

UNCERTAINTY AS A PRECURSOR TO DELAY IN SEEKING CARE FOR WOMEN
EXPERIENCING SYMPTOMS OF ACUTE CORONARY SYNDROMES

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Abstract

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Uncertainty as a Precursor to Delay in Seeking Care for Women Experiencing Symptoms for
Acute Coronary Syndromes
(Under the direction of Dr. Merle Mishel)

Purpose: The majority of studies have found that women take longer than men to seek care for acute coronary syndromes (ACS) symptoms. Women are more likely to have atypical symptoms, perceive themselves as invulnerable to heart disease, and keep their symptoms to themselves. The purpose of this study was to explore the sociocontextual experience of how women with ACS recognize and interpret their symptoms while simultaneously managing everyday responsibilities and deciding whether to seek treatment.

Methods: In this grounded theory, qualitative study, in-depth, semistructured interviews were conducted with 9 women diagnosed with an ACS event. Results: The mean age was 60.7 years ($SD = 9.0$). Four participants were African American; five were Caucasian. All participants went through a process of recognizing and interpreting their symptoms as they tried to make sense of the experience. This search was embedded in a larger social context because they had to manage ongoing relationships and obligations in their lives while discerning what was happening to them. Participants fell into 2 groups based on the noticeability of symptoms and their abilities to recognize a symptom pattern. Group A ($n = 5$) experienced uncertainty related to their bodily cues and were unable to recognize a coherent symptom pattern. All had variable symptoms that were drawn out over time. They could not make sense of them, despite trying various strategies to label them. When unable to

recognize a symptom pattern, they returned to their usual lives while continuing to monitor their symptoms. Eventually, they sought treatment because someone else encouraged them to. Group B ($n = 4$) had more prominent symptoms, recognized a coherent symptom pattern quickly, labeled their condition, and moved toward care sooner. While they spent less time trying to make sense of their symptoms, they spent more time preparing themselves and others for their departure. Conclusions: The importance of recognizing a coherent symptom pattern prior to seeking care has not been previously studied in women with cardiac symptoms. This study offers a theoretical understanding of how and why women come to their symptom interpretations and manage the uncertainties of an ACS event.

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Chapter 1: Introduction

1.1 Introduction

This introductory chapter begins with an overview of the background and context which frames the general research topic. I will discuss how prehospital delay is a significant public health problem, the benefits of early treatment, and the extent of the problem within the larger context of treatment delay. I will also discuss the traditional conceptualization of how prehospital delay has been studied, followed by a discussion of why more research is needed in the area, based on a theoretical foundation. This chapter is designed to orient the reader to the state of the problem and provide a foundation for the rationale for further investigation with an alternative conceptualization of prehospital delay (to be discussed in Chapter 2) followed by methods (in Chapter 3).

1.2 Prehospital Delay: A Significant Health Problem and Benefits of Early Treatment

Prehospital delay for those with acute coronary ischemia is a significant public health challenge in the United States. Every 25 seconds an American will have an acute coronary event and nearly half of these episodes will result in death (Lloyd-Jones et al., 2010). Seventy percent of coronary deaths occur before the victim ever reaches the hospital (Lloyd-Jones et al., 2010). Treatments for acute coronary ischemia are time dependent and the earlier they are given the greater the patient survival. Survival improves by up to 50% if definitive therapy is administered within an hour of symptoms and by 23% if within 3 hours of symptom onset (Simoons et al., 1986). Furthermore, every 30-minute increment of delay increases first year mortality by 7.5% (De Luca, Suryaprana, Ottervanger & Antman, 2004) and reduces average

life expectancy by 1 year (Rawles, Metcalfe, Shirreffs, Jennings, & Kenmure, 1990).

Presentation delay is also associated with higher rates of heart failure, shock, and stroke (Newby et al., 1996). Yet despite the clear survival advantage of timely treatment, many do not receive treatment in the optimal time period. Only 13.6% of those with ACS arrive within the first hour of symptoms (McGinn et al., 2005).

Because timeliness in receiving treatment is an important predictor of outcomes, pre-hospital delay has been the topic of study for over 25 years. Unfortunately time to seek care has not changed substantially during those years. Recently the Atherosclerosis Risk in the Communities (ARIC) study found that approximately 50% of those experiencing symptoms wait 4 or more hours before arriving to the hospital (McGinn et al., 2005). This percentage has changed little since the study started in 1987. Several other large population-based studies, observational registries, and clinical trials [e.g. the National Registry of Myocardial Infarction, the Cooperative Cardiovascular Project, the Worcester Heart Attack Study, and the Rapid Early Action for Coronary Treatment (REACT) study] have reported median prehospital delay times between 2 and 3 hours; which have likewise showed little improvement over the past 2 decades (Ting et al., 2008; Sheifer et al., 2000; Goldberg et al., 1999; Saczynski et al., 2008; Goff et al., 1999). Moreover, the problem of prehospital delay is not unique to the United States. The GRACE study, a multicenter international observational study, reported similar median prehospital delay times, also noting lack of noticeable improvement from earlier reports (Goldberg et al., 2009; Goldberg et al., 2002).

Thus Healthy People 2020 has retained the objective from Healthy People 2010 – which aims to increase the proportion of eligible patients with heart attacks who receive timely artery-opening therapy from symptom onset (U.S. Department of Health and Human

Services, 2010). Specific goals for timely treatment from Healthy People 2020 (based on the National Acute Myocardial Infarction Project from the Centers for Medicare and Medicaid) are for either percutaneous coronary intervention to be performed within 90 minutes of symptom onset or alternatively fibrinolytic therapy to be given within 60 minutes of symptom onset. This 60 - 90 minute time frame includes both the time interval from symptom onset to hospital arrival and the time from hospital arrival to receipt of therapy. However, research has shown that prehospital delay, or *patient-related delay*, accounts for majority of the delay in receiving timely treatment.

1.3 Traditional Predictors of Delay: Socio-Demographic and Clinical Factors

Since the early 1970s, studies have by convention primarily focused on sociodemographic and clinical predictors of delay. The majority of the studies to date (using both univariable and multivariable analyses) have found that women, compared to men, prolong seeking care for cardiac symptoms (Ting et al., 2008; McGinn et al., 2005; Gibler et al., 2002; Goldberg et al., 2002; Sheifer et al., 2000; Goldberg, Gurwitz, & Gore, 1999). Two large scale studies done in the last decade, including ~ 850,000 subjects combined, have shown a differential delay for women that was both clinically and statistically significant in magnitude (ranging from 24 - 27.5 minutes on average additional delay for women) (Ting et al., 2008; Goldberg, Gurwitz, & Gore, 1999). In addition to being female, other socio-demographic factors such as older age, low education level, low socioeconomic status, and of non-white race have all shown to be predictors of increased delay (Moser et al., 2006). Furthermore clinical factors such as having diabetes, hypertension, high cholesterol, a history of heart failure or angina, and tobacco use have all been shown to increase delay in seeking treatment (Moser et al., 2006). While these data have been very helpful in determining who

are at highest risk for prehospital delay, these variables do not lend themselves to modification. In one large study of approximately 500,000 people (33% women), sociodemographic factors only accounted for 10-30 min of the total average delay of nearly 2 hours (Ting et al., 2008). For this reason, much attention has been placed on *why* individuals delay seeking care early in the course of symptoms. To understand reasons for delay, one must first recognize the complexity and dynamic nature of the decision making process involved, particularly for women.

1.4 The Decision Making Process for Women with Symptoms

Health care providers and lay people are often puzzled by the seemingly unwillingness that some women have to seek treatment for a life-threatening illness. The decision to seek care may be one of the most important decisions a woman makes in her life time. Yet for some, a major disconnect arises in that many who experience acute symptoms do not recognize or respond to the urgency in the situation, and thus delay seeking treatment for hours. However the complex process of symptom interpretation and personal decision making related to seeking care is underappreciated.

The National Heart Attack Alert Program (NHAAP) recommends that anyone experiencing signs and symptoms of a heart attack seek care within 5 minutes of symptom onset (1999). This exceptionally short time frame assumes that the individual is prompt in recognizing the presence of abnormal symptoms, interpreting symptoms as a condition that needs urgent medical attention, and arranging transportation to the hospital. To understand the complexity of the decision making process, one must first examine what must occur prior to hospital arrival, highlighting potential factors that could affect timeliness. Three phases of prehospital treatment-seeking phases have been identified in the literature (Moser et al.,

2006). These phases include (1) the time from symptom onset to the decision to seek medical treatment, (2) the time from decision to seek medical attention to the arrival of the first medical contact, and (3) the time from the first medical contact to hospital arrival (transport time). The first time interval, the time of symptom onset to the time a decision is made to seek treatment, is uniquely dependent on individual decision making by the woman experiencing symptoms. Proportionally, this time period accounts for three-quarters of the total prehospital time interval (Rasmussen et al., 2003). The remainder of this chapter and chapter 2 will focus on this time interval.

1.4.1 Symptom Recognition and Attribution of Cause

According to the conventional model used to study prehospital delay, the time of symptom onset begins with awareness (Moser et al., 2006). Without symptom recognition, as in the case of silent ischemia, one may find out months or years later that they have suffered a prior myocardial infarction. Symptom recognition is dependent on the patient (rarely others) recognizing a change from their baseline. Unlike other acute conditions (e.g. asthma, acutely de-compensated heart failure, acute stroke, or seizures) signs and symptoms may not be readily visible to family members or onlookers. Moreover, unlike the hospital setting, patients don't have monitors attached to them that alarm when early ischemia appears. Nor are there implantable devices that indicate early signs of ischemia, as in heart failure patients in which fluid volume changes can be detected earlier than actual signs/symptoms arise. Thus for women experiencing acute ischemia in the pre-hospital setting, timeliness in receiving life-saving interventions is largely dependent on somatic awareness of symptoms and the ability/desire to respond to symptoms.

Symptom recognition is followed by a dynamic process of symptom assessment, evaluation, and interpretation. During this ongoing process one determines if the symptoms are a sign of illness (by considering the potential causes), determines the seriousness of the situation, and determines the potential impact of the symptoms. However the symptom experience is highly variable and is influenced by physiological, psychological, and situational variables. According to the conventional model, the process of symptom evaluation and interpretation is followed by decision making regarding seeking care.

Several factors related to symptom assessment and interpretation have been associated with prehospital delay. Women are more likely to experience atypical symptoms (Canto et al, 2000; Higginson, 2008; Shin, Martin & Suls, 2010), which increases the likelihood of attributing symptoms to non-cardiac etiologies which is in turn associated with prolonged delay (Dempsey et al, 1995; Foster & Mallik, 1998; Finnegan et al, 2000; Rosenfeld et al, 2005; Moser et al, 2006; Thuresson et al, 2007). Ironically for those women who have chest pain, severity of their symptoms is not a reliable cue for them to recognize these symptoms as cardiac in origin (Fukuoka, Dracup, Moser, et al, 2007). Women are also more likely to experience symptoms that do not match their preconceived expectations for what a heart attack is supposed to be like, which has been shown to increase prehospital delay (Dempsey et al, 1995; Moser et al, 2006).

Women are more likely to perceive themselves as low risk for heart disease, even if post-menopausal, believing it is a man's disease (Finnegan et al, 2000; Harralson, 2007; Higginson, 2008); worry about troubling others with their symptoms, which results in longer delay (Moser, McKinley, Dracup & Chung, 2005; Turris & Johnson, 2008; Turris & Finnamore, 2008); and to keep their symptom experience to themselves, often dismissing or

minimizing symptoms until symptoms disallow continuation of their usual activities (Alonzo, 1986; Dempsey, Dracup, & Moser, 1995). The perception of insignificance of the situation has been attributed by some researchers as some women's need to maintain control of the situation (Dempsey, Dracup & Moser, 1995). However the underlying reasons for these symptom interpretations and responses by women as determinants of delay have not been fully explored.

The conventional model of prehospital delay views the inaccuracies in the definability of symptoms and assessment of personal risk primarily as a knowledge deficit. The knowledge deficit is combined with either a conscious decision to delay seeking care and/or a suppression of the meaning of symptoms as a health threat by the woman (Dracup et al., 2006). However the underlying explanations for these processes associated with symptom interpretation and responses have not been studied extensively.

Interventions used to reduce prehospital delay has been to address the knowledge deficit by educating those at highest risk for developing an acute coronary event on the symptoms of a heart attack, the importance of receiving timely treatment, and the need to call an emergency number such as 9-1-1 to get to the hospital urgently. However, to date, public health efforts to educate the public via mass media, including one of the largest randomized studies to date, the REACT study, have shown limited success in reducing prehospital delay or increasing the use of emergency medical services (EMS) (Mitic & Perkins, 1984; Ho et al, 1989; Herlitz et al, 1991; Moses et al, 1991; Meischke et al, 1997; Bett, Aroney, & Thompson, 1993; Gaspoz et al, 1996; Luepker et al, 2000). A more recent trial used a different approach to address the knowledge deficit related to prehospital delay. In the Patient Response to Myocardial Infarction Following a Teaching Intervention Offered by Nurses

(PROMOTION) trial 3,522 patients with documented heart disease were randomized to either receive an educational intervention or usual care (Dracup et al., 2009). The intervention consisted of a one-on-one individualized nursing intervention which taught patients about the symptoms of recurrent ischemia, the importance of calling 9-1-1, and anticipating emotional responses (e.g. fear, anxiety); and environmental influences that may influence their timeliness to seek care. However, similar to the REACT trial, neither prehospital delay time nor use of EMS was different for the intervention and the control groups over the 24 months. While subjects demonstrated higher knowledge post-intervention, knowledge alone was not sufficient to reduce prehospital delay or increase the use of EMS.

Thus innovative approaches are needed to seek out underlying psychosocial causes of prehospital delay (beyond knowledge deficits) that are amendable to change (Ting & Bradley, 2009; Dracup, 2009; Sullivan et al., 2009). To date, sociocontextual issues have been treated largely as secondary or extenuating factors and have not been the targets of study or intervention (Sullivan, 2009). Editorials by thought leaders in the field have recognized a need to tie theory to findings in the current literature related to prehospital delay (Moser et al., 2006; Dracup, 2009; Sullivan et al., 2009.)

1.5 An Alternative Theoretical Approach to Studying Delay

This study will broaden the traditional conceptualization of delayed decision making in the current paradigm, to an alternative conceptualization to be considered. This study will use the Uncertainty in Illness Theory developed by Mishel (1988; 1990) to frame my study. In applying this model, this study will investigate whether uncertainty related to forming a coherent symptom pattern in addition to uncertainty related to relinquishing role responsibilities prevents women from fully evaluating their symptoms. A more theoretical

understanding of how and why women come to their symptom interpretations and manage the uncertainties of the illness-event is needed to build a cohesive body of empirical data to aid in the development of interventions to address prehospital delay

Chapter 2: An Alternative Conceptualization of Delay

2.1 Introduction

In this chapter I will discuss an alternative conceptualization of prehospital delay to be considered. The model used to frame the study is based on the Uncertainty in Illness Theory developed by Mishel (1988; 1990). I will first discuss how uncertainty related to the symptom experience is common among women experiencing ACS symptoms. I will next discuss the general tenets of the Uncertainty in Illness Theory followed by how this theory can be applied to uncertainty of symptom pattern recognition and other forms of uncertainty that extend to other aspects of the illness situation, in particular, uncertainty related to maintaining role responsibilities. The chapter will conclude with a discussion of the rationale for the study and why a qualitative methodological approach is well suited to explore the alternative conceptualization.

2.2 Uncertainty Related to the Symptom Experience

Most people, when asked about expectations of heart attack symptoms, visualize a “Hollywood Heart Attack”, in which case the victim and bystanders have no doubt about causality of symptoms and the appropriate actions to take (Finnegan et al, 2000). However, the uncertainty of the initial symptom experience, in conjunction with an inaccurate attribution of cause and misperception of personal risk, has been recognized as a central component of prehospital delay for women (Finnegan et al., 2000; Moser et al., 2006).

The National Heart Lung Blood Institute (NHLBI) emphasize in their educational materials that uncertainty related to ACS symptoms is normal and is a common reason for

delay in seeking care (*Act in Time to Heart Attack Signs* campaign, NIH Publication No. 01-3525, 2001). Clinical exemplars and anecdotal descriptions of uncertainty have been cited in the literature of women who delay seeking care for ACS symptoms. In the early stages of an ACS event, symptoms are often vague, mild, and atypical; not matching the expected symptoms of a heart attack (Finnegan et al., 2000). Women are frequently unsure and confused initially about the nature of the symptoms, resulting in uncertainty of the illness situation (Johnson & Morse, 1990). Some women describe knowing that something was “peculiar,” but attribute the symptoms to “nothing in particular” (Jensen & Petersson, 2003). Thus the expectation of certainty is often violated by the uncertainty that accompanies the experience, which is typically associated with a “wait and see” approach (Finnegan et al., 2000).

Although women may be knowledgeable of the “standard” symptoms of heart disease, their own symptoms often do not match prior expectations – frequently referring to the symptom miss-match as “throwing them off course” (Schoenberg, Peters, & Drew, 2003). Inaccurate attribution of symptoms to a cardiac cause has been associated with significantly longer prehospital delay (Moser, McKinley, Dracup & Chung, 2005). Given the inability to recognize the symptoms as a sign of a life-threatening illness, women often normalize symptoms, attributing the symptoms to minor conditions, while continuing with their daily activities (Johnson & Morse, 1990; Dempsey et al., 1995; Schoenberg, Peters, & Drew, 2003; Rosenfeld & Lindauer, & Darney, 2005). Women interviewed shortly after an ACS event have reported “not knowing” or “being unsure” of whether heart disease was as serious for women as for men (Dempsey et al, 1995). Not recognizing the seriousness of the symptoms has been associated with prolonged delay (Moser, McKinley, Dracup & Chung,

2005). Many women assess their personal risk for heart disease as low, due to the ambiguous nature of symptoms combined with the mistaken belief that heart disease is a “man’s disease” (Finnegan et al., 2000). The uncertainty of the initial symptom experience, in conjunction with an inaccurate attribution of cause and misperception of personal risk, has been recognized as a central component of prehospital delay for women (Finnegan et al., 2000; Moser et al., 2006). However, much of the research that supports the link between uncertainty of the symptom experience and prolonged prehospital delay continues to be preliminary and atheoretical in nature.

2.3 Theory of Uncertainty in Acute Illness

According to Mishel’s Theory of Uncertainty in Acute Illness, uncertainty occurs when an individual is unable to determine the meaning of an illness-related event and/or accurately predict the outcomes of the event (Mishel, 1988). Uncertainty is a cognitive state which occurs in situations where the “decision-maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcomes” because sufficient cues are lacking (Mishel, 1984, p. 163). Components of uncertainty include ambiguity, vagueness, unpredictability, and the lack of information centered on symptom pattern, event familiarity, and event congruence.

2.3.1 Uncertainty Related to Symptom Pattern

According to the theory, illness-related stimuli precede uncertainty. For women with ACS symptoms, the inability to recognize and classify symptoms into a consistent pattern creates a state of uncertainty, which influences decision making. A symptom pattern is defined as “the degree to which symptoms are present and with sufficient enough consistency to form a pattern” (Mishel & Braden, 1988, p. 98). An uncertain symptom pattern prohibits

the individual from clearly evaluating their illness state (Mishel, 1988). The definability of the symptom pattern is influenced by the number and quality of symptoms, the symptom course (insidious or abrupt onset), timing, frequency, location, intensity and duration of the symptoms, and the overall level of distress caused by the symptoms (Mishel, 1988).

According to the theory, a symptom pattern that is unpredictable, ambiguous, vague, indistinguishable, unclear, and inconsistent with prior knowledge of the situation generates uncertainty.

Unpredictability speaks to the changing, dynamic, amorphous nature of the symptom pattern. According to the theory, symptoms that gradually increase in a consistent fashion, are patterned, and are predictable create a less ambiguous illness experience (Mishel, 1988; Mishel & Braden, 1988). A more predictable symptom pattern implies control of symptoms so that the decision-maker can anticipate the range and limits of the symptoms (Mishel, 1988). Symptoms that are intermittent in nature have been associated with prolonged prehospital delay (McKinley, Moser & Dracup, 2000). Women often refer to symptom patterns that wax and wane, which increase the unpredictability of the symptom pattern. Women in the studies of prehospital delay speak of the unpredictability of not knowing how long the symptoms will last or whether the symptoms will worsen. Unpredictability of the situation also relates to not knowing outcomes of the symptom experience (Mishel, 1988). This has been described by women who had experienced an ACS event as not knowing the seriousness of the situation and potential consequences (Dempsey et al, 1995).

The ambiguous nature of ACS symptoms in women has been recognized in the literature. According to the theory of Uncertainty in Illness, ambiguity, resulting from the absence of a clear-cut conception of what events will occur, is the biggest factor in the

generation of uncertainty (Mishel, 1981). Unclear, vague, or ever-changing bodily cues about the state of illness make symptoms difficult to assess and interpret (Bailey et al, 2009).

Vagueness, a related aspect of the ambiguous symptom pattern, occurs when symptoms are ill-defined and lack unity. When symptoms are vague, individuals are unable to discern the meaning of physical differences due to the lack of a distinct symptom profile (Brashers, et al. 2003). According to the theory, symptoms need to be sufficiently prominent enough to be noticeable to construct a pattern (Mishel, 1988). Women who delay seeking care realize that something has changed in body, but are unsure if anything is “wrong”. Vagueness also applies to the distinguishability of the symptoms. According to the theory, symptoms may have multiple meanings, making it difficult to differentiate one symptom from another, because symptoms of different illnesses confound one another (Mishel, 1988).

Inconsistency of the symptom experience may affect one’s ability to evaluate the presence of a symptom pattern. According to the theory, a symptom experience that is inconsistent with prior expectations is more likely to generate uncertainty. This is referred to as “symptom mismatch” in the current conceptualization of prehospital delay, which is associated with prolonged decision making.

