A model of caregiving effectiveness for technologically dependent adults residing at home

Caregiver–care-receiver interactions unique to this model of caregiving effectiveness were tested longitudinally in a randomly drawn national sample of 111 caregivers. Path analyses results indicate that variables explain variance in caregiver and patient quality of life, patient condition, and technological side effects. These findings extend nursing knowledge related to caregiving motivation-to-help and mutual interactions and thus have implications for home care practice. Effective family caregiving of loved ones dependent on technology for survival can result in enhanced patient condition, return to work, normalization of family life, and for society a reduction in health care costs. Key words: *caregiving, parenteral nutrition, quality of life, technology*

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NURSES WORKING in home health care need to be able to identify variables leading to effective caregiving in the escalating numbers of families managing complex technological care at home. Specifically, home care nurses could benefit from a model describing effective family caregiving.[1] To be clinically relevant for guiding nurses' practice, models depicting family caregiving with adults dependent on technology for survival must include variables that predict outcomes for both the patient and caregiver. In these families, patient and caregiver interactions lead to effective home caregiving. *Caregiving effectiveness* is defined as the provision of technical, physical, and emotional care that results in outcomes of optimal patient quality of life and physical condition, minimal technologi-

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cal side effects for the patient, and the maintenance of the caregiver's health and quality of life.

Previous models and conceptual frameworks describing caregiving in the home have been based on care of cognitively impaired, frail elderly, or severely and terminally ill individuals.[2,3] These frameworks confirm the effects of caregiver depression, poor health, and financial strain on the outcomes of caregiving[4] and illustrate that patient education and positive reactions to caregiving are associated with improved outcomes. However, frameworks for the frail or terminally ill are not directly applicable in clinical practice with family caregivers of technologically dependent adults (those requiring a medical device and ongoing nursing care to sustain life). Knowledge is needed about family home care management for technologically dependent patients[5,6] who are not cognitively impaired and who participate in their own complex home care.[7]

Concept analysis, preliminary studies,[8-10] and longitudinal testing of a model of caregiving effectiveness in families with an adult member dependent on total parenteral nutrition (TPN) were undertaken to generate knowledge about home technology care and to meet this standard of clinical relevance. This study used path regression analyses to determine which variables explained significant amounts of variance in caregiving effectiveness outcomes for this population.

BACKGROUND AND LITERATURE

The number and acuity of patients at home have increased 17% to 25% annually over the past decade.[11] Cost containment; early hospital discharge; and advances in parenteral nutrition, mechanical ventilation, chemotherapy, epidural infusion, dialysis, and technological monitoring for pulmonary or cardiac status all strengthen this trend.

Caregivers provide physical and technical nursing care, organize needed home care clinic or laboratory services, manage equipment and supply inventories, and negotiate with third-party payers.[12] Both caregivers and patients make complex clinical judgments about the day-to-day impact of the technological treatment. The stringent treatment schedule leaves little, if any, time for normal routines or social activities. Even with these caregiving demands, the vast majority of reactions to technological dependence are positive. There are dramatic improvements in the patient's physical condition, activities of daily living, and prognosis for longevity, as well as lessened caregiver worry or strain. In fact, after technological treatments are begun, many caregivers spend fewer hours in caregiving than when the patient was debilitated by the disease. Research results substantiate families' strong preference for home technological care.[13,14]

Caregiving research

Several researchers indicate that caregiving characteristics such as age, hours per day of care, cumulative years of caregiving, and availability of resources predict patient and caregiver outcomes.[15] Investigators also demonstrate that the quality of the relationship between patient and caregiver is related to caregiving outcomes.[16-19] The quality of the relationship can include emotional investment, shared activities, affective states of closeness, and gratification. Mutuality, a measure of gratification and reciprocal benefits in a relationship, has been verified to lessen caregiving role strain.[16] Positive caregiving outcomes are also associated with adequate income, family coping, and esteem gained through caregiving and can be related to effective care.[20,21] Caregivers' positive reactions to caregiving and their motivation to help patients influence their own quality of life as well as their ability to provide care effectively.

