

2-2002

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### ScholarWorks Citation

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# Caring for Survivors of Prolonged Mechanical Ventilation

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*Approximately 54 million adults in the United States are involved in some form of family caregiving, with 15% of these individuals providing complex care in their homes. Therefore, it is essential to identify the nuances associated with complex community-based family caregiving. This study investigated family caregivers' perceptions of caring for individuals who survived tracheostomy for prolonged mechanical ventilation. Using a quantitative approach, family caregivers (n = 15) reported that they were somewhat prepared for this experience. The findings suggested that family caregivers experience considerable physical and psychological effects throughout their caregiving careers. Despite physical and mental health challenges, the caregivers were able to derive personal gratification from complex care provision. The challenge before home care nurses is to prepare family members for their newly acquired caregiving roles, implement interventions that support their physical and mental well-being, and facilitate the engagement in health-promoting behaviors.*

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**T**he hospitalization of a critically ill loved one is a stressful and often devastating experience for families. Once the initial crisis has resolved and progress has been made toward recovery, the complex care of these individuals is frequently transferred to the home environment. As a result, family members find themselves thrust into the role of primary caregiver, often without adequate preparation to address the phys-

ical, emotional, or technical care needs of these individuals.

Family caregiving is not a rare phenomenon; recent estimates indicate that 54 million Americans are involved in some form of family caregiving, reflecting a twofold increase over the past 12 months (National Family Caregiver Association, 2000). Fifteen percent of these individuals provide care for a seriously ill or disabled relative in their homes (Family Caregiver Alliance, 2001). As this population continues to escalate, it is essential to identify the nuances associated with complex community-based family caregiving. Guided by Smith's (1994, 1999) model of caregiving effectiveness, this study investigated family caregivers' perceptions of caring for individuals who have survived tracheostomy for prolonged mechanical ventilation (PMV) (Diagnostic-Related Group [DRG] 483).

## RELATED LITERATURE

A review of the literature revealed a paucity of investigations that have focused exclusively on the experience of caring for family members who are posttracheostomy and liberated from mechanical ventilation yet still require complex care. Several investigations have examined caregiving processes among both adults and children who are dependent on mechanical ventilation (Aday & Wegener, 1988; Findeis, Larson, Gallo, & Shekleton, 1994; Hazlett, 1989; Noyes, Hartmann, Samuels, & Southall, 1999; O'Brien, 2001; Petr, Murdock, & Chapin, 1995; Quint, Chesterman,

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**Key Words:** community-based family caregiving, complex care, home health care, prolonged mechanical ventilation

**Authors' Note:** This research was funded in part by Kirkhof School of Nursing, Grand Valley State University.

**Home Health Care Management & Practice** / February 2002 / Volume 14, Number 2, 122-128  
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Crain, Winkleby, & Boyce, 1990; Sevick et al., 1994; Smith, Mayer, Parkhurst, Perkins, & Pingleton, 1991; Thomas, Ellison, Howell, & Winters, 1992). In addition, Smith et al. (1998) described the caregiving experiences for family members using continuous positive airway pressure therapy, and Ferrario, Zotti, Zaccaria, and Donner (2001) explored caregiver strain associated with caring for individuals with tracheostomies.

Both positive and negative caregiving experiences are reported among ventilator-dependent populations. Most caregivers are willing to assume the role of primary caregiver (Findeis et al., 1994), are able to learn the skills necessary to care for their technological-dependent family members (Findeis et al., 1994; Noyes et al., 1999; Smith et al., 1991), and are able to express a positive appraisal of the caregiving experience (Sevick et al., 1994). However, this optimistic assessment may significantly diminish as responsibilities associated with technological and emergent caregiving intensify (Smith et al., 1991).

Family caregivers of ventilator-dependent care recipients often feel hopeless, resentful, alienated, and isolated (Aday & Wegener, 1988; Hazlett, 1989; Petr et al., 1995). These feelings are heightened when caregivers perceive inadequate support for their role as primary caregiver (Aday & Wegener, 1988) or experience strained interpersonal relationships (O'Brien, 2001). In conjunction, caregivers report being physically and mentally exhausted, as well as financially burdened (Aday & Wegener, 1988; Hazlett, 1989; Quint et al., 1990). Other sources of frustration include challenges and time management issues that surface when coordinating professional services (Hazlett, 1989; O'Brien, 2001). Often, individuals who are new to the caregiving role (less than 6 months) are more concerned with their ability to handle emergencies, whereas individuals who have been caregiving longer than 2 years tend to worry more about their ability to meet their financial obligations (Thomas et al., 1992).