Finally a situation which lacks information is more likely to generate uncertainty. According to the theory, unfamiliarity of the illness-related event influences an individual’s ability to create a frame of reference to the event (Mishel, 1988). Theoretically, women who are more knowledgeable of symptoms are better able to interpret symptoms due to enhanced familiarity of the event (Mishel, 1988). This link is supported by one study that found individuals with a history of heart disease are 5 times as likely to attribute their symptoms to a cardiac etiology as opposed to those without heart disease (OR 4.95; CI 2.39-10.25)

(Fukuoka, Dracup, Moser, et al, 2007). Conversely, as symptoms become more ambiguous or unfamiliar to an individual, uncertainty of the illness-situation increases, which is associated with delayed decision-making (Finnegan et al., 2000; Cytryn et al, 2009). Studies have shown that lay individuals relate ambiguous symptoms or situations with a “no action” or a “wait and see” heuristic approach (Finnegan et al., 2000; Cytryn et al, 2009). This not only applies to participants with first time events who lack familiarity to the situation, but also to those with prior ACS events.

Although Mishel’s theory indicates that uncertainty is highest when the diagnosis is absent (1988), it is plausible that women with repeated hospitalizations or symptoms may also experience uncertainty. Recurrent symptoms soon after a hospitalization may generate uncertainty of the situation due to the unpredictability and fear of frequent admissions. The individual’s equilibrium is disrupted by the inability to stabilize the condition.

2.4 Using the Theory of Uncertainty to Explain Empirical Findings

There is empirical evidence to support the plausibility of the link between ambiguous symptom patterns and inaccurate symptom attribution for women with ACS symptoms. The absence of chest pain or discomfort (i.e. the classic signs of an ACS event) is more common in women than men (37% versus 27%, respectively) (Canto et al, 2007). Women are more likely to report back pain, palpitations, nausea/vomiting, and loss of appetite (Canto et al, 2000; Higginson, 2008; Shin, Martin & Suls, 2010). The chest pain experienced is more likely to be reported as ‘pinching’ sensations in their chest and arms (Finnegan et al, 2000). Atypical symptoms for women frequently result in uncertainty related to symptom mismatch (i.e. the actual experience does not match expectations of what symptoms of a heart attack should be) (Dempsey et al, 1995; Moser et al, 2006). Thus women are likely to

attribute symptoms to those unrelated to their heart; instead to their back, gall bladder, other bodily functions, or an unknown cause (Foster & Mallik, 1998; Rosenfeld et al, 2005; Thuresson et al, 2007; Finnegan et al, 2000). Moreover for the women who have chest pain, severity of symptoms is not a reliable cue for women to recognize ACS symptoms as cardiac in origin (Fukuoka, Dracup, Moser, et al, 2007).

In addition to the ambiguous nature of symptoms, inaccurate perceptions of vulnerability to an ACS event have been reported in the literature. Some women perceive themselves invulnerable to heart disease thinking it is a ‘man’s disease’ – even if they are post-menopausal (Finnegan et al, 2000; Harralson, 2007; Higginson, 2008). The uncertainty of the symptom experience combined with the misperception of susceptibility generates more uncertainty. As the woman evaluates the possibility that she may be having a heart attack, another stimulus for uncertainty is generated, because the reality of the situation doesn’t match her existing cognitive structure that “women aren’t supposed to get this disease”. This link is plausible because inaccurate perceptions of vulnerability have been found in women who have had prior ACS events (Moser et al., 2006).

There is other evidence to link uncertainty of the ambiguous symptom experience to inaccurate assessment of cause, an unrealistic perspective of vulnerability to heart disease, and the lack of perceived seriousness of the situation. Studies have shown that knowledge of these factors is insufficient to making a timely decision to seek care (Cytryn, Yodkowitz, Cimino, Patel, 2009). This is supported by the studies testing whether fact-based information reduces pre-hospital delay. As a whole, community-based initiatives using mass media to educate the public on how to recognize symptoms of ACS, the importance of a rapid response, and how to contact EMS have been largely unsuccessful (Mitic & Perkins, 1984;

Ho et al, 1989; Herlitz et al, 1991; Moses et al, 1991; Meischke et al, 1994; Bett, Aroney, & Thompson, 1993; Gaspoz et al, 1996; Luepker et al, 2000). Despite the fact that study participants increase their knowledge of the information, reduction of pre-hospital delay and/or increased use of EMS did not occur.

Moreover, recent studies have shown that women are more knowledgeable than once thought about their vulnerability to having a heart attack, the appropriate actions to take when facing these symptoms, and were significantly more likely than men to know the benefits of reperfusion therapy and the need to call EMS rather than use private transportation to go to the hospital (Dracup et al, 2008). A study by Lovlien et al (2008) of patients with a first time ACS event found that for men, but not women, low education predicted delay. Yet despite potentially higher levels of knowledge for women, the gender differential in pre-hospital delay still exists.

An alternative explanation as to why knowledge alone is not sufficient to reducing pre-hospital delay for women is that women's decisions to seek care are tied to other social and psychological complexities related to the symptom experience, which can also add to the uncertainty of the experience (Caldwell & Miaskowski, 2002). For example, women report the need to finish ongoing social obligations as a prerequisite to managing and making sense of their ACS symptoms (Zuzelo, 2002). A few explanations have been offered as to why women attend to personal and social obligations instead of attending to their emerging symptoms. According to the traditional model of prehospital delay, the failure to disregard existing social obligations, in lieu of seeking care, has been viewed as a conscious process in which the ill person deliberately retains selected segments of their social roles, despite being acutely ill (Simon, Feinleib, & Thompson, 1972; Alonzo, 1986; Finnegan et al, 2000;

Schoenberg et al, 2003; Turris & Johnson, 2008). The failure of women to attend to emerging symptoms, as opposed to personal and social commitments, has been attributed to a lack of desire to impose upon others. In fact, women have been shown to delay seeking care an additional 42 minutes on average, compared to men, due to a reluctance to notify others of symptoms ($P = 0.02$) (Moser, McKinley, Dracup & Chung, 2005). Others have attributed the inability to give up social obligations as some women's desire to maintain control over themselves and their environment by deliberately choosing commitments to others over their own health (Dempsey, Dracup & Moser, 1995).

An alternative conceptualization to the traditional one, is that uncertainty in one area, such as symptom pattern recognition, serves as a stimulus for other uncertainties related to additional socio-contextual aspects of life (such as potential changes that are required from illness situation and how they will manage these changes).

According to the Mishel's Theory of Uncertainty in Illness, although uncertainty may begin in one part of the experience it can regress or can spread to other aspects of the illness situation (Mishel, 1990). The uncertainty of the symptom pattern competes with the individual's pre-illness level of functioning. If the individual stays within a certain cognitive state (pre-illness state), the uncertainty doesn't invade other areas/aspects of the illness experience and their life situation (Mishel, 1990). If however, uncertainty multiples by an increasing complex invasion into other aspects of a person's identity and life, the impact of the original insult increases (Mishel, 1990). Thus uncertainty in one area of the symptom experience serves as a feedback mechanism to generate more uncertainty in the broader areas of life.

2.5 Impact of Uncertainty on Socio-Contextual Aspects of Life

2.5.1 Studies of Socio-Contextual Factors

As discussed in Chapter One, the traditional model of prehospital delay views the definability of symptoms and assessment of personal risk primarily as a knowledge deficit; all of which precede the decision to seek care. An alternative conceptualization is that uncertainty related to symptom experience serves as a platform to uncertainty related to relinquishing role responsibilities. This link introduces the idea that the women may not be fully evaluating the symptoms until their social obligations are fulfilled. Uncertainty of the symptom experience combined with the confluence of the ongoing social obligations has been linked with prolonged delay for women experiencing ACS symptoms (Zuzelo, 2002; Schoenberg, Peters, & Drew, 2003). Women interviewed had difficulty conceiving the possibility of a life-altering event (such as a heart attack) which required reassignment of tasks that were considered essential to the survival of their household (Schoenberg, Peters, & Drew, 2003). The women talked about how things did not function without them; that they weren't "supposed" to get sick; thus deferring seeking treatment because it did not "fit" into their lives. Reassigning responsibilities due to the possibility of having a heart attack was not a part of their cognitive structure, thus not easily adopted.

2.5.2 Uncertainty Related to Forfeiting Role Responsibilities

For women whose self-identity is tightly linked to relationships with others, cutting ties with others in their social network in order to seek care creates uncertainty about how these ties can be maintained. This is illustrated in studies of women who experienced symptoms of ACS. In these studies, some women viewed their role responsibilities as essential to their identity and to the survival of their home or work setting and thus they

delayed seeking care in an effort to preserve social integrity in their daily lives (Schoenberg, Peters, & Drew 2003; Turrís & Johnson, 2008; Turrís 2009). The women who were engaged in role responsibilities that were an integral part of their self-identity spoke of ignoring symptoms in an effort to maintain these roles.

Role uncertainties are illustrated in interviews with women who were hospitalized for acute cardiac symptoms. During the initial pre-hospital period, the women avoided disruption in their daily routine while deciding to what extent they should continue performing their roles and who in their social network they should involve in making decisions about role modifications (Turrís & Johnson, 2008). Women expressed uncertainty about whether their household would survive without them if they sought treatment (Scholenberg, Peters, & Drew, 2003). In addition to uncertainty related to the actual tasks involved, the women expressed uncertainty about the psychosocial consequences of being unable to fulfill role responsibilities. The women were frequently uncertain as to whether they would be viewed as a burden to others (Dempsey, Dracup, & Moser, 1995; McKinley, Moser & Dracup, 2000; Scholenberg, Peters, & Drew, 2003; Moser, McKinley, Dracup, & Chung, 2005; Turrís & Johnson, 2008). Uncertainty also revolved around the unpredictability of social costs of forfeiting role responsibilities such as feelings of guilt, a loss of control of the situation, dependence on others, and letting go of ties to others in the social network (Stryker & Serpe, 1982; Turrís & Johnson, 2008; Turrís, 2009). Based on the Theory of Uncertainty, the unpredictability of these outcomes generates more uncertainty related to how to maintain roles and how to allocate them to trusted others or safely store them until they return.

2.5.3 Uncertainty Related to Ability to Exit Roles

Uncertainty related to relinquishing role responsibilities also relates to the unpredictability about the amount of time and resources needed to fulfill role responsibilities. Qualitative studies have shown that when an illness is perceived as serious, time is slowed and expanded beyond the body to include what is going on in the environment (Morse, 1997). Instead of measuring time in minutes or hours, individuals view time in relation to their environment. For many women with ACS symptoms, this means time is viewed in the context of their role responsibilities (e.g. work obligations, meal times, or other social duties) and they don't view themselves delaying seeking care (Schoenberg, Peters, & Drew, 2003; Turris & Johnson, 2008; Turris, 2009). In addition to the uncertainty of the seriousness of the condition and the unpredictability of how long the symptoms will last, the uncertainty related to time invades into unpredictability of how long one needs to relinquish duties.

Uncertainty also extends into perceived adequacy of resources to take over duties. According to sociology literature, individuals with high levels of resources take on more role identities and can also exit those roles more easily when needed; while those with inadequate resources exhibit reluctance to let go of role responsibilities (Thoits, 2003). This is consistent with the experiences described by women with ACS symptoms who delayed seeking care due to uncertainty of who would take over their duties. Often they reported being 'too busy' to seek treatment or being concerned about leaving things 'undone' (Schoenberg, Peters & Drew, 2003; Turris, 2009). For example, women spoke about not having anyone to watch their children or grandchildren if they sought medical treatment (Turris, 2009). In another study of women with ACS symptoms, 41% were caring for others (mostly grandchildren) at the time of symptom onset, and this negatively affected their time to treatment (Harralson,

2007). Thus, the perceived lack of adequate resources available to a woman experiencing ACS symptoms creates role uncertainty.

2.5.4 Uncertainty Related to Other Situational Factors

Other situational factors that influence the level of role uncertainty include the expectancy and suddenness of the acute disruption, the magnitude of the changes required, and the types of roles involved. Women with various medical conditions have described situations in which they experienced a threat to their sense of self and social identity due to the acuteness of the biological disruption in their life necessitating role changes (Young, Dixon-Woods, Findlay, & Heney, 2002; Charmaz, 1983). The immediate threat creates an internal conflict related to the uncertainty from event unfamiliarity. Thus for women with no prior cardiac symptoms (i.e., no prodromal symptoms or history of ACS symptoms), the novelty of the situation can influence the amount of role uncertainty they experience. Role uncertainty is also influenced by the number, type, and complexity of the role changes required. This has been referred to as the “ripple effect” by patients, who described what occurred when other family members had to make changes and, in many cases, react to changes (Knoll & Johnson, 2000).

Women have spoken of uncertainty spreading from one area of their life to other areas of life, disrupting ongoing life patterns, just as uncertainty in illness does (Mishel, 1990). Women who were normally able to balance multiple role responsibilities experience role uncertainty due to ACS symptoms and this affects other aspects of their lives. They describe a lack of clarity related to symptom interpretation, uncertainty about what resources are available to them at the moment, and inability to identify what is harmful to them.

Lastly, the type of role that a woman is engaged in when ACS symptoms occur may influence role uncertainty and the consequences if roles are left undone. According to Thoits (2003), the types of roles that an individual participates in make a difference in how easily a role can be exited. Obligatory roles (e.g., worker, parent, spouse, or caregiver) involve long-term commitments to others and reciprocal relationships, and they are harder to exit, both emotionally and instrumentally (Thoits, 2003). Moreover, when individuals contemplate exiting obligatory roles or fail to meet these types of role responsibilities, there is a higher likelihood of sanctions from those with reciprocal roles (Thoits, 2003). In contrast, voluntary roles (e.g., volunteer, neighbor, group member or leader) are typically more discretionary and have less uncertainty as they are easier to enter and exit. Ties tend to be shorter-term and responsibilities are less demanding and involve fewer consequences if they go unfulfilled (Thoits, 2003). Therefore for women experiencing symptoms of ACS, there may be more uncertainty related to exiting roles viewed as obligatory. This uncertainty may be crucial in affecting treatment seeking delay, yet these links to role uncertainty have not been explored in this patient population.

2.6 An Alternative Approach to Conceptualizing Delay to Include Role Uncertainty

Thus an alternative approach to conceptualizing delay would be that in addition to uncertainty related to symptomology, women who experience ACS symptoms also experience uncertainty related to managing current role responsibilities tightly tied to their identity. Role uncertainty is defined as a cognitive state women experience during an acute illness situation (in this case, symptoms of ACS) due to lack of clear information about how to manage their role responsibilities if they seek medical care. Role uncertainty may stem from lack of clarity and predictability related to changes in the scope and nature of role

responsibilities, the adjustments to behavior needed to complete on-going responsibilities including timing to get things done, and changes in role expectations that occur because of changes in the context of the life situation. However, the extent and the forms of role uncertainty that influence women's decisions related to seeking care are currently unknown.

2.7 Rationale for the Proposed Study

Sociocontextual issues have been treated largely as secondary or extenuating factors and have not been the targets of study or intervention (Sullivan et al., 2009). However exploration of an alternative conceptualization to understanding pre-hospital delay may provide new insight into better understanding of how women recognize, assess, and evaluate symptoms and the impact of these evaluations. Discovery of an unexplored alternative basis for understanding pre-hospital delay may yield novel targets for intervention.

2.7.1 How Uncertainty Fits into the Current Model

The current conceptualization of care seeking behavior suggests that women who delay seeking care inappropriately evaluate their symptoms, resulting in a lack of urgency related to seeking care. The traditional model contends that inaccuracies of symptom attribution and perceived susceptibility due to a knowledge deficit combined with a deliberate decision to dismiss or minimize symptoms in order to continue with activities of daily living heavily influence delay. Not addressed in the traditional model is the way in which women interpret symptom patterns when they are actually experiencing them and what factors support or negate the recognition of symptom patterns, which are related to health-seeking behavior. The traditional model also indicates that women with ACS symptoms actively monitor their symptoms and if symptoms persist or change in nature, then the action plan is re-evaluated. However, an alternative conceptualization views that the uncertainty

related to forming a coherent symptom pattern in addition to uncertainty related to relinquishing role responsibilities prevents women from fully evaluating their symptoms. Thus if women do not recognize the situation as a “problem” due to not fully attending to the situation, then they are not necessarily making an inaccurate or inappropriate decision. Appraising a situation as a threat implies that one has already attended to the situation (as in the traditional model). However, it may be in retrospect only, that one recognizes actions (or inaction) as delay.

2.7.2 Aim of the Study

This study aims to explore the alternative conceptualization of uncertainty of the symptom experience tied to the uncertainty of relinquishing role responsibilities, as a major precursor to pre-hospital delay. This study will explore how uncertainty related to symptomology produces a platform for uncertainty in other aspects of life during the acute illness phase. The Model of Uncertainty in Illness will be used to drive the investigation. While there is no empirical support of this relationship to date in this clinical population, further study may provide an opportunity for identifying novel avenues for addressing delay.

A qualitative approach is well suited to determine support for this alternative explanation, to flesh out more examples and details of the phenomenon including how it functions, and to identify the limit of this theme. In-depth one-on-one interviews will be used as the primary means of data collection. Emphasis will be placed on detailed knowledge obtained from in-depth interviews, constant comparison of cases, and a search for the implicit meaning behind the words provided by the women interviewed.

The study will examine the presence of symptom pattern uncertainty and role uncertainty in women with symptoms of ACS, the composition of these uncertainties, the

influence the uncertainties have on delay in seeking treatment and the management of the uncertainties during a time of ACS symptoms. Knowledge of these processes may lead to a more cohesive theoretical understanding of the problem which may inform interventions to manage the uncertainties related to the acute illness situation in order to decrease delay in seeking treatment.

Chapter 3: Methods

3.1 Introduction and Overview

The purpose of this study was to explore the socio-contextual experience of how women with acute cardiac ischemia assess and interpret their symptoms while simultaneously managing everyday roles and responsibilities when deciding whether to seek treatment. As a researcher, I wanted to move beyond the traditional biomedical model to better understand the socio-contextual meaning(s) of the experience from their individual perspective. The Theory of Uncertainty in Illness (Mishel 1988; 1990) was used to explore how uncertainty related to symptomology tied to uncertainty of relinquishing role responsibilities leads to prehospital delay in this population.

This chapter describes the study's research methodology and includes discussions pertaining to: (a) rationale for a qualitative research approach, (b) an overview of the research design, (c) the methods of data collection, (d) a description of the final sample, (e) how data were managed and analyzed, (f) ethical considerations taken during the study, (g) issues of trustworthiness, and (h) potential limitations of the study. Qualitative inquiry designs are emergent in nature (Patton, 1990; Sandelowski & Barroso, 2003), thus data collection, management, and analysis remained flexible as the study unfolded. This chapter provides credibility to the theoretical principles that shaped the logic of my inquiry, which ultimately supports my findings (Bloomberg & Volpe, 2008).

3.2 Rationale for Qualitative Research Approach

A qualitative research approach was chosen, under the paradigm of a realist orientation, as a means of exploring the phenomenon in its natural state allowing for contextual, historical, and situational variation. This type of inquiry is fitting when studying patient-related phenomena that involve a social process, such as decision-making, because it does not destroy the complexity of the phenomena. Qualitative inquiry allowed me to better understand the phenomenon from a range of women's perspectives, to flesh out examples and details of this process, as well as identify limitations of the theme. Although I sought to make analytical generalizations about commonalities in the experiences gained from multiple women, I strived to simultaneously preserve the integrity of their individual experiences (Sandelowski, 1993; Corbin & Strauss, 2008).

3.3 Epistemological Stance for the Study

As a researcher, I adopt a constructivist epistemological stance in which women in an acute illness situation seek to make (or *construct*) meaning(s) of the event in order to explain and make sense of the situation for themselves (Corbin & Strauss, 2008). For women experiencing ACS symptoms, making sense of the situation is highly individualized, evolving over time, and may be delayed in uncertain situations. The meanings constructed may not emerge consciously for each woman and may not lead to rational actions in the eyes of others (Corbin & Strauss, 2008).

A theoretical perspective that fits with this epistemology is that of symbolic interactionism. Congruent with this philosophy, my assumptions going into the study were that the women's actions are based on the meaning they place on the socio-contextual situation (as opposed to a mechanical response to symptoms) (Charmaz, 2006), that the

meanings are made in relation to interaction with others, and that the meanings may be modified (interpretively) by the women as they evaluate the situation (Crotty, 1998).

Furthermore the women will continue to construct meanings as the interviewer-interviewee relationship takes shape (Crotty, 1998).

3.4 Methodology

Multi-grounded theory (MGT), an extension of traditional grounded theory (GT), was chosen as a methodology for this study. Multi-grounded theory, developed by Goldkuhl and Cronholm (2003), builds upon the strengths of traditional GT, while systematically incorporating pre-existing theory. This methodology uses external theories during the planning phase of a study when reflecting on research interests, during various stages of data analysis and theory development, and when validating findings. As the name implies, three different grounding processes are used in this approach; theoretical, empirical, and internal grounding. An advantage that this approach allows is the flexibility of combining the inductivism of traditional GT with the deductivism of existing theory. Moreover, the use of multi-grounding processes of MGT allows for knowledge accumulation. Theoretical development is a continuous process and one that should be built on earlier work. Augmenting data collection and analysis with pre-existing theory adds to the explanatory power of the findings.

Multi-grounded theory offered this study the flexibility to using existing theory for refinement of the research interest (allowing me to have more focused research questions), served as a useful framework for organizing and thinking about the data, challenged concepts during analysis, and helped evaluate the validity of the findings. Multi-grounded theory provided an opportunity to consider a theoretical approach (the Theory of Uncertainty) and

components of a theory as sensitizing concepts when I entered the field. By using MGT methodology I was able to determine whether the alternative conceptualization that uncertainty related to symptomology and relinquishing role responsibilities served a stimulus for delayed decision making.

