

REVIEW

## Family caregiver training is needed to improve outcomes for older adults using home care technologies

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### ABSTRACT

Family caregivers, although uncompensated, provide daily care for more than 75% of the older adults who are dependent on home care technologies such as home enteral nutrition. The high complication rates and poor outcomes seen in older adults suggest that being an effective caregiver requires specialized training in home care technologies, and dietitians need to be more actively involved in discharge planning and follow-up home care. The level of knowledge and skill mastery required for technology-dependent care, along with the chronic, intensive nature of family caregiving and the disruptions in caregivers' daily lives, lead to negative emotional and physical consequences that may interfere with caregivers' ability to do caregiving well. Recognizing that care recipients and caregivers are underserved populations, dietitians should develop their professional competencies and expand their roles in technology-dependent home care. Dietitians can thereby contribute to better outcomes for both family caregivers and older home care recipients. *J Am Diet Assoc. 2002;102:831-836.*

Family caregivers are increasingly relied upon to manage and monitor technology-based home therapies like home parenteral and enteral nutrition. Technological home care is the sector of the home health care industry that provides technology-dependent medical treatments, including mechanical ventilation; cardiac electronic monitoring; hemodialysis; peritoneal dialysis and home infusion services such as chemotherapy, hydration, pain management, intravenous antibiotics, and anti-thrombotics; and antirejection therapy to patients in their place of residence (see the Figure) (1). Up to two-thirds of older adults who receive these home infusion services are simultaneously in need of nutrition infusions, that is, home parenteral or enteral nutrition, to aid treatment of their primary disease or to reverse primary malnutrition (1-5).

### INDICATIONS IN OLDER ADULTS

Adults aged 65 years or older comprise almost 20% of the home parenteral nutrition population, although usage is most common in adults aged 51 to 64 years (6). In contrast, older adults are the most prevalent users of home enteral nutrition. Primary diseases that typically affect older adults that are commonly treated with home enteral nutrition include neoplasms of the head, neck, and upper gastrointestinal tract and neuromuscular diseases that impair ability to swallow (eg, cerebrovascular accident or stroke, Parkinson's disease, Alzheimer's disease, multiple sclerosis, motor neuron disease, and traumatic head injury) (6-14). A variety of other bowel disorders, including malabsorption syndromes, and anorexia of illness make up the remaining numbers of older adults receiving home enteral nutrition (6-8,10,11).

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Cardiac electronic monitoring  
 External cardioverter devices  
 Hemodialysis  
 Mechanical ventilation  
 Peritoneal dialysis  
 Respiratory electronic monitoring  
 Home infusions (intravenous)  
 Antibiotic therapy  
 Antirejection therapy  
 Antithrombolytic therapy  
 Biologic response modifiers  
 Chemotherapy  
 Colony-stimulating factor therapy  
 Hemotherapy  
 Home enteral nutrition  
 Home parenteral nutrition  
 Hydration (fluid and electrolytes)  
 Inotropic drug therapy  
 Iron overload therapy  
 Pain management therapy  
 Tocolytic-drug therapy

*FIG. Technology-dependent medical treatments that can be provided to patients in their place of residence.*

### INCIDENCE AND COSTS

The precise number of older adults on home enteral nutrition in the United States is unknown because reporting requirements do not exist. In the 1990s, increased usage resulted from earlier and more aggressive identification of malnutrition by health care professionals, and by technological advances in techniques of enteral tube placement, infusion pump delivery systems, and liquid medical nutrition formulas (15,16). In the 4 years from 1989 to 1992, Medicare beneficiaries of home enteral nutrition increased from approximately 34,280 to 73,323 patients (17). Growing at a rate of approximately 25% per year, home enteral nutrition usage in older adults has been 1 of the most rapidly expanding segments of home infusion services (6,7,17-21). For example, with 98% of older adults enrolled in Medicare and Medicare enrollment of more than 33 million older persons (22), 1 out of every 400 Medicare beneficiaries may have been receiving home enteral nutrition in the mid-1990s (18).

Data from Medicare, the single largest payer for home enteral nutrition, can also be used to estimate costs (6,20). In 1992, the national cost of all home enteral nutrition was estimated at over \$600 million (6,18). This \$600 million covered only the items directly related to therapy, such as enteral formula, tube administration set, infusion pump loan, and tube dressing kits (19). This \$600 million did not include physician office or clinic visits, home nursing and other professional therapeutic care, medication therapy, laboratory charges, radiology, emergency room visits, and hospital admissions.

