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**Congestive Heart Failure And Quality Of Life: Can Patient
Education Make A Difference?**

by

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Abstract

Congestive heart failure is a widely prevalent sequel to other chronic medical and cardiovascular conditions. It is of growing concern to nurse practitioners in the primary care setting. Quality of life, as perceived by an individual, is directly affected while living with a chronic terminal illness. This pilot project conducted in a solo medical practice examines the effect of a patient education program on the quality of life of patients living with congestive heart failure. Basic patient education regarding anatomy, physiology, daily body weights, medication management, sodium restriction, regular exercise, and stress reduction was taught to a sample of patients with congestive heart failure. Quality of life measurements were made using the Quality of Life Index developed by Ferrans and Powers. Statistical data did not reflect a significant change in quality of life over the two month pilot study, but qualitative data suggested benefits to patients that could not be measured by the Quality of Life Index. The broad base of skills possessed by the nurse practitioner can improve care of patients and potentially enhance the patients' self perceived quality of life. This pilot study indicates a need for more research into this topic.

Introduction

The nurse practitioner in the primary care setting will encounter a great number of patients with congestive heart failure (CHF) in clinical practice. This clinical syndrome is a growing problem in the nation and an increasing financial burden in the health care community. According to the National Heart, Lung, and Blood Institute, there are 4.8 million Americans with CHF.¹ There are currently 400,000 new cases diagnosed each year.² Disease processes such as hypertension, coronary artery disease, and valvular heart disease lead to CHF.³ Several factors contribute to increased prevalence of CHF and these include prolonged survival and increasing age of the population.⁴ Decreased mortality from cardiovascular diseases results in increased morbidity and mortality rates for CHF.⁵ This is the most common diagnosis for hospital admission for patients 65 years of age and older.⁴ The expansion of managed care will result in medical management of these patients in the primary care setting.

Increasing numbers of patients with this diagnosis and the quality of life (QOL) for this specific patient population is of concern to nurse practitioners. Research suggests that patient teaching leads to better patient outcomes, and better outcomes lead to a better quality of life.

Research Question

This pilot study examined the effect of a nurse designed patient education module on the self perceived quality of life of patients living with CHF. The specific question addressed in this study was: does one on one patient education, for patients living with CHF, make a difference in self perceived quality of life? Patient education has historically been a

responsibility of nursing, and the need for education is integrated into nursing diagnoses. This study can help define the type of research needed to address QOL needs, and indicate the importance of this type of research. The impact of patient education on CHF patients has not been fully explored, and this pilot study could indicate feasibility and direction for a study with a larger patient population.

Literature Review

A review of the literature shows increasing numbers of research studies addressing QOL. Many of these studies are disease specific for diseases such as cancer, arthritis or HIV. A paucity of articles were found that address patient education and QOL in the presence of CHF.

Many studies assess pharmacological interventions in disease specific settings and evaluate the effect on QOL of the patient. One study by Rogers, Johnstone, Yusef, et al. found that of 5,025 patients randomized between a placebo and enalapril, there were no significant benefits seen in the QOL in either the placebo or enalapril groups after two years of follow up.⁶ The primary focus of this study was not QOL. The investigation tool used was admittedly a brief, quick, targeted, survey tool. There was a definition of QOL for this study, but there was no associated theoretical framework. Daley, Mitchell, and Jonas-Simpson state there is a lack of clarity regarding this phenomena (QOL), and that may be linked to the absence of QOL research that is discipline specific and linked to mature theoretical frameworks.⁷

There is no universal definition of QOL, according to Kinney, Burfitt, Stullenbarger, et al. in their meta-analysis of QOL research of cardiac patients. They further state there is no broad systematic review of QOL literature available that is specific for cardiac patients. There was a

failure to define QOL as a concept in more than half of the studies they examined. The meta-analysis of 84 studies did not demonstrate any negative effects of various treatments on QOL. Results did suggest a small, significant effect on QOL regardless of the type of treatment. This finding could support the concept that patient education could have an affect on self perceived QOL. ⁸

Bennett and Pressler contend that QOL is broadly defined as an individual's perceptions of satisfaction with the individual's life. They further state that QOL is as important, or more important than lengthening life. Their conclusion, in the case study of a 62 year old female with CHF, was that health care professionals must support patient QOL decisions even if they disagree with those decisions.⁹ There were no quantitative measurements in this case study.