3.4.1 How Traditional Grounded Theory May be Extended with Multi-Grounded Theory

A basic tenet and strength of traditional GT is that the theoretical rendering is grounded in the data that have been generated (Charmaz, 2006). Traditional GT has avoided the use of existing theory in data collection and analysis. This strict inductive approach emphasizes the emergence of concepts and categories from the ground up, as opposed to use of pre-existing categories from extant theory (Glaser & Strauss, 1967). Traditional GT has been recognized for the ability to discover new ideas and insights generated from the empirical data; a strength of the methodology. Detailed processes for coding (open coding, axial coding and selective coding) and analyzing data have been delineated over the years as traditional GT has evolved (Strauss & Corbin, 1998).

However some of the strengths of emergent processes used with traditional GT are also viewed as limitations. Entering the field with a “clean slate”, unprejudiced and without presumptions, risks being uninformed and risks obtaining large volumes of unfocused data. Being too open-minded may lead a large divergent data set, creating frustration and lack of focus, especially for novice researchers. Using a pure inductive approach, one also risks taking the collected data for granted by not comparing them to other informational sources. There is a risk of re-inventing the wheel or creating knowledge in isolation, leading to non-cumulative theory development (Goldkuhl & Cronholm, 2003). Thus more recent

modifications of traditional GT have endorsed a less strict approach to the pure inductive approach to analyzing data (Corbin & Strauss, 2008).

3.5 The Research Setting

Participants were recruited from two inpatient cardiac units at University of North Carolina Hospitals (UNCH), in Chapel Hill, North Carolina. This site was targeted to obtain a more heterogeneous sample in terms of age, race, ethnicity, and socio-economic status. One of the units, the Coronary Intensive Care Unit (CICU), is a 13 patient critical care unit specializing in the management of patients with a variety of cardiac conditions. These include myocardial infarction, acute decompensated heart failure/cardiomyopathy, pre- and post-cardiac transplant, cardiogenic shock, unstable dysrhythmias and multisystem organ failure. The nurse to patient ratio is usually in the range of 1:2 to 1:1, depending on severity/acuity of patients' conditions. The second inpatient cardiac unit, 3 Anderson North is a 29-bed unit that encompasses a 6-bed Intermediate Coronary Care Unit (ICCU) as well as 23 beds for cardiac patients requiring telemetry monitoring. The largest populations of patients are those with congestive heart failure and/or acute coronary syndrome diagnosis. Pre- and post-cardiac catheterization interventions are managed on this unit. The ages of the patients on both of these units are generally from late adolescence and higher. It varied as to how many women were admitted to each unit.

3.6 The Research Sample

3.6.1 The Patient Population (Arena Used for Sampling)

Eligible participants for the study included women age 35 years and older with a definitive diagnosis of ACS. The diagnosis of ACS included symptoms of acute cardiac ischemia and at least one of the following: positive cardiac biomarkers, changes to the 12 Lead ECG (ST

segment elevation, ST depression, and/or T wave inversion in at least two contiguous leads), and/or with significant cardiac disease as noted by a cardiac catheterization during the index hospitalization. Participants were excluded if they were experiencing hemodynamic instability and/or were unable to understand spoken English.

3.6.2 Initial Selective Sampling for the Study

Selective sampling, a type of purposive sampling, was used at the beginning of the study as a ‘place of departure’ based on pre-identified populations and settings gathered from the review of literature (Thompson, 1999; Charmaz, 2006). I sampled for diversity in relation to race, ethnicity, social class, and other person-related characteristics (e.g. educational level, employment status, past medical history) that emerged (Sandelowski, 1995b). The aim in using this initial sampling strategy was to collect as much initial data as possible, related to the phenomenon under study, by increasing heterogeneity of the participants (Draucker, Martzolf, Ross, & Rusk, 2007; Patton, 1990). As the study progressed, I continued to sample for diversity with person-related characteristics, especially for race and social class. I was successful in achieving a nearly even distribution of Caucasian and African American women. I would have liked to include women of other races or ethnicities, however was unsuccessful in doing so. I invited one woman of Asian descent to participate, however she and her husband declined. I also screened a few women of Hispanic origin; however they were ineligible because they could not speak English. While I would have liked to sample more intentionally for diversity in social class, employment status, and other personal related characteristics, many of these factors were secondary factors when selecting eligible participants. In fact, many of these factors were determined at the end of the interview when I was collecting the demographic data.

Criterion sampling, another type of selective sampling, was attempted during the study, in which participants were chosen based on a pre-identified set of selection criteria (i.e. ST-segment elevation myocardial infarction versus a non-ST segment elevation myocardial infarction). Distinguishing between these 2 types of myocardial infarctions has been the convention used in other studies that have studied pre-hospital delay to compare potentially different symptom features. However, during the course of the study it became very challenging to find women who had an ST-segment elevation myocardial infarction. In fact, the first participant was the only one that experienced this type of MI. There were other women who had this type of MI, however they were either too acutely ill when I was present for screening or they refused participation into the study. Moreover, I discovered during my screening that more women experienced non-ST segment elevation myocardial infarctions than ST-segment elevation MIs.

These preliminary selective sampling strategies provided a preliminary understanding of the characteristics of the phenomenon in this patient population as it took shape. Although the preliminary themes and relationships between concepts/categories were initially tentative, they began to take shape as data were generated (Charmaz, 2006).

3.6.3 Additional Sampling Strategies as the Study Progressed

As the study progressed theoretical variations began to emerge from data from the initial subjects. For example, after interviewing the first 4 women, the data generated revealed that some women knew what their symptoms meant from the very beginning, while others could not make sense of their symptoms for hours, days, or weeks. This seemed to be related to whether the women had a prior history of cardiac events. Therefore I began to

sample for variation in past medical history and variation in timeliness to seek medical attention.

Another theoretical variation that emerged was how the women entered the health care system. Some women entered without prior medical care, directly through one emergency department. While other women sought care as outpatients, from more than one emergency department, and/or from more than one hospitalization. Although initially in the study, I avoided atypical entry patterns into the hospital, I realized that different patterns of entry into the health care system provided additional insight into the decision making process the women went through. I began to sample for extreme or deviant cases (cases that were initially misdiagnosed or cases that were diagnosed with a confirmed heart attack but opted not to be hospitalized initially).

Another example of theoretical variation was the many of the women at the time of the interview had not yet been given a definitive diagnosis because of symptoms that were potentially confounded by another comorbid condition (e.g. a cardiac arrhythmia or heart failure). Initially I avoided approaching women who had symptoms that were less clear cut or women who had multiple conditions upon hospital admission. However, later in the study I realized that these cases provided an excellent opportunity to explore theoretical variation in how the women made meaning of their experience, especially when their symptoms might represent more than one condition.

All of these examples of theoretical sampling were used to test, elaborate, and refine theoretically derived variation which allowed for testing of relationships and interrelationships of categories (Charmaz, 2006). Thus as sampling continued in the later part of the study, cases were chosen to generate, confirm, or disconfirm theoretical

interpretations. Collectively these techniques for sampling helped develop a conceptually dense theory that was grounded in the data.

3.6.4 Participants in the Study

The sample for the study consisted of 9 women who met the selection criteria and agreed to participate. One participant was re-interviewed; thus there were 10 complete interviews conducted. Sampling ended when saturation was achieved (when generating more data no longer revealed new theoretical insights) (Charmaz, 2006). The women were interviewed from November 2009 until December 2010.

Demographics for the women interviewed are reported in Table 3.1. As shown, the women ranged in age from 49 to 74 years (mean 60.7; *S.D.* 9.0). Four of the women were African American, with the remainder being Caucasian. Five were married, two divorced (one living with a significant other), and two were widowed. Years of formal education ranged from 8 to 14, however most did not have formal education beyond high school ($n = 7$). Two-thirds of the women ($n = 6$) were on a fixed income (retired or on permanent disability). The other three women were hourly workers earning minimum wage. Household income levels were considerably low. Of the seven women that provided income information: 3 households were below \$ 20,000 (1-2 adults in each household), two households between \$ 20-39,000 (2 adults in each household), and two households between \$40-59,000 (1-2 adults in each household). With the exception of one participant, all were insured either through private insurance ($n = 3$), Medicare ($n = 4$), or a combination of the two. The participant who was uninsured had a pending evaluation for financial assistance from the Department of Social Services. At the time of hospitalization she was categorized as “charity care”.

Table 3.2 summarizes the clinical data for the women in the study. While all were admitted for symptoms of ACS, 6 participants had a confirmed myocardial infarction. The remaining 3 were diagnosed with Prinzmetal's angina (a type of ACS), acute heart failure, or a hypertensive urgency. However, all 3 had a history of coronary artery disease and a revascularization procedure done in the past. All participants had known risk factors for heart disease. However there was variation in the number of risk factors present and whether the women had been formally diagnosed and treated for these conditions.

Table 3.1: Demographics of Sample

| Case No. | Pseudonym | Age in Years | Race | Marital Status | Years of Formal Educ. | Employment Status | Annual Household Income (Range) | Number in Household (Other than Self) | Who in House | Insurance Status |
|----------|-----------|--------------|------------------|----------------|-----------------------|------------------------|---------------------------------|---------------------------------------|---------------|----------------------------------|
| 1 | Agnes | 62 | Caucasian | Married | 12 | Employed Full Time | \$ 20,000 - 39,999 | 1 | Spouse | Private |
| 2 | Beverly | 69 | African American | Married | 11 | Unemployed; Disability | < \$20,000 | 1 | Spouse | Medicare |
| 3 | Cecilia | 58 | African American | Widowed | 12 | Unemployed; Disability | < \$20,000 | 5 | Family | Medicare |
| 4 | Deloris | 74 | Caucasian | Widowed | 13 | Retired | \$ 40,000 - 59,999 | 0 | -- | Medicare Private |
| 5 | Eileen | 59 | African American | Married | 14 | Unemployed; Disability | \$ 20,000 - 39,999 | 1 | Spouse | Medicare |
| 6 | Frances | 58 | Caucasian | Married | 14 | Employed Full Time | < \$20,000 | 1 | Spouse | Private |
| 7 | Gloria | 49 | Caucasian | Divorced | 12* | Employed Full Time | Unknown* | 4 | Family | Private |
| 8 | Hazel | 68 | African American | Married | 8 | Retired | Deferred | 1 | Spouse | Medicare |
| 9 | Irene | 49 | Caucasian | Divorced | 12 | Unemployed; Disability | \$ 40,000 - 59,999 | 1 | Signif. Other | Charity Care. Insurance pending; |

Note. All of the women were of non-Hispanic ethnicity. *Case 7 did not complete the demographic form. All of the data for this participant were abstracted from the interview transcript, the medical record, or both except for household income that was unknown.

Table 3.2: Clinical Data for Study Participants

| Case No. | Pseudonym | Results of CK; CK-MB; and Troponin | Date of Symptom Onset | Time of Symptom Onset | Date of Hospital Arrival | Time of Hospital Arrival | Symptom to Door Time | ECG Findings | Discharge Diagnosis | Other Past Medical History |
|----------|-----------|------------------------------------|-----------------------|-----------------------|--------------------------|--------------------------|---|--|-----------------------|---|
| 1 | Agnes | 448, 33, 11.0 (all positive) | 11/18/09 | 22:30 | 11/19/09 | 03:53 | 323 minutes; 5.38 hours | 1 st : normal 2 nd : ST ↑ | STEMI | Tobacco use, Lipids, Family History |
| 2 | Beverly | 129, 1.2, 0.054 (all positive) | 11/23/09 | Unknown; Early a.m. | 11/24/09 | 07:55 | Unknown; over 24 hours. | RBBB; ST ↓ no new changes. | Stable CAD | CABG, DM, HTN, Lipids, RBBB, CHF |
| 3 | Cecilia | 376, 49.2, 7.9 (all positive) | 11/26/09 | 12:30 | 11/26/09 | 14:50 | 140 minutes; 2.33 hours | A Fib 191; ST ↓ | NSTEMI, A Fib | MI, CABG, DM, HTN, Stroke, PE, CHF |
| 4 | Deloris | 76, 0.9, 0.074 (troponin +) | 11/22/09 | Unknown; Early a.m. | 11/22/09 | 06:00* | Unknown; a few hours | ST ↑; ST ↓ | NSTEMI, ACS | CAD (95% RCA), HTN, Lipids, Renal Artery Stenosis, Tobacco Use. |
| 5 | Eileen | 73, 1.0, 0.241 (troponin +) | 10/13/10 | 09:05 | 10/13/10 | 10:30 | 85 minutes; 1.42 hours | Normal | NSTEMI | CAD, MIs, HTN, Lipids, CHF, Chronic Kidney Disease |
| 6 | Frances | 109, 2.8, <0.034 (negative) | 10/11/10 | 08:20 | 10/11/10 | 09:32 | 72 minutes; 1.20 hours | ST ↑; ST ↓; T wave inversion | Prinzmetal's ACS | CAD, MI, HTN, DM, Lipids, Carotid Disease, Renal Artery Stenosis, Tobacco Use. |
| 7 | Gloria | 41, 1.2, 0.41 (negative-hemolyzed) | Mid-October | Unknown | 11/19/10 | Unknown; Early a.m. | Unknown; Acutely worse a few hours prior to arrival | T wave inversion | Acute HF, LV Thrombus | CAD, History of Stent, HTN, Lipids, Peripheral Arterial Disease, Tobacco Use, Breast CA |
| 8 | Hazel | 362, 2.7, <.034 (negative) | Mid-November | Unknown | 12/10/10 | 17:00 | Unknown | T wave inversion | HTN Urgency | Many MIs, CABG, HTN, Lipids, Peripheral Arterial Disease, COPD |

| | | | | | | | | | | |
|---|-------|---------------------------------------|----------|-------|----------|--------|-------------------------------|--------|--------|--|
| 9 | Irene | 568, 22.7, 4.380 (all positive) | 12/18/10 | 06:30 | 12/18/10 | 10:00* | 210 minutes; 3.50 hours | Normal | NSTEMI | CABG, HTN, DM, Lipids, Strokes, COPD, Obstructive Sleep Apnea |
|---|-------|---------------------------------------|----------|-------|----------|--------|-------------------------------|--------|--------|--|

Note. *Approximate times based on patient recall of general time of symptom onset. Medical record did not indicate exact time of symptom onset. ACS = acute coronary syndrome, A fib = atrial fibrillation, CA = cancer, CABG = coronary artery bypass graft, CAD = coronary artery disease, CHF = chronic heart failure, CK = creatine kinase, CK-MB = creatine kinase-MB fraction, COPD = chronic obstructive pulmonary disease, DM = diabetes mellitus, ECG = electrocardiogram, HTN = hypertension, LV = left ventricle, MI = myocardial infarction, NSTEMI = non-ST segment elevation myocardial infarction, PE = pulmonary embolus, RBBB = right bundle branch block, RCA = right coronary artery, ST = ST segment, STEMI = ST segment elevation myocardial infarction.

3.7 Data Collection Methods

In-depth semi-structured interviews were used as the primary source of data. An interview guide, developed in advance of data collection, was used to provide an initial structure to the process (See Appendix A). The guide was not used as a verbatim script; instead I reviewed the guide prior to entering the interview setting and also towards the completion of the interview to see if the general areas from the guide were covered in the interview. Through-out the interview process I strived to maintain a fine-line between actively listening to what the participant wanted to discuss and redirecting the conversation to more relevant aspects of the situation, without being too intrusive (Kvale & Brinkmann, 2009).

As the study progressed I realized that the interviews conducted in the participant's homes seemed to be more relaxed – both from the participant's and my perspective. There were fewer interruptions and the women seemed to provide more reflective responses. As the study progressed, although I continued to provide the participants with the choice of location for the interview, I was more cognizant that place and timing made a difference in the quality of the data collected for some participants. Therefore for the subsequent interviews conducted in the hospital, I tried to schedule them for the evening hours that were more conducive to fewer interruptions by unexpected visitors, by the health care team, and/or from food service employees.

The interviews began with a broad open-ended question introducing the topic and inviting the participant to tell their story. An example of an opening statement to participants was: "I would like to understand more about what happens when women experience cardiac symptoms and what they do when symptoms occur – especially in terms of seeking care".

Follow-up questions were used to learn more about the initial symptom experience and whether the participant was able to construct a symptom pattern to assess and interpret the meaning of the symptoms. The follow-up questions served as a means to allow the participant elaborate on their individual experience (Kvale & Brinkmann, 2009). An example of a follow-up question was: “You said you knew exactly when the symptoms came on. Take me back to that moment, what did it feel like and what went through your mind?”

Probing questions were used to ask the participant to follow-up on responses or have the participant go in more depth - beyond their initial elaboration (Kvale & Brinkmann, 2009). As the interviews progressed, I probed into what thoughts the participant had regarding the other things going on in your life at the time and how this influenced their decision to seek care. For example, one of the participants said that she had “things to do” and couldn’t leave home despite having symptoms. I asked her to tell me more about the “things”.

In addition, *specifying questions* were used to obtain specific information related to whatever the participant had discussed (usually related to timing of particular events). On occasion *direct questioning* was used (e.g. was this different from the time before?) as well as *indirect questioning* (e.g. “Some women said they put the symptoms on the “back burner” because they had things to do, does this apply to your situation?”) to solicit more information (Kvale & Brinkmann, 2009). Towards the end of the interview, *clarifying questions* and *interpreting questions* were used to validate my initial understanding of what the participant’s responses were or to follow-up on inconsistencies in the interview (Kvale & Brinkmann, 2009). When I asked these questions, the participants answered with brief responses, generally saying “yes, that’s right” or “you’ve got it”. At the end of the interview,

I tried to ask a closing question about whether there was anything they wanted to tell me that I did not ask about. Most participants said no. However a few participants restated key points from the interview that were important to them. For example, at least two participants reiterated that the most troubling aspect of the whole experience was not having a definitive diagnosis.

3.8 Procedure

The procedure for data collection was dependent on the results of the incoming data and the ongoing analysis. This iterative process unfolded as the study progresses. Design flexibility required me to remain open, as well as pragmatic, with methodological decisions made as the study proceeded (Patton, 1990).

First I identified potential participants based on the sampling procedure and setting discussed earlier. A limited waiver of HIPAA authorization was requested from the Institutional Review Board (which also serves as the privacy board for UNC-Chapel Hill) to allow access to medical record information needed to review eligibility criteria and contact potential subjects. I reviewed the medical records of potential subjects to see if they qualified for the study by reviewing findings from their 12 Lead ECG, cardiac enzymes, or cardiac catheterization findings, if applicable, and documentation of the time of symptom onset until hospital arrival. If the woman qualified, I confirmed with the nurse that she was hemodynamically stable and pain free before inviting her to participate in the study. If the woman agreed to participate, she signed the consent form for the study (See Appendix B) and the HIPAA Authorization for Use and Disclosure of Health Information for Research Purposes consent form (See Appendix C). If a woman did not agree to participate, then the

data obtained to confirm eligibility was discarded in a confidential recycling bin on the clinical unit as per the hospital protocol.

At the time of consent, participants were given the option of being interviewed while still in the hospital or at a mutually convenient location within 2 weeks of hospital discharge.

Participants were also asked in advance if they were willing to be available for one or more follow-up interviews, if needed, for clarification of earlier responses. If a subsequent interview was requested, the participant was contacted at the phone number provided during the consent process. Follow-up interviews were utilized with selected participants to fill in gaps remaining from the initial interview and to pursue theoretical leads. More directive questioning was used during the subsequent interviews.

The one-on-one interviews with the participants lasted from 33 to 66 minutes (mean of 46.4 minutes; *S.D.* 9.4). The progression of the interview varied according to follow-up questions developed spontaneously from the initial exploratory questions (as described in the previous section). Demographic data were collected at the end of the interview to enhance interpretation of the interview material. Appendix D contains the demographic and clinical data collection form.

All 9 participants were approached and consented while patients on 3 Anderson. While some eligible subjects were identified while still in critical care, most were not hemodynamically stable at the time. Thus, they were introduced to the study once they transferred out to the non-intensive care setting.

Six of the 10 interviews were conducted in the hospital; half of those in the evening after visiting hours were over. Interviews were conducted in a private setting. If the patient was assigned to a semi-private, then a private conference room on the unit was used for the

interview. During the first interview, the participants spouse entered the room approximately 30 minutes into the interview. I halted the interview, cutting off the tape recorder, while the participant explained to her husband that she was being interviewed as part of a study. I offered to come back another time. However, she preferred to continue with the interview with her husband present, which he did not object to. At that point, I resumed the taped interview, directing my questions to the participant. For the most part the participant answered the questions on her own, with the husband interjecting added information from his perspective when she turned to him.

The remaining 3 interviews were conducted in the participants' homes, which was their preference. All of the home interviews were conducted when no one else was present. The last interview, a follow-up interview from an earlier participant, was conducted over the telephone, which was at the request of the participant.

3.9 Potential Source of Bias with Data Collection Procedure

During the interviews, I was mindful that presenting myself as a nurse/health care provider would have implications to data obtained. Based on the philosophy of symbolic interactionism, the interaction between the interviewer (me) and interviewee (the woman) influences the character and the content of the interaction and thus the data obtained from the interview (Rubin, & Rubin, 2005; Charmaz, 2006). Furthermore the power and professional status (me as the health care provider conducting interviews in the hospital setting) may affect the direction and content of the interview (Charmaz, 2006). The women interviewed may have assessed the situation, appraised me as the interviewer (health care provider) and acted on that information to share socially desirable answers based on how they "should have assessed their symptoms" and what they "should have done" in the eyes of me as the health

care provider (Charmaz, 2006). I was sensitive to these potential biases and tried to minimize them by projecting a non-judgmental attitude in the course of the interview.

