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Women's Quest for Treatment of Their Cardiac Symptoms:  
Exploring a Neglected Risk Factor

by

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## **Abstract**

Heart disease is a leading cause of death and disability for women. However little is known about women's experience in seeking care for cardiac symptoms. An interpretive descriptive study using conversational interviews with five women on two occasions each was done to explore this experience. These experiences were complex, and were characterized by tenuous understandings of their symptoms, and uncertainty in accessing and negotiating the health care system. Chief among these findings is the reciprocal nature of care seeking encounters in which women and health care professionals are constrained by traditional patriarchal scientific thinking. Impeded care seeking endeavors increased the risk to women's health by delaying the diagnosis and treatment of their cardiac disease. Three themes emerged: understanding their symptoms, avoiding humiliation and interacting with health care providers. Findings suggest that the experiential wisdom of women with heart disease must be included as an essential part of health care dialogues.

## **Acknowledgement**

I would like to first of all acknowledge my family, who has patiently watched me as I worked on this seemingly endless undertaking. My husband, Wayne, offered me his forbearance, his support, and his acceptance of my need to pursue this endeavor, which enabled me to complete this thesis. My daughter Jennifer, offered me inspiration to continue by frequently telling me how proud she was of me. My son Scott, despite not really understanding why I was doing this, offered me his concern for my struggle. He once put his arm around me as I was poring over some articles and gently said “You’re really not getting this stuff, are you Mom?”

I would like to acknowledge my committee members, Dr. Kathryn King, Dr. Beverly Anderson and Dr. Jim Field for showing a genuine interest in my work, and helping to expand my thinking around my research question.

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## **Dedication**

I would like to dedicate this thesis to my husband Wayne, my daughter Jennifer, and my son Scott. Our love for each other makes anything possible.

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## **CHAPTER ONE**

### **The Awakening of My Need to Understand**

The seeds of my curiosity into the current research question were planted long ago in my nursing career that began in 1977. My experiences in emergency room nursing, coronary care intensive care nursing, and cardiovascular surgical intensive care nursing have offered me an insight into the current question in a profound way that is not easy to articulate. Having the opportunity and the privilege of caring for so many men and women in life threatening situations as a result of their heart disease, gave me an incredible sense of the significance and importance of the care that we as health care practitioners provide to these people. I sensed on countless occasions that I and other health care practitioners that I worked with had contributed to the successful outcomes for these patients with heart disease as a result of our knowledge and expertise. This experiential understanding motivated me to learn more about the experiences of people with heart disease.

Through my experience I became aware of the notion that women's experiences with heart disease were unique as compared to men's. There were noticeably fewer women in the coronary care units that I worked in and those that were there seemed to be older and sicker. As I became more familiar with the literature regarding cardiac disease, my interest in women's experiences grew stronger. From my experience, the literature and my course work, my research question took shape.

One of the strongest influences in garnering my interest in the experiences of women with heart disease was my involvement as a nurse facilitator in a support group for

women with heart disease. It was at one of those meetings that I met Irene, who became the participant in this pilot interview.

### **Irene's Story**

“Are you feeling alright?” I say to the woman seated next to me. She is pale, beads of sweat are forming on her upper lip. Her hand feels cool and clammy to my instinctive touch. Her pulse is rapid. Irene's face is anxious. She is trying to avoid the gaze of the other women seated in the room, but lifts her head just slightly to look at me as she reaches into her purse for medication. Irene knows that I am a nurse that I am here to help her and the other women in this group come to terms with some of the difficulties they are having in living with heart disease. However, this is Irene's first meeting, and she has never met any of us before this moment. Irene nods her head as she slips a Nitro under her tongue, “I'll be OK.”

“Are you having some chest pain?” I ask quietly, seeing that she does not want to become the center of our attention.

“A little. I think I'll be OK in a while” she says.

We begin our meeting. Introductions are made, small talk and laughter ensue. As if choreographed, when the laughter dies, all eyes are on Irene. I look in the faces of the women seated there, and I see clearly the shadows of fear: fear for Irene, and fear for themselves. Tumbling around the vision of Irene's pale, anxious face, are scenes from their own experiences, experiences where they felt the chilling proximity of their own mortality.

The meeting goes on for a few more awkward moments, as Irene reaches twice more into her purse for medication. My hand is now staying on her pulse. I feel somewhat lost without the familiar security of cardiac monitoring. I suppress a wave of anxiety as I recognize that Irene is now soaked with perspiration. She flashes me a weak smile to reassure me and to reassure herself. Scenes from twenty two years of critical care nursing wash over me, no single experience as such, but the fusion of countless times I have touched the hand of someone who is critically ill. I know I will have to act on Irene's behalf soon. I sense the familiar feeling of being acutely aware of the need to act very quickly at any moment, balanced with the need to remain calm and appear in control.

Seconds drag on as if they were hours. Part of me is waiting for Irene to acknowledge that she needs help, to ask me to help her. Part of me understands that she may be waiting for me to take charge of the situation. I feel the pull of preserving her dignity against the pull of very possibly preserving her life.

“Do you think it would be OK if I lay down for a moment?” Irene asks.

Irene has now given me the clear signal that she needs help. She has not asked for help, she has not admitted defeat in her ability to handle this situation, but she has opened the door for me to step in. I tell her that I am getting a wheelchair to take her to the Emergency department just down the hall. Her face speaks of fear, frustration, resignation, and many other things.

I am filled with an awareness of the significance of this experience as I wheel Irene down the hall. I feel that I have become part of the very experience I have been studying for the past year, the experience of women dealing with symptoms of heart disease.

This feels so strangely different from my experiences as a nurse. My experience has been with women who have made it through this terrifying phase, and have successfully found treatment. Women who have lived through the experience of sensing that there is something wrong with their heart, who have felt the terror of feeling that their heart may at any second be unable to sustain their life. My experience has been from the distanced, more comfortable perspective of someone in control. My view of women's experience with heart disease has been from behind the shield of advanced cardiac monitoring, with a repertoire of drugs and resuscitation equipment securely at my side.

My knowledge of this pre-hospital phase has come from hearing the telling and retelling of countless numbers of these same stories in which I now participate. I remember having an awareness of the profound need for women to tell this part of their story. I remember wondering if by telling me they were trying to absolve themselves of guilt for not having handled their situations well, if they were looking for approval for their actions, or if they were trying to learn and prepare themselves for the ever present next time. I also remember listening with the ears of someone who cared, while at the same time thinking that this did not really make a difference to what it was that I needed to do for them. I realize that I, like many other doctors and nurses, did not really understand the significance of this experience.

Walking down that hallway toward the Emergency Department, I am beginning to understand. I am a player in the script of her experience. My senses become heightened as I struggle to capture every part of this experience.

Several weeks later I am in Irene's apartment. I am about to talk with her about what happened to her the night of that meeting. I know what I thought and how I felt, but I want to hear about this experience from her perspective. I want us to create a deeper understanding of this experience together. She is happy to talk to me about it. She finds an audiotape for her tape-recorder when I discover that mine does not work. She wants her words to be recorded. She seems to sense the importance of her story.

I turn the tape recorder on, and before I have a chance to make some introductory comments, Irene begins eagerly. I am touched by her earnestness. I will need to hear her words well. She is entrusting me with a most intimate story. She is entrusting me to understand.

Irene's story begins with a description of her previous experiences with chest pain.

*"I have had chest pains off and on, but I've got a lot of other problems, like fibromyalgia and so what many times I would have, I never knew what angina attacks were."*

Irene had experience with a complicated illness, fibromyalgia, an illness especially difficult to diagnose. I wondered how many doctor's appointments, how many diagnostic tests she'd had before this diagnosis had been made. I wondered how many times she had repeated to her doctor the myriad of symptoms she was having. I wondered if she had questioned the legitimacy of her symptoms of fibromyalgia. I wondered how many times she had questioned the legitimacy of her cardiac symptoms.

*I would get all of a sudden, sharp pains in my chest, and they would kind of consume me...they would go into my throat, into my jaw, into my neck, and into my head. It*

*made me feel very scary and so what I did for many years was to take an Ativan, and that subsided it, took a little while.*

Irene's symptoms of angina were typical for women with coronary artery disease (CAD), (Everts, Karlson, Wahrborg, Hedner, & Herlitz, 1996; Goldberg et al., 1998; Penque et al., 1998). For example, women have been found to experience more jaw and neck pain than men with CAD. It is from results of studies done almost exclusively on men in the past, that knowledge of symptoms of CAD has been shaped, (Steingart et al., 1996; Wenger, Speroff, & Packard, 1993) The voices of women with heart disease have been largely unheard until the past decade. I wondered if Irene's voice about her symptoms had been muffled by her own "knowledge" of cardiac symptoms.

I wondered why Irene had a prescription for Ativan, a commonly used sedative. I remembered being given an Ativan to 'calm me down' when I had sought help in Emergency for violent shaking secondary to what I later found out was a kidney infection. I remember taking the Ativan, feeling somewhat better, and then wondering on the way home if it really was only 'nerves', wondering if what the doctor said was true, that "women your age are often under a lot of stress". I wondered if Irene thought her symptoms were secondary to nerves.

*I would be all wiped out, just drained, but being a woman, being on my own trying to be very strong, as usual, having other problems. Just, it was I suppose, it could be stupidity, or being negligent, not even mentioning it to the doctors.*

Irene had been having symptoms of coronary artery disease (CAD) for many years without mentioning this to her own physician. She suspected that the symptoms might be

angina, since her mother had had the same symptoms, and had been diagnosed with CAD . Irene understood what her symptoms likely were, but Irene's past experiences with physicians were impacting how she now sought help.

*When you go to a doctor, it's kind of like, OK, what's wrong with you, here let's fix it, here's a prescription, and that's it. They don't have time to listen to you. I feel pretty self-conscious about it, like you know, like it's in my head.*

Irene had left an abusive husband after 22 painful years of marriage. Irene had experience in being discounted when she was in pain. Irene was careful about who to trust. Irene had raised four children on a single income, and had successfully put all of them through post secondary education. Irene had learned that she had only herself to rely on to survive difficult times.

Irene explained about a serious episode she'd had a few months earlier.

*I kind of didn't feel very good as soon as I was finished work, and I was going to sit down and relax for a little bit because I was exhausted, to the point of passing out almost, and I turned around to get a glass of water, and it hit me all of a sudden, my heart started jumping and jumping, just flying out of my chest, and I was all consumed, I was soaking wet, I got scared, and I was starting to pass out.*

Irene remembered every detail of the experience leading up to when the ambulance arrived. Her memory of the events in the hospital was much less clear. I wondered why she had total recall until she gave herself over to health care workers. It was almost as though she gave up thinking critically about what was happening to her when she gave up control of her situation.

Irene's experience in the hospital had been very frightening for her. She'd had several invasive procedures, where catheters were threaded into the heart on which she could no longer rely. The procedure results were inconclusive, as they so often are in women, and this had done little to appease her growing anxiety.

*I'm scared to go through it again. Maybe I'm an exception, maybe I'm a scaredy cat, I don't know, but what I went through was, it was, it was no fun. It was very scary.*

I wondered how Irene's hospital experience would affect the way she sought help the next time she had cardiac symptoms. I wondered if she would think twice about putting herself through this ordeal again.

*Right after that episode I just lost my strength. I'm so tired. Then I started to get more of these attacks in my chest, like angina attacks. I'd go into the hospital, and they told me as soon as you get a pain in the chest, go straight to the hospital. Oh, I didn't go for a long time, then I went one time they just kept me there for hours and hours, and nothing, they couldn't tell anything on their diagrams, their tests, they couldn't find anything, no angina, and yet when they sent me home from the hospital, they gave me everything for angina, all kinds of medication.*

Irene's reluctant trip to the hospital Emergency for her cardiac symptoms had left her more confused, frustrated, and anxious. I wondered about the mixed messages given to Irene by the staff in Emergency. She was told they could not find anything significant on their tests, and yet they sent her home with medications for angina. I wondered how this would effect the way Irene sought help for her cardiac symptoms in the future.

Irene then began to describe her experience the night of our meeting.

*It was an uncomfortable feeling in the cab. I came by cab. It was an uncomfortable feeling and then I don't know what came over me. I thought, gee, maybe I'm nervous to see all these women. But I'm not usually like that you know. It felt like a panic attack, because I'd heard of panic attacks, when all of a sudden everything happens to you, because I talked to my druggist about panic attacks and he told me that they could be very bad.*

I could see that Irene had been trying to make sense of her symptoms. She had engaged her pharmacist in her quest to discover what was wrong with her. She was still not convinced that her symptoms were cardiac in origin.

*So I didn't know what it was. I was scared, and yet I wasn't all that scared because I just didn't want to go through that to go to Emergency, and just stay there and not get anyplace. I figured I'm used to it already, so I'll take an Ativan and it will subside.*

Irene had not felt well the night of the meeting, but had made an extraordinary effort to come to this meeting to help her deal with her heart disease. The medication Irene had taken the night of the meeting was an Ativan. I had assumed it was Nitroglycerine. It was interesting that although Irene was making a great effort to be at the meeting to deal with her heart disease, when she began having symptoms, she chose first to use a medication to control the anxiety associated with her symptoms. It was as if the emotional reaction to her symptoms were more uncomfortable than the symptoms themselves. She had subsequently used Nitro during the meeting to treat her chest pain.

My mind flashed back to the night of the meeting. Irene had looked anything but complacent about what was happening to her. She had appeared very anxious, not at all like someone who was assured that her symptoms would subside. Irene was still trying to put on the brave front when describing these events. I questioned her further about her symptoms that night.

*I know I was very tired, I was reluctant to come. I wasn't feeling well at all, but I figured, Oh well I'll just be sitting there relaxing I hope. I felt a tightness in my chest, and it's hard to explain you know, your chest soreness it's like a heavy weight, sort of like a heavy burden, as if something is there that shouldn't be there, and it holds you, and you're kind of trying to fight it. It's like something pressing against you and it doesn't really hurt, there was no stabbing pain but I felt weak and very agitated, I was getting panicky.*

She had been frightened by her symptoms, but the fear of returning to Emergency was stronger.

*It's kind of like a waste of time to stay there in Emergency, and the last time, oh that's right you were there, the doctor examined me and he said there's no angina here. He was quite abrupt, and I know later he was talking to a nurse. He was laughing and I know he was laughing at me. Maybe not, I don't know, but I felt kind of anxious, like they were, I felt like they didn't believe me, that's how I felt. They didn't believe me because it goes away, and then I feel like, like I'm taking up the good space you know, in the hospital, but what can I do?*

I remembered Irene trying to persuade me not to take her to Emergency as we wheeled down the hall. I remembered feeling a pang of guilt for putting her through an experience that she so obviously did not want to endure again. I knew that once she entered the doors of Emergency, that she would be there for a long time. I knew that I would be unable to stay with her for the duration of the visit because of other commitments. It was a course of action, however, that I felt compelled to take.

I remembered arriving at the Emergency department. There was a long line of people waiting to speak to the nurse at the triage desk. I had worked in this Emergency department in the past and I was comfortable enough to wheel her past the lineup and into the department where I spoke to a nurse that I knew. My credibility got Irene into the department immediately. I wondered how long it would have taken Irene to get a bed if she had come on her own.

Since her hospital admission a few months ago, Irene had sought help in Emergency for her cardiac symptoms twice before this evening. This night Irene spent six and a half hours in Emergency, from seven thirty in the evening until two o'clock in the morning, when she took a cab home alone to her downtown apartment. I had contacted her daughter earlier in the evening, but Irene did not want her daughter to make the trip to the hospital. Irene's daughter had spent two long frustrating evenings at the Emergency department with her in the past two months, and Irene did not wish to put her through this again. All of the Emergency visits had been agonizingly long, and every time Irene had gone home with no clear answer as to what her symptoms were. Irene was losing faith in

her ability to judge her symptoms. More frightening still, Irene was losing faith in the health care system.

I remembered the “doctor” Irene referred to whom she thought had been laughing at her. This had in fact been a male nurse. I had been at the desk when he was showing her ECG to another nurse. Irene’s chest pain had subsided by the time the ECG was done, so there were only minor changes. I remember thinking that his knowledge of ECG interpretation was quite limited, but then, this was just one of a myriad of conditions he was faced with on a day-to-day basis. When the nurse was looking at the ECG, he made a comment that this was why he always gave an Ativan for every Nitro he gave, just to cover the possibility that the symptoms were brought on by anxiety.

I could imagine that his subsequent interactions with Irene were quite likely based on the assumption that her symptoms were not cardiac in origin because of the lack of ECG evidence to indicate cardiac ischemia. I knew from having worked in a cardiac intensive care unit for many years, that this was a very dangerous assumption to make. Too many times I had seen someone with very significant disease, who presented with a normal ECG when asymptomatic. We would often let someone’s angina go untreated until a diagnostic ECG had been performed for this very reason. Irene had yet to have an ECG done while she was having angina. The fact that her ECG was now normal did not tell us anything, although Irene’s perception of this was that her symptoms were not real.

The nurse’s laughter in fact had probably been a nervous reaction to my being there. I felt remorseful in that I had not recognized this incident as something that could have been misinterpreted by Irene. I had quite naturally slipped into the nurse’s role,

concerned with the results of her test, and she had been left alone to try and make sense of what she was overhearing. It was clear that although Irene and I were there together, we were having very different experiences.

I remembered an overhead page in which the arrival of a STARS helicopter was announced. I wondered if this had made Irene more uneasy about being there, about “taking up the good space”. I watched the frantic pace of activity, as nurses rushed to prepare for the incoming trauma patient. The nurses and doctors were doing their best to keep up with the pace of patients arriving at their door, but it was becoming clear to me that the situation in the department was beginning to get out of control. I knew all too well the feeling of being unable to keep up with the demands of a room full of critically ill people. At this point Irene’s chest pain had disappeared and her color had returned to normal. With twenty-two years of critical care nursing experience behind me, I was questioning my judgment in bringing her here. Irene’s reluctance to return to Emergency after her previous experiences was starting to make a great deal of sense to me.

Irene had been attending a cardiac rehabilitation program for the past four weeks. This is a program where people with cardiac problems can exercise in a monitored, controlled environment with nurses and exercise specialists close at hand. Education and counseling are offered to help people deal with their heart disease. Irene had discovered the program herself, and had insisted upon a referral from her physician. She was thrilled with her experiences in this program, and although I had come to ask about her experiences the night of our meeting, I was interested to know what it was about this program that had been so positive for her.

*I'm not embarrassed. I don't feel like it's all in my head. Like my own family doctor said, "You have to have a better attitude, you'll come along." It's really hard to have a better attitude when you are falling apart physically, emotionally, and spiritually, because this is what happens to you.*

*....out there (cardiac rehabilitation program) you're treated very, not special, we're treated like, like we're legitimate and that we count, and that our problems are real, regardless. They monitor us, they teach us, they watch us, they accept us, and they're just wonderful.*

Irene said after the taped interview that she could not have talked to me this openly before she had experienced the positive affirmation at the rehabilitation program. I could not help but wonder how many other voices had been silenced by a lack of confidence in their own stories?

*It's scary when you're in Emergency. You're lying there, and you don't know anything. You're waiting and waiting. They're busy, and I understand that there are many medical situations, but that doesn't matter when you're on the table. You're a victim, you're suffering, you need attention, you need somebody. There are a lot of people around but it's so sterile you're just like a thing there laying there, and they're doing their thing. It's very technical and I guess it has to be but I don't think that's the way it should be.*

At this point in the interview I could feel my eyes welling up with tears. I was mourning for what our health care system had become, for all the people like Irene whom we were failing. I was mourning for all of the wonderful dedicated doctors and nurses

whom I have worked with who would be dismayed to hear this story, who did their best in conditions beyond their control. I was mourning for all the men and women who had hesitated in seeking help because of experiences like Irene's, and had not lived to tell their story. I could see that Irene recognized the emotion in my eyes, and we quite naturally ended the interview. I shut the tape recorder off, and Irene came over to hug me.

This had been a journey that had begun as a conversation between a nurse and a cardiac patient, but somewhere in the interview, I had begun looking out from Irene's eyes as she described her experiences. I felt her pain, her fear, her frustration, and her joy at finding new life at the cardiac rehabilitation program. Irene had sensed my genuine commitment to understanding her experience, and I believe this had inspired her to expose her most intimate thoughts to me as well as to herself. Our hearts had touched for a brief moment. Perhaps our time together in the Emergency department had served to connect us. Perhaps it was simply that after twenty-two years, I had finally listened. This had been a journey that had taken both of us to a new level of understanding.

This experience, this interview, had allowed me a glimpse into the experience of one woman seeking treatment for heart disease. This glimpse however, left me with such a sense of profound understanding that I had not experienced in 22 years of nursing, nor had I experienced in preparing to study the question for over a year. I had a strong sense of the current literature regarding women and heart disease, and in fact it was the literature that led me to be interested in the way in which women seek treatment to begin with.