Women who care for individuals with recently placed tracheostomies (less than 14 months) experience prolonged caregiver strain (Ferrario et al., 2001). Contributing factors to persistent caregiver strain include worry related to the terminal nature of the care recipients' condition, as well as an expressed need for continuous education and reassurance. In addition, when perceived preparation to care is insufficient, the mental well-being of caregivers may be jeopardized (Smith et al., 1998). Inasmuch as sustained, negative effects of caregiving may adversely affect the health

status of caregivers (Schulz & Beach, 1999), it is imperative that investigations are conducted to enhance our knowledge of complex family caregiving and to guide professional nursing practice.

## METHOD

As part of a larger study that examined functional status outcomes and experiences of patients following tracheostomy for PMV, triangulated methodology was used to explore the caregiving experience as perceived by primary caregivers. These findings are the quantitative results of the caregiving component of the study. The family caregiver was defined as the person who had primary responsibility for the physical, emotional, and technical care of the recipient at the time of the study.

### Procedure

Approval to conduct this study was obtained from a medical center institutional review board. Patients who participated in the larger study were asked to identify a family member who had assumed primary responsibility for assisting with their home care following PMV. Once a family caregiver was identified and permission to contact him or her was obtained from the patient, each potential participant was telephoned to discuss his or her possible participation in the study and to answer any questions. After obtaining informed consent, these individuals were asked to appraise their preparation to care and to assess their reactions to the caregiving experience during a brief structured telephone interview arranged at their convenience.

### Instruments

Data were collected using three standardized instruments with established psychometric properties. In addition, a brief demographic questionnaire was completed for each participant.

*Caregiver preparation appraisal.* An eight-item Caregiver Preparedness Scale (Archbold, Stewart, Greenlick, & Harvath, 1990) was used to measure perceived preparation in seven aspects of caregiving. This 5-point summative scale, with mean scores ranging from 0 (*not prepared*) to 4 (*very well prepared*) reflects a self-appraisal of one's ability to provide care.

*Reactions to caregiving.* Two instruments, the Caregiver Reaction Assessment (CRA) and the Mental

Health Inventory–5 (MHI-5), were used to assess the reactions to caregiving. The CRA evaluates significant factors associated with family caregiving (Given et al., 1992). This 24-item instrument uses a 5-point Likert-type scale, from 1 (*strongly disagree*) to 5 (*strongly agree*), and contains five subscales: Caregiver Esteem (7 items), Daily Schedule (5 items), Family Support (5 items), Caregiver Health (4 items), and Financial Impact (3 items). Higher scores in the Caregiver Esteem subscale represent a positive aspect of caregiving, whereas higher scores in each of the remaining subscales denote a negative aspect of caregiving.

The MHI-5, a subscale of the Medical Outcomes Study Health Status Questionnaire Short Form 36, was used to assess caregiver mental health. The standardized scores for the MHI-5 can range from 0 to 100, with higher scores indicative of a better mental state (Ware, Snow, Kosinski, & Gandek, 1993).

