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The Lived Experience of Wives and Husbands with Coronary Heart Disease

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UNIVERSITY OF SAN DIEGO
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THE LIVED EXPERIENCE OF WIVES OF HUSBANDS WITH CORONARY HEART DISEASE

By

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ABSTRACT

The purpose of this feminist hermeneutic study was to discover the meaning of living in the community with a husband who has coronary heart disease (CHD). Ten women, aged 47-74 who were married from 4 to 55 years, participated in unstructured face to face interviews. The women were interviewed 6 to 18 months after their husbands were diagnosed with medically or surgically treated CHD. Audio recorded transcribed interview data were analyzed to identify the essential themes and sub-themes. Texts were interpreted guided by hermeneutic phenomenology (Gadamer 1960/1989; 1976) and van Manen's (1990) research activities. A feminist lens was applied to the texts throughout the analysis and interpretation. Methodological rigor was achieved through the assessment of trustworthiness adapted from the work of Guba and Lincoln (1989).

The thematic analysis uncovered the following essential themes: a) "walking on a tightrope;" b) "keeping an eye on him;" c) "wrapping him in cotton;" d) "right in the middle of it;" and e) "I have to get through it." The first three themes, "walking on a tightrope," "keeping an eye on him," and "wrapping him in cotton" revealed the wives' focus on their husbands. The women feared that their husbands were vulnerable and assumed responsibility for protecting them from harm. The further essential theme emerged, "right in the middle of it," reflecting the wives sharing or ownership of their husbands' CHD. The wives shared the illness experience with their husbands and their own lives became overshadowed by CHD. Another essential theme, "I have to get through it," revealed the women's personal meaning of their husbands' CHD. The unveiling of the narratives uncovered women's lives of silence and the conversations not held. The women searched for the meaning of the experience and examined a life in the future without their husbands. The women's lives revealed moments of suffering as they struggled with the uncertain and sudden threatening nature of CHD in their lives. The findings of the study provide an understanding of the experience of women living with a husband with CHD and suggest the need for further research and have implications for nursing praxis.

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I dedicate this dissertation to the women who participated in the study. They shared the stories of their lives so that perhaps other women would benefit.

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CHAPTER I

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Phenomenon of Interest

The prevalence of coronary heart disease (CHD) in the United States is 13.2 million individuals (American Heart Association [AHA], 2004). From 1979 to 2001, the incidence of CHD listed as the primary diagnosis for American patients discharged from the hospital increased by 27 percent (Department of Health and Human Services [DHHS], 2004). If a person with the disease is part of a couple, then each one of the individuals experiences the illness (Benner & Wrubel, 1989). The suddenness of CHD, the uncertainty about treatment procedures and outcomes, the lack of direct medical supervision, the demands of a distressed patient, the fear of reoccurrence, disability, or death, as well as the chronic nature of the disease, all combine to force immediate changes both in the patient and their partner.

Until the early 1970s, the research on the impact of CHD included only the person with the illness (Biegel, Sales, & Schulz, 1991, p. 117). However, over the last 30 years, there has been much interest in researching wives of male patients with CHD after hospital discharge (Adsett & Bruhn, 1968; Bramwell, 1986; Mayou, Foster, & Williamson, 1978a; Thompson & Meddis, 1990; VanHorn, Fleury, & Moore, 2002). Coronary heart disease has a physical, financial, and emotional impact not only on the individual but also on the well partner (VanHorn, Fleury, & Moore, 2002; Waltz, 1986; Wishnie, Hackett, & Cassem, 1971). The psychosocial aspects of recovery from CHD consistently suggest a relationship between the adaptation by the patient and the (wife's) ability to be supportive (Di Mateo & Hays, 1981; Foxall, Ekberg, & Griffith, 1985; Suls, Green, Rose, Lounsbury, & Gordon, 1997). Frequently, recommendations from reported research of women with husbands who have CHD are developed from the perspective of improving patient outcomes rather than from understanding and assisting the partner.

As early as 1984, Stern reported that the “wife is frequently forgotten in a medical environment devoted to the patient" (p. 464). Now patients are discharged home with their spouses after even fewer hospital days for medically or surgically treated CHD (Stewart, Davidson, Meade, Hirth, & Makrides, 2000), and only one-third of the patients attend formalized cardiac rehabilitation programs (AHA, 2004). Within the home, the woman assumes the role of informal caregiver for the partner with the chronic illness of CHD. However, the meaning and context of this role has remained relatively invisible in previous research studies. What is missing in the literature is an understanding of the meaning and caregiving practices provided by the women who live with men who have CHD.

Purpose of the Study

The purpose of this feminist phenomenological study was to describe the lived experience of wives of husbands in the community who have (CHD). The specific aims of the research were to describe the caregiving practices of wives of husbands with CHD and the meaning of their experiences. The feminist phenomenological hermeneutic approach was used to answer the research question: What is the lived experience of women who live with men in the community who have CHD? The women in this study were asked to describe what it was like for them to reside with someone with CHD in order to understand the context in which they live.

Background

According to the AHA (2001), CHD includes myocardial infarction, angina pectoris, and ischemic and atherosclerotic heart disease. The women partners in previous research studies consistently were married to the men with CHD and therefore in the following discussion are referred to as wives.

Being the wife of a patient living with medically or surgically treated CHD in the community is emotionally and socially demanding. The emotional distress includes anxiety, depression, guilt, fear, insomnia, and the experience of an overall decrease in the quality of life (O'Farrell, Murray, & Hotz, 2000). Distress was comparable to a sample of women with a history of breast cancer (Artinian & Hayes, 1992). Caregiver distress was not static over time as shown in longitudinal studies (Gillis, 1984). For example, if the husband experienced further chest pain after hospital discharge, the wife experienced an increase in anxiety. Frequently, part of the wife's distress was related to fear (Thompson, Ersser, & Webster, 1995). Some findings indicate that the fear was caused by the women believing that they had contributed to their husbands' illnesses (Wishnie, Hackett, & Cassem, 1971).

Some studies purported changes in social and intimate relationships. Wives of patients with CHD had a change in social relationships through a loss of independence. A decline in marital functioning and in marital quality was related by some wives, and for some spouses, their relationships improved. Wives reported experiencing conflict due partly to their husbands' moods and behavior after CHD (Wishnie, Hackett, and Cassem, 1971). Conflict arose because husbands lacked the motivation and ability to do for themselves or, in contrast, the wives perceived that their husbands were doing too much.

There was concern by wives that their husbands were not following the prescribed medical regimen. Adding to the dilemma, wives hesitated to express their feelings and worries. Fear of resuming sexual activity, as well as financial worries, also were reported by some spouses. Improvement in the marital relationship sometimes was reported as a positive impact of caregiving.

Few studies described the context of caregiving by wives of patients with CHD. From the research it was reported that the wives assumed the caregiver role and then felt responsible for preventing their husbands' future illness MI (Artinian, 1991). However, women sometimes felt unprepared for the assumed roles. In a study examining coping response to distress and fear, protective buffering was positively correlated with wife anxiety (Coyne, Elard, & Smith, 1990). One study identified the following caregiving activities: managing lifestyle changes, monitoring, surveillance, vigilance, and adjusting to difficult patient moods and behaviors (Stewart, Davidson, Meade, Hirth, & Weld-Viscount, 2001). Patients who reported greater limitations received more instrumental support from their wives (Bennett & Connell, 1999). What is not revealed in the earlier studies is an understanding and meaning of these caregiving activities.

Overprotection is the caregiving activity most frequently identified in the research (Riegel & Dracup, 1992). Reported causes of overprotection were wife hostility, aggression, anger, fear, guilt, and anxiety (Wishnie, Hackett, & Cassem, 1971). Overprotection was reported to negatively influence, as well as positively influence, physical and psychological patient outcomes (Coyne, & Smith, 1991). Additionally, overprotection correlated in some studies with wife anxiety.

It is interesting to note that, when medical prognostic factors were controlled, studies reported that the presence of a wife negatively influenced mortality after myocardial infarction (MI) (Gorkins & Schron, 1993; Williams et al., 1992). In addition to decreased husband mortality, support from a spouse has been correlated with reduced stress (Frasure-Smith, 1991) and improved readjustment, self-esteem, mastery, coping with physical restrictions, (Ben-Sira & Eliezer, 1990), adherence to risk reduction behaviors, and recovery time for patients with CHD (Mayou, 1984). According to the research, there is a negative impact from being the wife of a husband with CHD, but for the husband there may be benefits.

The impetus for this proposed study grew out of my clinical experience in cardiac nursing, my involvement as a coordinator of a family cardiac support group, and my Master's thesis. The literature supports this author's clinical experience that the women living with men who have CHD experience distress. However, the labeling of the women's behaviors as overprotection denies the deeper understanding of the experience of caregiving as it is heard in practice. In the researcher's experience, women described the complexity of the impact of heart disease on themselves and their relationships. The women in the support groups, and the participants in the research project, were highly involved in their partners' recoveries and carried out activities that they believed would keep their husbands safe. For the women in the support group, the impact of CHD continued for months after the patient's initial diagnosis. To date, neither the caregiving activities, nor the meaning of the caregiving experience, are well described in the research.

The husband's CHD has an effect on the wife, and she has the greatest responsibility for, and influence on, the patient's recovery. However, there is an absence of research in describing the everyday experience of women partners of men with CHD. What is missing from the descriptions is the web of meanings of the illness experience for the women. Also, the intricate complex human experience of caregiving practices needs to be disclosed through the women's voices.

It is important to enhance our understanding of women partners' experiences with a sensitivity to, and conceptualization of, these often unseen practices. The potential for burden, stress, and role overload is present; however, the possibility of demonstrating personally one's values and sense of commitment is also present in caregiving. Examination of the phenomenon of caregiving, as it is experienced by those currently in the lifeworld, can provide insight into the meaning of the experience.

Feminist Perspective

This study was framed and interpreted from a feminist perspective. Through a feminist lens, care is a complex moral work and a practice. Giving care is simultaneously enriching and difficult.

Care-ethic

The care-ethic is committed to an established understanding of moral epistemology. According to Tronto (1993), care is a moral perspective best understood when rooted in actual practice. Interest in the ethic of care and moral philosophy gained interest with the development of feminist ethics. Philosophical reflection on the ethical significance of caring became popular following Carol Gilligan's (1982) research in moral psychology and the writings by educator Nel Noddings (1984). The neglect and subordination of caring in the discourse of conventional moral philosophy supports exclusion of experiences, interests, needs, and desires characteristically associated with women. Social, political, and cultural institutions traditionally have been founded upon the masculine ideals of morality (Held, 1995).

When social practices are characterized by selective or segregated participation, then different moral perspectives are likely to develop among individuals along these lines of segregation. Segregated practices are characterized by differences in social and practical power; consequently, conceptions of virtue are shaped by these differences (Benhabib, 1992; Fedar & Kittay, 1999; Tronto, 1993). Much of what women know about themselves and their world comes from knowledge constructed by men and does not fully account for their experience as women, nor for their ways of comprehending (Belenky, Clinchy, Goldberger, & Tarule, 1986). Caring is the demonstrated ability to perceive the world through the eyes of the other. Different ethical concerns of women and men are created by the differing responsibilities of the different kinds of relationships in which they typically engage (Walker, 1997). This care-ethic is part of women's morality because women "not only define themselves in a context of human relationships but also judge themselves in terms of their ability to care" (Gilligan, 1982, p. 17). Women's sense of self is organized around being able to make and maintain relationships (Miller, 1976). Women's experiences of connectedness lead to enlarged concepts of self, morality, and visions of relationships (Gilligan, 1982). This care perspective favors a contextual relational approach to ethics and values a maintenance of relationships with particular others.

Noddings (1984) says that caring connotes a way of being in the world as part of a unit larger than the individual. The relationship comes to have a unique existence beyond the individuals: to be attended to, cared about, and nurtured. According to Noddings, the particular structures which involve caring-for grow out of the family. She adds that caring affects both the one-caring and the one cared-for. It affects the one-caring because she must become engrossed in the other; it affects the cared-for because respective needs are met and she must then respond to and accept the care offered.

Care-ethic as a moral practice.

Gilligan (1982) believes that caring, as an interpersonal process, forms the foundation of the ethical response in persons. She observes that caring has received attention only as an outcome of ethical behavior rather than as an underlying structure, which she believes is the motivation for it. She states that moral living is based on our innate desire to care for others. According to Tronto (1993), the care-ethic is a practice rather than a principle or an emotion. It involves thought and action directed to some end. This moral practice involves taking responsibility, the taking care of (Noddings, 1994; Tronto, 1993). This practice is distinct from the concept of obligation which implies formal (e.g. legal) bonds. Moral reasoning is better served by a flexible concept of responsibility than by a rigid concept of obligation. According to Noddings, at the moment one cares, it becomes impossible to be preoccupied with the self. This selflessness is a key element in what Noddings calls the crucial moral question in caring. One of the strengths of Noddings' view is that moral motivation is rooted in something other than a desire to be rational, logical, or consistent.

The effect of this alternative moral and ethical system can change social values (Held, 1995) and has far-reaching implications for altering standards of freedom, democracy, equality, and personal development. This ethic of care builds trust and mutual responsiveness to need, both on the personal and the wider social level.

Care-ethic as work.

Care is a necessary social labor involving a balancing effort between safety and risk as well as between controlling and letting go. In our society, care is frequently trivialized and associated with the private, the emotional, the needy, and the weak. There is an ideological advantage to not noticing how pervasive care is in human life. To acknowledge how much care makes our lives possible undermines the legitimacy of the privilege enjoyed by the powerful. Society treats public accomplishment, rationality, and autonomy as worthy, while care embodies the antitheses of these values. To preserve the view that we are not needy, routine forms of caregiving often are ignored. Friedman (1993) states that caregiving should be taken seriously and its intrinsic worth and value recognized. The invisible nature of the care-ethic has resulted in its devaluation as work, even if it is a labor of love. Caring is a skillful moral practice.

Care-ethic as a complex practice.

To care well is a complex practice. In order to care, one requires knowledge about the other's needs, knowledge that comes from the other. Caring rests on knowledge peculiar to the particular person being cared-for. To gain requisite knowledge, the caring person must devote attention to learning what the other person needs. It is defined culturally, rather than universally in regard to specific needs; but all humans need some form of care (Robinson, 1998). The care-ethic is diverse in its possibilities.

Care-ethic as both enriching and difficult.

The self gains vitality and enhancement in relationship, and is not reduced or threatened by connections (Gilligan, 1982). Ruddick (1989) states that the care-ethic transforms moral judgment and practice giving rise to a distinctive way of thinking. To care for someone has connotations of desire, including the desire for the other person's company, or enjoying being with another person. It has connotations of being careful with, understanding, or appreciating the other. However, the ethic of care is not always a simple practice.

Noddings (1984) states that to care for someone can have anxiety, a potential burden. Friedman (1993) in discussing personal relationships is cautionary on the ethic of care because of the danger of maintaining oppressive practices. Conflict may arise between the care-giver and receiver and between their interests (Feder & Kittay, 1998). It is neither self-referring nor self-absorbing; it implies action and the acceptance of some form of burden activity that includes everything that we do to maintain, continue, and repair our world so that we can live in it as well as possible (Tronto, 1993).

Addressing the burden of care is complicated by the reality that caring is also a labor of love and involves relations of profound importance. There is emotional work in caring for another that may be transparent to others. The care-ethic literature informs us that personal relationships, care, and attentiveness to contextual detail are crucial matters of ordinary moral reasoning. This perspective is not represented in the cardiac research literature.

Philosophical Perspective

Phenomenology

The philosophy and method that guided this research was hermeneutic phenomenology. The phenomenological movement emerged from the perceived inappropriate use of positivism for the study of human sciences (Gadamer, 1996). Throughout the philosophical literature several traditions or movements are identified as phenomenology. According to the father of phenomenology, Edmund Husserl (1931/1983), it is the science of *essences*, an *eidetic science.* In phenomenology, the *lifeworld (Lebenswelt)* or the world of lived experiences is important (Moran, 2000). Husserl moved away from the positivist orientation of the science and philosophy of his day towards the subjective experience as the source of all of our knowledge. Underlying phenomenology is the describing of the everyday experiences, the taken-for-grantedness. Husserl appeals to return to fundamental phenomenology, to the things (*Zu du Sachen*) to the things themselves (*den Sachen Selbest*). The meaning of this appeal is that philosophy must begin with the phenomenon and examine the revelations of its own insights. According to Moran (2000) the roots of knowledge are found in consciousness of the knowing subject where the knowing exists.

Hermeneutic phenomenology.

Simply stated, hermeneutic phenomenology is a human science that studies persons. A more complex definition is that hermeneutic phenomenology is a "philosophy of the personal, the individual which we pursue against the background of an understanding of the evasive character of the logos of other, the whole, the communal, and the social" (van Manen, 1990, p.7). The hermeneutic orientation of phenomenology has been most linked with Martin Heidegger and Hans-Georg Gadamer (van Manen, 2002b). Martin Heidegger, rather than focusing on the epistemology of Husserl, considered the ontological. Heidegger asked, “what does it mean to be a person?” rather than “how do we know what we know?” Hermeneutic phenomenology is not the purely descriptive phenomenology of Husserl, rather it is concerned with the interrelating and understanding of text (Gadamer, 1960/1989; van Manen, 2002a). According to Heidegger to be human is a self-interpreting activity that occurs in a background of shared culture and meaning (1927/1962). From this view, everyday human interpretation and existence can expand to include human existence as intrinsically interpersonal where we live out a network of relationships with others. Individual interpretation is a particular effort of realizing and making sense of itself. For Heidegger, a person’s *background* is handed down by culture. *Pre-understandings* are those common themes, such as language and traditional practices, which assists someone in understanding a culture (Heidegger, 1962). It is through interpretation that a person lives in a world.

Hans-Georg Gadamer, a student of Heidegger, moved hermeneutics away from the conscious method of interpretation towards ordinary language as a medium for interpretation (Gadamer, 1977). The importance of context and the hermeneutic circle included in Gadamer’s work have their foundation in Heidegger. However, Gadamer enlarged and somewhat varied from Heidegger in the view of the person and the concept of horizons and fusion of those horizons (Wildman, 1999). The philosopher Gadamer (1977; 1960/1989; 1996) specifically informed this study.

The goal of hermeneutic phenomenology is to “try to understand everything that can be understood” (Gadamer, 1977, p. 31), to arrive at a deeper understanding of human existence or *Being* through the interpretation of the phenomenon under study (Allen & Jensen, 1990). According to van Manen (1997), the purpose of a good phenomenological text is to make the reader suddenly see the phenomenon in a way that enriches understanding of that everyday life experience.

Subjective-objective.

According to Gadamer there is no subjective-objective dichotomy. The world is the one we are, the one we live. Looking from the outside or telling from the inside does not help us in finding meaning because humans are contextual: we are both inside and outside at the same time. The object is not the object, but a unity of object and viewer since the object being viewed is also the counterpart of self [the viewer]. Similarly, van Manen (1990) sees subjectively and objectively as not mutually exclusive because both find meaning and significance in the personal relation the researcher establishes with the object of the phenomenon of inquiry. The importance of being as perceptive as possible and maintaining an orientation to what is being studied in a personal way involves subjectivity. Being oriented to the phenomenon and remaining true to that which is being explored involves objectivity. A deeper understanding of the phenomenon happens when the investigator is both subjective and objective at the same time.

Context.

Important to hermeneutic phenomenology is context. Humans cannot escape culture or individual circumstances that include, but are not limited to, gender, ethnicity, social class, and tradition (Allen, 1995; Lawler, 1998). Individuals share commonalities with other members of the same group.

Each reader produces a new interpretation of a text based on her context as it interacts with the prior context. The real meaning of the text is not just understood by the original author: each interpreter places context within the new interpretation. To clarify, the importance of context does not end with the initial interpretation of the text. There is no finality of interpretation and there is no absolute truth (Gadamer, 1960/1989; Pascoe, 1996; van Manen 1990). Continuous interpretation is what Gadamer calls the "fusion of horizons."

Fusion of horizons.

The horizons of experience, before, after, and in the present are continually fused as people self-interpret and are interpreted by others. Context and history are part of that fusion. When interpreting a text, the horizons of the creator and the interpreter are fused to form a new horizon resulting in a new interpretation and understanding of the experience. Each reader of the new understanding brings her own horizon that fuses with the one present, creating yet a new interpretation and understanding (Allen, 1995; Gadamer, 1960/1989). The worldview that the participant brought into the fusion of horizons can lead to increased understanding of not only the phenomenon but the participant's reality (Smith, 1999). This interpretation is done within the hermeneutic circle.

Hermeneutic circle.

In the hermeneutic circle, interpretation reveals understanding, and that understanding rewrites interpretation as the researcher strives to uncover, layer by layer, meanings of the experience of interest (Allen & Jensen, 1990). The process of moving between background of shared meaning (the contextual whole) and the focused experience with it (the part) is the hermeneutic circle. Gadamer (1960/1989) put forward that every particular (part) is fully understood only in terms of the whole, which in turn is understood only in terms of the particular. It is within the hermeneutic circle that the fusion of the horizon occurs, and reoccurs again. This action allows the researcher to gain a deeper understanding of the meanings participants give to experience but maintains the human actions within the context of the world (Pacoes, 1996). The circle is neither subjective nor objective: it is the interplay of the text with its context and interpreter. The circle is not a methodological structure; it is an "element of the ontological structure of understanding" (p. 92).

Significance of the Study

Heart disease continues to be a major cause of disability and significantly contributes to increases in health care costs in the United States (National Heart, Lung, and Blood Institute, 1998). Coronary heart disease (CHD) accounts for the largest proportion of this heart disease (AHA, 2004).

The significance of this research lies in its potential contribution to nursing practice and education. A priority for the National Institute of Nursing Research (NINR) and the National Institute of Aging (NIA) is to identify research based interventions to improve caregiver health and quality of life, caregiving processes, and caregiving effectiveness and health outcomes. Their key positions are to advance science by focusing the research on the caregiver. The definition adopted by the NINR (2003) is that "caregivers are individual who provide extraordinary care, in the home setting involving significant amount of time and energy for months or years" (Biegel, Sales, & Schultz, 1991). The tasks may be . . . emotionally, socially, or financially demanding (Biegel et al.). They are not the normal activities that a family member regularly engages but rather the extraordinary activities of informal caregiving for someone with a chronic illness that requires partial or full dependency on others (NINR). The definition of a caregiver and caregiving by the NINR provides a lens to examine and understand the literature on partners of patients with CHD. Central to the NINR definition is the importance of understanding the caregiver, their quality of life and health, and the process itself.