Researchers find that declining physical or mental health status, financial difficulties due to the expense of technology, and loss of employment due to caregiving responsibilities are all associated with poor caregiving outcomes.[4] Economic stability of the family has also been identified as a major factor influencing the amount of tension in the family, and thus the quality of life.[12] Finances are an especially pressing concern for those dependent on TPN, since the average annual costs of therapy range from $150,000 to $200,000. These costs force the majority of patients to declare a medical disability, although their improved physical condition during treatment would allow them to return to work.

Situation depression (related to social isolation, financial strain, and worry over patient condition) is negatively associated with caregiving outcomes and can escalate to a major depressive disorder. Clinical observations indicate that situation depression is characterized by an inability to concentrate, possibly contributing to poor aseptic technique and touch contamination, a major source of sepsis.[22]

Motivation-to-help research

Motivation to help is defined as one person's underlying reason for assisting another.[23] Theorists propose that there are distinct types of helping motivations that are related to either empathy or personal distress. Empathic motivation is the desire to see the other person's needs met. Personal distress motivation is the desire to see the other's needs met so that one's own distress is reduced.[24–26] By classifying subjects' major type and by quantifying amounts of motivation to help, researchers can predict helping behavior.[27] In home care practice, nurses who understand caregiver motivation to help and patient response to help can intervene to ensure more effective help.

Prosocial or helping behavior theory assumes that reinforcing the motives of a person to help provides the impetus for continued effective helping and that the response from the care receiver, whether positive or negative, influences helping as well. The self-esteem–based theory of accepting aid posits that people with low self-esteem will perceive assistance as threatening and will respond negatively to help, while those with high self-esteem will respond positively to aid.[28,29] Patients responding positively to help might exhibit acceptance, reciprocal caring, or simply show gratitude for being valued and cared for by the caregiver. Patients rejecting help might try to maintain control decisively or show anger.

Patient education research

Approximately 2% of annual rehospitalizations of TPN patients for complications require reteaching techniques of technological care.[30] Patient education appraisal is defined as the caregivers' perception of how well prepared they are for managing home care. If caregivers perceive that they are well prepared, there is lower caregiver strain.[16,31] The greater the degree of preparedness, the more likely caregivers will have confidence and gain caregiving esteem, which are associated with positive caregiving outcomes.[21] Caregivers who feel prepared will better manage change and extensive learning, resulting in greater life satisfaction and overall quality of life. Patients who must adhere to strict technological procedures for survival and caregivers who must learn the complex technological treatments are required to make significant change. The magnitude of change perceived by the caregiver may negatively affect his or her capacity to learn reactions to caregiving and his or her ability to provide effective care.[14,32]

Research literature in the areas of caregiving, motivation to help, and patient education provides justification for the concepts and variables selected for measures in this model. The concepts are organized into caregiving context (environmental variables) and adaptive context (mediating variables)[33] and are based on the empiric relationships described in the literature.

CAREGIVING EFFECTIVENESS CONCEPTUAL MODEL

The equation across the top of the model shown in Fig 1 represents the joint influence of the caregiving context and the adaptive context variables on caregiving effectiveness. Caregiving effectiveness is represented in the right-hand column of the model by the four variables of caregiver and patient quality of life, patient physical condition, and technological side effects. The caregiving context, in the left-hand column, includes the caregiving characteristic variables as well as the quality in the relationship (mutuality) between the patient and caregiver. Caregiving–care-receiving interactions include caregiver motivation to help and patient self-esteem, which have been associated with giving and accepting help. These variables are enclosed in an ellipse, since they are unique to this model of caregiving. Patient education appraisal, the last variable in the right-hand column, is the caregiver rating of the preparedness and the magnitude of change experienced following initiation of TPN home care. The adaptive context, in the middle column of the model, includes mediating variables of family economic stability, caregiver health status, caregiver perceptions of family adaptation, and reactions to caregiving. Posits in the model are that variables in the caregiving context influence the adaptive context variables and thus lead to caregiving effectiveness. The diagonal arrows depict the empirically or theoretically based connections between the caregiving and adaptive context variables. The bracket and the four dashed arrows on the right represent relationships tested in the study as guided by the following research questions:

- What are the strengths of the relationships, singly and in combination, among caregiving and adaptive context variables?
- What are the strengths of the relationships, singly and in combination, among caregiving and adaptive context variables and the four measures of caregiving effectiveness?