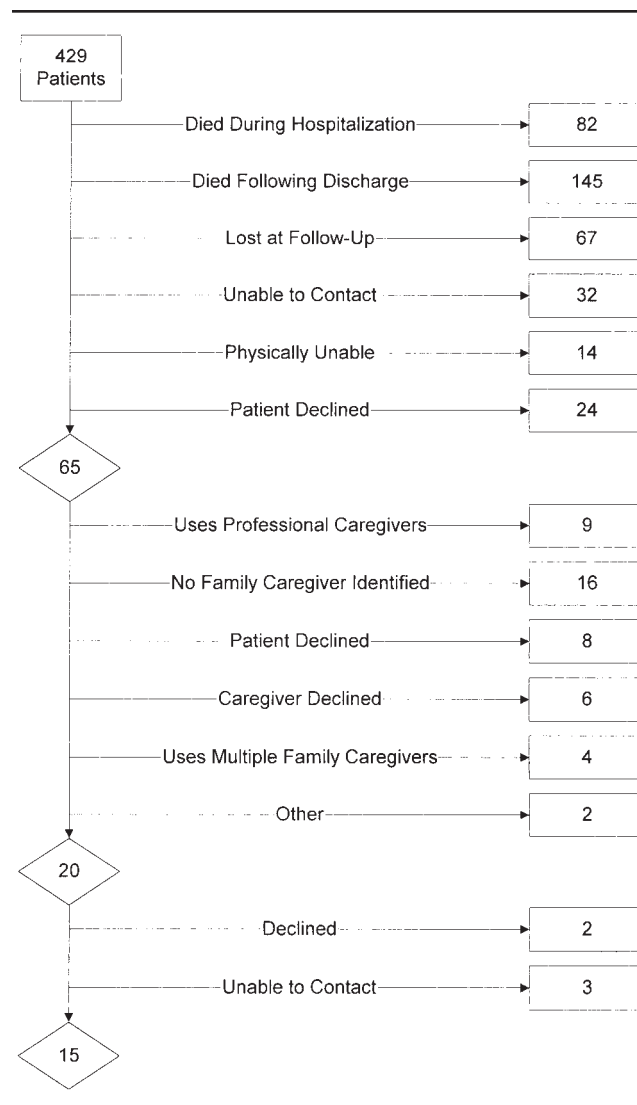
### Sample

The caregiving sample was derived from a population of patients at a tertiary care, university-affiliated medical center who underwent tracheostomies to facilitate mechanical ventilation between 1997 and 1999 (DRG 483). Of the 429 eligible patients, 227 expired either during their course of hospitalization or after discharge, 67 were lost to follow-up, 32 were unreachable, 24 refused, and 14 were physically unable to participate, leaving a total of 65 potential patient participants (see Figure 1). When these 65 individuals were asked about their caregiving arrangements, 16 reported not needing any assistance, whereas 15 identified receiving care from either professional caregivers or through other caregiving arrangements. Another 14 individuals refused to disclose any information related to their post-PMV home care.

As a result, 20 family caregivers were eligible to participate in this study. However, 2 of these individuals refused to be interviewed, and 3 were unavailable to complete the questionnaires. Therefore, a total of 15 family caregivers for individuals who had survived PMV composed the study sample.

These individuals were predominantly female (93.3%), varying in age from 37 to 70 years ( $M = 52.33$ ,  $SD = 8.90$ ). In addition to providing care for an average of 10 hours each day ( $SD = 7.69$ , range = 1.50 to 24), most caregivers were employed on a full-time basis (66.7%). Several of the caregivers reported being in this dual role for more than a year ( $n = 8$ ), whereas oth-

**FIGURE 1**  
**Caregiver Recruitment Summary**



ers indicated that their caregiving careers had been limited to 8 months or less ( $n = 6$ ). Although the majority of the caregivers were either the wives ( $n = 6$ ) or mothers ( $n = 4$ ) of the care recipients, other caregiving relationships included the care recipients' children or grandchildren ( $n = 3$ ), sibling ( $n = 1$ ), or fiancé ( $n = 1$ ).

### Data Analysis

Data were analyzed using the Statistical Package for the Social Sciences (Chicago, Illinois). Given the relatively small sample size, only descriptive statistics were examined.

## RESULTS

### Caregiver Preparation Appraisal

When asked to self-appraise their ability to manage the care of PMV survivors, the caregivers reported modest preparation for this role ( $M = 2.78$ ,  $SD = .80$ ). As an aggregate, the caregivers perceived that they were better able to access information ( $M = 3.26$ ,  $SD = .70$ ) and engage in diversional activities ( $M = 3.00$ ,  $SD = 1.19$ ) than to coordinate health care services ( $M = 2.60$ ,  $SD = 1.45$ ) and manage the emotional ( $M = 2.60$ ,  $SD = 1.24$ ) and physical ( $M = 2.53$ ,  $SD = 1.46$ ) needs of their loved ones. Moreover, the caregivers identified that they were least prepared for the stress associated with the caregiving role ( $M = 2.00$ ,  $SD = 1.56$ ). Despite a sense of inadequacy in managing their loved ones' physical care, the caregivers believed that they had adequate preparation to handle any emergencies that might arise ( $M = 2.93$ ,  $SD = 1.58$ ).

