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## Complex Home Care: Part III-Economic Impact on Family Caregiver Quality of Life and Patients' Clinical Outcomes

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### Abstract

These goals for this data collection were to use structural equation modeling to analyze the financial and emotional costs of complex home care. These findings identified significant relationships among family income adequacy patients' and caregivers' quality of life as well as patients' clinical outcomes and caregivers' mental health. Qualitative data supported quantitative findings that economic stress was the strongest factor affecting quality of life. This series of articles first identified the frequency and costs of health care services use, the associated non-reimbursed costs and finally related costs of complex care to clinical outcomes and quality of life in 80 families managing complex care.

### Keywords

Home Parenteral Nutrition; Family Caregiving; Cost; Home Care; Health Services; Complex Chronic Care

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Family caregivers perform a significant role in the care of patients with chronic illnesses and prescribed life-long complex home care treatments. For example, management of home parenteral nutrition (HPN) requires extensive time commitment and expertise for the daily 12 hour intravenous infusions on the part of family caregivers (Smith, 1993; Smith, 1994; Winkler, Ross, Piamjariyakul, Gajewski, & Smith, 2006). HPN is complex therapy with

risks for severe complications, such as intravenous related blood clots or infections (DiBaise & Scolapio, 2007). Yet patients are often sent home with family caregivers who have received little training or information about this complex therapy (Ellins & Coulter, 2005; Smith, 1999; Smith, Moushey, Ross & Giefer, 1993; Winkler, Ross, Piamjariyakul, Gajewski, & Smith, 2006).

## Background

Family caregivers of patients on HPN must procure, prepare, and infuse nutrient solutions through central venous catheters each night over 12 to 14 hours while adhering to stringent aseptic technique (Ireton-Jones & Delegee, 2007; DiBaise & Scolapio, 2007). Additionally, caregivers are expected to assess signs and symptoms and access appropriate health service providers at the appropriate time (McCloskey & McCarthy, 2007).

Providing home care for someone with a chronic illness can impact caregivers' physical and psychological health (Huisman-de Waal, Schoonhoven, Jansen, Wanten & Van Achterberg, 2007; Schulz & Sherwood, 2008). Gaskamp (2004) also found that constant reduction in health care coverage across time was associated with decreased quality of life and increased depression among HPN patients and their family caregivers. Also notable is a Canadian national study that found low income HPN patients who required welfare assistance experienced significantly increased risk of catheter related sepsis rates compared to those with average or above average incomes (Chang, et al., 2005).

Family caregivers managing HPN often report episodes of depression, fatigue, social isolation, sleep deprivation, and poor self-esteem associated with HPN (Silver, 2004; Smith, 1993; Smith, Moushey, et al., 1993; Smith, Kleinbeck, Boyle, Kochinda, & Parker, 2001). Huisman-de Waal, and colleagues (2007) reported a review of the daily life of HPN patients and caregivers. The review identified factors that impact quality of life including distress over managing complex HPN care, disrupted social activities, depression and fatigue, withdrawal of family or friends and even lost employment. These and other economic factors have been included in an evidenced-based practice framework of family caregiving (Smith, 1994). The purpose of this study was to determine the impact of family caregivers' characteristics and caregiving context variables on the patients' and caregivers' quality of life.

## Evidence-Based Framework Guiding This Study

The family home caregiving framework (Smith 1994) guiding this study has been empirically replicated in multiple HPN family studies over two decades (Smith, 1999; Smith, Pace et al, 2002; Winkler, et al., 2006). In each replication of the model, caregiver characteristics of esteem, depression, physical and mental health and in the context of caregiving (i.e. preparation for HPN home care and family income adequacy) have predicted patient outcomes (Smith, 2007; Smith, Leenerts, & Gajewski, 2003). This framework, defines home caregiving effectiveness as the caregiver's provision of technical, physical, and emotional care resulting in optimal patient outcomes while maintaining caregiver's and patient's quality of life (Smith, Mayer, Perkins, Gerald, & Pingleton, 1994). This family home caregiving framework was used to guide data collection and conduct structural equation modeling.