3.10 Data Management

Each interview was digitally audio-recorded. Brief field notes were made before, during (in a non-discrete manner) and after the interviews to make note of particularly important or interesting points thought to be relevant at the time. The digital recordings of all interviews were downloaded and transcribed verbatim into a Microsoft Word document, excluding all names of individuals to maintain confidentiality. Each participant was assigned a specific study code and the code was used to link baseline demographic information to the initial interview responses (Time 1) and responses from the follow-up interview (Time 2) for the one participant interviewed twice. A master log of study participants' names and study codes was kept in a secure file cabinet in the investigator's locked office. Pseudonyms (made up first names; no last names) were used to protect the identity of the participants. The original downloaded digital audio-recordings were stored on the investigator's personal computer with pass word protection until the completion of the study.

3.11 Data Preparation, Analysis, and Interpretation

In the following section I will describe how the data were analyzed realizing that the process was not always linear. While I describe these as separate processes, data collection, data analysis, and data interpretation were often intertwined (Sandelowski, 1995b). The sections below describes (a) the units of analysis for the study, (b) the process of data preparation which precedes analysis (transcribing the data, making a summary sheet and importing the data into a software program for analysis), (c) the process of coding, and (d) potential coding schemes that may be used.

3.11.1 Units of Analysis

The units of analysis for this study that were used for comparison were the (1) descriptions of the symptom experience by the women who experienced ACS symptoms, (2) what was going through their mind as they made meaning of the symptoms, (3) what they were doing at the time symptoms started and whether that changed during the course of symptoms, (4) the person/actions/emotions involved in the experience, and (5) the salient points in the decision-making process. In the tradition of GT methodology I used the text from verbatim transcripts for constant comparison coding during the discovery phase of the process to identify initial themes. For each interview my analysis focused on what the women said about their individual experiences and then moved onward to understanding the larger shared experience/meaning(s).

3.11.2 Data Preparation

Upon completion of each interview, I listened to the audio recordings to get a general gestalt of the interview. Data preparation then began by converting the raw data, the spoken recorded voices of the woman participants, to the written (typed) format. The original digital recordings were then transcribed verbatim into a Microsoft Word document. A color coded font was used initially to indicate who was speaking, which provided me with a sense of the amount of time the participants spoke, compared to me as the researcher. Once the transcription was completed, I cross-checked the document by listening to the audiotapes to ensure accuracy. The transcripts ranged from 362 to 671 lines of data (mean of 535 lines; *S.D.* 105.6). The last two interviews were the most conceptually dense and subsequently two of the longer transcripts (634 and 671 lines, respectively).

After reviewing the transcription, a single page contact (summary) sheet for each interview was produced which included descriptive information about the participant, an overview synopsis of the interview, what the main issues were that struck me after reading the transcript, and anything else that struck me as salient, interesting, illuminating or important about the transcript (Miles & Huberman, 1994). In addition a note was made of any remaining questions I had for the participant (as in the case of a follow-up interview or used for consideration when moving forward with other participant interviews). Each summary sheet also included the date the summary sheet was made, the participant's study number, the contact date, the time period (initial or follow-up) and the location of the interview. The time required for production of each transcript, transcript review, and completion of each summary sheet ranged from approximately 1 to 2 weeks per interview.

After producing the summary sheets, I then imported the electronic transcripts into a qualitative software program (N-Vivo version 8) to organize the data for analysis.

Advantages of using computer programs for analysis included the ability to organize codes, easy access to memos generated during the coding process, the ability to move materials around for re-coding purposes while providing transparency in the process to trace the analytical process I used (Corbin & Strauss, 2008). Once in the computer software program, I then coded one transcript at a time; then used subsequent transcripts to contrast the codes and make changes to the codes iteratively.

3.11.3 Analytical Strategies Used

Theory generation, a major aspect of MGT, started much like traditional GT, with inductive coding. Inductive coding (data-derived coding) was used initially to embrace an open-minded, creative approach that was as free as possible from pre-existing concepts or

categories in an effort to see what new information could be discovered from the data. This initial coding served as starting place, without a committed deductive approach that might stifle new directions (Miles & Huberman, 1994). These codes primarily consisted of assigning descriptive (factual) codes and topical codes with very little interpretation to short passages or “chunks” of data in the transcripts (coding that is “data near”) (Sandelowski, 1995). In using the N-Vivo software, I coded more broadly to avoid losing context or leaving out information; at that early point I was not sure what was relevant or not. I also coded sections of text with more than one code to allow for overlap when it was not clear which code was more fitting. As I used the N-Vivo software, I created short descriptors for each inductively generated code. These descriptors included definitions of the code, the origin, the importance, examples, and anti-examples of each code. I was careful to not code data for more than 1 hour (or so) at a time to avoid fatigue (and lose focus) (Miles and Huberman, 1994).

Conceptual refinement, the next step in theory generation using MGT, involved actively working with data as the coding process moved into a more interpretive phase. At this time I was more selective as the provisional codes became inadequate for explaining particular segments of the data. I began to use process oriented coding, making use of “gerunds” (codes that ended with –ing). Coding with gerunds, using verbs instead of nouns provided a sense of action and sequence to the experience (although they did not proscribe a particular order to the actions) (Charmaz, 2006).

The next phase of data analysis utilized a combined inductive and deductive approach. Theoretical concepts from existing theory (the Theory of Uncertainty) were used constructively to challenge the evolving concepts to ask what the phenomenon consisted of,

where it existed, what the contextual influences of the phenomenon were, what the purpose of the phenomenon was, how it functioned, what the origin of the phenomenon was, and what language participants used when the women spoke about it (Goldkuhl & Cronholm, 2010). Frequent meetings (weekly for approximately 1 hour) with my committee chair and frequent referral to the original data (audio data and/or transcripts) allowed for evolving, more interpretive, concepts to be generated and critically analyzed. We discussed specific cases and reviewed original transcripts. Visual displays and matrices were developed for a dual purpose; a way to organize the data as well as to analyze the data. With my committee chair's guidance, existing theory was used to inform theoretical sampling (i.e. sampling on theoretical grounds that emerged during the course of the study) to augment conceptual refinement. However, throughout the process I remained cautious of not allowing the empirical data to be overpowered by the existing theory.

Pattern coding was the next step in MGT that was used (similar to axial coding in traditional GT). Visual displays and graphics were used to conceptualize action patterns of the evolving relationships between concepts and categories to illustrate conditions, actions/interactions, and consequences of the social process under study. A preliminary model was created and critiqued as the data collection and analysis continued. As with conceptual refinement, theoretical sampling was used during pattern coding, to learn more about the relationships between the conditions, causes, antecedents and consequences of the phenomenon under study.

Next theory condensation (similar to selective coding) was used as a concluding stage prior to the grounding procedures for MGT. In using this step I attempted to raise the level of abstraction to a higher level of theorizing, yet didn't mandate that one single core category be

found (as in traditional GT). Theoretical sampling and constant comparison analysis was used during this phase until theoretical saturation was achieved (when no new properties were found).

Explicit grounding, the third working procedure used in MGT, consisted of theoretical grounding, empirical grounding, and internal grounding. These three types of grounding processes were used for analysis and control of validity of the evolving theory (Goldkuhl & Cronholm (2003; 2010). In using theoretical grounding, also known as theoretical matching, I asked the question of whether the evolving theory was in accordance with pre-existing theory. The evolving theory was challenged with the existing theory; primarily a deductively driven process at this stage. As in the theory generation stage, pre-existing theory was used to replace categories in the evolving theory as necessary. Theory matching resulted in modification of the evolving theory and served as a means to explicitly ground (or validate) the developing theory.

A second type of explicit external grounding, empirical grounding, which is the hallmark of traditional GT, was used. Use of this type of grounding asked whether the evolving theory matched the empirical observations. In doing so, an interrogation of empirical data was used to move the process from theory generation to validation of the theory. Negative cases were used to identify the limits of the themes. A comprehensive and systematic check of the theory's empirical validity was performed during this stage of grounding.

The third, and final type of grounding, explicit grounding was used in the study to evaluate theoretical cohesion, or internal grounding of the evolving theory. Visual displays were used to double check the theory for consistency, congruency, and parsimony. My

committee chair was consulted with on a weekly basis on average to help identify potential gaps in the evolving theory.

3.12 Limitations of the Data Analysis Plan

I acknowledge that I am a novice at transcribing digital recordings and using N-Vivo software. As a novice, I remained mindful that computer qualitative analysis software programs were to be used as supportive tools and not to take over or direct the research process (Corbin & Strauss, 2008). Analysis needs to remain research driven and be an evolving process (Sandelowski, 1995b; Corbin & Strauss, 2008).

In addition, the process was very time consuming in order to complete a thorough analysis of the data collected. One needs to allow time in between data collection and analysis sessions to mentally process the information. Time for reflection and reflexivity is essential to see the data for more than the face value. To off-set these limitations, I kept a journal as a record of my thoughts, feelings and actions that were aroused during the analytical process to allow for reflection of the process (Corbin & Strauss, 2008). I viewed this as a starting point for analysis and strived for depth in the analysis as opposed to breadth. My confidence increased as I began the process and received input from my advisors as to ways to improve.

3.12.1 Issues of Trustworthiness

Trustworthiness in qualitative research is evaluated by the credibility, the dependability, and transferability of the findings. Credibility refers to whether the participants' perceptions match the researcher's presentation of them (Bloomberg & Volpe, 2008). Participants were asked open-ended questions initially, in order to allow them to share their story unobtrusively. Data transcription was verbatim. Audio recordings have been

retained during the study to allow for listening to actual participants' words as new discoveries were made. Regular consultations were held with my dissertation committee members to discuss and account for all decisions related to data collection and data analysis procedures. I monitored my own subjective perspective by recording reflective field notes and keeping a journal throughout the research process. As theoretical sampling commenced, memos documented methodological decisions as they occurred. Selection of various analytical strategies from MGT maximized validity. Memo-ing documented each interpretation because interpretations provided a foundation for more inquiry and future decisions (Richards & Morse, 2007).

Dependability refers to whether the researcher can track the processes and procedures used to collect and interpret the data (Bloomberg & Volpe, 2008). Dependability for this study was addressed in many ways. Because the interviews were semi-structured and an understanding of the phenomenon under study developed over time, interview content changed over time. Thus a log of definitions used for coding, memos to track decisions for development of categories, recoding and relabeling categories as themes changed, and frequent referral to the original data were important to remain true to the data. Audio tapes of methodological discussions with my chair were kept to serve as an "audit trail" to provide detailed and thorough explanations of how the data are generated and analyzed.

Transferability refers to the likelihood that the findings from this study will be useful in other settings (Bloomberg & Volpe, 2008). In order to optimize transferability in this study I tried to capture thick-rich descriptions of the experience to use as a vehicle to present a realistic picture of the phenomenon. Secondly, I provided as much detailed information about

the context and background of the situation to allow the reader to judge whether the findings are relevant to a broader context.

3.13 Ethical Aspects of the Study

3.13.1 Protection of Human Subjects

Permission to conduct the study was obtained from the University of North Carolina, Chapel Hill Institutional Review Board.

3.13.2 Benefits and Risks to Participants

Participants may have felt that they benefited from being able to discuss their experience of having cardiac symptoms prior to their hospitalization. There were no anticipated direct benefit to participants. Because delay in seeking care continues to be a significant problem for women with ACS symptoms, this information will be used to inform future interventions aimed at remedying the problem. As an appreciation for their time and effort, participants received an incentive for study participation (a \$ 25 gift card for the initial interview and a \$20 gift card for a follow-up interview if applicable). There were no anticipated risks to participants. The only potential risk was that a participant might experience emotional distress while recounting her experience with cardiac symptoms – which did not occur during the interviews. To minimize this risk, the participants were told in advance that they can stop the interview at any point.

3.14 Limitations of the Study

No research is without limitations. One of the key limitations to this study is that the investigator is a doctoral student and was engaging in qualitative research for the first time. Recognizing this limitation I completed advanced coursework in qualitative inquiry, data collection methods, and data analysis techniques during the course of the study. In addition I

attended hands-on workshops and had one-on-one meetings with consultants using qualitative software programs to increase my proficiency in coding. My coding schemes and theoretical renderings were scrutinized by my dissertation committee to reduce potential bias related to my relative inexperience.

Another limitation was the relatively small sample size (9 participants, 10 interviews). However, the theory development is a continuous process and this work will serve as a foundation to future study. While there are no clearcut guidelines for determining sample size in various types of qualitative studies, Morse (1994) recommends that GT studies include 30 or more interviews, which optimizes the likelihood of theoretical saturation. However, as Sandelowski (1995a) contends, it is not the quantity of interviews that support theoretical claims, but the quality of the information obtained that produces credible results and a new, rich understanding of the phenomenon.

Another limitation, related to how the data are generated, was that some participants were more articulate than others. Moreover interviewing is a learned skill.

3.15 Chapter Summary

In this chapter I have provided a detailed description of the study's methodology and discussed how these plans served as a roadmap moving forward. Flexibility of research design, that was emergent in nature, was emphasized. I have provided rationale for the use of a qualitative research approach and the use of MGT as a methodology to obtain and analyze the data, one that allows for flexibility to use existing theory in interpreting the data. I have described the initial sampling strategies that were used to determine the initial inclusion/exclusion criteria, followed by a description of theoretical sampling that was used later in the study (sampling based on analytical grounds). I have provided information about

sample size, the research setting used, and discussed the procedure used for obtaining interview data. Data management and analysis were discussed, providing examples for ways I sought to ensure optimal credibility, dependability, and transferability of results. Finally I have discussed ethical considerations for the study as well as potential limitations of the study.

It is hoped that findings from this study will be of value in creating a more cohesive theoretical understanding of the problem of prehospital delay. A theoretical rendering of the whether uncertainty of symptomology and uncertainty related to relinquishing role responsibilities serves as a precursor for prehospital delay may yield new avenues for interventions to manage the uncertainties.

Chapter 4: Results

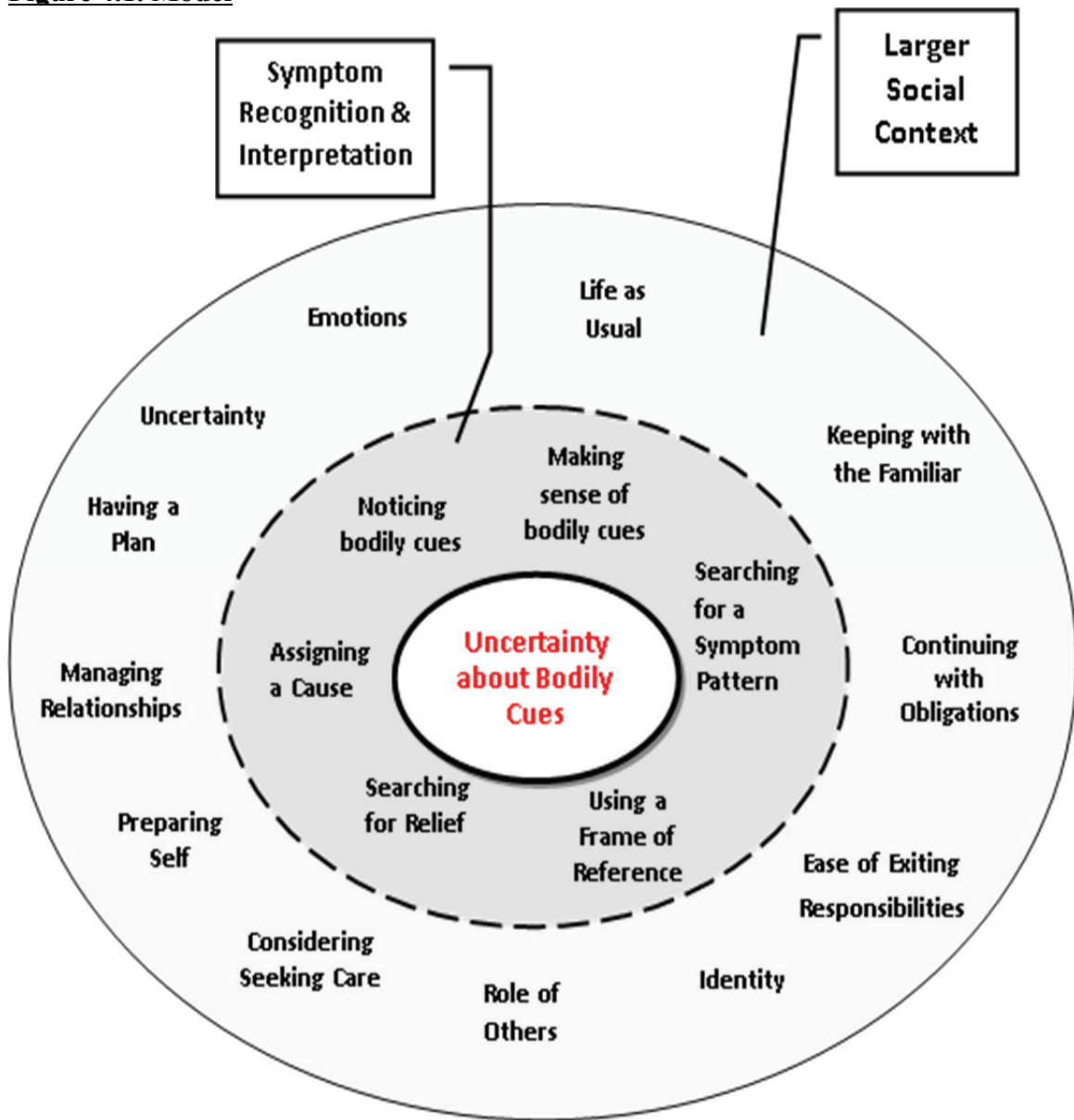
4.1 Introduction

The purpose of this grounded theory study was to explore to what extent and in what forms uncertainty influences women's decisions to seek care for symptoms of acute coronary syndromes (ACS). The specific aim of the study was to explore whether uncertainty of the symptom experience tied to uncertainty of relinquishing role responsibilities is a major precursor to prehospital delay. Semi-structured one-on-one interviews were conducted with 9 women who were hospitalized for symptoms of ACS. Data analysis revealed that all of the women went through a process of making meaning of the symptom experience which informed decisions related to seeking care. A description of the final sample, the context in which the women searched for meaning of the experience, the related social processes, and the emergent theory are described in this chapter.

4.2 Overarching Theme for the Study

The overarching theme that emerged from the interview data was that the women were searching for meaning behind the symptoms in an attempt to recognize them as something that made sense to them. This search for meaning was embedded in a larger social context as an attempt to manage relationships and ongoing social obligations in their life as they tried to discern what was happening to them.

Figure 4.1. Model



The model above illustrates the process of symptom recognition and interpretation (inner circle) and the importance of the larger social context (outer circle). The core of the inner most circle, uncertainty about bodily cues, provides the initial stimulus for the women's search for meaning of the illness-related cues. Within each of the larger circles several categories emerged from the qualitative data. The categories of the inner circle include strategies the women used in their search for meaning. These strategies include noticing the

bodily cues, making sense of the bodily cues, searching for a symptom pattern, using a frame of reference, searching for relief, and assigning a cause for the symptoms. Not every woman used all the strategies. Furthermore, there was no proscribed order for use of the various strategies. How and when each strategy was used for the women differed.

The categories of the outer circle (the larger social context) include life as usual, keeping with the familiar, continuing with obligations, ease of exiting responsibilities, identity, the role of others, considering seeking care, preparing self, managing relationships, having a plan, uncertainty, and emotions. These categories were examples of socio-contextual factors that influenced the symptom recognition and symptom interpretation (inner circle) which shaped decisions towards seeking care. Not every category was relevant to each of the women's situation. The amount of influence and how it impacted decisions moving forward differed among the participants.

The membrane between the two circles is free-flowing and permeable. At times symptom recognition and interpretation (inner circle) takes the forefront in the search for meaning. However, in other situations, the larger social context (outer circle) is used to search for meaning in an attempt to gain more information about the bodily cues.

4.3 A Search for Meaning of the Symptoms

A major finding of the study was that the women interviewed put great effort to recognize and classify symptoms into a consistent symptom pattern that made sense to them, which influenced their subsequent decision making. For all of the women in the study, formulating a consistent coherent symptom pattern did not occur at a single point in time, but rather was part of an unfolding process that took time, energy, and resources to complete. Their search for meaning of their symptoms did not center around one single piece of

information. The information (or illness related stimuli/cues) accumulated over time which helped shape and reshape the meaning of the experience for the women. Several influential factors shaped their thoughts during this search for meaning (see model). Key aspects of this process were described by the women interviewed as they came to make meaning of the illness situation.

The first step in the process of forming a symptom pattern is recognition of bodily cues. Bodily cues serve as a signal that something within the body has changed. In order to be noticeable, these cues need to be adequately intense, consistent in presentation, sufficiently repetitive, and distinguishable from everyday bodily aches and pain. I will first discuss the group of women whose symptoms were not noticeable from the onset.

4.4 Group A: Noticing Bodily Cues Over Time

For nearly half of the women ($n=4$) in the study, the beginning of the symptom course was not immediately noticeable. For discussion purposes, this group of women will henceforth be referred to as “Group A”. For those who did not immediately recognize a change, symptoms were less intense, less prominent, had decreased frequency and duration, and were indistinguishable from their usual bodily aches – thus not meeting the criteria discussed above. Initial symptoms were mild and vague in nature, intermittent, often spread out over days or weeks, ever-changing, and often mimicked other bodily conditions. Two of the women stated in hindsight that the early bodily cues were “not so unusual”. During the course of the interview, these women began to recognize that symptoms actually started much earlier than they had initially reported. The other women in this group noted that the symptoms were “peculiar”, but not initially concerning to them. Over time, the uncertainty of

the symptoms continued, as represented by the core of the inner circle of the model, served as an impetus for their trying to make sense of the bodily cues.

Irene, a 49 year old Caucasian female who was disabled from a prior heart attack and stroke, made reference to the indistinguishability of the initial symptoms from her usual aches and pains. She talked about how she tried to make sense of the bodily cues:

I have a lot of medical problems. I have a lot of pain and other issues. On an average day, I was ok, you know, nothing unusual. Not really with my heart. Up until then, it was just, I don't know, it was just funny that something wasn't right...that day.