Although the emotional distress of wives is recognized in the cardiac literature, little research has been done to uncover the meaning of that lived experience for the women. Symptom scales, survey questionnaires, and behavioral checklists attempt to quantify that experience. Within this framework, illness is understood to be like other stressful events and adaptation is achieved depending on how effectively the person appraises the event, mobilizes support, and copes (Hill, 2000). The thinned-out image of the wife during her husband's recovery from CHD that emerged from research may be scientifically replicable, but ontologically invalid. Without this study, the understanding of the meaning of being a partner of a cardiac patient remains hidden. What is it like to live with someone who according to the National Heart, Lung, and Blood Institute (1998) has a five to seven times higher risk for heart attack and death than among the general population?

It is important to look at what is currently available in practice for patients and their partners after the diagnosis of CHD. Some patients attend formalized cardiac rehabilitation programs that have remained relatively the same since the 1980s. After discharge a patient enters Phase II Cardiac Rehabilitation: that includes outpatient supervised telemetry monitored exercise, education, and lifestyle modification and counseling for approximately 12 weeks. Following this is Phase III Cardiac Rehabilitation: supervised non-telemetry monitored exercise and education programs (California Society for Cardiac Rehabilitation, 2005). A number of publications have greatly influenced cardiac rehabilitation programs. The Agency for Health Care Policy and Research (AHCPR) published guidelines in 1993. The outcomes included exercise tolerance, improvement in symptoms, lowering of lipids, reduction in cigarette smoking, reduction in mortality, and improvement in psychosocial well-being. There was a great focus on exercise and little on the partner or the nurse's role in rehabilitation. The AACVPR publications in 1995, 1999, and 2004 show the continued interest and changing recommendations but the major focus in these documents are also on exercise training and risk stratification. In the latest guidelines (AACVPR, 2004) there is one short paragraph that suggests consideration of "family issues" and "domestic needs". Even though nurses are the major members of the cardiac rehabilitation team, their expertise and nursing's knowledge is relatively invisible in the provision of care guidelines in these important documents.

A further concern is that all patients do not have access to cardiac rehabilitation programs. A minority of those who are eligible, particularly women, nonwhites, older adults, and the less educated participate (Thomas , Miller, Lamendola, Bona, & Kendrick, 1996) or are referred to cardiac rehabilitation (Halm, Penque, Doll, & Beahrs, 1999; Heldal, Steine, & Dale, 1996). Currently only a minority of patients and their partners are referred, attend, or have access to the benefits of cardiac rehabilitation.

Understanding the depth of the impact of CHD on the well partner and the context and complexity of the caregiving provided would help in the development of cardiac programs of support for each member of the couple. Understanding the caregiving provided by female partners of men with CHD will be essential as members of the nursing profession strive to understand the full meaning of the caregiving experience for caregivers and the ramifications of the experience for those individuals. Such research can identify areas for further investigation in both the practical and theoretical domains.

The uniqueness of the current study was that it went directly to the caregivers to give voice to their informed perspective of the experience. Insight into the lived experiences of the caregivers provides a foundation of understanding for healthcare providers. Nurses need knowledge about women that not only describes their unique health care needs but describes their reality without gender bias. Without this study another distinctive woman's experience remains concealed. This study contributed to current knowledge that is not influenced by a male perception of the world.

Authenticity in interaction depends upon the nurse's existential awareness of illness as experienced reality, rather than objective signs and symptoms. The ontolological approach to nursing care assumes that the understanding of the client's illness reality is central, as well as essential, to the provision of humanistic care. The provision of care is contingent upon an understanding of the couple and individual's illness reality as transformed by the event. Without this, and similar studies, nurses understanding of the illness experience remains rooted in narrow and static descriptions.

This study contributed to nursing education by providing a rich description of the experience of being a woman who lives with a man with CHD. There is a lack of narratives from nursing practice that can be used to teach students about the meaning of living with an illness. Skills that nurses provide to offer support to individuals and families are often taught out of context to students (Morse, 1991). That is, we are teaching appropriate responses to sadness, anger, and distress in a stimulus-response mode. The significance of the unveiling of the women's experience may lead to recognition that this living with is more complex than previously realized. Knowledge gained from the study might guide the development of interventions that are supportive and sensitive to the experiences of women. These interventions could be designed to enhance woman centered support. By making the experience visible to nurses this study would encourage nurses to reframe knowledge and care practices within the lives, values and norms of women. These changes could include how assessment questions are asked, how women partners are included in discharge planning and teaching, and how nursing support is offered. The results of this study can add a dimension to the ways health care providers can be of assistance and support to caregivers.

Greater theoretical understanding also can be gained about the concept of caregiving, adding to the body of nursing knowledge. Such theoretical understanding will be essential as members of the nursing profession strive to understand the full meaning of the caregiving experience and the ramifications of the experience for those individuals.

CHAPTER II

Context of the Inquiry

Patients who have medically or surgically treated myocardial infarction, angina pectoris, and ischemic and atherosclerotic heart disease have the diagnosis of coronary heart disease (CHD) (AHA, 2001). The literature review provides an overview of the cardiovascular research related to the female partner of a patient who is living in the community with CHD. In the research studies, the terms convalescence, recovery, and rehabilitation are used interchangeably to refer to the time after the patient is discharged from the hospital because of CHD. In the literature, the time frame for this period is from weeks to one year. In all of the studies, women partners were identified as wives, and so in the discussion of those studies, wives will be the label used for the women.

Impact of Caregiving on Women

For more than 30 years, research findings have indicated that wives of patients with CHD experience distress. The early interview studies of the 1970s by psychiatrists who identified and interpreted wife distress had great influence on the future research and healthcare for women. In a study examining convalescence, Wishnie, Hackett, and Cassem (1971) interviewed 18 male patients and their wives three to nine months following hospitalization for MI. They found that the wives had significant anxiety. The researchers reported a steadily eroding conflict in all couples over the implications of the illness. According to the researchers, the wives were frustrated because they were unable to express grievance and anger, fearing that these expressions would "bring on another MI" (p. 1294). The investigators concluded that wives felt guilty about being instrumental in their husbands' heart attacks. In another interview study (Stern & Pascale, 1979), wives also reported guilt because they had contributed to their husband's MI by not insisting before diagnosis on changes in diet, stress, exercise, or smoking. These researchers reported anxiety and depression in more than 25% of the 38 wives six months after their husbands' MI.

A further description of wives' distress was provided by Skelton and Dominian (1973). Their study was designed to identify, through interviews, the psychological consequences of MI on wives (n=65) at three, six, and 12 months. The wives reported stress as feelings of anxiety, loss, fear, depression, anorexia, tension, and sleep disturbances. According to the wives, these symptoms were due to experiencing a loss of control as well as fear of another MI and of their husbands' reactions to the MI. Of the 65 patient-husbands, 57 had chest pain after hospital discharge and their wives experienced an increase in anxiety due to feeling unprepared on what to do to help their husbands (p. 102). One year after the MI, 39 of the 65 wives continued to experience emotional distress, some sleep disturbance, depression, anxiety, and lack of sexual intimacy.

In a series of interview studies by Mayou and his colleagues, the wife suffered consequences which were often as great as for the patient following MI (Mayou, Foster, & Williamson, 1978a, 1978b; Mayou, Williamson, & Foster, 1978). In one reported study, the investigators used an interview guide and rating scale to measure psychological distress and mental status (Mayou, Foster, & Williamson, 1978a). These measures were not defined in the report. The researchers indicated that the wives of men (n=82) having a first MI, two months and one year earlier, experienced considerable distress (Mayou, Foster, & Williamson, 1978a). Eighteen wives reported severe mental disturbance and 19 reported moderate mental disturbance. In a later article reporting this same study, the researchers stated that there were unexpected difficulties among wives such as anxiety, depression, fatigue, irritability, poor concentration, and insomnia (Mayou, Foster, & Williamson 1978b).

A nursing study designed to determine couple satisfaction with information and emotional support during the husband's hospitalization provided further description of the wife distress (Thompson & Cordle, 1988). All of the 76 respondents, six weeks after hospitalization, reported in a mailed questionnaire developed for this study, feeling anxious and depressed. Over three quarters of the wives indicated that they experienced fatigue and insomnia, and more than one-half had financial worries and concern about the future. Thompson et al. (1995) further investigated through interviews the experience of 20 wives one month after their husbands' myocardial infarctions. The women were often tearful during the interview and reported anxiety and fear. The investigators noted that, in contrast, the patients minimized the significance of the MI and wanted things to get back to normal.

The previous studies, obtained from interviews and questionnaires, indicated wives of patients with CHD report various manifestations of distress. However, Croog and Fitzgerald (1978), drawing on a larger study, attempted to identify the wives' level of subjective stress with quantitative measures. Results on the Subjective Stress Scale, and a variety of demographic and clinical variables one year after the husbands' MI, were measured. This sample (n=263), larger than previous studies of wives, noted there was a high level of subjective stress. However, there was no correlation found between wives' stress scores and their husbands' (physician rated) degree of illness and impairment, nor did other variables, age, socioeconomic status, nor employment, explain the levels of subjective stress. Croog and Fitzgerald concluded that the wives' subjective level of stress may be less associated with external circumstances than with their "personality orientation and capacity" (p. 171). However, the researchers did not report scale reliability and validity for the population. Although not clearly correlated with the severity of patient illness, wife stress reports seemed highest for those husbands who had a subsequent hospitalization during the 12 month study.

A number of studies have investigated spousal distress by using a stress and coping framework. Nyamathi (1987; 1988) used a modified Lazarus and Folkman (1984) stress and coping interview guide to examine factors influencing coping in 40 wives whose husbands were hospitalized within the previous 12 months. The factors in this cross sectional design were: (a) cognitive appraisal; (b) personal and environmental factors; and (c) coping resources and responses. During the convalescent period women reported loss of independence, marital discord from spending long periods of time with their husbands, concern about leaving their husbands unattended, and worry about the resumption of sexual activity. More than one-half of the women reported concern about their husbands' lack of motivation and ability to do for themselves, their irritability and argumentativeness, and their unwillingness to follow physician's orders.

Most researchers using a stress and coping framework view adaptation from an individual perspective. However a group of social psychologists, from focus group input with couples after MI, redirected the traditional individual coping framework to an interdependent dyadic relationship focused coping one (Coyne et al., 1990).

From analysis of the focus group data, a cross-sectional retrospective design was used to investigate coping in 56 couples six months after a husband's MI (Fiske, Coyne,

& Smith, 1991). Wives completed the Michigan Family Heart Questionnaire that was developed from their earlier focus group study (Coyne et al., 1990). The Likert subscales for the questionnaire measured pre-coronary marital adjustment, spouse psychological burden, and spousal coping. Coefficient alphas for the subscales ranged from 0.67 to 0.86. According to the researchers, the overprotectiveness subscale modest reliability score (0.67) was related to the scale having only having four, rather than five, choices. Wives also completed the Hopkins System Checklist for depression; however, reliability and validity results were not reported for the study population. The researchers reported that wives were as distressed as the patients. In addition, wives' distress had a positive relationship with protective buffering. Hiding concerns, denying worries, and yielding to the partner in order to avoid disagreements, was the definition of protective buffering used in the study. The researchers stated that they were unable to reduce relationship focused coping to problem and emotion focused coping criteria.

The previous research studies were specific to wives of patients with MI. However, CHD also includes those patients treated with invasive procedures such as coronary artery bypass graft (CABG) and percutaneous tranluminal coronary angioplasty (PTCA). Distress and a significant decline in marital quality were noted in 67 wives of patients having CABG (Artinian, 1991). Marital quality at the time of hospitalization, and six months after discharge, were measured by the Dyadic Adjustment Scale. Additional scales used were the: Norbeck Social Support Scale; Indices of Coping Responses; and Strain Questionnaire. The previous scales were not normed on the study population. The Family Inventory of Life Events and Changes total coefficient alpha was 0.86 for the study population. Other measures used and developed for the study included: Spouse

Stressor Scale; Role Strain Scale; and a Cantril Self-Anchoring Ladder. Cronbach alphas were reported on the study population and ranged from 0.87 to 0.95. One year after hospital discharge, the 49 wives who still were in the study, had mean quality of life scores below those reported by a healthy sample and comparable sample of women with a history of breast cancer (Artinian & Hayes, 1992).

Another study examined patient and wife distress after medical and or surgical treatment for CHD. A cross sectional design was used to identify distress in wives (n=213) of patients who had an MI, CABG, or PTCA (O'Farrell, Murray, & Hotz, 2000). Of the 690 cardiac rehabilitation patients asked to participate, 388 declined. The researchers used the Brief Symptom Inventory Scale to categorize wives as either distressed or non-distressed. Sixty six percent of the women fell into the distressed category when compared to a non-clinical population. The distressed and non-distressed groups were then compared using the following instruments: (a) Heart Disease Hassles Scale; (b) Coping Strategies Scale; (c) Miller Intimacy Scale; and (d) the McMaster Family Assessment Device. Reliability and validity were reported from previous studies. Distressed wives reported as follows: using disengagement (t=6.91; p=.0001); having less intimacy (t=-3.99; p=.0001); and having poor family functioning (t=5.86; p=.0001). Psychological distress included feeling tense, having trouble falling asleep, and feeling (they were) easily hurt. The stressors included: (a) worry about recovery, prognosis, treatment, returning to work, and finances; (b) moodiness of the patient; (c) sexual concerns; and (d) experiencing helplessness. As in most previous studies, the wives after their husbands' discharge from the hospital experienced distress and changes in their own lives.

Synopsis of Research on Impact of Caregiving on Women

The cited research suggests that the caregiver tasks performed by wives of patients with CHD may be emotionally, socially, or financially demanding. Distress was comparable to a sample of women with a history of breast cancer (Artinian & Hayes, 1992). The emotional distress of wife caregiving for a patient with medically or surgically treated CHD included anxiety, depression, guilt, fear, insomnia, and decline in quality of life. However, other studies have found that women generally, whether patients or caregivers, were at an elevated risk for a variety of negative outcomes following MI or CABG (Moore, 1994; Revenson, 1994). In contrast Gillis (1984), in a study that included one-third men, reported that the role of caregiving spouse, rather than gender per se, most closely related to stress reports six months after hospitalization for CABG. However, the previous study was limited by sample size.

Further descriptions of the distress experiences were provided by some studies. Caregiver distress was not static over time as shown in the longitudinal studies. For example, if the husband experienced further chest pain after hospital discharge, the wife had an increase in anxiety. Frequently, part of the wife's distress was related to fear. Fear often was disease-related; however, anxiety was not related to physician rated husband illness in the Croog and Fitzgerald study (1978). Some findings indicated that the fear was due to the women believing that they contributed to their husbands' illnesses. A reported coping response to distress and fear was protective buffering which was positively correlated with wife anxiety. Most of the studies examined distress from an individual wife perspective; however, Coyne et al. (1991, 1992) suggest an interpersonal relationship-based understanding of the stress of couples living with CHD.

Some studies described changes in social and intimate relationships. Wives reported a change in social relationships through a loss of independence. A decrease in the quality of marital functioning was reported by some wives, and for some spouses their relationships improved. Wives reported conflict due partly to their husbands' mood and behavior after CHD. Conflict arose because husbands lacked motivation and ability to do for themselves; or for others, wives perceived that their husbands were doing too much. There was concern by wives that their husbands were not following the prescribed medical regimen. Adding to the dilemma, wives feared expressing their feelings and worries. Fear of resumption of sexual activity, as well as financial worries, also were reported by some wives. The only positive impact of caregiving sometimes was reported as improvement in the marital relationship.

Context of Caregiving

The following portion of the literature review examines the caregiving context through research studies that provide knowledge about the wives' caregiving roles and activities. The caregiving role includes both direct and indirect care activities (Swanson et al., 1997). According to Gottlieb (1988), caregiving activities include assisting with activities of daily living, managing medical treatment requirements, coordinating healthcare, making personal adaptations, and dealing with difficult patient behaviors associated with the illness.

Caregiving Role

Dickerson (1998) reported in a study on help seeking, that wives (n= 24) assumed the sole responsibility for the patient after hospital discharge. In this study, referred to as phenomenological, data were collected through semi-structured interviews and focus groups at three to four weeks after hospital discharge. However, in another study, whether the woman was the patient or the spouse, typically the woman assumed pre-existing caretaker roles after the hospitalization for CHD (Coyne et al., 1991).

Studies using role theory to describe patterns of behavior in couples after MI also indicated role responsibility for the wife. According to role theory interactions between members of the social structure define expectations for behavior, responsibilities, and privileges (Fife, 1985). The theory assumes that stability is the normal, desired state. A study framed by role theory, used a semi-structured interview schedule to examine the support role of wives ($n=82$) after their husbands' first MI (Bramwell, 1986). The wives were interviewed two to three weeks after hospital discharge. In the study, 44 percent of the women reported unclear role requirements and that this was due to a lack of guidance about their husbands' diets and physical activities. Bramwell and Whall (1986), using the same subjects, investigated the perspectives and perceptions of wife support role performance, the husband's condition, the ability to act supportively, as well as how these factors contributed to wife anxiety. Role clarity and support role performance instruments were developed for the study and included emotional, physical, and social factors. Anxiety was measured by the State-Trait Anxiety Inventory and self-esteem was measured by the Rosenberg Self-Esteem Scale. In this study, coefficient alphas ranged from 0.6 to 0.95. Path analyses to examine patterns of influence on anxiety demonstrated that wives' support role performance had a direct negative effect on their own anxiety ($r=-0.235$; $p< 0.05$).

Rather than using support role, Bennett and Connell (1999) used an instrumental support and coping framework for a cross-sectional study of the dyadic process in couples when the husband (n= 43) had an MI. The investigators used the Dyadic Adjustment Scale, DUKE Social Support Questionnaire, COPE Scale to measure coping, and PEEL index to measure MI severity. Reliability and validity scores were not reported on the study population. Patients who reported greater limitations also reported more instrumental support from their wives. Anxiety scores for the wives were significantly correlated with the disease variables. Stepwise multiple regression showed only perceived physical limitations to be associated with anxiety ($r=0.39$; $p<0.05$). Interestingly, the wives' anxiety scores were not associated with any measure of patient affect but, rather, associated with coping strategies (e.g., venting emotion and suppression of competing activities).

Caregiving Activities

A frequently reported wife caregiving activity is protection, usually referred to as overprotection in the literature. Classic early research developed the foundation for wife overprotection as a behavior that is both studied and interpreted in CHD caregiving. Wishnie, Hackett, and Cassem (1971) found in their interviews that wives tended to "overprotect their husbands in an aggressive way" (p. 1294). According to these researchers, "solicitousness was of a punitive nature, thought to represent an indirect expression of suppressed anger" (p. 1294). The researchers explained that the wives' anxiety was due to their perceived role in promoting or retarding the cardiac process.

Other researchers reported that wives (n=6) needed to control their husbands, be responsible for them, and inhibit negative expressions to prevent further heart attacks (Adsett & Bruhn, 1968). According to these investigators, the women denied their own needs in order to mother their husbands, and this was their way of coping and dealing with uncertainty. However, the wives were married to men who one year after MI were identified by the researchers as having “high drive and intense frustration” and “more than the usual psychological difficulty adapting” to their MI (p. 578). The husbands’ characteristics were identified from unreported psychological tests. The data were collected during wives’ and couples’ short term research and therapeutic psychotherapy sessions and group interviews. The investigators stated that the overprotective attitude of the wife influenced the patient’s emotional response to MI and his clinical outcome. However, this particular relationship was not demonstrated in this interview study.

Other studies interpreted the wife’s overprotection as an activity that negatively influenced the husband’s outcome after MI. The investigators reported that, one year after the MI, husbands were irritable, anxious, and overly demanding, and the wives colluded in their husbands’ dependency (Skelton & Dominian, 1973). Additionally, the researchers stated that because the wives felt guilty, fearful, and distressed, they continued to manage their husbands’ disease and maintain an overprotective role. According to the researchers, the wives used a frequent refrain of, ‘If he lives, I must protect him and never let him do so much again” (Skelton & Dominian, p. 101). In addition, the wives reported a lack of preparedness regarding what to do for their husbands.

Not only was husband dependency an outcome of the wife’s overprotection, but according to other investigators, this behavior usurped the activities and responsibilities of the recovering spouse and compromised husband recovery and rehabilitation (Stern & Pascale, 1979). The researchers described the women as being in a double bind: being accused by their recovering husbands that they were nagging and overprotective or that they were uncaring and cold. In a study of 201 Swedish men who had an MI, wife overprotection correlated with emotional instability, health preoccupation, and self reports of chest pain in the husbands (Wiklund, Sanne, Vedin, & Wilhelmsson, 1984). However, only seven percent of the husbands felt overprotected.

In the previous studies, overprotection was identified through interviews by investigators who were psychiatrists or psychologists. In contrast another study used quantifiable measures to examine the relationship of wives' overprotection of husbands and negative physical and psychological recovery outcomes (Clarke, Walker, & Cuddy, 1996). Husbands (n=52) were interviewed in the hospital by a research nurse who rated the patients' distress on a 1 to 10 point scale. At the same time, patients completed the Family APGAR and a Self Efficacy Scale estimating future functioning in three months. Additionally, wives completed the same two scales and a Zung Depression and Anxiety Scale. At three months the spouses completed the same scales with the addition of the Psychosocial Adaptation to Illness Scale. Husbands completed the PEEL Prognostic Index to measure MI severity and the Specific Activity Scale to measure cardiac recovery. The 34 item Influential Relationships Questionnaire was used to measure perceived overprotectiveness and criticism. This scale initially was developed to measure perceived interpersonal characteristics of care, overprotectiveness, and criticism in relationships of patients with schizophrenia. None of the scales were normed on the study population. Findings indicated that husband-perceived overprotectivness was correlated: (a) positively with husband's own anxiety and depression (r=0.051-0.056; p=0.0001); (b) positively with perceived wife criticism (r=0.063; p=0.0001); and (c) negatively with quality of life (r=0.06; p=0.0001). However, perceived overprotection was not related to husbands' confidence in their own functional recoveries and abilities. In fact, patients who were less optimistic about their functional ability in the hospital perceived themselves to be overprotected at three months. Interestingly, wives' anxiety was not correlated with their husbands' perceived overprotection.

Some researchers incorporated the concept of overprotection into the coping framework. Rather than being psychologically abnormal, Coyne and Fiske (1992) considered that overprotection may be part of coping, a normative process (p. 140). They defined overprotectiveness as a protective, buffering coping style. However, these researchers reported family descriptions of a nagging, overprotective spouse who felt responsible for controlling the behavior of a patient who wants to become more active than recommended by the physician in an attempt to determine the limits of his physical abilities. The researchers reported that the correlates suggested that the wife felt more burden than hostility. But, they add, wife overprotection undermines the patient's self-efficacy.

