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Caregiving and Care Receiving among a Technologically Dependent Heart Failure Population

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Abstract

This descriptive study investigated health-related quality of life (HRQOL) and caregiving/care receiving among 20 end-stage heart failure patients receiving community-based inotropic infusions and among their 18 family caregivers. The analysis revealed that care recipients perceived considerable impairment from their disease process and poor HRQOL despite the use of inotropic infusions. Perceived powerlessness was identified as a predictor of the recipients' mental health status, while caregiver esteem adversely affected recipient HRQOL. Although insufficient preparation to care and caregiving tasks significantly contributed to the negative aspects of care provision, the esteem and mental health of the caregiver significantly enhanced HRQOL among caregivers.

Heart failure (HF) has become a resource-intensive health care problem with significant socioeconomic implications for the United States. 1 Currently, there are 5 million individuals diagnosed with HF in the United States, with approximately 400,000 new cases diagnosed each year. 2 Of those diagnosed, 2 million individuals will require aggressive treatment and frequent hospitalizations, 3 especially in the end stages of the disease. As the number of individuals affected with HF continues to increase, there have been dramatic increases in its associated health care costs. Health care expenditures for the treatment of this disease have escalated from $7 billion in 1990 4 to $19 billion in 1998. 5 Of the estimated $21 billion spent on treating HF in 1999, 71% will be allocated to hospital care. 5

The epidemiology and economics of HF have begun to exert immense demands on families, society, and the health care system. In response, health care

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Outline

providers are implementing alternative approaches to meet the diverse, yet resource-intensive, health care needs of this population. One recent approach in the treatment of end-stage HF is the transfer of inotropic infusion therapy from the acute care arena to the community.

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TECHNOLOGICAL DIFFUSION

The transfer of technology into the community is not a new phenomenon. Since the 1960s, complex technology traditionally reserved for acute care settings has been disseminated into the community to meet the health care needs of the chronically ill. [6] Community-based technological care expanded in 1983, when Medicare reimbursement changed from a fee-for-service to a prospective payment system. [7] Consequently, health care organizations have financial incentives to decrease hospital length of stay. Through the use of early discharge programs, patients are sent home "quicker and sicker." Community-based care in the 1980s evolved to encompass dialysis; intravenous infusions for antibiotics, chemotherapy, and nutrition; mechanical ventilation; cardiac monitoring; and automatic defibrillation. [8-10] The most recent addition to this technology diffusion is the use of community-based inotropic infusion therapy for the treatment of end-stage HF.

Inotropic medications are potent pharmacologic agents that can be administered as either an intermittent or continuous infusion for palliative measures or as a bridge to cardiac transplantation. In addition, perceived improvement in health-related quality of life (HRQOL) is a desired outcome of inotropic infusion therapy. Although patients receiving inotropic infusions in acute care settings have demonstrated improvements in perceived HRQOL, including functional status and symptom relief, [11] research related to the effect of community-based inotropic infusions on HRQOL as a principal outcome has been limited.

Traditionally, the onus of responsibility for inotropic infusion therapy rested in the hands of the professional caregiver. However, the use of community-based inotropic infusions results in a partial shift of this responsibility to family caregivers who must learn numerous monitoring responsibilities and complex technological procedures. [11] As the acuity of individuals cared for within the community continues to rise, so does the need to understand the effect of technologically complex caregiving on both the caregiver and care recipient. Therefore, this study examines the variation in HRQOL among HF patients receiving community-based inotropic infusions and among their family caregivers. Second, it explores the biopsychosocial responses to caregiving and care receiving among a technologically dependent population.

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CONCEPTUAL FRAMEWORK

The theoretical underpinnings for this study were formulated from Wilson and Cleary's [12] HRQOL model and Smith's [13,14] model of caregiving effectiveness. In this formulation, it was posited that the preparation of the individual as caregiver and the perception of the health status of the recipient influence the biopsychosocial responses to caregiving and care receiving, ultimately affecting HRQOL. Therefore, the principal variables selected for investigation included the HRQOL of the caregiver and care recipient, caregiver preparation appraisal, recipient health appraisal, and the biopsychosocial responses to caregiving and care receiving.