## Study Design and Methods

A semi-structured telephone interview pertaining to family caregiving and caregiver health was conducted at a time and date convenient to subjects. The interviewers included the patients and caregivers and were completed over the telephone by well trained research

nurses familiar with HPN and home care. Data were also collected on the occurrence of intravenous catheter infections, the most life-threatening and costly side effect of HPN.

## Sample

Eighty families managing home HPN were enrolled in this Institutional Review Board approved study. Subjects were  $\geq 18$  years of age and included family caregivers and patients who were prescribed lifelong HPN therapy to treat life-threatening malnutrition resulting from non-malignant bowel disorders. Families were recruited through HPN home care infusion agencies and Oley Foundation which is a HPN Family advocacy non-profit 501(c)(3) organization.

Clinical outcome data for this study were completed by 78 family caregivers and 65 patients. Participating subjects represented diverse socioeconomic levels. Family income per patient reports ranged from \$3,000 to greater than \$200,000 per year with a mode of between \$40,000 and \$49,000 per year. Specifically, one patient reported their total family income for the year as \$3000, and the remainder was all above \$10,000 annually. The subjects in this sample ranged in age from 29 to 82 ( $SD \pm 13$ ) years with a mean age of 49 years for caregivers and 50 years for patients. One third (33%) of the patients and 42% of caregivers were male.

All patients selected white as their race except 1 African-American, which is typical since 97% of those with Crohn's and other illnesses leading to HPN are Caucasian (Crohn's/Colitis Foundation of America, 2010). The caregivers were 89.7% ( $n=70$ ) white, 5.1% ( $n=4$ ) Hispanic, 1 caregiver was American Indian/Alaskan Native and 1 Asian while 2 reported their race as "other". Sixty-eight percent of these caregiver subjects were employed; 16% were retired; only 27% of patients were employed (55% were medically disabled, thus unable to work). The education range of caregivers included college graduates (65%), completed some college (21.7%), and having completed 8–12 years of schooling (12.9%). The average length of time participants had provided home care to HPN patients was 8.8 years ( $SD \pm 8.04$ ).

## Measures

Table 1 lists the questionnaires and operational definitions that measured the caregiving and outcome variables in this research study. The outcome variables consisted of the patient and caregiver quality of life scores and the patient HPN catheter-related bloodstream infection occurrence. The family caregiving variables were: (1) Family caregiver characteristics: depression, physical and mental health, daytime sleepiness and esteem gained from caregiving; and (2) Caregiving context variables were: length of time providing home care, preparedness for caregiving, participation in problem-solving in HPN home care, and family income adequacy. In this sample each questionnaire had a Cronbach's alpha of 0.81 or greater indicating a high degree of internal consistency reliability.

## Data Analysis

Frequencies, means, standard deviations, and correlations among the variables measured by the questionnaires were determined using SPSS (Version 16, 2007). Structural equation modeling was conducted with the Mplus Version 5 (Muthén & Muthén, 2007) software to determine the association of the caregiver characteristics and caregiving context variables on the quality of life and patient clinical outcomes (Kline, 2005). Content analysis (Krippendorff, 2004) was used to summarize the subjects' qualitative responses to the interview questions.

## Results

### Description of Family Caregiver Characteristics

Table 1 provides the mean and standard deviation for caregiver characteristics and the caregiving context measures as well as quality of life and the patient clinical outcome. Thirty-four percent of caregivers were ranked moderately to severely depressed, and 15% reported receiving counseling for depression. It is notable that out of 78 family caregivers, 46% scored in the moderate to high daytime sleepiness category. The mean physical health score was at the national average for caregivers in this study, however, their mental health score was 5 points below the national average. Although the mean preparedness scores suggest that caregivers overall felt prepared to manage the complex HPN home care, 14.3% of caregivers rated themselves as ‘not at all’ or ‘only somewhat’ prepared. Over one-third (36%) of caregivers “rarely” had money left over after paying bills.

