

ABSTRACT

THE LIVED EXPERIENCE OF HEART DISEASE: A WOMAN'S PERSPECTIVE

By Amanda L. Woulf

Every minute a woman in the United States dies from cardiovascular disease (Weiss, 2009). Despite the prevalence of heart disease, women continue to underestimate the threat of heart disease. The diagnosis of heart disease can mean battling with uncertainties of what the future will hold. Further examination of the lived experiences of women with heart disease is needed to identify the uncertainties experienced by women that impact their health behaviors. The purpose of this descriptive, phenomenological study was to examine and describe the lived experience of heart disease from the perspectives of women.

Mishel's Uncertainty in Illness Theory (1988, 1990) served as the theoretical foundation for this study. Mishel's theory was developed as a guide in understanding how individuals cognitively develop meaning to their illness events. Data were collected from a purposive sample of women with heart disease. Data were collected through unstructured, face-to-face, audio-taped interviews. After data were collected and transcribed, it was analyzed using Giorgi's phenomenological method. Data were then described, compared, and applied to Mishel's Uncertainty in Illness Theory. Results, implications, and conclusions were then based on the data received.

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by

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A Clinical Paper Submitted
In Partial Fulfillment of the Requirements
For the Degree of

Master of Science in Nursing

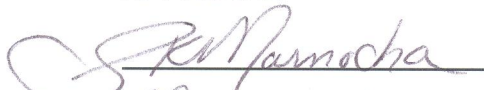
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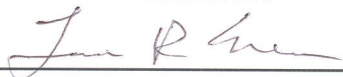
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May 2011


APPROVAL

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May 2, 2011 Date Approved

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5/3/11
Date Approved

FORMAT APPROVAL


4/21/11
Date Approved

ACKNOWLEDGMENTS

I would like to dedicate this clinical paper to all women who have experienced heart disease. This project has taught me that the best way to learn is to simply listen. Everybody has a story, and my story of graduate school is filled with chapters of emotions, gratitude, and joy. My sincere gratitude goes to my husband Joe, who has been my backbone through this 3-year long rollercoaster ride. Without your loving support and patience, I would not have survived this journey and would not be the person I am today. To my dear Allyson, you are the best surprise mommy has ever had! Your smile and silly giggles are sweet therapy for me, and I can't wait to see who you grow up to be. To my parents, there are no words to express my gratitude for the support you have given me throughout this process. Thank you to my parents, my in-laws, and my sister, Sarah, who have helped tremendously with caring for Allyson. I would also like to thank my dear friends Carla and Tiffany, you gals are awesome, and you will be forever dear to me. Thank you Dr. Marnocha for your kindness, positivity, guidance, and expertise in nursing and research, this project would not have been completed without your intelligent insight. My story ends with tremendous feelings of joy, the greatest feeling I have ever experienced!

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Chapter I

Introduction

The diagnosis of a chronic disease can lead to a life filled with uncertainties, the unknown effect that a chronic disease will have on one's life. Uncertainty in illness is when a person is incapable of identifying the meaning of illness-related events because he or she cannot formulate a cognitive schema of the event (Mishel, 1988, 1990). The purpose of this study was to explore and describe women's lived experiences with heart disease and to identify the uncertainties associated with living with heart disease.

Heart disease (HD) was once referred to as a male disease (Miracle, 2006). As time evolved, this belief has not held true; the most recent (2006) recorded mortality rates from cardiovascular disease [American Heart Association (AHA), 2010] were similar when comparing males and females. Coronary artery disease (CAD) contributed to the greatest number of mortalities for both genders (AHA, 2010). Heart disease kills more women annually than all cancers combined. Currently, over eight million American women are living with HD. Four million women live with symptoms of angina, and 2.6 million are battling with chronic heart failure (AHA, 2010).

When compared to men, women are more likely to die 1 year after having a myocardial infarction (MI), and are more likely to die after open heart surgery (Lerman & Sopko, 2006). These data may be due to the fact that women present with HD at an older age, and women tend to live longer than men. Women have been found to minimize the severity of their cardiac symptoms and the experience of their cardiac events (White, Hunter, & Holttum, 2007). This lack of perceived severity of cardiac events and the minimization of cardiac symptoms have prevented women from seeking

medical attention. Delayed medical care has resulted in greater morbidities and mortalities from HD amongst women (Rosenfeld, 2001). Previous research reports that women have delayed seeking medical care after identifying a breast lump or lesion due to the fear and uncertainty that their findings may be cancer (Demir, Donmex, Ozsaker, & Diramali, 2008).

Despite the convincing evidence that HD is a prevalent disease amongst women, women have failed to adequately acknowledge HD as a threat. The AHA conducted a survey in 1997 to examine the general public's knowledge regarding HD. Less than one-third of the women surveyed identified HD as the number one killer for females, but 40% of the women surveyed felt that they were well informed regarding HD (in Mosca, Ferris, Fabunmi, & Robertson, 2004). Despite perceiving themselves as well informed, less than one-third were able to correctly identify risk factors for HD. Since the 1997 survey, the AHA has initiated a public campaign, "Go Red for Women," aimed at educating women regarding the severity and threat of HD and promoting preventative health behaviors amongst women (Mosca et al., 2004).

A follow up study was conducted by the AHA to evaluate women's awareness, knowledge, and perceptions of HD 9 years after the original 1997 survey. The AHA efforts to educate women regarding the prevalence of HD among women were proven to be successful. The follow up survey reported a 13% increase in women identifying HD as the number one killer for their gender (Christian, Rosamond, White, & Mosca, 2007). Although women could correctly identify HD as the number one killer for their gender, they continued to identify cancer, specifically breast cancer, as the greatest health problem for women (Christian et al., 2007; Mosca et al., 2004). When comparing mortality rates, HD killed 1 out of 2.8 women, compared to breast cancer that claimed

the lives of 1 out of 4.5 women in 2006 (AHA, 2010). Although improvements have been made to educate women regarding the prevalence of HD, women continue to underestimate the threat of HD on their lives. Further research is warranted to examine the lived experiences of women with heart disease in order to better understand how women perceive HD and its affect on their lives and health behaviors.

After a cardiac event, individuals commonly are referred to outpatient cardiac rehabilitation (CR). Cardiac rehabilitation after cardiac events, such as myocardial infarction (MI), coronary artery bypass grafts (CABG) surgery, cardiac valve surgery, heart transplant, and heart failure has proven to be successful in reducing risk factors for heart disease (Stewart, Badenhop, Brubaker, Keteyian, & King, 2003). Research has proven that CR is effective in reducing mortality and morbidity in both men and women with HD (Stukel & Alter, 2009). The goal of CR is to limit the negative physical and psychological effects of HD, prevent further cardiac events, and reduce the risk for sudden cardiac death (Wenger, 2008). For those with a diagnosis of HD, CR efforts are aimed at preventing the progression of HD. Cardiac rehabilitation educates men and women with HD on the importance of adherence to secondary preventative measures that control risk factors that have been proven to accelerate the progression of HD. Additionally, CR educates individuals with HD on how to manage their cardiac symptoms.

Cardiac rehabilitation is commonly underutilized by women. Lack of utilization by women may be due to the fact that women are less likely to be referred to CR programs after cardiac events (Wenger, 2008). Sanderson, Shewchuk, and Bittner, (2010) investigated CR referral patterns and factors associated with women's utilization of CR. Only 59% of women eligible for CR were referred, 34% of the 59% that were referred

actually enrolled and participated. These data suggest that in addition to women minimizing the severity of their cardiac event experiences, healthcare providers may minimize the severity of HD in women. When women are referred to CR, they are less likely to adhere to recommended therapies and have a higher CR drop-out rate compared to men (Yohannes, Yalfani, Doherty, & Bundy, 2007). A qualitative study examining women's experiences of living with HD may reveal factors that influence or prevent preventative behaviors and adherence to prescribed therapies, such as CR.

Psychological implications of living with chronic illnesses have been researched. Uncertainty is common amongst individuals suffering from chronic illnesses, such as heart disease, cancer, end stage renal disease, and multiple sclerosis (Eastwood, Doering, Roper, & Hays, 2008; Lien, Lin, Kuo, & Chen, 2009; Madar & Bar-Tal, 2008; Olsson, Lexell, & Soderbert, 2008). Uncertainty affects an individual's ability to cope with his or her illness and plays a role in how individuals view life after diagnosis. Increased levels of uncertainty have been correlated with decreased health related quality of life in individuals living with HD disease 1 year after cardiac intervention of coronary angiography (Eastwood et al., 2008). Uncertainty can lead to additional psychological implications related to living with a chronic disease, such as anxiety and depression (Lien et al., 2009), anger, frustration, sadness, and loss of dignity (Olsson et al., 2008). Increased social support, particularly spousal support, have proven to be effective in easing uncertainty amongst individuals with a chronic illness (Sammarco & Konecny, 2010), along with physician's and nurse's authority, appraisal, and support (Madar & Bar-Tal, 2008).

Significance in Nursing

The severity of HD may be minimized by women, but the reality is that HD is a great threat to women. Healthcare providers are held to the obligation and liability of not only treating HD and its complications, but they play a crucial role in promoting primary and secondary preventative health behaviors amongst those at risk and those living with HD. Healthcare providers can exhaust all efforts in lecturing to their patients the importance in adopting preventative health behaviors, but in order to establish rapport with his or her patient a healthcare provider must first understand how patients perceived and experience HD and the uncertainties associated with living with HD.

Women are commonly non-compliers to CR after a cardiac event. It would be beneficial to healthcare providers if they simply asked women what prevents compliance to prescribed therapies, and what uncertainties associated with living with HD influence or prevent preventative health behaviors. Consultations and follow up visits with cardiologists and cardiac surgeons are minimal after cardiac events. Therefore, family practice healthcare providers may benefit from understanding the long term physical and psychological effects of living with HD from women's perspectives in order to coordinate appropriate care for women living with HD.

Problem Statement

Further examination of the lived experience of heart disease by women is needed to better understand the phenomenon of uncertainty and its impact on women living with heart disease.

Purpose of the Study

The purpose of this study was to explore and describe women's experiences living with heart disease and the uncertainties associated with living with heart disease.

Research Question

What is the lived experience of heart disease from a woman's perspective? A related question includes: Describe the uncertainty associated with living with heart disease?

Definitions of Terms

Conceptual definitions.