## **CHAPTER TWO**

### **Looking to the Literature**

Over the past fifteen years, much attention has been directed toward a better appreciation of the influence of gender on cardiovascular risk and management (Giles, Anda, Casper, Escobedo, & Taylor, 1995; Green & Ruffin, 1993; Heston & Lewis, 1992; Hochman et al., 1999; Lehmann, Wehner, Lehmann, & Savory, 1996; Lerner & Kannel, 1986; Marrugat et al., 1998; McGovern et al., 2001; Mosca et al., 1997; Schmidt & Borsch, 1990; Schwartz et al., 1997; Steingart et al., 1991; Tobin et al., 1987; Wong, Rodwell, Dawkins, Livesey, & Simpson, 2001). However, studies continue to show

gender bias in the treatment of women with coronary artery disease, as well as rates of mortality and morbidity that are significantly higher than men following an acute myocardial infarction (Bowling et al., 2001; Chandra et al., 1998; Marrugat et al., 1998; McGovern et al., 2001; Vaccarino, Parsons, Every, Barron, & Krumholz, 1999; Wong et al., 2001). There is evidence as well, that women with an AMI (acute myocardial infarction) delay seeking treatment significantly later than men, which could be negatively affecting their outcomes (Gurwitz et al., 1997; Lehmann et al., 1996; Malacrida et al., 1998; Maynard et al., 1995; Meischke, Eisenberg, & Larsen, 1993; Penque et al., 1998; Schmidt et al., 1990). These findings invited me to question what health care professionals might be missing in the current approach to the management of women with cardiac symptoms.

Coronary artery disease and acute myocardial infarction are the major causes of disability and death among women (Health Canada Health Statistics Division, 1999). CAD and AMI accounted for 28.1% of all deaths among women in 1997, and 32.5% of all deaths among men. Until the past fifteen years however, the magnitude of the problem in women has been overlooked (Steingart et al., 1996). There has been substantially less information about preventive strategies, diagnostic testing, and responses to therapies in women compared to what was known in men. This is related in part to the under-representation of women in clinical trials in the past (Steingart et al., 1996; Wenger et al., 1993), although researchers have begun to include women subjects (Harris & Douglas, 2000).

One issue that is evident in the literature regarding the treatment of women with heart disease is the difficulty with diagnosis of coronary artery disease (CAD) in women. The difficulty in diagnosing CAD in women using standard diagnostic tests such as ECG's, exercise stress testing, and coronary angiography has been recognized for some time (Hochman et al., 1999; Wenger, 1992; Wong et al., 2001). The most widely available non-invasive method for assessing chest pain is treadmill exercise testing, and most often it is a positive finding in this test which leads physicians to initiate coronary angiography (Wong et al., 2001). Unfortunately treadmill exercise testing has been found to have poor positive predictive value in diagnosing coronary artery disease in women (Hochman et al., 1999; Wong et al., 2001). Fewer positive angiographic results in women with positive treadmill tests, as compared to men, have resulted in the lower likelihood of women being referred for angiography. There is evidence however, that diagnosis of CAD in women using ECG parameters is improving. Results from the recent WISE study (Holubkov et al., 2002) demonstrated that selected ECG parameters independently predicted angiographic CAD in women with chest pain, including women who had also undergone radionuclide stress testing.

Numerous explanations have been offered from studies as to why women are more difficult to diagnose, including differences in anatomical patterns of coronary artery disease in women as compared to men and higher rates of clinically insignificant coronary artery disease among women with chest pain when angiography was done (Hochman et al., 1999; Wong et al., 2001). Another possible explanation for observed gender differences in diagnosis of CAD is the smaller anatomy of women's blood vessels

which may make insertion of a catheter for angiography more difficult (Travis, Gressley, & Phillippi, 1993). The difficulty in diagnosing coronary artery disease in women is even more perplexing when considering their continued higher rates of mortality and morbidity from coronary artery disease. It is important to note that Steingart et al. (1991) found that once a woman had a myocardial infarction, she was as likely as a man to undergo cardiac catheterization and revascularization with either coronary artery bypass grafting or angioplasty. Former NIH Director Bernadine Healy (Healy, 1991) referred to this as the Yentl Syndrome at work:

.....once a woman showed that she was just like a man, by having severe coronary disease or a myocardial infarction, then she was treated as a man would be. The problem is to convince both the lay and the medical sectors that coronary heart disease is also a woman's disease, not a man's disease in disguise. (Healy, 1991, p. 274-75).

There is strong evidence that women are treated less aggressively for symptoms of heart disease. Results from the Myocardial Infarction Triage and Intervention Trial (MITI) showed that women were half as likely as men to undergo angiography, percutaneous angioplasty (PTCA), thrombolysis, or coronary artery bypass grafting (CABG), even in the presence of a confirmed AMI (Kudenchuk, Maynard, Martin, Wirkus, & Weaver, 1996) . A report from the National Registry of Myocardial Infarction, a national database which followed 354,435 patients admitted with AMI to 1234 hospitals in the United States from September 1990 to September 1994, found compelling evidence of gender bias in the treatment of women with AMI (Chandra et al.,

1998). Women in this study were found to have rates of morbidity and mortality that were significantly higher than men, even after adjustment for age. Women were significantly less likely to undergo PTCA, or CABG, and were significantly less likely than men to receive standard treatment for AMI such as ASA, Heparin, beta-blockers, and thrombolytics. When thrombolytics were used in women with AMI, they were initiated an average of 14 minutes later from their arrival to hospital, than men receiving the same treatment (Chandra et al., 1998). Studies continue to show evidence of higher mortality rates and less aggressive diagnosis and treatment among women as compared to men with coronary artery disease (Bowling et al., 2001; Hochman et al., 1999; Wong et al., 1997; Wong et al., 2001). Wong et al., (1997) found that even among patients with a high indication for coronary angiography, use of coronary angiography as well as revascularization was significantly lower among women. In a subsequent study by Wong et al. (2001), women were again found to have lower rates of referral for angiography and revascularization than men in response to symptoms of chest pain, but this was found to be the result of the poor positive predictive value of treadmill exercise testing in women as compared to men.

One factor, which could influence better outcomes for both men and women with CAD, is a reduction in the time from the onset of symptoms to seeking medical intervention. It has been well documented in medical literature that early administration of thrombolytics or early angioplasty significantly reduces morbidity and mortality associated with AMI (Health Canada Health Statistics Division, 1999). Longer delay in presentation for treatment following an AMI has been shown to be associated with failure

to receive thrombolytic therapy, even when arrival is within the time frame where administration of thrombolytics would be beneficial (Goldberg et al., 1992; Malacrida et al., 1998). Several investigators have found that women with an AMI delay seeking treatment significantly later than men (Gurwitz et al., 1997; Lehmann et al., 1996; Malacrida et al., 1998; Maynard et al., 1995; Meischke et al., 1993; Penque et al., 1998; Schmidt et al., 1990). Although many studies document that women delay seeking treatment for their cardiac symptoms significantly longer than men, there remains a lack of understanding as to why this may be occurring.

There is evidence in the literature to suggest that women's symptom experience is unique, and this could be seen to be having an impact on their diagnosis and subsequent treatment in the difficulty recognizing these symptoms as significant by both medical personnel and women themselves. Several studies have shown that women experience different symptoms of CAD than men (DeVon & Zerwic, 2003; Douglas & Ginsburg, 1996; Everts et al., 1996; Goldberg et al., 2000; Goldberg et al., 1998; McSweeney, Cody, & Crane, 2001; Penque et al., 1998; Sheps et al., 2001). Women have been found to experience a range of atypical symptoms other than chest pain including edema, shortness of breath, lightheadedness, and dry cough (Miller, 2003). Women have also been found to experience more nausea as well as back, jaw, neck and abdominal pain than men with CAD. In one study of 1279 patients hospitalized with a validated AMI in 1986, 1988 and 1990, showed that the average delay between onset of symptoms suggestive of AMI and arrival at local emergency departments was just over 4 hours for all of the years studied (Yarzebski, Goldberg, Gore, & Alpert, 1994). Of the components

contributing to the delay in seeking medical care, time elapsed between the onset of AMI symptoms and the decision to seek care accounted for the largest proportion. This finding could support other studies, which have suggested that patients have denied or minimized their symptoms, or may not have been able to distinguish them from common complaints (Johnson & King, 1995; Schmidt et al., 1990)

There is other conflicting evidence in the literature regarding knowledge of cardiac symptoms as well as how this knowledge might affect care seeking for these symptoms. In one study of 862 women, a telephone interview survey was used to elicit responses to hypothetical symptom scenarios (Meischke et al., 1999). Of those surveyed, 65% labeled chest pain as indicative of a heart attack, but only 18% labeled shortness of breath or nausea as symptoms. Other studies have also shown high levels of awareness of classic AMI symptoms such as chest pain, shortness of breath and left arm pain (Goff et al., 1998; Zerwic, 1998). The question is however, how does this knowledge affect care seeking? It has been demonstrated that education regarding recognition of cardiac symptoms along with encouragement to seek immediate treatment for these symptoms does little to affect delay time (Eppler, Eisenberg, Schaeffer, Meischke, & Larson, 1994; Meischke et al., 1993; Moses et al., 1991). However, in one qualitative study of 43 patients seeking treatment for a confirmed or suspected AMI, it was found that participants whose delay in seeking treatment was less than 4 hours (non-delayers) had a wider range of knowledge of cardiac symptoms than those who delayed seeking treatment (Ruston, Clayton, & Calnan, 1998). Johnson and King (1995) found that most of their participants had expectations of what cardiac symptoms were, and those whose

experience did not match their expectations experienced an increased delay (Johnson et al., 1995).

There was no evidence found in the literature to suggest that increased knowledge of symptoms of cardiac disease, or knowledge of symptoms specific to women, resulted in women's reduced delay in seeking treatment. Perhaps one of the most seemingly confounding findings regarding symptom perception is that experience in having a previous AMI increased delay time for men and women seeking medical attention for cardiac symptoms (Schmidt et al., 1990; Yarzebski et al., 1994). McKinlay (1996) found that gender was not related to differential health care seeking in response to cardiac symptoms specifically. There does not appear to be clear evidence in the literature as to how women's recognition of cardiac symptoms affects health care seeking behavior (McKinlay, 1996).

Several qualitative studies were found in the literature which addressed women's experience of living with coronary artery disease (Fleury, Sedikides, & Lunsford, 2001; Helpard & Meagher-Stewart, 1998; King & Jensen, 1994; Miklaucich, 1998; Rosenfeld & Gilkeson, 2000; Sutherland & Jensen, 2000) as well as their experiences in having cardiac surgery (King et al., 1994). Ruston, Clayton & Calnan (1998) did a qualitative study regarding patient's actions during their cardiac event but women were not specifically addressed in this study (Ruston et al., 1998). Few qualitative studies have addressed women's experiences of having or seeking treatment for cardiac symptoms, which could capture some of the complexities of this experience.

Dempsey, Dracup, & Moser (1995) used a grounded theory approach to examine factors associated with women's delayed decision to seek treatment for AMI (Dempsey, Dracup, & Moser, 1995). This study was the only one found in the literature, which examined women's decision to seek care for symptoms of IHD or AMI. Sixteen women were interviewed following hospital admission for AMI. The two core categories identified in this study were maintaining control, and relinquishing control. The women interviewed focused on coping actions designed to reduce emotions related to feelings of threat while having symptoms of AMI, rather than focusing on the costs and benefits of seeking care in a deliberate manner. Though all of the women recognized their symptoms immediately, none acknowledged the seriousness of these symptoms until a variety of self-help measures had been tried unsuccessfully. These women described having a concern for others and not wanting to impose on the person from whom they were seeking help. None of these women sought advice from a physician, hospital, or emergency medical service, although two women had previously sought treatment from physicians for similar symptoms, and their symptoms had been dismissed as noncardiac. Four women in this study had had a previous AMI. These women delayed seeking treatment between 2.3 and 34.5 hours. Participants in this study sought the help of others only after their symptoms continued, and coping strategies were no longer able to control the emotional threat imposed by these symptoms. The results of the qualitative studies described reflect the complex nature of women's experience in seeking care for symptoms of IHD.

There is some suggestion in the literature that the unique roles that women fulfill within their families could be impacting the way in which they decide to seek care for their symptoms of IHD. The concern of women for enacting traditional roles has been well documented in the literature in terms of how it relates to women recovering from AMI (Boogaard, 1984; Fleury, Kimbrell, & Kruszewski, 1995; MacKenzie, 1993; Moore, 1996). The inability of women to fulfill their traditional roles soon after an AMI has been associated with higher rates of depression and anxiety in women as compared to men (Boogaard, 1984; Fleury et al., 1995; MacKenzie, 1993; Moore, 1996). Women have been found not to relinquish homemaking and family roles in the early discharge period following an AMI, and thus not allowing themselves adequate recovery time (Boogaard, 1984; MacKenzie, 1993). The women in the study by Dempsey et al. (1995) described having commitments that would not be fulfilled if their symptoms were found to be serious (Dempsey et al., 1995). This concern resulted in a desire for the symptoms not to be serious. This desire to minimize the seriousness of the symptoms women are experiencing could potentially be adding to the delay in seeking care for symptoms of IHD. The relationship of role enactment, self care, and emotional distress needs further study in terms of how they relate to women seeking treatment for symptoms of heart disease.

Although there is evidence that women have more health complaints, and utilize health care more often than men (Green & Pope, 1999; Hibbard & Pope, 1983; Verbrugge, 1985), there is evidence in the literature that it is women's unique experience in seeking treatment for their cardiac symptoms which may negatively influence their

diagnosis and treatment. There have been suggestions in the literature as to a larger sociological basis for differences in the way women find treatment. Stewart (1984) suggested that female patients are more likely to express tension and ask for help than male patients, but male patients are more likely to take the initiative by being more assertive in presenting suggestions and opinions, and more negative in presenting disagreement and antagonisms (Stewart, 1984). This finding suggests that women communicate differently than men, which could impact the way their care seeking is received. McKinlay (1996) suggests that the gender difference in CAD mortality and morbidity as well as incidence, diagnosis and treatment of heart disease is as much a function of how providers and the health care system respond as it is of the biophysiology of women and how they react to events (McKinlay, 1996). He suggests that women are systematically misdiagnosed and under treated so as to produce an overall gender difference in mortality. He postulates that this could be seen as a structural issue having to do with the social position of women and the system within which they are treated. His suggestion is that there are larger societal issues at play, which might be influencing the care received by women with CAD. This particular finding was not addressed in the literature that was reviewed.

There continues to be evidence in the literature that women's experience with cardiac disease is unique. The literature suggests that women have a unique symptom experience as compared to men, women delay seeking treatment for their cardiac symptoms longer than men, and women are being treated less aggressively than men for their cardiac symptoms until a confirmed diagnosis of CAD has been made. Most disturbing is that

women continue to have significantly higher rates of mortality and morbidity associated with cardiac disease than men despite years of gender specific research. There is still a gap in our understanding of what is occurring with women who have heart disease.

This literature bears upon the topic that has garnered my interest. What is occurring for women in the time between the onset of cardiac symptoms and successfully finding treatment for those symptoms? What is this experience like for women? Are there larger issues at play which serve to shape this experience? The understanding that I had gained from the initial interview with Irene compelled me to seek out further understanding of the experience of women seeking treatment for heart disease. What are the experiences of other women with heart disease? How could an understanding of the forces that shape their experiences help us as health professionals to provide more thoughtful care? The research question I had come to through the literature, through my clinical experience, and through the initial contact with Irene was, “What are the experiences of women seeking treatment for symptoms of heart disease?”

## **CHAPTER THREE**

### **The Way I Sought to Understand**

“What are the experiences of women seeking care for symptoms of heart disease?” At first glance, the question seemed glaringly simplistic. At first glance, the question begged a forthright reply, a satisfying answer. I would ask ‘the question’ and they would answer. I would hear their words and their words would tell the story. Their words would guide me. Their words would uncover the secrets that only they knew, that only they could know. I would create a piece of writing rich with the musings of the women I interviewed interwoven with my own. Their words would at once enlighten and support my reflections.

From my course work, I was drawn to a hermeneutic approach to understanding this question. Long before I had an understanding of hermeneutic philosophy, I had an intuitive sense that the experiences of these women were only part of a larger experience. As I began to explore this philosophy, I soon began to appreciate its complexity, and sensed that I could attain only beginning understandings at my current level of study. I was compelled to pursue this way of thinking because of the way this philosophy coincided with my own insights around the research question. Smith’s (1994) account of Heidegger’s philosophy, “human experience of the world takes place within a horizon of

past, present, and future” immediately made intuitive sense to me (Smith, 1994). I had sensed that the very reason I was drawn to hermeneutic inquiry was because of the frustration I had experienced in recognizing the limitations and naiveté of causal explanations.

I recognized that my assumptions about this experience included the belief that women’s experiences in seeking care for their heart symptoms were unique, that they were treated differently than men for their symptoms, and that they were perhaps less assertive in their interactions with health care workers. I had the disquieting sense that my vision of these women’s experiences had been too narrowly focused by my preconceived notions of what I was looking at. I needed to “break with my familiar acceptance” (Merleau-Ponty, 1962) of my understanding of the experiences of these women. I needed to step back, to hold my reflection and interpretations more tentatively, to ‘wonder’ in the face of the world as suggested by Husserl’s assistant, Eugene Fink (in Merleau-Ponty; 1962). I needed to look carefully as if for the first time. I had sensed that the experiences of these women were not simply happenstance occurrences, which set off a series of life events. It was the involvement of these women in the world and how that constituted their experiences and constituted them that I sought to understand. The question itself was beckoning me toward understanding.

I looked back on the transcript of the first interview I had done. This pilot interview had been with a woman I had met at the women’s cardiac support group that I attend once a month as a nurse facilitator. I found myself reading this text again and engaging in what Caputo (1987) described as “hermeneutic trouble-making” (Caputo, 1987). The

words that stood out for me were her early reference to her experience with fibromyalgia. The phrases such as “a lot of other problems” and “many times” spoke to me of how her own long history of dealing with other symptoms, of dealing with physicians, of seeking answers to her health problems, and of the complexity and messiness of being in the world. She had dealt with the pain of fibromyalgia, a pain which she seemed to put on the same plane of intensity as her chest pain. My mind drifted. In my mind’s eye I could see her taking a moment from work to make yet another appointment to help her deal with her pain, pain that she did not need while raising four children on a single income. I could see the painful steps she took to her physician’s office. I could see the pain in her face as she read the prescription for Ativan the physician had given her as she made her way back to work. I could imagine her mental rehearsals of the events that took place in the office. Had Irene been given the suggestion that her pain with fibromyalgia was related to anxiety? What would she do with this kind of invalidation? Why had she waited “a little while” for her chest pain to subside, a pain so intense that it consumed and frightened her? What was she afraid of? Did she really not understand the significance of this particular pain in relation to the pains she experienced with fibromyalgia? Was it possible that she had resolved to deal with her symptoms as best she could rather than go through the agony of divulging something so painful, only to have it trivialized? My interpretation of this text was raising questions, as hermeneutic inquiry does. I was beginning to engage in what Smith (1994) describes as a deep attentiveness to the language she used. Her words were reverberating with suggestions of her experience being part of a “grand scheme of things” (Smith; 1994).

The experiences she had had in dealing with her heart disease had not just happened to her, they had constituted her as Scott (1992) described. I wondered how her subsequent experiences might change with this new sense of validation she had acquired at the cardiac rehabilitation program. I wondered how her previous ones would constitute her next experiences. I wondered how these questions and this kind of perspective would reveal a greater understanding in my interviews with future participants in this research.

I stopped to reflect on this new dialogue I had created around the conversation I had with Irene. I had become more aware of the significance of the language she used, and the meanings embedded in it. I had started to become aware of the significance in the historicity of her experiences and how they constituted her as well as her subsequent experiences. I had for a moment looked further than the superficial description of her experience. I had ‘peeled back the layers’ of her experience to allow for a deeper understanding. I was beginning to catch a glimmer of the web of meaning behind her experiences. I had perhaps seen only a few strands, but I was beginning to see.

My thinking and my research approach evolved in this way from my research question as well as this initial interview I had with Irene. I had not chosen a hermeneutic approach to my research question prior to the pilot interview as much as I had found a way of thinking about my research question that resonated with my intuitive understandings of the experience in question.

The approach I used in this research is hermeneutic phenomenology, indicating that this approach is both descriptive and interpretive (Van Manen, 1997). The ways life experiences appear are described, and it is in the articulation of this description that

interpretation occurs through the medium of language. This research approach allows for a glimpse into this life experience through participants' reflection and articulation of their experience. The aim of this approach is to access and articulate aspects of the experience in question through participants' descriptions of their experiences, as well as through spontaneous sharing of experiences, which even the participants, may not see as significant. In this way, according to Gadamer (1989), it is through conversations and through the medium of language that an understanding of the subject matter takes place (Gadamer, 1989). Understanding is created in the conversational interviews when the participants and the researcher open themselves up to each other by talking to each other in a way that each person in that conversation can be genuinely involved with each other in a dialogue on the subject (Gadamer, 1989). Understanding can be created on many levels: through the conversation the participant has with oneself in recalling and interpreting their experience in order to articulate it; through the conversation between the participants and the researcher where interpretation and understanding of the experience are mutually exchanged; and yet again when the researcher converses with oneself in reflecting and analyzing the data generated in the conversations. Texts generated from analysis of the data as well as an inclusion of anecdotes from this research allow for the reader of the research to become involved in interpretation and creation of understandings as well. The intent of this research approach is not to prove something, to produce law-like statements, to establish functional relationships between things, to solve problems, nor to allow for generalizations as in traditional empirical analytic science (Van Manen, 1997). The aim of this hermeneutic phenomenologic

approach is to create a rich interpretive description of experience, in this case the experience of women seeking care for their symptoms of heart disease. The terms 'heart disease' or 'heart symptoms' and 'cardiac disease' or 'cardiac symptoms' are used interchangeably throughout this paper.

### **How This Research was Conducted**

The process that was used in this research was taken from van Manen's description of the phenomenologic method (Van Manen, 1997). Van Manen's six procedural activities involved in phenomenologic research will be presented below as they relate to this research.

