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12-1-1997

## Living with Chronic Heart Disease: A Pilot Study

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### Recommended APA Citation

Winters, C. A. (1997). Living with Chronic Heart Disease: A Pilot Study. *The Qualitative Report*, 3(4), 1-27. <https://doi.org/10.46743/2160-3715/1997.2012>

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### Abstract

Few studies have addressed the experience of living with chronic heart disease. Understanding how persons appraise and respond to heart disease will foster nurses' ability to provide holistic client care. The purpose of this pilot study was to extend understanding of the experience of living with chronic heart disease and to identify questions for further study. Qualitative inquiry was the interpretive approach guiding this descriptive explorative study. Individuals eligible for participation were (a) 18 years or older, (b) able to read and speak English, and (c) at least 1 year post acute cardiac event and free of chronic illness unrelated to heart disease. A purposive sample of 4 women and 6 men with chronic heart disease participated in the study. Data were collected using semi-structured interviews and the Mishel Uncertainty in Illness Scale (MUIS-C) and analyzed for common themes. Four themes emerged: (a) Uncertainty, (b) change over time, (c) conflict, and (d) playing the game. Living with heart disease is a dynamic experience characterized by periods of certainty, uncertainty, and changes in behavior and feelings that evolve over time. Understanding this experience will assist nurses in providing holistic care to clients and their family.

### Keywords

qualitative research

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# **Living with Chronic Heart Disease: A Pilot Study**

by  
**Charlene A Winters<sup>±</sup>**

*The Qualitative Report*, Volume 3, Number 4, December, 1997

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## **Abstract**

Few studies have addressed the experience of living with chronic heart disease. Understanding how persons appraise and respond to heart disease will foster nurses' ability to provide holistic client care. The purpose of this pilot study was to extend understanding of the experience of living with chronic heart disease and to identify questions for further study. Qualitative inquiry was the interpretive approach guiding this descriptive explorative study. Individuals eligible for participation were (a) 18 years or older, (b) able to read and speak English, and (c) at least 1 year post acute cardiac event and free of chronic illness unrelated to heart disease. A purposive sample of 4 women and 6 men with chronic heart disease participated in the study. Data were collected using semi-structured interviews and the Mishel Uncertainty in Illness Scale (MUIS-C) and analyzed for common themes. Four themes emerged: (a) Uncertainty, (b) change over time, (c) conflict, and (d) playing the game. Living with heart disease is a dynamic experience characterized by periods of certainty, uncertainty, and changes in behavior and feelings that evolve over time. Understanding this experience will assist nurses in providing holistic care to clients and their family.

## **Living with Chronic Heart Disease: A Pilot Study**

Heart disease is the leading cause of premature morbidity and mortality in the United States accounting for more than 42% of all deaths (American Heart Association [AHA], [1997](#)). Although significant, the number of deaths alone does not adequately reflect the impact of heart disease on the lives of Americans. Improvement in diagnostic and treatment modalities for heart disease has led to a steady increase in the number of patients surviving an acute cardiac event. More than 60 million Americans are now living with some form of cardiovascular disease (AHA, [1997](#)).

Expanding treatment options, the extension of therapy to older and sicker patients, and prolonged survival has resulted in a patient population of varying ages, symptoms, and recovery. According to the American Heart Association ([1997](#)), 5% of all myocardial infarctions (MI) occur in people under age 40 and 45% occur in people under age 65. About two-thirds of MI patients don't make a full recovery and 83% of people who die are age 65 or older. The variations in response to treatment, the potential side effects, and the possibility of exacerbation of symptoms, characterize the uncertain nature of heart disease (Hawthorne, [1991](#)). While some patients may be primarily asymptomatic, others present with complex clinical problems. Similar to other chronic illnesses, individuals with heart disease can experience periods of acute illness interspersed with periods of quiescence. An increasing number of people survive acute cardiac

events and their treatment to experience end-stage heart disease (AHA, [1997](#); Gillum, [1993](#); Kannel, Ho, & Thom, [1994](#)). Nearly 5 million Americans are living with heart failure and nearly 400,000 new cases are diagnosed each year (AHA, [1997](#); Kaiser, [1986](#); National Heart, Lung, and Blood Institute [NHLBI], [1996](#)).

Although cardiovascular disease affects more than 60 million Americans (AHA, [1997](#)), few studies have addressed the experience of living with chronic heart disease. Several studies reported in the literature between 1980 and 1996 used qualitative methods to explore select aspects of living with chronic heart disease (Mast, [1995](#)). The focus of the reported research included the management of heart disease by older women (Clark, Janz, Dodge, & Garrity, [1994](#)); the reproductive experience of young women with congenital heart disease (Gantt, [1992](#)); the postoperative experience of men and women following cardiac surgery (Hawthorne, [1993](#); Keller, [1991](#); King & Jensen, [1994](#)); the adjustment of family members to a heart transplant (Mishel & Murdaugh, [1987](#)); and the ability of women with cardiovascular disease to make lifestyle changes (Thomas, [1994](#)). Most studies reported during this time frame used quantitative methods of data collection, involved subjects experiencing an acute phase of the illness or its treatment, and focused on a specific aspect of the illness experience such as functional status, coping, social support, and quality of life (Allen, Fitzgerald, Swank, & Becker, [1990](#); Bennett, [1993](#); Grady, Jalowiec, White-Williams, Pifarre, Kirklin, Bourge, & Costanzo, [1995](#); Hawthorne & Hixon, [1994](#); Holahan, Holahan, Moos, & Brennan, [1995](#); Keckeisen & Nyamathi, [1990](#); Kinney, Burfitt, Stullenbarger, Rees, & DeBolt, [1996](#); Markle-Reid, 1989; Papadantonaki & Stotts, [1994](#); Redeker, [1992](#); Searle & Jeffrey, [1994](#); White & Frasure-Smith, [1995](#)). No studies reported between 1980 and 1996 addressed the question "What is it like to live with chronic heart disease."

## **Purpose**

Describing the experience of heart disease in its totality, within the context in which it is experienced, will facilitate nurses' understanding of chronic heart disease and may provide direction when planning and implementing nursing care. Given the significance of heart disease in our society and the number of individuals surviving acute cardiac events, there is a need for further study in this area. The purpose of the pilot study was twofold:

- a. To describe the experience of living with chronic heart disease, and
- b. To identify researchable questions for further study.