Lived experience: Understanding of an event, a phenomenological inquiry from individuals who have experienced the phenomenon first hand.

Heart disease: Includes coronary artery disease (CAD), cardiac valve disease, myocardial infarction, heart failure (HF), and structural heart abnormalities.

Woman's perspective: A woman's point of view or understanding of a phenomenon or event.

Uncertainty: The inability to cognitively process the meaning of illness related events (Mishel, 1988, 1990).

Operational definitions.

Lived experience: Women's subjective interpretations of their experience(s) living with heart disease

Heart disease: CAD, cardiac valve disease, myocardial infarction, and heart failure in women.

Woman's perspective: Women from Wisconsin, recruited from a Midwestern cardiac rehabilitation program, who will voluntarily share their lived experience of heart disease and the uncertainties associated with living with HD that they have experienced.

Uncertainty: Women's subjective descriptions of the unknown related to living with heart disease, the unknown regarding what the future holds after diagnosis.

Assumptions

1. Human beings are cognitively capable of developing their own perceptions regarding things and or events.
2. Subjects will be honest when answering questions regarding their lived experiences with heart disease.
3. Subjects will at some point after diagnosis experience uncertainties regarding their heart disease.
4. Patients develop perceptions of heart disease and feelings regarding their experiences and uncertainties.
5. Every woman with heart disease experiences uncertainty.
6. The patient is the authority of her experiences.

Chapter Summary

Heart disease is a prevalent disease amongst women. Living with HD impacts a person's life physically, emotionally, and psychologically. Therefore, adherence to prescribed therapies, such as CR, and lifestyle changes can be difficult to adopt. Living with heart disease and other chronic diseases create a sustained cognitive state of uncertainty.

In order to treat women with HD effectively, advanced practice nurse practitioners must understand the specific uncertainties that women identify during their experiences living with heart disease, so that adjustments and modifications to prescribed therapies can be altered to better suite women. The experience of HD and the uncertainties related to HD need to be further examined, specifically in women, in order to understand how women perceive HD and how it affects their daily lives.

Chapter II

Theoretical Framework and Review of Literature

The purpose of this study was to explore the lived experiences of women with HD and the uncertainties associated with living with HD. Mishel's Uncertainty in Illness Theory (1988, 1990) served as the theoretical framework for this study. The main concepts and their relationships from Mishel's Uncertainty in Illness Theory are summarized in this chapter. A literature review of previous studies examining the physical, psychological, and emotional effects of HD are summarized, along with the uncertainties of living with chronic illnesses.

Theoretical Framework

The purpose of this study was to explore and describe the lived experiences and uncertainties associated with living with heart disease from women's perspectives. Mishel's Uncertainty in Illness Theory (1988, 1990) served as the theoretical framework for this study. The main concepts of the model and their relationships are explained. A literature review of previous studies of women with heart disease and other chronic illness are summarized.

Mishel's Uncertainty in Illness Theory assumes that no matter what illness a person experiences, whether acute or chronic, uncertainty is experienced. Western society values predictability, control, and accuracy, so therefore, uncertainty associated with an illness event is feared. This may explain why women delay seeking help for physical symptoms, such as chest pain. The meaning of their chest pain and what it may lead to is unknown and, therefore, feared. The Uncertainty in Illness Model guides

a researcher in understanding how individual's process illness related events and how individuals apply meaning to those events. Uncertainty is described as the inability to cognitively construct meaning, or predict outcomes from an illness event (Mishel, 1988). According to Mishel's theory, the inability to comprehend the meaning of an illness is caused by a lack of adequate cues that help formulate meaning of an illness and predict outcomes.

Mishel's Uncertainty in Illness Theory (1988, 1990), as displayed in Figure 1., helps to explain how individuals cognitively process meaning of their illness events and the coping mechanisms used to reach the ultimate goal of adaptation. Understanding meaning of illness-related events begins with the stimuli frame consisting of symptom pattern, event familiarity, and event congruency. These three components that make up the stimuli frame are required to develop a cognitive schema that aims to prevent uncertainty after an illness event. When there is an insufficient amount of stimuli, uncertainty prevails, and the meaning of an illness-related event is unknown.

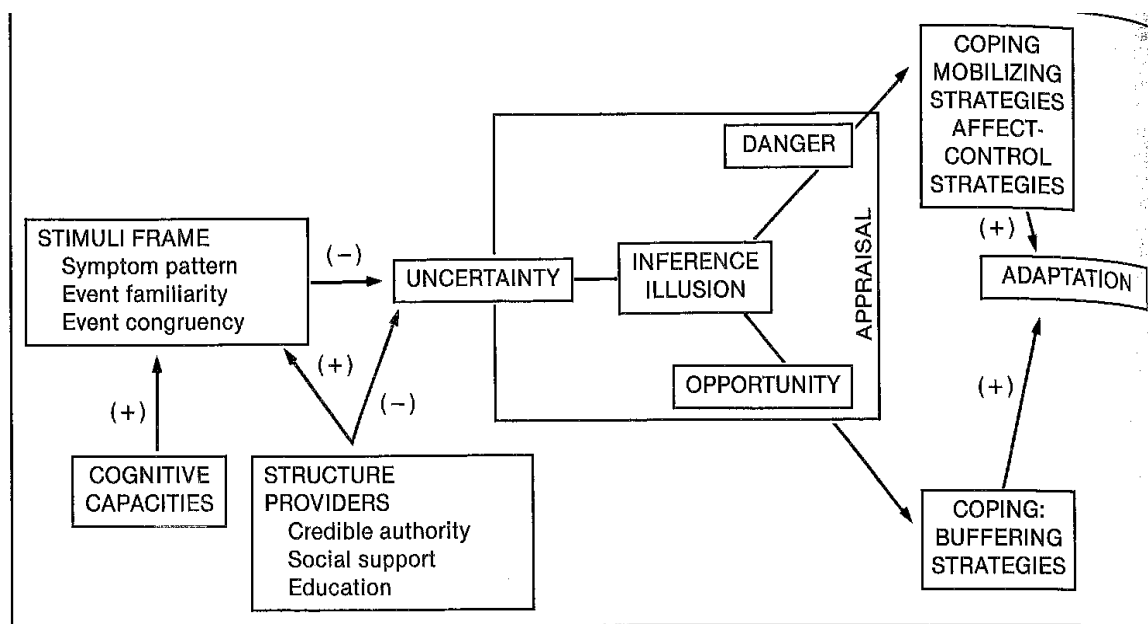


Figure 1. Model of perceived uncertainty in illness.

Figure 1. Model of perceived uncertainty in illness (Mischel, 1988, 1990)

The components of the stimuli frame are influenced by cognitive capacities, information processing abilities, and structured providers that consist of credible authority, social support, and education that serve as resources and assist individuals in developing meaning to the components of the stimuli frame. Symptom pattern refers to the consistency and predictability of symptoms. Symptom pattern can be described as symptoms that have a pattern, are perceived as having a pattern, or are consistent and enable an individual to develop meaning from their symptoms. Event familiarity is the degree to which an event can be recognized, a cue from memory of previously related events that facilitate in creating meaning to new events. Event congruence is the degree of reliability and stability of an event, whether or not there is congruence between what is expected and what is experienced (Mischel, 1988, 1990).

When uncertainty is experienced, an individual has not formed a cognitive schema for an illness-related event. and therefore. uncertainty predominates as the cognitive state (Mishel, 1988). An individual experiencing uncertainty then enters the appraisal phase, in which an individual either views uncertainty as an inference or an illusion. When viewed as an inference or danger to one's life, an individual works toward developing coping mechanisms that build a sense of control in one's life. By taking an illusion approach, one views uncertainty as an opportunity. These individuals maintain hope and focus on the positive beliefs regarding their illness in order to cope with the uncertainties associated with their illness. The goal of both approaches is to effectively cope with an illness and through coping mechanisms achieve adaptation. Adaptation can be defined as the biopsychosocial behaviors aimed at maintaining continuity of an individual's normal state (Mishel, 1988).

Case Study

Mary is a 65-year-old, married, retired, mother of four, and grandmother to five lovely grandchildren, who she cares for during the day while their parents are at work. She recently experienced a heart attack and had open heart surgery for coronary artery bypass grafting. Prior to seeking help, Mary had been experiencing chest pain intermittently for several months. Her pain was inconsistent, occurring sometimes at rest, during times of heightened emotions, and especially when she would be walking with her grandchildren to the park (lack of symptoms pattern). Mary ignored her symptoms because she was uncertain what they meant (event familiarity). She feared what would happen if she saw her family nurse practitioner for her chest pain. She feared that seeking help would lead to a diagnosis of a condition that would prevent her

from functioning as an active grandmother, a role that she enjoyed (event congruence). One day while watching her grandchildren, Mary's chest pain did not subside, and she passed out on her kitchen floor. Her oldest granddaughter, Allyson, called 911. Mary was rushed to the hospital and was diagnosed with coronary artery disease (CAD) which required emergent cardiac surgery for CABG.

After cardiac surgery Mary attended cardiac rehabilitation. While at CR, Mary attended a support group for women with heart disease. During one of her sessions, Mary shared her experience of having open heart surgery, her recovery, and her experience living with HD after diagnosis. She acknowledged her family, nurses, and physicians as key contributors to her understanding of what her symptoms meant prior to her cardiac event and the severity of her disease (structured providers). Although she has recovered well, Mary shared that she continually lives in fear that she will experience another cardiac event. She has experienced uncertainty regarding how to change her life in order to prevent further damage to her heart.

Two years after Mary's cardiac event, she is asked by her family nurse practitioner how she is doing managing her HD. Mary shared how she has adapted to having a chronic illness. She shared that she coped with her uncertainties by viewing her diagnosis as an opportunity to take control of her life and improve her health, so that she can maintain her normal state of functioning (Illusion approach). She has followed a cardiac diet that is low in salt, fat, and cholesterol; she exercises most days of the week walking at the local mall with some friends she met at cardiac rehab. Mary shared that it took 2 years for her to deal with the uncertainties of living with heart disease. By adopting a positive attitude and taking control of her health, she once again is confident in taking on her previous role of caring for her grandchildren. She coped by adhering to

a healthier lifestyle and paying closer attention to her physical symptoms. She accredited her lifestyle changes to the education and guidance she received at CR. Her uncertainty regarding her HD has diminished, as she has coped and adapted to living with HD.