### AVAILABILITY OF NUTRITION SERVICES

Medicare's prospective payment system (PPS), which began on October 1, 2000, may be negatively influencing the percentage of older adults who receive home enteral nutrition today. Under PPS, home health agencies receive payment for episodes of care at a nationally standardized payment rate (23). Recognizing that successful management requires frequent, lengthy, and intensive visits, home health agencies are apprehensive that accepting older adult clients on home enteral

nutrition will escalate administrative costs and outweigh the benefits of providing service. Consequently, many Medicare-certified for-profit agencies no longer agree to provide service. Another potential outcome of the Medicare change to PPS is to decrease the motivation of physicians, who have concerns for the efficacy of home enteral nutrition in older adults, to transition patients early from parenteral to enteral nutrition. Although home parenteral nutrition is more costly and less safe for older adults, it qualifies for better reimbursement and receives better attention from home health agency staff (24,25).

The Medicare change to PPS did not include payment for registered dietitians (RDs) or other nutrition professionals in home and community settings (26). However, the most recent revision of Medicare, approved by Congress on December 21, 2000, makes RDs eligible providers of medical nutrition therapy (MNT) services for older adults. The December 2000 legislation expands Medicare coverage for MNT only to patients with diagnoses of diabetes and predialysis renal disease despite recommendations by the Institute of Medicine that the provision of professional nutrition services by RDs be a widespread Medicare benefit including home parenteral and enteral nutrition (27). This lack of comprehensive reimbursement for nutrition services combined with no mention of a nutrition professional in the Code of Federal Regulations for home health agencies (28), plus the lack of Joint Commission on the Accreditation of Healthcare Organizations standards that nutrition evaluations be conducted by a nutrition professional (29), makes it unlikely that the nutrition-related needs of older technology-dependent home care patients are being met—especially those adults receiving enteral nutrition.

### OUTCOMES OF OLDER ADULTS

The use of home enteral nutrition among older adults has led to examination of the affect of age on achievement of enteral nutrition goals. The goal of transitioning older adults to full oral consumption remains illusive with only 10% to 30% of older adult patients ever resuming a full oral diet, (6,7,10-13,30,31).

From 18% to 44% of older patients are also unable to attain restoration of a desirable body weight (13,30,32). Although the duration of home enteral nutrition among the majority of older adults averages from 3 months to 1.5 years (6), low body mass index in older adults is associated with longer duration of tube feeding and occurrence of pressure ulcers (33). Low body mass index also correlates with impaired functional abilities in older adults (33,34). Hospitalization, nursing home placement, or death is more likely in older adults who are functionally dependent (35,36). Only 14% of older patients achieve partial or complete rehabilitation to normal activities of daily living, compared to 55% of younger patients who achieve complete rehabilitation (10,17,21,24).

Quality of life is another outcome measure used to evaluate the efficacy of home enteral nutrition in older adults. Although 50% to 75% of older patients say their quality of life improved with home enteral nutrition (13,37), many report being overwhelmed by the demands of the tube-feed regimen (13). Quality of life diminishes most as a result of disturbances in sleep, exercise, and social life (24,38). Travel and other activities outside the home are curtailed for the majority of older patients (24,38,39).

Results from quality of life studies also demonstrate the influence of tube feeding on psychological indexes. Depression, anxiety, fear, and anger are common emotional responses to initiation of home enteral nutrition (18,37). Altered body

image due to tube placement and loss of ability to eat, which cause psychological distress and social isolation, are the main reasons for these negative emotions (18,39). Agitation, due to anxiety and discomfort from feeding tubes, occurs in up to 33% of older patients and commonly leads to self-extubation (14).

### COMPLICATIONS

Along with poor outcomes, older patients often experience physical, technological, and metabolic complications. Wound infection, usually at the site of the stoma, is the most common major complication in older adults (9,10,12). Another complication related to the stoma is leakage of formula, which can be especially dangerous when the leak occurs intraperitoneally and increases risk of systemic sepsis (8,32). Stomal leak also contributes to malnutrition by loss of absorbable nutrients.

Pulmonary complications, which may result from improper tube insertion or aspiration of feeding formula, are potentially the most dangerous complications of tube feeding and occur in up to 59% of older patients (10). Aspiration pneumonia occurs most often in older dysphagic patients. It usually results in hospitalization and contributes to early mortality (8,10,14,40-43).