Data were also summarized to describe the general health status of HPN caregivers. Of 78 family caregivers, 18% reported being hospitalized in the last year for a variety of reasons including gastrointestinal complaints, renal abnormalities, chest pain, stroke, migraine, cancer, minor surgery, or orthopedic problems. One-third of caregivers reported receiving cardiac medications, 12% reported taking medications for anxiety, 11% reported taking sleep medications, 18% reported taking depression medication, and 15% reported taking medications that were not classified within the above categories.

### Structural Equation Modeling (SEM)

Structural equation modeling (SEM) was undertaken to examine the relationships among the caregiving variables and the combined outcome variables, referred to as the latent variable, of (1) patient quality of life, (2) caregiver quality of life, and (3) patient HPN-related bloodstream infection occurrence. In our previous testing with families managing home technology care in samples exceeding 200, we have consistently found that SEM combines these three outcomes. This latent outcome is labeled “Technology Related Quality of Life” because the variable encompasses both patients’ and caregivers’ quality of life scores along with the most common HPN technology side-effect, patient blood stream infection. Previous testing of this caregiving framework with other HPN samples has identified relationships between caregiving variables and the subsequent patient and caregiver outcomes (Smith, 1994; Smith, Pace et al., 2002). The advantage of SEM is that it allows for the examination of simultaneous effects of multiple caregiving variables on the combined outcome measures. Further, by simultaneously combining variables and using multiple sets of equations, SEM controls for measurement error. Further, SEM has the advantages of establishing parsimony by combining correlated variables (Kline, 2005).

The caregiving variables within this sample’s SEM statistical analysis accounted for 86% ( $R^2=.86$ ) of the variation in the patient and caregiver latent outcomes of technology related quality of life. This is similar to the 88% of variance explained in the latent outcome in the other technology dependent patients and their caregivers (Winkler, Ross, Piamjariyakul, Gajewski, & Smith, 2006). As the model fit analyses indicate, data from this sample had no deviations from similar variable and outcome associations predicted in the previous framework based studies.

In this sample, the best statistical model fit had two significant variables including the caregivers’ mental health status and the caregivers’ income adequacy ratings (ability to pay bills or not). Thus, caregivers’ mental health and their rating of the family income adequacy were associated with the combined latent outcome (i.e. infection occurrence and patient and caregiver quality of life). The clinical relevance of the caregivers’ mental health and families’ financial adequacy was also reflected in the interview data.

## Content Analysis

Content analysis (Krippendorf, 2004) was performed using transcription of the open-ended interview responses and the anecdotal data reported by patients and their family caregivers. First, all statements responding to HPN caregiving experience questions were tabulated. Then, the statements were evaluated independently by two researchers, who grouped the statements with similar content into topic sub-categories. There were only two disagreements on sub-category coding. These two were resolved per clarification between the two raters resulting in subsequent 100% inter-rater reliability (100% agreement).

These sub-categories were then grouped into two major themes, agreed upon by nurse investigators. These two major themes that emerged from these data were economic stress and psychological and emotional stress. These two themes and topic sub-categories, including examples of subjects' own words, are presented in the following section. These findings aligned with others studies and review articles (see discussion).

**Economic Stress**—Economic stress was the most frequent concern described by subjects. Economic stress described by subjects tended to be either related to non-reimbursed costs of health care or insurance coverage costs. When describing the non-reimbursed costs of health care one caregiver noted, “Regarding prescription medications, even if the co-pay is \$10, they add up.” Another patient stated because “[because of changing jobs and losing coverage] I am unable to provide proof of insurance. I am unable to get any prescription medications.” When faced with paying for the entire cost of HPN, one family noted, “Mortgaging our house will pay for about 1 year of HPN. At the end of a year we will be homeless and without money to pay for HPN.”

Another common expense was for regularly driving to an out-of-town specialty medical facility, “Even with the help from other non-profit organizations for travel expenses and additional HPN supplies, we have to pay co-payments, gas and travel time plus, we need to return the rental car with a full tank of gas.” Another example was described by a family needing extra baggage for air travel. “We paid an additional \$900 in extra luggage costs to transport HPN supplies when traveling.”