However, when the caregiver responses were analyzed by experience in the caregiving role, differences in preparation appraisal were noted. More specifically, individuals who had been providing care for more than a year perceived themselves to be most apt at handling emergencies, whereas less experienced caregivers perceived they were ill prepared for crisis management. A comparison of perceived preparation for the multidimensional aspects of caregiving is presented in Table 1.

### Reactions to Caregiving

A summary of the five factors of the CRA is presented in Figure 2. Based on these results, coupled with the findings from the MHI-5, the caregivers experienced both positive and negative reactions.

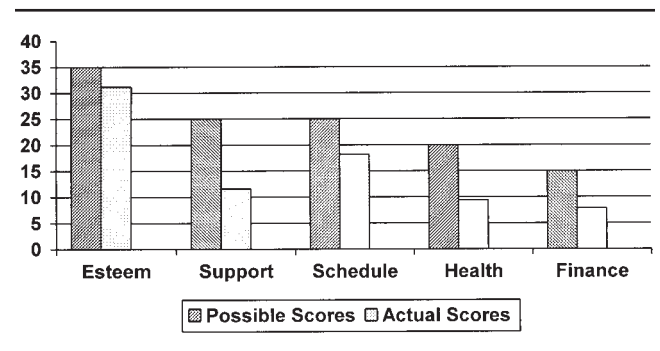
*Caregiver esteem.* All of the participants reported enjoyment and gratification from the caregiving role. These positive perceptions were buttressed by their strong desire to provide care, coupled with the value they placed on the caregiving role. None of the caregivers voiced feelings of resentment; instead, the caregiving role was considered a privilege. In spite of an overwhelming sense of satisfaction from successful role embracement, all of the participants still experienced challenges and hardships.

*Daily schedule.* One of the challenges identified with the caregiving role was the daily coordination of activities. Inasmuch as the care needs of the recipients deter-

**TABLE 1**  
Areas of Perceived Preparation for Caregiving

Aspects of Caregiving	Novice Caregivers		Experienced Caregivers	
	M	SD	M	SD
Handling emergencies	2.00	1.89	3.50	1.07
Accessing information	3.33	0.81	3.25	0.71
Making activities pleasant	3.00	0.89	2.87	1.46
Managing emotional needs	2.66	1.37	2.50	1.31
Managing physical needs	2.50	1.37	2.37	1.59
Arranging services	3.00	1.09	2.12	1.64
Managing stress	1.66	1.63	2.00	1.51

**FIGURE 2**  
Caregiver Reaction Scores



mined the schedule of the caregivers, 60% reported interruptions in their day-to-day activities. To meet their caregiving responsibilities, 9 caregivers (73%) reported eliminating activities from their schedules. In addition, almost half (47%) of the caregivers reduced their participation in family and social interactions and found it difficult to relax due to constant caregiving demands.

*Family support.* Most caregivers perceived that other family members supported them in their caregiving role. Although the caregivers had assumed primary caregiving responsibilities, 67% believed that it would not be difficult to obtain family assistance if needed, and 33% believed that their families worked together to provide care. However, 27% of the caregivers reported feeling abandoned by other family members during their caregiving careers.



*Financial impact.* When asked about the financial strain associated with care provision, 60% denied any monetary burden or difficulty paying for caregiving expenses. Yet, when asked to describe the adequacy of their economic situations, one third of the caregivers conveyed that their financial resources were insufficient to fulfill their caregiving responsibilities.

*Physical health.* The majority of the caregivers believed that they were healthy enough to provide care (87%) and had enough physical stamina (80%) to fulfill their caregiving obligations. Despite perceptions of an optimum physical health, more than half (53%) of the caregivers described feeling constantly fatigued. In addition, 5 caregivers (33%) reported deterioration in their health status since assuming caregiving duties.

*Mental health.* Although the caregivers perceived that they were in good physical health, the results of the MHI-5 suggested that they experienced compromises in their mental health. The standardized mental health scores for the caregivers ranged from 32 to 92 with a mean of 66.12 ( $SD = 20.27$ ). More than half (60%) of the caregivers had mental health scores less than the established population norm of 74.74 (Ware et al., 1993). Based on their self-reports, more than 53% of the participants were anxious. Forty percent reported experiencing feelings of depression, and 73% reported periods of despondency.

