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IMPACT OF MYOCARDIAL INFARCTION ON PATIENT AND PARTNER QUALITY OF LIFE

BY

FRANCES HELEN ALEXANDRIA WILLIAMSON ©

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled *Impact of Myocardial Infarction on Patient and Partner Quality of Life* submitted by Frances Helen Alexandria Williamson in partial fulfilment of the requirements for the degree of Doctor of Philosophy in Counselling Psychology.

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Dedicated to my mother

Marie Williamson
(1941-1991)

ABSTRACT

Quality of life is a primary concern in the care of post-myocardial infarction patients and their partners. This research explored the impact of a heart attack on patients and their partners quality of life. In phase one, participants were asked to provide written responses to an open-ended question asking them to "Describe how having (a partner who has) had a heart attack has affected your quality of life". Participants were asked to sort the statements, and multidimensional scaling and hierarchial cluster analysis (concept mapping) were used to analyse the data in order to generate visual representations of the underlying themes. Patients perceptions consisted of eight themes: lifestyle changes, physiological symptoms, depression, employment issues, future health concerns, confinement, partner support, and improved quality of life. Partner perceptions consisted of seven themes: fear of reoccurrence, caregiver stress, negative social consequences, changes in the pace of life, vigilance, improved quality of life, and nutritional concerns. Incidence surveys, developed using patients and partners reported experiences, were distributed to patients and their partners. These data provided a broad, multidimensional perspective of the experience of a myocardial infarction and how it impacts quality of life. Eight of the top ten patient statements were positive and adaptive perceived outcomes of the experience of a myocardial infarction. The improved quality of life cluster had the most patient-endorsed statements. The fear of reoccurrence cluster was most endorsed by partners. There was a great variation in the endorsement rates of the individual items highlighting the uniquely individual and complex nature of quality of life post-myocardial infarction. The picture painted by patient and partner reported experiences are somewhat different than that reported using standard quality of life measures.

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One thread is a strange thread - it is my steadying thread;
When I am lost, I pull it hard and find my way.
When I am saddened, I tighten my grip
and gladness glides along its quivering path;
When the waste places of my spirit appear in arid confusion,
the thread becomes a channel of newness in life.
One thread is a strange thread - it is my steadying thread.
God's hand holds the other end........

Thurman

CHAPTER I

Introduction

Statement of the Problem

At the core of the provision of health care to patients with coronary heart disease is concern for quality of life (Cella, 1992). In the early 1970s, cardiac rehabilitation programs were developed to help patients with heart disease return to enjoyable and productive lives. The initial focus of such programs was almost entirely on restoring the patient's physical functioning level. Contemporary programs adopt a more multidisciplinary approach (Dracup, 1994). The goal of therapy is usually not to cure the disease, but rather to relieve symptoms, retard disease progression, and improve the patient's functional capabilities (Cella, 1992; Ferrans, 1992; Hillers et al., 1994; Wenger & Furberg, 1990). It is argued that improvement of quality of life is an equally important outcome of rehabilitation research. However, quality of life is seldom assessed as an outcome measure in the rehabilitation literature (Wood-Dauphineé & Küchler, 1992).

Evaluation of quality of life as an outcome factor promises to reveal the needs of cardiac patients and allow clinicians with limited resources to promote optimal patient and family psychosocial adjustment and adaptation. Consensus in the literature is that quality of life is a multidimensional concept that is not easily defined (e.g., Cella, 1992; Gill & Feinstein, 1994; Hawthorn, 1993; Jenkins et al., 1990). Oleson (1990) stated that a concept that is difficult to define is also difficult to measure. The major challenge faced when examining this construct is achieving clarity of conceptualization, because differences in meanings can result in profound differences in outcomes for research and clinical practice (Ferrans, 1992; Wenger, Mattson, Furberg & Elinson, 1984).

Stern (1984) stated that spouses are frequently forgotten in a medical environment devoted to patients. Previous research (e.g., Anderson & Bury, 1988; Biegel et al., 1991; Delbanco, 1993) has indicated that the burden of chronic illness falls as heavily on family members as on the patient. In addition, existing literature supports the relationship between patient status and caregiver outcomes (Biegel et al., 1991). However, little research has examined the impact of chronic illness on the partners themselves. Most research (e.g., Beach et al., 1992; Brecht, Dracup, Moser, & Riegel, 1994) has focused on how caregivers' reactions impact the patients. Ell and Dunkel-Schetter (1994) found the lack of extensive partner-focused research in the area of chronic coronary care remarkable. It is evident that research that examines both patient and partner perspectives is warranted and necessary.