Irene serves as an exemplar for the descriptions given by the women who could not differentiate between familiar sensations from something changing within their body. As Irene put it in the interview:

My symptoms are kinda weird. I don't have really..strong symptoms. I just have this feeling. ...(..)..Well at that time it really didn't dawn on me that it was something new, you know. (..). It was not just all of a sudden – one thing.

For Irene, the early symptoms were mild in nature, nonspecific, intermittent, and very gradual in onset. It was only in hindsight that Irene realized this may have been the start of the event.

Likewise, Gloria, a 49 year old Caucasian factory worker, was unable to recall precisely when her symptoms began. She spoke to the insidious nature of the symptom onset of her most recent cardiac condition.

It probably started like a few months ago. I had started coughing a lot.

For Gloria, the emerging intermittent symptoms that were non-specific in nature, went undetected for weeks. The bodily cues, which lacked quality and definition, remained relatively unimportant at the time.

Another participant, Deloris, had difficulty describing the early symptoms and used metaphors to detail her first-hand experience. Deloris, a 74 year old Caucasian female who was retired, talked about her symptoms as if they had a life of their own:

I just kinda felt strange ...And I had a hard time explaining to everybody that it started in my back. And it was down the lower part of my back and would creep up to my shoulders. (...)..Later on ..(..)..it was only down one arm. But when it first started ...the pain wasn't as bad as it got to the point where it was....(..)..I didn't know (what it was).but I hadn't been bothered with it. I really wasn't that concerned with it....(..)..at that time.

For Deloris, who had no prior history of heart problems, the strangeness, the mild intensity, and the inconsistency of the bodily cues, made the cues less prominent for her. Thus she did not focus on them. The non-specificity of her bodily cues prevented her from recognizing and interpreting the bodily cues as a sign of illness.

The fourth participant, Cecilia, a 58 year old African American female who was disabled from a prior heart attack and stroke, recognized a change in her body as a sign of illness despite the vagueness of her symptoms. In some ways, she fits the other women that did not have definable symptoms. However, she differed from the other women in this group because her symptoms were definable as a sign of illness, although not specific to heart disease, at least initially. Even though she could not label a symptom pattern, she knew she needed care. In Cecilia's words, she said:

I was sick all last week. I felt it coming on all week, a week ahead of time. And I told my brother. And he said, how you knowed it? I said, I know my feelings. I said, I am going to the hospital. I don't know which day I'm going to the hospital, but I'm going to the hospital one of these days.

In discussing how she felt the week prior to her heart attack, she could not specify what her initial symptoms were or exactly when they came on; just that she knew something was “coming on” and talked to her brother about it:

I said, I am going to the hospital.... (talking with her brother) ...you don't have to keep fixing my food for a long time now. Cause, I'm going to the hospital.

She talked about knowing that she would end up in the hospital before that weekend was up.

She noticed a change from her usual state. She felt her symptoms building up and knew that it was a sign of "sickness" and that sickness requires care.

A fifth participant, Agnes, also had early symptoms that were mild in intensity, intermittent, and mimicked other bodily conditions. She too had difficulty assigning a specific label to her symptoms because of uncertainty about her bodily cues (inner-most circle of the model). However she entered the process in a different way. Unlike the other 4 women discussed, she was able to note with certainty the exact time of symptom onset due to the specificity of her symptom quality (*burning* in her throat). Agnes downplayed her initial symptoms while she was at work. She recognized her symptoms as being new and unusual for her, but did not know what they meant.

All five of the women in Group A had symptom courses that were intermittent, ever-changing, and drawn out over time. Eventually, as the symptoms continued, the five women recognized their presence and tried to interpret them using the various strategies from the inner circle of the model.

4.4.1 Forming a Symptom Pattern

One way the women tried to interpret the bodily cues was to link the symptoms together in an attempt to identify a symptom pattern. However, recognizing and interpreting the meaning of symptoms does not occur in one moment in time; it is a process that fluctuates over time (Mishel, 1988).

In order to have consistency sufficient for recognizing a relationship between symptoms, bodily cues need to be reliably present, predictable, and interrelated enough to be

united. Classifying a set of symptoms into a coherent pattern allows one to assign a name or a label to the situation, which then enables the person and the health care system to begin the process towards getting a diagnosis. Once the constellation of symptoms is frequent enough to be labeled, the person experiencing the symptoms has enough information to communicate their presence to the health care provider (which helps them initiate care). If the symptoms are not consistent enough to form a pattern, the individual has difficulty explaining/describing the symptoms to themselves or others; thus becomes one barrier in communicating needs to others.

The work to form a symptom pattern unfolds over time as additional information about bodily cues is sought to establish the links to form the relationships between the cues. For four women, noticing and making sense of symptoms took more hours, days or weeks.

Deloris talked about how her symptoms continued over time:

I kept having these strange (emphasis added) feelings that would last about five or six minutes. It would start in the back....go up to the shoulders....(and) run down the left arm, sometimes both arms. ..I never felt any real pressure in the chestThat was real strange because it was in both arms...Later on it would get to the point that it was only down one arm. But when it first started it was almost like it was down both arms. And eventually it would go away. ...About 4 or 5 minutes. The pain wasn't as bad as it got to the point where it was.

When I started having the main symptoms. I felt like I was going to get sick on my stomach. I was nauseated. I was dizzy. And then .. in about 5 or 6 minutes, it would pass.

Deloris differentiated the “early symptoms” from the “the main symptoms”, when the number of symptoms began to increase, and the location changed. As symptoms began to occur more frequently, Deloris monitored her symptoms more closely, in order to interpret and make sense of the bodily cues (inner circle of the model). Although the symptoms would only last 4-5 minutes, Deloris described how they “eventually” went away. As symptoms

continued over the subsequent 6 weeks, Deloris began to recognize a relationship among the symptom features based on the starting location (her back), radiation of symptoms (into her arms – initially both arms, later in only one arm), and the duration (~ 5 minutes). Although Deloris did not know the cause of the symptoms or what brought them on, she could predict their duration. Knowing that the symptoms lasted approximately 5 minutes helped Deloris manage the uncertainty of having no definitive diagnosis. Over time, however, her symptom course changed again. Deloris spoke of how unsettling this was:

I started waking up at night. Maybe 2-3 times at night I could be doing absolutely nothing but pulling the bed covers back. Uh, trying to get up to go to the bathroom... They (her doctor) were saying maybe over exertion was bringing it on. Well I wasn't exerting myself one iota to try to get up to go to the bathroom. Or pulling the covers back. They (her symptoms) were getting worse and more frequent.

Over time, she began noting other features of her symptom course, such as what brought on the symptoms. The changes in the symptom course (waking her up at night, occurring more frequently within the same 24 hours, and with increased intensity) began to challenge the stability of the relationship of symptoms that Deloris had recognized. Deloris began to monitor herself more closely for more cues (inner circle). She needed more information to form a consistent coherent symptom pattern. She talked about her experience one night when she awoke with symptoms:

Maybe they started about 1:00 o'clock, and another one around 3 and another around 6. ...I was sleeping in between them...I looked at the clock to see how long it had been, and to see if I could take another nitroglycerin. That was the only reason I would be looking at the clock. And then after that second one, (asking herself) what was I going to do if I had to have a third one.

She watched the clock when symptoms occurred to see how long they lasted and to determine when she could take another nitroglycerin tablet. Because the relationships that she had formed between the symptoms were provisional, she was uncertain about what to do

if she needed to take a third nitroglycerin tablet. The unpredictability of the limits of her symptom course was a central part of her uncertainty.

Similar to Deloris, Agnes attempted to make sense of her bodily cues over time. Agnes, a 62 year old hourly worker with no past medical history, first tried to discern if her bodily sensations were a transient condition as opposed to a sign of serious illness. She embraced a benign condition (indigestion) readily, like other participants who seemed to dismiss early symptoms, and attempted a quick everyday remedy to modify her symptoms without really understanding them. Thus early on she did not search for alternative explanations for the bodily cues.

The only thing that bothered me then was the burning in the throat....I just thought maybe it was indigestion or something...and maybe it would get better. I put a mint in my mouth and thought that might help a bit. But it didn't.

When information about the ineffectiveness of a temporary relieving agent (e.g. the mint) became available, like the others discussed, Agnes began searching for other explanations for the symptoms. There was not a strong connection between her symptoms and the temporary label she had placed on them. She needed more information to re-assess her bodily cues. Thus as with Deloris, early monitoring for Agnes moved to deciphering which bodily cues were present and which were absent. She monitored the symptom onset (sudden), number of associated symptoms (noted only one location initially- throat), the quality (burning), the intensity (not "bad"), and the duration (infrequent and intermittent). During this time, she compared her current symptoms with those of familiar bodily conditions (indigestion). This information allowed her to note similarities and differences.

I've had indigestion before, maybe a few times, but I've never had anything like this, of that burning. Like all the way down in your throat. Never had that before.... But see it won't be bad. It's just happened a time or two... And I wanted really hurting in my chest though.

Agnes tried to link the symptoms together to identify with enough consistency a symptom pattern (inner circle). However, this was challenging because the symptoms were low in number, infrequent, inconsistent and unreliable in presentation, and of low intensity. The element of novelty also produced a significant challenge for her as she had never had symptoms like this before. These features made it difficult for Agnes to find relationships between the symptom features to form a unified symptom pattern.

Similar to Deloris and Agnes, Gloria, talked about how her early symptoms changed over time. As her symptoms became more prominent, she started explaining the symptoms to herself:

I had started coughing a lot and I thought... I might have a touch of bronchitis. I had not had a chance to get the flu shot yet this year. I have smoked for years. I thought at one time, well maybe I'm just getting a smoker's cough. But the cough was just getting really bad, it was dry hacking. It was very, I don't know how to say it. I would have to get up out of bed, I was not getting air into my lungs and stuff. But it started out with a cough, and then, as the weeks went on I kept coughing, but I started feeling weaker. My body just felt weak. I felt like I won't, I don't know how to say, you don't get enough water to drink, you don't get enough food to eat (chuckles). .. your body just won't getting something it was supposed to be getting from somewhere. I didn't know if it was oxygen or food.(...) the symptoms of coughing was continuing to get worse. I was just aching and hurting all over so much.

Like Agnes, Gloria initially dismissed her early symptoms for weeks as benign conditions, such as a cold, the flu, or a smoker's cough. Explaining away symptoms to benign conditions seemed logical and convincing to Gloria at the time. These causes were less threatening and did not require immediate action. However, as with Deloris and Agnes, Gloria had difficulty interpreting what her symptoms meant as the symptoms were nonspecific and ever-changing. Over time the intensity and duration of the symptoms changed, causing her to notice that something was "different" in her body. She recognized a number of symptoms (a non-productive cough, air hunger, generalized weakness, and generalized bodily aches), that

seemed to be related, signifying “something” was different. Although she “knew” her symptoms were becoming something more than a benign condition, she was at odds with herself in how to connect the “parts”. Although she could not assign a cause to the symptoms, she now labeled them to be a sign of “badness”.

I just realized, I knew something, that I had more than just a cold or the average cough. And I was hurting really bad in my back.

Gloria did not have enough information in any one aspect of the symptom course to assign a specific label to the situation. Thus she needed more information to interpret the symptoms.

As symptoms intensified over time, Irene remained puzzled over what was happening to her. Irene dismissed her symptoms for 3 days prior to her heart attack. In trying to make sense of their symptoms, Irene tried to connect aspects of her symptom course (number of symptoms, quality, location, timing, intensity, and level of distress) to form a symptom pattern (inner circle). As she tried to interpret the symptoms, she compared her ongoing, ever-changing symptoms with those of other less life-threatening conditions (indigestion and pneumonia). The variation of symptom quality combined with an inconsistent location (moving into other body parts) created an ambiguous symptom profile.

Like Agnes and Gloria, Irene tried to explain the symptoms to herself. She recalled that it was not unusual for her to be short of breath. As her shortness of breath worsened, she was then able to differentiate her familiar sensations of dyspnea from the new symptoms. However, she remained perplexed about the meaning of these symptoms. Similar to Deloris, Irene compared early symptoms with those that came later in the course. However, Irene tried another strategy which was to understand her symptom course by reviewing in her mind the order in which particular symptoms “came into play”. Her attempt to sequence the appearance of various symptoms was her attempt to connect the symptom features. She

described how the symptoms progressed from flu-like symptoms, into a bad cough, then shortness of breath, followed by chest discomfort:

It was just the shortness of breath that had started. The chest part hadn't come in to play that time. I'm thinking what in the world are you breathing ... You never had any breath, but not this bad. I've had pneumonia- it won't that bad. But pneumonia was all coughing. And there just won't any coughing. It's just like (she took a deep breath in and out) out of breath. Gasping for breath...(.)...I was (also) having some chest pains that kind of resembled an indigestion. Little bit. The only difference in them... was it was in the right side of my chest and arm. Um, it started off kind of – like you know normal indigestion type. Not real, real painful. Just there. Something you knew that was there, but shouldn't be.

Even after being hospitalized, Irene continued in her attempt to link the varied symptoms into a meaningful whole to interpret what happened to her. Irene attempted to associate twitching of her extremities and other body parts to her heart condition.

Another thing that happened ...(..).. I had a couple of nights of really severe twitching to the point where I would sleep for a few minutes and wake up.... twitching so violently that it woke me up. ... I've always had a restless leg thing, you know. This was much worse, because it wasn't just my legs, it was my arms and everything....That's got to have something to do with the heart, I guess. I don't know.

She compared and contrasted her past symptoms of various ailments to her recent symptoms in order to find a relationship between all the bodily cues (inner circle). However, Irene remained uncertain of how or if these symptoms fit together. For Irene, the totality of the symptom experience, which went on for days, did not add up.

The number of symptoms were piling up. And they weren't really, you know, adding up to me. It's a big old jig saw puzzle. The whole symptom thing .. it didn't add up. It's not right.

Because Irene and the other women in this group could not link their symptoms into a meaningful whole, they used other strategies to make sense of the bodily cues.

4.4.2 Using a Frame of Reference

Past experiences were used as a frame of reference (inner circle) as a strategy to provide more information about their bodily cues in an attempt to form a symptom pattern. A frame of reference may include experiential (personal) knowledge, knowledge gained from other's experiences (by discussion or by observation), and/or knowledge obtained through instructional means. Using a frame of reference as a benchmark for comparison allows one to judge what was happening in their current situation. Whether a frame of reference is useful (or not) and how useful it is varies among individuals. Moreover, the accuracy of information matters. Receiving inaccurate information may distort symptom interpretation.

Four of the five women in Group A used a frame of reference to provide information in their search to form a symptom pattern. Some of the women called upon their frame of reference (inner circle) more than once during their search for meaning, especially if they had ever-changing symptoms. Some of the women also used past experiences of more than one person in their life (outer circle). Regardless of whether there was congruence or not with the past experience(s), the comparison of past and present provided the women with additional information.

Two of the five women (Gloria and Irene) used first-hand knowledge as a frame of reference. Two other women (Agnes and Deloris) used the experience of others for social comparisons, as they did not have their own frame of reference. The remaining participant (Cecilia) could not recall the details of her past heart attack; thus could not make use of a prior experience (nothing to compare to her current symptoms).

Gloria provides an example of how a personal frame of reference was used for comparison. In trying to interpret her symptoms, Gloria referred to her past "heart"

symptoms from 6 or 7 years ago. In comparing these two experiences, the current symptoms were different from her past frame of reference. She used a frame of reference in her attempt to assign meaning to the situation. As she tried to interpret her symptoms, she attempted to assign a potential cause (inner circle) for the symptoms. One feature in particular, the “breathing part”, was “the thing” that conflicted the most with the past. For her, it was *both* the totality of the experience *and* the presence of that particular symptom feature that troubled her the most. She explained how this situation was different:

(last time) I had tightness in the front of my chest and pain radiating up and down my left arm. I had felt some discomfort probably 2 or 3 weeks before then. Just, not a lot. But enough to, I noticed it, but I just kinda brushed it off... you know, I’ve just worked that arm too much that night or something. .. I put it on the back burner. ...that was the symptoms of that...(...).. But nothing like this. It was totally different. ..(..).. I was having to prop up more. I just couldn’t get anything in (air). I just couldn’t get any of the congestion out of my chest. And I felt that place in my back.

Gloria had a frame of reference to call upon. Despite the symptoms being different, the comparison provided her with additional information. For Gloria, the location, the quality, the associated symptoms, and the level of distress did not match her past. Thus Gloria provides an example of how, although her frame of reference was not a perfect match for her current experience, it was useful in providing information. Using the frame of reference told her what was different and how it was different. While she still didn’t know how to interpret what was happening to her, it was still helpful.

As the days passed, and her symptoms changed, she called upon her frame of reference again for comparison. This time she recognized similar features to her past heart condition (same location). However, this time the symptoms (chest tightness) had a different meaning (not relating to her heart this time).

I felt the tightness in my chest. You know I had some trouble with my heart in the past. But I wasn't relating the tightness to my chest. I didn't know whether to relate it to my heart or to relate it, you know, bronchitis or something or the flu, or whatever.

Once again, despite having a frame of reference to call upon, Gloria remained uncertain about the meaning of her symptoms.

Deloris provides an example of how the experiences of others can become a "surrogate" frame of reference. Deloris used others (outer circle) to help make meaning of the bodily cues which came late in the symptom course. Since she had no frame of reference of her own, she used others' experiences as social comparisons to help her interpret what was happening to her. She was on a beach trip with her friends a few weeks after the symptoms began. One night when she awoke with the "feelings", she alerted the others to the situation. At this point, she had not assigned a meaning to her symptoms.

I actually was with them when I started having the main symptoms(..). they were sleeping in the other room. I called them. One of the girls had had an actual (emphasis added) heart attack that was with me. But I never felt any real pressure in the chest like she said she had. She had tremendous pressure in the chest. And that happened 2 or 3 times while I was on vacation(..).. I had one the next morning (too)...(..).. And they knew something was wrong the morning that they took me down to the hospital.

Deloris used the experience of a friend who had had an "actual heart attack" to compare to her own symptoms. Deloris viewed her friend as a trusted other and an authority on the subject. Deloris compared the quality and intensity of her own symptoms with those of her friend's. In doing so, she noted that in comparison, her symptoms started in a different location and were less intense. However as the symptoms intensified, the friends played a role in helping Deloris interpret the meaning of the symptoms. Although Deloris and her friends did not know what was causing the symptoms, they recognized and interpreted them as a sign of illness. They knew "something was wrong" and in their view that meant Deloris needed to seek care.

Agnes provides an example, where the information received from others' experiences may distort their own symptom interpretation. Agnes used her husband's experience and knowledge to help her interpret her own symptoms. He offered input from his frame of reference as comparison to his symptoms from a prior heart attack (and acid reflux). Agnes talked about how she involved her husband. She viewed him as an authority.

After getting up for the second time (from bed), I told him I was burning in my throat...That's when he said go getcha some of those Tums and try them. Because my husband had a heart attack. So he sort of knew....I eat some Tum(s)...

Agnes' husband (unexpectedly) joined the interview and described his logic:

I thought she just had indigestion. She didn't have high blood pressure and her cholesterol was normal. I knew that the Tums didn't ease her. I knew that something was wrong. She had took two. I had acid reflux and if you took one and it relieved it.

Unfortunately Agnes' husband was unaware that symptoms may be different for women. Her husband's attempts to make connections between her symptom features, possible causes, and possible relieving measures were unsuccessful due to the mismatch with his past experience. Like Agnes, he was unable to make sense of her situation due use of his situation as a source of comparison. Regrettably, as in cases like this, the inaccurate information gained from others (outer circle) often served as a secondary reinforcement for uncertainty about the bodily cues.

Another example of using the experience of others as a frame of reference is by drawing upon historical observations. Some of the women witnessed others in their family experience a heart attack and referred to those observations when trying to make sense of their own symptoms (inner circle). Agnes provides an example of how the memories of others' experiences provided her with information to use as social comparison. Having no

frame of reference of her own to call upon, the role of others (outer circle) became important for Agnes in her search for meaning (inner circle).

My momma's had a heart attack and my grandma had a heart attack. ..I heard them say the same thing burning down the throat. And I have heard them say hurting in their arms too.

Some of her symptom features matched with the observations of her family members (quality and location). However, early on, the absence of one specific symptom feature (hurting in their arms) prohibited Agnes from being certain enough to make form a symptom pattern. For Agnes, reliance on the memory of these observed experiences may have distorted her current symptom interpretations. Her mother and grandmother were not present to share their first-hand accounts (as in Deloris' situation). Thus she could not ask her relatives if the symptoms evolved over time. Thus Agnes had to rely exclusively on her memory.

Hours later, when Agnes' symptoms started to involve her arms, she was then able to more closely connect her symptoms to the memories of her mother's and grandmother's experiences. Although she was still unable to form a symptom pattern with her own symptoms, this additional "clue" (a new symptom) helped her establish a provisional connection between her family's experience and her own. Agnes recalled her thoughts at the time when her symptoms moved into her arms.

I knew something was wrong..So when I thought of that (arms starting to burn/feel weak) I said I was having a heart attack too. That's what it was.

At this point, Agnes reassessed the situation, labeled the condition as a possible heart attack, and took actions to seek care. It took more information for her to link her symptoms to a more serious cause.

4.4.3 Other Strategies Used to Make Sense of Symptoms

Despite trying to link the symptom features together, with or without a frame of reference for comparison, four of the five women in Group A were still unable to form a symptom pattern. As the women continued to monitor their symptoms in their search for a pattern, they called upon additional strategies from the inner circle of the model. Three of these strategies included searching for relief, assigning a cause, and testing the limits of the symptom course. These strategies were often related to one another, thus occurred in unison.