In another study, investigators examined the relationship between the protective buffering of coping and psychological distress in both spouses (n= 43) at four weeks and six weeks after MI (Suls et al., 1997). Patients and spouses completed the short form of the Hopkins Symptom Checklist to measure distress. Husbands reported cardiac symptoms through four questions taken from the Michigan Family Heart Questionnaire. Coefficient alphas for the questionnaire ranged between 0.85 and 0.90. Marital satisfaction and protective buffering for each partner were measured with parts of the Michigan Family Heart Questionnaire. Coefficient alphas for the adjusted protective buffering questionnaire ranged from 0.86 to 0.92. Protective buffering by the wife was associated with wife distress.

The negative outcomes of overprotection were further explored through an empirical study of overprotection and its relationship to cardiac invalidism. One hundred and eleven spouses, 90 of whom were wives, completed questionnaires and rating scales measuring invalidism, emotional distress, health perception, and dependency on others (Riegle & Dracup, 1992). Overprotection was measured using the UCLA Social Support Inventory. This Likert scale measures emotional and informational support desired, received, sought, and reciprocated from another person. Most of the patients in this group (88) reported being overprotected, while 28 said they didn't get enough support; and two said they received just as much as they wanted. Emotional measurements included: (a) Self Perception Inventory for self esteem; (b) Profile of Mood States for emotional distress; (c) General Health Perceptions Questionnaire; (d) Eysenck Personality Questionnaire to quantify personality characteristics; and (e) the Interpersonal Dependency Inventory. Physical measurements included the Coronary Prognostic Index to assess disease severity and Specific Activity Survey to measure functional status. One month after hospital discharge, overprotected patients were significantly less angry, anxious, depressed, and confused than those receiving inadequate support. Four months after discharge, overprotected patients remained significantly less angry, though there were no significant differences in the other measurements.

A few studies have shown a positive or a neutral relationship between wife protection and outcomes for the patient and wife. Mayou (1984) found that 12 months after MI, protectiveness was not related to the mental state of either the patient or spouse, or the quality of the marriage. However, spousal protectiveness was positively correlated with patient coping, a finding also assessed by interview. Additionally, Waltz (1986) found that inadequate support in a marital relationship, hindered patient adjustment and increased psychological and physiological invalidism in patients after MI.

Overprotection has become part of the language that both spouses use in describing wife caregiving activities. Wives stated it was best not to nag or overprotect their husbands in the Nyamathi study (1987). Spouses dealt with fears and emotions of overprotectiveness by clarifying concerns and questions with support networks (Nyamathi, 1988). In a study examining social support, which included only one husband caregiver, spouses (n= 14) attempted to protect the patient and struggled with “miscarried helping efforts” (Stewart et al., 2000, p, 196).

Not many studies have used words other than overprotection to describe the caregiving activities. Nyamathi (1987) reported that in interviews over the three months following discharge from the hospital, the majority of women monitored their husbands’ behavior and controlled their diets and other daily activities. In Dickerson’s (1998) study on help seeking, women reported “maintaining vigilance over the patient” (p.16). In an Australian exploratory-descriptive study of Lebanese-born wives (n=7), the researchers described women “engaging in activities of surveillance that involved monitoring of everyday activities” (Thompson et al., 1995, p. 710). In the interviews women reported intensive monitoring, close surveillance, and diet supervision after their husbands’ MI.

In another study (including one husband caregiver), well spouses reported performing household activities such as shopping, preparing food, and monitoring patient medications and activity (Stewart et al., 2001). Social support framed this participatory research study where 14 patients and their spouses, 12 weeks after hospital discharge completed weekly diaries and attended focus groups. The previous study suggested some of the activities that wives of patients with MI are providing.

Synopsis of Research on Context of Caregiving

There was a scarcity of research that described the context of caregiving by wives of patients with CHD. From the research, it was reported that the wives assumed the caregiver role and felt responsible for preventing their husbands' future MI. However, women often felt unprepared for the assumed roles.

Based on the studies, caregiving activities included: managing lifestyle changes, monitoring, surveillance and vigilance, as well as adjusting to difficult patient moods and behaviors. Patients who reported greater limitations received more instrumental support from their wives.

Overprotection was the caregiving activity most reported in the research. Causes of overprotection in the research were wife hostility, aggression, anger, fear, guilt, and anxiety. In addition, overprotection both negatively and positively influenced physical and psychological patient outcomes. Overprotection was additionally correlated in some studies with wife anxiety. In other studies, there was no relationship between wife overprotection and wife or patient variables.

Interestingly, when medical prognostic indicators were controlled in studies, the presence of a wife negatively influenced mortality from MI (Gorkins & Schron, 1993). Support for a spouse after CHD has been related to reduced stress (Frasure-Smith, 1991) and improvement in readjustment, self-esteem, mastery, coping with physical restrictions (Ben-Sira & Eliezer, 1990), adherence to risk reduction behaviors, and speed of recovery

(Mayou, 1984). According to the research there is a negative impact of being the wife of a husband with CHD; but for the husband, there may be benefits.

Synthesis of Findings

Researchers not only have investigated the impact of CHD on the husband who is the patient, but also identified the effect of the disease on the wife and the marital relationship. Even though CHD is a chronic illness without a cure, the research studies examine a period of time referred to as rehabilitation and recovery lasting from some weeks to one year after hospitalization for medical or surgical treatment. In all identified studies, the focus of the research was on responses of wives following the initial diagnosis and or treatment and recovery.

Consistently, research studies reported various forms of wife distress. Cross-sectional, and especially longitudinal, designs showed that the distress for women varied but persisted, for wives up to one year after their husbands' discharge from the hospital for CHD. From the review of the literature, wives performed the role of caregiver for their husbands after hospital discharge. The presence of a wife had a positive influence on husband outcomes in a number of studies.

Some concerns emerge when examining the research. Only certain voices were privileged in these studies. Either there was a predominance of Caucasian participants, or the researchers did not report ethnicity specifically. When included in reports, it is difficult to discern the socioeconomic status of a given sample. For example, in some studies, only the wives' earnings, rather than family earnings, were reported. From those studies reporting education and employment, it appears that the women tended to be from middle to upper socioeconomic groups. Unmarried women who lived with men with CHD were not included in the studies.

In addition to the demographic limitations, most studies used convenience-based samples recruited from large hospitals or cardiac rehabilitation programs. This sampling limits studies to those patients who have access to these centers and to the mere one third of patients who attend cardiac rehabilitation programs. In most studies, sample size was small, and no single study reported power analysis. Because of the nature of the sampling methods, generalizations from the research findings need to be considered with caution. There are additional concerns about generalization of the research findings because of instrumentation. Frequently, instruments were not normed on the population. Few quantitative research studies used similar instruments, which precludes legitimate comparisons across studies. Weaknesses in measurement is further demonstrated by the studies on overprotection There was not only inconsistency of measurement between studies but a lack of definition or clear description of the methodology within studies.

There are also methodology concerns in the qualitative studies. Many of the interview studies did not provide methodologies or definitions of concepts. Studies using interviews were informed from a predominantly psychological framework with predetermined categories. Frequently, analysis and identified themes in qualitative studies were taken from the disciplines of psychology or sociology. Furthermore, some of the qualitative research studies used the method in ways that were not consistent with its underlying philosophical underpinnings.

A further concern is that the research was framed mostly from a biopsychosocial model. In this paradigm categorization and quantification has high priority. From this view, the key task becomes articulating the relationships and interrelationships of variables. This is especially a concern in correlation studies that assume a relationship direction that may not be there. For example, in what direction is the wife's distress and the patient's behaviors? A number of the studies hint at causation that was not suitable.

Both quantitative and qualitative studies did not provide depth of understanding of the women and their caregiving activities. These studies failed to grasp the emotion in the experience of the distress. Rather, they simplified the impact of caregiving by providing thinned-out descriptions failing to address the depth of the experience for the wives.

At first glance it appears that the research on spouses of CHD patients is focused on women and their health and that their lives are acknowledged as important. However, in the purpose statements of research studies wives were being investigated because of their contributions to their husbands' recoveries. From this perspective the research is about improving the men's health and the wives become a means to that end.

Few studies provided a context to the women's lives. For example, missing from the demographics were the number of years married, descriptions of the marital relationship previous to the CHD diagnosis, inclusion of additional family responsibilities (i.e. children, older parents), and their own health status.

Another concern is the consideration of protection as abnormal. In addition, referring to protection as overprotection and viewing it as dysfunctional may be pathologizing women's typical relational style. This label may indicate gender bias assuming that a more autonomous male sense of self is normal. Explanations of the motivation for protection in the studies brings into focus negative stereotypes of women. What is not clear is how the *over* was added to the positive term protection.

In addition, underlying the research is the undervalued expected role of women as tending the sick and promoting health. That a wife cares for her husband is an implied value and implied role in society. According to Tronto (1993) care is a moral perspective best understood rooted in actual practice. From this view, the women's distress is one rooted in the ethic of care, care for their ill partners, not one of women who are overprotective.

The focus of the research is on the wife, as an instrument in improving the husband's physical and psychological outcomes. The women remain hidden care providers who *work* to maintain their husbands' health. What the women do for their husbands may not be considered an extraordinary function but rather an expected function

of a wife. Whether this is an acquired social role or not, it is one that they perform. A role that is distressful.

Descriptions and interpretations of women's experiences have often reflected faulty theories about the nature of women (Levesque-Lopman, 1991). As long as women's perceptions of themselves are largely a product of men's perceptions and endeavors they will continue to perceive and be perceived in simplified manners. Rather than appending findings to existing beliefs the first step is to challenge the taken for granted assumptions, to become conscious of what women experience, and what significance and meaning women attribute to their own behavior. Despite the highly personal nature of being the spouse of a patient with CHD the dominant epistemology underpinning much of the inquiry is postpositivistic. Many of the previous research studies approached the impact on the spouse's lives from a pathological model with a subsequent determination that the subjects were psychologically well or unwell or coping effectively or not effectively. From this paradigm the caregiving activities remained relatively invisible. In addition, descriptions of the context of caregiving often devalued the everyday realities of the women. In studies women were held responsible for caring for their husbands since they were assumed to have the power to influence patient outcome but at the same time were evaluated negatively. What remains invisible is the practical knowledge of the practice.

Gaps in the Literature

The largest gap in the research to date on wives of husbands with CHD is the lack of qualitative research and feminist critique. Within a positivistic paradigm, research has focused on the effect of the wife's distress on the patient with cardiac disease, rather than on the source and meaning of that distress for her. Additionally, most of the caregiving activities remain invisible except for those that are labeled overprotective. What are the women's actual activities, and what is the meaning of these activities for them?

There is also a lack of quantitative research designs and interpretations which do not include gender assumptions about women. More studies should include diverse samples with instruments that are normed on the population. However, there is a need to further develop a theoretical framework of concepts that includes women's reality before there are more quantitative research studies based on old assumptions.

It is important to learn about what it means to be a woman who is living with a partner with CHD as well as to develop programs of support for them as individuals and as people in relationships. Feminist theory and hermeneutic phenomenology provides additional dimensions to the understanding of women living with men who have CHD. Previous intervention studies designed to support the patient and the spouse demonstrated varied and inconsistent results (Daugherty, Saarmann, Riegel, Sornborger, & Moser, 2002; Stewart et al., 2002; Van Horn, Fleury, & Moore, 2002). This may be due in part to the lack of depth in the understanding of the experience as lived.

After 30 years of research on women living with men who have CHD, it is time to reveal the experience in all of its complexities through a feminist hermeneutical phenomenological study, a study that reflects women's inner strength, interdependence, and power. Research where women's lived realities emerge that depicts their experiences *and* validates their perspective while acknowledging their expertise and authority.

CHAPTER III

Methodology

Method reflects the researcher's philosophical beliefs about the nature of reality and is situated in, and flows from, one's world-view and the nature of the question being researched. According to van Manen, "Lived experience is the starting point and the end point of phenomenological research" (1997, p. 36). The research process begins with the awareness of a phenomenon as it exists in the world.

Method

Research that includes uncovering meaning from a feminist perspective is a beginning step towards understanding the women's lives as lived. Because much of the women's lives remain hidden, a feminist hermeneutic phenomenological study was used to provide deeper understanding of the lived experience of women living with men with CHD. The phenomenological research approach was the appropriate philosophy and methodology to uncover the meaning of living with a man with CHD.

Phenomenology Research Method

Phenomenological inquiry, building on the philosophical underpinnings of phenomenology, differs from positivistic methods. It provides a different paradigm. Phenomenology, as a naturalistic inquiry, is uniquely suited to investigate from a feminist perspective the meaning of being a woman living with a man who has CHD. The assumptions about phenomenological research which follow serve to illustrate the appropriateness of this approach. Phenomenology, according to van Manen (1990), is the "study of the lifeworld- the world as we immediately experience it pre-reflectively rather than as we conceptualize, categorize, or reflect on it" (p. 9). Reality for a human being is accepted as that reality which exists in his own consciousness (van Manen, 1984). Perception combines with the concept of consciousness as the act which presents the things perceived in their reality (Spiegelberg, 1982, p. 116). Reality is an interpreted experience. Human beings are conscious (aware) of the environment through embodiment (bodily senses). Humans perceive the world and interpret it based on experience and perception (previous experiences). For humans, reality is the perceived world.

Focusing on individual lived experience uncovers shared meanings and commonalities, but it also acknowledges differences. The aim of phenomenological research is to reveal a deeper understanding of the nature or meaning of a person's everyday experiences. Rather than being a re-telling of the experience, the text is a reflexive reliving, and a reflective appropriation, of something that holds meaning. Stories told from this reflective stance are used in a systematic attempt to uncover and describe the nature or essence of the experiences as they are lived in the everyday world. Phenomenology as a research method is best suited to contact, to evoke, to describe, and to elaborate upon, the meaning for women living with a partner who has CHD. This method provided a way to gain deeper understanding of the women's fullness of living, and to gain more understanding of their experience in the world as women. Phenomenology, when tied to hermeneutics, is used in a systematic attempt to uncover, to describe, and then write about, the essences of the experience.

Hermeneutics.

Hemeneutics refers to the systematic interpretation of textual language used to increase the understanding of human experiences (van Manen, 2002b). The hermeneutic research method bridges the distance between minds and reveals what is in the *other* mind. Hermeneutics is not reconstruction, per se. To understand the meaning of a text, the researcher, and eventually the reader, must have listened to what was being said, rather than what was physically heard (Gadamer, 1977). The hermeneutic method reveals the hidden, often taken-for-granted meanings that arise from the everyday life experience. They emerge in the phenomenological telling. A deeper and richer understanding of the phenomenon is gained through respective analysis. This new understanding is used to examine parts of the whole and, and then to examine the whole with the use of what has been gained from the examination of the parts.

From the hermeneutic perspective, there is no privileged view. The researcher is affected by time and context in a similar manner as the participant who lives the phenomenon every day. However, the researcher does not simply accept the pre-understandings embedded in the context. The researcher is committed to remaining open to the meaning in the text (Gadamer, 1960/1989). The acts of gathering (phenomenology) and interpreting (hermeneutics) are interwoven parts of the process. Hermeneutical truth strives to discover what was meant, that is the significance the person attaches to the telling (Moran, 2000).

Feminist Research Method

A hallmark of feminist research is the collaboration between the researcher and the participant to remove the imbalance of power through collaboration in the process (Ramazanoglu & Holland, 2002). Feminist research begins with the standpoints and experiences of women as they live them. This methodology is therefore consistent with hermeneutic phenomenology and challenges the taken-for-granted categories and stereotypes. The researcher is committed to hearing the women's experiences from their own perspectives rather than from the dominant paradigm. The themes emerge from the women's words themselves.

Implementing the Methods

According to Gadamer (1960/1989) there is no hermeneutic phenomenology method. However, the phenomenological research tradition offers a set of guidelines and recommendations for inquiry. This study used van Manen's (1990) "six research activities" . . . of hermeneutic phenomenology ". . . to construct an interpretation of the human experience" of being a wife who lives with a husband who has CHD; furthermore, a feminist interpretive approach was used.

van Manen's research activities.

According to van Manen (1990), hermeneutic phenomenological research is the "dynamic interplay among six research activities" (p. 30) that serve as a practical approach. It is not the case, as van Manen cautions, that each activity is discrete and occurs in isolation.

The first activity is to turn to the nature of the lived experience. This activity involves the researcher giving herself over to the search for the meaning about the phenomenon. Meaning of the experience is revealed through researcher reflection. The researcher formulates, and reformulates, the research question while explicating assumptions and pre-understandings about the phenomenon. The researcher does not set aside these assumptions, according to van Manen (1990); rather, the researcher remains one as the text is interpreted.

The second activity requires the researcher to investigate the experience as it is lived, rather than as it is conceptualized. The researcher recognizes that the participant's stories are not identical to the experience itself; rather, the recounted stories already represent transformations of the experience. It is important to accept that the stories are the lived experience. Part of the activity is the gathering and interpreting of the text (van Manen, 1990). As in feminist research methodology, the participants are co-researchers in the study.

The third activity is the reflexive analysis of the texts in order to try and grasp the essential meanings of the phenomenon to contact the lived experience. This thematic analysis of the text is a "process of insightful invention, discovery, and disclosure . . . grasping and formulating a thematic understanding that is not rule bound but, rather, an act of seeing meaning" (p. 7). A theme always is the reduction of a notion. This step is discussed further in the data analysis section of this chapter.

In the fourth activity the researcher writes and then rewrites to describe the phenomenon. This step requires reflexivity, attunement to the life experience, as well as commitment, and patience (van Manen, 2002a). The researcher seeks to develop the phenomenological description that permits the reader to see the deeper significance of the experience. According to van Manen (2002b), "writing is our method" (p. 124) because it fixes on paper, forces the researcher to objectify thinking, and creates a reflective stance that is sought. This writing step manifests polarities in several ways: (a) both separating and uniting persons based on what they know; (b) distancing and yet drawing persons more closely to the lifeworld; (c) decontextualizing thought yet returning to practice; (d) abstracting experiences yet concretizing understandings of the world; and (e) both objectifying and subjectifying understandings of the phenomenon (van Manen, 2002a).

Activity number five encourages the researcher to maintain a strong and oriented relation to the phenomenon. The researcher always is oriented to the phenomenon, in order to keep the text strong, rich, and deep. The writing is thick and contains rich descriptions that explore all aspects of the phenomenon. The researcher accepts that a full understanding may never be reached, nor is it necessarily expected, or even necessary.

The sixth and last activity is the act of balancing context by considering parts and wholes. The part-whole context is similar to the hermeneutic circle that is, philosophically, part of Gadamer's (1977) work.

Data Collection

Recruitment of Participants

The researcher attended the Mended Heart Support Group (see Appendix A), and flyers were distributed to attendees (see Appendix B). The flyer introduced the study to the group and included a request for participation. In addition to attending the meeting, the researcher gained entrée through posting flyers in senior apartments, through the word of mouth process, and as a result of the snowball effect (see Appendix A). An attempt was made to select participants who represented different ages, cultures, races, and socioeconomic backgrounds. The purpose of selecting subjects in phenomenological research is to generate a full range of variation in the set of descriptions to be used in analyzing phenomena (Polkinghorne, 1989). However, the purpose of phenomenological research is to describe the structure of an experience, rather than to describe the personal characteristics of a group of individuals who have had the experience (Polkinghorne).

Eligibility criteria for participation in the research study included the following: (a) English speaking; (b) cohabitating with a male partner; (c) having known experience with the phenomenon under study; and (d) ability to articulate the experience. Exclusion criteria included the following: (a) diagnosed dementia or other cognitive impairments; and (b) untreated mental illness.

Participants

Because the phenomenological method seeks to uncover in-depth meaning and experiences, the sample size deliberately was small (Baker, Wuest, & Stern, 1992). Participants were recruited until there was saturation of the data collected. A convenience sample of ten women was recruited who met the inclusion criteria. Demographic data were collected with the use of a Demographic Data Sheet (see Appendix C). The women in the study were aged 45 to 74 years and married from 4 to 55 years. Of the wives, seven were Caucasian, two were African American, and one was Asian. The husbands ranged from 50 to 76 years in age. Nine of the wives stated that their husbands were Caucasian and one wife said her husband was African American. Five of the women were employed outside the home, two were self-employed with home businesses, two were retired, and one woman was unemployed. Approximate self-reported household income ranged from $2-9,000 dollars per month. One woman did not report income. The husbands experienced their CHD sentinel event from six to 18 months prior to the interview. The husbands' CHD events included medical treatment and interventional cardiology such as: stent placements; angioplasty; and cardiac bypass surgery. Four of the husbands had further cardiac intervention after the initial diagnosis. One husband attended a formalized cardiac rehabilitation program. No wife reported attending a cardiac rehabilitation program with her husband.

Setting

The women who agreed to participate in the study selected the interview site and time. All the women chose to be interviewed in their home when their husbands were absent from the home. When one of the husbands returned home earlier than the wife expected, the interview ended immediately. The signed consent was obtained prior to data collection, and a copy of the form was left with each participant (see Appendix E). Demographic data were obtained during the actual interview (see Appendix C).

Interview Process

The goal of the researcher was to obtain descriptions from the woman of her experience living with a partner with CHD. Data were generated through a dialogic interview. In-depth, unstructured, face-to-face interviews were conducted individually with each participant. Face-to-face interviews tend to enhance the development of a sharing relationship, with the participant, which in turn better enables the researcher to seek more detail in the women's stories. Unstructured interviews offer participants the freedom and flexibility to recall experiences from their own perspectives (Levesque-Lopman, 1991). A general statement and interview guide was developed (see Appendix F) to assist the researcher in helping the participants in the telling of their stories. The women were encouraged to tell a story from their life that portrayed what it meant to be the wife of a man who has CHD. Each person was asked to discuss her lived experience including thoughts, feelings, and perceptions. The participants' responses guided the questions. Probes were used to increase the richness of the responses as the dialogue progressed. The interview was directed toward gaining a clear understanding of what the participant wanted to share. The researcher used open listening and conveyed a genuine interest in what the participant had to say to reaffirm that the participant and not the researcher was the expert in the phenomenon (Benner, 1994). The interviewer maintained an effort to be genuinely present and to remain open to the participant so that a deepening of experience for both interviewer and participant would evolve (Weber, 1986). The interview thus experienced, facilitated the development of trust in which a deeper understanding of the phenomenon was pursued. Martin Buber and Maurice Friedman support this method, as they reiterate in their work that "it is the 'between' (entrée) that reveals and permits understanding" (cited in Weber, 1986, p. 68).