Purpose of the Study

The purpose of this research was to gain a better understanding of the impact of an acute myocardial infarction (AMI) on the quality of life of patients and their partners. Concept mapping (Trochim, 1989) was used to retrieve participant-centred data by combining both qualitative and quantitative strategies. Two research questions were addressed: 1. What are the reported experiences of individuals who have had at least one myocardial infarction and of their partners? 2. What are the themes or categories underlying their identified experiences?

Significance of the Study

Acute myocardial infarction is the primary clinical manifestation of coronary artery disease mortality risk (Teo, Ignaswaeski, & Gutierrez, 1992). In Canada, 60,000 new cases of infarction are anticipated annually with a 15% in-hospital mortality (Wielgosz, 1994). Those who experience AMI face two broad challenges. First, in the earliest hours following onset, patients must simply survive the physiological trauma of AMI (Rackley, 1992). In the long term, during recovery , the challenge for patients is to re-establish and maintain optimal functioning in their interpersonal, social, and occupational environments while managing the actual or perceived burden of an irreversibly damaged myocardium (Byrne, 1987).

Outcome following AMI is a complex phenomenon. Each individual responds in a unique manner. Clinicians are becoming more aware of the importance of including quality of life as an outcome measure in coronary rehabilitative care (Fletcher, Hunt, & Bulpitt, 1987; Wenger et al., 1984). Quality of life is a relevant outcome variable because it reflects the goals of rehabilitative care and also the patient's perceived health status, life satisfaction and personal value system (Wenger, 1992).

In the past, the focus of research has been the impact of chronic heart disease on the patient. The demands of chronic illness often precipitate changes in patients that interfere with normal behavioral efficiency, which in turn, elicits difficulties in psychosocial transitions for their natural caregivers (Woods & Lewis, 1995). Despite the potential significance of psychosocial factors for behavioral adjustment of partners of post-myocardial infarction patients, there has been relatively little systematic study of their quality of life (Wright & Leahey, 1987). It is important to address the impact of heart disease on partners because their perceptions and expectations may be quite different from that of the patient (Wenger and Furberg, 1990) .

In a comprehensive review of quality of life assessment, Gill and Feinstein (1994) discussed the relative inadequacy of commonly used measures of quality of life which are based on investigator-specific criteria. Previous investigators have selected specific domains that reflect what may appear important to the researcher rather than the patients. The intent of this investigation was to allow participants' collaboration in describing the organization and relevance of the various elements of their unique experience in a manner that was unconstrained by my previous conceptions. As Day (1993) said "we must ascertain the needs of the people with whom we are working, get their opinions about their lives in general and their evaluations of domains or aspects of their lives" (p. 139). This approach seems essential to developing "an insider's perspective" (Conrad, 1987, p. 1149) that focuses directly and explicitly on the experience of living with and in spite of chronic cardiac illness.

Evidence within the medical literature consists primarily of measurements of quality of life and research using methodologies which impose researcher-designed constructs or values. If the individual's phenomenological experience and interpretations are defined by researchers a wealth of information has been eliminated. Personal accounts of illness provide valuable and necessary insight into the personal meaning of the quality of life experience.

Clinicians and researchers agree that both objective and subjective indicators are required to accurately examine the impact of heart disease on the quality of life (Day, 1993; Wood-Dauphinée & Kuchler, 1992). The research questions in this study will be answered using concept mapping (Trochim, 1989). Concept mapping allows one to cluster data, e.g., phrases or short sentences in a substantively meaningful way, into underlying themes, since the participants' experiences are reported spontaneously rather than elicited and interpreted by investigators (Daughtry & Kunkel, 1991; Fitzgerald & Hubert, 1987). This approach is particularly appropriate for applications to larger participant groups in which researchers are seeking to clarify the domain, constituent elements, and underlying structure of the individuals' experiences.