In order to test the limits of the symptoms, the women looked beyond their immediate symptoms (inner circle) to other aspects in their life (outer circle) to gather additional clues about their situation. As they “tried out” their usual activities (outer circle) they received more information about the boundaries of their symptom course, which was part of the process they went through to form a symptom pattern (inner circle). Closely connected to determining the level of incapacitation was the search for relief of symptoms (inner circle). As symptoms recurred, often with activities of daily living, the women monitored what changes were needed in their lives to help relieve the symptoms. Paradoxically, identification of relieving measures gave the women information about the limits of their symptoms and helped them assign a potential cause to the symptoms (a third strategy) (inner circle).

While the women, at this point, did not completely understand their symptoms, the use of these additional strategies, as “trial and error”, allowed them to obtain more information to help with symptom interpretation. In “trying out” these strategies, the women moved back and forth between focusing on symptom recognition and interpretation (inner circle) and focusing on their “life as usual” (outer circle). There were no discrete boundaries between how and when each of these strategies was used, as some were used concurrently.

A fourth strategy the women used to form a symptom pattern (inner circle) was to involve others (outer circle). Discussing symptoms with others was typically used by this group of women much later in the process. The women sought input from others (outer circle) when symptoms had intensified as a means to reduce the uncertainty of their symptoms (inner circle). In addition to using others as a social comparison (discussed earlier), participants used others to solicit advice and/or to validate thoughts about their symptoms. Some women used others more than once, for more than one purpose, and used more than one mode of communication (in person versus via the telephone).

4.4.4 Testing the Limits of the Symptom Course

To determine the level of incapacitation brought on by the symptoms the women looked beyond their immediate symptoms (inner circle of the model) to their usual life activities (outer circle of the model). In doing so, they discovered to what extent that the symptoms intruded on their life by engaging in their usual daily activities.

Irene serves as an illustration for using some of these strategies (simultaneously) to gather more clues about her symptoms. Irene kept a mental record of what she could/could not do the days before her heart attack. She continued with as many of her usual activities (outer circle) as she was able to, while collecting information about the limits of her symptom course (inner circle). She was very specific and descriptive in her accounts of the days leading to her heart attack. When asked how her breathing a few days prior to her heart attack was, she said her body started “giving me clues”. One of those clues was how her exercise tolerance (walking distance) was declining each day as she attempted to do her usual activities (going to town).

(I was) very, very short of breath. I had to go to town.... normally I could walk let's say, the length of a football field... On Friday, I couldn't walk 100 feet. By Saturday (the day of her heart attack) I couldn't walk 50 feet.

As Irene tried to put the pieces together, she continued to monitor herself, paying attention to specific details. This was one way that she tried to make sense of the bodily cues (inner circle). Irene compared her level of her disability the day before the heart attack (Friday) to her “usual” functional ability (outer circle):

Friday, I was at home... I did my usual sitting on the couch and laying in the bed – that's all I could do. ..(..).. normally I don't have a problem getting up and fixing me something to eat. I was so tired that I really didn't feel like it. So I skipped breakfast. And I thought, aaaah, I'll get up and fix some lunch in a little bit. Lunch came,—naaa and I didn't. Supper time, I just warmed up something that was in the refrigerator. I just really didn't feel like doing anything....for myself..(..). I couldn't really do my usual because I couldn't breathe..(..)..If I can't get up and fix me something to eat, I mean something's wrong. Cause there's nobody else could do it.

Irene recognized, as the day progressed, that she could not get up and prepare her meals. Her inability to keep up with “life as usual” (outer circle) provided her with information about her symptoms. She used this information to re-interpret her symptoms as “something's wrong”. While still not fully understanding her symptoms, she realized that she was worse than her usual state.

Similarly, Gloria, tried to gauge the limits of her symptoms by returning to her life as usual (outer circle). Part of Gloria's attempt to form a symptom pattern (inner circle) was determining what helped relieve the symptoms (inner circle) and how the symptoms impacted her activities (outer circle). Gloria paid attention to how much the symptoms affected her work and how helpful her usual remedies to relieve the symptoms were. With this information she determined that she could not return to work “as usual” because of recurrent symptoms. Even after having a few days off, when Gloria returned to work, she did not feel 100 %. She remembered the specific details of her work schedule (days, then nights,

then days again) and talked about how she planned to modify her home routine in order to relieve her symptoms:

On the 3rd day, I started feeling bad again ..shortness of breath, ..while I was working. I kinda brushed it off. I got a few days before I start back on shift...I'll just try to self-medicate at home and try to get over that. So I done that.... I worked three 12s in a row...had a few days off and said I'm gonna take care of myself this weekend. Drink me some hot tea and lemon juice, just same old.. (..)That following Monday morning I was supposed to return on day light shift. I kinda felt tired....drained of energy. I was just putting (it) off to being sick, my body still hadn't recovered from it. So I got ready to go to work... 4 twelve hour days to go. I said, I can get through these. I will be on my seven day break and be okay.

Gloria initially discounted her symptoms, by trying to brush them off, in order to “rest up” before working three days in a row – as she had done in the past. Like Irene, she recognized that symptoms returned each time when she tried to continue with life as usual (outer circle). Knowledge of what exacerbated the symptoms and what relieved the symptoms (inner circle) provided more information about her symptom course. Although she could not fully interpret the meaning of her symptoms, these clues told her that this was a sign of “sickness”. Normally, when she felt bad, she rested up, used home remedies, and could “recover” by the time she went back on shift. However, continued monitoring told her this time was different.

In her continued search for relief of symptoms (inner circle), Gloria moved away from everyday OTC remedies onto prescription medications. These actions moved her into self-care as she tried to self-manage her symptoms. The process of trying to assign a label to the symptoms was informed by the fact that her “tried-and-tested” relieving factors were ineffective. This information helped her see that this situation was different; this time she could not “shake off” the symptoms in order to continue with life as usual (outer circle).

4.4.5 Searching for Relief

Like Gloria, other women searched for relief as they attempted to gather more information about the symptom course. As they tried various home remedies, they collected more clues about their symptom course and possible causes. For Irene, home remedies also initially consisted of OTC medications due to the perceived insignificance of the symptoms. However, as the symptoms continued, prescription medications were used. Although the symptoms had not yet aligned themselves to be labeled as one specific “thing”, the information about relieving factors helped both women with symptom interpretation.

Irene provides an illustration of how later in the symptom course she moved on to prescription medications (nitroglycerin), a proven remedy for past angina attacks, to see if the symptoms improved. However, the ineffectiveness of the proven therapy (combined with lack of usual side effects from the medication), provided her with additional clues that this situation was *different* from past cardiac events. While she still didn’t know what the symptoms meant, this strategy provided more information. She described her logic:

It was like angina, but not like angina. Because I am used to angina and having to take nitroglycerin. Because I did take nitroglycerin. I know, when I take nitroglycerin -if I don’t get a massive headache soon enough, I know something didn’t happen. And I took the nitro and none of that happened. I had no headache, it didn’t make me feel any better. Nothing.

In trying out proven therapies from her past experience, Irene was using her frame of reference to judge the new situation. She tried the nitroglycerin – just in case it was angina. As with the OTC medication, the ineffectiveness of these relieving factors helped her with symptom interpretation. After recognizing that her symptoms were relieved by the various remedies, she continued her search for more information. She seemed to talk to herself as she explained what went through her mind as she wrestled with interpreting her symptoms:

You start self-diagnosing in your mind. Maybe it's not (your) heart, maybe it's your lungs. I was thinking maybe it's a lung collapsing with the right side instead of the left side. Pain in your arm. I didn't really know what to think.

She tried to link the location of the bodily sensations to the potential organ. At this point she had narrowed it down to heart or lungs as she was beginning to consider a more serious situation. However, she remained uncertain about what these clues meant.

As symptoms progressed over days for the women, becoming more intense, moving into other locations with differing quality, and becoming more disabling the women tried other strategies to make sense of their symptoms.

4.4.6 Using Others

In the first of two telephone conversations Irene had with her friend on the day she had a heart attack, Irene tried to explain why she was so uncertain about the situation. Irene talked to her friend as if they were face-to-face, pointing to a particular location on her body:

I really don't understand what's going on. I have the pain here and it goes to the right. It almost feels like I have a shoulder rub. (Like) I had been playing baseball and throwing and it went out. You know, I threw it out of place. It's kind of similar, but not quite that way. And I don't know any other way to describe it. And she (her friend) said, well, that's kinda weird.

Irene's inability to describe the symptom quality and the uncertainty about the meaning of the atypical symptoms prompted a phone call to her friend. Irene called upon her resources, a trusted other (outer circle), to help her search for meaning (inner circle) of the situation. Her friend confirmed that, to some degree, the symptoms were out of the ordinary. So, while her friend did not offer advice about the situation, she confirmed that there was something unusual about the symptoms.

Irene went on to describe the features of her symptoms to her friend as if she was presenting "evidence" to "rule" something in or out. Irene needed someone else to help

“judge” the facts of the situation to help her come to a conclusion. Irene spoke as if she were negotiating with herself (and her friend) the pros and cons of this being her heart. She did not want to disregard her symptoms based on an atypical radiation pattern (discomfort radiated to right side versus the left).

This pain in my chest. ...it seems to be getting worse. And it's going into my right side, which is strange. Then again, I've seen all these things (that) say don't rule anything out on your own. Because it doesn't mean that it's not, just because it's left side. You know, I mean most people have their symptoms on their left side...Even though it's in my right arm and shoulder and you know comes around, I'm not going to be silly enough to think it might not my heart.

Irene recognized that her symptoms were getting worse. She remained puzzled about the atypical location (radiation) of the symptoms, because her symptoms did not match that of the “average person”. Although she did not completely understand her symptoms, she was trying to assign a cause to them (inner circle). Assigning a cause, in her mind, would help decrease the uncertainty of the situation. However, the one atypical feature got in the way of Irene assigning a cause. She used others (outer circle), so she would not be “on her own” in ruling “in” or “out” a cardiac etiology. She used a trusted resource as a sounding board to validate her thoughts about the symptoms. In doing so she sought affirmation that she wasn't being unwise or inappropriate in thinking this “may” be her heart.

Gloria on the other hand, pulled in others (outer circle) several days later in the process of trying to interpret her symptoms (inner circle). After trying to make sense of the symptoms on her own, using her past experience as a reference, she reached out to others when the uncertainty of the symptoms continued. She negotiated with herself whether the symptoms were a benign versus a more serious condition. She talked with a family member when the symptom continued and she couldn't figure it out on her own.

I was just kinda grasping for straws. I was telling my daughter-in-law, ...this is worst, I can't shake this cold. I can't shake this congestion in my heart, in my chest. Because usually if I got a cold or congestion or something, I take something over the counter.

She remained preoccupied with her inability to make sense of her symptoms. "Grasping for straws" described how her attempts to assign a cause were futile. She needed to find some way to succeed in this task. Considering conditions from opposite ends of a continuum of seriousness was an example of her inability to assign meaning to her symptoms. Discussing her symptoms with others was one attempt she used to sort things out.

Thus in their search for meaning of the symptoms, all 3 of these women tried to assign potential causes. Some did so early in the symptom course (Deloris), while others much later (Gloria and Irene). Some classified the potential causes into particular body systems and others hypothesized about specific things occurring in select organs.

Unlike the other three women, however, Cecilia, once again was different in how she came to make meaning of her symptoms. For her time was more compressed. Once her early (very non-specific) symptoms intensified, she quickly recognized and interpreted her bodily cues. She associated the quality, the specificity in location (heart) at that point, the number of symptoms, the intensity, the duration (continuous at that point), and the associated emotion (fear) with a serious situation that needed immediate attention. As pain set in and her symptoms rapidly became more prominent to her and others, especially after the paramedics arrived, she began to interpret what was happening.

I know if I didn't get no help, I was scared I was going to die. That's how bad I was hurting. They (the paramedics) lifted my sweat shirt up and you could see my heart, like it was jumping out of my chest.

At that point, the unmistakable presence of highly specific symptoms combined with the impending doom helped her label the symptoms as something specifically related to her

heart. She did not need to resort to other strategies to gather information about her symptoms as the other women because her symptoms progressed more quickly. When asked if this was similar to her past heart attack, she said she could not recall the symptoms from that event.

As depicted in the model, these illustrations show that all of the women in Group A were *eventually* able to notice a change in their body. However, as they tried to make sense of the bodily cues, with the exception of Cecilia, all were unable to find a relationship between the symptoms in order to form a symptom pattern. Their inability to form a symptom pattern prevented them from assigning a specific label of what was happening to them.

Thus most of these women in Group A with less prominent symptoms were unable to form one coherent interpretation (a symptom pattern). This inability to link the symptoms together may have occurred because of: 1) there was not enough information to connect (symptoms that came and went over a longer period of time); 2) there was too much information that did not relate (many symptoms from many different body parts); and/or 3) there was enough information, but the ability to connect them into a whole was limited.

4.5 Group B: Noticing Bodily Cues Right Away

For the remaining participants ($n=4$), the initial bodily cues were immediately noticeable. For discussion purposes, this group will henceforth be referred to as “Group B”. Two of the women (Eileen and Francis) could pinpoint the exact date and time of the onset of symptoms, which coincided with symptoms of severe intensity and immediate disability. Most had a prior history of a same (or similar) event. Three of the four were retired nursing assistants, thus may have used professional knowledge to help with symptom recognition and

interpretation. As all of the women in Group B came to make meaning of these early bodily cues, most knew almost instantly that the bodily cues were a sign of something very serious.

For example, Eileen, a 59 year old African American retired nursing aide, knew within minutes of her symptom onset that her bodily cues were a sign of “sickness”.

Although the bodily cues were intermittent initially, the intensity and quality of symptoms were unmistakable from the onset. The level of specificity was evident as she identified, with precision, the moment of when symptoms started.

All of a sudden, it just hit me. The sickness came out of no where. (...). At 5 after 9, I felt a pain and it sort of passed over (me). Here in my chest. (...). And then about 9:30 it started up again. It didn't ease up.

Her bodily cues met the criteria for being noticeable; they were adequately intense, consistent in presentation, sufficiently repetitive, and distinguishable from here every day bodily aches and pain. These features allowed her to pinpoint the exact moment that symptoms started.

Another participant, Francis, a 58 year old hourly worker, described early symptoms that progressed rapidly while she was pushing a shopping cart at work. For her, time was compressed. Francis decomposed, as best she could, the first 45 seconds of her evolving symptoms. She referred to the pain as if “it” were a lifeless thing that took over her body, immobilizing her until it went away.

Well actually, I could feel it coming on. It was like tightening in my neck, somehow. That's the only-ist way I can say it. ...(..).. It all happens really fast. But if I was breaking it down, that would be what it is. It's a tightening in my neck and I go, oh, no I'm getting a pain. ..(...).. it takes, I don't even know, 45 seconds, a minute, before it goes into an actual pain. But it don't take long... But once I get closer to having it, then it's more like my shoulder's tense up. I get real tightened up all in my chest and in my neck. And just start to sweating and you know it breaks out....Your chest would just hurt bad...And then.. it finally went away. .. And then about 10 minutes later, here it comes again. ..just wham.

Francis rated the intensity of her pain as a “9” on a 0-10 scale, “leaving room in case it got worse”. Her bodily cues met the criteria for being noticeable; cues were of sudden onset, intense, sufficiently repetitive (recurred within 10 minutes), consistent in quality, and indisputably distinguishable from everyday bodily aches and pain. These features allowed her to identify the exact moment that symptoms started.

4.5.1 Making Sense of Bodily Cues

Once a change from the usual status was noted, often suddenly and without warning, as depicted in the model, the women in Group B began to tune into their bodily cues in an attempt to make sense of the information (inner circle). Early monitoring of the symptoms included noting the quality, the location, the intensity, the radiation, and the duration of the symptoms. Paying attention to these features offered an opportunity to form relationships between the cues in order to assign a label to them. All of the women in Group B were able to assign a high level of seriousness to the situation early on, often within minutes. All of the women in Group B “knew” fairly quickly that the symptoms were related to their heart.

However the women in Group B varied in the process they used to assign a specific cause to the symptoms. Many of the strategies used during this process were the same as those used by the women who did not immediately recognize their symptoms. However, for the most part, these strategies were implemented much sooner (within minutes versus hours or days).

4.5.2 Use of Others to Make Sense of Symptoms

All of the women in Group B used others at some point in the process, but there was variation in when others were called upon. Some of the women used others (outer circle) in their lives to help recognize and interpret the cues (inner circle) contemporaneously. Other

participants solicited help within the first several minutes of symptom onset, after realizing they could not sort out the symptoms on their own. Still other participants kept the process of symptom interpretation primarily an individualized experience.

Hazel provides an illustration of how the women used others who were present to help recognize the bodily cues and interpret what the bodily cues meant. Hazel, a 68 year old African American retired nursing aide, spoke to the visibility of symptoms to her husband and her social network. From the onset they can see her pain:

All of a sudden, look like bam (slapping her hands together) it hits me and gives me a fit for a while. He (husband) knows it and he sees it. I get so much pain. I'm the type of individual I'll grunt and moan. (...)...The elders and the friends see it (too)...because the pain... it brings the hurt out on my face. (...)...when the pain comes, it shows. I can't hide it. Because it's very domineering. And I hurt so bad, it don't bother me who sees it.

Hazel, like the other women, noted how overbearing the symptoms were, which made them unmistakably present to her and others observing. She could not hide the symptoms, even if she wanted to. Hazel's husband helped recognize the bodily cues and then helped interpret them (inner circle). They were "pros" at sorting out the symptoms based on their "back experience" of 16 years. By using the past, as a frame of reference (inner circle), they both "tuned into" her bodily cues, linking the quality, the precise location, and the intensity to form a symptom pattern (inner circle) that they were familiar with. Part of sorting out the symptom features that they used was distinguishing the "heart" symptoms from other bodily sensations. This was possible through their communication of information about the symptoms. After "seeing the pain" on his wife's face, Hazel's husband would often simply ask *where* the pain was located. She explained the process that she and her husband used to connect the symptom features (specific location and radiation) to a possible cause.

Well ...the difference between...Ok..I have acid reflux, real, real bad and plus a

hernia. Alright. Now I can tell if it's the hernia or acid reflux than the heart. Because the heart, when I have pains, angina, from the heart, my whole arm aches all up and down here (motioning down her arm) my hand and all. And when it's just acid reflux I have pains in my chest but mostly down here. But up here is where I get concerned (demonstrating various parts of the body means what type it is). So therefore my husband asks ..(me), where the pain at? And I'll tell him. If it's up here I can tell it's the heart..and the pain goes all the way down my arm when it's my heart. And when it's acid reflux, I have a lot of pain right in here, right like in the bottom of your stomach.

As depicted in the model, Hazel and her husband jointly recognize the onset of the bodily cues and jointly interpret the cues by linking various symptom features together (inner circle). They used several strategies simultaneously to identify a symptom pattern and to confirm the relationship of features with their past frame of reference. For them, the recurrent symptoms matched exactly with their past experience which enabled them to jointly assign a cause to the symptoms with certainty. Thus the role of others (outer circle) in this illustration is to affirm what the participant (Hazel) knew within herself.

For other participants, soliciting help from others (outer circle) came minutes later, when they could not interpret the bodily cues outright. Like the participants who had a more insidious onset, some women with highly prominent symptoms sought out others when their symptoms intensified in order to manage the uncertainty of their bodily cues. Although there was no doubt about the presence of symptoms, there was skepticism about what the symptoms meant. These women involved others as a means to validate thoughts about their symptoms and/or to seek advice about the situation.

Eileen provides an example of involving others early on, when she had doubts about what her recurring symptoms meant. Eileen was a very independent woman, matriarch of her family, and only consulted with her husband for "urgent matters". Despite having a history of several heart attacks, Eileen was uncertain about what her bodily cues meant. Initially she

assigned a benign cause (inner circle) to the symptoms (a pulled muscle), linking it to getting up the wrong way from her chair. Assigning a temporary label helped her with the uncertainty of the acute disruption of the situation. The symptoms were of relatively short duration (a few minutes initially), characterized as “pressure”, and at that time remained relatively unimportant. However, when the symptoms recurred within a 10 minute time interval, became constant, and changed in quality (from a “pressure” to a “pain”), she began re-assessing the relationship she had formed between the symptom features. She re-interpreted her bodily cues (inner circle) thinking “something else” was going on. She tried to link various symptom features (the quality, the location, the radiation, the intensity, and duration) to form a pattern from the relationships. Eileen’s past 5 heart attacks provided a frame of reference (inner circle) that allowed for variation in intensity (mild to unrelenting pain) and quality (pain versus a burning quality). However, in evaluation her symptoms, she was very specific in how she differentiated the symptom quality. This distinction was important for Eileen because most, not all, of her past heart attacks had been associated with a burning quality. Because the quality was different, Eileen had reservations about whether her current symptoms matched her frame of reference. This incongruence served as a stimulus for uncertainty about the bodily cues. She reduced this uncertainty by calling upon others - her husband (outer circle). Although her “gut” was telling her she *may* be having another heart attack, she called her husband on the phone to discuss the “matter” with him. She did not want to jump to conclusions so wanted to be sure.

I called him on the telephone. He knows my voice. He said, I’m in the yard. What’s the matter? I said, I just got a pain, in my chest. He said, well I’m comin’ on. And by the time he finished, and got inside and looked at me, he said, just like he always do, what’s the matter. He know, I don’t call him unless it’s really some pain. I said, I’m done hurtin’. I don’t know what happened. I told him about the fact, I done got up and ... I thought I had pulled something . He said, where you hurtin’ at? He wanted me to

stop and point out where I was hurting. I said, somewhere in the chest area.... I said, it don't much feel like a heart attack. But something is going on....It started hurting in my chest. .. I was hurting bad. My shoulder down to my elbow and up here in my chest.....Because I didn't have the burning with it, I just had like the pressure, I had suspicion, but I was trying to ward off it being a heart attack. I'm saying (to herself), it's not a heart attack, it's something else. Even, when you get the burning sensation, you just can't say then, it's a heart attack. Even if you had them before, it's always, always different. It makes it more difficult for them to diagnose what it is, even within yourself. ...If it goes so long, then I 'bout know, it's something dealin' with the heart. I know. I know.