Almost 33% of the sample rated their health insurance coverage as inadequate and described this in the interview as due to: (1) restrictions in the plan that did not cover all of HPN care and (2) expensive co-pays and deductibles. For example, “The plan covered everything, but it is very expensive.” Another stated that if their doctors were out of the insurer's network, the patient felt “uncovered.” One family frustrated with obtaining antiemetic drugs stated, “Experimental drugs should be available, some antiemetic medications were considered experimental and therefore not covered by insurers for GI disorders.”

There were several comments about lack of clarity in insurance coverage. “HMO drops providers, without explanation.” “The rule changes cause uncertainty and worry.” “Plans should be written in a simple language and understandable.” “Medicaid was too strict; eligibility should not be based on your assets.” “Supplemental plans should cover all cost that was not covered by primary insurance.” “National health care is better, it covers for everyone.” “The coverage plan should cover for self-employed.”

Regarding the maximum lifetime coverage allowed, another family stated, “It is \$2.5 million. Most people would think this amount is huge, but for people with serious chronic illness, the \$2.5 million is nothing.” Another example, “It did not cover all costs associated with the condition, and the lifetime maximum benefits were easy to reach in a short time. I am nearly at the lifetime maximum.”

A family struggling through the process of obtaining Consolidated Omnibus Budget Reconciliation Act (COBRA) coverage stated, “My primary physician and infusion supplier are continuing to provide care and supplies during this time and are delaying submission of my billing statements until the insurer can verify my coverage.” Several concerns about medication costs were reported: “Prescriptions must be put on credit cards in order to meet the deductible expenses.”

**Psychological and Emotional Stress**—The second most common concern reported was categorized as psychological and emotional stress. The four subcategories under these stressors were fear of losing a lifeline, limited access to social activities, uncertainty about the life-long availability of an insurance plan, and fatigue due to the time requirements for HPN care.

Patients described their central venous catheters as their “lifelines.” Catheter-related infections often result in the removal of catheters and replacement in a different blood vessel. Because there are limited numbers of adequate blood vessels that can be used for HPN, there is a great deal of anxiety in this population about losing the last nutrition lifeline. Often reported was, “We were scared when the doctor told us that she (the patient) did not have any more intravenous catheter access sites; we lived with fear.”

Living with HPN may limit social activities for all ages. This was repeatedly described as very stressful. For example, a young adult patient said, “I have to stay [at home] most of the night infusing my nutrition and cannot hang out with friends.” HPN was reported to impact intimate relationships. A longtime caregiver stated, “I no longer had an intimate relationship, partially due to his/her physical loss of function and partially due to difficulties within our marriage arising from chronically stressful conditions.” Due to the cumulative cost, several families were unable to travel to national support group conferences. Another stated, “I miss contact with other people and others like myself. There’s no one like me around here.” Similarly, one patient described her first attendance at family HPN national nutritional meeting as “the sky opened up and for the first time I felt hope. I felt like the first year of HPN was a black hole with no one really understanding the complexities of living with HPN.” One family significantly downsized their home and lifestyle. Other families also reported delaying the caregiver’s retirement due to income losses.

Several families expressed uncertainty about the future and changed their long-term plans to accommodate HPN treatment. One caregiver reported, “I had planned to build my retirement home in a small town. But because of medical emergencies requiring hospital expertise unavailable in that small town, I will not be able to relocate and must change my life plans.”

Traveling to visit specialists required time and energy and many caregivers described a fatigue associated with caregiving. One caregiver reported, “If everything went as planned, it took us 2 hours to drive to the clinic from our home. Then the infusion took 45 minutes to 1 hour. Another 1 hour spent to checking and out of the clinic. Another 2 hours to drive home. The whole day was gone.”