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RELEVANT LITERATURE

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Quality of life

The importance of quality of life (QOL) has historic roots that can be traced to the days of Aristotle. In his era, happiness was considered a reflection of one's QOL. According to Aristotle, happiness was found when, in addition to living a virtuous life, one was sufficiently equipped with external possessions. [15] Over the years, QOL has remained an important concept for scientific inquiry with significant effort undertaken to develop a conceptualization that would capture its enigmatic nature. As a result, there are many QOL definitions, [16-18] with diverse perspectives on its dimensions [18,19] and measurement concerns. [20-23] Its coalescence with other concepts such as HRQOL, health status, and functional status has contributed to its ambiguity. Nevertheless, with the use of an explicit definition of QOL, an organizational framework, and methodologic rigor, QOL can be an integral variable in health care research. [22,23] Explicit differentiation between QOL and HRQOL is crucial when health-related phenomena are under investigation. [17] For the purposes of this study, HRQOL is defined as the overall effect and outcome of an illness and its treatment on an individual's physical, psychologic, and social well-being as perceived by that individual. [18]

Perceived QOL or HRQOL has been examined among conventional medical management and cardiac transplantation HF populations. In these studies, respondents have described progressive dyspnea and fatigue, functional disability, psychologic impairment, and poor QOL secondary to HF. [24-28] In a comparative study, [28] both medically and surgically managed HF populations experienced high levels of anxiety, depression, and hostility, as well as poor adjustment to their illness. Whereas cardiac transplantation recipients experienced improvements in functional capability and psychologic adaptation, physical limitations, family distress, and social dysfunction that negatively affected their QOL were reported. [25,28]

Although studies have identified significant physical debilitation and psychologic deterioration associated with living with this disease, Muirhead and colleagues [27] found that HF patients were optimistic regarding their medical treatment and future outcome. The results of a meta-analysis [21] indicated that adult cardiac patients experienced improvement in QOL, whether or not they were assigned to experimental or control groups. Given this caveat, the clinical significance of these results remains questionable. Of the 84 studies in this meta-analysis, [21] 16 examined interventions among HF populations. However, none of the studies investigated the use of inotropic infusions and their effect on the HRQOL among individuals with end-stage HF or among their family caregivers.

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Technological caregiving

The provision of complex health care in the residential environment by family members has been described as technological home care. [29] In addition, individuals are considered technology-dependent when they require medical equipment to compensate for the loss of a vital physiologic function and need continuous care to avert death or disability. [30] In the home environment, spouses, parents, relatives, or significant others become the primary provider of technological care, yet limited research has been conducted that specifically focuses on complex family caregiving. [29]

Only one study investigated family caregiving among the HF population. [31] The burden, stress, and psychologic effects associated with providing care were consistent with caregiving research among frail older adults and those with cognitive impairments. [32-34] In addition, prolonged, negative effects of caregiving were found to adversely affect the health status of the caregivers. [31] Although these studies have continued to build a knowledge base concerning caregiving issues, only initial efforts have been made to understand caregiving processes among technologically dependent HF care recipients in the community.

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METHOD

A descriptive, exploratory research design that incorporated triangulated methodology was used to examine the effect of community-based inotropic infusions for the treatment of end-stage HF. The quantitative component of the larger study 35 sought to answer the following research questions:

1. What is the perceived HRQOL of individuals with end-stage HF?

2. What is the perceived HRQOL of caregivers for individuals with end-stage HF?

3. How do caregivers of individuals with end-stage HF perceive their preparation to provide care?

4. What are the biopsychosocial responses to the caregiving/care receiving experience?

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Procedure

Participants were recruited through 10 coordinators of HF programs across the Midwest. In order to be eligible to participate, the patients had to have a diagnosis of end-stage HF that required the use of intermittent or continuous inotropic infusions for treatment in a community environment. The family caregiver was identified as the person who had total responsibility for the physical, emotional, and technical care of the recipient at the time of the study.

Potential participants were given a recruitment letter and postcard to mail to the principal investigator. Using a scripted approach, the principal investigator then contacted potential participants and obtained informed consent. Data were collected using standardized questionnaires that were read and completed by telephone to all but three of the participants. Three questionnaires were completed by mail because these participants were hearing impaired. All of the participants were mailed $5.00 remuneration for their involvement. Approval for this research procedure was obtained from all appropriate human subjects committees.