Literature Review

The experience of living with heart disease can involve not only physical changes in health, but HD can have psychosocial impacts on individuals. This next section will explore what previous literature has documented on individuals experiences living chronic diseases, such as heart disease, and the uncertainties associated with living with a chronic disease.

A phenomenological approach to exploring women's experiences of myocardial infarction was conducted by White et al. (2007). Women in this study minimized their cardiac symptoms and the impact their symptoms had on their lives in hopes to maintain a sense of control over their normal state of functioning. The researchers explored the participant's perceptions of their MI, relationships with others, and coping mechanisms. Women perceived their MI initially optimistically, viewing their cardiac event as an opportunity to make changes in their lifestyle; they sustained a sense of hope of returning to their normal life. This sense of hope was short lived, as women reported a loss of hope about 2 months after diagnosis, when their recovery time was longer than what they anticipated and perceived it to be. Women in this study found it important to view themselves as emotionally strong and effective in coping with their illness. Common coping strategies amongst the participants consisted of cognitively minimizing the impact of their MI and the severity of their disease. These coping strategies were

aimed at ignoring their symptoms and continuing to maintain their life roles. One participant actually rated her HD as mild and did not perceive attending CR as a priority. Social support that women received was acknowledged as important in coping with their MI event, but they shared concerns regarding their ability to maintain their caring role of providing social support to others. Results from this study suggest that women view HD and their cardiac events as a temporary obstacle in their lives rather than a severe chronic illness that requires lifelong adaptation.

Allen, Arslanian-Engoren, and Lynch-Sauer (2009) conducted a descriptive phenomenological study examining the lived experiences of women with New York Heart Association Class II Heart Failure. Four overarching themes were revealed from non-structured interviews describing both the physical and emotional distress experienced by women with living with heart failure (HF): (a) developing a new conception of self, (b) conceding physical limitations, (c) enduring emotional heartache, (d) accepting support, and (e) rejuvenating through rest. Women in this study described their life in two phases, life before heart failure and life after heart failure. Living with HF required these women to develop a new self-concept and acceptance of being "sick" was a part of who they were. The participants described their physical limitations as overwhelming and controlling of their contributions to activities of daily living and social life. Accepting social support and taking time to rest were identified as vital elements of living with HF. Women with HF experienced fear, depression, anxiety, and frustration during their exacerbations of HF, many times realizing the risk of mortality and the uncertainty of these episodes. Women's perceptions of living with HF in the Allen et al. study are more congruent and realistic with the severity of HD compared to women in experiencing MI as reported in White et al. (2007). Women with HF appeared to be

more attentive to their physical symptoms compared to women who have experienced MI, which may suggest a greater degree of adaptation in women living with HF.

Eastwood et al. (2008) studied the impact of uncertainty on health-related quality of life in individuals 1 year after cardiac intervention of coronary angiography. Participants in this study included individuals diagnosed with HD and individuals whose results from their coronary angiography were negative for HD. Perceived control, uncertainty, affective distress, and health-related quality of life were measured and compared for analysis. Baseline levels of uncertainty, as measured by Mishel's Uncertainty in Illness Scale, were taken prior to coronary angiography intervention and then 1 year after intervention. Women had higher baseline levels of uncertainty and were more likely to have symptoms of angina compared to those with lower levels of uncertainty. Increased levels of uncertainty at baseline were found to be associated with a reduced perceived health-related quality of life 1 year after coronary angiography, despite findings from the angiography. These results portray the psychological impact of uncertainty on quality of life, independent of the severity of a HD.

Due to advancements in medicine, individuals are living with non-functioning kidneys due to the help of peritoneal dialysis that can be performed in the privacy of an individual's home. Madar and Bar-Tal (2009) studied the experience of uncertainty among individuals having peritoneal dialysis. Participants identified uncertainty as greatly impacting daily stress, as compared to other factors, such as severity and duration of their disease, credible authority, social support, and education. Unlike previous literature, social support was not viewed as effective in reducing uncertainty. Physician's and nurse's credibility was found to decrease uncertainty amongst patients. Duration and severity of renal disease was not found to increase participant's levels of

uncertainty. This finding supports application of Mishel's Uncertainty in Illness to both acute illness events and chronic illness processes.

Psychological impacts of those living with cancer have been studied extensively. Lein et al. (2009) conducted a pre- post-descriptive study examining the relationships of uncertainty, social support, and psychological adjustment in older patient's having surgery for cancer. Increased levels of uncertainty correlated with increased levels of anxiety and depression, both before and after surgery. Increased social support eased levels of uncertainty in participants and improved symptoms of anxiety and depression.

Multiple sclerosis (MS) is a difficult chronic illness to live with due the uncertainty of the anticipated hindrances that MS can cause in one's everyday life. Olsson et al. (2007) took a qualitative approach to examine women's experiences living with MS. Two overarching themes were pulled from the qualitative data, which described living with MS as (a) an unrecognizable body, and (b) trying to maintain power. The sub-themes that emerged from the theme *unrecognizable body* describe women's encounters with the control that their disease had over their bodies and the questions regarding the unknown affects of MS on their future. Hope was a common theme amongst the women – hope that their disease would not worsen and a cure for MS would be found. As the women became more dependent on others for activities of daily living they yearned to feel needed by others too in order to maintain a sense of dignity.

Chapter Summary

Mishel's Uncertainty in Illness Theory (1988, 1990) served as the theoretical framework for this study. This model serves as a guide in understanding the

experiences of women living with HD and the uncertainties associated with HD that they experience.

The review of literature has looked at the psychological impact of uncertainty experienced by those living with chronic diseases, such as heart disease, end stage renal disease, cancer, and MS. Further qualitative research is needed to specifically examine the experiences of women living with heart disease to better understand their experiences and the uncertainties they experience. Phenomenological data will assist healthcare providers in understanding how women perceived their heart disease. Understanding women's experiences and uncertainties will guide healthcare providers in providing holistic care that is centered toward meeting the needs of women living with heart disease.

Chapter III

Methodology

The purpose of this study was to explore the lived experience of HD from women's perspectives and to identify the uncertainties associated with HD experienced by women. This chapter discusses the research design including the population, sample, setting, data collection, analysis, and limitations.

Research Design

A descriptive phenomenological design was utilized to explore the lived experience of HD from the perspectives of women and to identify the uncertainties associated with living with HD. This design was chosen because it enables healthcare providers to truly understand human experiences directly from the individuals who lived the experience, a phenomenological approach to learning. Phenomenology requires a researcher to become fully immersed in the chosen phenomenon. Data are collected from the subjective lived experiences of individuals and is then respectfully analyzed (Speziale & Carpenter, 2007). Heart disease has commonly been studied in men, as HD was once referred to as a male disease. Further research is warranted in order to better understand how women experience heart disease and what uncertainties they experience living with HD. This study required the researcher to become fully immersed in the lived experiences of women living with heart disease.

Population, Sample, and Setting

The target population was defined as women with a diagnosis of heart disease. The purposive sample was recruited from a Midwestern cardiac rehabilitation program. Prospective women who met the inclusion criteria were approached by a cardiac rehabilitation therapist, who informed them of this phenomenological study and asked them to participate. A handout introducing the researcher and a summary of the purpose and details of the study was given to women who volunteered to participate. After volunteering to participate, participants signed up for a face-to-face interview with the researcher. All interviews were conducted in a private room at a Midwestern cardiac rehabilitation program. Consent forms were reviewed with the participants by the researcher prior to starting the interviews, which allowed for adequate time for participant's questions to be answered. Consent forms were signed by participants, signed consent was witnessed by the researcher, and a copy of the consent was given to all participants. Participants completed a brief demographic questionnaire.

Inclusion criteria for the purposive sample included the following:

1. Women of any age.
2. Clinical diagnosis of heart disease (CAD, cardiac valve disease, status post MI/post stent placement, status post CABG, status post valve repair/replacement, status post aortic aneurysm repair) requiring referral to cardiac rehabilitation after a cardiac event.
3. Able to read, write, speak, and understand the English language.
4. Voluntary participation in the study.
5. Agreement to be interviewed and audio-taped.
6. Agreement to have their interview transcribed.

7. Physically able to tolerate a 30-minute to 1-hour interview.

Women participating in CR without a clinical diagnosis of HD, such as those participating due to pulmonary disease or peripheral vascular disease, were not considered for this study.

Data Collection Instrument

The researcher was the instrument for data collection. Efforts to ensure credibility, dependability, and overall trustworthiness of the data collected were made. After receiving approval from the Institutional Review Board for Protection of Human Participants (IRB) from the University of Wisconsin Oshkosh (Appendix D) and a Midwestern hospital (Appendix E), eligible participants were recruited from a Midwestern CR program. All participants invited to participate were given a letter discussing the nature of the research study, participant confidentiality, participant's right to withdraw from the study at any time, completion of a demographic questionnaire, audio-taping and transcribing of the interview, and data treatment. Arrangement of individual interview times was negotiated between the researcher and each participant through communication between the CR staff and the researcher via e-mail to ensure that the participant's identity remained anonymous to the researcher until the time of the interview.

Data collection strategies to ensure credibility and dependability of the data collected consisted of a brief demographic survey (Appendix E) and interviews lasting 30 minutes to 45 minutes. Unstructured, face-to-face interviews using open-ended questions were conducted. All subjects were asked, "Would you please tell me about your experience living with heart disease?" and "Describe the uncertainty you have

experienced living with heart disease?” Participants were allowed to talk about their experiences in an uninterrupted fashion and were prompted with additional follow-up questions if clarification or further examination of their experiences was necessary.

The demographic questionnaire consisted of questions regarding the participant’s heart condition that prompted their referral to CR, age, marital status, highest achieved education level, and socioeconomic status.

Digital audio-recordings of the interviews were performed. In order to ensure confirmability, field notes were kept, which assisted the researcher in identifying the main themes and sub-themes that were pulled from the interviews. Interviews were transcribed verbatim by the researcher. The audio-taped interviews were transferred from the digital audio recorder to a DVD. The transcribed interviews were then transferred to an external flash drive. Copies of the transcribed notes, demographic questionnaires, DVD, and the external flash drive are safely stored in a secured location in the IRB office at a local Midwestern hospital, per the hospital’s IRB request.