The interviews lasted from 60 to 98 minutes. Each interview continued until the participant felt that she had finished, or had exhausted her description of the phenomenon. The interviews were audio-recorded and transcribed verbatim, with permission from the participants.

Data Analysis

The aim of the phenomenological inquiry was to reveal and to unravel the structures, logic, and interrelationships of the phenomenon (Polkinghorne, 1989). The researcher gleaned from the texts a description, the particular structural relationships, and the elements of the unified experience (Polkinghorne). The process of data analysis and interpretation in this study employed an adapted method of the six activities described by van Manen (1990).

Data collection and data analysis took place simultaneously. Preliminary analysis from the initial interviews redirected the nature of the inquiry of subsequent informants

(May, 1991; Swenson, 1996). A professional transcriptionist was employed to transcribe the interviews verbatim. Pen and paper for note taking also were used for data collection. The researcher kept a journal to recall the particulars of each interview. Memo notes were added to the transcribed file to capture the contextual issues that may have had an impact on thematic analysis. These notes provided an audit trail of thought as well as served as a source of data in the hermeneutic phenomenological tradition.

Data analysis was not a linear process, as it might appear to have been. The processes of intuiting, analyzing, and describing continued throughout each phase of the analysis. The researcher returned to the original transcripts to ensure that she understood them adequately. The researcher allowed the phenomenon to direct and guide the process of analysis, so that the essence of the phenomenon could reveal itself. Analysis used phenomenological reflection to uncover the themes (van Manen, 1990).

Phenomenological Reflection

According to van Manen, the purpose of phenomenological reflection is to try "to grasp the essential meaning of something" (1997, p. 77). The researcher attempted to make explicit that which was implicit in the collected data. Two main endeavors constituted this process: thematic analysis of the data and the determination of essential themes.

Conducting Thematic Analysis

Phenomenological themes are the "structures of experience" (1997, p. 79). The themes are the units of meaning that occur in a person's description of an experience. However, van Manen carefully makes the point that themes are not categorical in nature, nor are they formulaic. Themes reflect the concerns of particular people examined through a more universal understanding. A further clarification provided by van Manen is that themes are the "point" of an anecdote, rather than simply being an inadequate "simplification" of the experience. Furthermore, a theme is a "capturing of the phenomenon one tries to understand" rather than something "one encounters at certain points or moments in the text" (1997, p. 87). The theme is not an objective thing that one locates at some point; rather, it is something one actually creates through self-reflection on what is presented in the data. A theme is a "process of insightful invention, discovery, and disclosure" that is "given" to the researcher from within the lived experience of the phenomenon (van Manen, 1997, p. 88).

The process of uncovering thematic aspects began in the study when the interview was conducted. According to van Manen, three different approaches can uncover the themes from a text. These include: the wholistic or sententious approach, in which the fundamental meaning of the text as a whole is considered; the selective or highlighting approach, in which statements or phrases that seem particularly insightful into the phenomenon are identified; and the detailed, or line-by-line approach, in which every sentence is examined for its relevance to the phenomenon (van Manen, 1997). The line-by -line approach was implemented in this study. The transcribed interviews were read by the researcher while listening to the audio-recorder in order to insure the accuracy of the transcription. Any deviations from the original recording were corrected in the transcription, in an effort to optimize accuracy. Each transcription was read carefully, line by line, and highlighted for further consideration. Following van Manen's (1997) lead, the themes were the meanings the researcher was able to discern from the interview. Through sensitivity to the lived experience of the participant as reported in the transcripts, the researcher developed a dialogue with what is being said. The resulting themes were the interpretive product of that interaction. The themes were revealed to the researcher in the interaction with the transcript.

Once the themes of the various transcripts were identified, the researcher composed linguistic transformations of the themes. The researcher interpreted the text, and moved the language to a more universal level of abstraction, while at the same time attempting to remain faithful to the participant's lived experience.

Determining Essential Themes

Part of the process of data analysis is to determine which themes are essential to the phenomenon and which ones are incidental. All phenomenological human science research is an examination of the lived world as experienced in everyday life, and therefore certain fundamental themes are relevant to all human beings, regardless of their particular situation in life (van Manen, 1997). He identifies these themes as existentials in order to differentiate them from more particular themes than one may uncover. Four of these existentials are common to all people and serve as guides to the reflective process. The themes consist of: "lived space (spatiality); lived body (corporeality); lived time (temporality); and lived human relations (relationality or communality)" (van Manen, 1997, p.101). According to van Manen essential themes as those that "make a phenomenon what it is and without which it cannot be what it is" (1997, p. 107). If the phenomenological description is to ring true to those who have lived this experience, or who currently are living the experience, the foundational themes upon which the description is based must first be accurate. In contrast, an incidental theme is one that could be altered or even removed without changing the phenomenon itself (van Manen).

In order to delineate between the essential and the incidental themes, van Manen recommends the method of "free imaginative variation" (1997, p. 107). Utilizing this method, the researcher asked if the phenomenon would be the same without this essential theme, or would it be fundamentally altered. By carefully considering each of the emergent themes in this manner, the researcher selected only those themes that were essential to the understanding of the phenomenon. It is upon these remaining themes that the phenomenological narrative was constructed.

Steps to Ensure Methodological Rigor

Evaluation of a phenomenological study cannot be addressed in a manner similar to that of a positivistic scientific inquiry. Conventional scientific inquiry uses the criteria of internal and external validity. However, these criteria are not useful for the evaluation of a qualitative design because they are based on different assumptions and principles than those underlying a phenomenological study. Trustworthiness (Lincoln & Guba, 1985) served as a measure of methodological adequacy for this study.

Trustworthiness

Meeting the four criteria of credibility (truth-value), dependability, confirmability, and transferability (constancy), aided in establishing the trustworthiness of the study. The researcher met the criterion of credibility through conducting unstructured, face-to-face interviews which were designed to facilitate a relationship with the participants. The researcher provided clear, vivid descriptions and interpretations which were faithful to the participants' lived experiences and perceptions of the phenomenon through verbatim transcripts. Themes were sufficiently grounded in the respective data. During the interviews, the questioning sought clarification of the participants' own descriptions. This method was used to comply with the feminist methodology tradition which strives to maintain “power with” rather than “power over” in the research encounter (Chinn, 1999). To assist with meeting the criterion of credibility the researcher used reflexive journaling to provide insights and to aid in methodological decisions.

Dependability and confirmability were established through the audit trail and through reflexive journals. The researcher maintained raw data, analysis and synthesis data, as well as notes that informed the study, in a safe place for audit trail use. To ensure confirmability, each participant was given the opportunity to receive a written copy of the study. However, hermeneutic interpretation always produces new meaning that is accepted and expected after each reader takes the written text and makes an interpretation.

The process of journaling assisted in supporting the criterion of transferability, another criterion of trustworthiness. Additionally, providing thick descriptions in the study, made the stories feel more real for the reader of the written study without compromising participant confidentiality. Purposive sampling was employed both to seek divergent and typical data as well as to obtain maximum variation.

Protection of Human Participants/Ethical Considerations

Approval of the research proposal was obtained from the University of San Diego Institutional Review Board before the research began (see Appendix F). Participants were informed that their participation in the study was voluntary and they had the right to: (a) not answer a particular question; (b) terminate the interview at any point; or (c) withdraw from the study at any time in the process. Participants also were advised that they might be at risk for painful memories during the discussion and recollection of their experiences. A list of community resources was provided to each woman in the event she needed to contact a healthcare provider.

The women who agreed to participate in the study were assured confidentiality. Appropriate measures were taken to ensure confidentiality. The names of the participants were equated with a pseudonym. No list was constructed to connect participants to the pseudonym. All audio recordings, field notes, and typed transcriptions were identified only by use of the pseudonym. Only the researcher had access to the data that was secured in a locked fireproof file. The audio recordings will be destroyed after the successful defense of the dissertation. These materials will be kept until that time in case revisions or clarifications are necessary. The transcripts will be kept indefinitely, as stated in the informed consent agreement, for purposes of future publications. In addition the two transcriptionists signed confidentiality statements (See Appendix G). To protect participant confidentiality all identifiers within the text of the research report were eliminated or changed.

CHAPTER IV

Findings of the Inquiry

The purpose of the phenomenological analysis was to discover the meaning and caregiving practices of women living with men with CHD. The participants provided a window into the lived experience of being the wife of a husband with a chronic illness. The participants gave voice to the disruptions in their lives that CHD illness generated. The wives situated illness within the contexts of their particular lives with the meaning unfolding for them in the midst of their everyday reality. Their husband's CHD was not a discrete episode, but, rather, an enduring part of their lives. In the women's new realities, they considered the very nature of routine experience and existence. The illness called into question experiences of the world, which previously had been taken-for-granted.

The thematic analysis uncovered the following essential themes of the women's lives in relation to their husbands and their husbands' CHD: a) "walking on a tightrope;" b) "keeping an eye on him;" c) "wrapping him in cotton;" d) "right in the middle of it;" and e) "I have to get through it" (see Table IV). The first three themes, "walking on a tightrope," "keeping an eye on him," and "wrapping him in cotton" revealed the wives' focus on their husbands. The further essential theme that emerged, "right in the middle of it," (see Table IV) reflected the wives sharing or ownership of their husbands' CHD. Another essential theme, "I have to get through it," (see Table IV) revealed the women's personal meaning of their husband's CHD. The essential common theme categories are supported by the women's words to portray a deeper understanding of the nature of the experience and insuring that the phenomenon speaks for itself. The dynamic themes are separated only momentarily for purposes of discussion because, in reality, they become intertwined, interrelated, and overlapping within the structure of the balancing practices of care. Each theme can be viewed and considered only temporarily before it merges with the other themes and makes up the structure. The usual patterns or routines of the participants' lives were changed by their husbands' illness. New practices had to be embedded in their everyday lives in response to living with their husbands who had CHD.

"Walking on a Tightrope"

The participants in the study described their daily lives as "walking on a tightrope", and they shared the challenges of trying to "maintain balance". Walking on a tightrope inherently is a dangerous activity because nothing can be taken-for-granted. For the women, "walking on a tightrope" included these personal processes: trying to determine what is normal for him; identifying the cause for their husbands' CHD; and acknowledging the threat to his life. The women recognized that the old definitions of normal did not hold, because their lives as they had known them were changed. From the moment of diagnoses, the taken-for-granted nature of their life was destroyed. The wives searched to determine the new meaning of normal in their lives. In addition, the women attempted to identify a definitive cause of their husbands' illness so that the disease could be controlled. Their husbands' illness permeated the women's everyday experiences. The women foresaw sudden threat and danger in their partners' futures because of their realization of the possibility of their husbands' death. Threaded throughout this essential theme and the sub-themes was the aspect of fear (e.g., fear of loosing one's balance).

Table IV Essential Themes

"Walking on a Tightrope"
- Determining what is normal for him
- Identifying the cause of his disease
- Acknowledging the threat to his life

"Keeping an Eye on Him"
- Judging his symptoms
- Observing his activities
- Being ready to save him

"Wrapping Him in Cotton"
- Shielding him from stress
- Arranging safe activities for him

"Right in the Middle of It"
- Sharing the illness
- Being responsible for him
- Changing their lives

"I Have to Get Through It"
- "I haven't spoken"
- "What if I lose him"
- "Why did it happen?"

Determining What is Normal for Him

Over the months since their husbands' CHD diagnoses, the women described not knowing what normal was anymore. Their husbands as they had known them now were different. The women felt unsure about the state of their husbands' health. This lack of understanding the new meaning of normal was expressed frequently by the wives. This particular lack of clarity about "normal" was expressed by Louise in her statement, "I am vague about what is normal." Ann, whose husband had had angioplasty 12 months previously, said to the physician:

> Well he gets very tired. Gets tired easily. And the physician says, "that could not be helped". (I asked him) Could he fly? And the physician says, "yes, you have to judge that yourself". I understand it but how could I judge by myself?

Ann noticed that her husband was tired and she did not know if he could go on a trip. By the physician telling her that her husband's fatigue "could not be helped" it meant that his condition was not fixable and now was to be considered normal. Making the decision about the safety of travel for her husband, who is fatigued, is up to her to "judge for herself." On what basis was she was to make this decision if she did not know what is acceptable or normal for him? Deciding what was now normal was not easy for Ann.

Similarly, Irena described a cruise she took with her husband 8 months after his angioplasty. Irena's husband told her he didn't "feel well" when they were on a cruise. She recounted, "He said, 'maybe it's my heart, maybe that's why I feel kinda dizzy'." And she added, "Finally, we realized it was the ship." In the past, seasickness would be considered normal and caused by the ship; but now symptoms are interpreted through a cardiac lens. Previously established understandings and explanations cannot be used because of the possibility that exists of another acute cardiac event. The women were learning more about their husbands in order to ascertain what was "normal" in their lives. This discovering "what was normal" was a recurring story told by the women in the study. Maria described her effort to interpret symptoms or events:

> When you have a symptom, or something's wrong, it automatically, especially those first 6 months, oh it must be something to do with the heart. So you know if you've got a bad cough, or you've got an ache, or your other arm hurts or something, it's like, oh my god, what if it has to do with the heart.

Maria acknowledged that, now, a symptom was assumed to be cardiac and (therefore) frightening, especially in the first 6 months. Now, no symptoms are ignored. According to Debra, it “sort of heightened our awareness to everything.” This “heightened awareness” was made even more difficult because the wives could no longer use the previous norms (before CHD) because “things are different.” Louise said she is unable to "know how he is.” Worry and fear are threaded throughout the womens’ descriptions of “not knowing what is normal.” The inability to judge whether their husbands were well was not the only change to their everyday lives.

Consistently, the women commented on observing a decrease in their husbands’ “energy”. Katia, nine months after her husband’s angioplasty, stated:

> . . . he doesn’t like to do anything that he . . . as far as work in the yard or anything like he used to, or you know, everything’s a . . . his favorite thing to do is to just sit there on the couch and watch TV, and eat, which is probably the worst thing he can do. . . he has no energy.

Katia continued to notice that her husband did not do the things he had done in the past. She further stated that this was due to [his] lack of energy.

> He did seem like a different person, in that he’s slowed down and I don’t know, even just the way he talks. I don’t know how to describe it . . . that he just seemed different.

Maria reported that her husband had “slowed down” and that this was different [for him]. Whether this “slowing down” or lack of “energy” was due to the disease and or the men’s emotional response to having CHD, is not clear. However, the women consistently blamed the disease for causing this physical change. Further, the wives also noticed a difference in their husbands’ moods.

All of the women spoke about how their husbands were not only physically, but also emotionally different, after the diagnosis sentinel event. He is "not his normal self," said Katia. Irena stated, "In a lot of ways it changed the person that I was used to." Jane's husband had stents inserted 16 months previously. She shared the following:

> . . . just personality wise, like I said . . . and he's more selfish. I can see he feels bad, but it doesn't seem to bother him. I don't . . . that part is kinda hard, and I don't know whether that's just the way he's gonna be now.

Jane also noticed that her husband was more selfish now, and she questioned whether that was how he would be "forever". He just was different. Maria's husband had had an MI, stents, and bypass surgery over the previous nine months, and this was her statement:

> I don't know if this is from the surgery, but he uses words that really irritate me. And he knows they irritate me because I told him but he . . . I don't know, can't help but saying them I guess. And he seems more concerned about...not concerned, but more interested in the things he's interested in.

According to Maria her husband deliberately said things that he knew were "irritating" to her, and he was more focused on his own interests. This change in her husband was difficult for Maria. Debra said about her husband, "His temper is a lot shorter than it used to be." Ann said, "The kids can annoy him easier"; and Irena said, "He has a way shorter patience level than what he used to have." These women found their husbands to be more irritable over the previous six to 18 months than prior to the CHD diagnoses. Another change in mood reported by the women was "depression." Linda said about her husband, "He never suffered from depression, always had more than enough to do in life and was always enthusiastic and stuff, so this was something because of the heart attack." In addition to his "irritability", Irena said, her husband was "less affectionate" and:

> . . . course the sex life went . . . completely gone from all the pills I'm sure, which does not bother me, there's probably some women that would be really…..the only thing that bothers me is that he's very non-affectionate, where before he was very affectionate.

For these women, the changes in their husbands' moods had continued months after the diagnosis. The women did not know whether this change in the men's mood was "forever."

The wives did not know whether the physical and emotional differences in their husbands were part of the new "normal." The women had been married to their husbands for a number of years, and they knew what they believed "normal" to be. According to Ann, "[my husband] as I knew him is gone." In addition to trying to determine the new meaning of normal, the women searched for what had contributed to their husbands' CHD.

Identifying the Cause of His Disease

After their husbands' diagnoses the wives continued to search for the *actual* cause for their husbands' CHD. Identifying the predisposing factors helped the women to know what things needed to be controlled or removed to keep their husbands safe. All the participants attributed their husbands' CHD to "stress" or "tension". The source of the stress may differ but in their thoughts it remained the primary cause. Betty searched for what she thought caused her husband's MI 12 months earlier and said:

> You don't understand why he had a heart attack because he's not smoking, he's not overeating, and his diet is down to right number of calories though it's not always, but he doesn't eat any fats. He doesn't eat any deli meats. Why? Ah, as I said the only thing that is in our life it is tension and this is we were thinking of course (stress reduction course) . . . we're thinking of taking, I don't know how good it is.

When Betty learned in the hospital that her husband had a heart attack, she thought about why it had happened and said "but that time he didn't do anything heavy, we didn't even have a fight, nothing." Betty looked for an emotional or physical incident that triggered the event, and she could not find one. Consistently, according to the women, “stress” was the significant factor that caused and triggered CHD. Irena contributed an additional dimension to the wives' opinion that stress was a significant threat when she blamed her husband’s CHD on work. She said:

> . . . if we could find a way . . . he could work part-time for the rest of his life it would suit me, the rest of his working life, or if necessary quit and find something else but the thing is, it's not easy to do especially when you're 52 . . . I guess the job in my mind is the big culprit and it's the least manageable thing. I mean if it was just food or if it was to stop smoking or if it were any of those obvious things then it would be easier.

Irena believed that if her husband worked less, then the “culprit” could be controlled. However, she believed that stress was the “least manageable” thing. It was difficult for her to balance the stress in her husband’s life. The belief that stress was the cause and an ongoing danger in CHD was further elaborated by Ann. When the doctor told Ann’s husband that he could return to work she compared that suggestion to her own view of the situation:

> . . . but the doctor's attitude towards him going back to work was that he's sitting just doing things, as far as the doctor could see that was no big problem, but we, my husband and I, and I especially, we both agree that his biggest problem is the stress that comes from his job, there's more than one way that your heart works harder, or that your arteries are going to restrict and all these things that happen, and I believe that the stress that comes from him being back to work full-time is much harder on him than going out on his bicycle, quite frankly.

Ann believed, even if the doctor did not agree, that job stress was a threat to her husband’s heart. She wondered about the future if the “the culprit” (work stress) was not controlled:

> . . . you find yourself thinking well you know how about a year from now when he's back to the same old stress and the same old job, and basically nothing else has changed. Will this just repeat itself? And I think that's

> probably on both of our minds too. It's sort of there on the back burner, it's not something that you think about, I'm consciously thinking about that . . . what's different? We haven't put our finger on something that we can make different to make this not happen anymore.

Ann believed if a change was not made in her husband's life, he would have another cardiac event. She was aware that something different needed to happen so "this" would not happen again. It was therefore important to correctly identify the cause in order to eliminate it. She said she was "thinking about it" and at the same time "not thinking about it". Ann worked to balance thinking and not thinking.

Debra also described the search for the cause of her husband's CHD. She said, "He has a family history and was really thin and fit and healthy but he doesn't eat vegetables." She believed (in addition to stress) the lack of vegetables and family history contributed to her 50 year old husband having CHD. Debra and her husband now eat more vegetables. Two of the husbands smoked, and that was an identifiable, controllable risk factor that could be changed. Irena said, "90 something percent of this was smoking, weight, whatever, but smoking was it." For Irena, there was a visible culprit that had been identified and that she believed could be eliminated.

Central to the biomedical understanding of CHD is the idea of the preprogrammed diathesis that exists inside the body. The women aligned themselves with this outlook and tried to identify the natural trajectory for the disease that could then be predicted and controlled. The women attempted to identify, control, and change those contributing factors to "hold off" CHD. Clearly identifying the cause of CHD was important for the women to decrease their feelings of vulnerability. "Stress" was identified by all the women as the reason their husband had CHD and that "stress" could bring on another sudden acute cardiac event. However, "stress" was not a concrete or an easily controlled event. Unfortunately, the identification of stress, or another contributing factor, did not provide the women with the peace of mind or security that they desired.

Acknowledging the Threat to His Life

The CHD sentinel event was a reminder to the women about the unpredictability of their husbands' future, and that realization now became embedded in the reality of their everyday lives. For the wives, there were possible frightening events that possibly could happen to their husbands and the outcomes were uncertain. Ann said, for example, "There may be another one around the corner"; and Linda added, "This was traumatic and we realize that he really could have died . . . and I am afraid for the future." Acknowledging the threat brought the chance of their husband's death to the forefront of their minds.

The uncertainty of their husbands' health was frequently in the women's thoughts. Louise recounted thinking about the future, and possible changes that might be required when she said, "You're conscious of the fact that, thinking down the road, there may be a problem here." She worries that an unknowable something could cause an unknowable effect. Linda worried about the terrible "something" in the future:

> [I] really worry because out there, something going to happen to him, something terrible, he's not strong enough to do, this he's not well enough to do that.

The "something" remained nameless in the women's minds - but nonetheless sudden, harmful, and lethal. She believed that her husband was vulnerable to the "something." Fear lay closely below the surface. All women described an incident months after the sentinel event that acutely brought the fear back into their lives – e.g. the sudden sound heard by Debra from upstairs; Jane's husband taking too long to take out the trash; and Jennifer's husband coming home late from an event - were all interpreted through the lens of cardiac disease and fear. Jennifer and Maria referred to their lives as “walking on a tightrope.” According to Debra, “I creep upstairs to see if he's alright” and Katia feared he was “gone.”

Hope for the future often eluded the wives. Betty recounted asking the cardiologist six months after her husband's diagnosis, “How should he live his life"? The cardiologist tells her:

> “No guarantees Mrs. B.” Well, there's no guarantees because I don't know if I won't have a heart attack in fifty minutes. You don't know what's going on in your heart. (A) cardiogram is really nothing because even the five minutes before he had a heart attack his cardiogram was completely normal. So it is a well known fact that you can have a cardiogram and come home and have a heart attack.