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Measures

A demographic questionnaire and health profile was developed to ascertain personal and socioeconomic characteristics of the caregiver and the care recipient, the context of caregiving/care receiving, and the status of the participants' health. Five standardized questionnaires that had established psychometric testing were used to assess the major variables of study.

* *caregiver preparation appraisal*. An eight-item Caregiver Preparedness Scale measured the level of perceived caregiver preparation. 36 Consistent with previous studies, 13,14 the alpha coefficient was .83.

* *recipient health appraisal*. The Minnesota Living with Heart Failure Questionnaire 37 (LHFQ) is a 21-item, 2-scale instrument that assesses the extent the disease process affects one's physical and emotional domains. The Cronbach alpha was .87 for the entire LHFQ, with .85 and .79 respectively for the physical and emotional subscales.

* *biopsychosocial responses*. The 24-item Caregiver Reaction Assessment 38 (CRA) measured influential factors associated with the effects of caregiving in five areas: caregiver esteem, daily schedule, family support, caregiver health, and finances. Whereas higher scores in the caregiver esteem subscale represent a positive

impact of caregiving, high scores in the remaining dimensions reflect a negative impact of caregiving. Reliability coefficients ranged from .56 (caregiver health) to .84 (finances). The Mental Health Inventory-5 (MHI-5), a subscale of the Medical Outcomes Study Health Status Questionnaire Short Form 36 39 (SF-36), was used to assess caregiver and care recipient mental health. Among the care recipients, a coefficient alpha of .70 was obtained. However, the reliability coefficient among the caregiver sample was .42, with a standardized item coefficient of .44. These low alpha coefficients may be indicative of the small caregiver sample or reflective of the caregivers' inability to self-assess their mental well-being.

* *health-related quality of life*. The Quality of Life Index (QLI) is a six-point summative instrument that measures perceived satisfaction and importance with various domains of life. 40 The QLI consists of 36 satisfaction items weighted by corresponding importance items. The score represents an overall assessment of perceived HRQOL that includes four domains: health/functioning, family, socioeconomic, and psychological/spiritual. Two of the 36 items are disease specific and were omitted for the caregiver participants. The total QLI reliability coefficients for the caregiver and recipient samples in this study were .92 and .96, respectively. All of the alpha coefficients for the subscales exceeded .70 except for the caregiver sample in the domain of socioeconomics (.64).

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Characteristics of the participants

Of the 22 infusion recipients that were eligible for the study, 20 agreed to participate. One individual entered a hospice program, and a second expired before the principal investigator could initiate contact. The participants were recruited from HF programs in five Midwestern states: Missouri (45%), Ohio (20%), Michigan (20%), Indiana (10%), and Texas (5%). Two of the male HF patients did not identify a primary caregiver.

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Care recipient sample

The 20 care recipients were predominantly married (90%), Caucasian (85%) males (90%) between the ages of 47 and 82 years (M = 69.30; SD = 8.97). Eighty-five percent of the participants had at least a high school education, with seven recipients having some college or postcollege education. Only one recipient was still employed on a part-time basis. The household income was less than $40,000 for 75% of the recipients, with 45% having annual incomes less than $20,000.

The length of time that the recipients had been diagnosed with HF ranged from 2 to 27 years (M = 11.00; SD = 8.19); however, only 18 care recipients were able to provide this information. Ten of these recipients (55.6%) reported having been diagnosed with HF within the past 8 years. Twelve of the recipients reported having at least one comorbid condition such as diabetes mellitus, hypertension, and chronic obstructive pulmonary disease.

Seventeen of the recipients were receiving inotropic infusions in an ambulatory care setting, and three were on home infusions. The mean length of time on infusion therapy was 29 weeks (SD = 28.48), with a median of 21 weeks. At the time of the study, two recipients had been on inotropic infusions for over a year, and one recipient had been on infusion therapy for almost 2 years (103 weeks). Since beginning inotropic infusion therapy, two recipients had been treated in the emergency department, and six individuals were hospitalized secondary to infusion-related problems. Although inotropic infusion therapy may be used as a bridge to cardiac transplantation, none of the care recipients were candidates for this procedure.