***1. Turning to the nature of lived experience***-This involves orienting to the phenomena, and formulating the phenomenological question. The phenomenon of interest in this research is the experience of women seeking care for their cardiac symptoms. Through reflections on professional literature, clinical nursing practice, and encounters with women experiencing heart disease, the question that emerged for this research was "What are the experiences of women seeking care for their cardiac symptoms?"

***2. Investigating the lived experience rather than a conceptualization of the experience***-Unstructured, open ended conversational interviews were conducted with the beginning question, "What comes to mind when you think about your experience with seeking care for your heart symptoms?" Personal experience as well as experiential descriptions from the subjects was explored. The premise of this research method was to respect the context bound nature of the experience rather than trying to separate past experiences from

present. The understanding of this experience was in the search for meaning in the experience. My experience as a cardiac nurse and facilitator in the women's support group allowed me immediate credibility with the participants, and I was able to elicit responses quite easily from the participants because of this. The interviews easily became conversational in nature because of the trust the participants had in me. My experience allowed me insight into the experience while continuing to elicit responses from the person's frame of reference. Further questions were developed during the interview in response to the participant's reflection, and this process was supported by the clinical knowledge I possessed.

The interviews were audio-taped, and then transcribed into textual data. New issues were explored as they emerged during the interviews. A second taped interview with each participant was conducted to fill in gaps and explore phenomena from the text generated in the first interview. Demographic data was obtained from the participants to allow for a fuller understanding of the participant's situation.

**3. *Reflecting on essential themes***- Phenomenological reflection involved thematic analysis and determining themes which Van Manen describes as the "structures of the experience" (Van Manen, 1997). These themes helped to organize the writing and interpretation of the data generated from the interviews. Thematic phrases helped to point to an aspect of the phenomenon of interest. Descriptive instances and phrases were sought out in order to evocatively convey aspects of the experience. Text was generated from participants' taped interviews, as well as field notes which described my observations during the interviews. Beginning interpretations were documented after

each interview to capture my initial responses, and these interpretations were reviewed with my supervisor after discussions with her regarding the interviews themselves. Beginning interpretations were shared with the participants in the second interviews to obtain their perspective and responses to my interpretations.

The next step in the data analysis was to review the data as a 'whole'. This was achieved by listening to the tapes, and by extensive reading and rereading of the transcripts. I then reflected on these texts in their entirety to reflect upon the significance of the text as a whole (Van Manen, 1997). A selective reading approach was done to highlight any revealing statements after the text had been reviewed several times. The meaning of each sentence or paragraph was considered individually as to how it related to the experience being described. Common, as well as unique themes were identified. The thematic statements were used as the structure around which the phenomenologic descriptions were woven (Van Manen, 1997).

**4. *The art of writing and rewriting;*** Attempts were made to articulate and present the phenomena in a way that would allow the reader to see the meaning of the experience. The intent was that interpretive writing would allow for the subjective experiences of the participants to become the object of reflective awareness. The aim was to allow the experiential wisdom of the participants to be made explicit to the reader. Anecdotes were used from transcribed interviews to enhance understanding of the text, to preserve contact with the lived experience of the participants, and to allow the reader of the text to participate in interpretation of the data generated.

**5. *Maintaining a strong oriented relation-*** Throughout all phases of the research process, the research question was the compass in guiding the researcher toward a deeper understanding of the experience being investigated. The large amount of text generated from this research approach necessitated vigilance on my part to ensure that the fundamental question was consistently in the forefront of my reflective awareness.

**6. *Balancing the research context by considering parts and whole-*** This phase involved ‘stepping back’ from the data to look at how the parts fit together to form the whole of the experience. Interpretations of each participant’s story was identified from the interviews, and then unique features and commonalities between participants were uncovered. These interpretations were reviewed with my supervisor.

### **Recruitment of Participants**

In order to identify participants who had had the experience of seeking treatment for their cardiac symptoms, purposive sampling was used. Women participating in a self-help and support group for women with heart disease were approached using an invitation to participate. A letter of support from the chairperson of the women’s support group was obtained prior to approaching the group with an invitation to participate. Members of this group were asked to pass on the invitation to participate to anyone they knew who might be interested in participating (Appendix A). The researcher met with the participants to explain the study and seek written consent. I did not limit the participants to those who had coronary artery disease or to those who had had a myocardial infarction.

I enlisted women who had experienced cardiac symptoms. I felt that a confirmed diagnosis was not necessary to understand the experience of women seeking treatment for cardiac symptoms as it was the unknown etiology of their symptoms that in itself was part of the experience to be described.

Interviewing was concluded when it was apparent that I was able to richly describe key aspects that constituted the experience. The total number of participants was five women, including the participant in the pilot study who was interviewed a second time after the research began.

### **Data Generation**

After the initial contact was made by the participant with the researcher, a time was set up for the initial interview to be held in the participant's home. At the time of the initial interview, demographic data was obtained that helped to contextualize the circumstances of the participants. At this time consent was obtained not only to participate in the study, but to have the interview audio-taped and transcribed (Appendix B). Participants were informed that the interviews would be one to two hours in duration. They were all told that the interview would be terminated at their request or if they became visibly tired. I chose to terminate interviews before two hours had gone by on three occasions for this reason.

After the audio-taped interviews, I made field notes in order to collect data that could not be captured on the audio-tape (such as non-verbal communication, participant appearance, researcher's perception of the content of the interview). The audio-tapes were then transcribed and reviewed by the researcher. A second interview was arranged

to allow the participant and the researcher an opportunity to share their reflections of the previous interview. The second interview allowed for any new ideas to emerge, and allowed the participants to give their impressions of my beginning interpretations of the initial interview. Field notes and transcriptions of the first and second audio-taped interviews all become part of the text to be interpreted and described. One participant provided me with several pages of handwritten notes she had prepared prior to the first interview to ensure she would not forget anything.

### **Trustworthiness**

The trustworthiness of the interpretations was supported in several ways. Beginning interpretations of the initial interview with each participant was shared with the participant to obtain their responses. New data and refined interpretations then emerged from the second interview. Interpretations of the data were discussed with my supervisor as well as fellow students to obtain their reflections on my interpretations as well as on the interviews themselves. I was also able to reflect on the data with a perspective of over 20 years of nursing, much of which had been in cardiology. I presented my reflections of the pilot interview to the Heart to Heart Women's group with the permission of Irene, and was able to get the perspective of several women who attended this meeting. This presentation was made after the interviews were complete with the other participants. Members of the group who did not participate in the research were able to offer me some insights of their own in regard to this woman's experience in addition to their appreciation of the congruence of my insights with their own understandings of this experience.

### **Ethical Considerations**

The proposal was reviewed by the Conjoint Health Research Ethics Board and was found to be ethically acceptable. Written consents were obtained from all participants. Participation was completely voluntary, and participants were advised that they may withdraw from the study at any time without penalty. All data collected remained anonymous and only the subject's pseudonyms remained on any data sheets. No names were recorded on tape or on typed transcriptions of the interviews. Participants were informed prior in the consent that data from interviews, in the form of excerpts, might be used in presentation of findings and for teaching purposes, but that anonymity would be protected. The possibility that members of the group might recognize the participants' stories was discussed with the group as well as the participants themselves before consent was obtained. None of the participants voiced concerns over this possibility.

All data and audio-recordings were kept in a locked file cabinet to which I had access. Copies of the transcriptions of the interviews were given to my supervisor. Audio-recordings will be erased and transcript copies will be shredded at the completion of the study. One copy of transcriptions of the interviews will be stored in a locked file cabinet and will be kept for five years after termination of the study. A summary of the results will be sent to all participants who request a copy. This provision for requesting a copy was included in the consent form. Details of the participants' demographic data were not included in this report to protect the anonymity of the participants.

### **Limitations of the Study**

Participants in this study were women who had sought help in a formal self-help group who may share some unique beliefs or practices that distinguish them from other women who experience heart disease and do not seek this kind of support. The sample size was small, but this is typical of a hermeneutic phenomenological study in which the intent is not to generate theory or to generalize to other samples. The intention of this study was to provide the reader with evocative descriptions of the phenomenon so that the reader can recognize and gauge possibilities for application of findings to their own practice.

My prolonged engagement with the participants as a nurse facilitator in their support group served to strengthen rather than limit the credibility of the findings. A trusting relationship had been established with the participants prior to the interviews, which enhanced the opportunity for difficult topics to be discussed more readily. Knowing the participants over a prolonged period of time increased the likelihood that I could offer a stronger interpretation that adequately described and uncovered their experiences.

### **The women's stories emerged from this process**

This research process gave me the opportunity to hear the compelling and insightful stories of the participants in relation to the research question "What are the experiences of women seeking treatment for their cardiac symptoms?" The possibilities in understanding this experience that emerged from the interviews were seemingly endless, and I began to immerse myself in the transcripts.

## **CHAPTER FOUR**

### **Their Stories Were Compelling**

What are the experiences of women seeking treatment for symptoms of heart disease? The answers I received in response to this question brought forth a lifetime of

experiences from the participants. The answers I received were the culmination of so many of their own experiences, which had brought them to this point. The answers I received resonated with the voices of women who had sought care before them, and those whose experiences lay ahead. My mandate was to find a trail of meaning in these women's' experiences. My mandate was to glimpse into the lives of the participants who sought to obtain care for symptoms related to their heart disease. I hoped that each of their stories would strengthen my understanding of this part of their experience in much the same way that Irene's story had in the pilot interview.

How had these women come to seek care for themselves in the way that they did? What experiences now molded the direction they took in finding care for themselves? I sensed that the way in which these participants understood the health care system and how it could be accessed or negotiated, was a product of many things. Each woman's experience seemed to have been pushed and pulled, molded and shaped by so many forces; forces that at once were outside of themselves and yet ones of which they themselves were an inextricable part. The experiences these women had were similar and yet were different in many ways. It was the distinctiveness of their individual stories, the similarity of their common experiences, as well as the dialogue itself that lent perspective, insight and understanding to the way in which they came to seek care for themselves.

From the participant's descriptions of their experiences in seeking treatment, my trail of understanding began. From the interviews I would begin to catch a vicarious glimpse at the experiences themselves that these women had in seeking treatment for their heart

disease. I began to recognize that it was the historical context in which each of these women had sought treatment for themselves that shaped their encounters in seeking health care. Experiences as far back as childhood seemed to be touching the participants now.

### **Doris's Story**

#### ***I knew there was something wrong.***

Doris is a 39-year-old woman who first contacted me through the women's support group that I am involved with. Doris's heart symptoms began as a teenager. Her initial symptoms were palpitations and anxiety brought on most often with exercise, which were deeply disturbing and frightening for her. She was told over and over by various physicians that there was nothing physically wrong with her, and yet she continued to have these symptoms. She was eventually sent for psychiatric treatment and counseling. Physicians told her that there was nothing physically wrong, and yet her body was telling her something else. She complied with the counseling and psychiatric treatment, but all the while was left feeling frustrated and confused. Her symptoms escalated over the next twenty years as she continued to seek an answer from various physicians, only to be told again and again that there was again nothing physically wrong with her. She continued to attend numerous counseling sessions in an attempt to control the overwhelming feelings of anxiety that she would experience in conjunction with her palpitations. She was led to believe that if she could control her anxiety; her palpitations would also be controlled. Physicians believed she was having panic attacks, which resulted in these symptoms. There was part of her that believed this as well.

What kind of mental anguish did this young girl endure: the self-doubt, the confusion, the humiliation of being told her symptoms were in some way not 'real'? How did she make sense of this? What effect did this have on her developing sense of self as a teenage girl? How did she manage to carry on with her life with the ever-present possibility of having these frightening symptoms reemerge at any time, yet knowing that her symptoms would most likely be again invalidated, and she would still receive no help for these symptoms that continued to alarm her? And yet she continued to seek help for her symptoms. The mental strength it must have taken to brace herself for her next physician's visit was difficult to imagine. It must have taken incredible courage to face someone so much more powerful than herself with yet another description of these same symptoms. At this point in her story she was 'just' a girl, and as such she may not have felt entitled to assert herself against a very powerful medical system.

Twenty years passed. She obtained a masters degree in psychology, married, and had two children. All the while she continued to have these frightening symptoms which she continued to pursue with various physicians over the years, only to be told again and again there was nothing physically wrong with her.

*I think, intuitively I knew there was something going on with my body, and I knew for so many years. Every single time I went to the physician I was told that it was in my head, and I would come away feeling so indignant, so angry, because I knew that something was wrong.*

She knew there was something wrong, but the physicians did not know, and she knew they did not know. She had been angry, and yet this anger was not enough to inspire any of the physicians from whom she sought help to investigate her symptoms further. Despite her perseverance in seeking help from so many physicians, she was unable to find the “secret passage” to the health care system that could treat her symptoms.

The symptoms themselves escalated over time to include shortness of breath, exercise intolerance, and then chest pain. Her life proceeded, although her quest to find answers to her symptoms did not. She now had an additional concern; she was now a mother. She worried that her symptoms may affect her ability to care for her children, perhaps even endanger them. She also worried that her symptoms might eventually leave her children without a mother. Her anger turned to indignation and an escalating cynicism about the health care system.

*Nobody else could see what I knew was there and it was so frustrating, going from one physician to another physician, and all it did was produce anger which made me want to prove everybody wrong around me, and that's what kept me going. One day I would find out what this really was, and I would be vindicated.*

Doris felt abandoned by the health care system, and felt the only option would be to try and find answers for herself. She read, she searched the Internet; she consulted with friends and her pharmacist, all in an attempt to find answers. Her research revealed a diagnosis that she thought might fit her symptoms: mitral valve prolapse. She

approached her physician with her research as well as her diagnosis, only to be rebuked. She repeated this with other physicians but was unable to convince any of them for several years that this was a potential diagnosis, or even to have a referral to a cardiologist. She contacted a support person at the Mitral Valve Society in the United States, and through her was able to get some validation and renewed diligence in finding an answer.

In February of the year that she contacted me, she was able to persuade a physician to send her for an echocardiogram. The results: mitral valve prolapse. She was elated. She could now conclusively put a name to her symptoms. She had finally been validated, twenty years after the onset of her initial symptoms.

*When I finally got this diagnosis, I was like, Oh my God, you have no idea. The day I found out I had mitral valve disease, my first reaction was I'm finally vindicated, and I didn't feel embarrassed anymore.*

*...I finally felt vindicated, it was like screw you! I even wanted to sue, and I still think about it.*

Having to deal with real heart disease was less frightening for her than the uncertainty of experiencing symptoms without a diagnosis. Her quest was still not over however. In addition to her palpitations and anxiety, she was having profound fatigue and chest pain and this caused her concern that she may have coronary artery disease as well. The pain was related to exercise, radiated down her left arm, and was relieved with rest. She knew from her reading that these were signs of cardiac ischemia. She was referred to a cardiologist for these symptoms, but the appointment was not for several

weeks. She went to the Emergency department one evening when she was having this chest pain, and her previous experiences of being invalidated returned.

*I went to Emergency and they put your finger in that little thing, and of course it was all over the place, so I waited for two hours, and I got in and they put me on a monitor, and she went to hook up an IV, and she said I don't think you need an IV just yet, so they had me all hooked up, my blood pressure was really high. A resident came to see me and I leaned over to talk to the nurse and I noticed that I was having one PVC after another, and I was concerned and she said rest assured that you're stable, you're not having an MI. There was a guy next to me that was two years older than me, with exactly the same symptoms. They had an IV in him, they had two Aspirins in him, and they had a cardiologist see him right away. I had the arm pain, and he had the arm pain, I had the chest pain, and he had the chest pain. I said, why didn't I get that? Well you're complicated; we're not sure what's going on, we're going to send you home. So I felt it was all a big waste of time. I left not knowing. I felt like I still might have a heart attack. I still felt like I was very unstable. I was still very anxious.*

She had her initial symptoms of mitral prolapse diagnosed, only to have similar experiences of invalidation with this new symptom of chest pain. Her experience in Emergency stopped her from seeking help there again during a subsequent episode of angina. When asked about this she said:

*Doris: I wanted to call an ambulance and I didn't. I made a physician's appointment instead.*

Researcher: *Even though you probably knew what the correct way of handling that situation would have been. Tell me what stopped you.*

Doris: *I thought they're going to come to the house and tell me I'm having an anxiety attack or something.*

Researcher: *So what was holding you back was saving yourself some embarrassment?*

Doris: *Yes, absolutely. I'm tired of being embarrassed. All those physicians' appointments when I left feeling humiliated.*

This was a woman who had done extensive reading about heart disease and was quite familiar with the signs of cardiac ischemia as well as the potential dangers. Despite this extensive knowledge and experience with the health care system, she chose to put herself at risk rather than endure another potential episode of humiliation. The description of this experience was powerful.

The time finally came for her to see the cardiologist. This was an extremely important event for her and she knew from experience that she would need to prepare. She had waited a long time for this moment. She did not want to waste this opportunity to seek answers from this expert physician. She considered how her approach might be contributing to her experiences with the health care system.

*It really wasn't until this time the symptoms came on that I changed the way I approached the physician.*

*...I think I mentioned the language that I used. When I went in I was very prepared, and I went in being very factual about the symptoms I was having, when*

*they occurred, how they occurred and how long they lasted, not talking at all about anxiety, leaving that part out of it completely. I said I read this book, I even brought the book with me, and I came totally prepared.*

Doris was a chartered psychologist, quite adept at communicating with other professionals and clients, and yet had to rehearse the way in which she would speak to this physician to ensure she would be heard. She felt she needed to leave out a description of her anxiety in order to be credible. She would need to leave out a description of the symptom that had troubled her in her quest for an answer to her symptoms of mitral valve disease. She thought she needed to communicate with the physicians “*more like a man*” by leaving out the emotional component of her experience. She described the doctors as “*glazing over*” when she described the emotional component.

*It's like they lost interest. All of a sudden they went o.k. here we go. They would just lose interest at that point. It wasn't something they could physically relate to. It was like something intangible and they aren't interested in intangible things. It was kind of like this is airy-fairy.*

The very symptoms she was used to discussing and taking very seriously in her professional world would need to be eliminated from this discussion.

*I used to spend so much time (rehearsing how she would approach doctors) because I thought if I could just say it a certain way they will listen to me this time, and then I'd go and I'd get blown out of the water. This time with Dr.--- I knew what I was going to do, I just stuck to the facts.*

She felt that this approach worked well with the cardiologist, and that she was finally taken seriously. Perhaps she had at last found a physician who could recognize and treat her symptoms. She was started on a medication that would control her symptoms, and at the time of the second interview she was feeling better than she had in a very long time. Her analysis of her experiences with the health care system was that after twenty years she had learned to play the game.

### **Linda's Story**

*All he ever said was that it was because of my diabetes.*

Linda is another of the participants whose past experiences seemed to shape her current experiences with the health care system. She is a 69 year old woman who was previously healthy but was first diagnosed with Type II diet controlled diabetes 25 years ago. After she was diagnosed as being diabetic, she would see her doctor occasionally for follow up, but for the most part her experiences with the health care system consisted of seeking care for her children as well as her aging parents.

The onset of Linda's cardiac symptoms began as far back as 10 to 15 years ago. She estimated she would see her physician five or six times a year during that 10 to 15 year period for various things. She reported mentioning her chest discomfort to him on many occasions. His response to these symptoms was that it was due to her diabetes. She was told that she could expect a number of unusual pains secondary to her diabetes.

*I went to my last doctor and said I feel like I have an elephant stepping on my chest, a band tightening up, or a drilling in the middle of my back. And all he ever*

*said was 'that's because of your diabetes'. Everything that I complained about was because of my diabetes. Never sent me off for heart tests or anything.*

*...I would mention it and he would turn around and tell me it was because of my diabetes. So I thought o.k. I just forgot about it after that and tolerated it.*

After many reports of this pain over a period of several years, the physician did an ECG, which appeared normal, and no further investigations were done. Linda seemed to be very confident in the way she handled her life, having raised four sons on her own for many years. In the encounters that had with Linda prior to our interviews, Linda had shown herself to be bright, articulate, forthright and insightful. She did not strike me as a person who would allow herself to be manipulated, controlled, or ignored. I wondered how it had come to pass that Linda had allowed so many years to go by without treatment for symptoms that she knew to be significant.

The family physician to whom Linda had first reported her cardiac symptoms had been her family physician since the early 1970's, and she described feeling comfortable with him. She reported trusting his judgment because "he's the doctor", and yet several things in the way she described her experiences made me wonder. The powerful descriptors she used in reporting her symptoms to her doctor spoke volumes to me. She described her symptoms as "*an elephant stepping on my chest*" and "*drilling a hole into my back*" and a "*clamp around my chest*". Her words spoke of the frightening and consuming nature of these symptoms. She reported her physician's response, however, with a shrug of her shoulders, "*all he ever said was that it was because of my diabetes.*"

Although she described these encounters with some nonchalance, the words she used to describe her symptoms were anything but nonchalant. Linda's persistence in regularly reporting these symptoms to her physician spoke of her intuitive knowledge that these symptoms were significant. She reported ignoring her symptoms because she took her physician's word for it, but had little difficulty recalling the nature and frequency of these episodes during our interview several years after they had occurred. It seemed unlikely that she had ignored her symptoms for her to have this kind of vivid recall years later.