Caregiving–care-receiving interactions include caregiver motivation to help and patient self-esteem, which have been associated with giving and accepting help.

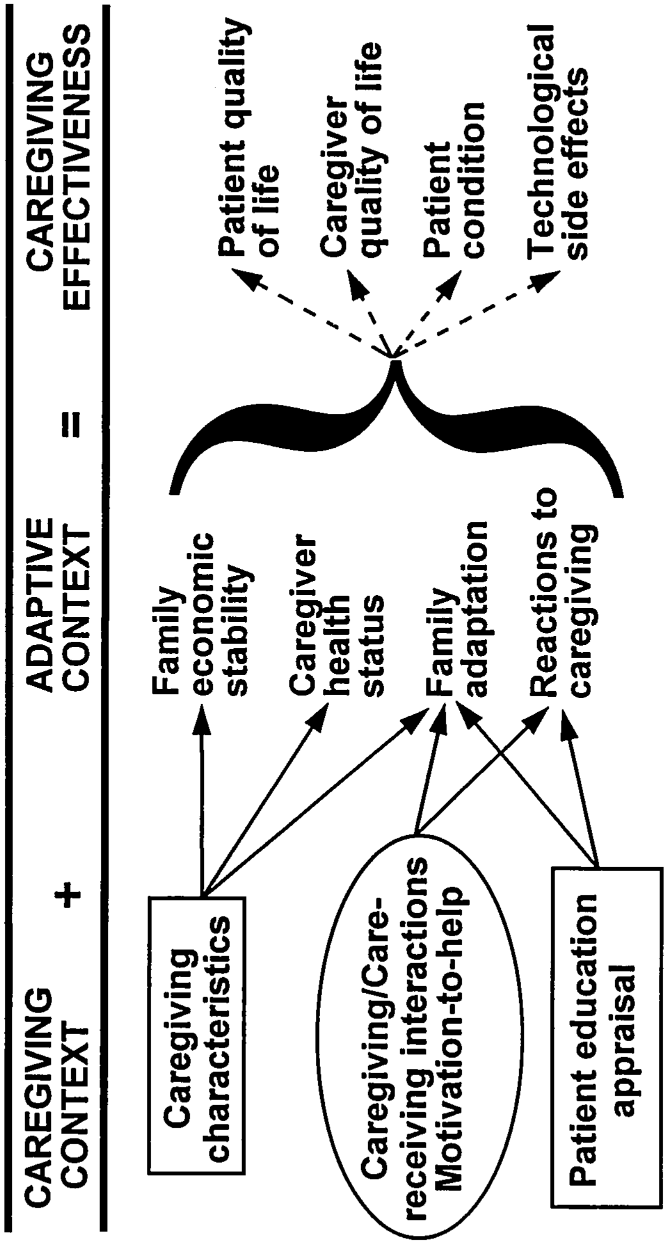

Fig 1. Model of caregiving effectiveness.