In order to maintain trustworthiness and rigor of the study, the researcher used bracketing to set aside prior knowledge and biases regarding heart disease in women prior to the interviews, during data collection, and during analysis of the data. An audit trail was utilized to show the researcher’s thought process when analyzing the raw data and in identifying main themes and sub-themes that emerged from the data and the conclusions that were made.

Protection of Human Subjects

Prior to data collection, permission to proceed with the research was obtained through the University of Wisconsin Oshkosh Institutional Review Board (Appendix A)

and the selected cardiac rehabilitation program's affiliated IRB (Appendix B). All participants received an information letter (Appendix C) regarding the nature of the study, potential cost of participation, protection of participant's identity, and confidentiality of their contributions to the study. Potential benefits of participating in this study were explained as follows; self satisfaction knowing that participants may help other women living with heart disease and healthcare providers who care for women with heart disease. Additionally, participation in this study may ease participant's uncertainty by reliving what they have already overcome. A potential cost to the participant was their loss of time by participating in the study. Participants were informed that the interview would take approximately 30 minutes to 1 hour to complete and that their shared experiences would remain confidential, they had a right to withdraw from the study at any time, they would be audio-taped during the interview, and their contributions would be transcribed for interpretation. A written consent was obtained (Appendix B) and a brief demographic questionnaire was completed by each participant (Appendix C).

Data Analysis Procedures

Giorgi's phenomenological approach to methodological interpretation was used to analyze the data for this study. Data from unstructured interviews were transcribed, and then the researcher read and reread the entire data in order to better understand the phenomenon as a whole. Once the researcher was able to understand the phenomenon, Giorgi's (1985) steps of phenomenological analysis were followed (in Speziale & Carpenter, 2007). First, the researcher identified the transition units of women's experiences living with heart disease. These transition units consisted of

different terms, aspects, or attitudes commonly expressed by the participants. Once transition units were established, they were compared and subjective data were added that provided psychological insights of the participant's experiences in order to better understand the phenomenon as a whole. Participant's experiences were compared, common themes and subthemes that emerged were identified, and conclusions were made. Lastly, the data was transformed into the researcher's insight to describe women's experiences of living with heart disease and the uncertainty they experienced.

Limitations to the Study

1. Small sample size may have limited the generalizability of the findings to the general population of women living with heart disease.
2. The researcher may have failed to bracket (put aside) personal perceptions, feelings, and past experiences regarding women living with heart disease prior to data collection, during the data collection process, and in analyzing the data, which could have lead to researcher bias.

Chapter Summary

A descriptive phenomenological approach was used to describe the lived experiences and the uncertainty experienced by women living with heart disease. This chapter discussed the prospective population, sample, data collection method, and analysis procedures for this study. A purposive sample of seven participants was sufficient to meet data saturation. Audio-taped, face-to-face, unstructured interviews were conducted to collect data. The data were transcribed by the researcher and then analyzed using Giorgi's methodological interpretation.

Chapter IV

Results and Discussion

The purpose of this study was to explore and describe women's lived experience of heart disease. Further examination of the lived experience of HD from a woman's perspective was warranted to better understand how women experience HD as opposed to men and to better understand the uncertainties associated with HD that women experience. The results of this phenomenological study are presented and discussed in this chapter.

Seven women were interviewed, and the interviews were transcribed verbatim. Transcribed data were then analyzed and main themes, subthemes, and meanings were identified and then described as women's lived experience of HD. Uncertainty associated with heart disease was described from the perspectives of women and was a main theme. All subjects were asked the same open-ended question: Please tell me about your experience living with heart disease? They were also asked: Would you please describe the uncertainty associated with heart disease that you have experienced? All women were allowed to share their experiences in an uninterrupted fashion.

Demographic Data

Participants were recruited by cardiac rehabilitation (CR) therapists at a Midwestern cardiac rehabilitation center during their CR sessions. All eligible women attending CR from January 31, 2011 thru February 25, 2011 were asked to participate. Seven participants volunteered to participate. Ages ranged from 54 years to 83 years,

with a mean age of 68 years. Three participants had recently suffered a heart attack and had coronary artery stents placed. Four participants had undergone open heart surgery; two had valve surgery, one had valve surgery and ascending aortic aneurysm repair, and one had coronary artery bypass grafts. Three participants had achieved either a masters or doctorate degree, one had an associate's degree, and three documented high school education as their highest achieved level of education. Three participants were married, three widowed, and one single. Two participants listed their present annual income at \$70,000/year or greater, one listed \$50,000-\$69,999/year, one listed \$30,000-\$49,999/year, one listed \$10,000-\$29,999/year, and one listed less than \$10,000/year. One participant declined to answer the annual income question.

The Interview Process

All interviews were conveniently held at a local Midwestern CR center either before or after the participant's CR session. Interview times were scheduled by CR therapists after CR therapists communicated with the researcher via e-mail to confirm interview times. Participants remained anonymous to the researcher until the time that the face-to-face interview took place. Interviews lasted 30 minutes to 1 hour and were performed in a quiet, private room within the CR center.

All face-to-face interviews were digitally audio-taped and then transcribed verbatim by the researcher. Participants were given a copy of their written consent, which provided the researcher's contact information if they wished to contact the researcher to obtain a copy of the final results of the study. Field notes were taken by the researcher during and after each interview. Field notes contained non-verbal behaviors of participants pertinent to the research and main highlights of the interviews.

Results and Discussion

Data were analyzed using Giorgi's (1985) method of analysis (Speziale & Carpenter, 2007). Transcribed interviews were read and reread multiple times by the researcher to grasp main concepts and integrate a sense of the data as a whole phenomenon. The researcher attempted to bracket feelings, perceptions, and potential biases during the analysis process. Specific participant statements and phrases were highlighted throughout the analysis process and then compared using note taking to identify main themes and subthemes.

Main themes were revealed during data analysis along with several subthemes that supported the main themes. Each theme, along with the subthemes, will be discussed with direct quotes and narratives from participants lead to the emergence of the themes. These themes and subthemes were:

1. Everyone has a story
 - a. The event
 - b. Role switch
 - c. Cardiac rehabilitation
2. Uncertainty
 - a. Fearing the unknown
 - b. Damaged goods
 - c. Physical symptoms
3. Adaptation: Life after diagnosis
 - a. Life style changes
 - b. Greater awareness of HD

Theme 1: Everyone Has a Story

Women were asked to describe their experience living with HD. Participant 5 summed this main theme up best when she stated, “everyone has a story.” Three subthemes identified were: (a) the event, (b) role switch, and (c) cardiac rehabilitation. Every participant began to share their experience by beginning with a description of the symptoms or the events that lead to their diagnosis of heart disease. Every story was different and unique to the individual. Each participant shared their experience undergoing the cardiac intervention they received and their recovery period at CR. Physical and emotional responses related to the diagnosis of heart disease differed amongst women interviewed. The extent of emotional response to the diagnosis of heart disease differed amongst participants and appeared to be dependent on whether the women’s cardiac event was urgent or planned. Depending on others and coping with a loss of independence was a common difficulty shared by women. Cardiac rehabilitation provided social support and eased uncertainties for women during their recovery period. Every participant acknowledged gratitude for the care and support they received at cardiac rehabilitation and the friendships they formed with other CR participants.

The event.

The events leading up to the diagnosis of HD varied greatly. Each participant experienced cardiac symptoms differently and responded to their symptoms in a different way. Making modifications to their lifestyle in order to avoid their cardiac symptoms was a common coping mechanism for two participants.

Participant 3 quit volunteering at a local hospital because the physical requirements of the job caused her to have cardiac symptoms. She shared,

I couldn't do steps, I had a hard time doing steps for a good five years at least and ahh, I could go up one flight of stairs, but I volunteered at the hospital and you were running up and down the steps all the time, there's 16 steps in one flight and it makes a big difference from 12 or 13 steps in your house, and I could go up once and after that if I went again I would have to help myself with the railing so then I would have to take the elevators so umm, I quit because it takes too long to take an elevator..

Participant 5 reflected on the cardiac symptoms she experienced, "I used to go walking and feel this pain in my chest and stop for, on the side of the road, until it kinda subsided and then continue walking because I just thought that I had acid reflux." She continued to elaborate on how women respond to their symptoms and rationalize women's actions, or lack of,

I think that women, we tend to, cause you know I got laid off ahh, was kind of asked to retire because of budget cuts in June and but, I think with women, if I hadn't gotten laid off and if all this other stuff wouldn't have happened I would have still been working and ended up having a stroke at my school, or a heart attack. Because women feel more, for some reason, we feel that if we are not there the job is not going to get done and we tend to go longer, and men if they feel a little pain in their toe they're like, "oh my toe hurt," they are wiser than we are, they will stop and do something. Women, we don't, we tend to push it to the limit.

Participant 6 took sought medical care for her cardiac symptoms, which lead to her diagnosis of coronary artery disease. She describes her reaction to her diagnosis and her cardiac symptoms as,

It hit me like a ton of bricks I remember that, umm, ahh, but at the same time I really thought that I did, I really had no symptoms, umm what you would think of as symptoms ... the heaviness in the chest, the tightness in your chest, I didn't have them, my symptom was shortness of breath and I experienced that most dramatically when I was in an airport trying to keep up with my friends trying to catch another flight and that's what prompted me to talk to my doctor about it.

Reactions to their diagnosis of heart disease varied depending on whether the participant's cardiac event was urgent or planned. Participant 2 described her urgent cardiac event as, "It wasn't like go home and think about it. It was an experience where things went boom, boom, boom, boom, boom, in the hospital." She described her experience having open heart surgery as,

I guess it's almost like a hysterectomy, a change of life I guess, what I would compare it too ... I've had a few surgeries in my life and a lot of things happened in my life but once somebody had touched my heart, literally, that ... was umm, a brand new experience and...it changed me somehow, I couldn't understand what was happening but something was definitely happening to me mentally.

Participant 6 shared her reaction to having an urgent cardiac intervention as,

I have had several surgeries, two hip surgeries, one knee recently, but nothing hit me ahh, like realizing that I needed some, some either surgery or some procedure for umm heart blockage. I really had to face my own immortality and that was difficult, I mean it, it was a shocking experience.

Participant 1 had a scheduled valve replacement and ascending aortic aneurysm repair surgery, which she was able to plan and prepared for. She described her preparation,

You know everyone you talk to when you tell them you have this problem their like, “oh yeah you need to go somewhere like Mayo, some bigger place with all these specialists” but umm I really wanted to be close to home when I had my surgery.