Linda had prepared several pages of notes for me to ensure that we would not miss anything she felt was important to her story during our interview. These notes were prepared without my request, and she had obviously spent some time preparing them. I found it particularly enlightening that Linda began both our interview and her own notes with a very clear description of the way in which she had reported her symptoms to her family physician over the years. It seemed as though she was demonstrating that she had fulfilled her part of the patient/physician relationship by reporting these symptoms. She described her reaction to her physician's assessment of her symptoms in the following way: "*He still just said, it's because of your diabetes, and I thought, ok, you are the doctor, I guess you know.*" At another point in the interview she said: "*he's the doctor, he should tell me what's wrong.*"

Linda described bowing to her physician's knowledge and expertise, and yet the language she used and the way in which she had chosen first to describe this part of her

experience spoke to me of her intuitive knowledge that she was not being heard by her physician. The following are the first of the notes she had prepared for me:

- *Dr. A knew I had heart murmur*
- *Cold feet – because of diabetes*
- *Skin mottled – told not to worry about it*
- *Elephant stepping on chest – Dr. says its because of my diabetes*
- *Clamp around my chest – because of diabetes*
- *Drilling hole into back – because of diabetes*
- *Double breath – because of diabetes*
- *Twinging in chest – because of diabetes*
- *Doctors don't really listen to patients*

The long list of her symptoms, followed with her physician's reaction, "because of my diabetes", speaks of frustration, fear and even anger. She finished off this series of descriptions of her symptoms with the statement "doctors don't really listen to patients." I sensed that she felt this at the time she was reporting her symptoms, and that perhaps articulating her experience served to clarify this notion for her. This notion that perhaps her doctor had not really heard or responded to her symptoms the way that he possibly should have, was a notion that perhaps she did not dare to pursue at the time of her symptoms. She continued to allude to this notion several times during our interview without actually putting this consideration into words. Was she stepping on sacred ground to suggest that her physician had failed to do the very thing she had most entrusted him to do over the years? By Linda's actions, she had demonstrated that she

continued to trust that her physician would care enough to listen to her and then use the professional knowledge and expertise that Linda herself did not possess to address these symptoms. Over the twenty-five years that Linda had gone to this physician, they had gone through many profound personal experiences together. This physician had seen her through the illnesses and deaths of her parents, the illness and death of her first husband, and the death of one of her sons. I could begin to understand why she might be reluctant to believe that this physician would do anything that was not in her best interest after having been there with her and her family during all of those life-altering experiences. Her relationship and trust in her physician was not just about how he handled her cardiac symptoms. Her own experiences were intricately tangled up with the experiences she had with the rest of her family. To question her physician's integrity now would be to question the way in which all of those other profound experiences with illnesses in her family had been handled. Perhaps it was more comfortable for her in a sense to believe that she was being taken care of in the best possible way. After describing an incident with her physician in which he had "brushed off" her symptoms of sciatica, I pursued the notion that perhaps this was not the first time she had been handled in a less than diligent manner. What followed was fascinating.

Researcher: *So this wasn't the first time you had had experiences with him – would you call it brushing you off?*

Linda: *Yes. The same with my Mom*

Researcher: *So you saw that kind of treatment with her as well?*

Linda: *Yes and my son*

Researcher: *What goes through your head? I know you were realizing this. I can tell you realized that you weren't being treated as aggressively as you should have been – not just with these other symptoms but especially with your heart symptoms. What's going through your head when you're thinking about that? I'm just trying to understand that*

Linda: *When I'm thinking of Dr. A?*

Researcher: *Yes. And him brushing you off*

Linda: *Like you didn't do for me what you should have done. You should have taken notes or made a follow-up or send me for a second opinion or something or even call in one of your colleagues in the same building you're in. but he didn't seem to want to do that.*

Researcher: *So that was going through your head as you were seeing him. What stopped you from pursuing that with him?*

Linda: *I think just turn around and the leg and finding a different doctor*

Researcher: *If you had been taking your child to a doctor and you didn't think he was pursuing something the way he should have been, how would you have dealt with that?*

Linda: *Probably the same way I dealt with me. Just keep going to him and hoping for the best. Because I often wonder if I should have pursued it about my son. Because he was under Dr. A's care too.*

Her 26-year-old son was admitted to hospital with abdominal pain on a Tuesday, and was found dead Thursday morning before any diagnostic tests had been done. Even after autopsy, his death was never explained.

*That kind of played on my mind, like did you do everything you could have done for him?*

The passivity in the language that she used to describe the unexplained death of her 26-year-old son struck me as astonishing. This was a woman whose passionate love for her sons was more than apparent, and yet her words to describe her analysis of her son's death were almost again, nonchalant. It seemed again that her words did not correlate with the story she was telling. Was it that again she was afraid to suggest, even to herself, that a physicians' care might be less than thorough? It was only after she sustained a fractured leg that the direction and quality of medical care began to change for Linda.

*I had gone to him (Dr. A) and he never sent me for x-rays or anything and then I had gone to a cattle show with my husband. I stood up and I fell down. And I thought this is not normal for me. So I just went to the walk in center and that doctor said, maybe we should send you for an x-ray and then they ordered this walking cast and everything and I went to the old doctor and I said, look this is what has happened. I have this cast on now and he said well you are probably getting too old and your bones are getting too brittle and that is what happens when you have diabetes.*

This time, the 'hard' evidence of an x-ray done by another physician, in which a fracture was found, was enough to persuade Linda to consider seeing another physician. Although she was impressed with the doctor she had met at the walk-in clinic, and wished to continue seeing him for her fracture, she felt compelled to get her old physician's approval for this and approached him by saying she did not want to negotiate the steps to his office with her cast. Her old physician was not supportive of her seeing another doctor, and so after almost 25 years with this physician, she left him. She had not been brave enough to tell her physician she was unhappy with his care, and perhaps at this point she was not brave enough to admit this even to herself.

Linda's new physician was quick to order a cardiac workup including an ECG, Thallium scan and eventually an angiogram in response to his assessment of her cardiac symptoms. It was discovered that she had triple vessel CAD which would require open heart surgery. She would have her open-heart surgery, and would have a very complicated course of recovery. She developed an infection at her pericardial pacing wire insertion site after her surgery, and was readmitted to hospital within days of her discharge. The antibiotics that were used to treat this very serious infection would cause a clostridium difficile infection in her gut, which eventually led to her having a bowel resection and creation of a colostomy. She was in the hospital for months, and was close to death on several occasions. She was discharged from hospital in a very weakened state. This was the experience of a woman who had repeatedly reported her cardiac symptoms to a health care professional over ten years, with no resulting treatment or

investigations to speak of until circumstances led her to seek the advice of a new physician.

*Researcher: So if you were able to say to women who were going to go through similar experiences to what you've been through in the last 10-15 years, what would you say to them?*

*Linda: I would tell them to make sure they ask their doctor everything. What is he doing? What are the pills for? Why is he giving it to you? What are the side effects? What do you expect afterwards? Feel confident with your doctor. If you don't feel confident – get a second opinion and question everything.*

Linda's horrific experiences had left her with a much more assertive attitude. She had learned to be less passive in her interactions with her physician, and not to assume that "he should know because he's the doctor" as she had previously described. I sensed that she had lost a great deal of confidence in the health care system, but perhaps this was a healthy skepticism that could serve to empower her in future encounters with health care providers.

I was drawn to reflect on the differences in the experiences of Doris and Linda. Both women had gone many years with significant cardiac symptoms without diagnosis or treatment, and both women had recognized that their symptoms were significant and had persisted in reporting them. However, Linda had never sought a second opinion of her symptoms over a ten year period, and even when she did get a diagnosis and treatment for her cardiac disease, she was still reluctant to cast any blame on her former physician. She had remained subservient to her former physician's opinion and

expertise for over ten years. Doris on the other hand had persevered in seeking treatment for her cardiac symptoms by seeking many medical opinions over the years, and had no difficulty in asserting herself in discussing her own assessment of her symptoms. Doris's assertiveness, however, did little to make her diagnosis and treatment any more timely than Linda's. Indeed she had wondered if her self-assured manner had annoyed the physicians she had sought care from, possibly to the point of delaying the tests she would need to diagnose her symptoms. Perhaps the differences in the way they sought care was a reflection in the differences in their ages, Doris being 39 years old and Linda 67. These two women had grown up in different social climates. Perhaps it was the difference in their socialization as women that served to influence the way that they had negotiated and even challenged the care that they received. There seemed to be a difference in their sense of entitlement to care, as well as their sense of entitlement to influence the direction of their care. The two women had both persisted in seeking treatment for their cardiac symptoms, although their approaches were quite different, and yet the care they received had been very similarly delayed. Were there other forces at work shaping their experiences? Further interviews provided further insights.

### **Pam's Story**

*It wasn't really anything but it bothered me enough to get it checked out.*

Pam is a 59 year old woman whose experience in seeking care for her cardiac symptoms began two years before her heart attack. She had some episodes of chest pain during this time: one episode was diagnosed as costochondritis, and one as pneumonia.

During the two years prior to her heart attack Pam had experienced some tingling in her neck with exertion, which disappeared with rest. She began to have “skipped beats” as well which she reported to her doctor, and was told to cut down on coffee and to quit smoking as well, which she did not.

*Many times I would ask the doctor “How come my heart is beating extra beats?” He would say “Oh, too much coffee, get rid of the stress, take care of yourself, oh we’ll check your cholesterol. It’s probably nothing, because you don’t have a history of heart disease, you’re 48 years old and you just don’t have a history of heart disease in anyone under 65 .” Women of course, we women at 48 are not supposed to do those kind of things.*

Despite the fact that she was a smoker, had been diagnosed with high cholesterol, and was having some cardiac irregularities, she did not associate her symptoms with heart disease.

*I was a smoker, I was overweight and I had high cholesterol, four things out of five that are big red flags. All I was told is that my cholesterol was high. I better start working at getting it down. I was given some literature and not sent to anybody special, not sent to a dietitian. I suppose if I had asked I guess I could have.*

Her physician did not follow up on these symptoms with any other cardiac investigations or referrals.

*Well it wasn’t really anything, and yet it was enough that it bothered me enough that I went and had it checked out, or others thought that I should get it checked*

*out. And then it was dropped, it was never followed up, furthered up, referred to anything beyond that one situation, that one day when I went to Emerg.*

This day that she referred to was the day she had her heart attack. She had a tingling sensation in her neck the day before, which came on with exertion, and disappeared with rest. The day of her heart attack she had been sitting reading the newspaper when she began to have this same numbing, tingling sensation in her neck. After half and hour or so, her symptoms escalated

*It was a good half hour, 45 minutes, or an hour before I finally thought, “something is wrong here....something in this picture is not right” because then I started to feel lightheaded, that same numbing feeling. It wasn’t a crushing pain, it just went down my arms and I was feeling sweaty and not doing anything. I thought, “How could I be sweaty?” ...and I went and woke up my daughter because my husband had stepped out.*

She had lost her color, and become acutely short of breath. Her daughter immediately called for an ambulance. She was taken to the nearest Emergency department where she suffered a cardiac arrest shortly after arriving. She had endured the initial symptoms of her heart attack for nearly an hour until they escalated to a point where she could no longer ignore them. She was lucky to have survived this experience.

Pam sustained a large myocardial infarction. During her hospitalization she underwent coronary angioplasty, and developed pericarditis, for which she was treated. Her recovery otherwise was unremarkable according to her, and she was discharged from hospital.

Over the next two years Pam developed several subsequent episodes of pericarditis. The symptoms she experienced with these episodes were somewhat different from those she experienced with her heart attack, but were nonetheless very worrisome for her.

Researcher: *Tell me about the symptoms that you were having with the pericarditis, were they different from your angina?*

Pam: *They were very different. They were all on the chest wall. They would start at the bottom most of the time, or here (indicating her left chest), either one. They were just, how would you describe it, they were very, very sharp. I would equate it to a knife. You're being cut without being put to sleep or without an anesthetic and at the same time a sense of 'squeeze', a sense of constriction, and I would have difficulty breathing, because in taking a deep breath that would kind of slam it.*

Researcher: *So were you able to differentiate between that kind of pain and the angina kind of pain that you had?*

Pam: *No, at the onset no, because I would do the squirt and it would ease it momentarily somewhat but there would be a difference.*

Now Pam had several potential diagnoses to consider when she began to have symptoms. She had been told prior to her heart attack that the chest pain she was having was due to pneumonia and costochondritis. She had experience with having the pain associated with pericarditis following her heart attack, and of course most disturbing of all was the thought that these symptoms could be signs of another impending heart attack. One can only imagine the anguish associated with trying to deal with symptoms that could once again put her in a life threatening situation. Pam's experience of seeking

care for cardiac symptoms included another dimension, and that was the perceived need to self diagnose before seeking care. She felt compelled to ensure her symptoms were legitimate even after having suffered a cardiac arrest following her initial symptoms. The influences that served to have her question the legitimacy of her symptoms were strong enough to compete with her very real fear of revisiting another life threatening situation.

*I had to be careful also so that I didn't make mountains out of molehills....because your mind can play awful games with you during those times ....you don't want to become a hypochondriac or a psychosomatic either.*

Although she had come disturbingly close to death on one occasion, she was still concerned about being seen as a hypochondriac. She had sought help for these pericardial type symptoms on many occasions during those first two years after her heart attack. After she had received treatment for the first five episodes, she sensed a change in the way in which she was being managed. I asked her what she had meant by her comment in which she referred to her fear of being seen as a hypochondriac.

*Pam: Well the other 10 or so events after those initial 5 or 6 I was made to feel that 'this is all in your head lady, and so I would stall going to the hospital for three or four days and then get Royal poop.*

*...Some times I would immediately be put on the monitor, immediately hooked up and at other times they would be a little more flabbergasted and they would put me in an off room with just the regular Emergencies with cut fingers and sprains and stuff. Usually the room had hookup for oxygen if needed and they could have*

*whipped me around the corner if they needed to but most times I was put in that room hooked up questioned and if there was nothing going on then some 4 or 6 hours later I would be discharged. They would say “well you did the right thing coming in but we really can’t find anything so be careful, don’t wait so long the next time” but then the next time it’s just, I don’t know, I guess it just got to be me. Was I looking for sympathy? I don’t know.*

Researcher: *Is that the impression that you got?*

Pam: *That’s the impression I had at the time, somewhat, I guess when I think about it I just felt, oh no here I go again, and then you say to them “I guess there’s really nothing after all so I’m sorry I bothered you” (and they would say) “No, no, no,” but you really can’t see through that. I think they were trying to be genuine but they’re so busy too so maybe it’s just me, I don’t know, it’s confusing, it’s very confusing now that I have to think about it in this vein, , that’s confusing.*

Where did the confusion come from? I sensed that it was probably the result of many things. She was having symptoms that were potentially warning her of an event that nearly took her life in the past, and could very well do so again, and yet she had many things to sort through in assessing her symptoms. Her symptoms of pericarditis were indeed different from her anginal symptoms prior to her heart attack, and yet were disturbing enough for her to seek treatment 15 times in Emergency in the two years following her heart attack. These trips to the Emergency department were in addition to times she had sought the advice of her family physician for these same symptoms. She had admittedly gone through some soul searching prior to seeking treatment in

Emergency so she would not be seen as a hypochondriac. On the occasions when she did seek treatment for her symptoms of chest pain, she risked the embarrassment of being told they could not find anything significant, to the point of being “flabbergasted”. And yet she knew that these were symptoms that she could not ignore, and was always told, “you did the right thing coming in”. At other times she would receive immediate medical attention, and these differences in the quality of her care must have caused great confusion for her. She too was caught in a contradiction. Her symptoms frightened her, and yet the potential embarrassment or humiliation worried her as well. She was told to immediately seek care for her symptoms if they persisted longer than fifteen minutes, and yet when she did they often became “flabbergasted” and she was kept waiting several hours for symptoms that she thought might take her life when she made the decision to seek care in Emergency.

*Many times I was taken in when I presented it worked, but there was also times when I presented and it didn't. I wasn't acknowledged. It was, yeah sure and then put aside. That's hard to take. I would be 6 hours in emergency, doubled up in pain and I not even triaged. That's a little hard to take. When you think, they don't even care if I die. When you are going through the throes of that kind of pain level, your mind is not working properly. You've gotten to the point where you've gone to emergency, hoping to have some sort of relief some help, acknowledgement something. And you're not getting it. In retrospect you feel selfish during that time.*

I found it fascinating that she would describe her feelings when seeking care as “selfish”. What was it about wanting immediate attention for her potentially very

serious symptoms that led her to think that it was selfish? Did she think that she was not entitled to immediate care under these circumstances? Did she think others were more deserving of immediate attention, even though she herself could be in a life-threatening situation? Was she, like Linda, intimidated by the power of the health care providers, and perhaps did not feel entitled to challenge them in their hectic environment? Could it be the natural response as a woman and nurturer to place her own needs behind others in a room filled with people in need of health care?

Pam's experience in dealing with her heart disease was confounded by having to deal with a number of very serious personal issues. She was divorced from her husband one year following her heart attack. At the same time she was pursuing seeking legal custody of her daughter's son, whose home environment was very unstable for a number of reasons. So in the midst of this incredible emotional turmoil, Pam was dealing with her very serious cardiac disease. She needed to remain vigilant in attending to her symptoms, for after all, she might soon be solely responsible for her six year old grandson. Her frequent episodes of chest pain following her heart attack were intertwined with this staggering emotional upheaval in her personal life. I wondered how this backdrop of her personal life could have affected the way in which she sought care. I wondered about the sense of entitlement she would have when she had experienced such profound personal struggles, when the people she was closest to continued to let her down.

Five years after her own near fatal heart attack, Pam's 33 year old son died following a cardiac arrest secondary to an AMI. He had not been diagnosed with CAD, and

apparently had no previous symptoms. To add to this incredible tragedy, her second son suffered a major heart attack later that year, and he too very nearly lost his life. The heartrending life events of this woman seem difficult to comprehend, and yet this was her reality. Her understanding of heart disease took on a whole new dimension when her own sons were so tragically touched by this same disease. From the midst of her incredible personal life events, this woman had to make sense of her symptoms and make some difficult decisions about seeking care for her very serious cardiac disease. Pam describes one experience she had about four years ago now, three years after the death of her son and eight years after her own heart attack:

*Pam: It was New Year's day, oh several years ago now and I had had this stupid chest pain for I don't know, probably two or three days, and it was about all that I could handle, and I went by cab over to the hospital, yeah because I was ambulatory. I walked in and they go through the routine and because they were absolutely swamped I sat there for 6 or 8 hours, probably closer to 8 hours, somewhere in there, before I was even looked at*

*Researcher: and you were having chest pain?*

*Pam: I was having chest pain. They never even took a blood pressure, they were doing a bit of triaging in the waiting room but I wasn't one of the ones that got triaged, and low and behold about three hours after I got there was three traumas that got there so that set everything back even more. I was in a state of, I don't know what state I was in. I guess I was, emotionally I was a mess. My body was a mess.*

I could sense her uncertainty about whether she was receiving the proper attention in Emergency once she had made the decision to seek treatment. She appeared to be vigilant in her assessment of her symptoms, although she did seem reluctant to always pursue care in the way that she knew she should. She described the motivation in how she would seek treatment as being a triangle whose sides included the assessment of her symptoms, the anticipation of how her story would be received once she got to Emergency, and then concern for the people left behind. In Pam's case, she had her young grandson to consider if she needed to seek treatment.

*Like Barry (her grandson), now when he was younger, now it's not so bad, he's 16 and he can be left alone overnight if necessary and that's not a problem, but when he was 10, 11 and 12 years old and it was bad enough for me to think 'whoops I better go, this is not getting better, it's getting worse, or whatever it was that I perceived at the time. I'd have to phone up a friend. So you're dealing with that as the nurturer, as the breadwinner, as the whatever. All these things go through your head to, you're the provider, you're the nurturer. So you've got to make sure that all of those things are taken care of and you still get put on the back burner. Maybe that's where all these confusions, these mixed messages come from. And it just compounds the pain. I think that's what it does, it just adds to the pain because you are unable to let go and go and get treatment to the extent that perhaps you should. Because any of these crises don't pick a right time to happen. So you're in the throes of something, you're expecting company, you've got a dinner or whatever, and then you've got to rip abruptly and put that aside. I'm not one for putting*

*something aside. You need to finish what you are doing or make sure that someone can pick it up and finish it.*

This passage speaks to the complexity of her life. It was not just her symptoms that she had to consider in seeking care; it was her responsibilities that were left behind as well. She knew only too well about what the course of events could look like should these symptoms be the sign of another heart attack, and how this could potentially complicate her already very complicated life. The struggle in her decision is palpable. Pam's heart disease was just one more issue in a long list of issues that she needed to deal with on her own; the breakup of her own marriage, having to assume custody of her grandson, the difficulties with her daughter, the death of one son, the critical illness of another, and added to this, the pressure of surviving on a very limited income due to her disability.

*One thing I do find with anything, when you present into Emerg with anything, whether it has to do with heart whether it has to do with whatever, that is the only track that they're on. If you have other issues in your life that may or may not have contributed or have anything at all to do with why you're there its not looked at, and that makes you feel out of place, and I guess that in turn rebounds as you're not being heard.*

She speaks of other issues in her life as needing to be considered as well when she was seeking treatment for her heart symptoms. How could she even begin to have the staff of Emergency understand the place that she came from in seeking treatment?