METHODOLOGY

Descriptive correlational design using telephone interviews and mailed questionnaires from caregivers and adult patients was selected to test the model. Following Institutional Review Board approval, a national sample was randomly drawn from lists of families receiving care at one of four academic health centers, four teaching hospitals, and eight infusion agencies across the United States. Of the 343 caregiver–patient dyads who gave permission to be contacted, 178 were interviewed using a semistructured guide. Following interviews, 121 caregivers and 116 patients returned questionnaires (67% return rate). There were 111 questionnaires returned from matched pairs of caregivers and patients residing in the same household. One year following receipt of the first questionnaire, a second was mailed to the matched pairs. There were 44 matched pairs who returned this longitudinal survey. Five patients had died, and three families could not be located (40% return rate). Analysis of anonymous responses from those choosing not to participate, as well as those not returning questionnaires, revealed no significant differences between nonparticipants and study subjects. Nurses indicated reasons for nonparticipation as too busy, too ill, or too overwhelmed. There were an equal or greater number of subjects in the sample who characterized themselves with these same terms.

Subjects

The sample used to test the model was the 111 caregivers (52.3% female) from the dyad pairs, who ranged in age from 21 to 87 years (mean = 52.5). The 111 patients ranged in age from 19 to 85 years (mean = 52.0). Patients required lifelong TPN for nonmalignant gastrointestinal disorders such as Crohn's or ischemic bowel disease. All caregivers were related to the patients; 84 were spouses. Patients' and caregivers' gender was almost equally spread between male and female. The average daily care provided was 4.2 hours (SD = 7.73). Caregivers reported managing home TPN for a mean of 4.6 years (SD = 4.8; range, 1 month to 20 years) for patients who had intravenous feedings infused over 8 to 24 hours each day.

Instruments

The measures used in the study are listed and described below in relation to the variables tested in the model. All patient data were reported elsewhere[8]; only three patient variables were used for model testing: (1) the patient Quality of Life Index score,[34] (2) the self-esteem score, and (3) the mutuality score.

Caregiving effectiveness measures

Quality of Life Index

The Quality of Life Index, a 70-item index that measures perceptions about health and function, socioeconomic status, psychologic–spiritual status, and family life was used for both patient and caregiver.[34] Internal consistency on subscales and overall scores have been reported to have alpha coefficients greater than .66 and in this sample ranged from .83 to .91.[35]

Patient physical condition and technological side effects

Patient physical condition was measured by the following information: energy to carry out everyday activities, presence of debilitating diarrhea, maintenance of weight, and self-rated improvement since starting TPN. Technological side effects were measured by frequency of line or catheter site infection, frequency of rehospitalization over the previous year, and presence of TPN concomitant illness such as hepatic or bone disease.

Caregiving context measures

Caregiving characteristics

Measures of caregiving characteristics included the caregivers' estimate of daily hours of caregiving routinely provided, age, family income, and cumulative length or months of caregiving.

Quality of relationship

The quality of the dyad relationship in both the patients and the caregivers was measured by a 15-item scale called "mutuality."[16] *Mutuality* is defined as the ability to find gratification and reciprocal benefits in the relationship with another person. A high mutuality score indicates one partner perceives he or she shares love, attachment, experience, and reciprocal meaning in the relationship with the other. This instrument was tested for construct validity and reliability. The alpha coefficient was reported at .70 and for this study was .94.

Caregiving–care-receiving attribute measures

Helping motivation

The Index of Empathic Concern and Personal Distress, a 14-item Likert-type scale, was used to measure the caregivers' type and amount of motivation to help.[24] The empathic concern motivation-to-help subscale measures the desire to see the other person's needs met. The personal distress motivation-to-help subscale measures the desire to see the other's needs met so that one's own distress is reduced. Factor loadings of .60 or greater on the subscales established construct validity. Alpha coefficients have been reported to range from .79 to .94 and in this study were .80 and .90.

Patient's self-esteem

Rosenberg's Self-Esteem Scale was used in this study to measure self-esteem as an indicator of patient's self-worth.[36] This 10-item scale was developed by National Institute of Mental Health staff and has extensive use as a measure of self-worth. Items include perceptions about self-pride, satisfaction, respect, and usefulness. Alpha coefficients have been reported to range from .95 to .99 and in this study were .88.

