rewards. As such, assuming the role as technological caregiver afforded participants the opportunity to have “one more day” at home with their loved one.

Participants perceived providing technological care to a terminally ill spouse as a gratifying experience that elevated the caregivers’ self-esteem. Caregivers derived “a lot of satisfaction” from being able “to do things for [other] people” and to “help” extend the life of their loved one. One of the “most rewarding” aspects of caregiving described was “just knowing” that they “had a part in helping to keep [their spouse] going.”

Receiving community-based inotropic infusions allowed the care recipients and caregivers to regain a sense of normalcy in their lives. Being home allowed the care to be delivered in familiar surroundings where friends and families could visit. Technological care-

giving was viewed as “a regular thing” that gave the family an opportunity to have “as normal” a life as possible.

Challenges of caregiving. Even though the caregivers experienced intrinsic rewards, several challenges of caregiving were revealed. Four specific categories of challenges emerged from the data: financial, psychological, behavioral, and self-care. Congruent with other populations, caregiving was seen as financially burdensome (Aday & Wegener, 1988; Hazlett, 1989; Quint et al., 1990; Smith et al., 1993). One caregiver verbalized, “It’s extremely hard. . . . We couldn’t afford to go to all these doctors that they sent him to if somebody’s insurance wasn’t going to pay.” Another caregiver summarized the financial ramifications of providing technological care by saying, “I can’t spend a nickel, and I don’t like that.”

One of the major psychological challenges associated with caregiving was the depression experienced by both the caregiver and the care recipient. Referring to the recipients’ mental health, the caregivers commented, “He’s been getting down in the dumps,” “most of the time he’s depressed,” and “[being on tranquilizers] has helped his state of mind.” When speaking of their own mental state, the caregivers described similar feelings of despondency as being “right on the edge.” Moreover, the caregivers’ narratives revealed thoughts of escape or retreat from caregiving responsibilities, such as, “I don’t know how many times I’ve thought I would just get in the car and go away and never come back.”

The behavioral challenges that caregivers encountered emerged as a separate theme. As the context of technological caregiving resulted in new roles among the family members, the caregivers described new behaviors and interaction patterns. One caregiver described an intolerance of the care recipient’s “contrary” behavior in her statement that “I’m not going to take a lot of stuff from him. . . . I’m doing the best I can for him.” When speaking of the behavior changes and challenges associated with caregiving, another participant said, “It’s hard to change . . . after 75 years. Doing what you want to do and all that’s got to change.”

As the caregivers’ role responsibilities expanded, it became a challenge for them to meet their own self-care needs. The caregivers described alterations in sleep and dietary patterns. One caregiver remarked that “I have not been able to sleep well at night [because of the cycling of the IV pump],” so being able to “get enough

rest has been a big challenge.” Another stated that she was aware that the stress of caregiving caused her to overeat. “I’m eating too much. . . . I may not know what I’m eating, but I’ll eat it.”

Preparation to Care

When the caregivers were asked about their preparation for the role, two themes emerged from the caregivers’ descriptions: providing the technical aspects of care and obtaining problem-solving skills. According to the caregivers, their ability to provide the technical aspects of care was learned in various formal and informal ways. Formal methods included learning through observation of health care professionals. Although one caregiver said that she had “never had any medical training,” she tried to mimic the nurses by doing what was “observed while he has been in the hospital.” Another caregiver said that she “learned to do a lot of things [from] the nurses who came [to the house].”

Informal methods used by the caregivers to learn technological caregiving included “pamphlets” and trial and error approaches. A common method employed by the participants to gain technical skills was “just by trying things.” These same strategies were used to obtain problem-solving skills. One caregiver said that problem-solving skills were gained from “what the nurse has said to me” or “the directions they told me over the phone.” Another caregiver typified how problem-solving skills were obtained: “I’m not quite afraid [anymore] . . . after a year. I try things . . . things that I would not have done right away. It’s been an experience.”