Chronic heart disease was defined for this study as a non-reversible pathological alteration in heart structure or function which required intervention by health professionals.

## **Method**

Qualitative inquiry was the interpretive approach guiding this descriptive explorative study. Because multiple methods of data collection can enhance understanding of the phenomena under study (Breitmayer, Ayres, & Knafl, [1993](#); Ford-Gilboe, Campbell, & German, [1995](#)), two methods of data collection were employed in this study: a semi-structured interview and the completion of the community form of the Mishel Uncertainty in Illness Scale (MUIS-C).

Qualitative research methods are appropriate to use when describing a phenomenon about which little is known and are particularly suited when describing a phenomenon from the emic (individual) perspective (Morse, [1992](#); Morse & Field, [1995](#)). When used sequentially with qualitative data, numeric measurement can further the researcher's understanding of characteristics and patterns which emerge from the analysis of qualitative data (Ford-Gilboe, Campbell, & Berman, [1995](#); Morse & Field, [1995](#); Polit & Hungler, [1991](#)).

Ten interviews were conducted in this study. During analysis of the first 5 interviews, uncertainty emerged as an underlying theme. To better understand the emerging pattern of uncertainty, the last 5 individuals participating in the study completed the MUIS-C.

## Sample

A purposive sample of 4 women and 6 men with chronic heart disease participated in the study. Selection criteria included:

- a. Adults, 18 years of age or older,
- b. The ability to understand and speak English, and
- c. At least 1 year post acute cardiac event.

To better understand the experience of living with heart disease, individuals with chronic illness unrelated to heart disease were excluded from the study. Participants reported their initial diagnosis as coronary artery disease (60%), cardiomyopathy (20%), congenital heart disease (10%), and rheumatic heart disease (10%) ([Appendix A](#)). Participants were recruited from a private cardiology practice and a large academic medical center and ranged in age from 49 to 69 years ( $x = 56$ ; S.D. = 5.39). Ninety percent of the participants were married. Level of education ranged from 10 to 23 years ( $x = 13.2$ ; S.D. = 3.4); 50% of the participants had one or more semesters of college education; 80% were unemployed. All participants had undergone at least one acute cardiac intervention ranging in complexity from angioplasty to heart transplant.

## Procedure

Institutional Review Board approval was obtained before conducting this study. Written consent was obtained from each participant prior to their interview. Five of the interviews were conducted over the phone and 5 interviews were held in either the participant's home or a conference room scheduled by the investigator. Interviews were conducted using open-ended questions. The interviews began with a request for the participant to talk about the time when they first noticed that something was "just not right." This usually led to a description of the events surrounding the diagnosis of heart disease and the subsequent procedures and treatments. Near the end of the interview, participants were asked if they had anything else to add and if they had any advice for other people with heart disease. Probes were used to clarify what was said. Interviews lasted from 1 hour to 1.5 hours in length.

Theoretical memos (Maxwell, [1996](#); Miles & Huberman, [1994](#)) were used during data collection and analysis. Interviews were transcribed and analyzed as soon as possible using the following method:

1. The transcribed interview was read completely to get a sense of the whole.
2. The interview was reread and divided into units denoted by a change in subject matter or a change in activities being described.
3. Individual units from each interview were coded using topical codes.
4. The process of coding continued until all of the data were classified.
5. The codes were grouped into clusters of similar topics and recoded using interpretive codes.
6. The interpretive codes were grouped to reflect patterns / themes.

The simultaneous collection and analysis of data from the first 5 interviews served as a guide for subsequent data collection. Based on the analysis of the data from the first 5 interviews, the remaining participants were asked to complete the community form of the MUIS. The MUIS-C was developed for use with individuals or family members of chronically ill persons who are not hospitalized (Mishel, [1990](#)). The MUIS-C is a 23 item, one factor Likert-format scale that measures the uncertainty perceived in illness. The possible uncertainty scores range from 23-115, with a mid-range score of 69. The MUIS-C is scored in the direction of higher uncertainty; the higher the score, the higher the perceived uncertainty. Based on normative data from eight samples, reliability scores for the MUIS-C are reported in the moderate to high range ( $r=.75$  to  $r=.90$ ). Construct, discriminant, and convergent validity have been reported (Mishel, [1981](#), [1984](#), [1990](#)).

Two participants completed the MUIS-C at the end of their in-person interview. Scales were mailed to 3 participants following their phone interviews, along with a self-addressed, stamped envelope for return to the investigator. The MUIS-C was scored according to instructions provided in the scale manual (Mishel, [1990](#)). Internal consistency reliability was tested with 5 participants in this study, revealing a Chronbach's alpha for the scale of .98. Audio taped interviews, their written transcriptions, memos, and scores from the MUIS-C constituted the data.

## **MUIS-C Results**

Five MUIS-C scales were scored. Uncertainty scores ranged from 28 to 78 ( $x = 41.8$ ; S.D. = 20.54) with a median score of 33. All 5 participants had end-stage heart failure and participated in a heart failure / heart transplant program. Three participants who were an average 1.66 years post orthotopic heart transplant (OHT) had MUIS-C scores ranging from 32-38. One participant on hold for a heart transplant scored 28; another participant waiting for a heart transplant scored 78 ([Appendix A](#)).

The mean uncertainty score for the sample in this pilot study ( $x = 41.8$ ; S.D. = 20.54) fell below the mid-range score (69) and the mean uncertainty scores (range 42-76) for the eight sample normative data reported by Mishel ([1990](#)). The MUIS-C scores from this study indicate little uncertainty for 4 participants (MUIS-C < 38) and more uncertainty than average for the participant waiting for a transplant (MUIS-C = 78). All 5 individuals were actively involved in a transplant / heart failure program, completed routinely scheduled checkups, and participated in support group sessions for heart failure / heart transplant patients and their families. Support group participation is not addressed by the MUIS-C.