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Caregiver sample

The 18 family caregivers were primarily females (89%) who were married

(90%). The mean age was 63.0 years (SD = 12.25), with a range of 40 to 80 years. Seven of the caregivers were between the ages of 65 and 75 years, and three participants were older than 75 years. Thirty-nine percent were employed on either a full-time or part-time basis.

Sixteen of the 18 caregivers were spouses, and the remaining two were either a daughter or sister of the care recipient. All but one caregiver resided with the care recipient. The sister, who was married and had two children of her own, moved into her brother's home to provide his technological care. According to these participants, care was provided to the recipient 7 days per week, for a mean of 8 hours each day (median = 5). Although care provision included minimal personal care needs, the instrumental activities of daily living (IADLs) and the technical aspects of care were high. The caregivers reported assisting with up to seven IADLs; administering oral, injectable, and intravenous medications; and providing diversional activities.

When caregivers were asked to compare their health to individuals of the same age, most of the caregivers perceived themselves to be in good (28%), very good (50%), or excellent (11%) health. Two caregivers (mean age = 48.50 years) perceived their health as fair or poor. Although the majority of caregivers reported an optimum health status, nine (50%) had at least one medical condition, and six caregivers had two or more medical conditions that included cardiovascular disease, diabetes mellitus, and cancer. Eleven of the caregivers perceived that their health status had not changed with the initiation of caregiving; however, five (28%) perceived that their health had declined. Since the initiation of caregiving, three of the participants had been treated in emergency departments and one caregiver had been hospitalized.

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Statistical analyses

Data were analyzed using the Statistical Package for the Social Sciences (Chicago, IL), with a level of significance established at .05 for all statistical procedures. Because of the small, homogenous sample of mostly ambulatory infusion recipients, the subsamples were analyzed as aggregate groups and not separated by infusion location. Descriptive, bivariate, and multiple regression analyses were used to examine the variables of interest. A principal components analysis (PCA) was performed to create a more manageable database because of the size of the sample. [41,42]

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RESULTS

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Caregiver preparedness

In response to a self-appraisal of their preparation to provide care, the caregivers reported that they were somewhat prepared for the role. The mean scores for the Caregiver Preparedness Scale ranged from 1.50 to 3.75, with an overall mean of 2.92 (SD = .75). The caregivers perceived that they were more prepared to access resources (M = 3.39), obtain services (M = 3.29), and provide physical care (M = 3.00) than they were to handle emergencies (M = 2.94) and psychosocial issues (M = 2.67). The participants reported being the least prepared for the stress associated with caregiving (M = 2.11). Of the 18 caregivers, one third reported that they were unprepared for the stress involved with caring for someone with end-stage HF.

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Recipient health appraisal

All of the care recipients indicated a degree of burden related to their disease, with scores ranging from 30 to 89 (M = 54.85; SD = 19.52). The recipients perceived more physical than emotional effects secondary to HF. The physical effects scores ranged from 0 to 37 (M = 23.9; SD = 9.99), compared to the emotional dimension scores of 4 to 25 (M = 12.6; SD = 6.38). The areas of greatest perceived impact, in descending order, were related to sexual activity, diet, walking, and climbing stairs. Forty percent of the care recipients reported loss of control in their lives as the most significant emotional impairment. In contrast, experiencing side effects from medications, earning a living, and being hospitalized were perceived as least affected.

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Biopsychosocial responses to caregiving/care receiving

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Mental health status

Prior to standardization and scoring, the responses to the five statements of the MHI represented a self-appraisal of how the individuals felt during the last 4 weeks prior to data collection. Based on these responses, 55% of the care recipients and 50% of the caregivers had experienced anxiety during this time. Furthermore, 65% of the recipients and 45% of the caregivers reported feelings of depression, with nine care recipients (45%) and seven caregivers (39%) experiencing episodes of despondency.

The standardized mental health scores for the recipients ranged from 32 to 100, with a mean of 64.0 (SD = 18.81). Sixty-five percent of the care recipients had mental health scores less than the population norm of 74.74, with 75% failing to reach the norm of 76.87 established for the 65 to 74 age group. 38 Similarly, the mean mental health score for the caregivers was 64.44 (SD = 17.29), with scores ranging from 20 to 92. The mental well-being scores of 72% of the caregivers were below the normative values established for the general population. Moreover, 89% of the caregivers had mental health scores less than the established age norm.