Diarrhea, the most frequently reported gastrointestinal side-effect, occurs in up to 97% of older patients (14,39,40). Although bacterial contamination, viral infection, hypoalbuminemia, or medication side-effects may cause diarrhea (40), it also indicates intolerance to home enteral nutrition. Diarrhea is a major clinical concern because it causes fluid and electrolyte losses, creates acid-base imbalance, produces skin breakdown, and inflicts patient distress. When caused by malabsorption it may also compound preexisting malnutrition by the extraneous loss of nutrients. Constipation, flatulence, vomiting, nausea, abdominal distention, cramping, and ileus are other frequent expressions of intolerance to home enteral nutrition in older adults (8,12,24,35).

Maintaining feeding tube access, that is, clearing tube blockage and avoiding tube displacement, are other common problems in older adults (13). Clogging of feeding tubes can be caused by inconsistent flushing of the tubing, medication administration through feeding tubes, or build-up of enteral formula residue. Loss of access can interrupt the feeding regimen, thereby delaying nutrient intake. Replacement of the feeding tube causes patient discomfort and adds to health care costs.

In addition, older adults are at risk for metabolic complications such as hyperglycemia, dehydration, azotemia, hypercapnia, and abnormalities of electrolytes and trace elements (44). The high prevalence of polypharmacy among older adults makes complications from drug-nutrient interactions another likely occurrence (45).

Although more than half of complications discussed here are resolved in the home, 20% require physician office or emergency room visits, and 9% to 15% result in hospital admission (6,11). The latter is 14 to 18 times more costly per day than home care (37). Fewer than 5% of actual deaths in older patients are directly attributable to therapy itself (6,10,11,21). Nevertheless, older patients on home enteral nutrition have a substantially lower 1-year survival rate than the expected survival rate of age- and sex-matched peers in the general population (54% vs 93%, respectively) (7,8,17). Comparing the 1-year survival rate (54%) for older patients to younger patients (89%) further elucidates the relationship between age and mortality (17,20). Those patients aged 75 years or

older have even more diminished outcomes with a 20% survival rate at 3 years (46).

Patients on home enteral nutrition are reportedly dissatisfied with the quality of home care they receive due to inadequate interactions with professionals who are knowledgeable in medical, nutrition, and infusion-related issues (47-49). Consequently, less than one-fourth of older patients are able to cope with their tube-feed regimen unassisted (8). Thus, they rely on considerable support from family caregivers (ie, immediate family members, relatives, friends, or neighbors) who voluntarily manage and monitor the majority of their daily therapy (20).

### CHARACTERISTICS OF TECHNOLOGY-DEPENDENT FAMILY CAREGIVING

During the 10-year period from 1987 to 1997 the prevalence of family caregiving in the United States tripled (50). Currently, family caregivers function as a large pool of unpaid home health labor in more than 54 million US households (50). Typically, family caregiving responsibilities include physical tasks like bathing and positioning care recipients or cleaning a wound, daily chores like housecleaning and shopping, technical tasks like changing an ostomy bag or administering injections, and making health care decisions like transporting their care recipient to an emergency room.

Family caregivers are also depended upon to provide emotional care and support. As family caregiving responsibilities progress, the demands of caregiving cause the nature of family caregiving to transform from a mutual caregiving-care receiving relationship to a more 1-way, dependent, intense, long-term obligation that may overwhelm the caregiver's life (51). In general, the chronic, intensive nature of family caregiving combined with conflicts arising from other demands on caregivers' lives (eg, work, family life, social, and recreational life) lead to an imbalanced state termed "caregiver burden" (51-55). Although the common characteristics of family caregiver burden have been described elsewhere (56), the demanding nature of technological home care adds another dimension to caregiver burden because many additional challenges confront these caregivers.

For example, caregivers of patients receiving home parenteral nutrition must master new, unique knowledge and skills, such as that required for utilizing aseptic technique, infusing nutrient solutions, manipulating tubes and equipment, responding to emergency care needs, understanding the mechanics of infusion pump mechanisms and alarms, and monitoring their care recipients' fluid and nutrient balance (49,57,58). While adapting to the parenteral nutrition regimen, family caregivers report physical fatigue, often to the point of exhaustion (59), and a great deal of frustration and anxiety from learning the array of tasks required for daily management and monitoring (57).