## Interview Results

Data from 10 interviews were analyzed. The initial coding yielded 77 topical codes ([Appendix B](#)). During further analysis, codes were renamed, clustered, and grouped into 4 broad categories:

- a. Uncertainty,
- b. Change Over Time,
- c. Conflict, and
- d. Personal Issues: Playing the Game ([Appendix C](#)).

Interview data reported in this paper are identified by the 3 digit code number assigned to each participant.

### Uncertainty

"Uncertainty" was used to describe an experience of the participant characterized by indecision or confusion about what the experience means or what actions should be taken. Uncertainty was experienced in varying degrees by all the participants in this study and underlies the three themes discussed later in this paper; change over time, conflict, and playing the game. Uncertainty was experienced by participants

- a. During the onset of symptoms,
- b. During the initial diagnostic period,
- c. When making treatment decisions,
- d. When adapting to therapies,
- e. During times of symptom exacerbation or recurrence, and
- f. When thinking about the future.

The experience of uncertainty influenced the participants' ability to make sense of their symptoms and their ability to make treatment decisions about them. Uncertainty was a major factor influencing the participants' need for information and support regarding symptoms and treatment options. The sense of uncertainty affected how participants responded to therapies and impacted their thoughts about the future. Examples of uncertainty are provided throughout the remainder of the paper as part of the discussions of the major themes; change over time, conflict, and playing the game.

### Change Over Time

The theme "change over time" was used to reflect the dynamic aspect of living with heart disease. Descriptions provided by the participants reflected a life characterized by change in feelings and behaviors that evolved over time. This theme was not meant to represent static stages where the participant clearly experienced one change and then moved on to the next. The intention was to describe a dynamic state where periods of uncertainty and exacerbations of the disease state, as well as periods of stability, influenced changes in behaviors and feelings experienced by the individual. The movement tended to mirror the changes in health they experienced. "Change over time" comprises five categories:

- a. Immortality and death awareness;
- b. Symptom recognition and response;
- c. Thinking of the disease;
- d. Health within illness, and
- e. Support and information.

All five categories share in common a sense of progression, reflecting a change in the way the participant experienced chronic heart disease over time.

1. *Immortality and death awareness.* This category represented the changes that took place in thinking and behavior related to immortality. Because of their illness experience, participants changed from viewing themselves as "immortal," or acting as if they were through the practice of questionable health behaviors, to an acute awareness of death and an appreciation for life. Each participant expressed an understanding of the nearness of death, and the desire to live life more fully. "Life is too short" commented one participant (005) who had undergone cardiac bypass surgery (CAB), triple valve surgery, and was now dealing with congestive heart failure (CHF). She expressed a strong desire to "live the way she wanted" and not how others "expected" her to live. Expressing his renewed appreciation for life following a heart transplant, another participant (009) stated, "You're told you're gonna die. And now you have a chance to live. So you go for it!" The sense of immortality was explicitly expressed by one participant (001) who had suffered a myocardial infarction (MI). "Prior to my MI, I thought that I was immortal and could do whatever I wanted." Although participants knew on an intellectual level that death was a part of life, they came to understand this in a very intimate way when faced with the symptoms, diagnosis, and treatments of heart disease. "I felt that everything happens to everybody else but not to me. I don't feel that way anymore. I realize it is very possible to have future problems" (001).

The awareness of death experienced by the participants was accompanied by a desire to live a more healthful lifestyle. "The fact of having new life, I mean your whole outlook on life is different" (009). The illness experience served as a powerful reminder to participants of their own responsibility in maintaining health. Following a MI, one participant (001) summed up the experience by saying, "I needed to be hit with a really big stick (MI) before I did anything." Although the awareness of death served as a powerful motivator to live a more healthful life, participant enthusiasm and compliance with healthful living was inconsistent. These inconsistencies are discussed further in this paper under the theme "playing the game."

2. *Symptom recognition and response.* This category referred to the changes that occurred in the way participants recognized and responded to their symptoms and the meaning they attached to them. During the early stages of illness, before diagnosis, individuals first ignored the symptom, often going about their daily routines. Participants often denied the severity of the symptom or ascribed inaccurate meaning to them based on previous experiences with illness or an unfamiliarity with the symptoms of heart disease. One participant (001) described her response to pain by stating, "I had that pain for 10 hours that day. Drove myself to work; attended some meetings; and drove myself back home." Because her pain was centered over her left breast, she didn't think it was cardiac. The gastrointestinal tract was often cited by participants as the source of the problem. Some participants described their initial symptoms as indigestion. One stated that

she experienced a "dull ache in the back" (008) similar to one she had years before that "turned out to be gallbladder." She expressed uncertainty about the meaning and significance of the pain. "I didn't know I was having a heart attack" (008). Other participants thought that their pain was "just gas" or "stomach trouble."

The initial response to symptoms was based on what the individual "usually did" in similar situations. Interventions described by the participants included ignoring the symptoms, resting, napping, taking antacids, and belching. The participant with the "gall bladder pain" described how she took a hot bath because that is what she did to relieve the gallbladder pain in the past. "I didn't know any better" (008).

Recognition implies an awareness of the importance of the symptom. Only 1 participant described having the classic symptoms of substernal chest pain with radiation to the left arm. Because of an earlier experience with chest and arm pain diagnosed as pericarditis, this participant recognized the significance of the symptoms and immediately sought medical care. "I knew exactly what it was" (002). Although the other participants didn't connect their symptoms to heart disease, recognition of their importance occurred when symptoms were severe enough to disrupt activities of daily living and "usual care" failed to produce the desired outcome. At this point, the individuals sought medical care; often at the urging of family members. One participant described his discomfort as "gas pain" and then as if an "elephant" was sitting on his chest. When belching no longer relieved his discomfort, he knew he was in trouble. After nearly two hours of pain and uncertain of its cause, he asked his wife to drive him to the emergency department. "Something's wrong. It's not gas" (009).

Following diagnosis of heart disease, participants expressed less uncertainty and a clearer understanding of the symptoms of heart disease and the importance of early treatment. They were aware that heart disease can manifest itself in a variety of ways and is not limited to pain beneath the sternum. "I know now that the pain can be anywhere" (001). Having had the experience, participants reported seeking medical intervention more quickly when faced with similar symptoms, or an intention to do so should symptoms occur. "If I had any kind of discomfort now, I would do what I know to do, which is to try nitroglycerin. If I didn't get relief, I'd get right in" (001, 004).