The recurrence of the symptoms with increased intensity (changing from pressure to pain) and increased duration (continuous) caused her to re-label the symptoms as something more serious than she initially thought. She acknowledged, with “suspicion”, that “something else” may account for the symptoms, perhaps her heart, but was at odds with herself about this. Despite having 3 prior heart attacks, because of the incongruence with her frame of reference (specifically the symptom quality), she needed more information to form a symptom pattern. To manage the uncertainty she solicited help from others, while simultaneously trying to “ward off” a heart attack.

Like Hazel, Eileen had a regular routine for communicating with her husband during symptomatic episodes. She provided her husband with the “facts” and used him (outer circle) as a sounding board to gain more information in her search to assign meaning to her symptoms (inner circle). She described the quality of the sensations, pointed to the location of the pain, and told him about her initial thoughts. She called upon others because, as she put it, “even within herself” she had difficulty interpreting the symptoms or assigning a cause. Eileen wanted her husband's help to assign a label to her symptoms, using him as a form of confirmation.

4.5.3 Making Sense of Symptoms By Themselves

For other participants making sense of bodily cues was an individualized process. For example, Francis, a 58 year old female eventually diagnosed with Prinzmetal's Angina, quickly recognized when her symptoms recurred, within a 10 minute timeframe, that the quality and location of her symptoms were consistent, yet stronger with the recurrence. She referred to her past anginal episodes as a frame of reference for comparison (inner circle). In doing so, she realized with absolute certainty, that her current symptoms were an exact match with her frame of reference. This allowed her to form a symptom pattern (inner circle) quickly. She was confident what her bodily cues meant. She did not need others to confirm her symptom interpretation(s). She talked about how she knew right away:

When the first one left, (I thought) well ok, that was only one. Maybe it's gone. And when the second one came, more like 10 minutes (later), I said forget it. ...It was actually more intense. Your gut is already thinking that was your heart (first one). So it wasn't a question was it your heart. No, that was never a question for me. Because I knew by that time, that feeling, I had had that too long.

As depicted in the model, Francis compared her current symptoms to her past frame of reference, noting that these symptoms were an identical match in quality and location, to form a symptom pattern. Despite having not experienced the symptoms for several years, the fact that the symptoms were reliably consistent in quality, consistently present (returned within 10 minutes and was continuous thereafter), and were growing more intense added to the absolute certainty she had about the symptom pattern. This absolute certainty of the symptom pattern, coupled with emotion (a fear for her life), helped her interpret the symptoms as acute cardiac symptoms. She was rather surprised that the symptoms were more intense this time. However the increased intensity helped expedite symptom interpretation.

It was a little bit different in that it was more severe. And I knew what it was.. If it was more severe than the last time, it might really take me out. Because I knew it was

my heart. So I was thinking, gosh this one really hurts, this one is really bad. I may not be here tomorrow.

Thus the women in Group B, with more prominent symptoms, were all able to form one coherent interpretation (a symptom pattern). Their ability to link the symptoms together may have occurred because of: 1) the bodily cues were more prominent, more specific, more intense, of sudden onset, and more disabling – thus unavoidable; 2) more of the women experienced fear for life with the symptoms within minutes of onset, thus more readily labeled their symptoms a high level of seriousness; 3) the women were more experienced in recognizing and interpreting their bodily cues; and 4) most of the women called upon others sooner (rather than later) in the process to help validate their interpretation(s).

4.6 The Larger Social Context

As discussed above, there were two distinct groups of women in the study, Group A and Group B. Most of the women in Group A did not immediately notice their symptoms. However, once all of them eventually recognized their symptoms, despite using several strategies to try to make sense of their symptoms, most of the Group A members (4 of 5) could not form a symptom pattern. This was different for the women in Group B. This group of women recognized their bodily cues promptly, were able to form a symptom pattern, and were able to determine what the symptoms meant fairly quickly.

In addition to both groups differing in their ability to form a symptom pattern (inner circle), both groups differed significantly in how the larger social context (outer circle) influenced their trajectory towards seeking care. Group A remained uncertain about the meaning of their symptoms. However, over time, Group A transferred their focus and energy *from* their symptoms (inner circle) *towards* other things going on in their lives (outer circle),

at times out of necessity. When the women in Group A eventually moved towards seeking care, it was because someone or something else made the decision for them.

Group B, on the other hand, understood the meaning of their symptoms and labeled them rather quickly and moved their attention *from* their symptoms (inner circle) *towards* considering seeking care (outer circle). For Group B, the larger social context influenced how and when they sought care. Thus depending on which group the women were in, moving on to the larger social context served different purposes and occurred at different time points in the process.

4.6.1 Influence of the Larger Social Context on Group A

The women in Group A eventually, in some ways, moved their primary focus from trying to understand their symptoms (inner circle), to returning to life as usual (outer circle). In doing so, the women compensated for their inability to understand their symptoms by *moving towards* the certainty of daily life (outer circle). Others seemed to be *pulled away from* their symptoms (inner circle) *towards* the ongoing obligations (outer circle). Regardless of how they moved into the larger circle, they all moved their primary focus away from their symptoms.

For most of the women in Group A, their larger lives consisted of attending to ongoing social obligations and role responsibilities. These were most often referred to as “things” that the women “needed to do”. For most (n=4) of the women in Group A, obligations included working for an hourly wage or caring for others (persons or animals). These obligations were tightly connected to their identity and viewed as essential. All of these obligations were long-term and not easily exited. Failure to complete these obligations often resulted in sanctions (by themselves or others).

Continuing with Life As Usual

Continuing with life as usual (outer circle) helped the women in Group A replace the uncertainty of not being able to form a symptom pattern (inner circle). Thus, keeping with the familiarity of ongoing obligations (at work or at home) provided the certainty they needed. Most (4 of the 5) of the women in group A talked about putting their bodily “aches and pains” on the “back burner” (as one participant put it), which allowed them to continue with life as usual. The women differentiated which symptoms could go on the back burner (vague, non-specific, less intense symptoms) and which symptoms needed more immediate attention (those that were associated with a threat to her life). They talked about when the symptoms became more intense, how they moved them back to the front burner until things were better. Thus they did not abandon their symptoms, they just put them into a place where they could still monitor them, while getting back to life as usual.

Many of the women in Group A (3 of the 5) talked about how they cared for others on a daily basis. For example, one participant, Cecilia, was the primary caretaker for her mentally challenged adult sibling. Another participant, Irene, was the sole caretaker of a pet and the primary caregiver of her grandson during the week she experienced heart attack symptoms. Both women talked about how they couldn’t leave their dependents with “just anybody”. For these women, putting symptoms on hold (inner circle) allowed them to maintain the important roles (outer circle), providing certainty that their loved ones would be properly cared for. Thus, *bringing* their obligations *back* to the forefront of their life allowed them to avoid the emotional sanctions of leaving these obligations undone.

Many of the women in Group A also discussed how continuing with their obligations served as a way to maintain their identity. Gloria’s statements below provide an illustration

of how maintaining her job was an integral part of her identity. As the primary provider for her 4-person household, she talked about how important this was to her:

That's my home. I worked hard for it... I took it on. I pay my bills. .. My job is my livelihood. I take care of myself. No one else does... That's a big accomplishment for me. It's very important. I guess it is a pride thing, because I don't own a mansion or anything. But it's mine. And the dirt underneath it is mine. And I have done it by myself. No man didn't help me do none of that... Blood, sweat and tears.. It's mine. I paid for it.

For Gloria, returning to life as usual (obligations) served as a means to retain her identity as a “well person”.

For some women in Group A, the timing of the symptoms affected how soon they returned to their obligations. Some of the women were not as free as others to leave their obligations due to possible sanctions by their employers. For these women, *moving* their primary attention from the uncertainty of their symptoms (inner circle) *back* to their ongoing obligations (outer circle) was prioritized, to avoid being sanctioned. These women were *pulled* away from their symptoms *towards* their obligations and responsibilities. Two women who were hourly workers shared how their employers discouraged diversion from their work responsibilities, especially at the beginning of a shift. They discussed how replacements were rare, offered only in the event of an emergency, thus they needed to be absolutely certain if they were “sick”. Agnes’ comments illustrate how she felt compelled to continue with her duties at work, setting her symptoms aside, the night she had her heart attack.

We have to stand all the time; we can't sit down; we can't lean against anything.. You can't go to the bathroom, unless you're on your break. Unless you have an emergency and someone has to come out there and take your place. I didn't leave work. They don't like for you to leave work for nothing.... They don't like for you to be ever sick. I have never been sick at work.

When faced with the ambiguity and unfamiliarity of her symptoms (first time cardiac event), Agnes repressed the uncertainty related to her symptom experience (inner circle) by

transferring energy to continuing with her work requirements (part of the outer circle), an element of certainty for her. With only 30 minutes left in her shift, Agnes did not label her symptoms as an emergency. Labeling her symptoms as an emergent situation would have qualified her for finding a replacement, which was not condoned in her workplace.

Moving Toward Definitive Care

The women in Group A eventually sought medical attention for their symptoms. However, for this Group A, someone or something else made the decision for them. Despite moving towards care, the women carried the uncertainty related to their symptoms with them to the hospital.

Others Making the Decision

For the women of Group A, others, from the larger social context, played a vital role in moving them towards seeking care. For three of the five women in Group A, others noticed a change in behavior and/or appearance and insisted they seek care. Trusted others witnessed their steady decline in bodily function and moved them towards care. For some of the women, having others point out the need to seek medical attention gave them permission to exit their obligations – especially if they were engaged in activities that were not easily exited.

Gloria serves as an illustration of how others in authority insisted that she seek care when she had symptoms of her first heart attack:

We had shut down for a safety meeting. My supervisor noticed me rubbing my arm. I was going back to my machine and he caught onto meHe asked me, are you ok? ..He said, well you look a little pale...I said, I'll be alright, I've just be working hard..He took my arm and said, just wait a minute. I'm gonna, have them check your BP and stuff. Something ain't right. He could tell.

A similar scenario occurred prior to her current event, when her symptoms intensified on the

way into work. It took a co-worker, walking into work with her, to notice how markedly short of breath she was. He alerted the emergency medical team on her behalf, which she agreed to reluctantly.

The Disease Making the Decision

Some of the women in Group A referred to how their bodies “decided for them”. At some point the symptoms became so remarkable that the women sought care to assign a cause for the symptoms still in question. These situations were characterized by the women as a turning point; a time when symptoms had lasted so long, becoming acutely worse, and was often associated with a marked increase in heart rate or respiratory rate; one that made them fear for their life. Two of the women stated they “had no choice”. These women viewed their having to seek medical attention as a decision that was “made for them” on their behalf; a situation that they viewed as “giving up”. Paradoxically, even though they perceived this as giving up (control), they commented on how relieved they were that someone/something else made the decision for them.

Some of the women insisted on going home after experiencing symptomatic relief from treatment in the emergency department. Two participants left the hospital, both returning by EMS within hours when the symptoms recurred. One participant left the hospital against medical advice, despite being diagnosed with a heart attack. Prior experiences informed her that she typically was hospitalized for several days whenever she had a heart attack. Although she had packed her suitcase and computer in advance of going into the emergency department, once the symptoms resolved she told the doctor she had “things to do”. Irene described her dilemma:

You can't just walk out of your house and be gone for a week. Mentally I won't ready (to stay)...I really really need to do a couple of things before I go. I just don't like to leave and not come home. All of a sudden don't work real well for me.

For Irene, as well as some of the other women in Group A, when the symptoms intensified, she shifted attention from her life as usual (outer circle) back to the symptoms (inner circle). However, once the symptoms resolved (at least temporarily), she wanted to return to her obligations (outer circle). The fact that she had been told her blood work was positive, indicating that she had experienced a heart attack, did not make a difference in her reasoning. She planned to return home, take care of her obligations, and would come back in a few days for treatment.

4.6.2 Influence of the Larger Social Context on Group B

The women in Group B were able to form a symptom pattern; thus understood what the symptoms meant, and knew that they needed to seek care. However, how and when they sought care depended on the other aspects of their life. These women used their understanding of their symptom pattern and their past experience to judge the timing for seeking care. Some of the women had more time (hours or days), while others had minutes to make plans to seek care. Their plans were based on personal thresholds. Part of these plans included how to manage others, while attending to their symptoms. Another important aspect of planning was taking care of personal matters that related to social presentation before seeking care.

Having a Plan

All of the women in Group B used personal or professional knowledge to establish a personal threshold to know when to consider seeking medical attention. This threshold coincided with their evaluation of whether the symptoms were becoming unstable. Their

definition of instability was usually based on a specific duration and frequency of symptoms, whether the usual relieving agents became ineffective (a specific number of nitroglycerin tablets), and/or whether their symptoms were impinging on particular activities of daily living (sleep, driving a car, or occurring when they were alone). Once their symptoms exceeded this threshold, they labeled their condition as “unstable” and moved them towards care.

Hazel serves as an exemplar for explaining how she knew it was getting time to go to the hospital as she considered seeking care. Her symptoms had been going on for several weeks, were starting to occur more frequently, and she was beginning to use more nitroglycerin. As she anticipated her condition becoming “unstable”, she made plans for her family to drive her to the hospital.

If I get to 3 (nitroglycerin tablets) and it don't calm down (I) get to the ER quick as I can, call 9-1-1... See if I took 3 nitroglycerins that means there is a serious problem. I did not want that to happen..(That's) the reason why my husband and I decided we would go down to UNC (that day) while I was stable..I refused to wait until I was unstable.”

Like other women in Group B, using her personal frame of reference Hazel developed her own definition of instability and knew what that label meant for the situation. To Hazel, becoming unstable would have required her going to the local hospital by ambulance (two things most of the women wanted to avoid). Like the other women in this group, Hazel wanted to seek care before it was “too late” in her mind.

Preparing Self and Others

Many of the women in Group B put energy into preparing themselves and others *while* taking action to seek care. These women were able to move towards care, as long as they did so on their own terms – a part of maintaining control (or certainty) to the situation.

They knew what actions were required (including anticipated reciprocal role changes needed), made arrangements through their social network, and took care of their own personal needs – all based on the timeline they had estimated in their mind. They used information from their symptom pattern and their frame of reference to predict the limits of their symptom course and gauge the timing for their actions.

Part of preparedness involved the social presentation of self. Social presentation and the hesitation to give up presentation of self was part of their identity. The women viewed these activities as essential, frequently having witnessed other female relatives doing the same before seeking care. For the women in Group B, social presentation most often involved taking a bath prior to going to the hospital. Eileen talked about how, from the time her husband came into the house, she knew she needed to go to the hospital. However she had some personal “things to do” before going and knew how long she had to do them.

I knew I was gonna have to make a move.. out of there. .. I knew after 5 or 10 minutes I needed to go. I just wanted to prolong it as long as I could. I had to do some things I had to do before I went. I am well in control about when it comes to my body. About what is going to happen to me and what's gonna happen and what I am gonna do.

When Eileen's symptoms intensified during the process, she solicited help from her husband to finish the activities, in order to complete the task, albeit it more rapidly.

For another participant, Francis, preparing self for seeking care, also meant controlling the location she was in. As she waited for her husband to arrive to transport her to the hospital, she recalled making sure she *moved* from one particular location to a better place at her place of employment. She was fearful that she may lose consciousness while waiting for her husband. The uncertainty related to others (strangers) seeing her in a

compromising position troubled her. Thus, she made decisions related to finding the right place and the right persons to be around, while taking action to seek care.

For other women, preparing to go to the hospital also meant preparing others. Some talked about how family members could become very “emotional” during their symptomatic episodes. Thus, as the symptoms progressed, the women did not always disclose certain facts to these particular family members. Full disclosure may have meant their family members may have rushed them directly to the hospital and/or notify others of their acute health situation. The women did not want the risk others making decisions for them. The women wanted to keep the situation on their own terms, staying in the role of the decision maker. Thus managing (and preparing) others often involved deciding who to tell about symptoms, when to tell them, and how much to tell them.

Full disclosure also may have meant they may worry others unnecessarily. Some women did not want to put others through an emotional “roller coaster” (as one participant put it). Thus they preferred to wait until after the initial medical evaluation was completed before notifying family members – so as not to cause a false alarm. This was especially true for those women who were the matriarchs of the family, serving as the primary caregiver/decision maker for the family. These women preferred to shelter their children and spouses from “tending to them”. They were uncomfortable with others focusing on them. Eileen explained how she could see the impact of her symptoms on others close to her:

I can see the worriation..on my husband’s face, of being scared to death. ...My feelings when I am going through this actually is more, more focused on L____ (husband) ... It’s not really about me..

Even after being hospitalized, the women felt guilty about being in the hospital. Thus they took actions to minimize the burden to their family members by downplaying their

hospitalization, insisting that family members go home, get some rest, and continue with their own lives.

All of the women in Group A and Group B eventually were hospitalized. The women in Group A arrived to the hospital holding onto the uncertainty of their symptoms. The women in Group B arrived to the hospital fairly certain that the symptoms were serious and were most likely related to their heart. These women went on their own terms, on their own time.

4.7 Summary of Results

Overall, the study participants fell into two groups, based on the noticeability of bodily cues and their ability to form a symptom pattern. This distinction between the groups determined what the women spent their time and energy doing while still in the pre-hospital setting.

For the women who could not form a symptom pattern (Group A), time and energy primarily focused on trying to make sense of the symptoms. When they were unable to do so, they moved their primary attention away from the uncertainty of their symptoms to other aspects of their lives, but entered treatment later than needed.

For the women who were able to form a symptom pattern (Group B), they moved very quickly through the process of making sense of their symptoms. Time and energy for this group primarily focused on the larger social context by preparing self and others to move them towards seeking care. Thus, depending on which group the women were in, the ability to form a symptom pattern determined to what extent and when the larger social context shaped the decisions related to seeking care.

Chapter 5: Discussion

5.1 Introduction

This chapter begins with an overview of the purpose of the study and the major findings. Following the overview is an interpretation of these findings and conclusions drawn from the research. Strengths and limitations for the study are discussed; including insights into the main contributions this research offers the field. Next, recommendations are provided for clinical practice and future research, followed by concluding remarks from the researcher.

5.2 Overview of the Purpose

The purpose of this study was to explore the socio-contextual experience of how women with acute cardiac ischemia recognize and interpret their symptoms, while simultaneously managing everyday roles and responsibilities when deciding whether to seek treatment. The specific aim was to explore whether uncertainty of the symptom experience tied to uncertainty of relinquishing role responsibilities is a major precursor to pre-hospital delay.

5.3 Major Findings of This Study

5.3.1 Uncertainty of Symptoms

Results from the qualitative data revealed that all of the women went through a process of recognizing and interpreting their symptoms, as they tried to make meaning of the symptom experience. They used several strategies to interpret the symptoms as something that made sense to them. The qualitative data supported that about half of the women *did*

experience uncertainty related to their bodily cues and were unable to form a coherent symptom pattern (Group A). This group of women could not make sense of their symptom experience despite spending hours, days, and in some cases weeks trying various strategies to assign a label to what was happening to them.

When the women in Group A could not form a symptom pattern, over time, they transferred their energy and primary focus *away* from their symptoms *towards* life as usual. Yet, they continued to monitor their symptoms, in their search for meaning. When the women in Group A entered treatment, it was because someone or something else moved them towards care. The remaining women (Group B) were able to form a coherent symptom pattern, which helped them label their condition and move them towards care. Group B did not necessarily arrive to the hospital sooner; instead they used their pre-hospital time differently. Proportionally, because they formed a symptom pattern quickly, they spent less time trying to make sense of their symptoms. Instead, they used the available time to prepare themselves and others for their departure.

5.3.2 Uncertainty Concerning Relinquishing Role Responsibilities

The qualitative data did not support that among the women in the study uncertainty was related to relinquishing role responsibilities. While most (7 of 9) of the women did have ongoing social obligations and work responsibilities, they did not lack information related to exiting those activities. In fact, the women knew with *absolute certainty* what (if any) changes were needed in their absence and who would take over their responsibilities. The findings did not support that uncertainty related to the symptom experience served as a platform for uncertainty in relinquishing role responsibilities during the acute illness phase. Instead for the women in Group A, role responsibilities provided a familiar routine. For the

women in Group B, who recognized the hospital routine, they spent time preparing for hospitalization.

5.4 Conclusions Drawn from the Research

The major strength of this study is that findings from these data offer a theoretical explanation for some of the determinants of delay as cited in the literature. As noted in the Chapter 1, the traditional model of pre-hospital delay views the inaccuracies in the definability of symptoms primarily as a knowledge deficit combined with a conscious decision to delay seeking care and/or a suppression of the meaning of symptoms as a health threat by the women (Dracup et al., 2006). To date, interventions used to decrease prehospital delay have focused primarily on educating those at highest risk for developing an acute cardiac event. More recently educational intervention studies have expanded to include information on anticipating emotional responses to symptoms and addressing potential environmental influences (Dracup, et al, 2009). However, the importance of forming a coherent symptom pattern prior to considering seeking care has not been previously studied in women with cardiac symptoms. This study offers a more theoretical understanding of how and why women come to their symptom interpretations and manage the uncertainties of the illness-event.

These data also explain why severity of symptoms is not a reliable cue for women to recognize chest pain as cardiac in origin (Fukuoka, Dracup, Moser, et al, 2007). Data from this study show that while higher symptom severity helps with noticeability, especially if the symptoms are incapacitating, severity is just one part of forming a symptom pattern.