The doctors and diagnostic tests did not supply the reassurance Betty desired. The needed information was not attainable to anyone. The women recognized that the future was tenuous. Irena said that the nurse told her his “arterial descending was blocked” and “this one’s called the widower, because a lot a men die from that one if it’s blocked.” Irena later added that “it was too much information.” Betty was told there were no guarantees, and Irena knew her husband had the “widower” in his chest. Both of these explanations by healthcare providers merely reinforced the fragile nature of their husbands’ health and tenuous future.

Irena also spoke about the future, saying, “It’s the unknown that’s so fearful, and what will tomorrow bring, how bad will it be?” The uncertainty and fear of the future was evident in Irena, Betty, Jennifer, as well as in the other women’s words. The wives were aware that a possibility existed that an acute cardiac event could happen again, but they didn't know if, or as they feared, when it would happen. The sudden event forced the wives to “look into the future”, and they were afraid. There were no guarantees that their husbands would be healthy and survive another acute cardiac event. When Debra discussed the fear she said, “I mean, what else (her husband living) is more important?”

“Keeping an Eye on Him”

Because the wives feared for their husbands lives, they “kept an eye” on them. “Keeping an eye” suggests a nonstop watching over or monitoring. Included in the practice of “keeping an eye on him” was: judging his symptoms; observing his activities; and being ready to save him. All of the participants monitored their husbands by observing, and collecting information, in order to evaluate the state of their husbands’ health, as well as, at times, to reassure themselves. The women watched their husbands’ physical activities to insure that their husbands were “not overdoing it.” Beyond that, the women thought about what they would do for their husbands if they had another acute cardiac event.

Judging His Symptoms

The women monitored their husbands to identify a behavior that might be caused by the CHD threat. It was more than simply watching, because the women made a judgment about what they observed. It was not the identification of the symptoms that was most important – but, rather, the powerful significance of it. The women wrestled with the meaning of the symptoms that they observed.

Part of this judging process was based on their husbands’ pre-diagnosis experiences. The women, in retrospect (only), could recall clearly that their husbands had not “been well” for some time prior to the initial CHD diagnosis, and they were not about to let them go undiagnosed, and therefore untreated, again. Because they, or the healthcare providers, had missed the signs of CHD then, their diligent monitoring was especially important now. Louise described her husband's health before he was initially diagnosed:

> … that was something I noticed before the MI when he was complaining of this neck and jaw pain that I would notice his color would go slightly off. That's what partly made me twitch that it was (his) heart even though the doctor said, no, he had the flu. The whole thing triggered that it was exertion based it was coloring, it was posture. That whole thing triggered, heart to me. And I keep watching for that color to go off again.

Before he was diagnosed, Louise thought her symptoms were due to cardiac disease and not the "flu." Now she is prepared, and now she looks for the changes in his coloring. Louise believed that she saw the "early signs" of cardiac disease that were missed by the physician and she is determined that this will not happen again. She no longer has the same trust that he will be diagnosed correctly. For Ann, she cannot trust that her husband will know if he is having cardiac symptoms. She said, "He couldn't even, himself, really really differentiate between the actual heart attack and an angina attack that he was obviously was having before Christmas" [when he had the MI]. Ann learned that there are certain subtle behaviors that are significant, and she cannot trust her husband to "get it right" because she was correct about him being sick earlier. Linda continued to appraise her husband's condition for twelve months after bypass, and she wondered:

> . . . that he's not telling me the truth, that he's not alright, that you wonder if it's blocking again. You wonder if . . . there's something else wrong. He hasn't had as many spells as I consider worrisome. Although I still ask him five or six times a day "Are you OK, do you have any pain?" He seems to get breathless, he seems to wheeze and get breathless, and I'll say "Are you short of breath?" "Not that I'm aware of" is his answer. And yet you can hear it. Or, I can hear it. Whether it's there or not is another story. And so you just sort of file that down.

Linda did not trust that her husband would tell her if his CHD was getting worse. She noticed subtle changes in him; she tried to interpret what she observed. She asked him numerous times how he was. Louise described a similar process:

> And again observing, like I noticed that he'd sit like this, and every now and again I'd ask him how he was feeling, and then I just got used to it. And now if he does it, he almost does it unconsciously, he doesn't do it very much but I'll check in, I'll say, you feeling ok, oh yeah, yeah, I just pulled a muscle. But I feel like he's sorta got me to keep an eye on how he's doing, but his color's really good, he's so different from before he got it.

Louise "keeps an eye on him" while comparing observations to decide whether her husband was having an acute cardiac episode. Irena also watched:

> . . . if he's achy, complaining about being achy, cause he does a ton around the house, you know. He built the fence last weekend, so I'm kinda, I kinda keep an eye on what parts are hurting, and . . . it seemed like before he had the surgery he had a lot of more digestive upset, so I'll kind of watch, and if he's got an upset tummy or something, I'll kinda, oh, what's that all about. And just give . . . I guess it's sort of a watchful thing, but I don't really think he knows I'm doing it.

The responsibility of this appraisal continued daily as the women attempted to discover the truth about their husbands' health status. If Louise, Ann, and many of the other women, were unable to trust their husbands, or their healthcare providers, to correctly recognize an acute cardiac event, then the responsibility fell on them. At any moment, the chest pain might sound an alarm, warning of limits that cannot be breached, a warning of inevitable death.

Their development of assessment skills was elaborated on when the wives recounted, for example, the new aspect of chest pain appraisal in their lives. Betty described the difficulty and confusion in distinguishing between different types of chest pain:

> . . . he had heartburns, they were always very upsetting for me because as you know heartburns may be the symptom of heart attack. . . Ah, but now

> he doesn't seem to have the heart that is giving you the symptoms and the warning.

She continued:

> There are no warnings. He said, "the chest pain was different" the way he felt" but will he know that difference then?

Betty faced confusion in distinguishing between chest pains and she also could not trust her husband's assessment to be accurate. How will she know if he has cardiac chest pain? Chest pain was now a reality in her world because it had actually happened.

Irena also described her effort at learning to assess chest pain accurately:

> . . . you don't know whether the pain is heart related. You're worried about every pain that he has, and for the first few months it was like that and all, with every little pain that he had, "Are you OK?" "Are you OK? Are you sure? How are you feeling? How long is the pain? Where is it? How long is it lasting?"

And now, sixteen months later, she said:

> I'm not quite as apprehensive these days, although I still have to ask him about five, realistically, about five times a day and I'm sure I've asked him three already this morning . . . because he got up very slowly this morning. He didn't seem ok. He was still in his pajamas, that's unusual. I said, "Are you all right?" (He said), "Yeah." (I said), "Any pain?" (He said), "No." So, and when he came back, he sat here, and that was unusual. And usually he just gets himself a cup of coffee . . . and he didn't. I got up and got him a cup of coffee, and said "Are you alright?" It just it's out before I can [stop myself]. That's three times today and the days young.

A year later, Irena continued to monitor her husband and assess for chest pain. However, symptoms considered dangerous now included more than chest pain. For example, how quickly he moved, when he drank his first coffee in the morning, when he changed his pajamas; all were interpreted through a cardiac lens.

Distinguishing different symptoms also was elaborated on by Betty:

> And he had an indigestion the other day, thank god that's all it was, because for me, is this going to be a heart attack? And I said to him, "Maybe you should take a Tylenol, you know? "No, no", he answered, "my body is adjusting". And it passed, thank god.

Betty learned that indigestion symptoms may indicate cardiac problems. When the indigestion stops, she is relieved – for now. Indigestion may just be indigestion. No symptom is insignificant, but rather a portent of disaster.

Frequently, the women questioned their husbands about how they were feeling. The women asked, "How are you?" numerous times but often were not reassured by the answer of "I am well." The decision regarding whether he was well was made by their own assessment of the situation. The women looked for subtle changes in their husbands' behavior to judge the state of their health. The monitoring provided information that might offer reassurance or it might awaken fear.

If the women could not be reassured by watching their husbands, then acute fear and worry returned. Jennifer expressed how she felt during a time when her watching her husband did not provide the reassurance that he was well. She said:

> If he becomes quiet . . . I immediately become afraid every time he became quiet or went to lie down or became the least bit breathless, I just went right through the roof. "Are you all right, do you have any pain, are you short of breath?" . . . Or his color goes a slight bit off .

Jennifer "goes through the roof" with fear when her husband becomes "quiet," "lies down," his coloring changes, or he is "breathless". She interpreted these symptoms as "red flags" that he was not well. Because of these observations, she became alerted enough to ask him questions. Similarly to the other women, her husband's response that he is "OK" did not reassure her, and she continued to watch.

The types of behaviors that the women interpreted as worthy of concern varied. According to Linda:

> It's constantly watching and even when you think you're not, if he sits down and you're aware of his posture or if he has a sigh you're aware of how he did it. "Are you OK?" You know like it's, if he said, "well what did I do?" and I said "well you just sort of seemed to sigh as if you were tired, are you very tired?" (He says), "No, not particularly." It's just constant watching.

Watching is embedded in Linda's life. She looked for subtle changes in her husband's health. She too moved from her observation to asking her husband how he was. She later elaborated on the attentiveness of the watching," I just watch him like a hawk, I watch his color, I watch his movement." The symbolism of the hawk reinforces the idea of the vigilance of the watching.

Monitoring included various observations and interpretations. Irena found it "scary" watching her husband taking his blood pressure. She interpreted the number of times he took his blood pressure with how he was feeling:

> I notice he's been taking his blood pressure more often. It's just very scientific and he's an experimentalist so that's just what he does . . . . noticing him checking his blood pressure a few more times, and I thought, now why's he doing that, oh cause it was scary.

Irena was not interested in the actual blood pressure reading but rather the meaning behind the number of times her husband took his blood pressure. If he took his blood pressure more frequently, she interpreted, "something is wrong."

Judging symptoms was an essential element in the lives of women whose husbands have CHD. The watchfulness included observing and asking questions to learn the state of their husbands' health. Intertwined with this attentiveness were fear and the need for reassurance about his health.

The women arranged to monitor their husbands even when they were not with them. Debra talked about her concern about her husband having an MI when he was at work and she was not there. She said, “He knows that I’m concerned so . . . so, he’d be good at checking in on the phone, so that’s ok.” Irena made sure her husband had the cell phone when he was on the treadmill and that the dogs were there “watching him” when he exercised:

> . . . if I wasn’t home. And I make a point, he likes having me home when he’s doing that (exercising), so if I’m not home I make sure he has the phone right there. I make sure the 2 dogs are there too because they’ll know if something is wrong. So yeah, I worry a little bit, ‘cause you don’t know. To me it was like, wow, ok, there was a stent in there, it makes everything better. On the other hand, wow, there’s a little piece of metal in there, and who knows what it’s gonna do, and is it gonna re-stenos, or is he gonna be exercising and suddenly it will blow up?

Debra and Irena maintained contact with their husbands through a mobile phone. Irena depended on her dogs to watch over her husband who she believes is vulnerable because of the stents. The dogs and cell phones are reassuring for the wives when they are not home.

The women consistently judged the state of their husbands’ health. This forced attention to his body was ongoing. The wives learned the subtleties of assessment: a sigh, a move may mean something important. The husband’s self-report was not believed or trusted. The result of their watching provided reassurance or fear. The women watched not just the how, but what, their husbands were doing.

Observing His Activities

All the participants said they did not know how much activity or exercise was safe for their husbands. Not being able to determine for themselves what now was a safe level of activity created a great amount of distress for all the women in the study. Linda felt inadequately informed when her husband was discharged home:

> But nobody tells you when you leave the hospital. I don't care what kind of good teaching, discharge teaching you get, nobody tells you what's too much, what's not enough, how far, how much how you're going to feel, what to look for. And I'm sure that I can't be that much different than any other wife.

Linda was uninformed about what was the safe amount of activity for her husband when he was discharged from the hospital. Subsequently, Linda described the result of still not knowing what he was able to do twelve months later.

> I was just at the window, almost in tears. He had decided that he didn't want all the sand on the driveway. He was going to clear it. He got out there with one of the heavy shovels and cleared that driveway and, no matter how much I yelled, no matter what I said, he took about two days, but he cleared that double driveway. Well he did . . . he drove me just about . . . He obviously hasn't died in the process right? At least that's what he says.

Linda saw danger in physical activity for her husband long after hospital discharge. She tried to stop him from doing what she thought was unsafe but she was unable to control her husband's activity. She feared that he would die, and she almost cried watching him. Betty also revealed her lack of knowledge and sense of security twelve months after her husband's diagnosis:

> I don't still don't know how much he can lift. I don't know how much work he can do, in the garden. I know they say, "Pace yourself," well what does this mean? You know, pace yourself. Of course it's quite obvious that . . . if you get very tired, you stop but with the heart ah, contrary to for instance asthma you don't really know how far you can go before you have overdone . . . I know all the arguments you can't be (a) heart invalid and you can't be a heart slave.

Betty continued not to know the safe amount of activity for her husband. The suggestion from healthcare providers for her husband to “pace himself” was ambiguous. Betty tried to find a balance between her husband being “a cardiac invalid” and her husband performing activities that were dangerous. She added further detail:

> Ah, he doesn't feel well. And then it is either I’m, kind of (in a) dilemma either to push, kind of push him aside to some extent and . . . Now, if you don't have this kind of illness you don't understand and I have heard people say, "What's the matter with her? After all, he's not the first one to have a heart attack and somebody (can) live twenty-six years after the heart attack and somebody went to work and somebody is digging ditches with a heart attack."

Betty’s dilemma was the decision to encourage, or to discourage, her husband’s activity. This effort to find the right balance created distress. Her friends did not understand how difficult it was for her. At the six month mark (since the CHD diagnosis), Ann still worried about how much her husband could do. She pondered the thought,, "I guess some day you must let go." How are these women to know what their husbands can do or not do? How do they gain trust again? The demands of watching their husbands be active, and still not knowing which activities actually were safe, were very tiring for them.

Compounding the fatigue of watching what and how the men were doing during the day, the wives lost sleep watching their husbands sleeping. Observing their husbands' breathing during sleep was a consistent monitoring activity for the women. Debra vividly recounted her experience the first night after her husband was discharged home from the hospital:

> So when we got home, I remember the first night he came home, got him into bed and both went to bed early and the thing that I kept watching for was his breathing pattern. His breathing was so quiet; he used to snore, before the heart attack. He hardly snores now. I don't know what happened. . . The first night he'd come

> home got into bed and he goes off to sleep and I couldn't hear him breathing and I woke up with this bolt and I had to reach over to touch him to make sure. But the fear was: My God he could die in his sleep here and I wouldn't know it. It just scared you so much so for the rest of the night I just sat there watching him sleep, watching him breathe. I thought he seems to be OK, he's going to be fine, you know everything's going to be fine, don't panic, if you need anything just call 911 and they'll be here but. . . I remember the first couple of nights just watching him breathe, just checking to make sure and that he's OK and everything's OK.

When Debra was not reassured at night by her husband's snoring she was frightened. She was afraid he would die in their bed and she would not know. Watching their husbands sleeping occurred most intensely during the first six months after discharge but it continued sporadically for all of the women. "His rhythmic breathing" (and snoring, for Debra) was a reassurance that he was alive and well. Betty described the nightly vigil listening to her husband's breathing six months after his MI.

> When he's asleep I listen to his breathing because (if) he has this heart attack (and) he is asleep. I wouldn't know.

Eighteen months after discharge from the hospital, Louise described how she continued to check on her husband at night even if she was sleeping in a different bedroom:

> I'll check-in now and then but also I go listen sometimes when he's sleeping. Sometimes I sleep in the front bedroom 'cause he snores so loud. So sometimes I'll wake up, and usually he gets up first, and if I don't hear, there's always that little, uh, is he ok? And I'll go sneak in and make sure he's ok. And if he's asleep, I'll look, he's breathing, that's good.

Louise, as well as the other women, expressed fear for their husbands when they slept. Activities, including sleeping, were times of threat which necessitated vigilant monitoring by the wives. The possibility of their husbands' deaths always was present for the wives. The women remained ready at all times for the "just in case."

Being Ready To Save Him

Part of the wife's "keeping an eye" was recognizing that she might be called upon to act in an event that her husband experienced another acute coronary event. This meant that the wife was not only active in monitoring her husband but that she was also prepared to intervene if necessary. The wives were ready to call 911, give their husbands nitroglycerin, or get them to the hospital. Debra described the watching and being prepared take action if 'something' happens:"

> I'd usually just sort of be watching and as I said I felt like everything was going to be ok, I just had this core belief that they did a great job and that probably things were going to be ok. But I was always, you know, if I needed to call 911 or something, I would have done it in a second.

Debra said she believed everything would be fine, but she had a 911 plan in place just in case. All the women talked about 911 or how they would get an ambulance.

Included in being ready was that the women checked that sublingual nitroglycerin was "close at hand." An example of this activity was included in Ann's description:

> I worried and I still, and I don't think this is unusual or an unnecessary worry, but I do want him to tell me where his Nitro is. But I want to know where it is, so I need to know where it is, in case I need it in a hurry. I remember asking him that, trying not to ask him too often because I didn't want him to think I was spending all my time worrying about it, but wanting to know, where it (was). When we go out somewhere, where is it? and that sort of thing, And he was very . . . there was no problem. But. . . sometimes I think about it.

Ann felt she needed to know where the nitroglycerin was in order to be prepared if she needed to act quickly. The "nitro check" was a common activity for the women. Many of the women said they made sure the "nitro was close at hand" or counted how many pills were left in the bottle. Louise said, "I don't know, like I say, I have to fix his pills, and if I didn't refill 'em and stuff, he would never do it.' Ann 13 months after her husband's angioplasty, also still checked his nitroglycerin. She said she asked her husband:

> "have you got your nitro with you?" Like on vacation, I remember asking him where he'd put it so that I would know, it has been my concern that it was isolated, and everything. I think I asked him there, but I think that as, I don't think of it 'round the house anymore, for instance, I know he's got one in the family room and I know he's got one in the bedroom, and that's where they are and so that's fine.

Ann made sure her husband had his nitroglycerin especially if they were not close to a hospital. However, even in the house she considered the location of the nitroglycerin. She tried to limit asking her husband about where the "nitro" was and if there was enough of it. Ann said she didn't need to ask her husband anymore because she knew where the "nitro" were in the house. She almost allowed him to take the responsibility for the nitroglycerin but she knew exactly where they were located. Most of the women described exactly where and how many nitro bottles were in the house. Many of the participants regularly did a "nitro check" to make sure their husbands had the medication before they left home. Sometimes the women were required to test their readiness plans.

In this study, all the men had an emergency department visit, or even re-hospitalization for CHD subsequent to the initial diagnoses. All of the wives were instrumental in getting their husbands to the hospital or physician when there was a return of the cardiac symptoms. These hospital visits were for chest pain, another stent placement, angioplasty, or for one husband, a bypass surgery. Linda described an incident three months after her husband had stents inserted, when she recognized that he "was not himself." She insisted that he go to the hospital:

> But that week . . . he was readmitted I was beside myself at that point. But he got quiet, he got that he wouldn't get out of bed he wasn't shaving I knew Charles. I was noticing . . . I knew there was no way this man was right and that's when I started to get scared, when I called the hospital.

> And I couldn't take it anymore. . . he was back inside, back in his the bedroom lying down again . . . I just thought, there's something drastically wrong here. And there was no way. . . So I didn't know what was going on but I knew whatever it was, it's not my husband.

Linda recognized that her husband was "not himself". She knew he was not well and acted on it by getting him to the hospital. The appraisal included not just perception but action. She was resolute in getting him to the hospital; against his resistance. Her husband went for an angioplasty that week which further reinforced the need for her to continue monitoring him. She picked up on the clues, and she was proven right.

Debra described a similar incident:

> One night we were sitting here, we had a nice dinner. We had a little episode. We had a little trip down to the hospital. I had come home from work and we had a nice dinner and I went upstairs to get something and come downstairs. Dan had that look on his face. After awhile your spouse gets a certain look on their face that tells you about them without verbalizing it that, "I'm having some difficulty here." I said, "you're not feeling well, are you having pains?" And he says, "yeh, I've got this pain right here and it won't go away." (I said) "How long have you been having pain?" (He said) "It's so funny it started toward the end of dinner time." So I said, "OK well, you know, time it for a few minutes and see if it gets any worse or if it subsides." We waited for about five minutes and it was still there, it wasn't any worse but it wasn't any better, so I called the emergency.

Even though her husband didn't say anything Debra correctly concluded that he wasn't feeling well. She took her husband to the hospital where an electrocardiogram and blood tests were done. He was kept for a few hours and then discharged home. The doctors needed diagnostic tests to ascertain that his "heart was OK". The women lacked objective diagnostic tests and had to depend on their ability to judge and act. Debra commented, "I like to pick up on cues, and to be able to sort of turn it around." Encompassed in the watching was the readiness for action. If he had a return of symptoms or stopped breathing something must be done. If a woman realized that her husband was having possible cardiac symptoms then she persisted in getting him to the hospital. The women did not accept their husbands' refusal to follow-up on symptoms. The women believed that it was their responsibility to keep their husbands alive. Each woman "kept an eye" on her husband and did not blink. Maria expressed the forever nature of watching when she said, "It sounds like a cliché. I think I'll always be watching." Her fear was evident when she added in the next sentence, "and I said to him (her husband) what is our prognosis now, now that it has been a year?"

"Wrapping Him in Cotton"

The wives believed that since their husbands' CHD diagnoses, the men were more vulnerable and needed protection from physical harm. "Wrapping him in cotton" suggested a protected cocoon that was impermeable to danger. A wife wrapped her husband in cotton by shielding him from stress and by arranging safe activities for him. The collected narratives uncovered women's self-claimed responsibility and the actions they took to protect their husbands from physical harm. Debra said:

> You just, you just, want to wrap them in cotton wool so that nothing can touch them and nothing can hurt them. And you want to shut the rest of the world out so that it's just the two of you because you're so scared. That maybe you don't have that much time left so you want it just for the two of you. And you protect and protect.

The fear for her husband's life was evident when Debra added, "maybe you don't have much time left." Protection was needed because the women feared that their husbands would have a heart attack, or arrest, or die. This concern for their husbands' lives guided the need for, and particularly their responsibility for, this protection. Betty described the responsibility of protection:

> Because I find that with being the wife or a cardiac patient, you assume so much of the responsibility for cushioning them, for making things comfortable and less

> stressful and calmer. I figure that this is your role and I have to do this, if I want things for him in our life [to be] as calm as, nice as possible.

Betty believed that she needed to take the responsibility for keeping her husband safe. However, tempering this protectiveness was the image of what the women reported not wanting to be: “a guardian,” “a nag,” “solicitous,” “smothering,” or “overprotective.” Louise said that part of the challenge, in protecting her husband was “trying to figure out” what he needed protecting from, as well as her desire to refrain from “mothering him.” Maria stated, “I’ll say, you know, that’s not good for you, and then he says ‘I don’t need a mother,’ what can I do?” Jane said, “I didn't hover over him. I have to admit I didn't hover. But I was protective, but I didn't hover.” The women tried to balance this concern for "protecting too much" with wanting to protect their husbands from the coronary threat.