Grady reports that QOL research has increased over the past decade, and it has been acknowledged as relevant and deserving of continued exploration. She writes that CHF as an outcome measure was used in studies that primarily examined symptoms and functional ability. Global measures for QOL are limited in ability to measure changes in QOL related to medical therapies. QOL measurements in specific disease settings require a tool that is disease specific.¹⁰

English and Mastrean define QOL as multidimensional and encompassing functional capacity, health perceptions, and symptoms. They report that patients living with CHF have a poor QOL due to: (a) functional disabilities, (b) physical symptoms, (c) emotional and economic burdens, and (d) poor prognosis. They define the role of nursing as one that can identify strategies for management of CHF. These authors encourage patient education that emphasizes self-care management. They discuss

the importance of exercise to reduce muscle atrophy and maintain exercise capacity. They advocate discussing advanced directives with all CHF patients, and this discussion should take place before a crisis.⁴

Ferrans writes that a clearly defined definition of QOL is required to be clinically useful. She advocates an instrument for research that reflects the selected definition for QOL. Individual perceptions are important in evaluating QOL, and individual values are significant in the concept of QOL. Health concerns should not be the only focus, but the broad nature of life must be addressed to assess QOL.¹¹

Dracup, Baker, Dunbar, et al. concluded that CHF patients, who have counseling and education about CHF, will have improved outcomes and fewer unnecessary hospitalizations. They reviewed studies published in English from the year 1966 through 1993. The conclusion of this review emphasizes the role that nurse practitioners can play in counseling and educating patients and their family about CHF. Current goals of therapy for CHF is to maintain function, improve QOL, and prolong survival. These goals are best met when patients and family members are well informed and actively involved in the care plan.¹²

There is considerable desire for education from patients hospitalized with CHF according to Hagenhoff, Fuetz, Conn, et al. Patients and nurses do not rate educational needs in the same rank order, and CHF patients have their own priorities concerning learning needs.¹³

Chan examined patient perception of importance of content for cardiac teaching after myocardial infarction. Her study demonstrated that nurses and patients valued different areas of patient teaching content. Patients valued knowing medications, anatomy and physiology, and risk factors. Patients wanted to know what caused the myocardial infarction,

how to prevent a future infarction, and how the medications were going to benefit them. Patients considered this knowledge primary for their survival, and they learned more effectively at home during convalescence than in the hospital.¹⁴

According to Miller patient education is a primary focus for management of CHF. Miller enumerates the importance of compliance with prescribed diet, medication, activity level, and daily weights. She also lists the importance of reviewing advanced directives with CHF patients and family.¹⁵

Conceptual Framework

The conceptual model developed by Ferrans was the conceptual model of this pilot study. There is a hierarchical relationship between the quality of life concept, four domains, and specific content of each domain. The four domains are: (a) health and functioning, (b) psychological and spiritual, (c) socioeconomic, and (d) family. Specific aspects of the family domain are: (a) family health, (b) the children, (c) family happiness, and (d) spouse or significant other. The psychological and spiritual domain consist of: (a) peace of mind, (b) faith in God, (c) goals, (d) happiness, (e) life satisfaction, (f) personal appearance, and (g) self. The socioeconomic domain is inclusive of: (a) friends, (b) emotional support, (c) home, (d) neighborhood, (e) standard of living, (f) job or unemployment, (g) education, and (h) finances. The last domain of health and functioning is made up of: (a) own health, (b) health care, (c) chest pain, (d) shortness of breath, (e) energy level, (f) family responsibilities, (g) usefulness to others, (h) stress, (i) leisure activities, (j) travel, (k) retirement, and (l) changes in lifestyle.¹⁶

Quality of life is a personal, subjective value that is usually based on an individual's lived experience. Ferrans' definition of QOL grows from the idea that a person's sense of well being comes from satisfaction or dissatisfaction with areas of life that he or she values. Satisfaction is used in the construct development because it compares what is desired to what is the actual condition of life. Ferrans states that objective conditions of life influence the QOL, but are surrogate measures of the actual lived experience. This is a subjective concept, and the reality of the condition of life is subject to the individual's perceived experience of living that condition.¹⁷

This conceptual model that reflects the individual's self perceived QOL fits this study of the effect that basic nursing measures can have on the QOL of patients with CHF. The patient information used as the intervention in this pilot study was designed to cover the four domains of Ferrans' conceptual model. There are overlapping areas between the subscales, and parts of the patient education module can cover more than one subscale. Including a spouse, family member or significant other in the educational process was important for the family domain. The stress management and relaxation information encompassed the psychological and spiritual domain. The medical management information covered the health and functioning domain. The information about community resources and advanced directives addressed the socioeconomic domain.