3. *Thinking of the disease.* Individuals reported that their thinking about their illness changed over time. The experience of heart disease moved from being central in their life and the primary focus of their thoughts, to one that lurks in the background. Events that shaped this transition were

- a. Illness stability,
- b. Consistency of a treatment regime, and
- c. Comfort with the illness routine.

The illness was central to the thoughts and behaviors of the individuals during the diagnosis and treatment phases; during times of uncertainty. It receded, but never left their thoughts, during times of comfort and certainty. A transplant patient talking about the time immediately before and after the transplant, demonstrated how the focus of her thoughts changed over time. She

described the 2 years she waited for a donor heart as a time consumed by doctor visits, worry, and "sitting around," unable to leave town for fear she would miss her "phone call" and a chance for a donor heart. The first year following transplant was a time full of "new challenges" and "adjustments;" medications to learn; doctor visits to keep. "Problems and doctors. That's my life" (008). Now, nearly 2 years post transplant, she had settled into a routine, traveled when she wanted, and no longer felt as if her life revolved around her disease.

Uncertain times challenged participants' ability to put thoughts of their heart disease in the background. Uncertainty was experienced during the time of initial diagnosis of heart disease, with recurrence of symptoms, when treatment decisions were being made, and when adjustments in therapies were needed. One participant, when describing his initial symptoms and diagnostic work-up, stated, "I didn't know from nothing. They couldn't make up their minds to do a bypass or not" (006). He then detailed the many second opinions he sought in order to come to a clear decision about his treatment. "I had all different opinions. So I decided that I was going to go with the transplant." While he thought less about his illness once on the transplant list than he did during the diagnostic phase, his illness was not completely out of mind. Although he didn't "dwell on it," he planned to "just keep going," doing what he had to do, while others decided when and if he would be transplanted. Another participant "did well" for the first year post coronary artery bypass surgery and was able to resume most of his normal activities; not giving his condition much thought. He then found himself facing new symptoms and treatments, a constant reminder of his heart condition. He stated that he felt "experimented" upon because of the frequent adjustments in his medications. "I think they're just practicing" (004).

The following statement from a man 2 years post transplant summarizes the change in thinking experienced by the participants. "You get by that first year. I mean it's real hard work. Once you get by that, it's routine; just like getting up in the morning and putting your pants on" (009).

4. *Health within illness.* The way participants viewed their health changed over time. During the diagnosis and early treatment phase, as well as during times of illness exacerbation, participants saw themselves as ill. Following diagnosis, and during times of stability and consistency, participants saw themselves as essentially healthy. This attitude was influenced by comparisons the participants made with their previous state of health and to the health of others diagnosed with a serious illness.

Eight of the participants saw themselves as essentially healthy even though they were hard at work dealing with chronic heart disease; exercising, taking medications, and seeing their physician on a regular basis. They came to accept the changes in their health, the side effects of treatment, and the medical interventions as "their life." Most participants were able to separate the diagnosis of heart disease and treatment from their overall view of themselves as healthy. On hold for a transplant, one participant remarked, "As far as I'm concerned, I'm 100% healthy except for my heart" (006). Another participant 2 years post transplant detailed numerous symptoms he was experiencing as a result of prescribed medications (leg cramps, tremor, frequent bowel movements, and nightmares) but added that he "felt great" and was "doing just great" (010).

Through comparison, most participants saw themselves as "better off" than others, or better than they had been prior to diagnosis and treatment. "I never felt this healthy. I thought I was healthy, but it was nothing compared to how I feel now" (009) was the response of one transplant recipient. Another heart transplant recipient referred to the medications she took and the regularly scheduled exams she underwent as "the things you do to stay healthy" (008). They chose to look on the positive side, seeing their glass as half-full, and spoke of trusting their health care providers and having "faith" in them to steer them in the right direction toward health. One participant, post MI, followed the advice of her physician and made significant life style changes. "I'm feeling better than ever because of the changes I've made" (001).

Two participants, 1 post CAB and 1 post CAB / mitral valve surgery and now waiting for a donor heart, viewed themselves as sick. Again, comparisons with their previous state of health or with the health of others, influenced their views. Both were experiencing bothersome symptoms and undergoing adjustment to treatments. Both appeared distrustful of their health care providers. During his postoperative recovery following CAB and mitral valve surgery, one participant concluded that he was "not doing well" after comparing himself to much older men who he perceived to be recovering more quickly from the same surgery. And although he was "supposedly all right" and discharged home, he continued to have problems. "I really didn't have problems until I had the diagnosis of the heart stuff" (007). He was now waiting for a heart transplant. He used the phrases "lied to" and "shoved off" when talking about the health care system and referred to himself as "sick" on several occasions.

The other participant, with a long history of heart disease, was despondent about the decline in health he had experienced in the past year. He was concerned about his decreasing stamina and "inability to do what he used to do" (004) since undergoing CAB surgery 2 years ago. "I'm not much good anymore." Prior to his surgery, he paid "no attention" to his heart condition, taking his medications and going "on his way." And, although he has never felt "100%" since the operation, he did feel "pretty good until they started experimenting with drugs" to relieve bothersome symptoms of cough and chest congestion. He described his physician's attempts to adjust doses of newly prescribed medication as "still practicing" yet recognized that "you never know what might work" and that adjustments in therapy were sometimes necessary. He summed up by saying that this was "just part of the game," a comment made by several of the participants when referring to treatment.

*5. The need for support and information.* Over a period of time, changes occurred in the needs of participants related to information and support. The amount of information and support needed decreased over time, and participants changed from primarily needing information and support, to needing to give information and support to others facing a similar situation.

The need for information was greatest during times of uncertainty; during diagnosis, when making decisions about treatment choices, and during recovery from acute events. In times of stability, the amount of information required decreased and remained constant. An increased need for information and support occurred during times of illness exacerbation. Participants identified health care providers as a primary source of information. However, except for those in transplant programs, participants reported that information was often provided only after requested, was at times sketchy, and did not adequately address the mental and emotional aspects

of living with heart disease. "We never talked about emotions at all. It's totally about medications, diet, and exercise" (001). Participants felt inadequately prepared by their health care providers for the long recovery time following cardiac surgery. "No one told me what to expect" (002, 004) Individuals with similar illness experiences to theirs were identified as valuable sources of information.