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Reactions to caregiving

The majority of the participants felt positive about their role as caregiver. The caregiver esteem scores ranged from 24 to 35 (M = 29.50; SD = 3.49), with 45% of the scores higher than 30. All of the caregivers indicated a desire to provide care, with 56% reporting a strong desire to perform the role. Yet the caregivers experienced negative aspects of providing care in other areas, particularly affecting their daily schedule, health, and finances. Fourteen (78%) of the caregivers reported that daily activities centered on caring for the recipient. More than 55% of the caregivers described having to eliminate things from their schedule or having to interrupt their current activities to provide care. Despite perceiving themselves to be in good to excellent health, 39% of the caregivers reported constant fatigue. One third of the caregivers described financial difficulties associated with meeting the health care needs of the care recipient.

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Health-related quality of life

In general, HRQOL among the care recipients was perceived as poor, with 70% of the scores less than 15. Twelve individuals (60%) had scores less than 10, eight (40%) had scores less than five, and three care recipients had scores less than one (15%). The total scores of the care recipients ranged from 0 to 27.50 (M = 9.34; SD = 8.08). Similar trends were noted in the HRQOL dimension scores for the care recipients. The average scores ranged from 8.92 to 9.96, with the lowest score obtained in the family subscale.

The individual satisfaction and importance item means were examined for the care recipients. As a whole, the care recipients did not identify an area of complete satisfaction in their lives. Ten areas were identified as a source of moderate satisfaction, with item means of 5.00 to 5.55. The areas in which the care recipients obtained their greatest satisfaction were from their children and spiritual beliefs. In addition, emotional support from family and friends was identified as an important source of satisfaction. The care recipients identified 15 aspects of life as sources of dissatisfaction, with 80% of these areas related to health and functioning. The areas of most discontent were associated with sexual activities, health status, travel limitations, and lifestyle changes necessitated by their disease.

In comparison, the caregivers reported perceptions of higher HRQOL (M = 20.11; SD = 7.64; range = .97 to 30) than did the care recipients. While 77.7% of the caregivers had scores exceeding 17, one caregiver had a HRQOL score of less than one. The mean scores on the HRQOL dimensions were between 19.77 (health and functioning) and 21.05 (family). Similar to the recipients, the caregivers derived their greatest satisfaction from their spirituality, friends, and family. The caregivers expressed moderate dissatisfaction in their employment status and travel restrictions. Furthermore, the caregivers were dissatisfied with lifestyle changes and the stress associated with caregiving.

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Principal components analysis

Table 1

Table 2

The bivariate relationships among the study variables were examined for inclusion in the PCA. According to McLaughlin and Marascuilo, 41 PCA is more effective if the absolute values of the correlations are between .30 and .80. Using this criterion, coupled with conceptual congruence, 15 variables or items were selected for data reduction, creating six component variables (Table 1). Although the correlations among variables used to generate PCA should be high, low intercomponent correlations are ideal for use in multivariate analyses in an effort to minimize multicolinearity. While ideal, this is rarely accomplished, 41 as was noted when the intercomponent correlations were assessed following the PCA. Two moderate correlations were identified between the components of impact of care provision and caregiving tasks ($r = .60$; $p = .009$) and the impact of care provision and caregiver efficacy ($r = -.52$; $p = .03$). The intercomponent correlations are presented in Table 2.

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Multivariate analysis

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Biopsychosocial effects of care receiving

Three regression analyses were conducted to identify the biopsychosocial effects of care receiving. The first regression analysis was conducted to examine the effects of disease history and powerlessness associated with HF on the mental health of the recipient. The results indicated a significant effect on the care recipients' mental health status (F[2,15] = 18.99; $p < .001$). Although disease history (b = .19) did not have an influential effect, feelings of powerlessness (b = -.85) explained 72% of the variance in care recipients' mental health status. Because feelings of powerlessness explained such a large proportion of the variation in mental health, it was examined as a predictor of HRQOL in place of the care recipients' mental health scores. The findings of this analysis indicated that disease history and feelings of powerlessness did not have a statistically significant effect on care recipient HRQOL. However, in a final regression analysis using powerlessness and caregiver esteem as predictors, caregiver esteem was found to have a significant effect on the care recipients' HRQOL (b = -.55), accounting for 30% of the total explained variance.