Definitions of Terms

Cardiac patient education module refers to a packet of educational and informational materials that cover: (a) basic anatomy and physiology of CHF, (b) simplified dietary instructions, (c) daily weight instructions,

(d) medication management, (e) exercise instructions, (f) relaxation and stress reduction, (g) local support services, and (h) advanced directives.

A study participant or study subject is a volunteer that has been diagnosed with CHF and classified with the New York Heart Association Classification (NYHAC) of I, II, or III. Volunteers are men or women between the ages of 50 and 75 years.

A support subject refers to a spouse, significant other, family member or friend who is willing and available to accompany the study subject when meeting with the investigator.

Quality of life is a concept that is defined in many ways. In this pilot study, QOL is defined according to Ferrans' conceptual model. This model has four domains, they are health and functioning, psychological and spiritual, social and economic, and the family domain.¹⁸

The New York Heart Association functional classification is used to classify CHF patients. Class I is no dyspnea with exertion. Class II is dyspnea with maximal exertion. Class III is dyspnea with minimal exertion. Class IV is dyspnea at rest.

Methodology

This pilot study was conducted using a quasi-experimental research design. Patients from a solo medical practice, with the diagnosis of CHF, were solicited for voluntary participation in the project. The criteria for participation in the pilot study were: (a) adults between the ages of 50 and 75, (b) the ability to speak, read and write English, (c) a diagnosis of CHF, (d) the stamina to complete the required paper work, (e) the physical and mental capacity to implement life style changes suggested in the cardiac patient education module, and (f) a spouse, significant other, family member or friend willing to participate in the study. The primary

care provider from the medical practice provided a list of potential participants who were contacted by phone and invited to participate in the project.

The treatment, which was spread over a two month period, consisted of four meetings with the investigator. During these meetings the content of a CHF patient education module was covered. The support person accompanied the patient to listen to the instructions, but instructions and educational information were directed to the patient. The Ferrans and Powers Quality of Life Index (QLI) was administered as a pretest and posttest. Permission to use the Quality of Life Index Cardiac Version III was obtained from Ferrans. On the final visit the patients answered four open-ended questions on a short questionnaire.

The first encounter was the longest in time, lasting 35 to 40 minutes. The pilot study was explained to the participants, a consent form was signed, the pretest was administered, the patient education module introduced, vital signs and body weight recorded, and physical assessment completed. The second encounter one week later included recording of vital signs and body weight, physical assessment, review of medications, and review of the patient education module. The third visit, three weeks later, was a repetition of the second visit. The fourth and final visit, occurring two months after the initial encounter, was a repetition of the other visits. It also included the posttest, the questionnaire, and closing verbal comments from the participants.

Instrument

The original Quality of Life Index was a tool that was developed to assess overall quality of life. As this generic tool was used in research around the world, a number of disease specific versions were developed to

address the needs of patients living with those specific conditions. The Quality of Life Index Cardiac Version III is a refinement of the original generic tool. The Quality of Life Index Cardiac Version III has two sets of 36 items. The first set of 36 items rates satisfaction with certain areas of life, and the second set of 36 items rates importance of those same areas. These items are rated on a six point Likert scale ranging from very dissatisfied to very satisfied on the satisfaction questions, and ranging from very unimportant to very important on the importance questions.

This multidimensional construct was developed with extensive literature review and factor analysis of data from hemodialysis patients.¹⁶ Internal consistency reliability was supported by Cronbach's alphas ranging from .86 to .98 across 12 studies. Temporal reliability was supported by test and retest correlations of .87 at a two week interval to .81 at a one month interval. Construct validity was provided by factor analysis and supported by the contrast group method. Construct validity was also supported by extensive literature review and patient reports regarding quality of life.¹⁸

Data Analysis

Demographic data was analyzed and reported as numerical values and percentages. The QLI scores were reported as numerical values and calculated by pairing importance responses with satisfaction responses. The weighted scoring produces the highest scores for responses that indicate the patient is highly satisfied with an area of his or her life, and values that area as very important. The lowest score is achieved with a patient response of very dissatisfied with an area of life that the patient values as very important. Ferrans believes that people who are highly satisfied with the areas of life they value highly will enjoy a higher QOL

than individuals who are unhappy or dissatisfied with the areas of their life they value.¹¹ A QLI score can range from 0 representing the lowest possible score to 30 representing the highest possible score. The range of 0 to 30 applies to the four subscale scores as well. Data were subjected to a paired t-test to determine if there was a statistical significance of the difference between the pretest and posttest QLI means. An alpha level of .05 was established as a level of significance. Patient responses to open-ended questions and handwritten notes of patient conversations were reviewed, to determine if there were other benefits to teaching that could not be measured by the QLI.