## DISCUSSION

Overall, family caregivers in this study managed the complex care needs for survivors of PMV remarkably well. This occurred in spite of assuming a role for which they had limited preparation or forewarning. Although personal sacrifices were required to actualize this role, caregivers were committed to caring for their loved ones, deriving a sense of accomplishment and fulfillment from their newly acquired responsibilities. Given and Given (1991) noted that learning skills, dealing with adversity, and meeting familial obligations contribute to increased self-esteem and confidence in one's ability as a caregiver. As the caregivers are able to derive rewards from care provision, other family members may benefit tangentially. Carruth, Tate, Moffett, and Hill (1997) found that family satisfaction was directly related to the individual's ability to find happiness and contentment within the caregiving role.

Their ability to recognize the positive aspects of caregiving and to gain a sense of mastery may have contributed to their ability to balance a caregiving career with full-time employment. Another factor that may have contributed to their ability to engage in this dual role was the perceived support and recognition from their family members. Unfortunately, this is not always the case; all too often, caregivers are often forced to choose between caring for their loved ones and continuing in the workforce (Stone, Cafferata, & Sangl, 1987). It may be that sustained employment provided the caregivers in this study a means to fulfill their financial obligations and caregiving responsibilities while maintaining a sense of normalcy.

A major component of meeting their caregiving responsibilities was their preparation to care. The results indicated that more experienced caregivers were better prepared to address one facet of the complexities of care, handling emergencies, than the novice caregivers. Nevertheless, all the caregivers struggled with the physical and psychosocial aspects of care. Moreover, the caregivers were unprepared for the unforeseen stresses of caregiving and the subsequent effects on their physical and mental health. Similarly, Scott (2000, 2001) reported that insufficient preparation to care contributed to negative aspects of caregiving, leaving caregivers alone to navigate their way through the caregiving experience.

The physical and mental demands of full-time caregiving, coupled with full-time employment, were evident in the caregiver responses. Even though the caregivers perceived that they were in good health, most described being physically exhausted. This finding was not surprising; fatigue has been a constant thread throughout the caregiving literature. What was surprising was that only a few caregivers reported declines in their physical health status given the multiple roles and responsibilities they assumed.

Although physically able to provide care, the burden of caregiving may have affected their mental well-being, as evidenced by their MHI-5 scores. Perceptions of adequate family support were not enough to thwart the negative effects of caregiving. Boland and Sims (1996) described caregiving as a solitary journey that encompasses perceived burden, feelings of isolation, and intense responsibility. Moreover, the length of caregiving intensifies perceived burden, which in turn negatively affects the health and well-being of the caregiver (Bull, 1990; Gaynor, 1990). Because a majority

of the caregivers had caregiving careers longer than 1 year, this may explain the predominance of low mental health scores.

## IMPLICATIONS AND RECOMMENDATIONS

A limitation of this study is the small sample size, which resulted despite recruitment efforts. Although this convenience sample was derived from a large pool of potential participants, accessing caregivers of clinically complex individuals remained difficult and, hence, limited the ability to perform inferential statistical analyses. Although these descriptive findings are not generalizable, they do provide a window into the elusive world of complex family caregiving; thus, they have implications for both nursing practice and research.

As the dissemination of high technology care into the community becomes ubiquitous, it is imperative that nurses provide individuals with the knowledge and skills to actualize informal caregiving roles effectively and efficiently, while minimizing potential negative consequences to the recipient, other family members, and themselves. Inasmuch as nurses are the coordinators of care across the health care continuum, they are in an ideal position to prepare family members with the education and skills to be effective in their caregiving careers. Equally important to this process is the nurses' ability to actualize the roles of health care advocate, advisor, and ally for patients and families. The challenge before nurses is to establish collaborative relationships with other disciplines for the development of supportive infrastructures that will provide timely reassurance, resources, and respite.

In summary, the findings suggest that family caregivers experience considerable physical and psychological effects throughout their caregiving careers. As such, nurse clinicians and nurse researchers must join forces to improve the preparation, transition, and adaptation to the caregiving experience. It is particularly important to develop, test, and implement evidence-based nursing interventions that will augment the caregiver's preparation to care, physical and mental well-being, and engagement in health-promoting behaviors. Working together, nurses can improve this experience for both primary caregivers and their families.

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