She described meeting her heart surgeon for the first time,

We were sitting there waiting for him to open the door and I said to my husband, “whoever he is I better like him since my life is in his hands!” and you know me and my husband had like, like forty questions for the doctor so when he sat down, the first thing my husband said was, “tell us about yourself” and Dr. Secombe just started telling us about how he started out as a stocking boy stocking shelves at a store and I thought, oh boy! I don’t know if I trust this guy, but then he went on and on about his schooling and how he practiced at Mayo for 14 years and we were relieved, and he talked to us for like three hours straight and answered every question that we had and he was so helpful.

Participant 3 had a planned coronary angiogram and had a stent placed after she had a significantly positive calcium score test. She describes her experience,

I was awake when they did it, so I didn’t have to come out of anesthesia or anything so yeah they did it at 11 and I walked out at 5 so yeah it was quick ... It’s ... it’s like it didn’t happen, you know, it’s fixed and ahh ... I really, you know, I really didn’t have to worry that there was something there and so it’s ... I don’t, you know ... there wasn’t anything to compare it to, I wasn’t afraid that I was going to die, you know so ...

It is important to note that the cardiac event that participant 3 experienced was short and quick, as opposed to participants who required open heart surgery. Her

emotional response to her diagnosis of HD differed from those who required open heart surgery. This could possibly suggest that emotional responses to the diagnosis of heart disease may be dependent on the severity of cardiac disease and the degree of invasiveness of treatment required. Participant 6 supports this, as she describes how she felt as she anticipated the results of her cardiac catheterization, "I really felt like I was facing, going, like it was judgment day and I was going to find out if I was going to heaven or hell. Heaven being the stent and hell being the bypass surgery."

Role switch.

A common difficulty among women interviewed was the role switch that they went through, becoming the patient that needed to depend on others instead of their normal role of others depending on them. Dealing with a loss of independence and control was expressed by many participants.

Participant 1 describes the difficulty she experienced in her role switch from being mom to having her daughter care for her, and how her role switch caused hostility between her children.

My daughter was umm, yeah, she did not handle mom being sick very well and it was emotional for me to have my daughter take care of me versus I always looking after them so that was very hard for me to switch that role and get used to her taking care of me and it umm, well, they got in a fight at Christmas because my daughter felt that my son should have stayed and visited me more in the hospital but well you know I understand, he has a two year old and lives two hours away but my daughter took it very hard and it caused anger between them.

Participant 6 described her difficulties being dependent on others,

I am a widow and I live alone, and it's very hard, I have one daughter and you know she works, umm, I have plenty of friends that would be more than happy to help me out but it's very hard for me to ask for help, so that was real difficult for me, you know facing that ahh, situation ahh, I think that was probably the hardest thing, the time after, the recovery, being dependent on someone else.

Participant 7 describes her loss of independence during her role switch when she received help from a nurse after she returned home,

She laid all the medication for me and put it in all those boxes you know, day by day by day you know, and that's not part of who I am, I've always been responsible for my own medications, taking them when I needed to and ahh, I think that situation kind of, I lost a little bit of umm ... privacy if you will, a little bit of independence if you will, I lost a little bit of independence because I was having to depend on her.

Cardiac rehabilitation.

Every story had a chapter on participant's experiences at cardiac rehabilitation (CR) and how CR provided the necessary social support that eased the uncertainties experienced during the recovery period. Each participant acknowledged the importance of attending CR after a cardiac event and the need for continued social support after completion of CR. Sharing stories was a common coping mechanism amongst participants in CR, and story-telling created friendships that provided social support to many participants. Participant number 1 tells how CR helped during her recover, "Part of rehab that is helpful, not only the rehab, but the exercise, but just talking with everyone else at rehab and feeling like you are not alone is helpful, it's very helpful."

Participant 6 acknowledged how the CR staff helped her cope with her uncertainties related to her physical symptoms and the anxiety that she felt after her diagnosis, "They are wonderful here and they really have tried to calm my nerves and tell me really what things would be significant that would be you know related to the heart and what's just run of the mill stuff."

Participant 5 spoke about the social support she received at CR, "You'd be amazed by how we feed off of one another when we all meet out there, I mean everyone comes and when someone new join us we'd start telling out stories all over again." She continued to elaborate on how participants at CR naturally form a support group for one another and how essential social support is for individuals with heart disease after a cardiac event,

You know, you share and that makes you feel good and I think that they should have something like that, that at least a couple of weeks after you get out you get that group, support group together cause that's what we end up doing, being a support group for each other, and I think that's so, you know, so important that they can do that cause you'd be amazed, you go and talk to this one and everybody have their own story and its all of them are different, and it's amazing. She reminisced about the friendships she has made at CR, "They're not lifelong friends as far as seeing them but they are lifelong friends in my heart, I'll always remember them and their story."

Theme 2: Uncertainty

Uncertainty was experienced by women living with HD. Three subthemes emerged from the data after participants were asked to describe the uncertainty related

to heart disease that they had experienced. These subthemes included: (a) fearing the unknown, (b) damaged goods, and (c) physical symptoms. After diagnosis, many participants feared what would happen next; some even feared death. Many of the participants yearned to return to their normal functioning state and experienced great uncertainty when their time of recovery did not meet their anticipated recovery timeframe. This great desire to return to normal created a distorted self-image for one participant, who referred to herself during her recovery period as “damaged goods.” Coping with the uncertainties related to physical symptoms, after the diagnosis of heart disease, was a common difficulty for women. Deciphering between what physical symptoms could be cardiac and what symptoms are benign was a challenge for women after diagnosis.

Fearing the unknown.

Uncertainty was certainly experienced in some way by all participants before, during, or after their diagnosis of heart disease. The illness trajectory for HD is uncertain. Participant 2 describes her uncertainty living with HD, “Now I live scared of what might happen next, I want a plan ... I need a plan!” She reflected on her cardiac event and the uncertainties that she experienced, she explains them as,

The uncertainties are all I think the unanswered questions ... and still are, umm, each time something happens I would have liked to have the possibility of these things happening explained to me thoroughly, umm ... I know what heart disease is but ... the things that follow a surgery from heart disease I did not know.

Participant 4 described the uncertainty she experienced prior to having her planned valve replacement,

Just not knowing exactly how I was going to cope with it, that was scary and I am not used to relying on people so the uncertainty there with myself was ... probably the most stressful for me ... we have had heart surgeries in our family before, my step dad had bypass surgery years ago so you kind of knew what was going to happen but when it's you, it is something different.

She describes how she prepared and coped with her uncertainties, "You know that you have to do it, and it's going to happen and you know, you just put all your p's and q's in a basket and in line, and a lot of prayers, lots of prayers!"

Participant 5 described life after diagnosis and the uncertainty she experienced and how she has coped with her uncertainty,

I'm getting better now thinking that I'm not going to die tomorrow, I've heard that stents last for about ten years and I don't know if I'm going to have another one umm, then or what, you know when you have your life on a time table and you know in ten years this is gonna, you're gonna have to do it over again

It makes me think about my kids a lot, it makes me think about my family, it makes me try to get things in order.

Damaged goods.

Every participant discussed their desire to return to their normal self, their state of functioning prior to their cardiac event. Participant 1 reflected on her previous understanding of individuals with heart disease and her desire to return to her life before open heart surgery,

I used to think of people who had heart surgery as umm, oh, they have to be so careful you know, they're walking on egg shells, and now I think of myself and

often think to myself, I don't want to be that way, I should be better than how I was before the surgery ... I feel like like I'm a, I'm damaged goods.

She continued to rationalize her distorted self image and contributed it to the fact that her anticipated time of recovery did not match her actual recovery time. She explained,

I think it's probably because I haven't gotten back to life as normal yet and when I do, everything will be fine but you know I'm still ... I think I need to get back to work cause, I, cause I need a schedule, I need a routine I should say in my life and umm, work is a big part of that, working out is a big part of that, neither of which I have even started to do yet.

Participant 2 had open heart surgery 5 years ago and recently had a stent placed, she continues to struggle with the uncertainties living with heart disease and attempting to function at the level she was before she had open heart surgery. She explained her experiences of uncertainty as,

Fearing doing certain things, not being able to do certain things ... functioning from day to day, wanting to be the person that I was before I had heart surgery ... still desiring to be able to be full bore you know, be able to do everything.

Participant 3 experienced uncertainty after having a stent placed, but found that attending cardiac rehabilitation helped relieve that uncertainty,

Well, the first month I would say I was, I was kind of afraid that something else would happen. I was really afraid to do too much of anything. But, once I got started on the rehab, then that passed and now I'm back to normal.

Physical symptoms.

Women living with heart disease developed a greater awareness of every ache, pain, or physical symptom they experience. The difficulty with their greater awareness

lied in distinguishing cardiac symptoms from benign physical symptoms. Women in this study discussed the change that they experienced after their cardiac event as they became more in tune to their bodies. Having a greater awareness of physical symptoms caused women to experience uncertainty. Participant 6 described her uncertainty with physical symptoms,

I am really working on not getting paranoid or panicky that every ache or pain that I feel is related to my heart somewhat and that's, that is probably a scary thing for me, to know what is ... what is significant and what is you know, just run of the mill. And I don't think of myself as being a hypochondriac but that is on my mind a lot more than before.

Participant 5 expressed how she is more aware of her physical symptoms now that she has heart disease,

You wake up at night and you got a pain, could be a gas pain, but it's still there You are more in tune and alert to your body, I'm more alert to this side of my body than I've ever been before. If, if any little ink goes I'm going, Oh! You know it's, it's you're aware.

Participant 2 elaborated on her physical symptoms of palpitations that she continues to be more in tune to, even 5 years after her open heart surgery, "I still deal with these things, and you know the heart still does its own things at times, it does these little pitter patter in its unusual way and then it will stop and everything is fine."

Participant 4 anticipated what she would feel physically after her open heart surgery; what she had anticipated was not what she experienced, "I don't think that my heart is beating any faster, umm, it's a slow heartbeat, and I thought that it would start really pounding and it doesn't."