This research may contribute to our understanding of the problems experienced by patients who have had a myocardial infarction and their partners, and how these problems affect their quality of life. It may expand and clarify the field of knowledge relative to the management of myocardial infarctions within a contemporary Western health care system. It may have practical utility with positive psychosocial consequences for improvement of quality of life of those living with chronic cardiovascular disease and their partners.

Delimitations

In this study, the research was limited to patients who have had a myocardial infarction and their partners. Thus, the results cannot be generalized across other cardiovascular diseases or other chronic illnesses such as multiple sclerosis or cancer. The statements obtained during data collection may not accurately reflect the impact of a myocardial infarction on participant quality of life. The individuals' reported experiences may be influenced by denial or a reluctance to divulge all aspects of their experiences.

There was no attempt made in this study to explore the interaction between patients and partners. It was anticipated that some of the patient and partner items may reflect similar themes, but each data set was treated as separate at this intial stage of investigation. Since reinfarction is unpredictable and potentially fatal there was a risk that a small percentage of the sample would be at a high risk for mortality.

This study is organized as follows. Chapter II consists of a critical review of the relevant literature related to myocardial infarction, caregiving and chronic illness, and the quality of life research. Also, a brief overview of the concept mapping methodology will be provided in this chapter. A more detailed description of the methodology used in both phases of the research will be contained in Chapter III. The results of the study and a detailed discussion related to previous literature will be the focus of Chapter IV. The final patient and partner concept maps and the results of two incidence surveys are provided, along with validation of the conceptual themes. Finally, Chapter V contains a summary of the major findings, limitations of the study, and suggestions for future research directions.

CHAPTER II

Review of Literature

This chapter contains a critical review of the literature specific to the impact of coronary heart disease, in particular, myocardial infarction, on the quality of life of patients and partners. It will include an overview of caregiving and chronic illness issues, a critique of the quality of life research in relation to chronic illness, and an overview of the concept mapping methodology.

In recent years, tremendous tension for change has been exerted on North American health care systems (Montague et al., 1995). Technological innovations and pharmacological advances have vastly altered how people live. A whole new set of health issues has emerged from the growth of industrialization world-wide (Afifi & Breslow, 1994). The prevalence of chronic illness within a steadily aging population is of particular concern (Lewis & Bell, 1995).

Health care professionals and the general public are becoming more aware of the great social and economic consequences of this chronicity. A formidable challenge is to ensure effective management in all phases of illness and to juggle this work with the requirements of everyday living. The complex regimens employed to achieve such equilibrium involve physical, behavioral, psychological, social and economic strategies, and hence a considerable amount of specialist personnel (Strauss, 1990).

The goal of therapy for most people with chronic illness is not cure, but helping the individual decrease or retard acute exacerbations and thus slow disease progression (Lewis & Bell, 1995; Wenger et al., 1984). Previously, when one spoke of health outcome, one was usually referring to the endpoints of survival and prolongation of life. Health meant essentially the absence of disease, disability and death (Afifi & Breslow, 1994). Strictly biomedical explanations of health have received much criticism.

For several centuries the definition of health has been ambiguous. (Kaplan, 1994). Over the last thirty years, a subtle yet fundamental paradigm shift has prompted change in our conceptualization of health. The definition of health status has evolved to include physical, mental, social, spiritual, economic and educational dimensions (Feinstein, 1992). It has a more positive meaning and focuses on how people can live more fully and achieve a sense of balance in their lives (Greenfield & Nelson, 1992). Although progress is evident, many, large conceptual issues still remain.

There is a need to deepen our understanding of the problems that people encounter in managing their illness and maintaining a quality of living despite disability and suffering (Strauss, 1990). Disagreements have arisen about which entities should be included and emphasized as the focus of attention. An issue today is that the choice of what is important may not be made by the patient. For example, consider two women who have crippling rheumatoid arthritis of their hands and feet. One woman might enjoy knitting and be eager to have her hands improved, and may be relatively unconcerned about mobility. The other woman might be eager to walk because she enjoys accompanying her friends to the park, but be less concerned about her hands. It is Feinstein's (1992) contention no-one other than the individual patient should determine what target is the focus of health and her quality of life.