The interview data confirmed the SEM findings of income inadequacy, insurance coverage expenses, and uncertainty (all mental health stressors) as significant contributors to quality of life and patient clinical outcomes. The amount of out-of-pocket expenditures paid by families for HPN care could be up to \$17,923 per year for HPN therapy. Another \$12,943 on average could be spent annually for the non-reimbursed health services used and for one hospitalization (as described in Piamjariyakul et al., 2010). Overall, lower family income adequacy, higher caregiver daytime sleepiness, depression, lack of preparedness, and need for problem-solving skills were associated with the most expensive outcome of patient



bloodstream infection. Thus, the qualitative data support the quantitative findings and associations between caregiver characteristics and patient and caregiver outcomes.

## Discussion

The study identified significant relationships between the perceived adequacy of income reported by caregivers, caregivers' mental health, patients' HPN related infections and quality of life measures for both patients and caregivers. Furthermore, depression, income inadequacy, and lack of sleep highly impacted the mental health of caregivers, which related to their HPN caregiving. The results were consistent with past studies associating income adequacy with quality of life and clinical outcomes (Smith, Pace, et al., 2002). Thus, despite the limitation of this relatively modest sample size, SEM analyses confirmed the findings previously verified home care framework relationships (Smith, 2007). In the SEM as previous analyses, the common home care risks of patients' catheter-related infections and HPN complications requiring hospitalizations and expensive health services (Howard, 2006) were a constant worry and stress for patients and caregivers (Baxter, Fayers, & McKinlay, 2006; Huisman-de Waal et al., 2007; Smith et al, 1993).

The content analysis findings in this study illustrates the heavy emotional and financial burdens of chronic healthcare expenditures similar to reports by Houser and Gibson (2008). Caregivers report stress related to obtaining training and participating with multiple health professionals involved in HPN care (Kalaitzakis, Carlsson, Josefsson, & Bosaeus, 2008; Marden, 2005). Statistics reported by the National Family Caregivers Alliance (2009) indicate almost two-thirds of all caregivers must make adjustments to work life in order to provide care to a family member (Tranmer, Guerriere, Ungar, & Coyte, 2005) and caregivers contribute an estimated \$306 billion dollars per year in "free" health care.

In addition, the physical health of caregivers cannot be ignored. As found in previous studies, caregiver characteristics such as depression, sleepiness, and their preparedness to manage home care impact both caregiver and patient outcomes. Descriptive data of this study revealed that 12% to more than 33% of caregivers reported health problems and took medications for chronic conditions or sought physical and mental health treatment. The longer the time of caregiving, the poorer the caregiver's physical health, which in turn impacts the patient/caregiver combined outcomes (Schulz & Sherwood, 2008).

## Implications

The U.S. health care reform passed in March 2010 expands home and community based care that is coordinated and established training for family caregiving (Family Caregiver Alliance, 2010). Guidelines for assessment of caregiver health have been published by the Family Caregiver Alliance (2006, Volume I & II). These guidelines emphasize the importance of educating healthcare professionals about the important role of family caregivers.

Caregivers are an essential resource for national health care (Schulz & Sherwood, 2008). Yet, caregiver health often succumbs to disruptive schedules and fatigue of caregiving which generates more health care bills. The generalization of these results are limited as these findings are from caregivers managing HPN which has unique responsibilities related to night time 12-hour infusions that are associated with fatigue. Establishing the economic value of family caregivers (Russell, 2009) and developing national standards and guidelines for supporting and preparing them for formal and informal care are essential (Raphael & Cornwell, 2008).

Both quantitative and qualitative data from this study suggest that the mental health burdens and financial costs of HPN caregiving are extensive. Based on these data, interventions to improve caregivers' sleepiness, depression, and physical health could be hypothesized to improve both patients' and caregivers' quality of life and reduce the frequency of patients' catheter-related infections. These specific nursing interventions also could improve caregiver health and subsequently reduce the costs of caregivers' health care). One possibility is that complicated clinical care and caregiving guidance can be coordinated via the Internet and other new picture cell phone mobile technologies as "virtual nursing care services" (Fuhrman, 2009; Smith, 2002; Smith, 2008).