Patient education appraisal measures

Preparedness

Preparedness is the caregivers' appraisal of their ability to manage the physical, emotional, and other needs of caring for the patient at home.[16] This five-point Likert scale has been tested for reliability and validity. Alpha coefficients have been reported to range from .67 to .70 and in this study were .88.

Magnitude of change

Cantril's[37] Self-Anchoring Scale, which distinguishes among present, past, and future life satisfaction, was used to measure the amount of change experienced before and after TPN was begun at home. This instrument has been tested in various chronically ill populations and found to be reliable for comparisons between groups and over time.[38]

Adaptive context measures

Family economic stability

Caregivers rated their incomes based on their ability to get along on a monthly income scale of "I can't make ends meet" to "I always have money left over." This scale has been used in other studies as an indicator of perceived income adequacy and found reliable with an alpha coefficient of .85.[39]

Caregiver mental health

The Center for Epidemiologic Studies Depression Scale (CES-D) was used to measure caregivers' mental health condition.[40] The CES-D is a 20-item scale that measures cognitive, affective, and behavioral aspects of depression in nonpsychiatric populations and represents situation-based depression. The alpha coefficient for this study was .89.

Caregiver Reaction Inventory

The Caregiver Reaction Inventory measures factors that influence reactions to caring for ill family members.[21] This Likert-type scale has established construct validity using factor analysis of large samples; factor loadings of .35 or greater are achieved. Alpha coefficients on the five subscales (lack of family support, caregiving esteem, impact on daily schedule, impact on finances, and impact on caregiver physical health) are reported to range from .66 to .95 and in this study range from .60 to .80.

Family Crisis Oriented Personal Evaluation Scales (F-COPES)

F-COPES was developed to measure the coping strategies and problem-solving approaches used by families in response to problems or difficulties.[20] Construct validity and reliability have been established for the five subscales (acquiring social support, accepting help, passive appraisal, spiritual support, and reframing family problems). The alpha coefficient was reported as .86 and for this study was .81.

Family Adaptability and Cohesion Evaluation Scales (FACES-III)

FACES-III[41] is a 20-item instrument used to measure family cohesion, or the degree to which family members are separated from or connected (emotionally bonded) to the family, and family adaptability, or the extent to which the family system is flexible and able to change. Both adaptability and cohesion were considered as separate measures. Alpha coefficients were reported as .62 and .77 and for this study were .85 and .87.

DATA ANALYSIS

Path regression analysis was used to test the model. Four separate regression analyses were used to estimate the direct and indirect effects of the caregiving and adaptive context variables on each of the four dependent variable measures of caregiving effectiveness. The standardized regression coefficients (path coefficients or β scores) were calculated using a set of ordinary least squares regression equations. Prior to model testing, as a control for multicollinearity, the criterion of correlation coefficient upper limit of .50 and tolerance greater than .01 was used to eliminate redundancy. No variables in the model exceeded this criterion. Graphic residual analysis was used to test the assumption of normality. To be considered as having a clinically relevant effect on caregiving effectiveness outcomes, variables had to explain at least 3% of the variance at the .05 level of significance. Descriptive and bivariate statistics were calculated for variables.

RESULTS

Caregivers' mean scores on all measures were within the ranges published for healthy adults. Patients' mean quality of life scores were below those reported for healthy adults but were consistent with scores reported for patients on hemodialysis, peritoneal dialysis, liver transplant, or chemotherapy.[42] There was a wide spread of scores on all measures, indicating that the sample included caregivers with low and high ratings on the variables measured.

Tables 1 and 2 display the direct and indirect effect results that accounted for 33% (adjusted R^2 = .33) of the variance in caregivers' and 43% (adjusted R^2 = .428) of the variance in patients' Quality of Life Index scores. Direct effect results accounted for 17% (adjusted R^2 = .173) of the variance in patient physical condition and 27% (adjusted R^2 = .270) of the variance in technological side effects. Only one variable in the model, length of caregiving, accounted for variance in technological side effects.