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Biopsychosocial effects of caregiving

When regression analyses were conducted to examine the effects of caregiver preparation appraisal and caregiver risk factors on the impact of care provision, a significant effect was noted (F[2,15] = 3.57; *p* = .05). Although caregiver risk factors did not contribute to the impact of care provision, a significant effect was noted with caregiver preparedness (b = -.58; R^2 = .32). Because of the moderate correlation between caregiver preparedness and caregiving tasks (*r* = -.41; *p* = .08), a simple linear regression analysis was conducted to examine the effects of caregiving tasks on the impact of care provision. The results indicated that the number of caregiving tasks provided by the caregivers (b = .60) explained 36% of the variation in the caregivers' perceived impact of care provision (F[1,16] = 8.92; *p* = .009). Although insufficient preparation to care and caregiving tasks had an adverse effect on caregivers, the impact of care provision or the number of caregiving tasks did not have a significant effect on the mental health of the caregivers.

When HRQOL was examined using disease history, care provision, preparation to care, or caregiver efficacy as predictors, no significant effects were found. However, a statistically significant effect was noted when HRQOL was regressed on caregiver mental health and caregiver esteem (F[2,15] = 7.25; *p* = .006). The mental well-being of the caregiver, combined with the esteem of the caregiver, accounted for 49% of the variation in caregiver HRQOL.

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DISCUSSION

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Care receiving and health-related quality of life

The results of this study indicated that individuals with end-stage HF perceive their HRQOL to be severely compromised, despite the use of inotropic infusions. Factors that contributed to poor perceptions of HRQOL included physical and emotional impairments secondary to the disease process and the psychologic consequences associated with living with an end-stage disease.

Decreased QOL or HRQOL have been noted in other chronically ill populations using various versions of the QLI. However, none of the investigations reported perceptions of QOL or HRQOL as low as those reported by the HF participants in this study (CE Ferrans, personal communication, May 20, 1999). In these studies, QOL was assessed among individuals who had survived a life-threatening or near-death disease such as acute myocardial infarction, arrhythmia, or cancer. Survival afforded the individuals an opportunity to change their perspective on life, reassess priorities, seek positive meaning in life, and discover a greater appreciation for life itself. 43 However, in end-stage HF, the opportunity for a second chance is not available. The use of inotropic infusions is a final, palliative treatment option that does not ameliorate the disease process or prolong life; their use may even precipitate death. 44-46 As individuals come to realize that no other recourse is available, they begin to face the finality of their disease.

Feelings of powerlessness generated from worry, depression, and loss of control were found to explain 72% of the variance in the care recipients' mental health. This finding is not surprising, given the devastating physical and psychosocial effects of HF. The perpetual sensation of dyspnea combined with disturbed sleep patterns and physical impairment results in constant worry. The physical effects of the disease restrict social activities and relationships, making it difficult to find meaning and purpose in life. As individuals begin to lose control over the illness and life events, feelings of helplessness, hopelessness, and depression may occur. 47

Whereas the care recipient's disease history and feelings of powerlessness did not have influential effects on the care recipients' HRQOL, caregiver esteem was identified as a significant predictor of the recipients' HRQOL, with a counterintuitive effect as caregiver esteem increased, the care recipients' HRQOL decreased. This finding may reflect the escalation in feelings of helplessness among care recipients as their caregivers become more competent and secure in their role. Moreover, as the caregivers attempt to protect recipients from stress by concealing problems and issues, [48] the care recipients may experience further dejection, dependency, and isolation. Loss of intimacy and closeness with the caregiver, especially a spousal caregiver, may compound the burden of the disease experienced by the care recipient and adversely affect his or her HRQOL.

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Caregiving and health-related quality of life

Caregiver preparation was found to have a significant effect on the impact of care provision. When caregivers perceived that they were unprepared for the caregiving role, they experienced more adverse effects, such as in coordinating daily activities and maintaining their own health. As the caregivers became overwhelmed with caregiving responsibilities and experienced physical ramifications from care provision, they perceived that there was insufficient family support for their caregiving role.