Advice for New Caregivers

Three themes captured the essence of advice participants offered to new caregivers: to have self-confidence, to cherish the relationship with the recipient, and to initiate self-care strategies. The participants felt that it was imperative for new caregivers to “not give up” and to believe “that they can do it.” Furthermore, participants declared that, “whoever has to do this, has to know that they are doing it for a good reason. Without it, the answer isn’t very good.”

As such, the participants believed that new caregivers needed to cherish the relationship with the care recipient. According to the participants, new caregivers must have “lots of love and lots of patience.” In addition, it was recommended that new caregivers practice tolerance, being mindful “to hold your tongue.” Above all, it was advised that anyone who is new to the

caregiving role should be “very flexible” and should learn to “go with the flow.”

The third theme that emerged from the narratives was the implementation of self-care strategies. The participants perceived that new caregivers needed to learn to “always ask for help” from “the nurses, the IV people, or the doctors.” Engaging family members in technological caregiving activities was recognized as an important facet of self-care; “the family is there . . . we just have to ask.” New caregivers were encouraged to “just think of themselves, just a little bit, so that they don’t get down” as they assume the technological caregiving role. By practicing these self-care management strategies, participants believed new caregivers would have a more “positive” caregiving experience.

DISCUSSION

The findings of this investigation revealed that caregivers of HF patients were able to describe both positive and negative aspects associated with technological care. The ability to recognize a positive dimension to technological caregiving is consistent with care provision in other populations (Flaherty & O’Brien, 1992; Maurin & Schenkel, 1976; Palmer et al., 1982; Sevic et al., 1994; Smith, Giefer, & Bieker, 1991). It may be that positive appraisal of the caregiving experience is necessary to give meaning to the experience. Furthermore, the active participation of the caregiver in their relative’s technological care afforded an opportunity for caregivers to “do something.” The caregivers’ efforts on the care recipients’ behalf may contribute to the coping and adaptational processes needed when caring for a loved one with an end-stage disease.

In this study, the caregiving role was perceived as an extension of the marital commitment. These findings coincide with those of other investigators who have identified the decision to become a caregiver as one made out a sense of duty, responsibility, obligation, or reciprocity (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991; Wilson, 1989). However, the marriage bond is no guarantee that one will be satisfied with the caregiving role or be an effective caregiver. Yet for the participants in this study, caring for their loved one was perceived as a source of satisfaction and gratification.

The reunification of the family in the home environment contributed to the benefits of caregiving. As such, the transfer of inotropic infusions into the community,

particularly to the home, provided a sense of normalcy. Caregivers perceived that they had much more control over their lives in their own homes. Furthermore, the familiarity of the environment was comforting and convenient for both the caregiver and care recipient.

Each additional day that the care recipient survived was perceived as a benefit of caregiving. This finding deviates from caregiving literature concerning the cognitively impaired and frail elderly populations. In these populations, a peaceful and timely death of a cognitively impaired care recipient may be perceived as a relief in most instances as caregivers observe the care recipients’ deterioration and suffering (Aneshensel et al., 1995). Although individuals with end-stage HF progressively deteriorate, they usually remain cognitively intact. As a result, caregivers may view the terminal nature of the care recipients’ disease process as premature. They are grateful to have any additional time with their loved one.

Despite the positive components of caregiving, several negative aspects and challenges associated with the role emerged. Anxiety, burden, and lifestyle changes, a consistent thread throughout the caregiving literature, coupled with confinement and lifestyle changes were apparent in the descriptions of the caregiving experience. The technical aspects of care, constant attention, and vigilance resulted in overwhelming responsibilities, social isolation, situational depression, and fear. As reported in other investigations, the care recipient became the focus of the caregivers’ lives, with all activities centered on the technical needs of the care recipient (Boland & Sims, 1996; Karmilovich, 1994; Maurin & Schenkel, 1976).

The challenges of caregiving illustrated from the participants’ experiences encompassed financial, psychological, behavioral, and self-care issues. In isolation, each dimension is burdensome; however, in concert, the challenges of caregiving can be immense and have untoward effects on the caregiver. Inasmuch as the negative consequences and burden associated with caregiving have been the focus of caregiving research for several years, these findings were not surprising.