Theme 3: Adaptation: Life after Diagnosis

When asked to share their experience living with heart disease, participants identified beginning to live with heart disease starting after completion of cardiac rehabilitation. This specific period of time appeared to be the start of their adaptation phase to living with heart disease. Making (a) lifestyle changes and having and (b) having greater awareness of the prevalence of heart disease were two subthemes that emerged from the data.

Lifestyle changes.

Change can be difficult, and adapting to change can be the greatest challenge. Women with heart disease acknowledged that making lifestyle changes was a crucial part of their experience living with HD. Exercising was a big adjustment for participant 6,

I do need to change my lifestyle and that has been different, I was rather an inactive person, I love to read so I love to sit. My idea of a good exercise was a good brisk sit, I never thought of moving around too much, I mean I thought of it but I didn't want to do it.

Participant 1 expressed her insecurities initiating exercise on her own now that she has completed cardiac rehab,

They are telling me today that I should be released to do whatever I want including going back to Curves so, I think that I will wait a couple weeks to do that ... cause it's kind of scary ... when you are here at cardiac rehab you're being monitored, you know, you are on a heart monitor, and they're taking your blood pressure two, three times so they know you're in your range that you

should be when you are working out. When you are on your own you don't know that.

Participant 4 questioned her abilities to adapt to her lifestyle changes long term, and this contributed to her feelings of uncertainty, "It's a challenge, umm, so the uncertainty it's just, well, I'm uncertain if I will be able to stay motivated to keep doing the exercises, that's my scary thing."

Making diet modifications was a struggle for participants. This lifestyle modification does not only directly affect the individual with heart disease but can affect those they share meal time with, such as their family and friends. Adjusting to diet changes requires meal planning and making adjustments for special occasions when meals are prepared by others and not modified to a cardiac diet. What we eat is habitual and breaking habits can be a challenge. Participant 3 discussed her struggle with breaking her eating habits and making healthier choices after her diagnosis,

I was mostly a beef eater, beef and pork, chicken once in a while, and the cardiologist says you can eat beef once a week, everything else is chicken, turkey or fish and I don't like fish so chicken and turkey, I feel like I'm going to get sick of that pretty soon ... it's getting use to what you're not use to.

Participant 7 acknowledged the dietary changes she has made and describes her thought process when choosing her meals, "If it's beef or chicken, I choose chicken, you know what I mean, always the lesser of, and less of things too."

Participant 5 described her dietary modifications,

It's scary cause you have to watch what you eat, low sodium, low cholesterol, I'm on a 2,000 sodium diet a day, I take less than 2,000 cause I'm scared I have to plan if I'm going out for dinner, I make sure that I eat grits or something that

doesn't have sodium in it in the morning and no cholesterol cause I know that if I go out for dinner that is my sodium and my cholesterol I'm learning to alter myself.

She shared how her lifestyle changes have influenced her husband to adopt better eating habits,

He's changed, and that's the good thing, he is, he's watching and I know he is going to go back to regular eventually cause my husband's like that, he gets on a kick and then he gets off of it. I know that I can't go back to regular, this is going to have to be a lifetime thing for me.

She compared and contrasted heart disease with alcoholism and recommended support groups for individuals with heart disease that would help people make lifestyle modifications,

If they can have support groups for an alcoholic why can't they have that for people who have had surgery I mean it is, it's worse than an alcoholic cause you are stuck with what is inside of you for the rest of your life.

Greater awareness of heart disease.

Throughout the interview process, many women mention that they gained a greater awareness of the prevalence of heart disease after their cardiac event. Experiencing the phenomenon of heart disease helped women to understand the impact of heart disease as a whole phenomenon. After experiencing heart disease, women were more in tune to others who spoke of their experiences with heart disease and found greater interest in their stories. Although heart disease is the number one killer in women, it appears that unless a woman has experienced heart disease, its impact on life is not completely understood.

Participant 1 explained the realization she experienced after having open heart surgery,

I'm only 54 but ahh, you know, until you've experienced it you don't realized that there are more people out there that have had the same things that I had or had heart surgeries, I mean even younger in their thirties or twenties, umm, so even though I'm in my mid fifties I'm thinking, wow there are a lot more people out there that have had heart disease that I've never heard or even, you know, thought of, but now I will because I've experienced it.

Participant 5 found herself intrigued by others who had experienced heart disease. By experiencing heart disease herself, she had a greater understanding of what others experienced and enjoyed listening to others tell their stories at cardiac rehab,

It's a feeling that you don't know if you never had it and you heard it tell by people with it, it's like you find yourself asking people, especially if you hear them say I had a heart attack last year ... so you look for people, and that's why I said that I enjoyed coming here because everyone has a story.

Participant 7 commented on how attending cardiac rehabilitation helped her to understand the prevalence of heart disease,

I come here and I see men and women here in rehab which tells me that it is not a disease for men or for women, I don't know if it is comparable, compared to the sexes in terms of men and women, it seems that it is from what I see.

Discussion of Results Relative to the Literature Review

The first main theme that was revealed in this study was *Everyone has a Story*, which summarized how women experience heart disease. Every story was different, implying that every woman experiences heart disease differently. Three subthemes made up this main theme which consisted of: *The event*, *role switch*, and *cardiac rehabilitation*. Overall, there has been little research on how specifically women experience heart disease and the uncertainties associated with heart disease that women experience. Previous studies have looked at how individuals experienced other chronic illnesses, such as heart disease, heart failure, cancer, multiple sclerosis, and chronic kidney disease.

A previous study examined how women experience myocardial infarction (White et al., 2007) and found that women tend to minimize their cardiac symptoms. Several women in this study admitted to minimizing the severity of their cardiac symptoms and made lifestyle modifications to prevent the reoccurrence of their symptoms. These findings are consistent with what White et al. (2007) identified as a coping mechanism amongst women in attempt to maintain their life roles and avoid illness. After a review of literature, there were no studies identified that examined emotional response to a diagnosis of heart disease. Nor did any study identified in the review of literature evaluate emotional response in comparison to the severity of an individual's heart disease. In this study, there was a clear distinction in the way in which women experienced and responded to the diagnosis of heart disease dependent on whether they had percutaneous coronary stenting or required open heart surgery for treatment of their cardiac disease.

Accepting social support was a common difficulty found in women living with heart failure identified in a descriptive phenomenological study by Allen et al. (2009). This finding is consistent with the subtheme of role switch that emerged from this study. Women in this study had difficulties coping with their role switch of moving from being depended on to becoming dependent on others.

Many participants acknowledged their gratitude toward the social support that they received at cardiac rehabilitation. Participants reminisced on how sharing their stories and listening to others tell their story of living with heart disease helped them cope during their recovery period. They compared and contrasted their cardiac symptoms and sequence of events that lead to their diagnosis of heart disease. Previous research has examined the impact of social support on predicting cardiac rehabilitation participation. Sufficient social support was a determinant of whether one completes cardiac rehabilitation after coronary artery bypass graft surgery. This research did not address social support received at cardiac rehabilitation and its impact on participant's recovery (Husak et al., 2004).

Uncertainty is experienced in chronic illness. Uncertainty was a main theme in this research as women reflected on their experiences living with heart disease. Even after surgical interventions, some women still feared death. Each participant feared the unknown, the unknown trajectory or impact that heart disease would have on their lives. Women living with multiple sclerosis (MS) experienced doubts about life living with MS, and they questioned their strength in coping with this uncertain illness trajectory. This uncertainty created feelings of fear, fear of the unknown. Women with MS feared losing control of their bodies, which created a distorted self-image that emerged as a subtheme, *unrecognized body* (Olsson et al., 2007). This subtheme and its content was

similar to the subtheme *damaged goods* that emerged in this study, as women experienced great anticipation to return to their normal state of functioning during their recovery period. Prior research has focused on how women experience cardiac symptoms prior to or during their cardiac events (White et al., 2007). Women in this study described in detail the awareness of physical symptoms after diagnosis and how their increased awareness led to greater uncertainty.

The American Heart Association has strived to increase women's awareness of heart disease since its original survey in 1997 examining women's awareness of heart disease, which concluded that women were unaware of the threat of heart disease. Since 1997, women have gained a better understanding of their risk for heart disease and the lifestyle modifiers that decrease their risk (Mosca et al., 2004). Experiencing heart disease themselves made women in this study better aware of the prevalence of heart disease for both men and women. Women in this study identified making lifestyle changes a challenging but essential part of adapting to life living with heart disease.

Chapter Summary

Qualitative interviews with seven women living with heart disease yielded three major themes and eight subthemes describing the lived experience of heart disease from the perspectives of women. Living with heart disease creates great uncertainty amongst women attempting to adapt to life living with a chronic disease. Within the review of literature, some themes identified in this study correlated with previous research. New themes emerged from this research that help to describe how women experience heart disease and the uncertainties associated with heart disease they experience.

Chapter V

Summary, Conclusions, Limitations, and Recommendations

The purpose of this study was to explore the lived experience of heart disease from the perspectives of women and to identify the uncertainties associated with heart disease that women experience. Women were studied due to the fact that heart disease was once known as a male disease, and further research regarding women's experiences with heart disease was warranted. In this chapter, data will be examined in relation to the theoretical framework, and a summary of women's experiences living with heart disease will be summarized. Limitations to the study will be discussed, and recommendations for further research will be made.

Relation to the Theoretical Framework

The theoretical framework for this study was Mishel's Uncertainty in Illness Theory (1988, 1990). Uncertainty is experienced with any illness, both acute and chronic. Living with HD causes great uncertainty regarding the unknown impact HD will have on one's trajectory of life. Uncertainty is experienced by women living with HD from the time of their diagnosis of HD, during their cardiac events, and through their rehabilitation, and continues as they adapt to living with heart disease. Adaptation is the desired end after coping with uncertainty (Mishel, 1990).

Mishel's theory concludes that uncertainty is experienced with any illness, whether it is chronic or acute. Individuals experience uncertainty as they attempt to find meaning in their illness when outcomes of their illness are unknown (Mishel 1988, 1990).

This is consistent with the findings in the main theme *Uncertainty*. Women described fearing the unknown, fearing what would happen next. Some women experienced the need to have a plan in place for when they had another cardiac event, an attempt to conquer the uncertainty.