Support was particularly important during times of illness exacerbation, when activities of daily living were disrupted, and when making and carrying out treatment decisions. Participants recognized the significant role friends and family members played in providing support. Six participants referred to their spouses as their "partners" in dealing with their illness. Another participant commented on the tremendous support she felt from her children. "They hardly left the room at all when I was in ICU and slept on the floor at night" (005). A special form of support came from others who had similar experiences to those of the participant. "The doctors are fine, medically. Friends and family are there for you. But you have a special bond with others who are going through the same thing you are" (008). Formal support groups were cited by transplant recipients and those waiting for a transplant as very helpful. Sharing information about symptoms, medication side effects, and treatments were seen as particularly useful. Although this information was available to them from their health care providers, the participants placed more value on the information they received from others who had "gone through it."

The need for information and support extended to spouses and other family members. Participants noted the important role family members played in helping them to successfully meet treatment prescriptions and recognized their need to be fully informed and supported in this role. "It's tough on families. Especially the spouses. We put them through hell" (009).

Although the participants continued to need information and support when changes in health status or treatment occurred, their need shifted to one of providing information and support to others. Each participant mentioned how helpful it was to hear from someone who had "been in their shoes" and spoke of their efforts to share their experience with others as a means of providing information and support. One participant, post CAB surgery, routinely visited friends hospitalized for heart disease as a way of providing support and information. "I've talked to a dozen different people who are going through what I've gone through. I think it's helpful to hear from someone who has been through it"(002).

## **Conflict**

The conflicting emotions experienced by the participants in this study are described by the theme "Conflict." Conflict occurred intermittently throughout the course of the illness and was characterized by the following emotions:

- a. The desire for self reliance versus the need to rely on others;
- b. The need for medical technology and treatments versus the cost, fear, and intrusion they bring; and
- c. The desire for control versus the feelings of being out of control.

Participants expressed a desire to care for themselves yet recognized that they needed help from others when their usual care no longer provided the desired outcome or they were too ill to perform activities of daily living. While the need for help was acknowledged, participants were often reluctant to accept it, feeling embarrassed about needing help with activities they were once capable of completing on their own. During times of distress, help was more readily accepted and activity restrictions more easily maintained. When feeling "healthy," some participants had difficulty limiting their activities as prescribed by their health care providers. This statement given by one participant doing well and on hold for a heart transplant described the conflict he felt about his health: "I feel healthy as a horse, and yet I'm sick as a dog" (006).

While the participants were appreciative of the skill of their physicians, and the technology and treatment options available to them, they were also frightened and annoyed with the frequency of treatments and the lack of certainty regarding an outcome. One participant sought opinions from several health care providers regarding treatment options. When he received conflicting opinions, he chose to go with the one that seemed "most certain" (006) for a positive outcome. Another participant, remembering what her first surgery entailed was undecided about going through with a second surgery. Although uncertain about what to do, she realized she needed help in order to live. "What else could I do?" (005). While waiting for a heart transplant, one participant stated, "I'm sick and tired of people sticking needles in me and sick and tired of taking all this medicine" (007). The conflict he felt was evident when he explained further, "Don't get me wrong. If they call me up this afternoon and say they have a heart for me, I'm not going to say no."

Participants expressed a desire to control their own fate and felt positively reinforced when their efforts paid off. One participant commented that she would have felt better had the decrease in cholesterol she experienced been a result of her diet, and not the medication she was taking. The following excerpt from a participant who had undergone CAB surgery, valve replacement surgery, pacemaker insertion, and left ventricular assist device implantation prior to a transplant, was typical of this theme.

I had the pacemakers and plastic valves. Until I had the transplant, I had it all. And it was just a machine. I wondered, is that screw going to fall out? Is the spring going to break? Is that battery going to go dead? You know you don't know what's going to happen. You always constantly have that on your mind. After the transplant, it's like you're born all over again. I can control my life....not somebody in some manufacturing company that made this thing (009).

### **Personal Issues: Playing the game**

"Personal issues" refers to the thoughts, needs, emotions, and activities common to the participants interviewed. Personal issues included

- a. The "work" associated with chronic heart disease,
- b. The desire to live, and
- c. The response to illness.

Personal issues arose from the recognition, meaning, and impact heart disease had on each participant. The personal issues were shaped by a sense of resignation and by the realization of a "second chance" at life. "It's what has to be done. It's part of the game" (004).

1. *Work.* The personal work engaged in by the participants included undergoing the diagnostic process, physical and emotional recovery from an acute event, adherence to medication and treatment regimes, and life style changes; dieting, exercising, and attempts at smoking cessation. The work of living with chronic heart disease required effort and perseverance. Participants engaged in work in an inconsistent manner. The ability to engage in work was influenced by the participant's trust in their health care provider, fear of recurrence of symptoms, deterioration in heart function, and the response gleaned from their efforts. Some participants referred to the diagnostic process and their treatments as "the game" noting the uncertain nature of responses to treatments.

Participants were consistent when describing the process of diagnosis as a time marked by fatigue, anxiety, uncertainty, and fear. Two participants felt "stupid" for not recognizing their symptoms as cardiac and most regretted not seeking help sooner. "I should have gone right to the hospital. I just didn't know how bad it was" (008). In retrospect, participants recognized fatigue as a consistent symptom present prior to diagnosis. The diagnostic process included numerous tests and multiple appointments with primary care physicians and heart specialists. When faced with treatment decisions, participants expressed a sense of resignation and concern that treatment would be completed before their condition deteriorated. "What else could I do?" (005). "I hope they can do it in time" (006).