In this study, the variability in HPN out-of-pocket expenses and the uncertainty of incurring such extensive costs created additional financial worries within already stressed families. Longitudinal studies are needed to understand the cause and effects of costs related to complex chronic care and patient and caregiver outcomes.

The wide array of numerous services and concomitant costs to families at varied times throughout a lifetime of HPN therapy undergirds the need for new approaches to chronic care service delivery that are integrated, efficient, cost-effective, and insure quality outcomes for both patients and caregivers (Carrier, Gourevitch & Shah, 2009, Picker Report, 2008; Kelly, Reinhard, & Brooks-Danso, 2008). Actions such as the National Family Caregivers Alliance (FCA, 2010) creation of caregiver assessment guidelines proposing coverage by insurers and through Medicare policies for caregiving are needed.

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Table 1

## Family Caregiving Measures and Operational Definitions with Sample Mean Scores and Questionnaire Reliability

Questionnaire Title, Author and Reference	Operational Definition	Mean, SD, Reliability
<b>Family Caregiver Characteristics: Depression, Quality of Life, Physical Health, Daytime Sleepiness, Caregiving Esteem</b>		
Center for Epidemiological Studies - Depression Scale (CES-D) (Radloff & Rae, 1979), 20-item Likert	Behavioral (nonpsychiatric) reactive depression/symptomatology	$M = 8.01$ , $SD = 5.74$ Cronbach $\alpha = .86^*$
Physical and Mental Health SF-12v2 (Ware, et al., 1996; Larson, 2002), 7-item Likert	Physical and mental health status from the person's perspective	Physical: $M = 51.21$ , $SD = 10.55$ , Cronbach $\alpha = .92^*$ Mental: $M = 45.89$ , $SD = 10.63$ , Cronbach $\alpha = .87^*$
Epworth Daytime Sleepiness Scale (Johns, 1991), 8-item Likert	Daytime sleepiness, inability to concentrate in various situations	$M = 8.22$ , $SD = 4.38$ Cronbach $\alpha = .84^*$
Caregiving Esteem (Given, et al., 1992), 7-item Likert	Positive and negative esteem gained from caring for ill family member	$M = 29.84$ , $SD = 6.86$ Cronbach $\alpha = .81^*$
<b>Caregiving Context Concepts: Length of Time Providing Home Care, Caregiving Preparedness, Participation in Problem-Solving in HPN Home Care, Family Income Adequacy</b>		
Length of time providing home care	Number of years the patient has been on HPN	$M = 8.66$ , $SD = 8.04$
Caregiving Preparedness (Archbold, Stewart, Greenlick, et al., 1990), 1-item Likert	Ability to manage home care; low score equals caregiver strain	$M = 3.27$ , $SD = 1.10$
Participation in Problem-Solving in HPN Home Care (Gustafson, Hawkins, Boberg, 1999), 5-item Likert	Rating of knowledge, assertiveness, treatment management participation, & problem solving with professionals	$M = 41.11$ , $SD = 6.14$ Cronbach $\alpha = .89^*$
Family Income Adequacy (Fillenbaum, et al., 1981), 4-item: 1 = can't make ends meet; 2 = have just enough; 3 = have a little extra; 4 = have money left over.	Ability to pay monthly bills in relation to current income	$M = 2.69$ , $SD = 0.92$
<b>Outcomes of HPN Caregiving: Patient and Caregiver Quality of Life &amp; Occurrence of Catheter Related Infections</b>		
Caregiver (CG) Quality of Life Self Anchoring Ladder Scale (Cantril, 1965), 3-item Likert	Past, present, and future life satisfaction; reliable over time (Derenowski, 1991).	Patient: $M = 5.96$ , $SD = 2.23$ Caregiver: $M = 6.26$ , $SD = 2.03$
Patients' HPN-related bloodstream infection occurrence (Yes/No)	Occurrence of bloodstream infections in the past 1000 days	Yes = 83%; No = 27%

\* All calculations of instrument reliability in this sample were above acceptable Cronbach scores ( $> .70$ )