The three components of the first part of Mishel's Uncertainty in Illness Theory (1988, 1990) include the stimuli frame, structure providers, and cognitive capacity. The stimuli frame consists of symptom pattern, event familiarity, and event congruency. Credible authority, social support, and education make up the structure providers. Cognitive capacity is necessary to process information; it influences an individual's ability to perceived symptom pattern, event familiarity, and the congruence of events to attempt to make meaning of their illness event and recognize uncertainty (Mishel, 1988).

The stimuli frame in this study was summarized in *Theme 1: Everyone has a Story*, as each participant told their story of how they experienced HD for the first time, starting with descriptions of their cardiac symptoms and the uncertainty they experienced as they received their diagnosis of HD and anticipated what surgical intervention they would undergo.

Participant 1 identified credible authority well, as she described her experience meeting her heart surgeon for the first time. She described the uncertainty she felt knowing that her life laid in the hands of her surgeon. Credible authority can have either a negative or positive influence on uncertainty. The credible authority in this case positively influenced the uncertainty experienced by Participant 1, in that the education her surgeon provided reduced uncertainties she had in determining where her surgery should be preformed and by whom. Physical changes and social support from peers at cardiac rehabilitation positively influenced participant's understanding of their

uncertainty. Through socialization, participants were able to identify event congruency and symptom familiarity by listening to other participants tell their cardiac event stories and compared and contrasted what they experienced and what others experienced.

Cardiac rehabilitation therapists served as structured providers in this study. Education and guidance provided by the therapists helped to ease the fear of dying in some participants. Education provided at cardiac rehab was identified in the subtheme *physical symptoms*, as it helped participants to distinguish what physical symptoms were cardiac related and which were benign in nature.

Participants in this study were either just starting or finishing their cardiac rehabilitation. At this stage of recovery, all participants were still experiencing uncertainty related to their heart disease. The transition from uncertainty to adaptation was still work in the making for many women. Some were beginning to move into the appraisal phase by viewing uncertainty in heart disease as a danger and adopting *lifestyle changes* as identified under *Theme 3: Adaptation: Life after Diagnosis* to help reduce their uncertainty regarding the severity of their disease.

Summary

From the onset of cardiac symptoms to the beginnings of life after the diagnosis of heart disease, uncertainty is experienced by women. As with many chronic diseases, the illness trajectory of heart disease is uncertain. As participant 4 theorized, "Life is uncertain, you find out that life is quick and uncertain, things happen very quickly."

Heart disease is a prevailing disease in women and is no longer viewed as a male disease. Therefore, women were chosen as the study subjects for this research. A descriptive phenomenological approach was utilized for this study in attempt to better

understand how women experience heart disease. A phenomenological approach was used because the way humans experience a phenomenon is essential to healthcare's initiatives to treat chronic diseases, such as heart disease.

Uncertainty was experienced by all participants. Feelings of uncertainty were experienced starting at the onset of cardiac symptoms, through cardiac events, and continued as women adapted to life after diagnosis. The theoretical framework used in this study was based upon Mishel's Uncertainty in Illness Theory (1988, 1990). Findings from this qualitative study were consistent with the first three variables of Mishel's theory: stimuli frame, structure providers, and cognitive capacity. Every woman had a different story, but within their stories emerged common themes regarding their experiences living with heart disease.

Conclusions

Findings of this study indicate that women living with HD battle with both physical and mental challenges, as they attempt to understand the uncertainties related to their heart disease. The following are some conclusions:

1. Every woman with HD has a story, every story is different.
2. Uncertainty is experienced by women living with HD.
3. Story telling was a common coping mechanism amongst women participating in cardiac rehab after a cardiac event.
4. Making lifestyle changes and becoming more aware of HD are ways in which women adapt to life living with heart disease.
5. Cardiac rehab provided social support to women with heart disease.

6. There may be a possible correlation between the level of uncertainty experienced and the severity of HD.

Limitations

Inexperience and lack of skill of the researcher in qualitative data collection and analysis for a phenomenological research study may have resulted in errors in data collection and analysis (Speziale & Carpenter, 2007). The researcher may have failed to completely bracket or recognize personal biases and perceptions of women with heart disease prior to the start of the study and data collection process. Due to the small sample size of this study, lack of data saturation may have limited the results of this phenomenological study. Lastly, due to the inexperience of the researcher, improper data analysis may have distorted the actual lived experience of women with heart disease.

Implications for Nursing Practice

The results of this study may indicate that healthcare providers are not aware of the extent to which women experienced heart disease. A better understanding of how women experience heart disease and the uncertainties they experience may help healthcare providers to better assess and treat women with heart disease. Primary care providers, including nurse practitioners, will encounter women newly diagnosed with heart disease and may experience women who are struggling with the uncertainties associated with their disease. Implementing support groups for women with heart disease may help to ease uncertainties experienced during women's recovery periods after a cardiac event. While some of the findings from this study were consistent with

previous research, the findings of this study add greater insight into the lived experience of heart disease from the perspectives of women.

Recommendations

Further qualitative research is needed to describe and explain women's lived experiences with heart disease and to better identify the uncertainties related to heart disease that women experience. Women in this study who underwent open heart surgery appeared to experience greater uncertainty, as compared to women who underwent coronary artery stenting. A quantitative study, measuring levels of uncertainty in women with heart disease alone compared to the severity of heart disease, may be warranted to examine this possible correlation.

Chapter Summary

In this chapter, the current study was summarized including a description of how the results applied to Mishel's Uncertainty in Illness Theory. Limitations to the study were identified. Based on the study findings, recommendations were made for nursing practice and further research.

APPENDIX A
UNIVERSITY OF WISCONSIN OSHKOSH IRB



December 3, 2010

Ms. Amanda Woulf
2520 Garden Park Terrace
Green Bay, WI 54311

Dear Ms. Woulf:

On behalf of the UW Oshkosh Institutional Review Board for Protection of Human Participants (IRB), I am pleased to inform you that your application has been approved for the following research: The Lived Experience of Heart Disease: A Woman's Perspective.

Your research has been categorized as NON-EXEMPT, which means it is subject to compliance with federal regulations and University policy regarding the use of human participants as described in the IRB application material. Your protocol is approved for a period of 12 months from the date of this letter. A new application must be submitted to continue this research beyond the period of approval. In addition, you must retain all records relating to this research for at least three years after the project's completion.

Please note that it is the principal investigator's responsibility to promptly report to the IRB Committee any changes in the research project, whether these changes occur prior to undertaking, or during the research. In addition, if harm or discomfort to anyone becomes apparent during the research, the principal investigator must contact the IRB Committee Chairperson. Harm or discomfort includes, but is not limited to, adverse reactions to psychology experiments, biologics, radioisotopes, labeled drugs, or to medical or other devices used. Please contact me if you have any questions (PH# 920/424-7172 or e-mail:rauscher@uwosh.edu).

Sincerely,

A handwritten signature in black ink, appearing to read "Frances Rauscher".

Dr. Frances Rauscher
IRB Chair

cc: Dr. Suzanne Marnocha
1925

INSTITUTIONAL REVIEW BOARD
UNIVERSITY OF WISCONSIN OSHKOSH • 800 ALGOMA BLVD • OSHKOSH WI 54901
(920) 424-3215 • FAX (920) 424-3221
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APPENDIX B
ST. VINCENT HOSPITAL IRB

P.O. Box 13508
Green Bay, WI 54307-3508
www.stvincenthospital.org
920 433-0111



St. Vincent
Hospital

December 10, 2010

Mandy Woulf
2520 Garden Park Terrance
Green Bay, WI 54311

Dear: Amanda Woulf:

RE: IRB10-03 – The Lived Experience of Heart Disease: A Woman’s Perspective

At the full Board meeting of the St. Vincent Hospital Institutional Review Board (IRB) held on November 8, 2010, the Board reviewed and **approved** the above-referenced study.

The IRB recommended changes to the informed consent document. A revised consent was submitted to the IRB on December 6, 2010, and approved via the expedited review process.

The research project and the informed consent are approved for a period of twelve months.

St. Vincent Hospital IRB approval for this protocol will expire on November 7, 2011.

The St. Vincent IRB is organized and operates according to written procedures in compliance with 21 CFR Parts 50 and 56, 45 CFR 46.

Sincerely,

Gary Cribb, Acting Chairperson
St. Vincent Hospital Institutional Review Board

JM/nb

Enc. Responsibilities of Investigators
(Stamped) Informed Consent



An Affiliate of
Hospital Sisters
Health System

APPENDIX C
INFORMATIVE LETTER

The Lived Experience of Heart Disease: A Woman's Perspective
Informative Letter

Dear Study Participant:

My name is Amanda Woulf and I am a registered nurse currently completing my Masters in Nursing Science degree at the University of Wisconsin Oshkosh to become a nurse practitioner. I am interested in studying women's experiences living with heart disease.

You are invited to participate in my research study, which seeks to explore your experiences of living with heart disease and the uncertainties associated with your disease that you experience. Results from this study may be used to better educate women regarding cardiac disease and may play a significant role in structuring continued cardiac care after cardiac events to better meet the needs of women living with heart disease.

Participation in this study is completely voluntary and you may decide to withdraw from the study at any point in time. If interested, sign up for an interview time either before or after your cardiac rehab session. I will be at your facility where your interview can be conveniently conducted in a private room provided by St. Mary's Cardiac Rehab. If the pre-scheduled interview appointments do not work for you, you may schedule a different time and place where I will meet you and conduct your interview. I suggest that you choose a place that is quiet and private to insure that your shared experiences remain confidential. At the time of the interview you will be asked to complete a short demographic questionnaire and sign a consent form consenting to participation in the study, audio-taping, and professional transcription of the interview. Your shared experiences will remain confidential and your identity will remain anonymous.

The interview will take approximately 30 minutes to one hour. I do not anticipate that participation in this study will cause any medical or social risk to you, and will be of no cost to you. You will only be inconvenienced by the time it takes to complete the interview. Your time and participation are greatly appreciated.

I am hopeful that you will participate in the study and I am eager to learn about your experiences.

I gratefully appreciate your voluntary participation in my study. If interested, please consult with one of the cardiac rehab therapists to sign up for an interview.

Thank You,

Amanda L. Woulf, RN, BSN

APPENDIX D
INFORMED CONSENT

The Lived Experience of Heart Disease: A Woman's Perspective

I, Mandy Woulf, Masters in Nursing Science Candidate at the University of Wisconsin Oshkosh, am conducting a study to examine the lived experience of heart disease in women. Your participation in the study would be appreciated to assist health care professionals and women to better understand how women perceive heart disease and the uncertainties associated with living with heart disease.