Participants described the time immediately following their acute event, as a period of uncertainty, fatigue, little stamina, and anxiety. "Limit setting" and "patience" were essential to a recovery period that the participants characterized as "taking time." While improvements in symptoms provided positive reinforcement for the participants, enhanced their trust in health care providers, and eased fears of reoccurrence, participants remained cautious, and uncertainty lingered. Following her MI, one participant quit smoking, changed her diet, and began a modest exercise program. She was anxious about following the recommendation to increase her activity for fear that "something else was going to happen" (001) and carried her nitroglycerin everywhere she went. After a year, when "nothing happened," she increased her activities, becoming more trustful of her physician's advice and more confident of her ability to exercise without a reoccurrence. She was able to go about her daily activities without her nitroglycerin at hand. "I know where I can get it if I need it." When describing his feelings about being put on "hold" for a transplant, one participant stated, "I don't know if I should say thank God I'm lucky or what. If I can get by without it, I would rather not have it. Like I said, I don't know if that is good or bad" (006).

For some participants, improvement in symptoms and a sense of well being led to a decrease in adherence to treatment prescriptions and lifestyle changes. Four participants returned to smoking and 1 did not take medications as recommended. On hold for a heart transplant, 1 participant stated, "I was feeling better. I had no problems so I stopped taking some of my medications. I started smoking. Then I got sick again" (006). Feeling better than he ever had been following his MI and CAB surgery, another participant walked regularly and found it easy to stay on his diet.

He stated that he doesn't worry about a return of chest pain. "If it happens, it happens" (002). Because he still smoked, he admitted that he must not be "that concerned" about a recurrence.

The return of symptoms and deterioration in heart function provided incentive for some participants to return to exercise, diet, and smoking cessation recommendations and led to a heightened sense of their importance. With the return of symptoms, came a sense of resignation that the therapies, medications, and change in lifestyle were an integral part of the participant's life and must be continued. "I stay on my medications. I'm a firm believer in that now" (006).

The use of medication was frequently addressed by the participants. Individuals were able to discuss the drugs they were taking; their purpose, dose, and prescribed schedule. They enjoyed a sense of accomplishment when a medication dosage was reduced or positive results were achieved without the use of medication. Dealing with the side effects of medications was a common occurrence for participants. Frequent visits with physicians were thought of as necessary in order to "get things under control." Although burdensome at times, participants accepted these as "part of the game."

When asked if they had advice for others regarding heart disease, each participant mentioned the importance of regular exercise and maintaining a low fat diet; "doing what you're told to do." Although at times participants had difficulty following their own advice, they were adamant about the importance of maintaining a healthy heart lifestyle. The sentiment expressed appeared to be "learn from my mistakes" and "do as I say, not as I do."

2. *The desire to live.* Each participant expressed a desire to live and the willingness to do what they had to do to stay healthy. Doing what had to be done included life style change, taking medications, and undergoing multiple diagnostic tests and surgery for some participants. The participant's desire to live was tempered by

- a. The fear of becoming so ill as to be a burden on someone else, and
- b. A desire for a better quality of life.

The desire to live required trust and meant "putting yourself in somebody else's hands." While making her decision to have triple valve replacement surgery, one participant recognized that the chance at a better quality of life far outweighed the risks of surgery. "I would rather take the risk. The alternative is a very debilitating life and I don't want to live like that" (005). After receiving conflicting advice from physicians about the best course of action, one participant chose to be placed on the list for transplant rather than have CAB surgery. "The outcome seemed more certain" (006) for improved quality of life. In the meantime, he is "fighting to feel better" so he doesn't have to be transplanted. But if he needs it, he'll "just do it."

3. *The response to illness.* Response to illness refers to the coping strategies used by participants living with chronic heart disease. Common strategies included

- a. Not thinking about it,
- b. Keeping active,
- c. Looking at the positive aspect of illness, and

d. Surrender.

A common way participants dealt with heart disease was by "not thinking about it" and "keeping busy." When talking about her feelings related to the recall of her pacemaker, one participant stated "I hadn't given it much thought" (003). Another when asked about his future, said "I try not to think about it" (003). Participants mentioned keeping busy which included visiting with friends, enjoying hobbies, traveling, doing housework, taking care of family members, and participating in support group activities. One participant on hold for a transplant stated, "I keep active with friends. Enjoy myself. I don't let it get me down" (007). Another, with a 50-year history of heart disease, stated that she never thought of herself as having a disease. "It was just something I had; like a scar from chickenpox" (003). She has dealt with the effects of rheumatic fever and recent CAB surgery and pacemaker insertion by "not dwelling on it" and keeping very active. She refused to let it "control" her life. "You could make yourself sick thinking about all the terrible things that could happen."

Participants spoke of the positive aspects of their illnesses. Once diagnosed and treated, this was expressed as an improvement in physical functioning. Even those who were experiencing troublesome symptoms or a decline in cardiac status found something positive in the experience. One participant noted that his illness allowed him to stay home with his young daughter, something he ordinarily would not have done. "It's been an experience of a lifetime. It's one of the blessings of being sick" (007). Participants expressed happiness to "just be alive" and to get a "second chance" to enjoy life and spend additional time with family and friends. Some saw their recovery from acute illness as a "gift" and improved health an opportunity to give something back to others.

Participants responded to chronic heart disease and its treatment by surrendering responsibility to others. Participants explained their illness as "just the way life is" and as part of the "bigger picture." They spoke of fate, luck, guardian angels, higher authority, and God when explaining their survival of acute events and procedures. When describing her response to needing triple valve replacement, one participant summed up her feelings this way: "I really didn't dwell on it. It had to be done and I just knew that God was going to take care of me" (003). Allowing that their lives were not completely in their control but in the "hands of a higher authority," participants made some sense of the uncertainty of their illness and survival. "There's a reason for it. There are reasons for everything in life. I'm just not sure what the reason is" (005).

## **Discussion**

The purpose of this pilot study was twofold:

- a. To describe the experience of living with chronic heart disease, and
- b. To identify researchable questions for further study.

Several studies reported in the literature between 1980 and 1996 explored select aspects of living with heart disease. Most studies reported during this time frame used quantitative methods of data collection and involved subjects experiencing an acute cardiac event or its treatment. No

studies addressed the question "What is it like to live with chronic heart disease?" for individuals at least 1 year post acute event.