Although caregiver preparation accounted for 32% of the variance in the impact of care provision, a large amount of variation was unexplained. However, the number of caregiving tasks was found to explain an additional 36% of the remaining variation. These findings support previous research that identified the strain of care provision as secondary to insufficient caregiver preparation, [13,14,36] as well as the numerous technological tasks provided by caregivers. [31] It was expected that the level of caregiver preparation and technological caregiving would have a direct effect on the mental health of the caregivers. The lack of an association between these variables may be attributable to the sample size.

Caregiver mental health and caregiver esteem were identified as significant predictors of caregiver HRQOL, accounting for 49% of the explained variance. This finding implies that caregivers' psychologic well-being and confidence in their performance enhance perceptions of HRQOL and may even ameliorate the negative consequences associated with technological caregiving. Based on these findings, two hypotheses are offered for the role of caregiver mental health and esteem in the amelioration of the negative aspects of caregiving.

First, caregiver commitment and satisfaction derived from the fulfillment of family obligations, in concert with the caregivers' gratification derived from helping others, may serve to enhance mental well-being and caregiver esteem, while buffering adverse effects. Second, as caregivers find a renewed purpose in life from the caregiving role, they discover unknown strengths and abilities. With a new purpose in life and confidence in their abilities, their perceptions of HRQOL are enhanced. As a result, caregivers find that the caregiving experience is more meaningful than burdensome.

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IMPLICATIONS FOR RESEARCH AND PRACTICE

The utilization of inotropic infusions for palliative measures, particularly in the community, must begin with a screening protocol that includes a risk-benefit assessment. Integral to the screening process is assessing the patient's perception of how this intervention will affect the prognosis of HF. A psychologic assessment of the patient's readiness for acceptance of an end-stage prognosis, as well as the purpose of inotropic infusion therapy, must be determined. Moreover, it should be clarified to patients and families that inotropic infusions do not cure or alter the pathology of the disease.

Caregiver screening and selection must evaluate the individual's readiness and capability to fulfill the role expectations of technological caregiving. The most appropriate person for the role need not be the spouse of the individual with HF. All options to provide care must be explored to identify the most effective individual to be the primary caregiver. Once the effects, benefit, and caregiver options have been explored, determination can be made if inotropic infusions will be an effective community-based intervention for a HF individual.

The findings concerning care recipient HRQOL have important implications for caregivers of technologically dependent care recipients. Preparation for care should include strategies that support and enhance role transition for both the caregiver and the care recipient. As care recipients become dependent on family and technology for survival, interventions are needed that will assist recipients in maintaining a sense of control and independence. The development of caregiver esteem should not occur at the sacrifice of recipient self-worth.

Caregiving is not limited to meeting the physical needs of the care recipient. It must encompass the psychologic and affective components as well. As a result, caregivers must be adequately prepared for the psychologic consequences of living with someone with a terminal illness. In addition, support systems need to be implemented that maximize the caregiver/recipient relationship. As familial roles change to accommodate caregiving and care receiving, individuals will need assistance in learning how to effectively communicate and interact within this new context of their relationship.

It is important to establish a mechanism for the evaluation of both the care recipients' and caregivers' responses to inotropic infusion therapy. In addition, alternatives to treatment need to be discussed with families when there is evidence that inotropic infusions are no longer effectively managing the care recipients' symptoms. Families should be introduced to the concept of hospice programs early in the course of inotropic infusions so that there is familiarity when end-of-life management decisions are discussed.

This investigation sought to elucidate caregiving and care receiving processes among a population in critical need of study, yet caution must be used in the interpretation of its results. Although the methodology incorporated a multicenter data collection strategy to maximize the sample size, the number of participants remained low. However, it is important to note that the use of inotropic infusions is not a widely disseminated practice at this time. The sample size was affected by the recency of the technological diffusion and tenuous reimbursement practices for its use beyond the acute care setting. Although the statistical analyses were hindered by the small sample size, the use of PCA for data reduction enhanced the statistical power in the multivariate procedures. In addition, the degree of distortion in computed R^2 values was fairly small, augmenting the validation of the regression analyses. Generalizability would be facilitated with a larger, random sample and higher statistical power.