Several caregiving context variables explained variance in adaptive context variables and had indirect effects on caregiving effectiveness. Caregiver situation depression was explained by the helping motivation of personal distress as well as the length of time in caregiving. Caregiver family coping was explained by mutuality. Caregiving esteem was explained by mutuality, empathic-concern helping motivation, and age. The significant effects are all in the expected direction and conform to the original model configuration. Variables in the model that did not meet the .05 level of significance were patient mutuality toward the caregiver, family income, family adaptation and cohesion, and caregiver reactions (other than caregiving esteem).

The longitudinal survey sample size precluded path analysis, but regression coefficients from variables that met the .05 level of significance were used to generate predicted caregiver and patient quality of life scores for the longitudinal survey. The predicted scores

Table 1. Direct and indirect effects on caregiver Quality of Life Index

Variable	Direct effect	Indirect effect	Total
Economic stability	.252		.252
Family coping	.418		.418
Depression	–.202		–.202
Age	.188		.188
Mutuality	.296	.118*	.414
Length of caregiving	.231	.059†	.290
Personal distress		.066†	.066

*Indirect effect through family coping.

† Indirect effect through depression.

Table 2. Direct and indirect effects on patient Quality of Life Index

Variable	Direct	Indirect	Total
Length on total parenteral nutrition	.179		.179
Family coping	.289		.289
Patient self-esteem	.506		.506
Caregiving esteem	.193		.193
Caregiver mutuality		.069*	.069
Caregiver age		–.030*	–.030
Caregiver empathic motivation		.047*	.047

* Indirect effect through caregiving esteem.

were correlated with each actual caregiver ($r = .49$, $P = .0001$) and patient ($r = .53$, $P = .0001$) quality of life score from the longitudinal survey. These moderately strong associations indicate that the variables explaining variance in caregiving effectiveness outcomes are consistent over time.

DISCUSSION

This model testing extends the knowledge of caregiving by exploring helping motivation and caregiver–care-receiver interactions. Overall, in this sample, length of time in caregiving, preparedness, motivation to help, mutuality, income adequacy, family coping, and situation depression are the salient variables associated with the caregiving effectiveness outcomes. Although the longitudinal sample size is small, the moderate associations over time indicate that the relationships tested in the model consistently predict quality of life outcomes.

Patient side effects and physical condition

Technological side effects were explained by length of time on TPN in a negative association, which is consistent with reports that more complications occur within the first 2 years of treatment.[30] None of the patient education variables explained variance in side effects, yet national registry TPN data indicate that a need for reteaching accounts for 2% of annual rehospitalizations.[43] Measures of patient education variables in future model testing will be expanded to include this reteaching need, particularly in the areas of aseptic technique and monitoring for symptoms of infections.

It is noteworthy that both the patient education appraisal variables (preparedness and magnitude of change) and caregiver motivation to help explained variance in patient physical condition. Preparing caregivers to anticipate changes that caregiving will bring in their lives, as well as how to manage the patients' physical, emotional, technical, and home health care needs, does influence the patients' physical condition.

The patients' physical condition was negatively associated with the caregivers' personal-distress motivation to help (helping to reduce one's own anxiety). The possibility that a distressed, anxious caregiver has a deleterious effect on patient condition is plausible and deserves further scrutiny. Clinically, home care nurses must continue to assess for caregivers who may need assistance with their own anxiety. Empathic-concern motivation to help has a positive yet indirect effect on the patients' quality of life. The findings support the supposition that both types of motivation to help are important factors in caregiving that relate to the patients' physical condition and quality of life.

Patient quality of life

Patient quality of life was explained by caregiving esteem and self-esteem, as well as family coping and the cumulative length of caregiving. A significant and unanticipated finding was that caregiving esteem contributed variance to patient quality of life. Caregiving esteem items included "I really want to care for ______," "I enjoy caring for ______," and "Caring for ______ makes me feel good" and "is important to me." Possibly, caregivers' responses to these items represent a positive attitude toward caring that was conveyed to the patients and enhanced the patients' quality of life. The study results confirmed the supposition that patient self-esteem would explain quality of life and that subjects with higher esteem would have greater quality of life scores. Family coping and length of caregiving (synonymous with time on TPN) were associated with quality of life. Conceivably, as the patients' health improves the longer they are on TPN, family coping also improves.