The value dimension in health status is inescapable. Our judgement that one level of functioning is better than another level of functioning is ultimately tied to subjective evaluations. For example, if a cardiologist advises an individual to change his/her diet in order to avoid heart disease, we inherently assume that the reduced probability of disease in later life is valued more than displeasure of dietary change. The term quality of life has emerged to refer to indicators that assume some valuation of states of being. It presumes a qualitative judgement (Cella, 1992; Kaplan, 1994).

In a study (Parkerson, Broadhead, & Chiu-Kit, 1992) examining the quality of life and functional health of adult ambulatory primary care patients, severity of illness was the strongest predictor for patient reported physical health function and for patient quality of life when assessed by the health provider; However, the strongest predictor of patient quality of life, when assessed by the patient was home confinement. Very little agreement was found between patient-assessed and provider-assessed quality of life. Furthermore, family stress was the strongest predictor of function in terms of mental health, social health, general health, self-esteem, anxiety, and depression. These findings have important implications for the improvement of quality of life and functional health as clinical outcomes. There is the danger that medical interventions perceived as successful by health-care providers, may be very unsuccessful in the eyes of the patients being treated.

The intrinsic importance of the patient's uniquely subjective experience to the quality of care has not figured prominently in shaping health care services and institutions. The ideology of "hard" science values that which is quantifiable, generalizable, and amenable to technological interventions. The qualitative and human aspects of the patient's experience are difficult to evaluate in a manner that is accepted as scientifically valid, even though they are acknowledged to be important (Gerteis, Edgman-Levitan, Daley & Delbanco, 1993).

The foundation of patient-centred care demands understanding and respect for patients' values and expectations. The paradox is that there is less time to listen to the concerns and questions of patients (Allshouse, 1993). The essence of the problem is captured in this physician's slip of the tongue:

> It happened the other morning on rounds, as it often does, that while I was carefully auscultating a patient's chest, he began to ask me a question. "Quiet," I said, "I can't hear you while I'm listening." (Baron, 1985, p. 606)

Coronary Heart Disease and Myocardial Infarction

Coronary heart disease (CHD) is a major cause of death and also a major contributor to disability, lost productivity, and medical costs (American Heart Association, 1994). The differential affluence of CHD between and within countries can only be understood with reference to the social, cultural, and economic features of those societies (Marmot, 1992). Coronary heart disease is the clinical manifestation of an underlying pathological process, coronary artery atherosclerosis. Atherosclerosis refers to the development of fibrofatty plaques (atheromas) within the inner lining of the artery. Progressive disease interferes with the normal rhythmicity and essential function of the heart. Common clinical expressions of CHD include acute myocardial infarctions, angina pectoris, cardiac arrhythmias and sudden death (Alpert, 1990; Cohen, Kaplan, & Manuck, 1994).

As with most chronic disease processes, CHD has a multifactorial etiology (Leon, 1987, 1995; Smith & Leon, 1992). Coronary risk factors include a 'rich' diet, cigarette smoking, above-optimal levels of serum total and low density lipoprotein cholesterol (LDL), reduced levels of high density lipoproteins (HDL) cholestrol and elevated levels of systolic and diastolic blood pressure. Other important controllable variables known to increase risk are physical inactivity, stress, obesity, and diabetes mellitus (Leon & Norstron, 1995; Stamler, 1992). In cardiovascular research, Type A personality characteristics, such as high competitiveness, time urgency, and work overload, have been found to correlate with CHD (Friedman, Powell, & Thorensen, 1987). Other behaviour patterns include hostility, depression and lack of social support. Demographic characteristics indicate that age and gender strongly influence the degree of risk.

The severity of atherosclerosis and the risk of CHD progresses with age more quickly in men than women until after menopause. Women over 65 years are at a greater risk of CHD than men (Becker & Corras, 1992). A consequence of this imbalance is that much of the literature on coronary patients focuses on male patients and their caregiving wives (Biegel et al., 1991).