There must have been many things in her life that were too overwhelming for even her

to understand with clarity. Pam reminded me again and again of the complexity of her life during the interview, and much of the interviews were spent in discussing some of the multifarious issues in her life, as if she understood that I needed to understand her life in order to understand the way in which she sought treatment. The direction she took in seeking treatment was not one-dimensional but was tangled in this very intricate and convoluted web of her life. It seemed remarkable to me how she was able to deal with her heart disease with as much lucidity as she did. Her strength in dealing with these horrendous life experiences as well as her heart disease, seemed exceptional to me, and yet her vulnerability remained apparent:

*I think I can pretty well gauge the severity of what I am feeling, and I guess I need to know that I'm sure that I really am having something and it's not a pretend thing, it's for real and I'm not going to waste anybody's time and I'm not going to be laughed at because I boo-booed. When I say boo-boo I mean like, yeah there is something definitely there, it isn't all in my head, it's for real, it's and absolute physical thing and I need to get it attended to, and they're going to look at it and say "yeah, it is something, continue your treatment, we'll change your treatment, your medication," whatever needs to be done, and yeah I did make the right decision and I did go to the hospital or go to the doctor or whatever. I did get it looked after and I'm back on track again.*

The contradiction in her words spoke volumes. "I think I can pretty well gauge the severity of what I am feeling" spoke to me of the knowledge she had of her own body as well as her vigilance in reading her body. Yet there was still part of her that worried

“it was all in her head”, and that she would be “wasting someone’s time”. Twelve years after her initial cardiac event, she was still struggling with how she might approach the health care system. There seemed to be a real reticence to seek treatment without some certainty that her symptoms were legitimate.

*Like is this for real? Is this going to pass? Automatically you take a shot of nitro. You wait. You time it. It's still there. I'd better take another one. Then you go into thinking mode. Well if this doesn't work I'm going to have to present. What happens if the third one works and it's not there when I get to the hospital? Because, not that I would go to the hospital at that point in time. It would depend on how hard the pain is. That determines whether I go in by ambulance or with a friend or in a cab. That's about a half hour window there. If it was absolutely crushing, I'd be in the ambulance right now! But if it's like not crushing and I can still breathe and I'm not really gasping a whole lot for air, I'm not turning gray and I'm not diaphoretic, I'll call a friend.*

The description of the symptoms that would cause her to take immediate and urgent action, such as calling for an ambulance, sounded very much like the symptoms she was having when she had her initial heart attack, the very symptoms that predicated her subsequent cardiac arrest. This account of the way in which she assessed her symptoms and made the decision to seek treatment, sounded like someone who was less likely to seek immediate attention for her symptoms because of her experiences, despite her intimate knowledge of the potential grim consequences of these symptoms. It seemed as though the experiences that she had in seeking care since her heart attack were

increasing her threshold of response to her symptoms. The fear associated with her symptoms did not seem to have diminished, nor had her vigilance in reading her body, but somewhere in her experiences she had learned to be very careful about seeking treatment. Instead of having gained confidence over the years in making decisions about her symptoms and seeking help from the health care system, she seemed to have lost confidence. This again seemed like a contradiction. The implications of this revelation seemed staggering. Would she really wait until she was having absolute crushing chest pain, was gasping for breath, turning grey and becoming diaphoretic before she sought urgent care? These were the symptoms that had previously heralded the narrowly missed termination of her life, and yet now she was willing to wait until she faced these same symptoms before seeking urgent care again. Without the presence of these very grave symptoms she was willing to find transportation to the hospital that could easily delay her access to treatment by an hour or two if not more, time which she could ill afford if her symptoms were signs of cardiac ischemia. This was indeed a powerful statement about the forces that had shaped the way in which she sought care for her heart symptoms. Her symptom experience prior to her AMI was most intricately tied to her previous experiences, as was the way in which she considered seeking treatment. This woman's story continued to build on my understanding of this very important experience.

### **Irene's Story**

**I felt like I was being consumed by something in my chest and I was going to die.**

Irene is a 67-year-old woman whom I first met at a women's support group meeting.

Irene's story was first relayed to me in the pilot interview that was described in the first chapter. The second interview was eighteen months after that initial interview, and Irene's story had become more desperate than ever. When I had last spoken to Irene, she had just completed a cardiac rehabilitation program, and was beginning to feel empowered and in control of her heart disease. Her story now however, was quite different. Over the past year, Irene had been experiencing frightening symptoms that had essentially confined her to her couch. She had been experiencing extreme fatigue, as well as chest pain, dyspnea, and diaphoresis with minimal exertion.

*I had these attacks only they weren't really angina attacks. They were the funniest attacks. They would come on me and I would be very weak and just drenched in perspiration. I felt like I was being consumed by something from my chest and that I was going to die. That's how I felt. I was very scared. It's like more of a real pain instead of a pressure. There's pressure now too but it's more like a stabbing pain and it moves from side to side but mostly on my left side and into my arm and hand. And sometimes when I do a lot of work one day I'm wiped out the next day. I can't do anything. It's just funny. I've got no strength. I can't even talk. It's hard for me to talk. I just lie on the sofa. So I quit all this business of doing all these things in one day. I don't do anything. I'm scared to work." "That has been going on for about one year and it's getting worse and worse.*

In an effort to prevent the onset of these terrifying symptoms she had eliminated all but the most essential activities from her life, and had spent most of her days on the couch. It is difficult to imagine the meager existence endured by this woman struggling

not just to maintain her independence, but to survive the symptoms that threatened to take her life. She had experience in enduring pain through her experience with fibromyalgia, but this was a much more frightening and sinister kind of pain. These were not merely symptoms of pain or discomfort; they were symptoms that continually reminded her of the fragility of her health, and indeed her life.

*I've got fatigue every day. But the very bad fatigue and the angina I could have that every day too if I got off the sofa. I go and get my groceries. I quit driving. I got my insurance again the other day. I said I'm going to start driving again. I was afraid if I went driving I was going to kill somebody. Because something is going to happen to me. Because by the time I get my groceries I'm all done. And by the time I carry them in I'm all done. So I quit doing everything. I quit doing my laundry. I think it's a blessing that I'm living alone. This would be embarrassment. That's how I feel – embarrassed already.*

Irene's symptoms were having a profound impact on her life, not only in the performance of basic activities of daily living, but in the way the fear of the reoccurrence of these symptoms had held her hostage in an impoverished existence for over a year. It was clear how the fear of the recurrence of these symptoms controlled every aspect of her life. The fear of her cardiac symptoms had stopped her from driving because she was afraid of harming someone else when "something happened to her". She was also feeling frustrated and ashamed of her meager existence. I found it interesting that she described feeling 'embarrassed' in living this way, all in an effort to control her debilitating symptoms. I would have thought that her feelings would include

anger or even rage at having to live this way. Why did she not describe these emotions? Did she not feel entitled to become angry at the lack of aggressive management of her symptoms or even some validation?

She had sought treatment from her family physician every week to every two weeks for these symptoms, and her physician had not referred her for any further investigations or another consultation with a cardiologist. When asked how she felt about this she said :

*I felt intimidated. I felt that I've got this problem. I'd better keep my mouth shut – not complain too much. Bear the pain; this is how it has to be because he's not telling me any different. This is how it has to be. I don't want to be any different than other people. I'm going to try to grin and bear it. Maybe I'm just... I'll try my best on my own. I'm going to eat tofu until it comes out of me at all angles. And I'm going to use olive oil and cut out all of the red meat, which I did years ago. And I'm going to walk and I did. I started doing all those things. There is something wrong with this heart of mine but nobody seems to know what it is.*

Irene was feeling intimidated by her physician. My mind flashed back to my last visit with my physician when I had a number of small things I wanted to bring up, but did not when I began to feel self-conscious about all of these little complaints. I sensed that Irene had similar feelings but felt a need to “keep her mouth shut”. She would ‘grin and bear it’ even though these symptoms were terrifying her, and stopping her from leading an active life. She was obviously having difficulty bearing these symptoms however, as they had terrified her enough to motivate her to continue making physician

appointments every week to two weeks for over a year. She had continued to see her physician this frequently despite the fact that her physician had not initiated any further investigation of these symptoms that continued to plague her.

Irene seemed to be trying her best to be a 'nice' patient. Perhaps this attitude, similar to Linda's, was a remnant of the era she grew up in where women were taught to be 'nice' and 'not complain too much'. Was the way in which she was pursuing her health care now also a product of her own socialization as a woman? Did she continue to accept her physician's lack of response to her symptoms because of her deference to his authority and power as the physician, or even perhaps as a man? What was she afraid would happen if she did not keep her mouth shut? Did she perhaps think that she might be rewarded for 'being a good girl' by being heard when her symptoms became really serious?

Irene seemed aware of how her symptoms were being dismissed by her physician, and yet she continued to make appointment after appointment after which she would leave feeling dismissed and invalidated.

Researcher: *When you went to your doctor with these symptoms – you would explain what you were explaining to me just now about how you are feeling – tell me what kind of response you got or what kind of...*

Irene: *Not much of a response. There wasn't any response. He would listen and write out a prescription for me and send me away.*

*...My doctor is very compassionate. He's very compassionate towards me but maybe that's why I'm so loyal to him. He's a good person. But he doesn't know very much.*

Irene's words resonated with the voices of Doris, Linda and Pam who had also had these same kinds of experiences when they had sought care, only to be dismissed. Irene seemed conscious of having her symptoms invalidated by her physician, and yet the way in which she described her symptoms to me gave me some insight into why her physician may have responded in the way that he did. She frequently used words such as "funny", "crazy", or "it's so hard to explain" to describe her symptoms. Clearly there was some perceived inconsistency in her own mind regarding her expectations of what cardiac symptoms should look like and the symptoms that she was having. Perhaps she had been told that her symptoms were not typical for someone with heart disease and she had come to doubt the legitimacy of her symptoms, even though they frightened her enough to continue making weekly or monthly appointments with her physician to have them checked out. Her apparent lack of confidence in the significance and legitimacy of her symptoms came through in the words she used to describe them, and yet her actions spoke of someone who understood how significant these symptoms might be. Again, as the previous participants described, she was caught in a contradiction. Her symptoms were profound and terrifying, and yet how could she not come away with a lack of confidence in her story when these symptoms were not being pursued by her physician?

*Researcher: So in the last year and a half, how many times have you been to see a doctor about these symptoms?*

*Irene: Every week for a long, long time. Every week for months and months and then every two weeks and then a couple times I missed and I visited him every month. But in the mean time, I went to the clinic for a few other things.*

*Researcher: When you were having these symptoms?*

*Irene: No. I didn't want to go with these symptoms any place any more. I was too tired to even explain these symptoms to anybody because I wasn't getting any help. Nobody's helping me. I'm taking the medication, it's not helping me. I felt like throwing all that medication away and just staying with pain killers.*

*...Then I'd say to myself why don't I just die – one thing or the other? Nothing happens I don't die and I don't get better.*

The predominant symptom that seemed to be communicated to Irene's physician in her weekly visits was her profound anxiety. It appeared as if this symptom overshadowed all of her other symptoms, which then may have distorted her physician's interpretation of her symptoms. It appeared by his actions, that it was reassurance that he thought Irene required. It may have been his compassion for Irene that led him to respond to her care seeking in this way. Irene may have communicated an acceptance of this course of action in that she never challenged the way he pursued her symptoms. Both Irene and her physician appeared to be caught in an endless cycle of miscommunication and misinterpretation of her cardiac symptoms, which led not only to more anxiety, but also a lack of proper management of her illness. In the midst of Irene's anxiety, it seemed that she recognized the ineffective communication between herself and her physician. My initial interpretation of Irene's experience was that she

was not being heard. I began to see that it perhaps it was not this simple. The "communication" between Irene and her physician involved so many other things besides an understanding of the words she used to describe her symptoms. It may have been her physician's interpretation of her anxious demeanor as well as his interpretation of the way in which she frantically sought his advice week after week that influenced how he approached her care.

At the time of this second interview with Irene, she was beginning to lose patience with her physician, although it had taken a year and a half for her to arrive at this point. She had not risked explaining her cardiac symptoms to the physicians at the walk in clinic, which she sometimes attended for 'other things'. She had chosen to isolate herself and minimize her daily activities in order to deal with her symptoms rather than insisting on more aggressive management.

Researcher: *So even in this past year you've been seeing your physician weekly or monthly?*

Irene: *Yes. Weekly, sometimes twice a week*

Researcher: *And nothing, he hasn't sent you for...*

Irene: *No.*

Researcher: *Boy. When you start to get these symptoms, these symptoms of angina, tell me the routine you go through to help yourself deal with them*

Irene: *I get scared of course. I take the nitro and lie down and by the time that starts working I at times take an Ativan. But I'm on Ativan quite regularly. I take it two or three times a day. In this past year I've increased my Tylenol and my Ativan.*

*I hate that but what can I do? I'm not getting any help. Now I'm going to need help to get off these drugs because I'm addicted.*

Researcher: *So that worries you too?*

Irene: *That worries me. I feel like I'm a drug addict. I feel that that is what is wrong with me is that I'm not strong enough. I have to be strong. I get up in the morning and I feel so lousy. I get up in the morning with a good feeling that today it is going to be a good day. I'm satisfied with my life, with what I've got, which is very little. But I'm blessed with what I've got. I'm a happy person. I love people. I like to go out for coffee, just walking. I like to dress up. There are many times, this has been going on many times, I've been checking myself. Instead of writing it down it's up here in my brain. I have a bath and I do up my hair, which is very little. It's straight. I just put in a few curls with a curling iron and then I sit down and watch some TV, try to rest. I dress up and I'm too tired to go. I'm all consumed like I've been run over by a truck. So I don't go and this happens. I take my clothes off and I get into my pajamas or whatever and I don't even feel sorry for myself anymore. I just lie down on the sofa and have a little snooze if I could. With the drugs that I'm taking I could snooze – sort of – half snoozing- or watch some television. That's my life. I've isolated myself, Heather, to the point of no return. This isn't right and there's nothing I can do. I don't even want to live this way. I've been telling my daughter...I guess I'm too much of a coward to commit suicide. I told her, she said don't die Mommy, you'll be fine. I told her yesterday we talked and I told her don't worry if I die. You be very thankful if I die. Be very thankful for*

*me because I'll be an angel on your shoulder and I'll always be with you but I won't suffer any more. I told her that. She was crying. She's going to school in Edmonton, taking Pharmacy and it's very hard on her. So hard on her. I try not to, because she can't do anything about it. She tells me Mom you are not explaining your symptoms the right way to the doctor*

Researcher: *Do you think that's what it is?*

Irene: *I don't know*

Researcher: *How do you make sense of that?*

Irene: *I don't know any more. Maybe I don't explain because my symptoms are so crazy. They are different. I talk to women you know and how I feel with the heart to heart society. They haven't felt the pain or the agony that I'm feeling ever, even when they had their heart attacks.*

Irene's poignant story spoke of frustration, weariness, fear and a sense of abandonment by the health care system. I asked her why she had not considered seeking the advice of another physician and she reported not wanting to 'disappoint' her old physician.

Researcher: *So when you say you are afraid of disappointing Dr. X, are you more afraid of that than of living the kind of life that you are right now? Of avoiding any kind of activity to avoid angina? Are you more intimidated by his reaction than having to deal with the kinds of symptoms that you are having?*

Irene: *It seems like it. In the scheme of things it seems that way. But I don't want to, I'm not afraid of him that much. It's just that I feel that he's a doctor and he*

*should know. He's above me. He knows, sort of why rock the boat. Who else is going to help me? I'll tell you. I don't want to say it to you. Nobody might ever want to help me. I might never be able to get a doctor.*

Researcher: *You made a comment yesterday or this morning when I spoke to you on the phone. You said that this isolation that you are feeling now because you are trying to control your symptoms and you said you are starting to feel depressed. And the isolation you thought was mostly because of the health care system. Tell me about that*

Irene: *The isolation?*

Researcher: *Yes and how you feel the health care system is...*

Irene: *It's letting me down. Because there is no recourse. There is no light at the end of the tunnel. There's no help. And I feel and I'm doing what I feel – that we have to be our own care-givers unfortunately. This is the way it is right now. If things don't change it's going to get worse and worse.*

Irene again expressed a sense of intimidation of the health care system, not just her physician. “He’s the doctor, he should know, He’s above me” speaks of her knowledge of their power differential, as well as a reluctance to believe that her physician would give her anything except the best of care. Her words sounded very reminiscent of the words that Linda had used to describe her physician’s care. Again I wondered at the absence of anger in her words. She had described a resignation to her present state many times in the interview, and indeed her reluctance to seek the advice of another health care provider demonstrated this same kind of thinking. She was feeling isolated and

abandoned. She had considered suicide, but had not considered seeking out more aggressive care. These were the words of a woman who felt helpless to change her situation without “rocking the boat” or “complaining too much”.

I was interested to understand her reasoning when she had sought help again and again, when she was looking for the care that had seemed to evade her for so long. I asked her what her overriding sense was when she thought about seeking care for herself:

Irene: *Intimidation. Just going through the motions. Going to the doctor but before I even go I know it's pretty scary. If it wasn't so scary...*

Researcher: *But you keep going back because there is a hope?*

Irene: *There is a hope – yes. But there's really no help*

Researcher: *But you are motivated enough to keep going back to him. You are probably worried. Is that what's making you...*

Irene: *Sure I'm worried.*

Researcher: *And your experiences with your children – thinking back. You had four kids that you raised on your own. When you took your child to the doctor and nothing was happening, how would you handle that?*

Irene: *I'd take him to another doctor.*

Researcher: *So how is that different? How can you explain that that you would be willing to do that for your child but not for yourself?*

Irene: *Because my child was the most precious thing to me. He or she was my child. It was important. It was their life. It was my responsibility and my love as a mother. What else?*

Researcher: *Do you feel that you are not entitled to the same kind of care that you looked for for your children?*

Irene: *Yes. I feel I'm entitled. But where am I going to get it?*

Researcher: *Help me to understand that. Is it because of how you are feeling physically now? Is that the biggest part of why you are not pursuing this more do you think?*

Irene: *Yes it is. If I felt better I'd have gone (to Emergency). But if you feel better I guess you don't have to go. If I felt better I would sit on the bus or take a cab or make appointments. But I don't have any good days during the week . If I have a good day or half day – in order to still live by myself I have to do things. I'm not rich that I can hire and get maids and get everything done. I want to be independent. I always was all my life and responsible. But I'm kind of losing that now because of my health. I sure don't want to give in to it – not yet.*

In the year and a half that Irene had been having these debilitating symptoms, she had not once sought care at the Emergency department. She had plenty of experience in seeking care there as described in the first chapter, and now felt that she was not strong enough physically to make this kind of effort.

I had talked to Irene on the phone the day before our next interview, when she was about to see her physician yet again. She described her symptoms to me and I indicated

that indeed these were symptoms that needed to be investigated. She described how she approached her physician this time:

*I told my doctor that this is an emergency. I have to see a cardiologist and I want an angiogram. I want a procedure that is going to check my heart and see what damage is in there because in two years with the way I've been feeling – nothing has helped – it's getting worse. I want to live. I really want to live for a while.*

I believe our phone conversation had given her the courage to insist on seeing a cardiologist. Her physician had done another ECG and told her to return the following week. Three days after this second interview, she went to the Emergency department, had insisted on being seen by a cardiologist, and was subsequently admitted to hospital. There she was given a Thallium scan as well as an echocardiogram to assess her heart function and any potential ischemia. Irene's medications were changed by the attending cardiologist, and she was released from hospital after two days, feeling much improved. The medication she had been receiving to control her arrhythmias were having a negative effect on her heart function, causing her worsening symptoms. She had been started on this medication two years previously by the attending cardiologist when she was originally admitted to hospital following the event described in chapter one. A simple referral to a cardiologist could have easily corrected this situation, and yet she had lived with debilitating symptoms for all this time, despite her vigilance in seeking care from her physician. The anguish this woman had endured for a year and a half, not to mention the risk to her health, was staggering. In a conversation some time after the

interview, Irene was actively seeking a new physician. My understanding of this experience was continuing to grow.

### **Trish's Story**

#### **I had no elephant sitting on my chest.**

Trish is a 70-year-old woman whom I also met through the Heart to Heart Women's Support Group. Early into my first interview with Trish, I began to sense that this woman's story was quite different from the stories I had heard thus far. Trish had first gone to her physician with some very vague symptoms in December of 2000. She went to him with an "awareness" that something was different. She had a couple of episodes of heaviness in her upper arms along with fatigue and nausea that fall, and in December she made the decision to have this checked out by her physician. Her mother had died of heart failure and her father had a heart attack when he was 55 years old, which contributed to her decision to seek treatment for these symptoms. Her family physician did an ECG, which was normal, but still immediately referred her to a cardiologist. By mid-January, 2000 she had undergone a stress test, thallium scan, and an echocardiogram. The results of all of these tests were normal, and she was given a clean bill of health from the cardiologist. I was immediately struck with the significance of how quickly Trish had undergone these diagnostic tests after first reporting these symptoms. This was not the usual course of events, in my experience, especially since her symptoms were really quite benign, and had only occurred a couple of times over the past 2 to 3 months. In my mind this was very aggressive pursuit of her symptoms.

Was it just that she happened to have a very vigilant family physician and cardiologist, or was there more to her experience?

She spent some time describing the course of events surrounding her husband's death several years ago. It had been five years from her husband's initial diagnosis of colorectal cancer to his death. A few months before his death, his attending oncologist had moved away from Calgary. Trish did not have her own family physician, and a pediatrician up until this point had seen her son. She described how difficult it was finding a family physician who was willing to take on a terminal patient. Her oncologist suggested the name of one family physician who was not taking patients anymore, but who recently had lost one of his patients. The oncologist had phoned him and suggested to him that because he had just lost one patient, he should have room for another one. Trish and the new physician arranged to meet at the hospital where she 'interviewed' him. She remembered him asking after the interview "will I do?" This was extremely interesting to me. She obviously felt a sense of entitlement to check out this physician, to ensure that he was going to meet their needs. This seemed quite different from the experiences of my previous participants who seemed to put up with inattentive care for so many years before switching to another doctor.