The preliminary results of this study indicate that, regardless of cardiac diagnosis or treatment differences, living with chronic heart disease involved living with uncertainty, change, conflict, and tremendous personal, medical, and family issues; what some participants referred to as "playing the game." Participants demonstrated changes in their thoughts and behaviors that evolved over time in response to changes in their heart disease. Participants gained an awareness of their own mortality; increased their ability to recognize and respond to symptoms; changed from thinking about their disease most of the time during diagnosis, treatment, and periods of exacerbation, to rarely thinking about it during times of stability; saw themselves as healthy when their condition was stable and they were seemingly better off than others; and moved from needing information and support to wanting to provide these to others.

The experience of living with heart disease included conflicting emotions. The participants' desires to care for themselves often conflicted with the need for complex medical care. There were conflicting emotions regarding the ways in which participants viewed the intrusion of medical care into their lives. It appeared that living with heart disease meant moving between periods of certainty and uncertainty. Participants expressed less uncertainty once their diagnosis was made, treatment decisions were finalized, and symptoms stabilized. Uncertainty was experienced when information was lacking or usual care failed and as a result individuals fluctuated between feeling in control and feeling out of control.

The personal issues confronting participants were referred to by some participants as "playing the game." Living with heart disease involved a significant amount of work associated with diagnostic testing, recovery from acute events, and adherence to medical therapies. The work required perseverance and time. The participants' trust in their health care providers, fear of symptom reoccurrence, and changes in their condition influenced their ability to engage in the work associated with the diagnosis and treatment of heart disease. Participants demonstrated a strong desire to live, to improve their quality of life, and to avoid becoming a burden for loved ones. They responded to their illness by not thinking about it, keeping busy, looking for a positive aspect to their illness, and surrendering some responsibility for their illness to another. Some participants saw heart disease as part of a poorly understood larger plan and their illness and survival as serving some unknown purpose.

All 5 participants who completed the community form of the Mishel Uncertainty in Illness Scale were diagnosed with end-stage heart failure and were involved in a heart failure / heart transplant program. Three participants were post heart transplants and 1 participant was on "hold" for a heart transplant because of his stable condition. MUIS-C scores for these participants fell below the normative sample mean demonstrating little uncertainty concerning their illness (MUIS-C < 38). One participant waiting for a heart transplant (MUIS-C = 78) scored above the mean uncertainty score for the eight sample normative data reported by Mishel (1990). These findings are consistent with the themes reported above related to uncertainty, change, conflict, and response to illness. The extent to which participation in a structured program influenced the uncertainty scores is undetermined. Support group participation is not addressed by the MUIS-C.

Because of the participants' involvement in a heart failure / heart transplant program and support group, the use of the community form of the MUIS with this population requires further study.

The preliminary findings, uncertainty, change over time, conflict, and playing the game, may facilitate nurses' understanding of chronic heart disease and provide insights that alter clinical practice. Resultant nursing interventions should support the individual's growing understanding of the symptoms of heart disease and desires for self-care and self control. Individual strategies for coping with heart disease should be identified and facilitated. Interventions aimed at improving communication between the individual and their health care providers are warranted. Teaching the individual about the symptoms, emotions, and physical recovery that accompanies heart disease is essential. Nurses should facilitate the individual's desire to provide information and support to others with heart disease through the development of support groups, mentoring programs, and informal resource networks. Understanding that the work associated with heart disease is inconsistent and dependent upon the recognition and meaning of its impact upon the individual will assist nurses in their understanding of patients living with chronic heart disease.

Preliminary findings suggest that individuals may respond to chronic heart disease in a similar fashion regardless of differences in diagnosis or treatment. Because differences may exist that were not identified in this study, a further exploration of living with chronic heart disease utilizing a larger sample is warranted. Future research is also needed to examine potential differences in response to chronic heart disease based on diagnostic group, prescribed therapy, age, and gender undetected in this study. Studies which explore the impact of structured programs of care and support groups on the uncertainty associated with chronic heart disease, and the appropriate use of the MUIS-C in the heart transplant population, are also suggested.

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## Appendix A Participant Data

<b>Id #</b>	<b>Education (years)</b>	<b>Age (years)</b>	<b>Gender</b>	<b>Diagnosis</b>	<b>Procedures</b>	<b>MUIS-C Score</b>
001	23	49	Female	MI	PTCA	
002	12	62	Male	MI	CAB	
003	12	64	Female	RF	Valve Pacemaker	
004	12	69	Male	MI/CHF	CAB	
005	13	66	Female	CAD/CHF	CAB Valve Pacemaker AICD	
006	12	65	Male	MI/CHF	Transplant listed	28
007	10 GED Some College	55	Male	Cardiomyopathy	CAB Valve AICD Transplant listed	78
008	12	56	Female	MI	OHT	32
009	12 Some College	51	Male	CHD	Valve OHT	33
010	14	53	Male	Cardiomyopathy	OHT	38

## Key:

AICD:	Automatic Internal Cardiac Defibrillator
CAB:	Coronary Artery Bypass Surgery
CAD:	Coronary Artery Disease
Cardiomyopathy:	Structural or Functional Abnormality of the Heart leading to heart failure
CHD:	Congenital Heart Disease
CHF:	Congestive Heart Failure
MI:	Myocardial Infarction
PTCA:	Percutaneous Transluminal Coronary Angioplasty
OHT:	Orthotopic Heart Transplant
RF:	Rheumatic Fever
Valve:	Heart Valve Replacement or Repair Surgery

## Appendix B Initial Coding Grid: Living with Chronic Heart Disease

#1 49 Female MI PTCA	#2 62 Male MI CAB	#3 64 Female RF Valve Pacer	#4 69 Male MI CAB	#5 66 Female CAD CAB Valve AICD Pacer
Best thing to happen	Slows you down	Does have a condition; an illness led to this	Not good anymore	Completely changed her life
Tired	Tired	Tired	No stamina	Tired
More energy after	Can't work	No wind / no good	No wind	No breath
Rely on MD advice	Rely on MD advice	Rely on MD advice		MD advice
Nervous		Nervous		
MD optimism				
Time	Time			Time