Caregivers also experience disruption in daily schedules. They have to negotiate with equipment vendors and insurance providers; arrange delivery schedules; maintain equipment, supplies, and nutritional formula; and coordinate the infusion regimen (50,58,59). In the same way that other types of family caregivers who find that chronic caregiving necessitates taking time off work by leaving work early, arriving late, or taking a leave of absence (52,53), nearly one-third of family caregivers find that managing parenteral nutrition interferes with employment by decreasing number of days worked or number of hours worked per day (60). Work absenteeism is a problem

shared by family caregivers of adults dependent on mechanical ventilation as well (61). Caregivers of both parenteral nutrition-dependent and ventilator-dependent persons have found that the demands of technological home care often require that they refuse promotions, take a lower employment status, or quit their jobs altogether (60,61). Overall, as the number of caregiving hours increases, conflicts with caregivers' daily schedules multiply (61).

Also like other family caregivers, technology-dependent caregivers relinquish their social lives, vacations, recreation time, hobbies, and time with friends (52,54,59,60). Social isolation is a source of caregiver stress due to lack of understanding and support from friends and society (60). Caregivers of patients on home parenteral nutrition report feeling socially ostracized when transporting their care recipients, who are often attached to infusion equipment or have visible tubes, in public (49). In addition to inadequate social support, technology-dependent caregivers lack other home and community-based resources including financial support, information, instructions, and skilled assistance (49,57,58,61).

The challenges, conflicts, and strains experienced by caregivers of technology-dependent persons result in negative emotional reactions to caregiving. Depression, loneliness, fear, anger, frustration, anxiety, and sadness are common responses (49,57,59-62). Depression and impaired ability to cope, along with duration of caregiving and financial strain, are associated with poor quality of life for the caregiver managing parenteral nutrition (58,60). Financial strain compounds caregiver burden because family caregivers spend approximately \$1.5 billion per month nationally as out-of-pocket expenditures related to care and treatment of their older care recipients (53). The disruption in caregivers' quality of life has been associated with burden in family caregivers of patients on home dialysis infusions also (63). For these caregivers, as burden increases, quality of life decreases (63).

Additionally, caregiver burden makes caregivers susceptible to physical and metabolic adaptations that impair their own health. Family caregivers experience physical injuries such as back strain, altered immune function, hyperinsulinemia, hypertension, insomnia, chronic fatigue, altered appetite, and body weight gain or loss (52,64-70).

### EFFECTIVE CAREGIVING

The concept of doing family caregiving well (71) or providing effective caregiving has been termed "caregiving effectiveness" and defined for technological caregiving by Smith (72) as "the provision of technical, physical and emotional care that results in outcomes of optimal patient quality of life and physical condition, minimal technological side effects for the patient, and the maintenance of caregiver's health and quality of life". Being equipped to do family caregiving well requires knowledge and skills in processes that resemble professional clinical skills: monitoring, interpreting, decision-making, taking action, making adjustments, providing hands-on care, accessing resources, working together with the care recipient, and negotiating the health care system (71). The level of skill needed by family caregivers is a necessary condition of the current system of health care delivery where family caregivers are responsible for the daily management of technological home care.

### CAREGIVERS' TRAINING NEEDS

At least three-fourths of family caregivers report interest in obtaining formal training in management of home medical

therapies (73,74). Primary educational needs identified by caregivers of adults with chronic diseases include how to manage caregiver tasks, the aging process, the nature and course of the care recipient's illness, how to administer medical therapies, signs and symptoms of side-effects, evaluating changes in the health status of the care recipient, stress management, and how to connect with community resources (52,54,73-75).

Educational interventions concentrating on management of home health care for other clinical therapies have demonstrated the effectiveness of training family caregivers. For example, individualized educational sessions conducted in care recipients' homes that focused on case management were effective in improving caregivers' knowledge as well as improving the overall caregiving experience (76). Educational sessions have also been conducted for family caregivers in small-group settings. These sessions improved caregivers' knowledge and skill levels, increased their health prevention behaviors (ie, exercising, eating and sleeping consistently, not consuming alcohol, and not smoking), and decreased their social isolation (69).