Within one month of seeing the oncologist, Trish's son began having hip pain. Her son was 22 at this time and was in Edmonton attending medical school. It turned out that he had a benign cancer that was removed in June of that year. He underwent numerous diagnostic tests that winter and spring, and it was not until after the surgery in June that the threat of malignancy was removed. Trish described this time as being very

traumatic and her thoughts were totally consumed with concern for her son. I asked her if she had any cardiac symptoms at this time, and she denied having any. She said that after the cardiologist told her she was fine, she really was fine. She did however say that she did not have any “bad” symptoms during this time, which led me to believe that she did indeed have ‘some’ symptoms. She described needing to be fine for her son.

*That was a very stressful spring because he had a biopsy, which was inconclusive. So when he went into surgery in June we did not know if it was malignant or not. The stress did not help matters much. They sent the results to the Mayo clinic and it took seven weeks until we found out that it was a benign tumour. He finished his year successfully - I don't know how because he was back and forth here. We decided our GP was our advocate and was orchestrating everything.. So that was the problem in my life that spring, which didn't help with my situation.*

Six months after her visit to the cardiologist, and a few days after receiving the good news about her son's tumor, Trish's symptoms escalated.

*My grandkids were coming the next day to stay. I was all set and ready for them and then I had this great bout of nausea. I was so sick. I did not have a history of heart.*

At the end of July one night, Trish woke up with a heaviness in both of her upper arms with severe nausea and abdominal pain. She endured this pain for most of the night before seeking the assistance of her brother to take her to the Emergency department the next morning around ten o'clock. She described taking ginger ale in an attempt to relieve her symptoms, without success. She denied thinking her symptoms

were cardiac, saying that she had “no elephant sitting on my chest.” This suggested to me that she was including the possibility of cardiac origin in her assessment of these symptoms. She also took an Aspirin at one point in the night, as she had read that this was what you should do in the event of a heart attack. She was obviously considering the possibility that this might be a heart attack, but her recent clean bill of health from the cardiologist stopped her from seeking immediate treatment. Within a few minutes of calling her brother, she was on her way to the hospital emergency department. At this point she had no heaviness in her arms, just nausea and abdominal pain. She was taken into the department immediately and placed on a cardiac monitor. This again was somewhat surprising to me. She had just undergone several cardiac investigations, all with normal findings. She now presented with arguably vague symptoms that were not classic cardiac symptoms, and yet she was immediately investigated for a cardiac origin of these symptoms. This is the way Emergency care should look, but in my experience, this is not usually the case. I wondered what made the difference in her care.

She was eventually admitted to CCU, had an angiogram, and was found to require open heart surgery which she subsequently had two weeks later after she had recovered from what they found to be an acute anterior myocardial infarction. Her recovery from surgery and her AMI was unremarkable. She enrolled in a cardiac rehabilitation program the following January. During a routine treadmill test there, she was found to have cardiac ischemia again. She was sent for another thallium scan which revealed recurrent cardiac ischemia, and she was booked for another angiogram in 4 months. Trish called her cardiac surgeon to discuss this course of events, and suggested that her

date for angiography be moved up if she was indeed having recurrent ischemia. The surgeon called the cardiac catheterization lab and was able to move up her date from 4 months later to 2 months later. A new 80% lesion was found on angiography, and it was suggested to her by the angiographer as well as her cardiac surgeon that she required another coronary artery bypass surgery. This part of her story was again fascinating to me, and was again very telling about the kind of care that typified her experience. She had her angiogram, and the femoral catheter had been removed from her groin. Under normal circumstances, the femoral catheter used for angiography is left in if there is a plan to do immediate angioplasty that day. This is done to avoid another femoral arterial stab and catheterization. Under normal circumstances, if the femoral catheter has been removed, it would only be reinserted if the patient develops acute ischemia requiring immediate intervention. Trish had completed her angiography and the femoral catheter had been removed, since both the cardiologist and the cardiac surgeon felt that she required further surgery at a later date. These physicians came to her bedside to discuss the option of further open heart surgery.

*I was on the table in there and Dr. X said 'You know we're going to have to do more surgery' and I said 'I don't think so!' You know you're lying on your hands just about dying and I said take another look and he said well, let's see if Dr. Y is available. He was and I said 'come on you guys, let's try angioplasty.' So they sent me back because they had already taken the catheter out – they sent me back to the room, and I waited for three hours and then went back and had angioplasty.*

The cardiologist who performed the angiogram, the angioplasty cardiologist, as well as her cardiac surgeon were all present. Again, the description of this scene was very interesting. In my experience, it is very rare to have all of these physicians gather at a bedside at the same time unless a patient is crashing. In my experience, it is even more unusual for the patient to change the mind of two cardiologists who have decided on a course of action. In this case, both the surgeon and the cardiologist who performed the angiogram agreed that further surgery was appropriate. Trish, however, was able to convince them to do an immediate angioplasty, and not leave her waiting for treatment.

*I felt so helpless, I said 'don't you dare put me at the bottom of the list'. I said 'come on guys, you're going to have a neurotic woman'. The person who did the angioplasty, and Dr. X came by and they called Dr. Y and there was a resident or two, I was surrounded. I told them this isn't fair, I said 'come on now you guys, just put it back in and let's do it'. They were very gracious and so on. I gave them an offer they couldn't resist.*

Trish got her angioplasty within a few hours of her angiogram. How many women in her position would have had the courage to speak this confidently to a group of cardiac specialists? What were the circumstances of this woman's experiences that afforded her such prompt treatment from the very onset of her symptoms? I spent some time discussing her success in getting treatment in the second interview. She acknowledged that her own vigilance had a great deal to do with her prompt treatment. She described her manner with physicians as being "quietly tenacious". I wondered if she ever expected to have to put up much of a fight in order to receive this kind of care.

*Part of it is my expectations, they need to know that they have a commitment to me and I will honor their commitment. I grant you - it's my expectations. I say 'do I check with the receptionist now for that appointment?' He says 'no, she'll call you.' I say, 'within the week?' I try not to say will she call me in two days. But within the week I'll say 'OK, I'll be sitting by the phone.' I chuckle, but I need to know for my own mental health. But they also need to know that they have a commitment to me, and I will be there to honor it.*

This woman was not afraid to advocate for herself. She had demonstrated her expectations of excellent care in the way she handled her husband's as well as her son's illness, as when she had "interviewed" her new family physician. She described having confidence in her family physician to listen to her as well as orchestrate plans in the health care system.

*Trish: I have been very fortunate. I think our family doctor has been the key. The only one really traumatic time has been when we were trying to find my husband a doctor, but I haven't had that.*

*Researcher: So you've been pretty confident in the care that you've been given?*

*Trish: Yes, and that I'll be heard. ...They also know that my son is a medical student and that they have to send me a copy of the report or I tell them to talk really slowly so I can write down everything they say, so they send me a copy of the report. I have no problem asking for those things. It's my body and I really need to pass it on to my son. I discovered that I could certainly advocate for my husband and for my son. I was a real lion there. I don't feel that I've*

*ever had any serious problems up until the last couple of years and now I have a big fat file. But no, I never would have advocated for myself before. What I have found out in life is if you don't ask, you're not going to find out. I'm willing to stick my neck out. Sometimes they say no but not often. If I don't know what I'm doing I ask for suggestions, and in turn I follow their rules and their suggestions.*

I was reminded that the previous participants had also persevered in seeking treatment for their symptoms, but their outcomes in terms of immediate care had not been as successful. Perhaps it was Trish's direct manner of communicating with the physicians. Certainly all of the experiences she had had in seeking treatment for her husband's and son's critical illnesses had contributed to her confidence in not only negotiating the health care system, but to her confidence in collaborating with health care providers in negotiating a plan for her care. It struck me that perhaps this was indeed what had set her experiences apart from the other participants I had interviewed. I had the sense that Trish felt that she was part of the 'team'. Other participants had repeatedly sought treatment for symptoms, but Trish had really taken ownership of the direction of her care, and the health care providers, in particular the physicians she was involved with, who seemed to have a sense of this as well. She was able to maintain her poise with the physicians, but underneath this graciousness was a simmering strength of character, which I certainly did not miss in our interviews, and one which I'm sure was not lost on the physicians who cared for her. She said that she was willing to stick her neck out. I wondered about the meaning of this statement. I wondered if her confidence

in her own intelligence, in her level of education, in her social standing that was comparable to the physicians', had all contributed to this willingness to "stick her neck out". I wondered if her experience with advocating for her husband as well as her son had given her strength to pursue her options. She said that she felt as if she would not have advocated for herself in the same way years ago prior to these experiences with her husband and son's illnesses. She was also now a single parent, and she wanted to be here for her son until he was "settled". She described feeling that her son had enough trauma. I had the sense that her motivation to be so vigilant in pursuing her own treatment was her son's well being more than her own. I could imagine that her sense of protecting her son amplified many fold since he was diagnosed with bone cancer.

Trish made an interesting comment in the second interview, again about her success in finding treatment. She said that her experiences with her husband's cancer, her son's cancer, her mother's Alzheimers' disease, all came together to help her meet her own health care needs when she required them. Did all of these experiences lead her to be able to advocate so successfully for herself? Was it knowledge of how the health care system worked that allowed her to manipulate the course of her care? Did she learn how to communicate with physicians and the healthcare team to get the best results? Did all of these experiences teach her about the fragility of health and the need to assertive in maintaining it?

Her strong sense of entitlement to excellent care rang through in both of the interviews I conducted with her. Was this sense of entitlement a product of the excellent care that she had received from her family physician, and had become a standard to

which she was accustomed? I had the strong sense that she expected nothing less, and that those around her were very clear about this.

Trish's clarity in describing her symptoms and her vigilance in pursuing treatment for these symptoms was similar in many ways to the previous participants I had interviewed. It seemed as though the way that she communicated her symptoms, as well as her expectations of the healthcare providers set her apart from the previous participants. She described, "not wanting to muddy the waters with emotional stuff." She felt she would lose credibility if she became emotional, although she admitted to being very anxious about her health at times.

*Trish: Once in a while (I became emotional) but usually I cried alone. Oh you cry your tears- because I knew I just wanted to be really clear and not muddy the waters with emotional stuff. I could go to the car after and cry but...*

*Researcher: That's another thing that tends to happen it seems with women, they go to the doctor and they're describing their symptoms and they become emotional and somehow that negates...*

*Trish: Yes it does, your credibility. It shouldn't – but it does.*

*Researcher: So the fact that you were able to maintain your composure...*

*Trish: I thought 'God help me- just keep it together until I get out of here.' So how I do it is I try to process it ahead of time and I do write down my questions. Because I get as anxious as anybody in the situation and it's a new vocabulary and a new experience. I don't know what to ask. And Dr. X, my cardiologist, he always laughs, and I say you know I've just got a few things,*

*And at the end he'll say, "now look at your list have you covered them all? And I laugh. He's so fine, and he's the one that when I had bad news in the summer he said, 'you know, we have to look at this further. I'm going to get this lined up for you.' I'd had this echo in the last month and he had it arranged within two weeks. I just really ... when they talk about the health system being so awful, I just feel so grateful that everything has gone so smoothly.*

This ability to control the emotional reactions to her symptoms set her apart from the other women whom I had interviewed. Doris had eventually learned, over the course of several years of seeking treatment, to leave out descriptions of the emotional reaction she had to her symptoms, and had eventually successfully found a physician who heard her and pursued treatment. Trish however, seemed to have an innate sense about this. It appeared as though her success in finding treatment was in some way related to the way she had been 'heard' by every physician she had come into contact with since her symptoms started. Again I wondered about this.

There seemed to be something else that was unique to the way in which Trish sought care for her symptoms as compared to the other participants I had interviewed. All of the other participants had in their own way attempted to control the direction of their care, either by repeated visits to their family physicians or the Emergency department, until they were able to find the treatment that they all had sought. Trish however, seemed to be able to find the secret entrance to the health care system, again and again. She was able to make the system work for her at every turn. She had

described her physicians as being ‘very gracious’ and yet the description of the way in which she took ownership of her situation belied an incredible strength of character. Trish did not appear to be intimidated by her physicians or the sometimes-convoluted health care system. The confidence she had in herself as a person, as well as the trust she had in her family physician to help her negotiate the health care system seemed to empower her to seek out and expect excellent and immediate care. I continued to have the strong sense that her success in finding treatment was not just a happy coincidence. Many things had come together to create this experience.

My understanding of the way in which women seek treatment continued to grow as I thought about the similarities and differences in the participants’ experiences. These participants’ stories were rich and compelling. My challenge now was to find a way to articulate the understandings of this experience that had emerged from these interviews, to do justice to these women’s stories. I felt an enormous pressure to ensure that these women’s stories were heard in a meaningful way. At the onset of this research I had felt that I was somehow taking advantage of these women’s stories in order to complete this research. This sense had been with me from the onset, as I developed my proposal, as I sent out invitations to participate, and even up until the point I arrived at their homes to begin the interviews. I was concerned about taking advantage of their respect and fondness for me as the nurse facilitator in their support group. I was relieved to discover that these participants truly wanted their stories to be heard. They felt privileged to share their stories, and their earnest involvement in the interviewing process was reassuring and heartwarming. My initial misgivings about taking advantage of their

stories was replaced with a genuine desire to create new understandings from their experiences that they had so graciously shared with me.

## **CHAPTER FIVE**

### **Their Stories Were Telling**

#### **Understanding is in the Interpretation, Which is in the Writing**

The stories of the participants' experiences in seeking treatment for their symptoms of heart disease were compelling. With each interview, and as I listened again and again to the transcripts, as I read and reread the transcripts, a rich landscape of experiences formed in my mind. Each interview seemed to allow me to look at this landscape from a new vantage point. At times I would catch myself looking too closely at one aspect of this image, preventing me from appreciating how each detail of the picture worked to create this image as a whole. I often needed to step back to allow the landscape to come into view.

It was more difficult than I first realized to let go of the picture I had imagined in my mind's eye before starting this research, and to let myself see with new eyes, to look at this experience as if for the first time. My nursing career in cardiology had given me countless opportunities to listen to the stories of women who had sought care for their heart disease. I was able to have a perspective in hearing their stories that I would not have had without this experience. My nursing career had also served to solidify my preconceptions about this experience. My familiarity and comfort with the words they used to describe their experiences could easily lull me into an artificial confidence in my ability to truly hear their words. Many times it seemed as though my experience was working against me in my quest to understand this experience. The lens I had come to know over twenty years of nursing was a powerful one and would not easily be removed.

My vision would need to adjust to accommodate a new perspective. My hope was to articulate this new perspective in a way that would allow the reader of my research to catch a glimmer of new possibilities in understanding this very complex experience.

I was surprised to find how difficult the writing was. I had come to know the transcripts of the interviews so intimately as to be able to recite certain portions of each interview. I was able find a given passage in a given interview from memory. I was convinced I understood what stood out for me in these interviews and that I would have no difficulty articulating my interpretations. I started this chapter again and again, only to find that what I was writing did not quite ring true with my beginning understandings from the interviews. It was in the writing that my understanding took shape. To articulate my thoughts was more difficult than I first suspected because it was in the writing that my interpretations were challenged to achieve congruence with what I had comprehended on a sort of instinctive level during and after the interviews. What I learned was that it was the writing that was my interpretation that was my understanding.

### **When does the experience begin?**

Analysis of the text gathered during the interviews with these five women quickly began to reveal some important insights into the question I had asked: “What are the experiences of women seeking treatment for symptoms of heart disease?” The notion of “experiences” in itself seemed to insinuate that there was a beginning, an end, with a series of events in between that formed this experience, that is the experience of having the symptoms as well as the experience in seeking treatment. What I began to see was

that these experiences were neither linear nor sequential. It would become impossible to delineate where their experiences began and where they ended.

Early in the interviewing process I found myself asking questions such as “when did your symptoms start?” and “how long did you have your symptoms before seeking treatment?” These were questions that effortlessly rolled off my tongue, questions that I had asked hundreds of times in my career. These were questions that I had come to expect a clear and concise answer in order to document an ‘accurate’ history. The answers I received were neither clear nor concise.

Previous events in their care seeking had profoundly shaped their subsequent experiences and they were not able to separate the acute event from their previous experiences. Experiences from years before became an inextricable part of their acute experiences in seeking treatment. It was difficult for them to describe how they had handled their current care seeking experiences without qualifying their answers with a description of all of their other care seeking experiences. The participants’ experiences in seeking treatment for their acute symptoms were not so much ‘an event’ but something like an act in play of their lives. To capture the meaning and nuances of the plot, I would need to look at these “plays” in their entirety. I would need to understand how the supporting characters and the setting all worked together to create these care seeking experiences for each of the participants. The participants’ experiences in seeking care for heart symptoms required a perspective of many years.

Pam’s experiences in seeking treatment for her heart disease began at least two years prior to her massive myocardial infarction. Her experience in seeking care for her

symptoms of an AMI was not an acute crisis, but a gradual crisis, which culminated in the near termination of her life. The frustrating experiences she had in seeking treatment for ongoing cardiac symptoms after her AMI influenced her subsequent care seeking as well. Her incredible personal circumstances also had a profound effect on the way in which she sought care for her cardiac symptoms.

Linda's symptoms of chest pain had been described to her physician over the course of ten years, with all of these symptoms being attributed to her diabetes. The way in which she thought about her heart symptoms was most certainly shaped by her physician's assessment and response to her symptoms over all of those years. Her reaction to her physicians' lack of response to her symptoms was in itself that product of years of care seeking for herself as well as her family members. The experiences she had in seeking care for her symptoms spanned many years, and included countless physicians' appointments. To look at her experiences in isolation would be to discount all of the forces and experiences that had guided her to this point, and which now influenced the way in which her experiences unfolded.

Doris, whose symptoms began as a teenager, spent over twenty years seeking treatment for her heart symptoms before a diagnosis was made. The countless times she had experienced her symptoms, the countless times she had struggled with herself to choose the proper course of action, and the countless times that her cardiac symptoms had been dismissed, became part of the fabric of her life. These experiences not only created a backdrop to her life events, they served to constitute who she was. Her very essence was shaped by the innumerable sessions with physicians, psychologists and

psychiatrists over the course of those twenty years. No doubt her decision to become a psychologist was influenced by these experiences. To attempt to delineate her experience in seeking treatment would be impossible. To separate her experience in seeking treatment from other aspects of her life and from her previous experiences would be to destroy the very thing I was trying to understand.

Irene's experience was no less tangled in the labyrinth that was her life. Her experience of living with an abusive husband for many years, her experience with struggling to raise four children on her own, her experiences with living with fibromyalgia, were only some of the life events that colored her experience in seeking treatment for her heart symptoms. Life had taught her many things, and the knowledge that she had acquired became part of her and shaped the way her experiences now unfolded.

Trish's past experiences and the way they had constituted the person she had become as well as the way she interacted in the world, seemed to shape and pull the experiences she now had in seeking treatment for her heart symptoms. She had been an independent professional woman for many years before she married. Her husband was a successful businessman, offering her financial independence and a certain social stature. Her assertiveness in seeking treatment for her heart symptoms and the subsequent aggressive management of her heart disease was not just a happy coincidence. Many circumstances served to create the possibility for her experience to unfold in this way. Her experiences also could not be understood in isolation.

The significance of the question at hand remains however, and our attempts to understand this very important experience should not be undermined by the threat of oversimplifying (or perhaps overstating) dimensions of this experience. Our vigilance in striving for new ways to view and to approach the care of women with heart disease should be undeterred by the complexity of the experience.

This attempt to shed light on the complexity of human experience is by no means novel, and could easily be seen as self-evident. So what is the significance of this discussion regarding this notion of experience? How does this new perspective change the way in which we understand the experience in question, and the way in which we understand the text gathered in this research? What possibilities do these understandings create for clinical practice with women experiencing heart disease? Perhaps this work reminds us to attend to the meanings that can be created with these women as they interpret their experiences.

Perhaps the greatest significance might be to allow ourselves to look at the insights discussed here, and to hold them tentatively. We should strive to have a reverence for the fathomless nature of possibilities that constitute experience and the way that we understand it. It is possibilities for understanding the experience in question that I have attempted to evoke through this research as well as possibilities for practice in the care of women experiencing heart disease. With this perspective in mind, I will respectfully attempt to call to mind some understandings in response to this very important and complex question: “What are the experiences of women seeking treatment for symptoms of heart disease?”

### **The Quest To Seek Treatment**

Early in my conversations with the participants, I was struck with the way that participants felt compelled to discuss previous health care seeking experiences to clarify the experiences they now had in seeking treatment for their heart symptoms. All of the participants discussed at length the way in which they had addressed their heart symptoms in the past. Many stories of care seeking experiences for themselves as well as family members emerged in our conversations. As I listened I began to see that these women had learned about seeking care in the health care system from all of their past experiences. I could sense that much of what they had learned was intricately tied to other experiences in their lives.

These women's stories were rich, and offered many new possibilities in understanding this very complex experience. Three distinct themes, which influenced the way in which the participants sought care for their heart symptoms, revealed themselves in this research, and these were:

- Understanding their heart symptoms
- Avoiding humiliation
- Interacting with health care providers

### **The Quest to Understand Their Heart Symptoms**

There has been a great deal of attention paid in the literature to the notion of recognition of cardiac symptoms and how this recognition might influence treatment seeking behavior, as described in chapter two. There does not appear to be clear evidence in the literature as to how women's recognition of cardiac symptoms affects health care

seeking behavior. In this study, it became apparent that it was not simply a matter of recognizing their cardiac symptoms, it was how the participants understood their symptoms that influenced the experiences they had in seeking care.