Reinforce	Reinforce			
Immortal	Immortal			
Problems possible				
Chance				Chance
Denial of symptom				
Mistook symptom				
Symptom recognition	Symptom recognition		Symptom recognition	
Usual care			Usual care	
Lucky				
Death awareness	Death awareness	Death awareness	Death awareness	Death awareness
Disbelief				
Stupid				
In control	In control	In control	In control	In control
Lack of info	Lack of info	Lack of info	Lack of info	Lack of info
Nurse vs patient				Nurse vs patient
Handle it yourself				Handle it yourself
Support of family, friends	Support or family, friends, patients	Support or family	Support or family	Support of family
Set limits	Set limits	Set limits	Set limits	Set limits
Prioritize		Prioritize		Prioritize
Take help				

Partners			Partners	Partners
Learning		Learning		Learning
Comparison	Comparison	Comparison	Comparison	
Made changes	Made changes	Made changes		Made changes
No control	No control		No control	Lack control
	Cost			Cost
Focus shifts to less important	Focus Out of thoughts	Focus Out of thoughts	Focus Out of thoughts	
MD visits Multiple MD	MD visits Multiple MD	MD visits Multiple MD	MD visits Multiple MD	MD visits
Share info	Share info			Share info
	Not old won't make it			
Family role	Family role	Family role	Family role	Family role
	Doesn't want to be a burden			Doesn't want to be a burden
		Deal with it	Deal with it	
Symptom severity >	Symptom severity >	Symptom severity >	Symptom severity >	Symptom severity >
		Side effects	Side effects	Side effects
Ignored symptoms	Ignored symptoms	Ignored symptoms		Ignored symptoms
Type A?		Type A?		Type A?
	Keep active	Keep active		
Needs Rx		Needs Rx	Needs Rx	Needs Rx
		Do what have to do		
Spirituality		Spirituality		Spirituality

	Irritated by others' illness behavior	Irritated by others' illness behavior	Irritated by others' illness behavior	
			Experiment	
			Resignation	Resignation
			Regret	
		Emotional	Emotional	Emotional
				Technology conflict
				Ignore women
Self-less		Self-less		Self-less
				Desire to live
	Deciding on diagnosis			Deciding on diagnosis
Not doing what should	Not doing what should			
				Decision making

**Appendix B (Continued)**  
**Initial Coding Grid: Living with Chronic Heart Disease**

#6 65 MUIS-C = 28 Male MI	#7 55 MUIS-C = 78 Male CAB Valve AICD Myopathy Listed	#8 56 MUIS-C = 32 Female MI Transplant	#9 51 MUIS-C = 33 Male CHD Valve Transplant	#10 53 MUIS-C = 38 Male Myopathy Transplant
<BR.< td>	Unexpected + outcome	Purpose for living	Unexpected + outcome	
	Tired	Tired	Tired	Tired
Can't breathe	Can't breathe		Can't breathe	Can't breath

Rely on MD advice		Rely on MD advice	Rely on MD advice	Rely on MD advice
Nervous / fear	Nervous	Nervous / fear		Fear
		Time	Time	Time
Reinforced			Reinforced	Reinforced
	Exchange 1 set of problems for another	New challenges; what med may do to you		Learn to live with it
Chance	Chance	Chance	Chance	
Symptom recognition	Symptom recognition	Symptom recognition	Symptom recognition	Symptom recognition
		Usual care		Usual care
			Disbelief	Disbelief
Death awareness		Death awareness	Death awareness	Death awareness
		Stupidity		
In control (taking?)		In control	In control	In control
	Lack of info	Lack of info		Lack of info
		Handle it yourself		Handle it yourself
Support of patients	Support of patients	Support of patients	Support of patients	Support of patients

		Set limits	Set limits	Set limits
		Prioritize		
	Take help		Take Help	Take help
	Partner		Partner	Partner
		Learning	Learning	Learning
Comparison	Comparison	Comparison	Comparison	Comparison
Made changes		Made changes	Made changes	Made changes
No control	No control	No control	No control	No control
	Cost			
Focus out of thoughts	Focus out of thoughts			Focus out of thoughts
MD visits Multiple MD	MD visits Multiple MD	MD visits Multiple MD	MD visits Multiple MD	MD visits Multiple MD
	Share info	Share info	Share info	Share info
	Accomplishment just to make it this far			
Family role	Family role		Family role	Family role
Deal with it		Deal with it	Deal with it	Deal with it
Symptom severity > MD	Symptom severity > MD	Symptom severity > MD	Symptom severity > MD	Symptom severity > MD
Side effects	Side effects	Side effects	Side effects	Side effects
Ignored symptom	Ignored symptom			Ignored symptom
Keep active			Keep active	Keep active
Need Rx	Need Rx	Need Rx	Need Rx	Need RX

Do what have to do		Do what have to do		
		Spirituality	Spirituality	
Resignation	Resignation	Resignation		Resignation
		Regret		
	Emotional	Emotional	Emotional	
			Technology conflict	Technology conflict
		Desire to live	Desire to live	Desire to live
Deciding on a diagnosis	Deciding on a diagnosis	Deciding on diagnosis		Deciding on diagnosis
Not doing what should				
Decision making			Decision making	Decision making
Waiting for something to happen	Waiting	Waiting	Waiting; waiting for something to happen	Waiting
Wellness within illness			Wellness within illness	Wellness within illness
Treat in time		Treat in time	Treat in time	Treat in time
Impossible				
	Changing	Changing		
	Share info	Share info	Share info	Share info
	Give back	Give back	Give back	Give back

	Distrust, Skeptical			
	Hope	Hope		Hope
	Taken identity away			
	Known / Unknown			Known / Unknown
		Struggle to understand	Struggle to understand	
		Winning	Winning	
		Thankful	Thankful	Thankful
		Becomes routine	Becomes routine	Becomes routine
			Disbelief	Disbelief
			Work to goal	Work to goal

**Appendix C**  
**Code Categories and Clusters**

	<b>Uncertainty</b>	
<b>Change Over Time</b>	<b>Conflict</b>	<b>Personal Issues: Playing the game</b>
Immortal and death awareness	Self reliance vs reliance on others	Personal work
Symptom recognition and response	Need for medical technology vs fear / intrusion of technology	Desire to live
Thinking of disease: Primary focus > routine	Control vs no control	The response to illness
Health within illness		
Need for information and support		

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