Results

Demographic data of the convenience sample (n=8) were summarized in a table format (table 1). The majority of study subjects were Caucasian males. They were married and had children, but only one study subject had a child living at home. The study subjects ranged in age from 55 to 75 years with a mean age of 68 years. All study subjects had a minimum of a high school education, and all subjects were unemployed due to disability or retirement.

There was a slight change in mean QLI from 21.420 (SD \pm 3.94) on the pretest to 22.062 (SD \pm 3.28) on the posttest. There were six study subjects that showed increased total QLI scores on the posttest (75%). Two subjects had decreased total QLI scores (25%) (table 2). The two individuals with decreased QLI scores were males, one classified as class II NYHAC and one was classified as class III NYHAC. A paired t-test of two sample means was computed to determine significant difference of mean scores. The t-value of -0.96886 (critical-t=1.8244) (df=7) indicated no statistical significance between the pretest and posttest.

The change in mean total score of the QLI and the change in subscale scores is not statistically significant (table 3). None of the study subjects answered questions 22 or 23 on the satisfaction or importance questionnaires. These two questions related to job and employment, and are a part of the socioeconomic subscale. This may have contributed to the lack of improvement in the socioeconomic subscale. It is difficult to impact a patient's economic status with a health education module. The lowest pretest score was in the subscale of health and functioning, and after the posttest the most improvement in mean subscale score was also in health and functioning. The focus of most patient education is to improve health and functioning. The highest scores were recorded in the family subscale.

This data could suggest that improvement in the area of health and functioning is a possibility, but supporting statistical data is lacking. The high scores in the family subscale may indicate the value of family for individuals with chronic illness.

Qualitative Data

The four open-ended questions asked: (a) what has changed over the past two months, (b) what are your feelings about the material in the patient education module, (c) can you describe your quality of life, and (d) is there information you want to share?

The most frequent response to the first question was "no change." The study subjects interpreted this question to mean, was there a change in their medical condition. Three study subjects (37.5%) were happy to have maintained the status quo and not see a decline in their physical health. The remainder of the study subjects (62.5%) felt their particular medical condition was unchanged or remained the same as when the pilot

study had begun. This group felt neither good nor bad about "no change" in their physical status.

"Informative," "interesting," "very good," and "comforting" were descriptive terms used to respond to the second question. Every study subject, by the end of the study, felt more informed either about their medications, about CHF, about symptoms or about diet. One male subject began the study by stating that he did not like to talk about his condition because it made him feel uneasy. This subject used the word "comforting" as a descriptor at the end of the study. He was more comfortable talking about his heart condition at the end of the study, than he was prior to the study.

One male patient described the quality of his life as "great" (12.5%), three males used the term "fair" to "fairly good" (37.5%), one used the term "middle range" (12.5%), and one described his life as "alright-not great" (sic) (12.5%). The two female patients (25%) used narrative descriptions such as "blessed to be able to care for myself," and as "having more good days than bad."

The responses to the fourth question were expressions of gratitude for care or appreciation for the information offered by the study. All study subjects expressed positive feelings about being able to talk about CHF and to ask questions that may have been previously unanswered. Study subjects felt that they had been listened to, even in the short 15 minute visits. Having their complaints validated and discussed was important to all of the subjects in the pilot study.

Open discussion revealed that patients use medical terms and information they have heard without really understanding them. One example is the term "congestive heart failure." One male patient knew that

he had congestive heart failure, but to him that meant he was going to die immediately. As a mechanic, he interpreted "failure" to mean his heart no longer functioned, not that it was working less efficiently. He did not understand that by taking medication and following instructions, he could enhance his heart's ability to function properly. The fear of impending death has made it difficult for this patient to sleep at night. Another male patient said he had been repeatedly told to watch his salt intake. He assumed it must be bad for his heart. He was never told that fluid retention not only made his feet and legs swell, but also made his heart work harder. The new information that he could help his heart work more efficiently inspired him to eliminate excessive salt from his diet. All patients expressed gratitude for new information about the medications they were taking and were happy to learn what these medications did for their heart and health. One female patient summed it up by writing that she "was more aware of the things she had no control over, and could make better use of the things she could control."