Maria said, “Sometimes I think about it, but one of the things I've tried not to do is mother him too much.” Jane said, “The thing of it is, I don’t say take it easy, like I’m bossing him, that won’t do any good. But just…I gotta be careful how I say it.”

The difficulty in finding the line between protecting their husbands sufficiently and protecting them “too much” was a consistent concern for all of the women in the study. The women feared being a “nag.” The women in the interviews were concerned about being accused of being overprotective. and or the other names, but at the same time needed to provide just the “right amount” of protection. The women sometimes questioned whether their husbands really needed protection, as revealed by Maria’s statement:

> I feel protective, I just fret over him a lot. Like make sure . . . I don't know . . . gosh, I have to take care of him, but maybe I don't.

Maria later added, "I need to watch . . . watch him." She questioned whether she needed to "fret over him" but she did it anyway. The function of "wrapping him in cotton" became embedded in the women's lives. However, the criticism for doing this provided an added concern for the women. According to the wives their husbands needed protection from "stress" and the activities that they deemed were unsafe; but this protecting activity needed to be done surreptitiously.

Shielding Him from Stress

The women frequently labeled "stress" as a danger to their husbands' lives. The women saw stress as the cause of their husbands' CHD and the trigger for the next acute event. According to the women, stress came from different sources. The women identified "stress from others" as a major threat to their husbands' hearts. When Debra's twenty year old son, who lived at home, was upset that they were "walking on eggshells" at home she tells him how to behave towards his father:

> .... I had told (him) "You can't upset him because his heart has been damaged. It is weak and any trauma will really upset him. I mean it can bring another one on and this is not, I'm not fooling around here, this is real. I don't want you pushing buttons or pressing your father's nerve. If you have to go out of the house or whatever. . . but you're not going to do this, you're really not going to do this . . . Whether it's a mild heart attack or a big heart attack, the heart has been damaged. Okay, and you have to give him time to recuperate. So I suggest if you have something to say to him, just take your time."

Debra identified their son as a potential source of stress for her husband. She used herself to protect her husband from the stress she believed her son would cause. Debra warned her son about the seriousness of a heart attack and in this warning, it is apparent why she believed she needed to protect her husband. Her husband and his heart were vulnerable and fragile. Irena also reported talking to their adult children when she said, “oh yeah, we babied him, you know, don’t make dad do that, I’ll do it, you know.”

Maria protected her husband from her parents’ criticism. She further reported, “I also find myself running some interference between him and my folks, because you know, my moms been through 8 zillion health experiences, and she thought he was being too obsessive.” The women saw others as a potential source of the stress threat. Furthermore, the women believed that their husbands needed to be protected from the wives themselves. Louise reported on how she silenced herself to protect her husband:

> If I notice he’s stressed, I think well, maybe it’s his anxiety coming through. Maybe it’s not, but I’ve been more lenient with him in the way that in the past when he was gruff or angry I’d call him on it, you know, like, hey . . . now since his heart attack and his pending operation, I say well ok . . . so I’m kind of letting him be more miserable you know.

Louise was “more lenient” with her husband than before CHD. She did not speak to her husband about his “difficult moods” but rather kept it to herself. Protecting their husbands from themselves is further illustrated by Debra. She described her husband's "complaining" about his doctor that "went on for months:"

> Initially after the heart attack when he would come home with something like that (complaining about the doctor) .I would sit and I would sort of listen. . . I would try to placate him because I didn't want to sort of respond angrily because I figured I’m just going to get another anger response and it's just going to make it worse. . . I was sometimes kind of really really upset with him you know, just didn't let my anger out because I sort of. . . sort of keep. . . I would keep the anger repressed. Because I was so afraid of upsetting him.

Debra listened to her husband and tried to calm him and did not get angry, in order to protect him. Nearly one and a half years after the cardiac bypass surgery she decided he could "take it" and that “she had listened long enough,” and she suddenly became angry. She said, “I told him to knock it off.”

Besides their anger, women protected their husbands from their own worry. Ann commented on keeping her concern for her husband, regarding going to the cottage to herself:

> I didn't want . . . I didn't want to be specific with him that I didn't want him going off by himself because I don't think he would have appreciated that I would not let him go, by himself.

She further stated that keeping concerns to herself was:

> . . . different, I am keeping it more inside and I think probably this has been a more stressful . . . a year . . . in that sense . . . I don't say, you know, as much to him obviously.

Since her husband’s diagnoses Ann kept her own stress and concerns to herself. She believed that it was necessary. Louise described how she kept the “burden” from her husband at the expense of herself:

> And so as I said I didn't want to put the burden on him in any way and I was trying too hard to keep the burden off of him to the point that I was putting too much in that situation on myself and it became silly, quite frankly I thought it became silly.

Louise said she knew that shielding her husband so much was “silly”, but she continued doing it. Jane described how she didn’t let her husband know she was worried when he went to the Emergency Department for chest pain. She saw that her husband was worried, and Jane said:

> I tell you big, I've never seen anybody so scared in all of my life. I mean he was just in an absolute panic (He said), "What if I'm going to have another one? What if I have another heart attack?" And I said, “You’re not going to have another heart attack, you're probably just have tension

> and you're going to be fine." (He said), "No there's something really wrong, I've had pain before but this is something like the pain I had before." At this point I'm trying to calm him down, I'm scared as hell now. . . and I said "just wait . . . obviously the doctors right now aren't overly concerned . . . if anything happens, we're in the right place that they'll take care of you. . . try and calm down." In the meantime, I'm thinking to myself, What if something really is wrong here? I mean what if he is on his way to have another one?

Jane also worried, but she kept this to herself. She reassured her husband to help "calm" him so he was not more worried, and she blamed his chest discomfort on tension. After a few hours in the Emergency Department, and being given nitroglycerin, Jane's husband was discharged home to her. Throughout the telling of this experience Jane shares how frightened she was, but that she shielded him so "he didn't know." She said, "I was strong." Being strong, in her thinking, was keeping her concerns to herself. She was alone in her fear. The practice of providing protection was lonely, isolating, and silencing.

The threat from stress comes not only from specific people but also from other demands. The women saw danger for their husbands' hearts when there were emotional demands. Work was considered a threat for those women with husbands who worked. Jennifer said her husband "becomes (too) engrossed" in work, and she tried to get him "to take it easy." Maria encouraged her husband to not return to work because she believed "it may be fatal." However, her salary now is the only income for their family, and she worries about finances. Related to this, Louise shared her concerns about her husband starting a new business:

> I don't think he could take the stress or the strain of it, another business. No, he really doesn't have the strength to handle it. He gets too involved and he gets too worked-up and too nervous. For heart patients it's fatal, just do what you're doing. Don't worry, just take it easy, everything's fine. Financially, we're not wealthy or anything, we're not even rich, but we're comfortable.

Women who had husbands who were working were concerned that their husbands would be unable to decrease their stress in the work environment. Work was perceived as an important threat since the women identified stress as the key component for causing the CHD. The women worried because when their husbands were at work they could not monitor nor protect their partners from stress. But the women were not successful in getting their husbands to stop, or even limit, working. Jane said, “I cannot keep him from working, I tried.” Emotional stress from others, and from work, was identified by the women as a threat to their husbands’ health. However, physical activity also was of significant concern for the wives.

Arranging Safe Activities For Him

Women provided protection from physical activities that they believed would cause a “strain” on their husbands’ hearts and jeopardize their lives. The women arranged for certain physical work to be done by their husbands. Ann described the kitchen renovation that was done on their house:

> Last week, we were in the middle of the renovation and the man who was doing the renovation, said you're going to have to take all the wallpaper off your wall and of course that's me all of a sudden.

Ann did the work that would normally be shared by the two of them and protects him from the physical work in the house. Linda expressed concern about the physical activities that her husband did that she believed were unsafe. She often advised him to “wait for their sons-in-law to do the heavy work.”

In their new post CHD world the women organized or made adaptations to activities to minimize the risk of certain activities. The wives arranged safe undertakings for their husbands when they were not home. Debra said:

> I've started to have an agenda (of things) for him to do when I'm gone so I know pretty well, if I give him a few things to do. . . then I know what he's doing. He'll do that. (He says), "Tell me what you want done and I'll do it." So if I tell him what I want done, but there's nothing more that I really want done. There's lots of things that need to be done but I'm damned if I'm going to have him . . . Not while I'm not here they're not.

Debra arranged for "safe activities" even if there were no more activities that she viewed as safe. She, like the other women, did not trust her husband to choose safe activities. Linda described the "activity" dilemma in the following quote:

> I worry when he works outside, I'm always thinking of him carrying anything. He's attempting to undo this problem, this plumbing thing we have today. And last night, like that was what came . . . can he handle that, is that stressful, is it? . . . so like I think of it, I don't say but I'm thinking we should try to get a plumber even if it costs $200, maybe more than that, you know? Like at whatever it costs, we'll have to pay it, we'll get a plumber. Like I want to . . . not coddle him but, it is a process that I have, can you cope with that? Like when there is digging outside, like I want our son to do it, he's just automatically out there and I think, Sam (son) maybe you should do this. I don't know, you know? Maybe he (her husband) should be doing some exercise, maybe it's good for him to work outside. So like there is that part too. You know, I love to dance, but is dancing good? I mean I don't know how much he can . . . and I assume that the doctors would have told him what his limitations are, and he should know to apply them. So, when I think, oh, maybe he shouldn't dig, then I say, oh well . . . So, yeah, it is a constant consideration now, and I never thought of it before. I mean maybe it would occur to me saying, gee, he's a prime candidate, his age, his weight, he's a smoker, he's in...he's stressed. So he's got all these notches against him. . .

Each of Linda's sentences revealed a struggle. She worried, is he doing too much or should he do more? Should she do something like arranging for her son to do the work? She didn't know how much was safe for him to do and what she should do. According to Linda her husband is at risk or as she says he has "notches against him."

Underneath the wives' daily decisions and actions was the potential threat from their husbands' heart. The wives believed that their husbands were "fragile" and therefore in need of protection. The women felt responsible to shield their husbands from potential harm or injury. However, the women were balancing protecting their husbands with not being what they called being "overprotective." Therefore the women provided this care, often secretly, in ways that they believed would keep their husbands safe. In the action of protection the women often limited their own lives. Jane said, "I could never leave Joe for a couple of weeks. I probably could, but I would be a wreck to leave like that, you know what I'm saying?" The illness did not exist independently but rather as something to be negotiated in the world. Protection was an activity that was threaded with fear, silence, and insecurity.

The mainstay of the previous themes concerned specifically the wife in relation to her husband who has CHD. The following theme reveals the shared nature of CHD in the women's lives.

"Right in the Middle of It"

The husbands have the cardiac disease and are now living with a chronic illness but the women also experience this illness. The women viewed the illness as something that happened to both of them. Jane described being part of her husband's illness when she says, "you can't distance yourself because you're right in the middle of it." To be in the middle suggests one is encircled by something. In their daily lives the women were part of their husbands' CHD. Because of the perceived ownership, the women struggled with the responsibility for their husbands' disease and the illness. Also from this shared illness perspective the women not only attempted to make lifestyle changes in their husbands' lives but to make changes in their own lives as well. The women changed their own lives because of their "shared" illness even though they did not have the disease.

Sharing The Illness

The wives did not view their husbands' illness as separate from themselves but rather they were part of it. Speaking about their husbands' CHD as a shared illness was a common sentiment by the wives. Debra said, "*We* are dealing with an illness together." Katia said, "Of course what happens to him affects me." Jennifer recounts "*We* went through three cardiologists until we found the right one." Betty shared, "*We've* come through two heart attacks and everything else and *we're* still alive, *we're* still together." The women frequently referred to the experience as "ours." Their husband experienced the disease but the wife shared the illness experience with them. Debra's said:

> I went through it too and really it's very painful to go through this and I'm scared to death . . . I'm frightened that it happened to us.

The illness caused emotional pain for Debra because she said it happened to *us*. Coronary heart disease not only changed the husband's life but also affected the wife. According to Ann the diagnosis of CHD was a "milestone in *our* lives" and an "instant life change" for Debra. Maria said that after the diagnosis "your life from then on is not the same." There was a sudden transformation to both of their lives and according to Irena it "changes your everything." If this illness is not separate from them but part of them then they have some responsibility for it.

Being Responsible For Him

Sharing the illness with their husbands created challenges for the wives. The women experienced another's illness and struggled with the responsibility of trying to control another person's life. Sometimes the wives even questioned whether they should be responsible. All the wives experienced the frustrations of trying to change someone who did not always want to cooperate.

Louise said, “I feel it’s all my responsibility, what he eats, how much he eats, whether he’s up, whether he’s down, whether he’s active, whether he’s not . . .” Many of the women researched on the World Wide Web and read about CHD for advice on what to do for their husbands. The women took the responsibility for being the expert on their husbands’ disease.

Debra described in detail how she tried to influence her husband and his health even sixteen months after his diagnosis. She told him:

> “. . . you know that you have to do things in moderation. Even though you might be feeling on top of the world.” Last week he went golfing to practice his swing and he went out for two hours, two. or three hours and of course his arms were sore when he got up the next couple of days and I said “well you did too much.” I said “I know you’re feeling very well you’re feeling great and that’s great I am very happy that you’re feeling well. I would like to see you continue to feel well. So the next time when you go out and you’re doing your swing try for an hour. OK, OK if you want to swing for an hour swing for an hour and then putt, because your putting doesn’t take you the same you know force.” I said “do maybe a half an hour of your swing and then go do some of your putting to give your arms a break. And then you can go swing again a little bit more but don’t overdo it. Don’t get yourself overtired. I know you’re feeling really great.” He’s feeling really well. “I’m very happy that you’re feeling well, I’m glad that you’re feeling really well” But they tend to feel that oh well I’m well now I’m 100% better and I can do anything that I did before and I don’t have to worry. And I said “you have to always be aware, not to overtax yourself.”

Debra believed that her husband was not careful when he went golfing. She scolded him and gave him advice on how to do it differently in the future. She tells him that he may think he is better but he must always be aware of the danger; as she is. The women did not trust their husbands’ bodies or their husbands to make safe decisions. In response to this lack of trust and fear the women tried to manage the disease and their husband. The impossibility of this task was a struggle for the women. Maria described the difficulty:

> So, and it's very hard . . . to be responsible or feel responsible for somebody's health. I know cognitively I know every way that you can think of, except emotionally, that Mat's health is his problem. But that's not the way it is.

Maria's attempts to distance herself from the responsibility for her husband's health were not successful. The frustration that existed with the responsibility was more acute when their husbands "refused" to change identified unsafe behaviors. Irena said, "so it was just trying anything, just . . . sometimes he would go for it, sometimes he wouldn't." Part of the challenge for Maria and many of the other wives was that their husbands did not always "cooperate" and change their behavior. Linda's husband continued to smoke, eat poorly, and not exercise. The physician told them that "smoking accounted for his problem." Knowing that he did not change his behavior Linda said:

> And no matter how many times I tell myself, look, I can't stop him doing these things, it's not my responsibility, if he kills himself that's his problem. But it's not (laughs).

Linda admitted that she could not control what her husband did, or did not do, to manage his CHD. She tried to disown the effects of his decisions however they affected her. Trying to control the disease, the events, and a husband that cannot or will not be controlled, created distress for the women. In response to the inability to controls their husbands' behavior some women attempted to distance themselves from the responsibility and questioned if it was necessary. Maria said, "I kinda separate myself from it a bit, but I kinda teeter." Their responsibility for their husbands' illness invited self-reflection. Jane shared, "I'm removing myself but I'm really right in it, you know?" The women attempted to limit their overwhelming feelings of responsibility but were not successful. The wives struggled with the impossibility for being responsible for someone else's life.

The women sometimes vacillated on whether they should be responsible for their husbands' health. Katia recounted:

> I always feel like, yeah, I have to take care of him, but maybe I don't. I don't know, like I say, I have to fix his pills, and if I didn't refill 'em and stuff, he would never do it. If I don't make the doctor's appointments, he doesn't go.

Katia questioned whether she needed to be responsible for her husband's health but continued to fix his pills and made his physician appointments. In the end the women held themselves responsible for their husbands and struggled with the challenges inherent with trying to control another's illness and hold off another cardiac event. This responsibility meant that life change was necessary.

Changing Their Lives

A further example on how the wives experienced the illness was that they made lifestyle changes and changed their own lives in response to their husbands' CHD. The women incorporated CHD lifestyle changes into both of their lives. Kaita did not have heart disease but said, "it's just a lifestyle change for both of us, so we get out of the habit and get into a different pattern." Betty said:

> The main thing for us now is try to keep as healthy as possible. That's really important that we keep healthy. The diet here at home has changed considerably since he had the heart attack. I, we really watch what we eat.

Changing both of their diets was a common practice for the women. The wives included: "cutting down on eggs to one a week"; "cutting cottage cheese from four to one per cent"; "drinking only decaffeinated coffee" and; "not eating out in restaurants." The women made dietary changes even if they were not convinced it was necessary. Katia said, "We have changed our eating habits quite drastically. Not that we were ever bad eaters." Katia, like many of the other wives, changed her diet even if she believed it wasn't necessary. Food was a concrete thing to change that the women had some control over since they were the ones that mostly did the shopping and cooking.

In addition to lifestyle changes, the women made additional changes in their own lives. Limiting social activities was a consistent change reported by the women. Betty's husband was diagnosed with CHD 6 months before the interview and she said:

> I haven't seen a lot of my friends over the last few months, because the time has been full, full for one reason or another . . . so I'm only just getting beyond that now . . . friends would come and say hi and how is Bob and all that stuff, but we really haven't been visiting and doing the things that we might have been doing but . . . we would have...going out bicycling with people or something like that we just haven't done, and as a result we haven't been seeing them.

In the past Betty and her husband participated in activities together. Because her husband had not been able to do certain things since his CHD Betty has not done them either. Betty has limited the things she liked to do to focus on her husband and his disease. In addition, to withdrawing from mutual activities, she spent less time with her own friends and activities. She suggested that the limiting of activities was changing now after 12 months. Louise also described limiting her social activities. In looking back over the last year Louise described how time changed the limitations on her social life:

> I used to feel I shouldn't go out and leave him alone. So I wouldn't go out much with friends. What would happen if I wasn't there? Now I can go out with friends. A year ago I felt nervous, even guilty. I kind of realized I need to take care of myself . . . I have to do this for me but I couldn't do it before.

A year after diagnosis Louise was re-connecting with her friends. She recognized that her life had been consumed with her husband's illness. She was able to do things now for herself because he was "ready." She trusted that after a year he would be safe if she was not there. However, this state of trust was tenuous because she added:

> . . . you know, I guess that's the long term thing, I suppose, I wonder, I mean I'm not concerned about this I'm not saying it in a negative way, but I wonder if it is ever, is is it ever all over, it depends I suppose.

The forever nature and fear of living with a husband with a chronic illness was shared by Louise as she lived "in the middle" of CHD. The previously discussed themes emerged revealing the wives experience with their husbands and CHD. In addition, CHD brought new personal meaning to the women's lives.

"I Have To Get Through It"

The final theme that emerged was "I have to get through it." The expression of "getting through" gconnotes working and surviving through adversity and challenge while attempting to sustain oneself. The expression "I have to" when added to "getting through" suggests the compelling nature of the task. The participants in the study "struggled" through living with their husbands with CHD by: being silenced and asking questions that did not have reassuring answers. Looking into the future twelve months after her husband's MI, Louise stated:

> (I was thinking) Oh my God, you know, I mean, I could really lose this man, I could really lose him. And what am I going to do? I'll just never make it. I'm never going to get through this . . . and that I have to get through this . . .

Louise worries how she will get through the present with the threat of her husband having CHD and the future if her husband dies. Maria said how difficult each day was to "get through," and Jennifer said "it is so hard just getting through the days." Part of what the women do to "get through" is to remain silent.

"I Haven't Spoken"

The women in this study kept thoughts, feelings, and conversations more to themselves after their husbands' diagnosis. This attempt at remaining silent was especially true when speaking to their husbands. As previously discussed in the section on "wrapping him in cotton," the women protected their husbands from their own worry and anger. Many of the women did not share their daily concerns and worries with their husbands. The women believed that speaking out loud about their worry would add lethal "stress" to their husbands' lives. Betty hid her anger from her husband. She said:

> Since the heart attack I'm afraid to bring it up. I'm afraid to explode. Now I'm afraid which is bad because I keep it and keep it and keep it and then when it is something bigger coming up I explode and then of course I feel scared because of all this business of tension and so then I get scared and of course guilty but mainly scared after the heart attack. . . Now I feel so scared that I precipitated a heart attack . . . now when I create some tension over stupid things I feel very frightened and I don't say anything.

Betty was afraid of getting angry and kept her anger to herself. If she didn't control her anger then she was afraid she would harm her husband. When she did get angry she was frightened and guilty. She believed she needed to be silent because her anger may precipitate a heart attack. In addition to Betty silencing her anger, Linda did not confront her husband when he was "miserable." She said:

> . . . now since his heart attack I say well ok . . . so I'm kind of letting him be more miserable you know. It's just harder on me 'cause I'm giving it excuses you know. I better lay off, what if it's . . . so that's stressful too, kind of pussyfooting a little bit.

Betty said things were harder for her because she was "pussyfooting." Linda was silenced and this silence was "stressful." In response to their fear about putting stress on their husbands' hearts the women were silent; and the stress became theirs. Speaking may harm their husbands. The absence of voice was part of the women's descriptions of their everyday life.

In addition to the unspoken thoughts and feelings the women lived under further fear of giving voice. As discussed earlier in the theme "wrapping him in cotton" all the wives feared "smothering," "mothering," "overprotecting," or "nagging." It was suggested in the women's words that their behaviors were interpreted in this manner by their husbands. However, a number of the women learned to "be careful" not to "nag" from healthcare providers and teaching material. Women's voices were silenced when they were being careful about what and how they said things. The wives tried to protect secretly because of the risk of disapproval from their husbands and others. To confound their actions even more, the women feared the very act of protection may put added stress on their husbands' lives. However sometimes according to Maria, "I can't help myself, I have to ask how he is."

In addition to remaining silent, the women described a dialogue that they had had with their husbands that were examples of conversations not being held. All of the wives included the "how are you" dialogue in their descriptions of their lives. An example of this dialogue was reported by Louise:

> "Are you alright, you know?" "OK." (he says) "You're sure?" "Yes, yes." (he answers). I keep asking.