However, from 59% to 88% of family caregivers dependent on home care technologies receive no formal instruction despite the recognition that providing technological home care is a complex task requiring learned, trainable skills (53,73). Caregivers of patients on home parenteral nutrition learn by experience, obtain information from other family members and friends, or turn to the Internet for instruction (49). Lack of formal training leaves caregivers unprepared for the technical, physical, and emotional aspects of home care. This lack of preparedness adds stress to caregivers and predicts development of caregiver burden (77). Importantly, inadequate training may lead to mistakes and contribute to the development of serious complications and poor outcomes in the care recipient's medical and nutritional condition (72,74).

### IMPLICATIONS FOR HOME ENTERAL NUTRITION

The provision of home enteral nutrition for older adults aims to restore and maintain nutritional status. Concomitant goals include preventing hospitalizations and nursing home admissions, increasing functional independence, improving quality of life, and prolonging life in a safe and cost-effective manner (78,79). Benefits experienced by older adults include decreased length of hospital stay, reduced risk of nosocomial infections, and containment of health care resources (1,37). By providing treatment at home, home enteral nutrition has reunited older adults with family members and allowed them to regain a sense of independence and control over their daily lives (25).

Nevertheless, it may be caregivers who provide much of the physical aspects of enteral home care, including maintaining patency and flow of feeding tubes, using aseptic technique for stoma and skin care, and positioning care recipients to facilitate gastric emptying. Caregivers may be responsible for monitoring response to therapy, evaluating side-effects of treatments, and responding to emergencies (60). Like family caregivers of children on home enteral nutrition, caregivers of older adults need training to develop problem-solving skills to manipulate treatment and prevent complications, that is, to make the technology of home tube feeding work (80).

One of the greatest personal rewards for caregivers can be seeing improvement in their care recipients' health (53). However, the occurrence of multiple complications and poor out-

comes in many older adults on home enteral nutrition suggests that when faced with deterioration in their care recipients' health, and impairments in their own physical and emotional health, caregivers may themselves experience disruption in their quality of life comparable to that of their care recipients (60). When considering the high complication rates and poor outcomes that add to the already high costs of home enteral nutrition for older adults, it is apparent that education and training of family caregivers on daily management and monitoring is needed. The lack of educational programs for caregivers in home nutrition support, especially for caregivers of older adults receiving home enteral nutrition, is a serious gap in the delivery of safe and cost-effective health care.

## APPLICATIONS

- RDs in clinical practice should take a more active role in interdisciplinary rounds and discharge planning by developing evidence-based protocols that include immediate referral to an inpatient RD skilled in home nutrition support before discharge and referral for routine RD follow-up after discharge.
- Recognizing that family caregivers are an underserved population in need of education and skills training, RDs can develop practical, hands-on educational materials based on adult learning theories (81) that empower caregivers to provide effective technological home care.
- RDs in ambulatory care should establish evidence-based protocols for follow-up, monitoring, and reassessment of home care patients. This will enable RDs to make practical changes in the home nutrition regimen to prevent complications and improve outcomes.
- Dietetics curricula, including online courses, should incorporate home care topics, especially those pertinent to home-based interventions for older adults. Practical experience in home care can be a component of dietetic internships by developing partnerships with home health agencies.
- The American Dietetic Association report on home care practices (82) describes the need for RDs in home care, the skills RDs need to be successful in home care, the possible roles for RDs in home care, and approaches RDs can take to obtain home care positions. RDs can use participation in the Commission on Dietetic Registration's Professional Development Portfolio as an opportunity to expand their scope of practice into the field of home care by taking courses, attending workshops, and developing partnerships with home health agencies as consultants.
- The report on home care practices (82) also discussed the practice materials available for RDs in home care from the Dietitians in Nutrition Support and Clinical Dietitians in Health Care Facilities dietetic practice groups and the American Society for Parenteral and Enteral Nutrition. Along with information from other dietetic practice groups, including the Gerontological Nutritionists, Clinical Nutrition Management,

and Dietetic Educators of Practitioners practice groups, this practice report can be used as a framework for developing home care protocols and designing regional workshops to train RDs in skills necessary to be successful in acquiring jobs in home care.

- Utilizing the Institute of Medicine report (27), which highlights the paucity of meaningful data currently available in the field of enteral and parenteral support, nutrition researchers should design randomized, controlled clinical trials to collect data on health and cost-related outcomes such as readmission rates of older adult home care patients.
- All RDs should be actively involved in supporting the expansion of Medicare coverage of MNT into home enteral and parenteral therapy.

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