Limitations of the Study

A major limitation of this pilot study was the small sample size. A larger sample population of 30 or more subjects would allow for more meaningful statistical analysis of the data. It is possible the changes in QLI scores for this pilot study could have occurred without any patient teaching. This type of study should be conducted over a period of more than two months. A six to 12 month study would be preferable, although the life expectancy of this population is limited. The investigator provided the teaching as well as conducted the testing of the sample population and this could bias the results. Better defined patient outcomes would strengthen the study. The investigator could monitor vital signs, daily

weights, medication compliance, exercise compliance, and hospital admissions.

Conclusion

This study examines if patient education makes a difference in the lives of patients living with CHF. Due to the limited sample size no statistical significance can be attached to the data collected. Findings are only applicable to this particular practice setting. The evidence that each practitioner can impact his or her own practice is suggested in the data. Clarifying information for patients and increasing understanding can, as the one female patient implied, help patients exert some control over their circumstance. Nurse practitioners can conduct organized, ongoing patient education programs while assessing and treating patients in a 15 to 20 minute office visit. Patients with long standing conditions can benefit from informative material about their condition. If the patient feels better as a result of some information or discussion, that has value for the patient even if it cannot be measured by a tool.

There is no conclusive support of improvement in QOL for this patient population, but there is evidence of positive benefits for the patients. The individualized, subjective nature of quality of life, makes it difficult to measure with a standard tool. Patients expressed feelings about their health that were difficult for them to measure or quantify, and they expressed difficulty with verbalizing how they felt. The opportunity to talk about their illness, to feel actively involved in managing their care, and to have a better understanding of their body made this population feel that participation in the pilot study was beneficial. The major difference for these patients was the one on one teaching that personalized the information. It is feasible to conduct this type of

research in a clinic or office setting. There is a need to continue to explore and learn about quality of life from patients who are living with CHF, and to study the effects of one on one patient teaching as compared to other methods. This research is of value to the patient as well as the health care provider, and more research in the office or clinic setting is needed.

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Appendix

table 1. Demographic Data				
		Subjects	n=8	%
Sex				
	Males	6		75%
	Females	2		25%
Race				
	Caucasian	8		100%
Marital Status				
	Married	7		87.5%
	Divorced	1		12.5%
Children				
	Living at Home	1		12.5%
	Outside of Home	7		87.5%
Education				
	High School	8		100%
	Vocational Sch	2		25%
	College	1		12.5%
Religious Pref				
	Roman Cath.	3		37.5%
	Protestant	2		25%
	Declined	3		37.5%
Work Status				
	Retired	4		50%
	Disabled	4		50%

table 2.		INDIVIDUAL QLI SCORE								
SUBJECT	1	2	3	4	5	6	7	8	SD±	
PRE	19.875	28.367	25.636	22.318	16.985	19.132	18.114	19.951	3.94	
POST	18.071	26.779	25.808	22.591	22.265	21.868	18.5	20.609	3.28	

table 3.	QLI MEAN SCORE AND SUB SCALE MEAN SCORE				
MEAN	QLI	H&F SUB	SOC SUB	PSY/SP SUB	FAM SUB
PRE	21.42	17.873	24.345	22.859	26.875
SD ±	3.94	5.61	4.32	4.53	2.38
POST	22.062	20.062	22.336	23.125	27.125
SD ±	3.28	4	3.5	4.45	2.57

Department of Medical-Surgical Nursing (M/C 802)
College of Nursing

November 14, 1997

Ms. Mary Beth Perniz

Dear Ms. Perniz:

Thank you for your interest in the Ferrans and Powers Quality of Life Index (QLI). I have enclosed the cardiac version of the QLI and the computer program for calculating scores. I also have included a list of the weighted items that are used for each of four subscales: health and functioning, social and economic, psychological/spiritual, and family, as well as the computer commands used to calculate the subscale scores. The same steps are used to calculate the subscale scores and overall scores.

At the present time there is no charge for use of the QLI. You have my permission to use the QLI for your study. In return, I ask that you send me a photocopy of all publications of your findings using the QLI. I then will add your publication(s) to the list that I send out to persons who request permission to use the QLI.

If I can be of further assistance, please do not hesitate to contact me. I wish you much success with your research.

Sincerely,



Carol Estwing Ferrans, PhD, RN, FAAN
Associate Professor