Louise, as well as the other women, asked some form of this same question repeatedly; and the husbands answered simply, "yes," "fine," "OK." When the interviewer asked Betty why she asked the question she replied:

> I probably bug the life out of him but I think he's not telling me the truth, that he's not alright that you wonder if it's blocking again.

Betty "cannot help herself" from asking her husband how he is. She asked the question, and he gave her an answer that was not reassuring. She did not trust that he was being honest with her. These "how are you dialogues" were not actual conversations. Rather they reflected a litany of seeking reassurance and then getting responses that did not provide reassurance. The ritual of these questions and answers was similar to an incantation. The woman asked and the husband answered with fixed responses. What they did not say to each other spoke loudly about their fears. The "how are you dialogues" replaced the conversations not being shared.

Some of the women spoke about how they had not spoken to their husbands about the meaning of the illness either for him or for them as a couple. Jane said, "I don't know how he's really feeling about his heart condition." Katia said, "it's interesting cause we talk about everything else but I guess we just decided . . . different huh?" Katia and her husband talked about "everything else," but not about the disease that was at the center of their lives. When Jane tried to understand why her husband had "lost his compassion", she wondered if he was afraid:

> And I don't know whether it's because he's scared he's gonna die, and doesn't want to feel like he's . . . maybe he's afraid of being too close that he'll make it even harder, I don't know.

Jane thought of a possible reason for her husband's behavior but did not talk to him about it. Words and conversations remained unspoken. During the interview Linda said, "now that I'm sitting here talking about it, it's like, I should talk to him about it." In talking with the interviewer most of the women came to realize that they had not had a conversation with their husbands about his illness. Many of the women had not talked to anyone at all about what it was like for them to live with their husbands who had CHD. In the interview itself, Betty realized that she had been talking for 90 minutes to the interviewer, and said:

> I almost feel like I've got verbal diarrhea because I'm just talking like this, and I suspect that probably a lot of it has just been sitting in there with nobody wanting to listen, with me assuming that nobody wants to listen, maybe that's an

> assumption that isn't correct, but I haven't I haven't spoken to my friends or my family about this.

Considering the insecurity and fear in the women's lives, the described silences become even more powerful. For many of the women, conversations with their husbands were missing. Speaking the words out loud was dangerous for her husband but perhaps to say the words out loud was dangerous for both of them since articulating the fear placed the reality more into focus. There was terror for them, in the words themselves and also fear in speaking them out loud. The conversations not being held denied the lived experience and rendered the women feeling more frightened and alone.

"What If I Lose Him?"

Uncertainty consistently beleaguered the women in the study due to the unpredictability of CHD. The women faced "constant insecurity" and were required to reposition their hopes and dreams within the framework of the new realities of their lives. Life as they had known it was gone now and there was a shift in concerns and priorities. The wives described not only how their present lives had changed but also their view of future possibilities without their husbands. The women reluctantly questioned what their future life would be like without their husbands. Ann described her thinking:

> You know, I kinda like, try to put it in perspective, but I am a big worrier. I imagine things. I always say, well I'm preparing myself you know, instead of just letting it happen as it comes I do let it really affect me . . . you know, I'm prepared for the worst.

Ann worried and prepared herself for what she feared was her future, a future she called "the worst." Part of the present insecurity for her was the potential sudden change in the future that might come due to the death of her husband. Debra also experienced insecurity and fear when looking towards the future:

> So for me it's one of constant insecurity and every time he gets quiet I go right through the roof. I find (that) you try not to look too far into the future I think it's just that way.

Debra's dread of impending possibilities interfered with her desire to look into the future. This insecurity was now a regular part of her life. This sense of insecurity was also shared by Irena:

> . . . the security issues have always been a thing, but you realize, hey, in an instant life can change. . . It's a wake up call that you realize, hey, in an instant life can change. So if anything . . . made me realize it a little bit more, that ok, you have to . .. this is the way life is.

Life, as she knew it, might possibly change in "an instant." Irena recognized that her present life was tenuous. Life might suddenly change and she did not have control over this. Irena's dreams, as well as the other women, were altered because of their husbands' diagnoses. A crucial factor in all of the women's future dreams was having their husbands in their lives. The potential loss of her husband of 25 years and the subsequent loneliness were a worry for Debra:

> You know, that was, that was probably one of the first sort of private thoughts I had was that this I really do not want to go through the rest of whatever amount of life left to live I really don't want to go through it alone.

Debra did not want to go through life alone and this possibility was now evident. Louise also wonders how she "will live" if her husband died:

> What am I going to do if I lose him how do I handle it if I lose him now? I'm not ready for this, I'm not ready for this, I can't I can't imagine not have having him around.

Louise was concerned about a future that does not include her husband. She feared how she would manage. Even one year after her husband's MI Betty shared her continuing fear and the centrality of her husband in her life:

> The bottom line is that at any moment you can lose this person and how do I deal with it when and if it happens and even right now that's a concern in my head. Even now 1 year later you run these scenarios through your head, I don't know if other wives do it. If I were alone tomorrow, how (do) I cope with being alone? How can I cope with not having that man who's been so much a part of my existence? . . . you start trying to do things independently just sort of to prepare yourself for when it happens. Because you think inevitably one of us is going to go before the other and the law of averages with heart patients tells you that down the road maybe that you're alone and your husband goes, so how do I protect myself? How do I prepare myself for being alone? The biggest fear, the biggest, for me that is one of the biggest fears that I have to deal with and if it happens how do, how do I handle it, how will I deal with it? I just run scenarios through your head to try…

Betty was faced with the possibility even one year later that her husband would die at any time and so he would not be part of her future life. She worried how she would manage if her husband was not part of her life. Betty tried to think of a way to prepare and protect herself from what she believed was the inevitable. She found no answer.

Looking towards the future without their husbands created more fear and insecurity for the wives. According to Linda, "Life isn't what it was . . . you have to deal with immortality." The immorality that the woman was facing was not her own but rather that of her husband. Although death is inevitable, this reality was not in the forefront of the women's minds before their husbands' diagnoses. Now this reality was brought to the forefront of their minds; furthermore it was close at hand. Living with this new awareness lead to shattered dreams, despair, and suffering for the women. For Louise 16 months after her husband's initial diagnosis, insecurity and fear were part of her every day life. She said that friends did not understand and they said to her that:

> . . . it should be over for you now you see. They don't see that it's an ongoing thing and that there's a little corner in the back of your mind. That little corner is filled with that memory and the little corner tells you well that it may not happen again and it may happen again and the chances of it happening again are more so than it not happening again. If you're being realistic. So, it's there in the back of your head, I mean you don't think about it all the time but you know it's there as a

> reality. And it's just different. It's quite something, I just never thought, no I, I never thought in my wildest dream that I would be going through something like this. Yeah it's um…really something really something (quiet).

According to her friends it "should be over" and she needed to get on with her everyday life. She was expected to return to her life as it "was before." However, her friends did not understand that for Louise that her everyday life had been forever changed as well as her future possibilities. Louise claimed that the chances of her husband having another acute coronary event were greater than the chances of him not having one. With these possibilities in focus, life could not be the same. According to Louise, the threat was "not there all the time," but "it is there." When she considered that her present life was not what she had anticipated, then it was with trepidation that she looked to her future and did not feel confident. Part of having hope is believing that there are future possibilities.

The fear of being alone was a recurrent concern for the women in the study. When considering that they might be without their husbands in the future some of the women re-established their friendships. For the most part, each woman wondered and worried about how she would "survive without him" in her life. How would her life be in the future if he is not in it? The question of "What will I do if I lose my husband?" is one without an answer. This question is not the only one that cannot be answered with certainty.

"Why Did It Happen?"

The women in the study continually searched for the meaning in their experience, and were forced to face the harsh awareness that some things were unknowable and uncertain. This search was not merely to find the cause of the disease but perhaps more significantly for the women an answer to the question “why did it happen?” in the existential sense. The women searched for some meaning in their newly fragile world.

The wives’ lives following the CHD diagnoses were qualitatively different than the ones that were lived before the illness. For the participants in this study, their reality changed after CHD. A person cannot live unchanged after a “brush with death,” even if it is the brush with death of another. The women were in relationship with their husbands and they shared in each others’ lives and futures. After the CHD diagnoses the women were suddenly thrown into a world with unfamiliar possibilities and constraints for living. Moreover, they now lived with the possibility of even more abrupt and unexpected change occurring while they also were confronted with facing the truth that the future is unknowable. An integral part of the process of living with change, fear, and dealing with the unknowable for the wives was a search for meaning in the experience.

All of the women struggled with the dichotomy inherent in the meaning of the experience. According to the women their husbands’ survivals were due to luck, a miracle, or God. At the same time that the women were feeling thankful they were also feeling the polarity of feeling “unlucky” or that “life is unfair.” They “count their blessings” and according to Jennifer:

> . . . for us it has been a frightening experience, but an edifying experience and it has brought us much closer together. I appreciate every day that I have him. I enjoy every minute that I'm with him . . . My frustrations you ask "why did it happen?" but it's a silly question, there are no answers, there aren't any answers. I mean this could happen to anybody and you just say . . . why does this happen? Why now? Why? Why now? And there are no answers, there are no answers. It's just the scheme of life. It's a learning process. Thankfulness, that's the only word, thankfulness to God. That we have this opportunity, you know we've been given another chance. . . . I don't know. I guess it was meant to happen maybe we needed to be shaken up, maybe we needed a good kick in the seat. Fate has a way of handling things so that your perspective changes.

For Jennifer, the experience was "frightening" and "edifying" and it brought her closer to her husband. She said she had learned from the experience and was more appreciative of every day. Further, Jennifer believed that they had been given another chance to "get it right." However, she still struggled with the answer to her question of "why" it happened.

A positive view of the experience was included in a number of reports about "thankfulness." Many of the women examined how "it could have been worse." For one wife, she was thankful "it wasn't like a big bypass" and, for another, "at least he could have a bypass." Maria said "stents are becoming almost like routine, they're miraculous, I am thankful it happened these days." The women were thankful that their husbands had not had their CHD diagnosis "on a plane," nor when they were "on vacation", and for one woman "at least we're not in Omaha." The distress was more tolerable for a woman when she was able to assign a positive meaning to her husband's disease.

A more negative view of the experience was described when Irena said, "It is difficult when, your body's betrayed you." Debra whose husband had had an MI and stents twelve months earlier, described the day-to-day "struggle" of finding meaning:

> . . . and each day I struggle, and it gets easier, but each day you have to tell yourself, ok we're each here for our own life's lessons, our own journeys, and we've got to go down that road . . . we can give love and support, but we can't change it.

Debra further revealed the unalterable effect of CHD, as well as the struggle, in the search for meaning. She believed that "it happened for a reason", "a life lesson." Leaning towards possibilities, and confronting losses at the same time, is to live the paradox of CHD. Louise called it a "blow" but also stated "I think we're fairly lucky. Life certainly hasn't turned out the way we expected it to but I mean what can you do?"

Louise resigned herself to the "blow" as the "luckiness" in her husband's diagnosis. Maria said, "it's not fair, damn it it's not fair, that's . . . that's the thing." Irena said " . . . like there's times when I feel really cheated." The search for meaning does not hold one single truth. The meaning of CHD for the wives can hold both positive and negative understandings at once.

Louise talked about a moment shared with her husband at a party on the anniversary of his MI:

> . . . and while we were sitting at the table that New Year's Eve with all of our friends. . . all of this was going through my head . . . but to the end of it all I could think of was I am so thankful, I am so thankful. That's all I could think of, I'm so happy that we're here, this is so special and Dan just kept on. . . he just . . . we were sitting across the table from one another and when midnight came we all got up and he just put his arms around me and just held me for dear life and you couldn't say anything, you know like you just, because I know if I say anything here I'll just start crying now. So you, you're just so full. . . and he told me, he says, I never realized how precious life is, how much it means to you. . . how little things, little things that you take for granted, just little things that you don't think about. . . and when something like that to you happens you never take it for granted again because you know that in a minute it could be over. . . and as a result he's so much more attentive, well it's been it's been, it's been great. . . , for us it's been an edifying experience. Even through all the pain and anguish and the fear. . . I think we've come out winners, we've really come out winners with this.

Experiencing the poignancy of life after the event was evident in Louise's story. In retrospect she saw that they had "come out winners" after the year was over. They were closer and they shared these feelings together. The centrality and tenuousness of their relationship was uncovered in the telling of the evening. Louise savored this moment of happiness and tucked it away in her memory. She later added that it was a "celebration" but also stated "it could all be over." Louise oscillated between hope and fear. For her the future remained uncertain and still threatening. Louise was the only wife who reported actually speaking to her husband about her fears but on the anniversary (of his diagnosis) she spoke to him for the first time like this.

Their husbands' illness was not an intrusion in the women's lives but rather a new way of life for them. The women frequently used the words "surviving" and "getting through" when assigning meaning to the experience. The women attempted to regain mastery of their lives; yet beneath the surface lay fear and vulnerability. The wives faced the fearsome reality that the present and future are neither controllable nor predictable. The women were reminded of our human finitude and the reality that everyday life involves inevitable compromise. The existential question, "What does my husband's illness mean to me?" is at once both urgent and profoundly disturbing. This question was addressed over and over again with varying answers.

Because the women shared in their husbands' illness they likewise experienced the tension which arises from living a life that is teetering on the edge. To acknowledge that there is no meaning is to open a person up to considering the possibility that one is defenseless in a precarious and chaotic world filled with unpredictable and uncontrollable forces. The women searched for meaning in their experience in order to help live with their new reality. Poised on the boundary between finitude and transcendence the women revealed the very aspect of human existence.

Chapter V

Discussion

The findings from this feminist hermeneutic research study expand our current understanding of women in relationships with men who have a chronic illness. Most early studies of wives of men with CHD tended to focus on the measurement of distress and coping and they ignored the interpersonal relationship as well as the women themselves. Frequently the studies imposed the dominant perspective that denied the meaning and significance of the couple's relationship while marginalizing the wife's experience. The wives in this study were involved in a relational practice that implied significant commitment and responsibility. The women saw their husbands as vulnerable to the threat of sudden cardiac death. Protecting their husbands to keep them alive was not a physical labor but was a moral, though essentially invisible, practice. This work by women might be considered even more distressing because of its complexity, relational nature, and invisibility.

The results of the study challenge the taken-for-granted assumptions, of what the women experience and the meaning that suddenly becomes part of their everyday lives. Every woman in the study is unique, but shares some common responses with all of the other women. The first three essential themes revealed women's lives as they were directly related to their husbands' illness.

"Walking On A Tightrope"

The women in this study described how their husbands, their relationships, and their lives were changed after the diagnoses; and their everydayness was threaded with the fear of the unknown. This finding was consistent with previous research. What the women in this study provided was more of a context and an understanding of that distress and fear.

In 1984, Stern reported that, "The wife is frequently forgotten in the medical environment of the patient." The women in the study likewise experienced feeling "forgotten"; specifically, they believed that they were left uninformed and unprepared for their new life and responsibilities. The women lost trust in their ability to know about what was considered to be normal. A unique finding in this study was that the wives consistently reported that they could not trust their husbands to tell them the truth about the state of their health. Furthermore, the wives did not trust their husbands to make correct decisions about safe activity levels.

The wives further reported that the husbands themselves personally were changed by the disease and the illness. Similar to the Nyamathi (1988) interview study with 40 women whose husbands had had a MI twelve months earlier, the wives in this study reported that their husbands had become noticeably more irritable. In a previous quantitative study of 213 wives, "husband moodiness" after MI was identified as a "wife stressor" (O'Farrell, Murray & Hotz, 2000).

Causal searching by wives was not reported in previous spousal cardiac literature. The women of this study revealed how it was necessary to identify the physical causes of their husbands' CHD so they could limit or control those factors. The women acknowledged the threat to their husbands' lives as only a moment away, and they steadfastly performed certain activities which they believed were necessary to keep their husbands alive.

"Keeping An Eye On Him"

A primary part of the care the women provided in this study was "watching over" and monitoring their husbands. This practice of watching is similar to the findings in other studies. Nyamathi (1987) reported that three months after discharge following MI, typically women monitored their husbands' behavior. Also, in a similar exploratory-descriptive study, women reported intensive monitoring, close surveillance, and diet supervision after their husbands' MI (Daly et al., 1998) with similar accompanying distress as in this study.

The activity of monitoring by wives is referred to as "vigilance" and "surveillance" by other researchers. Women reported "maintaining vigilance over the patient" (Dickerson, 1988 p.16) months after hospital discharge. Thompson et al. (1995), based on interview data, reported that wives "engaged in activities of surveillance that involved monitoring of everyday activities" (p. 710). This study provided further context to the monitoring and vigilance by uncovering the watching to reveal the subtle appraisal that was involved in such a practice. The wives *knew* their husbands before the illness and now they were trying to determine the qualitative difference in the new state of what was considered normal. The vigil was firmly embedded in the wife's ongoing appraisal of her husband's health and his activity tolerance. Any activity could be a time of potential threat, and the women watched carefully during these times. In a previous study it was noted that wives tended to have more conservative opinions of heir husbands' ability to engage in physical activity than their husbands (Taylor, Bandura, Ewart, Miller, & DeBrusk, 1985). Whether the participants in the study were accurate in their risk assessment of their husbands cannot be addressed, but certainly they lacked confidence in their husbands' ability to perform tasks which they believed to be unsafe.

In another study, which involved twelve of the thirteen participants being wives, the “well spouse” (the partner who was not ill) reported performing household activities such as shopping, preparing food, and monitoring patient medications and activity twelve weeks after hospital discharge (Stewart et al., 2001). These activities also were reported in this study; moreover, these activities were ongoing for six to 18 months after their husbands’ diagnoses.

Previous studies did not address the women’s constant state of diligent readiness, nor the ongoing actions related to preparing for a subsequent acute coronary event. Having a “911 plan”, and ensuring consistent nitroglycerin availability, became a regular part of the everyday lives of the women in this study. According to the wives, their husbands were reluctant to follow-up on symptoms that they experienced. These women were instrumental in obtaining the necessary healthcare for their husbands. All of the husbands in this study experienced a return of cardiac symptoms which necessitated a subsequent hospital visit. The true worth of the wives of cardiac patients has not been acknowledged in the literature to date. It may be more than just "being married," as has been suggested, that most influences the mortality and morbidity of the husbands who become ill with CHD but the activities that the wives provide.

“Wrapping Him In Cotton”

The women in this study feared that their husbands were vulnerable; therefore they immediately assumed the responsibility for protecting them from harm. The wives sheltered their husbands, both from stress and from activities that they thought were dangerous. Previous studies identified the act of protection by a wife with the use of other labels. For example Stewart et al., referred to protection as "miscarried helping efforts" (2000). Another term suggestive of protection was "protective buffering" which was defined as a style of coping in which the individual hides her concerns from the respective spouse (Suls et al., 1997). In previous research examining coping responses to the experiences of distress and fear, protective buffering was positively correlated with wife anxiety (Coyne, Elard, & Smith, 1990; Suls et al., 1990). Rather than viewing it as psychologically abnormal, Coyne and Fiske (1992) considered that overprotection may be part of a coping, a normative process (p. 140). However, these researchers reported that wives "nag" and "overprotect" because the women felt responsible for controlling the behavior of a husband who wanted to become more active against physician orders. The behaviors that are labeled in previous research as "overprotection" and "nagging" (Clarke, Walker, & Cuddy, 1996; Riegel & Dracup, 1992; Wishnie, Hackett, & Cassem, 1971) may be the same actions revealed as "protection" in this study.

Rather than labeling their activities as dysfunctional in this study, the wives' involvement and protection-oriented activities were interpreted as caring for their husbands accompanied by the fear that they would die. Unique in this study was the wives' reported concern about being "overprotective," "smothering," "mothering" "nagging," or "solicitous." Societal pressures added more distress to the women's lives. The subordination of the very act of caring in the discourse excludes the consideration of experiences, interests, needs, and desires associated with the women. According to Held (1995), the social, political, and cultural institutions have traditionally have been founded upon the masculine ideals of morality. Furthermore, the differences in social and practical power and consequently conceptions of virtue segregate practices and are shaped by the differences in power (Fedar & Kittay, 1999; Tronto, 1993).

"Right In The Middle Of It"

Previous research studies viewed the wives' roles merely as a means to improving the men's health. However, this feminist study focused on the women themselves and their meanings as created in the experience. From this perspective, the women in the study revealed that they were actually part of their husbands' chronic illness experience. By definition, illness refers to how a disease is perceived, and how it is lived with, and responded to, by the individual (Larsen, 2006); and in this study, the other (the wife) who does not have the actual illness.

The illness trajectory framework defines the course of an illness over time, along with the actions that a patient and family use to manage that course (Corbin, 1998, p .3). The diagnosis of CHD sets in motion certain changes, and the illness trajectory was then shaped both by the husband and the wife. All of the women, in their stories of their husbands' illnesses, revealed the pre-trajectory (before the diagnosis) and the trajectory onset. In all of the interviews, the pre-diagnosis time and the sentinel moment of diagnoses, were integral parts of the women's stories. The following parts of the trajectory framework: moments of stability; unstability; acute phase; and crisis (Corbin, 2001) were revealed in the women's words. During the stable phase of the illness, the husband's CHD was under control, and the woman attempted to manage the illness in their home. However, all of the husbands experienced a reoccurrence of symptoms and subsequent hospital visits or admissions which demonstrated the unstable, acute, and crisis phases of the trajectory that the husband and wife all experienced. For the women the threat was never completely removed so there was no experience of the comeback phase in the Trajectory Model. The women's experiences of the stable, unstable, acute, and crisis phases were not on a linear, or on a continuum basis, but rather they moved between phases depending on their assessments of their husbands at any given time.

Key problems related to chronic illness, as identified by Strauss and colleagues (1984), resonated for the wives in this study who were living with a husband with a chronic illness (e.g., prevention and management of a medical crises; controlling symptoms; carrying out the prescribed medical regimen; adjusting to changes; attempting to normalize life; and confronting psychological and marital problems). From this study's perspective, the women were active participants throughout the illness experience, rather than merely something to be manipulated in order to improve husband recovery. This study's unveiling of the women's meanings provided a context to the key problems of chronic illness. Furthermore, the key problems of chronic illness, were lived with, and personally experienced, rather than simply "managed".

In this study, the wives' lives were surrounded by their husbands' illness, and they often appeared, themselves, truly lost in that illness. In the wives' stories, the shadow of their husbands' disease was constantly present. It always was there, lurking threateningly, just around the corner. With such threat, so clearly in view, the wives in this study claimed responsibility for protecting and monitoring their husbands to keep them alive.