In this study, all of the participants were able to recognize their symptoms as being significant enough to seek medical attention, although none of them were able to attribute their symptoms to a cardiac origin initially. None of the participants except Trish had undergone immediate cardiac investigations in response to their symptoms. Four of the participants had gone several years without investigations, which would diagnose their cardiac conditions. All of the participants except Trish had persisted in seeking care for their symptoms despite being initially told that their symptoms were non-cardiac in origin. Their symptoms were attributed to many things including anxiety, diabetes, pneumonia, costochondritis, fibromyalgia, and pericarditis. Trish was the only one who had undergone immediate cardiac investigations in response to her symptoms, although she had not undergone coronary angiography. Ironically, Trish was not diagnosed as having CAD and went on to have a large AMI later in the year despite this aggressive investigation initially. Trish's understanding of her symptoms in the period after her diagnostic tests and before her AMI had been influenced by the cardiologist's interpretation of her investigations.

It seemed as though these women had been taught how to think about and assess their symptoms as a result of the care seeking they had engaged in with their physicians as well as other health care providers they encountered in their care seeking experiences. It wasn't so much that they did not recognize their symptoms as being cardiac as it was

their deference to the expert opinions of their physicians. Although they had varying degrees of acceptance of these opinions, the experiences of all of these women in seeking care for their heart symptoms could be seen to be closely tied to the way in which they had learned to view their symptoms. For all of the participants, their understanding of their heart symptoms was shaped by their primary physician encounters as well as encounters they had in seeking care in Emergency.

The participants described their symptoms as “weird”, “crazy”, and “different”, as though their symptoms were not what they had expected to experience with cardiac disease. Other phrases such as “I had no elephant sitting on my chest”, and “it wasn’t a *real* pain”, and “it wasn’t a *crushing* pain” demonstrated their preconceptions regarding what cardiac symptoms should look like. It seemed as though these preconceptions however, had been profoundly influenced by the very people they relied on to treat their symptoms, and this is what had constrained them from acquiring the treatment and investigations they needed. Their preconceptions regarding heart symptoms had also been influenced by information they had obtained through the media, the internet, and other reading materials they had accessed in an attempt to make sense of their symptoms. This finding is similar to the findings of other authors who found that beliefs about the seriousness of symptoms of AMI influenced evaluation and interpretation of symptoms (Dempsey et al., 1995; Horne, James, Petrie, Weinman, & Vincent, 2000; Rosenfeld et al., 2000; Ruston et al., 1998). None of the participants reported that discussion of their symptoms with friends or family had a significant impact on their decision to seek care as

has been reported in other studies (Alonzo & Reynolds, 1998; Dempsey et al., 1995; Penque et al., 1998).

The interactions these women had with health care providers in seeking treatment for their symptoms had a profound effect on the way they thought about their symptoms as well as the way in which their disease was managed. For Pam and Irene, it was only after a life threatening cardiac event that their symptoms were investigated. Doris and Linda had both sought treatment over the span of many years and it was only after they found a physician who would initiate cardiac investigations that their disease was discovered and managed. All of these women had significant cardiac disease for which they had sought treatment again and again before finding success. The conflicting messages that the participants had received in response to their symptoms over the years had left them confused, anxious, and tentative to continue pursuing treatment. The way in which they had learned to understand their symptoms, the meanings they had attached to their symptom experience, and the manner in which they responded to their symptoms had put their health at risk by delaying diagnosis and treatment of their cardiac disease.

These women seemed to have fallen prey to the powerful medical discourses that exist regarding illness and symptom perception. A traditional theme in medical discourse is that only medical professionals have the expertise to describe and validate experiences of the body. If symptoms cannot be verified through direct observation or if a cause of the symptoms cannot be found through objectively observable means, then patients are often told “there is nothing wrong with you”. Physicians as well as nurses in this way become the authority on the reality of women’s experiences of their own bodies. This has been

described as the cognitive authority of medicine (Wendell, 1993), and this authority is almost universally accepted without question. The person whose bodily experience is different from medical descriptions of their condition is invalidated by medical professionals who possess this 'knowledge'. Experiential and embodied knowledge is not valued in that it is 'soft' evidence, and not in keeping with traditional scientific evidence which has survived rigorous scientific scrutiny to assume its place as 'true' knowledge.

Women's ways of knowing about their health, described by Lewis and Bernstein (1996) as being intuition, sensing, and skilled pattern recognition, have been devalued by the medical system as well as nursing. The very reason the women in this study sought care for their symptoms in the first place was out of their interpretation of their bodily experiences, but it seems that this is where attention to this type of knowledge ended. Women in this study understood that the physicians and nurses they sought care from had more 'cognitive authority' regarding their symptoms as well as their own bodily experiences. This perhaps led to a loss of confidence in their own ways of knowing as well as an undermining of the relationship of their symptoms to an identifiable cardiac cause as seen by health professionals. The participants' symptom experiences lasted many years in some cases without any validation by the health professionals from whom they sought care. It occurred to me that the women in this study may have sought out the support group to deal with their heart disease in order to fill the gap between their own understandings of their disease and the understandings imposed upon them by traditional medical discourses.

Benner and Wrubel (1989) describe how even the language we use to explain symptoms comes from biomedical science and that the meaning of the symptoms and an understanding of the embodied nature of this experience is lost with a reliance on this type of discourse. Doris's description of the need to remain very 'factual' in her communication with physicians, and attend to things such as when the symptoms started, how long they lasted, and specific descriptions of the nature of the pain and its location, demonstrated her understanding of the need to speak in a language that medical professionals would understand. These were words that the health professionals could 'hear', that were in keeping with the language they used in medical discourses.

Comments from the participants such as "*I learned to ignore whatever popped up*" and "*I better keep my mouth shut and not complain too much, bear the pain because this is how it has to be because he's not telling me any different*" demonstrated how the voices of these women were silenced regarding their embodied knowledge of their disease. These women had access to a particular knowledge that comes only from access to the experiences of symptoms. This knowledge had not been legitimized by the health professionals they sought care from however, and they had learned to suppress their understandings.

This finding is of particular significance for health care providers who encounter women seeking treatment for their cardiac symptoms at the entry points to the health care system such as physician's offices and Emergency departments. Physicians and nurses need to try to access and respect women's physical experiences and learn about the patterns they have discerned, to access this experiential wisdom. As health professionals

we need to understand that the nature of bodily sensations is ambiguous, as described by Benner and Wrubel (1989), and we should expect that descriptions of these experiences may be uncertain, vague, and not necessarily in keeping with traditional medical discourse. This should not undermine the credibility of these descriptions however, and we need to be reminded to value the knowledge that women possess as a result of their embodied symptom experiences. The knowledge acquired by women through their embodied experiences becomes invisible when we devalue it and rely only on rational data gathering and focus on whether symptoms are 'real' in accordance with traditional scientific thinking. If dialogues regarding the embodied experiences of women who have the symptoms are suppressed, how can health professionals benefit from this knowledge to diagnose and initiate treatment, and how can knowledge of this experience grow?

This finding underscores the pivotal role that health care providers play in teaching women about their unique symptoms and the best way in which to manage them. The significance of those brief encounters in physician's offices and Emergency departments, where health care providers are given a window opportunity to cultivate understandings regarding cardiac symptoms, cannot be underestimated. This implication for practice is similar to that put forth by (Penque et al., 1998). As a nurse in an emergency department, I should be just as excited at the prospect of validating women's symptom experience, creating new understandings for them regarding their symptoms, and creating an atmosphere in which it is clear that their voices will be heard regarding their symptom experience, as I am about treating an evolving AMI. There is a need for women themselves to have access to current information about cardiac symptoms, and especially

those that are unique to women, and perhaps in this way they can be less reliant on health care providers as their primary source of information. Several authors have suggested this previously (Dempsey et al., 1995; Fleury et al., 2001; Jackson et al., 2000; Rosenfeld et al., 2000). This finding leads us to the question of what else might be at play in influencing the experiences these women had in seeking treatment for their cardiac symptoms.

### **The Quest to Avoid Humiliation**

The experiences the participants in this study had in seeking treatment for their cardiac symptoms seemed to have been profoundly influenced by their anticipation of how their care seeking would be received by health professionals. A common thread seemed to weave itself through the stories of these women, and that was a reluctance to subject themselves to embarrassment or humiliation as a result of an anticipated negative response by the caregivers from whom they were seeking treatment. I was unable to find reference in the literature to this particular finding for comparison.

The embarrassment these women felt seemed to be a result of many things. Many of the participants had for many years performed this frantic dance between the fear of symptoms reoccurring with potential life threatening consequences, and the fear of encountering yet another physician who would discount their symptoms. Participant's experiences in seeking care for their heart symptoms were influenced by experiences they had in seeking care for many other things including fibromyalgia, arthritis, diabetes, and pericarditis. Their frequent experiences in seeking care for these and other conditions seemed to not only confuse the diagnosis of their heart disease, it served to augment their

reluctance to seek care yet again for additional symptoms. The perception that they were taking up the valuable time of the very busy health care workers, that they were “taking up the good space”, led to much of their discomfiture. All of the participants remained at home on several occasions when she should have sought help for their cardiac symptoms, hoping that they would pass.

The participants’ years of experience in enduring symptoms of other conditions including fibromyalgia, arthritis, pericarditis, and diabetes without significant treatment or even a diagnosis in some cases, seemed to have elevated their tolerance of ambiguity regarding their health while at the same time elevating their sensitivity to having their symptoms discounted. They were hesitant to reveal themselves to an unfamiliar health care provider in either the Emergency department or a medi-clinic. Irene’s story spoke most poignantly of this vulnerability in the way she had sought care for her symptoms on a weekly basis for over a year without relief. She had been ‘embarrassed’ at the way she was living, ‘embarrassed’ enough to consider suicide rather than risk subjecting herself to yet another dismissal in the Emergency department, where “there were so many sick people” for the doctors and nurses to take care of. Threads of this same heartrending tale showed themselves in the stories of the other participants.

The participants’ reluctance to seek care for their symptoms was influenced by the agonizingly long waits they had endured in Emergency departments in the past. The prospect of enduring their frightening symptoms for hours in an Emergency care waiting room contributed to their reluctance to access care in an Emergency department unless they deemed their symptoms were life threatening. This anguish was only compounded

by the embarrassment of being told by health care providers that they could not find anything of cardiac significance in their assessments of them. All of the participants had experienced this outcome in their treatment seeking experiences. The experiences that Pam had in seeking treatment in Emergency for her symptoms were different from the other participants in that she had clear evidence that she had serious coronary artery disease. However, the number of visits she made to the Emergency department for her symptoms of chest pain with no clear evidence of further cardiac ischemia seemed to erode her credibility in the eyes of the nurses and doctors as well as in her own eyes. Doris and Irene expressed this same concern that seeking care for symptoms that were found not to be noncardiac in origin was diminishing the credibility of their stories in the eyes of health care providers, and they both described this as embarrassing. The participants were more comfortable in having their symptoms assessed by their own physicians rather than seeking care in an Emergency department, despite the distressing nature of their symptoms and the realization that avoiding Emergency could cause a significant delay in their treatment. They chose to risk this on many occasions rather than subject themselves to these embarrassing experiences in Emergency. Only when they perceived their symptoms to be life threatening did the participants access Emergency care without hesitation.

The participants' experiences in seeking treatment for their cardiac symptoms in some instances did not reveal so much a sense of embarrassment in seeking treatment, as a matter-of-fact acceptance of their physician's opinions. However, their vivid recollection of what they had told their physicians about their symptoms, spoke of the countless times

they had mentally rehearsed their symptom scenarios in order to make sense of them. Their vigilance in continuing to report these symptoms revealed their understanding of the significance of their symptoms. The participants had for years 'hinted' that they did not agree with their physicians' assessments of their symptoms through their persistence in reporting these symptoms. They had been reluctant to confront their physicians regarding the pursuit of their symptoms. "He's the doctor, he should know" were the words which both Linda and Irene used, which seemed again to speak to their deference to their physicians' power and authority. They feared they would be humiliated or feel foolish if they sought the care of another physician who might also dismiss their symptoms. They did not want to risk revealing their heart symptoms to another doctor who might also discount them.

The loyalty that most of the participants felt for their physicians served to keep them from making another most shameful decision in their quest to find treatment for their cardiac symptoms, and that was to seek another opinion. The many profound health experiences the participants had with their physicians had made it difficult to now question the way in which their care was orchestrated. These women's family physicians had been with them through countless family crises, and it was most difficult for them to consider the possibility that their physicians had not always given them the very best care. How disgraceful to question the advice of these highly educated and knowledgeable professionals that had time and again guided their families through illnesses. These women felt indebted to their physicians for the years of care they had provided for them and their families, and this would not be easily dismissed. It required a major event for

these women to consider seeking help from another physician. This event for Linda was a missed fracture, for Irene it was a phone call from me to validate the significance of her symptoms, and for Pam it was the experience of a having massive AMI which very nearly took her life. The reluctance of the participants to appear disloyal to their family physicians was a powerful force in the way these participants' care seeking experiences unfolded. They felt ashamed for considering leaving the care of their physicians who were so tightly connected to many profound events in their lives, such as the deaths and illness of family members. Only Doris had sought the advice of many different physicians before finding an answer to her symptoms, although the first several years of her experience with cardiac symptoms were with the same physician. The participants' acceptance of the lack of care they received for their cardiac symptoms as well as their failure to consider alternatives in their care was shaped in part by their reluctance to abandon their family physicians' care.

Pam's embarrassment in seeking care had another dimension. She was caught in the midst of incredibly stressful life circumstances. After her AMI she remained overweight and did not exercise as she had been instructed to, she continued to smoke, and she continued to be a heavy coffee drinker. It would also be impossible for her or the health care staff to ignore the impact that these issues might have on the way in which she handled her symptoms. She admonished herself on several occasions during our conversations for continuing to smoke after her heart attack. I could not help but wonder if her sense of entitlement to care was influenced by the role she perceived she played in the development of her disease, as well as in her ongoing cardiac symptoms. She brought

with her the humiliation of her life and her personal circumstances in her quest to seek care for herself. Her personal life struggles had served to constitute who she now was, which included the entitlement she felt in the way in which she would seek and receive care for her cardiac symptoms.

The participant, whose interview seemed to shed the most light on this particular issue, was Trish, who it seemed had felt no shame or embarrassment in seeking care for her symptoms. It seemed as if her physician's immediate response to her initial symptoms of cardiac disease was just another chapter in her story of successful health care seeking experiences. Her experiences in seeking treatment for her family members seemed to have taught her not only how to negotiate the health care system, they had also taught her about the power she herself had to manipulate the direction of her care. The lack of self-consciousness she had in approaching the health care system for treatment was very apparent during her interviews. It was clear that she expected no less than excellent care from those that she encountered, and those expectations seemed to be communicated without overt reference to them. It seemed again that it was the "language" of her education level, the "language" of her social standing, and the "language" of the very ease and composure with which she was able to communicate with the health care providers she came into contact with, that served to allow her immediate credibility and attention to her symptoms. She seemed to have an innate sense of confidence that this 'language' would be understood by the health care professionals she interacted with, so she had no need to consider the possibility of embarrassing herself. It was life

circumstances that seemed to allow this woman's experience in seeking treatment for herself to be so successful.

The avoidance of humiliation of all but one of the participants could be seen to be a significant force in the direction and course of the participants' treatment seeking experiences. Most of the participants seemed to have a great deal of respect and even reverence for the power and knowledge held by those in the health care system, particularly their physicians. The meaning they had attached to their experiences seemed to affect the way in which they sought care for their cardiac symptoms. One meaning that seemed to arise for them was that to seek treatment for symptoms that were found to have no cardiac significance would weaken their credibility in the eyes of the health care providers, and this increased their reluctance to seek care with subsequent episodes of their symptoms. As well, their confidence in assessing the significance of their symptoms was shaken with every embarrassing situation they placed themselves in when seeking care. They feared that they might not be heard when they really needed urgent care if they continued to present with these insignificant symptoms. The respect most of the participants had for the health care providers served to augment their fear of humiliation. It was imperative that they not lose their credibility with the people who held the key to the system that could potentially save their lives. To seek help when their symptoms were not critical, and to take the time away from busy professionals who had other patients to care for, was painfully embarrassing for them and seemed to profoundly influence their subsequent experiences in seeking care for themselves.

The subservience demonstrated by these women to their physicians seemed to be evidence of the women's acceptance of another thematic within traditional medical discourse, and that is an acceptance of paternalism traditional to medicine. Paternalism has been described as a moral issue where beneficence (ie do no harm and promote good by providing the best medical care, thereby healing, caring and saving lives) outweighs the patient's right to autonomy or self determination (Gauthier & Krassen-Maxwell, 1991). Paternalism has been traditionally defended by the assumption that patients are unable to make health care decisions for themselves because they lack the knowledge, experience and skill of a trained professional. It has been assumed that patients may not understand the information necessary to make self determined choices even if it were offered to them. Decisions about medical diagnosis, prognosis and treatment that are routine for physicians, are not for those seeking care. Most cannot spend the time required to investigate alternative diagnoses and treatment options, and are restricted in their options for care by a lack of availability of physicians. Time constraints on physicians have been identified as a justification of their paternalistic treatment of patients in that it is much faster for physicians to simply make decisions for patients (Gauthier & Krassen-Maxwell, 1991). In this way, patients are manipulated into allowing health care providers to make these decisions for them, even when they may be dissatisfied with their care. Unfortunately paternalistic as well as traditional scientific discourses may result in the dismissal of opinions and experiences from those seeking care as being insignificant and uninformed, and this had the effect of marginalizing experience. Women's experiences in particular have been discounted in the past in that

women have been seen to be hysterical, narcissistic and lacking good judgement (Nadelson, 1983). Women's experiences in this way have been doubly silenced in that their experiences are marginalized again by the very fact that they are women.

The participants' acceptance of paternalistic treatment was demonstrated in this study by their willingness to set aside not only their deeply embodied knowledge of their disease as previously described, but their right to engage in a non-hierarchical dialogue regarding their health care. They reported feeling humiliated rather than indignant at the paternalistic treatment they received. The participants seemed to have internalized the dominant culture of paternalism and seemed concerned with relating to and appeasing physicians as well as nurses they encountered in Emergency. It is not difficult to see how this way of thinking arose from the paternalistic treatment they encountered in seeking treatment for their cardiac symptoms again and again. Indeed, they were very likely treated paternalistically by health care professionals repeatedly throughout their lives. Acceptance of paternalistic treatment could be seen to be a natural outcome when attempts to influence decisions regarding the treatment of their symptoms were continually blocked, as was the case in the care seeking experiences of most of the participants in this study.

The significance of this 'embarrassment' in itself was fascinating upon further reflection. It was particularly significant in light of what these women were trying to accomplish, and that was to seek treatment for potentially life threatening symptoms. Why was anger or frustration not the predominant emotion described in these women's accounts? Most of the participants had just cause to feel angry at how their care had been

managed, and yet seemed reluctant to acknowledge this. These women were frantically trying to be “nice” and to avoid confrontation, even in the face of situations in which could possibly end in their own death. The humiliation these women experienced could be seen to be a product of societal expectations of women’s behavior where the female patient is expected to be passive, receptive and non-demanding, to work at being a ‘good girl’ in order to be eligible to receive treatment (Lewis & Bernstein, 1996). In part this embarrassment could be seen to be due to the subordination of these women to the health care providers’ power and expertise, and this potentially served to limit their alternatives in seeking care for themselves. This feeling of humiliation on the part of the participants could be seen to be evidence of the weak, tentative and emotional way in which women have been described to interact in the world (Adams & Ware, 1995). Their sense of entitlement to attentive care was hidden from view by their submissive posturing in their health care encounters. In part this humiliation could be seen to be a gendered response to an androcentric and paternalistic medical system in which these women felt powerless to influence the direction of their care.

Trish’s experiences in seeking care had not been characterized by the same paternalism that the other participants had encountered. The absence of feelings of humiliation in her experiences were reflective of this. Perhaps her social circumstances, her demeanor, her level of education, as well as the fact that her son was a medical student had contributed to the sense that she was ‘one of them’. This recognition may have prevented the physicians she encountered from treating her in a paternalistic way,

and indeed she may have recognized this herself which allowed her to assert herself in a stronger way in her interactions with physicians.

This embarrassment had significantly influenced the way in which the participants sought care. In many instances they had chosen not to seek care at all for their cardiac symptoms rather than risk embarrassment. At other times they continued to accept a lack of aggressive management for symptoms that they suspected were significant. Their care seeking behavior in response to their fear of humiliation had served to delay their access to appropriate treatment, and again had put their health at risk.

These findings might be of particular interest to Emergency nurses, family physicians and cardiologists. These findings point to the need for a heightened awareness regarding the vulnerability women experience in seeking care for their cardiac symptoms, and the profound effect a negative or paternalistic response from a health care provider can have on their subsequent care seeking experiences. A heightened awareness of the reverence that many women feel towards their family physicians might remind these physicians to ensure that women's opinions are heard and included in their plan of care. When paternalistic discourses are invoked, they need to be challenged by women themselves, nurses, as well as physicians. An understanding needs to be created as to the silencing effect of paternalistic discourses on women's voices. As a nurse in Emergency I might be reminded to hear women's stories with sensitivity, and understand the courage it can take to access care in such an intimidating setting. These findings might encourage a new dialogue between health care providers and recipients of care in which consideration of alternatives in seeking care is natural and acceptable rather than awkward and

embarrassing. The creation of an equitable dialogue between health care providers and recipients could serve to empower women to engage actively and assertively in their health care encounters.