What was unanticipated was that, for the most part, the caregivers were expected to learn to manage the challenges of technological caregiving on their own. It was difficult for the caregivers to request assistance, even when they were extremely overwhelmed, unprepared, and “right on the edge.” Formal educational preparation for the technical aspects of care and the development of problem-solving skills was almost

nonexistent, leaving the caregivers no choice but to initiate skill development and acquisition on their own.

Moreover, meeting the challenges associated with financial, psychological, and behavioral issues often superseded addressing their own self-care needs. This may be the result of the caregivers' commitment to the care recipient and the responsibilities of the role. Even though caregivers did not prioritize their own needs, they were still able to offer self-care strategies for new caregivers. It is important to note that although the caregivers experienced adversities with technological caregiving, no one recommended that new caregivers not assume the role. Instead, the participants recommended the practice of self-care, the development of caregiver self-confidence, and the maintenance of a cherished relationship with their family member as a foundation to a positive technological caregiving experience.

IMPLICATIONS

It is clear from this investigation that caregiving among a technologically dependent population is a complex, multifaceted phenomenon. As such, careful consideration and planning must occur before the transfer of technology from tertiary care to the community becomes a more frequent occurrence. Although technological caregiving had positive effects, it was also perceived as financially burdensome, socially confining, and psychologically distressing. Moreover, caregivers were not prepared for the complexity associated with inotropic infusions.

Therefore, the administration of inotropic infusions in the community using nonprofessional caregivers must begin with careful assessment of the home environment. Caregiver selection should include an evaluation of the individual's willingness to provide care as well as an assessment of his or her capacity to fulfill the expectations of the technological caregiving role. Once selected, caregivers must be prepared for the technological caregiving experience using a structured process that maximizes skill acquisition. Furthermore, preparation to care should include a mentoring process to facilitate retention and the development of skill proficiency while affording the opportunity for skill evaluation.

It will be important not to limit preparation of caregivers to the technological aspects of care. Caregivers must be prepared for the psychosocial challenges of

caregiving as well as for caring for a loved one with a terminal illness. The results of this study indicate that caregivers prioritize the psychological, behavioral, and financial aspects of caregiving and neglect their own self-care needs. In preparing caregivers for the challenges of technological caregiving, self-care practices should be incorporated into the educational process. As technological caregivers become more efficient with caregiving tasks, they will be able to incorporate self-care and health-promoting behaviors into their daily activities.

The perceived lack of support for the technological caregiving role was apparent during the interview process. As the caregivers described their experiences, they also exhibited emotions that ranged from anger to frustration. According to the caregivers, this was their first opportunity to verbalize their innermost thoughts and feelings about their terminally ill loved one and share their fears of providing technological care. Although these participants readily assumed the technological caregiving role, their comments made it clear that their caregiving efforts did not receive expected or needed support from health care professionals. Therefore, formal and informal support systems in conjunction with interventions such as telephone triage, follow-up care, and respite services should be incorporated to assist families with the physical, emotional, and technical aspects of care.

LIMITATIONS AND RECOMMENDATIONS

This study explored an area in urgent need of research and will serve as a catalyst for future investigations. Yet its findings are from a small, nonrandom sample; therefore, the results are not generalizable beyond the study participants. Replication of this study will enhance transferability of its findings and identify other themes germane to the technological caregiving experience. In addition, investigations are needed to identify interventions that will maximize effective technological caregiving outcomes and prepare individuals for caregiver role enactment.

A second limitation of this study was the exclusion of the care recipients' perspective. Although the inclusion of the care recipients' experience of living with end-stage HF would be insightful, it was not included in order to minimize the participant burden for this vulnerable population. Concurrent exploration of techno-

logical caregiving and care receiving processes would ultimately enrich our understanding of this complex phenomenon.

In conclusion, this study identified multiple positive and negative aspects of providing community-based technological care to end-stage HF patients. Continued research in this area will contribute to the existing body of knowledge related to caregiving among technologically dependent populations.

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