As part of the study, an audio-taped interview will be conducted concerning your experiences with living with heart disease. The interview is anticipated to take 30 minutes in length. The interview will be conducted in a private room at your cardiac rehabilitation facility or at a place and time more convenient for you. You will also be asked to fill out a demographic questionnaire at the time of the interview. You may choose to refrain from answering questions on the demographic questionnaire. Your audio-taped interview will be professionally transcribed for data analysis.

You may not experience any benefit from participating in this study. Your shared experiences may help other women with heart disease and health care providers caring for women with heart disease. I strongly anticipate that the study will not present any medical or social risk to you and that you will only be inconvenienced by the time required in completing the interview. Your identity will be revealed to only the researcher at the time of the interview. Audio tapes will be labeled according to the consecutive order that your interview takes place such as interview # 1 in order to ensure that your shared experiences remain confidential and your identity anonymous during transcription and data analysis.

Audio tapes, informed consents, demographic questionnaires, and professionally transcribed data will be stored safely in the St. Vincent Hospital Institutional Review Board office. Your shared experiences will remain confidential and will not be released to your physician or cardiac rehab personnel. A professional transcriptionist associated with the University of Wisconsin Oshkosh will transcribe your interview. Your identity will not be revealed during the transcription process unless you provide identification during the recorded interview. After your interview is transcribed, data will be analyzed by the researcher and may be viewed by the researcher's graduate chair at the University of Wisconsin Oshkosh Master of Nursing program. Your identity will not be revealed in the transcribed data. Results from this research will not be professionally published. A copy of the final clinical paper will be available at the University of Wisconsin Oshkosh library and at St. Vincent Hospital. Please contact the researcher if you would like a copy of the results.

You must have a diagnosis of heart disease to participate in this study. Your participation in this study is strictly voluntary and will not affect the care that you receive during your cardiac rehabilitation. You may withdraw from the study at any time, no questions asked. If you choose to withdraw simply cancel your interview appointment by notifying cardiac rehab personnel at the number provided below.

If you have questions regarding the study before results are available or you would like to cancel or reschedule your interview you may contact a therapist at St. Mary's Cardiac Rehab and cardiac rehab will then relay any questions or cancellations to the researcher:

Mandy Woulf
 2520 Garden Park Terrace
 Green Bay, WI 54311
 E-mail reedya34@uwosh.edu
 920-660-8211

If you have concerns or questions regarding your rights as a participant in this study please call or write:

Chair, Institutional Review Board For Protection of Human Participants
 C/O Grants Office
 UW Oshkosh
 Oshkosh, WI 54901
 (920) 424-3215

Although the chairman may ask for your name, all complaints are kept confidential.

St. Vincent IRB
 Contact: Gary Cribb
 920-884-5719

I have received an explanation of the study and agree to participate.

- I understand that the participation in the study is strictly voluntary and that I may withdraw at any time. I understand that I may withdraw by contacting the researcher, Mandy Woulf, I understand that any information used or disclosed pursuant to the revoked authorization may be subject to further re-disclosure and no longer protected under state and federal laws.
- I understand that I have the right to refuse to sign this authorization. Treatment, payment enrollment or eligibility for benefits may not be based upon your decision to sign this authorization.
- I have been informed regarding audio-taping of the interview and follow-up questions and agree to this process. I understand that I have a right to inspect or receive a copy of the information to be used or disclosed for this study. I may arrange to review or obtain copies by contacting the researcher, Mandy Woulf.
- This authorization will remain in effect until conclusion of the interview.
- A photocopy of this authorization will have the same force and effect as the original.
- I understand that I have the right to receive a copy of this authorization.

 Name of participant (Print)

 Date/Time

 Signature of participant

 Date/Time

 Witness Signature

 Date/Time

Copy of authorization provided to participant (date/time): _____

APPENDIX E
DEMOGRAPHIC QUESTIONNAIRE

Demographic Questionnaire

Today's Date _____

1. What cardiac event lead to your referral to cardiac rehabilitation
 - Heart attack
 - Heart attack, stent placement
 - Cardiac surgery for CABG
 - Cardiac valve surgery
 - Cardiac valve and CABG surgery
 - Heart Failure
2. What is your age? _____
3. What is your marital status?
 - Married
 - Widowed
 - Divorced
 - Separated
 - Not married but have a significant other
4. What is your highest achieved education level?
 - Less than high school
 - High School
 - Associated degree
 - Bachelor's degree
 - Master's/Doctorate degree
5. What is your present annual income?
 - Less than \$10,000
 - \$10,000-\$29,999
 - \$30,000-\$49,999
 - \$50,000-\$69,999
 - \$70,000 or above

REFERENCES

- Allen, J. W., Arslanian-Engoren, C., & Lynch-Sauer, J. (2009). The lived experience of middle-aged women with New York Heart Association Class III Heart Failure: A pilot study. *Progress in Cardiovascular Nursing*, 24, 96-101.
- American Heart Association. (2010). *Heart Disease & Stroke Statistics-2010 Update At-A-Glance* [Data]. Retrieved from <http://www.americanheart.org/downloadable/heart/1265665152970DS>
- Christian, A. H., Rosamond, W., White, A. R., & Mosca, L. (2007). Nine-year trends and racial and ethnic disparities in women's awareness of heart disease and stroke: An American Heart Association national study. *Journal of Women's Health*, 16(1), 68-81. doi: 10.1089.jwh.2006.M072
- Demir, F., Donmex, Y. C., Ozsaker, E., & Dirmali, A. (2008). Patient's lived experiences of excisional breast biopsy: A phenomenological study. *Journal of Clinical Nursing*, 17, 744-751. doi: 10.1111/j.1365-2702.2007.02116.x
- Eastwood, J., Doering, L., Roper, J., & Hays, R. D. (2008). Uncertainty and health-related quality of life 1 year after coronary angiography. *American Journal of Critical Care*, 17(3), 233-242. Retrieved from www.ajconline.org
- Husak, L, Krumholz, H.M., Lin, Z.Q., Kasl, S.V., Mattera, J.A., Roumanis, S.A. et al. (2004). Social support as a predictor of participation in cardiac rehabilitation after coronary artery bypass graft surgery. *Journal of Cardiopulmonary Rehabilitation*, 24, 19-26.

- Lerman, A., & Sopko, G. (2006). Women and cardiovascular heart disease: Clinical implications from the Women's Ischemia Syndrome Evaluation (WISE) study: Are we smarter? *Journal of the American College of Cardiology*, *47*(3), S59-S62. doi: 10.1016/j.jacc.2004.10.083
- Lien, C., Lin, H., Kuo, I., & Chen, M. (2009). Perceived uncertainty, social support and psychological adjustment in older patients with cancer being treated with surgery. *Journal of Clinical Nursing*, *18*, 2311-2319. doi: 10.1111/j.1365-2702.2008
- Madar, H., & Bar-Tal, Y. (2008). The experience of uncertainty among patients having peritoneal dialysis. *Journal of Advanced Nursing*, *65*(8), 1664-1669. doi: 10.1111/j.1365-2648.2009.05013.x
- Miracle, V. A. (2006). Coronary artery disease in women. *Dimensions of Critical Care Nursing*, *25*(2), 209-215.
- Mishel, M. H. (1988). Uncertainty in illness. *Image: The Journal of Nursing Scholarship*, *20*(4), 225-231.
- Mishel, M. H. (1990). Reconceptualization of the uncertainty in illness theory. *Image: Journal of Nursing Scholarship*, *22*, 256-262.
- Mosca, L., Ferris, A., Fabunmi, R., & Robertson, R. M. (2004). Tracking women: Awareness of heart disease: American Heart Association national study. *Circulation: Journal of the American Heart Association*, *109*, 573-579. doi: 10.1161/01.CIR.000011522269428.C9
- Olsson, M., Lexell, J., & Soderbert, S. (2008). The meaning of women's experiences of living with multiple sclerosis. *Health Care for Women International*, *29*, 416-430. doi: 10.1080/07399330701876646

- Rosenfeld, A. G. (2001). Women's risk of decision delay in acute myocardial infarction: implications for research and practice. *American Association of Critical-Care Nurses: Clinical Issues, 12*(1), 29-39.
- Sammarco, A., & Konecny, L. M. (2010). Quality of life, social support and uncertainty among Latina and Caucasian breast cancer survivors: A comparative study. *Oncology Nursing Forum, 37*(1), 93-99. doi: 10.1188/10.ONF.93-99
- Sanderson, B. K., Shewchuk, R. M., & Bittner, V. (2010). Cardiac rehabilitation and women: What keeps them away. *Journal of Cardiopulmonary Rehabilitation and Prevention, 30*, 12-21.
- Speziale, H. S., & Carpenter, D. R. (2007). *Qualitative research in nursing* (4th ed.). Philadelphia: Lippincott Williams & Wilkins.
- Stewart, K. J., Badenhop, D., Brubaker, P. H., Keteyian, S. J., & King, M. (2003). Cardiac rehabilitation following percutaneous revascularization, heart transplant, heart valve surgery, and for chronic heart failure. *Chest Journal, 123*(6), 2104-2111. doi: 10.1378/chest.123.6.2104
- Stukel, T. A., & Alter, D. A. (2009). Effects of cardiac rehabilitation on mortality of coronary patients. *Journal of the American College of Cardiology, 54*(1), 34-37. doi: 10.1016/j.jacc.2009.04.010
- Weiss, A. M. (2009). Cardiovascular disease in women. *Primary Care: Clinics in Office Practice, 36*, 73-102. doi: 10.1016/j.pop.2008.10.012
- Wenger, N. K. (2008). Current status of cardiac rehabilitation. *Journal of the American College of Cardiology, 51*(17), 73-102. doi: 10.1016/j.pop.2008.10.012

White, J., Hunter, M., & Holttum, S. (2007). How do women experience myocardial infarction? A qualitative exploration of illness perceptions, adjustment and coping. *Psychology, Health & Medicine, 12*(3), 278-288. doi: 10.1080/13548500600971288

Yohannes, A. M., Yalfani, A., Doherty, P., & Bundy, C. (2007). Predictors of drop-out from an outpatient cardiac rehabilitation programme. *Clinical Rehabilitation, 21*, 222-229. doi: 10.1177/0269215506070771