The result on the women from the perspective of assuming a level of responsibility of care was not addressed in previous studies. The act of caring, in itself, implies a certain measure of responsibility and commitment. In this study, the result of feeling so responsible for another person's fate led to deep frustrations and limitations on the women's own lives. The women in the study did not identify themselves as caregivers but rather as fulfilling an expectation of what they "must do." It was not an extraordinary activity that they were providing but merely what they were required to do as wives. Gilligan (1983) noted that women "not only define themselves in a context of human relationships but also judge themselves in terms of their ability to care" (p. 17). Because women have experience with caring, we tend to disregard it because "we know what it is" (Fisher & Tronto, 1990). The women in this study cared for their husbands and this displayed their experience.

Giving care is an embodied experience that has both physical and affective aspects (Poirier & Ayres, 2002). In this study, the women did not see themselves as providing care because there was little physical care involved in what they did. For these wives, the care they provided was relational and therefore could not be separated from the couples' experiences of each other in a shared past, present, and anticipated future. The wives' emotional work in caring for their husbands frequently went essentially unnoticed, unarticulated, and generally devalued by others, as well as themselves.

Because of the common, everyday nature of this caring relationship displayed by women, it traditionally has been taken for granted. The aim of this study was not to define a grand care-ethic theory for cardiac rehabilitation but rather to avoid the reductionism that typically denies the complexity and diversity of a wife's experience with a husband who has CHD. It is important to understand more deeply the *carer* experience to prevent marginalizing of various gender, culture, race, and sexual preference practices. To ignore the diversity of experiences, and wide range of practices, limits the possibilities and also reinforces the traditional ways of viewing women living with men who have CHD.

"I Have To Get Through It"

The final essential theme uncovered the personal meaning of CHD in the women's lives. The understandings provided by the consideration of this theme were unique to this study as a result of the research method and the interpretation. Through a feminist lens, the women in this study revealed lives of silencing themselves and asking questions without answers.

The women silenced themselves out of fear of negatively influencing their husbands' health. An early interview study involving 18 women, three to nine months after their husbands" MI (Wishnie, Hackett, & Cassem, 1971) found that wives feared that expressions of anger would "bring on another MI." These previous researchers reported that the wives felt guilty for causing their husbands' initial MI. The women in this study did not report that they believed that they caused their husbands' MI; rather they were concerned that they could trigger a subsequent acute coronary event if they created stress in their husbands' lives. It is not known whether the silencing attempts by the wives were actually a destructive process of burying feelings and needs, or a necessary protective strategy designed to preserve their relationships, or a combination of these. Regardless of which it is, the women's continuing silencing and essential invisibility perpetuated the marginalization of their needs and lives.

The missing conversations with their husbands have particular importance in appreciating the women's lived experience. Uncertainty about their own futures and the possibility of their husbands' deaths were in effect powerful constraints to spousal conversations regarding the meaning of the diagnosis and the illness in their lives.

It was impossible for the researcher to listen to the women and not be touched by the quiet suffering in their everyday lives. All of the women cried at some point during the interview and at times lost, and then re-gained, their voice in the telling. The participants' lives were consistently filled with a general lack of trust, as well as with fear, about the present, the future, and the subsequent search for meaning and coherence. The narratives revealed women who realized the temporal nature of their relationships with their husbands, and they deeply feared being left alone. Their world was not composed of just one person; rather, it was relational with their husbands. The threat to their husbands' lives meant that the women examined their own lives as well their lives together with their husbands. The intricate nature of looking for meaning is about more than identifying one isolated cause; rather, it reveals a web of meanings. It is a meaning created specifically by women who care for, and are living in an interconnected world with, their husbands.

For the most part, suffering has been considered an individual, subjective state, or emotional state of distress (Cassell, 1992). This view does not consider that the response to someone else's illness may cause personal suffering. The wives in the study lived many moments of suffering. According to Chesla, "moments of suffering" comprise the heart of the matter for families living with chronic illness (2005, p. 374.). The women in this study were in relationship with their ill husbands; consequently, they experienced a breakdown in their own everyday lives. The breakdown often led to suffering deeply.

This suffering often, in effect, distanced the women from their husbands whose illnesses were the source of their suffering.

The women's moments of suffering were displayed in the revealing of their lives. After their husbands' CHD, they no longer could take for granted the everydayness of their lives. The women managed to work out the day to day functions such as: medications; eating; activity; and communication. These activities were not taken-for-granted because they needed to be re-negotiated on a daily basis. In addition the wives shifted the patterns in their own lives in order to accommodate those needed changes for their husbands' welfare. The women were unable to remain confident in their husbands' everyday body capabilities and overall health. The women shared a history with the husbands who were ill and whose futures were uncertain. Each woman foresaw a threat to her husband's life, her relationship with him, and their future together. Within the context of chronic illness, the tension between hope and despair, as well as between suffering and possibility, vacillates repeatedly (Barnard, 1995). The women did not suffer physical pain but rather moments of suffering emerged as threat and fear rose and fell in their lives.

Chapter VI

Critique and Implications

The essence of this study was revealing the meaning of being a wife of a husband who has CHD. It uncovered the many significant challenges involved in sharing a chronic illness with another person for whom one cares. The wives revealed their struggles in living with a spouse with CHD, whose diagnosis was not merely a single event in their lives but, rather a catalyst for major and ongoing life changes.

This study described the lived experiences of care; of women who watched over and attempted to protect their husbands from harm. These activities were not of the same nature as physical care activities typically provided for patients with other chronic illnesses, such as Alzheimer's disease; nonetheless, their activities were the wives' personal commitments to care. Neither, the literature, the research, nor the women themselves represented wives of husbands with CHD as "caregivers". Rather, everyone considered what the wives do for their husbands with CHD simply as what was expected of them as wives. In addition to experiencing the devaluing of the care provided, the wives continued to provide that care to their husbands despite the additional risk incurred of criticism for being overprotective. The participants' lives were threaded with fear and uncertainty due to the centrality of their husbands in their lives; and the continuing fear of loosing them. The women revealed their moments of suffering as they lived daily in an uncertain present and looked toward the future with the potential loss of their husbands.

Critique of the Study

The results of this study contributed to the understanding of chronic illness and to the moments of suffering experienced by the partner. This study was unique in that it used a feminist hermeneutic methodology to uncover caregiving meaning in the lives of the women who live with men who have CHD. Because of the method used, deeper understanding of the experience emerged that otherwise might have remained hidden. This study supported previous studies that likewise indicated that wives living with husbands who have CHD are distressed, but it provided a context and depth to the understanding of the wives' experience as well as to the enduring nature of the wives' distress. Through the phenomenological methodology, the women's personal meanings were uncovered rather than measures of coping and quality of life. In using an interpretive feminist lens, the meaning of the care activities which were provided by the women was revealed. The study brought to the foreground women who shared the illness experience with their husbands and who frequently lived lives filled with care, silencing, and suffering.

This study is limited by the recruitment location from the geographic area of Southern California. Following the tradition of phenomenology, only a small segment of women were interviewed; therefore only certain voices were heard. Including more ethnically diverse participants would have enhanced the study rather than provide privilege to just certain voices.

Also consistent with phenomenology, the analysis of the text and the emerging themes reflected just one interpretation of the text rather than representing all possible interpretations. Thus, caution is advisable when transferring findings to other populations. The reader must assume responsibility for coming to her own understanding of the phenomenon studied and then decide upon its applicability.

Implications

Research

The current study examined the experiences of a small group of wives of husbands who have CHD. While the investigation led to insights about what the experience was like for them, it also raised a number of questions. These questions form a basis for potential future research investigations.

A similar phenomenological study of wives who have CHD and their husbands would provide useful information in determining whether the findings would be similar to those from this study. It would be important to learn whether the couple experience involved in CHD represented a specific type of relational caregiving, or rather, was gender specific. In addition, a further study is necessary that includes participants from various cultural backgrounds, in order to determine whether the themes in this study reflected a universal experience, or rather reflected only certain privileged voices.

This study explored the experience from one perspective, the wife. Further research on the meaning of the experience for each individual and the co-created meaning for the couple would add depth to the knowledge and understanding of the phenomenon. Investigation in this area would help clarify the meaning of behaviors and emotions, both to the person experiencing them and to those who support them, both professionally and personally. Furthermore, a grounded theory study could assist in the development of a chronic illness model that would address the issues of an individual who is in relationship with another with a chronic illness.

In addition, research using quantitative methods is necessary. Current instruments may need to be adapted because, as demonstrated in this study, the women's beliefs and feelings were complex and not static. The women's experiences in this study go beyond the current stress and coping and quality of life indicators. It is difficult to capture meaning and suffering by current research tools. Instrument development and testing that captures the experience would be a future step in moving the studies forward.

Further inquiry is necessary on what interventions are supportive to the spouses of partners with CHD. Understanding these factors could lead to more focused interventions for those who work with such couples. After the development of support groups founded on reported experiences, longitudinal studies could be conducted in which the well-being of the participants is compared to the well-being of a control group who did not attend such a group. An additional inquiry could investigate whether women who saw themselves as caregivers would have more positive outcomes.

Existing research gives evidence that caregiving can have a negative impact on the physical and emotional health of those in the role. Services need to be available to support the women who do not have the illness but are in need of care. In order for caregiver spouse support groups to be viable, resources would be needed to fund them. If improved outcomes were found in those people who attended support groups, funding of the groups is possible. For the partner of a patient with CHD to obtain insurance coverage to attend a support group it must be demonstrated that such groups are cost-effective and necessary.

The current healthcare model has its focus primarily on the disease. Neither community concerns nor health issues are emphasized in the current illness care model. In order to more effectively treat illness, as well as address the many related issues for individuals and for the community, an important element in any healthcare policy needs to be a commitment to encourage public discourse on the issues of wellness. Private and public government funding is needed to promote new research and practices which will support major system change. Truly effective accessible service delivery begins with the research which leads to the valuation and development of effective practice models. A nationally-based caregiver strategy and research is necessary to support the initiatives (counseling, respite care, and family leave) that would more adequately assist the women and men who are providing care to their partners with a chronic illness including CHD.

Significantly improving the sensitization of professionals to the differences in caregiver needs, and individual experiences, requires a broad range of research. This study laid the groundwork for further research into the CHD shared experience. Continued research in this area can increase the body of nursing knowledge and enhance the quality, scope, and depth of nursing care provided to spouses of patients with CHD.

Praxis

The meaning of what it is like for a wife to live with a husband who has CHD was revealed in this study and has ramifications for praxis. Praxis is the practical application of knowledge (Gadamer, 1996 p 6). With the understanding of an experience comes the potential for greater empathy. The dissemination of the findings from this study can enable nurses to understand the experience of these participants so that hopefully they become more able to appropriately assist other women in the hospital and outpatient settings with similar situations. Enhanced insight can lead to improved practice through more sensitive interactions with the spouses and more focused assessment of their needs.

Despite the wives' general beliefs in the psychosocial causes for CHD, patients and their partners are given little or no support for dealing with these factors; rather they are being instructed to adhere to treatment regimens that do not seem relevant to them. Individuals coping with the aftermath of a CHD diagnosis need to make sense of their life-threatening experience within a framework that is relevant to, and influenced by, their own experiences. Gaining increased understanding about the relevance of patient and couple teaching could influence more development of effective patient education and support. The results of the study suggested a reconsideration of the current focus in teaching programs. The wives in this study who did attend cardiac support groups related how these groups helped them learn more about their husbands' disease; however the programs did not address their personal needs.

Cardiac rehabilitation and support groups exist, but they tend to focus on the person with the illness. Lack of appropriate representation and voice in these groups means that only a few are privileged. The presence of adequate support in the community is likely to improve outcomes for the well wife and husband for whom she cares. Support should be provided to the wife individually and directly in order to provide her the opportunity to express her concerns without having to worry about the effect on her husband. A support group, which in effect, allows the participants to tell their own stories, would be a place for the women to be heard. The researcher learned that the women's stories are soulful and deep, and they are worthy of truly being heard. The rich, contextual descriptions presented by the participants bridge research and practice.

A function of a new support group that could reflect actual lived experience would help wives in working through the roles and responsibilities that they hold in context of living with husbands who have CHD. A nurse-led support group focusing on the actual care that the women provide would offer participants the opportunity to share their own experiences, perhaps better understand the experience by doing so, and possibly learn new skills that would enable them to more successfully to navigate their way more successfully through the shared illness experience. The wives will then learn that they are not alone in their efforts or in the emotions that they experience regularly. Referrals should be made for appropriate support sources, counseling, or other healthcare services as needed. External guidance might be necessary if the woman is assuming responsibilities which cause feelings of being overwhelmed.

The women in this study identified the specific care activities that they provided but did not recognize that they were providing care. An appropriate new role for advanced practice nurses, within medical groups and in home health facilities, would be to identify and consider the care activities provided by wives of patients who have CHD. Not fully recognizing that one is a caregiver can result ultimately in the resources and support to which one is entitled, not being offered or made available.

In this study the women provided care as expected, as a wife, believing they should do these things. Their activities remained essentially invisible and under-valued. Furthermore, previous studies and clinical practices referred to the women, and their activities of care, in negative terms. In addition, the women revealed their ongoing efforts to remain silent in their everyday life without even realizing that in effect, they were being silenced. The silencing of women, along with their caregiving activities needs to be fully addressed. To fail to fully acknowledge the existence of these care activities is to dishonor its moral imperative.

Initiatives for sensitizing healthcare providers are necessary to challenge the historical perceptions of wives as “nags” and as being “overprotective.” It is imperative to uncover and to challenge the existent negative stereotypes. These labels, as applied to the women in the study, only added distress in their lives. Further, it is essential to challenge the long held view in healthcare that the wives are just a resource for their husbands' well-being. A more appropriate action involves responding to the unique and similar needs of both partners in the relationship. Fully recognizing that the women are in relation with their husbands, the well spouse should be included in the care.

A final implication for practice is a simple reminder about the power of listening. A number of the participants brought this issue clearly to light when they expressed thankfulness that the researcher listened and the women experienced surprise when they realized that they had so much to say. Although this insight forms the basis of phenomenological research, it also is at the foundation of authentic communication. If we are sincerely interested in our patients, and others with whom we talk, we will offer them the opportunity to say what they want to say. People have stories to tell. If we, as nurses, are to be genuinely present with people, we cannot afford to miss drawing out these stories.

Telling one's story and having it genuinely heard is a powerfully cathartic, as well as an empowering experience, as was repeatedly demonstrated in the study. At present, the wives' role in men's cardiac illness is generally under- acknowledged and, in many ways, invisible since it occurs within the privacy of the home. By the nature of their role, caregivers are at an increased physical and psychological risk. If the women's stories are encouraged in practice, interventions and support are more likely to be offered. It is imperative for nurses to recognize that the women in these situations frequently experience moments of suffering when they live with husbands who have CHD. The “heart” of a nursing encounter is the awareness of the human context of suffering (Georges, 2002).

Epilogue

The findings of this study uncovered common meanings embedded in the lived experience of wives of men who have CHD. The women revealed the true nature of their everyday lives. According to van Manen, "It is inappropriate to ask for a conclusion in a phenomenological study" (p. 39). He remarks "to summarize . . . in order to present the result, would (be to) destroy the result" (p. 39). From this premise then, this author returns to Debra who lived the experience, to offer meaning for the reader:

> And I remember sitting on the edge of the bed and I put my arms around him. I started to cry and I said, I love you. And I said, I was so scared, I was so scared I was going to lose you. That's the first time I told him, I think. I let him know that I was petrified that I was so scared, I was so scared. I'm still scared you know. (I said to him), "I was so scared that I was going to lose you. All I could think of, was they're going to take you away from me and I wasn't ready to give you up.”

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Appendix A

Mended Hearts Letter of Support

Mended Hearts Inc.
San Diego Chapter 62
9404 Genesee Ave, Suite 240
La Jolla, CA 92037

November 10, 2005

University of San Diego Institutional Review Board
c/o Pat Bradley RN
7805 Highgate Lane
La Mesa, CA 91942

Dear Review Board:

I am writing this letter on behalf of Pat Bradley RN and PhD candidate in Nursing at University of San Diego. As President of San Diego Mended Hearts, it is my understanding that Pat Bradley has chosen to use our support group to recruit participants for her PhD research on women who live with men with coronary heart disease. We agree to her request to seek participants from our group and will provide cooperation and support of her research by allowing her to solicit participants for her study. Please use this letter as acceptance and support of her research.

Sincerely,

Harold Schwartz

Appendix B

Recruitment Flyer

Would you like to take part in a study about women who are living with men who have heart disease?

- **If you are a woman married to (or living with) a man diagnosed with heart disease within the last 18 months**

You are invited to share your personal experiences

- **Sharing your personal experiences of what it is like for you will assist nurses to learn how to better help women who live with men with heart disease**

- Your participation will include a 60 to 90 minute audio-recorded interview

- **A student nurse-researcher from the University of San Diego is looking for 10 women to participate in this research study**

If you are interested and want to discuss the study

Please contact
Patricia Bradley, MS, RN
619-644-7892 or email; patbrad@cox.net

Appendix C

Demographic Data Sheet

Demographic Data

CODE

Wife Demographics
Date of Birth
Ethnicity
Marital Status
Number of years married (living with partner)
Income/month:
Work outside the home
Attended/did not attend cardiac support group
Attended/did not attend cardiac rehabilitation

Husband Demographics
Date of Birth:
Ethnicity
Work outside the home
Type of heart disease husband has
When diagnoses with heart disease first made
How CHD disease treated medically ______ and/or surgically ___________
If any additional treatment for CHD after initial diagnoses ______ What?
Husband attended/did not attend cardiac support group
Husband attended/did not attend cardiac rehabilitation

Appendix D

Participant Demographic Data
(self-identified)

Participant Demographic Data (self-identified)

"Name"	Years Married	Age Wife/ Husband	Ethnicity Wife/ Husband	Employed or Retired Wife/Husband	Combined Household Income/ Month	Months Since Initial Diagnoses	Husband's Initial Diagnoses/ Treatment/ Additional Treatment	Attended Cardiac Rehab Wife/ Husband	Attended Support Group Wife/ Husband
Ann	28	67/66	Caucasian/ Caucasian	Retired/ Manager	$3000	13	MI Angioplasty	No/No	No/No
Betty	30	52/58	Caucasian/ Caucasian	Stay at Home/ Manager	$5000	12	MI Angioplasty	No/No	No/No
Debra	25	45/50	Caucasian/ Caucasian	Office/Office	$6000	16	CHD/ Stents	No/No	Yes/Yes
Jennifer	39	58/59	Caucasian/ Caucasian	Home Business/ Instructor	No report	12	CHD/ Bypass	No/Yes	Yes/Yes
Louise	30	54/56	African American/ African American	Nurse/ Photographer	$9000	16	MI/Stents	No/No	Yes/Yes
Katia	32	55/55	African American/ Caucasian	Waitress/ Construction	$3000	8	MI/Stents	No/No	No/No

Participant Demographic Data (self-identified) – cont'd

"Name"	Years Married	Age Wife/ Husband	Ethnicity Wife/ Husband	Employed or Retired Wife/Husband	Combined Household Income/ Month	Months Since Initial Diagnoses	Husband's Initial Diagnoses/ Treatment/ Additional Treatment	Attended Cardiac Rehab Wife/ Husband	Attended Support Group Wife/ Husband
Jane	55	74/76	Caucasian/ Caucasian	Retired/ Retired	$2000	9	MI/ Angioplasty /Stents	No/No	No/No
Linda	32	55/55	Asian/ Caucasian	Home day care/self employed sales	$3000	12	MI/ Angioplasty /Stent	No/No	No/No
Maria	10	50/56	Caucasian/ Caucasian	Teacher/ Teacher	$8000	18	CHD/Stent/ Bypass	No/No	No/No
Irena	4	47/58	Caucasian/ Caucasian	Reporter/ Researcher	$8000	14	CHD/Stents /Stents	No/Yes	Yes/Yes

Appendix E

Research Participant Consent Form

Research Participant Consent Form

The Experience of Women Who Live with Men Who Have Heart Disease

Pat Bradley is a doctoral student in nursing at the Hahn School of Nursing and Health Science at the University of San Diego. You are invited to participate in a research project for the purpose of exploring women's experiences of living with a man with heart disease.

The project will involve one interview that asks questions about what it is like to live with someone with heart disease. The interview will be about 60 to 90 minutes and will include a demographic questionnaire. If you agree you may be contacted once by telephone for clarification of something you said in the interview.

The interview will be at a time and place convenient for you. Participation is entirely voluntary and you can refuse to answer any question and/or quit at any time. Should you choose to quit, your information will be destroyed right away.

Your interview will be audio-recorded, written, coded, and studied in a manner that protects your identity. A transcriptionist who has signed a pledge of confidentiality will type the interview. Any information provided and/or identifying records will remain confidential and safeguarded in a locked fireproof safe/file for a minimum of five years.

The results of the research project may be made public and information quoted, but all individual data will remain confidential. Participation or nonparticipation or refusal to answer questions will have no effect on services that you are entitled to receive from health or social services providers. There may be a risk that talking about the experience during the interview may bring up sad memories, make you feel tired, or anxious. The benefit to participating will be in knowing that you helped nurses learn how to better help women who live with men with heart disease.

If you have any questions about this research, please contact Pat Bradley at (619) 667-0139 or (619) 644-7892 or Pat Bradley's research advisor, Dr. Patricia Roth at (619) 260-4572.

I have read and understand this form, and consent to the research it describes to me. I have received a copy of this consent form for my records.

______________________________	__________________
Signature of Participant	Date
______________________________	
Name of Participant (Printed)	
______________________________	__________________
Signature of Principal Investigator	Date

Appendix F

General Statements/Interview Guide

General Statements/Interview Guide

1. Talk about what it is like for you to live with someone who has coronary heart disease
2. Tell me a story that demonstrates what it is like for you to live with your husband who has coronary heart disease
3. Describe for me things that you do because your husband has coronary heart disease
4. Is there anything you would like to add?

Appendix H

Transcriber's Pledge of Confidentiality Form

Transcriber's Pledge of Confidentiality

I will be participating in the dissertation research project entitled:

The Lived Experience of Women Who Care for Partners

With Coronary Heart Disease

I will be transcribing audio-recorded interviews into text. I will not know the names of the informants, but if I should recognize information that enables me to identify any of the participants I agree to mintain their confidentiality. By signing this agreement I pledge to keep all information strictly confidential. I will not discuss the information I transcribe with any person for any reason. I understand that to violate this agreement would constitute a serious and unethical infringement on the informant's right to privacy.

Signature of Transcriptionist Date

Signature of Principle Investigator Date