These data also help explain the paradox of why some women with past myocardial infarctions do not always equate recurrent symptoms of ischemia with a cardiac etiology and

thus delay seeking care more than those with a first time event. Prior studies have attributed this additional delay in those with recurrent events to inaccuracies in perceived vulnerability. However these data demonstrate that symptoms from one event are not always identical to those from subsequent events. Moreover, a prior frame of reference is helpful, but not enough, to form a symptom pattern, especially if at least one symptom feature differs. Thus, one factor that does not match the prior experience may impede one from forming a symptom pattern, halting the process of symptom interpretation.

These data also help explain why some women seemingly dismiss evolving symptoms to continue with their life as usual. The traditional model views continuing with social obligations and role responsibilities as a deliberate attempt to avoid seeking care. However, data from this study show that for at least half of the women (Group A) returning to social obligations and role responsibilities was due to a lack of understanding of their symptoms and/or a desire to minimize the uncertainty of the situation. Furthermore, for the women in Group B, focusing on the larger aspects of their life was part of their routine to prepare themselves and others for their departure. Therefore, the women were very deliberate in their actions – but for different reasons.

5.5 Limitations of the Study

One potential limitation of the study was that the sample was selected from one institution in one geographic location (southeastern United States). In addition, the sample did not include women who did not seek medical care and/or those who died prior to reaching the hospital. However, the intent of the study was to explore an alternative explanation to pre-hospital delay to serve as a foundation for future work.

5.6 Contributions to the Field

This study was an initial attempt to get into an area that had not been explored. This study answered the call from thought leaders in the field to provide an innovative theoretically based target for treatment of pre-hospital delay. These findings offer a theoretical link how women with acute cardiac ischemia recognize and interpret bodily cues in an attempt to inform subsequent decision making. Factors were identified that supported (or negated) recognition of bodily cues and the ability to form a symptom pattern.

These findings offer support for a continued need to study socio-contextual factors concurrently with other psychosocial factors when examining pre-hospital delay. In the past the larger social context has been treated as secondary or extenuating factors. The traditional model views the time it takes to recognize and interpret symptoms as a “patient-related” delay. However, these data have shown several ways in which the larger social context influenced symptom recognition, symptom interpretation, and subsequent decisions related to seeking care.

5.7 Recommendations for Future Practice

As clinicians we have the need an opportunity and an obligation to use every opportunity to evaluate women that we treat for the presence of heart disease. This includes paying close attention to potential recurrence of symptoms, often not recognized by the patients themselves. Three of the five women with known cardiac risk factors from Group A were seen by health care providers at some point during their symptom course (prior to their hospitalization). All three were misdiagnosed; two to non-cardiac etiologies. It is unclear whether the misdiagnosis was associated with the participants’ ability to communicate their

symptoms. As clinicians we should be very diligent in evaluating every female with risk factors for cardiac disease at every visit.

Based on these findings, clinicians should also take in to consideration that not all women who have had a past cardiac event will recognize subsequent angina symptoms as cardiac in origin. The data from this study revealed that having a frame of reference *did not always guarantee* formation of a symptom pattern. Thus education for women with prior events should include the expectation that future heart attacks may be different. Thus the women (and clinicians) should expect variation between subsequent heart attacks.

These data also suggest that others are important in the lives of the women experiencing acute cardiac ischemia. Education should include family members and other support persons.

While these educational strategies won't solve the entire problem of pre-hospital delay, they are a start in the right direction. Individuals make meanings with interactions with others (Crotty, 1988). Moreover, meanings may be modified as more information is interpreted (Crotty). As shown in this study, some women may interact with health care providers during their search for meaning. Thus, clinicians have an opportunity to modify this process, if they recognize it.

5.8 Recommendations for Future Policy

Symptom onset has been used as part of a metric (time of symptom onset to hospital arrival) in the recent years to measure quality care – thus has served as a target for intervention. However, these findings challenge whether researchers and clinicians should focus on the precise point at which symptoms start. Findings from this study call attention to question “which symptoms” signify the start of the event. In this study, it was difficult to

distinguish between premonitory symptoms (early “minor” symptoms), prodromal symptoms (symptoms that typically precede an ACS event by 7-10 days), and the actual ACS symptoms – especially for those women who had symptoms that evolved over time (Group A). For this reason, approximately half of the women in the study did not have complete data to determine exact symptom onset. Thus, other metrics should be identified to use in measuring quality care.

5.9 Recommendations for Future Research

Additional work is needed as follow-up to confirm that the phenomenon exists and to explore the limits of this theme. This work is preliminary and is hypothesis generating, with more work to be done. The data demonstrated that uncertainty rests more around making sense of the bodily cues, which gets in the way of forming a symptom pattern for at least half of the women interviewed. The data also revealed that the larger social context has an important role for all the women in how they interpret symptoms and move towards care. The larger social context came in for all at some point (from visibility of symptoms all the way out to the decision to seek care).

Recommendations for future research include additional qualitative work to gather more information about the phenomenon. Sampling can expand to those who with different people related characteristics (women of higher income and socio-economic status), those with a similar disease process (those with acute heart failure), those without risk factors and/or those with a first time event (to further evaluate the influence of novelty), those who entered the health care system via alternative paths (outpatient settings), and/or those who were seen by a provider, yet decided to return home despite being advised to stay.

Research is needed to determine how noticeability of symptoms may be enhanced; for example, which factors influence one's ability to detect symptoms. Somatic awareness is one aspect of symptom detection and has been a topic of recent inquiry for adults with heart failure. Riegel and colleagues (2010) have found that older patients have more difficulty in detecting and interpreting shortness of breath compared to younger patients. Their findings revealed a decline in symptom detection as one ages. Miller (2000) also found cue sensitivity to be a core process that influenced decisions to discount or attend to bodily cues in her grounded theory study of 10 women with heart disease. Thus, research into age and other person-related factors that influence noticeability is needed.

Research is also needed to determine what other factors help with formation of a symptom pattern. A better understanding of tolerability for uncertainty related to matching up current symptoms with past events. This study found that some women's efforts to form a symptom pattern were halted when one particular symptom feature did not match up exactly to their past events. A better understanding of which person-related qualities influence a tolerance for not having an exact match would be helpful.

5.10 Concluding Remarks

Exploration of the process of symptom recognition and symptom interpretation in the context of forming a symptom pattern offers a new theoretical basis for studying prehospital delay. Although this study served as a foundation of knowledge upon which to base future research and interventions, questions remain. The next phase of this study involves learning more about the phenomenon.

Conclusions drawn from this study reinforce the need to search for theoretically based targets for intervention. While these findings require further verification, viewing pre-

hospital delay in relation to how women make meaning of their symptoms would be more clinically useful than viewing delay as a deliberate attempt to avoid seeking care. This particular perspective has not been described in the literature to date.

Appendix A: Interview Guide

| Topic | Interview Question |
|--|--|
| Broad open-ended question to start | <p>I would like to understand more about what happens when women experience cardiac symptoms and what they do when symptoms occur – especially in terms of seeking care.</p> <p>Tell me the story about when you first thought you might be having symptoms of a heart attack and how you thought about managing the other things in your life.</p> |
| Definability of symptoms: <ul style="list-style-type: none"> • Quality of symptoms • Number of symptoms • Symptom course (onset and continuation/duration of symptoms) • Timing, frequency, location and intensity of symptoms • Level of distress • Thoughts about causality • Thoughts about seriousness • Thoughts about susceptibility to heart disease • Thoughts about anticipated outcomes | <p>That was a good overview. I would like to learn more about the beginning; what you thoughts and feeling were early on about what was happening to you.</p> <p>How did it come on? (<i>get to onset & try to get to acuteness of the disruption</i>)</p> <p>How did it feel? How long did they last?</p> <p>Did you know what was happening right away or did it take some time to figure things out?</p> <p><u>Follow-up re. being unsure or uncertain about what was going on (if that comes up; otherwise probe):</u> So it sounds like you were not sure initially about what was happening, tell me more about that (<i>use their words</i>). What did your “gut” tell you was going on?</p> <p><u>Follow-up re. needing to figure out things (if that comes up):</u> So you felt that you needed to figure things out ...tell me more about how you did that.</p> <p>What did you think was going to happen?</p> <p><u>Follow-up re. unpredictable (if that arises):</u> So initially you did not know what was going to happen. Did that concern you?</p> <p>Tell me how you first came to know you might be having symptoms of a heart attack.</p> |
| Situational influences related to symptoms: <ul style="list-style-type: none"> • First time event • Acuteness of disruption • Personal knowledge of ACS symptoms | <p>So it was the first time this happened? Have you had similar experiences in the past?</p> <p><u>Follow-up re: a similar situation in the past:</u> So how was this the same as the previous experience? Was it different in any way? If so, how was it different?</p> <p>Had you ever thought about what it would be like to have a heart attack?</p> |

| | |
|--|--|
| | <p><u>Follow-up re: prior expectations:</u> Was your experience similar to what you expected?</p> |
| <p>Life events going on at the time of symptoms:</p> <ul style="list-style-type: none"> • Activities at the time of symptoms • Number, type, and complexity of role involvement during the experience • Importance of role responsibilities to identity • Ease of exiting role responsibilities • Perceived adequacy of resources | <p>Can you tell me about what was going on when the symptoms started? Where were you? What were you <u>doing</u>?</p> <p>What your thoughts were regarding the other things going on in your life during this time?</p> <p>Did you do anything differently after the symptoms started?</p> <p><u>Probe about predictability re. changes required r/t responsibilities:</u> How did you know what to do? What did you think you needed to do (or not do)?</p> <p><u>Probe re. being unsure or uncertain about what to do next:</u> So it sounds like you were not sure of what to do next (try to use their words).</p> <p><u>Probe re. needing to make a decision quickly if that comes up:</u> So you felt that you needed to figure things out quickly...tell me more about how you did that.</p> <p><u>Probe re. about reluctance to stop activities if that comes up:</u> So you initially did not want to stop _____, tell me more about how you did that.</p> <p><u>Follow-up re: needing others to take care of something they were “supposed to be doing” if that comes up:</u> How did you decide who would do what? How did you know what to do? What did you think you needed to do? How did you feel about that?</p> <p><u>Follow-up re: the ‘newness of the situation’:</u> So it was the first time you had to stop _____? How was this the same as the previous experience? Was it different in any way? If so, how was it different?</p> |
| Decision about seeking care | <p>When did you make the decision to go to the hospital?</p> <p><u>Follow-up re. not being sure about seeking care:</u> So it sounds like initially you did not think about going to the hospital (try to use their words).</p> <p>How did you make the decision to go to the hospital?</p> <p>What influenced that decision to go into the</p> |

| | |
|--|--|
| | <p>hospital?</p> <p>What are consequences of going to the hospital?</p> <p>What are consequences of not going to the hospital?</p> <p><u>Probe related to influence of others related to going to the hospital</u>: Did others influence the decision to go to the hospital? How so?</p> |
|--|--|

Appendix B: Consent Form for Participation

University of North Carolina-Chapel Hill
Consent to Participate in a Research Study
Adult Participants
Social Behavioral Form

Participant ID: _____

IRB Study # 09-2023

Consent Form Version Date: September 21, 2010

Title of Study: Women's Experience of Seeking Care during Symptoms of Acute Coronary Syndromes

Principal Investigator: Leslie L Davis

UNC-Chapel Hill Department: School of Nursing

UNC-Chapel Hill Phone number: 919-949-2718

Email Address: lldavis@email.unc.edu

Faculty Advisor: Merle Mishel, RN, PhD

UNC-Chapel Hill Phone number: 919-966-4272

Email Address: mishel@email.unc.edu

Funding Source: Sigma Theta Tau, Alpha Alpha Chapter (International Nursing Honor Society)

What are some general things you should know about research studies?

You are being asked to take part in a research study. To join the study is voluntary. You may refuse to join, or you may withdraw your consent to be in the study, for any reason, without penalty.

Research studies are designed to obtain new knowledge. This new information may help people in the future. You may not receive any direct benefit from being in the research study. There also may be risks to being in research studies.

Details about this study are discussed below. It is important that you understand this information so that you can make an informed choice about being in this research study. You will be given a copy of this consent form. You should ask the researchers named above, or staff members who may assist them, any questions you have about this study at any time.

What is the purpose of this study?

The purpose of this research study is to learn about the experiences of women having symptoms of acute coronary syndromes and what they do about the symptoms. Some women have different experiences than others, therefore it is important to find out more from women like you.

You are being asked to be in the study because you had chest discomfort or other symptoms that were related to a condition called acute coronary syndromes.

How many people will take part in this study?

If you decide to be in this study, you will be one of approximately 30 women in this research study.

How long will your part in this study last?

If you agree to take part in this study, there will be at least one interview and possibly more if the researcher would like to ask more questions or clarify something discussed. The interviews will last approximately 45 minutes to one hour. You may be asked to participate in a second interview, which would occur at a mutually agreed upon date.

What will happen if you take part in the study?

After agreeing to take part in the study, a mutually agreed upon date and time will be determined for the first interview. In this interview you will be asked about the experiences you had before you came to the emergency room or hospital. The interview location will be either in the researcher's office, a private room in the hospital or clinic, your home or another mutually convenient location. The interview session will be digitally audio tape recorded (audio). You may request for the recorder to be turned off at any time during the interview. You may stop the interview at any time or choose to not answer any or all of the questions.

If a second interview is requested and you have agreed to be contacted for the interview you will be contacted at the phone number provided at the end of this consent form. If you are contacted for a second interview and you are not at home, the researcher will leave a message with my name, phone number, that we met at UNC Hospital and you were expecting my call.

What are the possible benefits from being in this study?

This research is designed to benefit society by giving us new knowledge about the experiences of women with heart disease. You may not benefit personally from being in this research study.

What are the possible risks or discomforts involved from being in this study?

Taking part of this study is not expected to be associated with any risk or discomfort; however you may experience uncommon or previously unknown risks. You should report any problems to the researcher. There is a potential risk of experiencing becoming emotionally upset when you talk about your experience with your heart symptoms. If this occurs keep in mind that you can stop the interview at any time.

How will your privacy be protected?

After each of the interviews the conversation from the audio tapes will be transcribed (typed up) removing any identifying information (your name or other information that could be linked to you). The original recorded conversation will be put on to the researcher's personal computer that is secure and will be kept until the end of the study at which time it will be deleted. All records will have a special code number on it for you so that you will not be identified by name. For example, people interviewed will have a number – 001, 002, 003.

Participants will not be identified in any report or publication about this study. Although every effort will be made to keep research records private, there may be times when federal or state law requires the disclosure of such records, including personal information. This is very unlikely, but if disclosure is ever required, UNC-Chapel Hill will take steps allowable

by law to protect the privacy of personal information. In some cases, your information in this research study could be reviewed by representatives of the University, research sponsors, or government agencies for purposes such as quality control or safety.

Will you receive anything for being in this study?

As part of this study you will be receiving a \$ 25.00 gift card from Wal-Mart for completing the first interview and a \$20.00 gift card from Wal-Mart for each follow-up interview (if needed).

Will it cost you anything to be in this study?

There will be no costs for being in the study

What if you are a UNC employee? Taking part in this research is not a part of your University duties, and refusing will not affect your job. You will not be offered or receive any special job-related consideration if you take part in this research.

What if you have questions about this study? You have the right to ask, and have answered, any questions you may have about this research. If you have questions, or concerns, you should contact the researchers listed on the first page of this form.

What if you have questions about your rights as a research participant?

All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject, or if you would like to obtain information or offer input, you may contact the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

Title of Study: Women's Experience of Seeking Care during Symptoms of Acute Coronary Syndromes

Principal Investigator: Leslie L Davis

Participant's Agreement:

I have read the information provided above. I have asked all the questions I have at this time. I voluntarily agree to participate in this research study.

Signature of Research Participant

Date

Printed Name of Research Participant

_____ I agree to be contacted for a second interview, if needed.

Contact Information for Second Interview:

Phone number: _____

Alternate phone number: _____

Signature of Person Obtaining Consent

Date

Printed Name of Person Obtaining Consent

Appendix C: HIPAA Authorization

University of North Carolina-Chapel Hill HIPAA Authorization for Use and Disclosure of Health Information for Research Purposes

IRB Study # 09-2023

Title of Study: Women's Experience of Seeking Care during Symptoms of Acute Coronary Syndromes

Principal Investigator: Leslie L Davis, MSN, RN, ANP

Mailing Address for UNC-Chapel Hill Department: School of Nursing, Campus Box # 7460

This is a permission called a "HIPAA authorization." It is required by the "Health Insurance Portability and Accountability Act of 1996" (known as "HIPAA") in order for us to get information from your medical records or health insurance records to use in this research study.

1. If you sign this HIPAA authorization form, you are giving your permission for the following people or groups to give the researchers certain information about you (described below):

Any health care providers or health care professionals or health plans that have provided health services or treatment for you such as physicians, nurses, hospitals, and laboratories, including but not limited to the UNC Health Care System.

2. If you sign this HIPAA authorization form, this is the health information about you that the people or groups listed in #1 may give to the researchers to use in this research study:

Your demographic information (age, gender, race, ethnicity), your admitting diagnosis, a review of your 12 lead EKGs that have been placed in your medical record, a review of your laboratory work related to your heart attack, and a review of your medical record that describes your symptoms you had before you came to the hospital.

3. The HIPAA protections that apply to your medical records will not apply to your information when it is in the research study records. Your information in the research study records may also be shared with, used by or seen by collaborating researchers, the sponsor of the research study, the sponsor's representatives, and certain employees of the university or government agencies (like the FDA) if needed to oversee the research study. HIPAA rules do not usually apply to those people or groups. If any of these people or groups reviews your research record, they may also need to review portions of your original medical record

relevant to the situation. The informed consent document describes the procedures in this research study that will be used to protect your personal information. You can also ask the researchers any questions about what they will do with your personal information and how they will protect your personal information in this research study.

4. If this research study creates medical information about you that will go into your medical record, you may not be able to see the research study information in your medical record until the entire research study is over.

5. If you want to participate in this research study, you must sign this HIPAA authorization form to allow the people or groups listed in #1 on this form to give access to the information about you that is listed in #2. If you do not want to sign this HIPAA authorization form, you cannot participate in this research study. However, not signing the authorization form will not change your right to treatment, payment, enrollment or eligibility for medical services outside of this research study.

6. This HIPAA authorization will stop in 3 months: _____

7. You have the right to stop this HIPAA authorization at any time. You must do that in writing. You may give your written stop of this HIPAA authorization directly to Principal Investigator or researcher or you may mail it to the department mailing address listed at the top of this form, or you may give it to one of the researchers in this study and tell the researcher to send it to any person or group the researcher has given a copy of this HIPAA authorization. Stopping this HIPAA authorization will not stop information sharing that has already happened.

8. You will be given a copy of this signed HIPAA authorization.

Signature of Research Subject

Date

Print Name of Research Subject

For Personal Representative of the Research Participant (if applicable)

Print Name of Personal Representative: _____

Please explain your authority to act on behalf of this Research Subject:

I am giving this permission by signing this HIPAA Authorization on behalf of the Research Participant.

Signature of Personal Representative

Date

Appendix D: Chart Information Obtained After HIPAA Authorization

| | | | |
|---|-----------------------------|------------------------------|-------------|
| Documentation of ACS event (from the medical record): | | | |
| 1. 12 Lead ECG: | <input type="checkbox"/> No | <input type="checkbox"/> Yes | Date/Time: |
| ST segment elevation | <input type="checkbox"/> No | <input type="checkbox"/> Yes | _____ |
| ST segment depression | <input type="checkbox"/> No | <input type="checkbox"/> Yes | _____ |
| T wave inversion | <input type="checkbox"/> No | <input type="checkbox"/> Yes | _____ |
| Other | | | |
| (specify: _____) | <input type="checkbox"/> No | <input type="checkbox"/> Yes | _____ |
| 2. Cardiac enzymes: | Date | Time | Lab Normals |
| Peak CK-Total level | _____ | _____ | _____ |
| Peak CK-MB level | _____ | _____ | _____ |
| Peak troponin level | _____ | _____ | _____ |
| 3. Documentation of Ischemic Symptoms: | Date | Time | Comments |
| Date/Time of Symptom Onset: | _____ | _____ | |
| Date/Time of Hospital Arrival: | _____ | _____ | |
| 4. Documentation of Prodromal Symptoms: | Date | Time | Comments |
| Date/Time Prodromal Symptoms started | | | |
| (if applicable): | _____ | _____ | |

DEMOGRAPHIC CHARACTERISTICS (completed by the study participant)

The following information is requested so we can describe the general characteristics of the people participating in our study. The information will remain confidential and your name will not be used in any way.

For the following questions, please circle or write in your answer.

1. Age: _____
2. Marital Status:
_____ Single
_____ Married
_____ Divorced/Separated
_____ Widowed
3. Do you currently live with another person(s)?
_____ No
_____ Yes; Number other than self living in home _____
Relationships of the persons who you live with _____
Ages of children/grandchildren who live with you if applicable: _____
4. Race:
_____ Black or African-American
_____ White or Caucasian
_____ Asian
_____ American Indian or Alaskan Native
_____ Native Hawaiian or other Pacific Islander
_____ Other (please specify _____)
5. Ethnic Group:
_____ Hispanic or Latino
_____ Not Hispanic or Latino
6. Years of education completed? _____
7. Employment status:
_____ Employed
_____ full time
_____ part time

☐ Unemployed
 ☐ by choice
 ☐ work as a homemaker
 ☐ disabled
 ☐ temporary (example sick leave)

☐ Retired

☐ Other (please specify): _____

8. Household Income:

☐ less than \$ 20,000 per year
☐ \$ 20,000 - \$ 39, 999 per year
☐ \$ 40,000 - \$ 59, 999 per year
☐ \$ 60,000 - \$ 79, 999 per year
☐ \$ 80, 000 or over per year.

9. Do you have some insurance or other assistance to pay for your care?

☐ Yes

☐ No

10. If yes to question 9: what type of insurance or coverage do you have?

(Please check all that apply to you.)

☐ Medicare
☐ Medicaid
☐ Private Insurance
☐ SSI
☐ Other
Specify: _____

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