### **The Quest to Interact with Health Care Providers**

Another thread in the fabric of these women's experiences began to reveal itself as I reviewed the transcripts of the interviews. There seemed to be something about the way in which the participants presented their stories and the way in which they interacted with the health care providers from whom they sought care that influenced their current and subsequent care seeking experiences.

Cardiac disease is often very difficult to diagnose without extensive diagnostic testing such as exercise stress testing, thallium scanning, echocardiography, and angiography, and this is particularly true among women (Kim, Kwok, Saha, & Redberg, 1999; Kwok, Kim, Grady, Segal, & Redberg, 1999; Wong et al., 2001). The cost of these diagnostic tests is significant as is the difficulty with availability of these diagnostic resources (Kim et al., 1999). The literature suggests that it is the referral for diagnostics in which women have a gender disadvantage in the care of their cardiac disease. It has been shown that once the diagnosis of CAD has been made, the gender disparity in access to cardiac care disappears (Steingart et al., 1991). It would seem then that the history and physical assessment done by the physicians and nurses would take on a great deal of significance in the successful treatment of women with heart disease. In this study, the interaction

itself between the participants and the health care providers seemed to profoundly influence the direction of care that they received.

One difficulty the participants had with communication of their symptoms when seeking care was that many times their symptoms had resolved by the time they were seen in the Emergency department or in their physician's office. This poses a problem in the detection of cardiac ischemia or cardiac arrhythmias in that often when these cardiac symptoms have resolved, the electrocardiogram (ECG) has returned to normal. Unfortunately, the only diagnostic tool available for nurses and physicians in the points of entry to the health care system such as physician's offices or Emergency departments is an ECG machine. Cardiac disease, in the absence of acute symptoms, is in this way an invisible disease until a diagnosis can be made with more advanced diagnostics, or until the person reaches the point of an acute crisis such as acute cardiac ischemia, hemodynamically significant arrhythmias, or an acute episode of congestive heart failure. Much of the onus, therefore, is on the patient to convincingly describe their symptoms in order for further diagnostic testing to be initiated. The stories of the participants in this study revealed an apprehension regarding the accuracy of their symptom reporting. As well, the participants perceived that the way in which they reported these symptoms had an influence on the care that they received.

The participants had the common experience of feeling anxious about how their stories would be heard. Participants reported needing to rehearse their stories before seeking treatment for their cardiac symptoms. It was almost a performance anxiety that these women experienced in seeking care. Not only was there the need to recognize and

recall all of the significant symptoms after an acute cardiac event, there seemed to be a perceived need to make the symptoms sound convincing, especially when the ECG failed to show any evidence of an acute cardiac event. All of the participants except Doris had had a diagnostic ECG at some point in their symptom experience, which failed to show anything significant. There seemed to be a lack of understanding among the participants as to how unreliable an ECG is in diagnosing cardiac disease, with or without the presence of acute cardiac symptoms (Kwok et al., 1999). The experience of being told their ECG was 'normal' in itself seemed to color the way in which they considered seeking treatment. The ECG machine seemed to serve as a sort of lie detector for many of the participants. The power of traditional scientific discourses in which the 'hard evidence' of the ECG results outweighed the participants' descriptions of their experiences again served to erode the credibility of the participants. This seemed to be true for both the participants and the health care providers, especially if their symptoms had resolved by the time they were able to speak to a physician or nurse.

For all of the participants, anxiety was a significant part of their symptom experience. Doris's recollections of the experiences she had in enduring her cardiac symptoms were filled with descriptions of her profound anxiety. In her experience it was this anxiety that was the most distressing aspect of her symptoms. It would seem only natural that she would include a description of this facet of her experience when seeking care for her symptoms. However, what she came to understand was that it was the description of this part of her experience that served to diminish her credibility with the physicians she sought care from. Her description of the physicians "glazing over" when she recounted

her feelings of anxiety and agitation, suggested that this part of her experience was somehow less important to them. Doris described needing to speak “more like a man” and “just sticking to the facts” regarding her symptoms in order to be taken seriously. Her advice to other women in this same situation was to take someone with you to back you up. She advised other women to be very factual and leave the emotion out of it, “until you’ve got control.” Doris had learned that this short interface with the health care providers she had sought care from was extremely important in setting the stage for her care or investigations to unfold. This finding is similar to those in the study conducted by Birdwell et al. (1993) in which they found that physicians were much more likely to attribute cardiac symptoms to CAD in women with a businesslike portrayal of their symptoms versus patients with a histrionic portrayal..

Irene’s experience with anxiety as a result of her debilitating cardiac symptoms, and the communication of this anxiety to her physician also seemed to affect how she sought and received care. The anxiety she experienced seemed to be the result of not only her symptom experience, but the lack of reaction she saw from her physician in response to her symptoms. Week after week she would see her family physician to report her ongoing cardiac symptoms that had confined her to her couch. She too seemed to be performing a frantic dance between trying desperately to manage her symptoms at home, and seeking the care and advice of her physician. She seemed to be caught in an escalating vortex of anxiety and care seeking.

I wondered about the role that her physician had played in the continuation of this “dance”. Irene was frightened and desperate for help, but this desperation seemed to

affect the meaning that her physician had attributed to her symptoms. As well, the credibility of her story may have been compromised by her anxious demeanor, the close association of her cardiac symptoms with anxiety, and her continuing need to see her physician every week. Once again, it seemed to be this moment of communication between the participant and their physician that was so powerful in shaping the course of events in the care of their cardiac symptoms. It may also have been Irene's reluctance to challenge her physician's interpretation of her symptoms that impeded clear communication. The encounters she had with her physician seemed again to be hampered by Irene's subservience to her physician's power and expertise. Perhaps the nature of her cardiac disease in itself had affected the way in which she approached her physician. The possibility of life threatening outcomes may have made the stakes too high to risk questioning his expertise. These symptoms carried much more significance than her symptoms of fibromyalgia for instance. The threat of the disease itself may have shaken the confidence of Irene as well as the other participants in their own judgment and insights into their illness.

Linda's descriptions of her experiences with cardiac symptoms and the way in which she sought care were virtually free of any description of anxiety. Linda's nonchalant way of communicating may have led her physician to believe that she did not deem these symptoms to be significant. Again, Linda's failure to challenge or question her physician regarding the pursuit of her symptoms may have given him silent approval for his actions. I soon came to realize that behind this casual style of communication was a very intense and intelligent woman who now deeply regretted the lack of aggressive

management she had received for her cardiac symptoms. She had spent nearly a year in hospital following her urgent coronary artery bypass surgery, during which time she had almost lost her life on several occasions. I wondered what her outcome might have been had her cardiac symptoms been addressed earlier, and if the way in which she sought care had influenced her delayed diagnosis.

Again it was Trish's interview that helped to shed light on this particular issue. Trish intuitively knew to "not muddy the waters with emotional stuff" in order to be heard. She knew that if she communicated her anxiety, the clarity of her message would be lost. She too learned she had to rehearse the way in which she presented her symptoms, even to the extent of bringing written reminders, in order to allow for an unambiguous understanding of her story. She would take notes in her physician's office to help her to remember everything that he said, and to perhaps give her the opportunity at a later time to decipher this 'new vocabulary' that her physician was using. She made certain to ask for copies of her diagnostic reports, so there would be no confusion as to what the results were. She understood how pivotal these moments of communication were with her physician, and perhaps it was the experiences with seeking care for her family that had taught her this. I sensed that it was the clarity of her communication, and the clarity that she expected from her physician, contributed to the success she had in finding treatment.

It is the heart's reaction to intense situations that we all learn to recognize, perhaps more so than any other organ system. A pounding heart in response to pain, fear, intense physical strain, and excitement is so recognizable as to make it almost a part of our sensory interpretation of the world. The arousal or anxiety that is experienced in

conjunction with a pounding heart is sometimes difficult to interpret as being causal or consequential, as in the case of panic disorders. For example, most people who experience a sudden onset of rapid heart rate also experience concurrent anxiety. Perhaps it is this connection of the heart to our emotional arousal that may have served to confuse the diagnosis of cardiac disease for some of the participants.

It seemed as though the description of the participant's anxiety associated with their cardiac symptoms was confounding for the health care professionals from whom they sought care. It was not only the confusion in symptom attribution that was affected by reports of anxiety, it was the credibility of the stories themselves that was eroded in response to women's descriptions of the anxiety associated with their cardiac symptoms. Doris and Trish both recognized that a more feminine way of communicating their symptoms, such as a description of the emotional content of their experiences, would reduce the credibility of their stories. The participants again seemed to have internalized the dominant medical discourses that exist by disguising themselves with a more masculine way of communicating in order to relate to and appease the physicians from whom they sought care. They needed to "stick to the facts", "leave the emotion out of it", "not muddy the waters with emotional stuff" and "speak more like a man" in order to be heard. In a sense it was more comfortable for them to indirectly manipulate their interactions with physicians in this way rather than risk asserting themselves and possibly colliding with the only people who could potentially save their lives. This finding again speaks to the lack of power these women experienced in their health care encounters.

The participants' stories of their interactions with health care providers reflected a lack of understanding regarding the health care system as a whole. There was a sense of anxiety and intimidation on the part of the participants in accessing care and negotiating the health care system. This was in part because of the mismatch between what the participants expected to experience in health care encounters and what their experiences actually were. There was a recognition of their lack of power in relation to physicians and nurses they encountered, and this seemed to translate itself into submissive posturing in health care encounters. This submissiveness was striking in its contrast to the incredible strength they showed in their personal lives.

There was a lack of appreciation among the participants of the fragmented nature of the health care system. There seemed to be a naïve sense among the participants that the health care system was highly integrated and efficient, and that they would be "taken care of" when they entered this system, especially in the earlier parts of their care seeking experiences. I wondered if this had contributed to the subservience the participants demonstrated in their experiences in seeking care initially. Over time the participants' experiences in seeking care began to reflect a more realistic, even cynical perception of what they could expect from health care encounters, and this was demonstrated in their reflections on what they would do "next time" to ensure their care seeking would be more effective. In retrospect, the participants understood that the care that they had received for their cardiac disease was not optimal and that this was in part due to the way in which they had sought care for their symptoms. Without naming it, they seemed to have learned

to recognize and challenge paternalistic interactions in the later parts of their care seeking experiences.

There was also a perception among the participants that there was invisible communication between health care providers to which they themselves were not privy to. Participants worried about finding a new physician if they left their current one, and complaining about their care. As Irene said, “who would want to take care of me?”, as if the physicians discussed individual cases amongst themselves or shared each other’s records. This also led to anxiety regarding how their care seeking would be received.

The participants’ reflections on their care seeking experiences demonstrated that they had been concerned about compromising their future care through “inappropriate” or “objectionable” care seeking behaviors. The participants’ interviews reflected apprehension about displeasing members of the health care system for fear of compromising their reputations as health care recipients. The participants’ stories did not suggest so much a loss of control in their experiences of seeking care, as has been suggested by other authors (Benson, Arthur, & Rideout, 1997; Johnson & Morse, 1990), but an angst in approaching their care in a way that was acceptable to health care providers. The participants were very reluctant to acknowledge their lack of care, they were reluctant to question the opinions of physicians and other health care providers they sought care from, and they seemed hyper vigilant in their assessment of how their care seeking was viewed by health care providers. This submissive attitude demonstrated by the participants could be seen to be an expression of their understanding of the patriarchal

nature of the health care system which serves to maintain power control over health care recipients.

This finding suggests the need for women to have a greater understanding of the way in which the health care system works. Women should have a clear understanding of their rights as health care recipients, as well as the pivotal role they play in orchestrating their own care. As health care providers we should ensure that we include women in discussions about their care, and help them to have a realistic sense of what they can expect in the diagnosis and treatment of their cardiac disease. We could in this way begin to enable women to assume a higher level of ownership of their health care, and they could be engaged as an essential part of the health care team.

### **How Could These Stories Change Practice and Outcomes for Women with Heart Disease?**

Upon reflecting on the findings of this research, I was surprised with what I did not find. I expected to hear that these women's stories were simply not being heard by physicians and other health care providers they sought care from, and indeed this is what I heard in the interviews until I began analyzing the text in depth. The participants' subservience to their physician's knowledge and expertise, the respect and loyalty they felt towards their physicians, the incredible anxiety that they experienced as a result of their symptoms, the confusion they had regarding the legitimacy of their symptoms, and the mismatch between their expectations of health care encounters and their actual experiences, were all issues that had shaped their interactions with the health care providers from whom they had sought care. These nuances seemed to be influencing the

care seeking behavior of these women as well as the way in which they were assessed by their physicians and other health care providers. The participants, as well as the health care providers' past and ongoing experiences with care seeking seemed to shape these influences, but even more so it was their interpretations of those experiences that seemed to affect the direction of the participants' care. Interpretations of the participants' care seeking experiences were profoundly influenced by the dominant scientific discourses that predominate in the health care system, and these discourses influenced both the participants and those from whom they sought care. The participants' experiences were affected by physicians' and nurses' lack of attentiveness to their embodied experiences of their symptoms. Paternalistic discourses from both physicians and nurses served to augment the participants' feelings of powerlessness in health care encounters.

Each participant had their own unique encounters in approaching the health care system for care of their cardiac symptoms. In turn it was the participants' unique life circumstances and past experiences that seemed to shape the way they interpreted their care seeking experiences as well as the way their care seeking was interpreted by the health care workers from whom they sought care. The participants' care seeking seemed to be an elaborate dance between themselves and health care workers. Each step taken by the participants and the health care providers was taken in response to meanings they attached to their interpretations of these care seeking experiences. The way in which the participants interpreted their symptoms, the way in which they sought to avoid humiliation in health care encounters, and the way in which the participants interacted

with health care providers were some of the elements that profoundly shaped the way this health care seeking ‘dance’ seemed to evolve for each of them.

The participants’ success in finding care for their cardiac symptoms seemed to hinge on the face-to-face encounters the participants had with the health care providers. This moment in time seemed to be pivotal to the way their care would proceed. This moment in time was not a moment at all, as previously described in this chapter, but an expression of so many events and circumstances that shaped this and countless other experiences in their lives. Of particular significance were the times that the participants put themselves at risk by choosing not to seek care for their cardiac symptoms. All of the participants had an increased risk of developing serious complications as a result of delayed diagnosis and treatment of their cardiac disease. Four of the participants had developed life threatening cardiac complications, which might have been avoided with prompt diagnosis and treatment of their cardiac disease. The way in which their care seeking unfolded had profoundly influenced not only their personal lives but their subsequent health as well. The care seeking experience in itself had put the health of these women at risk.

An understanding of the experiences these women had in seeking care for their cardiac symptoms is significant in that this understanding could influence the way in which health care providers interpret similar experiences they may be faced with in clinical practice. Having heard these women’s stories might allow health care providers to take pause and consider other possibilities outside of their accustomed interpretations of similar stories. A recognition of the reciprocal nature of this care seeking experience might allow health care providers to hear women’s’ stories with a different

thoughtfulness and wisdom. For example the true depth of women's insecurities regarding care seeking could be taken into consideration in initiating care, as could a recognition of the impact of flippant remarks or contradictory advice (eg. "There's *nothing* on your ECG, but you did the right thing coming into Emergency"). An understanding of these women's experiences might allow for health care providers to challenge their reliance on rigid scientific ways of thinking about cardiac disease.

These findings suggest that as health care providers we should be vigilant in ensuring that in our encounters with women we maintain a respect for the women's stories, a respect for women's expertise and insight into their illness, and a respect for the emotional context of cardiac symptoms. Opportunities for genuine dialogues to exist in our health care system have been stifled by limitation of resources, including physicians and nurses themselves, and an increasing reliance on technologies to 'describe' illnesses that patients experience. In the frantic pace of healthcare today, we must remember to not allow science to be invoked beyond the limits of its real competence (Gadamer, 1996). We cannot allow scientific ways of thinking to replace clinical judgement which involves an exchange of the knowledge and expertise of health care providers with the experiential wisdom of the patient. For this exchange to occur unimpeded, dialogues between health care providers and recipients must take place in a non-hierarchical milieu. There should be an expectation of reciprocity and negotiation in health care encounters in which stereotyped roles of health care providers and recipients are avoided. When paternalistic discourses are invoked in health care encounters, they need to be challenged by everyone involved, and a new dialogue created. Nurses in particular have unique opportunities to

act as patient advocates when patriarchal interactions are recognized between physicians and patients. Nurses have a unique perspective on this dilemma in that they themselves have been silenced into submission by these same patriarchal discourses in the past. We cannot allow ourselves to become complicit in this way of interacting by being constrained to speak out about it.

As I wrote about the experiences of the women in this study, I could feel the breath of this powerful medical patriarchy on my back. I felt as if I were disloyal or disrespectful to suggest that the physicians these women encountered had not always given them the most attentive care. I literally imagined the faces of physicians I had worked with as I wrote, and imagined their expressions of betrayal as they read my work. I myself was feeling the silencing effect of this powerfully patriarchal scientific discourse. However, I felt compelled to write about these experiences in the way that I did. My intent was not to engage in what some would call 'physician bashing', but to not allow these kinds of understandings to appear would be to perpetuate what these women were experiencing. I understood as well that the nurses the participants encountered had also demonstrated an acceptance of these same dominant discourses previously discussed.

As I wrote, I began to understand that these physicians had in a sense been trapped and constrained in the care of these women by the same rigid scientific and patriarchal discourses that had constrained the participants from acquiring treatment for their heart disease. These physicians had not engaged in a malicious or sinister plot to prevent their patients from receiving the care that they needed. They were not intentionally paternalistic in order to silence these women. It seemed that it was more that they

themselves were caught in this rigid and oppressive way of thinking that prevented them from engaging with these women in a way that would allow for a mutual exchange of wisdom. These powerful discourses had in a sense held both the health care professionals and the participants hostage in a constricted way of thinking, and this had served to delay the treatment these women required for their heart disease. An understanding of these insights might help to begin a new dialogue between physicians, nurses, and women seeking care for cardiac symptoms.

This study points to the need for a greater use of qualitative methods than as has been the case thus far in looking at women and cardiac disease. Qualitative inquiry could help to take into account the complexity of women's lives in relation to their cardiac disease. There remains a need to understand how women reflect upon their lives and their health and the way in which this is translated into action in seeking health care.

An understanding of the experiences of women seeking care for their cardiac symptoms could allow for women themselves to challenge the way in which they have sought care for themselves in the past, and to recognize the crucial role they play in their own health outcomes. This recognition could lead to a stronger sense of entitlement of women to be part of their plan of health care, and perhaps this in itself could change their health outcomes. Education material could be developed for women in which communication with health care providers, recognition of cardiac symptoms, as well as what to expect in a thorough cardiac investigation could be addressed. An understanding of how the health care system itself works might allow for an increased confidence in accessing care.

An understanding of the experience of women seeking care for cardiac symptoms helps to shed light on some of the issues involved in the experience of women seeking care for cardiac symptoms. The findings of this research might help to clarify and extend our understanding of women's experience in seeking health care for their cardiac disease by revealing the nature and significance of this critical period of time in a renewed empathetic and thoughtful way. The understanding gained from this research project could increase the thoughtfulness and practical resourcefulness of health care professionals, which could improve the future care of women with cardiac symptoms. Understandings gained from this research into the experiences of women seeking care for their cardiac symptoms could influence the way in which women access and negotiate the health care system in response to their cardiac symptoms which could lead to improved outcomes for women with cardiac disease.

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## Appendix A

### **Invitation to Participate**

**You are invited to participate in a research study exploring:**

**The experiences of women seeking health care for symptoms of heart disease.**

**If you are a woman who has been diagnosed with heart disease, and are willing to share your experiences in seeking health care by participating in this study,**

Please contact or leave a message for Heather Russell at:  
~~247-2800~~ or e-mail: ~~hrussell@home.com~~

*Heather Russell is a Master of Nursing student at the University of Calgary who is interested in having interviews with you in order to understand your personal experience of seeking health care for your heart condition.*

*This study is being carried out as part of a program of studies within the Faculty of Nursing at the University of Calgary.*

*Supervisor  
Dianne Tapp, RN, PhD  
Assistant Professor  
Faculty of Nursing  
University of Calgary  
Ph 220-6332  
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## Appendix B – Consent Form

Title: Women's experiences in seeking health care for symptoms of ischemic heart disease.

Researcher: Heather Russell, R.N., B.N.

Principal Investigator: Dianne Tapp, R.N., PhD. Assistant Professor, Faculty of Nursing, The University of Calgary, Calgary, Alberta, Canada.

This consent form, a copy of which has been given to you, is only part of the process of informed consent. It should give you the basic idea of what the research project is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully.

### **Purpose of the study:**

The purpose of the study is to learn about your experience of seeking health care for your heart symptoms. From listening to you, the researcher hopes to understand your experience of seeking health care. This information should help health care professionals to develop plans for caring for people who are having heart symptoms.

### **Description of the Study:**

If you consent to take part in this study you will be interviewed twice about your experience in seeking health care for your heart symptoms. The interviews will be arranged at a time and location that is convenient for you and will typically last one to two hours. The second interview will allow you to reflect on the first interview, and to bring out any new ideas about your experience. The first and second interviews will be tape recorded, and will be later typed by the researcher or a typist. There will be no financial costs to you if you participate in this study. There will be no financial compensation for your participation in this study.

### **Voluntary Participation:**

Your decision to take part in this study is strictly voluntary. You may refuse to take part without this affecting your care in the hospital or at home. If you decide to take part, you have the right to ask the researcher any questions concerning this study at any time. You



-----  
Witness' Signature

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Date

A copy of this consent form has been given to you, and you will keep it for your records and reference.

Would you like a summary of the study results?    Yes            No

Please write your mailing address:

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