Caregiver quality of life

Caregiver and patient quality of life were similarly affected by family coping, age, and length of caregiving. Caregiver quality of life correlated positively to economic stability and negatively to depression. The perception of economic stability and adequacy of income per month was significant. Even the highest incomes did not cover home infusion costs ($150,000 yearly). Fluctuating reimbursements, costly rehospitalizations, and the loss of days from work were reported as common causes of caregivers' situation depression.

The caregiving context variables that had direct effects on caregiver depression, and thus indirectly decreased their quality of life, were length of time caregiving and amount of personal-distress motivation to help. In contrast, empathic motivation to help (and mutuality) had positive effects on caregiving esteem, indirectly enhancing patient quality of life. The reciprocal benefits the caregivers perceived and the caregivers' empathic-concern motivation to help appeared to enhance their own as well as the patients' quality of life. A greater understanding of the contribution of empathic concern to patient quality of life should emerge as qualitative study methods are used to explore relationships between mutuality and motivation to help. Further study will examine these relationships in light of recent theoretical analyses of empathy in nursing literature.[44–46]

Findings in the adaptive context related to income adequacy and situation depression are similar to findings in other caregiving studies. These data support the contention

Preparing caregivers to anticipate changes that caregiving will bring in their lives, as well as how to manage the patients' needs, does influence the patients' physical condition.

that families who use a variety of coping strategies function more effectively than those who use only one strategy exclusively. Verifying the association of mutuality to family coping, however, is new information. Further analysis to identify feedback loops between caregiving and adaptive context variables in the model is being planned.

Implications for nursing

Home care nurses have observed the link between negative caregiver–care-receiver interactions and patient complications, while positive interactions have been associated with increased compliance[47] and quality of life.[13] The implications of these data are that home care nursing practice can enhance caregiving effectiveness by supporting mutuality, caregiving esteem, and preparedness. Nursing interventions to enhance mutuality have been found effective in caregivers of adults with Parkinson's disease and could be applied in this population.[48] Nurses will also want to assess the impact of preparedness, magnitude of change, and length of caregiving as influences on patient condition and side effects. The measures of the variables used in this study are short Likert scales that could be incorporated into a clinical assessment guide.

Unlike other caregiving studies, the hours per day of caregiving were not significant.[4] The low mean number of hours (4.2) was related to the involvement of patients in their own care once they were feeling well. Nurses need to consider that even those few caregiving hours do cause difficulty with work schedules, sleep disturbances (infusion throughout the night), and loss of social activities.

Knowledge gained in this model testing about the significant impacts of income adequacy and situation depression indicates the need to assist families in dealing with the unpredictable economic and health status of technologically dependent adults. Nurses need to advocate financial counseling, which has been shown to decrease strain due to perceived inadequate income and lessen depression related to worry over expenses.[49,50]

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Many families in this study described a dramatic improvement in patient condition and family coping. In one family, the wife and mother was suffering from Crohn's disease and required TPN to sustain life. Along with her data, she mailed in photographs and lengthy letters from her husband describing not only his technological care responsibilities and motivation to help his wife, but also his reliance on her for monitoring her symptoms and observing for side effects. Letters from her teenage son expressed thankfulness for the technology. His mother had gained the strength to dress herself, bake his birthday cake, and use the device he had made allowing her to take her TPN equipment on their camping trips. This family was describing their mutuality, motivation to help one another, multiple family coping strategies, and the technologically dependent adult's ability to return to her highest potential level of health and functioning. Replication of this model testing with other technologically dependent populations is needed. It is hoped that this model will guide nurses working with technologically dependent populations to assess the caregiver–patient–family interactions to enhance caregiving effectiveness and, ultimately, quality of life.

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