Another limitation pertains to the instrumentation used to measure HRQOL. Even though the QLI has been used in other chronically and terminally ill populations, it has not been employed to assess HRQOL at the end of life (CE Ferrans, personal communication, May 20, 1999). Therefore, the utility of the QLI may be decreased for end-of-life HRQOL assessments. The focus of the QLI is on satisfaction and importance of various aspects of life; it does not contain items pertaining to personhood or the meaning of life. As individuals approach the end of life, it may be more important to have instruments that emphasize meaning, purpose, and spirituality than the physical dimension in palliative care populations,[49] coupled with explicit QOL/HRQOL definitions that capture the elusiveness of the concept at this stage of life.

Controversy continues concerning the role of inotropic infusions in the management of end-stage HF. Although there is consensus on the use of inotropic infusions for palliative care and as a bridge to cardiac transplantation, its enhancement of HRQOL is ambiguous. The health care community must further evaluate the scope of its use. It may be that the use of inotropic infusions should be limited to the management of end-stage HF amenable to transplantation.

Future investigations involving the use of inotropic infusions and their effect on HRQOL ideally should be conducted over the trajectory of the treatment. Longitudinal designs would facilitate the identification of incremental or decremental changes in HRQOL. The assessment of perceived HRQOL and clinical data provide a vehicle to ascertain the effectiveness of inotropic infusion therapy in the community. Studies such as these, conducted with investigations that involve cost analyses, facilitate the development of clinical practice guidelines and health care policies for this population. Although technological diffusion may be cost-effective for hospitals and payers (eg, health maintenance organizations, insurance companies), there may be a large cost shift to families. Financial evaluation of this phenomenon may find that community-based inotropic infusions are not cost-effective in any arena.

Future research is needed that will identify interventions for effective caregiving outcomes for both caregivers and care recipients. In particular, screening processes and preparation to care, as well as the mediating role of caregiver mental health and caregiver esteem, are important areas for interventional studies. Given the effects of insufficient preparation on the negative aspects of care provision, caregiver preparedness is worthy of further consideration in future investigations with larger samples. Moreover, studies for the identification of interventions that enhance role transition, independence, and control are crucial.

It is clear from this investigation that technological caregiving and care receiving for individuals with end-stage HF are complex, multifaceted phenomena. These results have implications for the foci of nursing, health services, and policy development. As research is continued in this area, further knowledge will be developed that can be used to maximize the technological caregiving experience for caregivers, care recipients, and their families in the community.

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Key words: caregiving; care receiving; community-based care; heart failure; inotropic infusions; quality of life; technological caregiving

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IMAGE GALLERY

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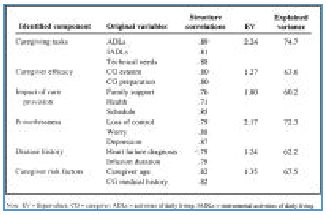
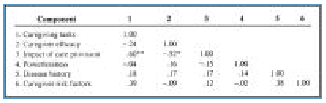


Identified component	Original variables	Structure correlations	EV	Explained variance
Caregiving tasks	ADLs	.89	2.24	74.5
	IADLs	.81		
	Technical needs	.88		
Caregiver efficacy	CG esteem	.80	1.27	63.6
	CG preparation	.80		
Impact of care provision	Family support	.76	1.80	60.2
	Health	.71		
	Schedule	.85		
Powerlessness	Loss of control	.79	2.17	72.3
	Worry	.88		
	Depression	.87		
Disease history	Heart failure diagnosis	−.79	1.24	62.2
	Infusion duration	.79		
Caregiver risk factors	Caregiver age	.82	1.35	67.5
	CG medical history	.82		

Note. EV = Eigenvalue; CG = caregiver; ADLs = activities of daily living; IADLs = instrumental activities of daily living.

☑ Table 1



Component	1	2	3	4	5	6
1. Caregiving tasks	1.00					
2. Caregiver efficacy	−.24	1.00				
3. Impact of care provision	.60***	−.32*	1.00			
4. Powerlessness	−.04	.16	−.15	1.00		
5. Disease history	.18	.17	.17	.14	1.00	
6. Caregiver risk factors	.39	−.09	.12	−.02	.38	1.00

☑ Table 2

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