A myocardial infarction is exemplary of an acute life-threatening presentation of a chronic illness (Byrne, 1987). Improvements in medical therapy have increased survival among myocardial infarction patients (Ockene, Doerfler & Ockene, 1990). Each individual has an unique outcome after a myocardial infarction episode. The multidimensional nature of outcome is well documented in the literature (Byrne, 1987). Medical complications may cause recurrent infarction, discomfort, disability, and protracted incapacity. The psychological and social consequences of this major cardiac event are variable, often profound, and sometimes as severe or even worse than the physical disease itself (Brecht, Dracup, Moser, & Riegel, 1994; Ockene et al., 1990). A significant minority of patients, as many as 25%, continue to experience distinct psychosocial problems as much as 24 months following myocardial infarction (Croog, 1983; Mayou, Foster, & Williamson, 1978a; Wilkund, Sanne, Vedin, & Wilhelmsson, 1984). The recognition of quality of life as a legitimate index of patient outcome after myocardial infarction has substantially expanded the realms of cardiac patient management (Byrne, 1987).

Evidence of a successful recovery from myocardial infarction, for many patients, is a return to work without loss of status and earning (Cay, Vetter, Philip & Dugard, 1973). Occupational outcome has been regarded as an important index that may occur at three levels. First, it can be defined as whether or not the patient is able to return to active and productive paid employment. Second, a delay may occur between onset of myocardial infarction and resumption of active employment. Third, the patient may have to eventually resume work and accept a job involving decreased activity or diminished status and responsibility. More recently, Fletcher, Hunt, & Bulpitt (1987) refuted the assumption that a return to work is an accurate indicator of improvement in quality of life after a heart attack.

Substantial evidence in the literature indicated that the social and psychological contexts surrounding acute cardiac episodes influence cardiac outcomes and the overall quality of life of patients and their families (e.g., Ell & Dunkel-Schetter, 1994; Fletcher et al., 1987; Folks, Blake, Fleece, Skol, & Freeman, 1986; Williams et al., 1992). Depression is an important risk factor for mortality following myocardial infarction, and is largely independent of cardiac disease severity (Waltz, Badura, Pfaff, & Schott, 1988; Wiklund, Sanne, Vendin, & Wilhelmsson, 1984). The impact of depression, depressive symptoms, or a history of depression parallels the impact of traditional risk factors, such as a previous heart attack (Havik & Maelands, 1990; Frasure-Smith, Lespérance, & Talajic, 1995). Conn, Taylor, & Wiman (1991) found that depressive scores accounted for 49% of the variance in quality of life scores of older adult heart attack survivors 12 to 24 months after their initial infarction. While, Watz et al. (1988) found that among 400 men recovering from their first myocardial infarction 33% showed substantial depressed mood at a three year follow-up.

Other important psychological variables that may influence prognosis following myocardial infarction are psychological distress or anxiety (Follick et al., 1988; Frasure-Smith, 1991) and social isolation or low social support (Case, Moss, Case, McDermott, & Eberly, 1992; Ruberman, Weinblatt, Goldberg, & Chaudhary, 1984; Ell & Dunkel-Schetter, 1994), and those patients with high levels of anger directed inward (Frasure-Smith, Lespérance, & Talajic, 1995). Each of these variables contribute independently of each other to the risk of recurrent cardiac events, and are largely independent of cardiac disease severity (Frasure-Smith, Lespérance, & Talajic, 1995).

Patients' misconceptions about the myocardial infarction often contribute to depression (Hackett, 1985). The basis of depression is thought to be the perceived threat of invalidism, loss of autonomy and independence. Primary stressors described include the threat of sudden death, depression due to inactivity and job uncertainty, depression due to deprivations (e.g., reduced eating, no smoking), and fear of recurrent heart disease (Ockene, Doerfler & Ockene, 1990; Zimmerman & Vyden, 1983). Findings emerging from the literature suggest that women with cardiac illness are more symptomatic, more depressed, experience poorer functional capacity and adjustment (Holahan, Moos, Holahan, & Brennan, 1995; Murdaugh & O'Rourke, 1988), and reported a poorer quality of life than men (Loose & Fernhall, 1995). Many psychological problems of patients, such as depression, anxiety, and fear, may retard or prevent subsequent vocational, interpersonal, and sexual adjustment (Zimmerman & Vyden, 1983).

Studies have explored heart attack patients' experiences, primarily middle-aged men, at various phases of the illness, from hospital admission through to discharge, and then follow-ups at home within their community during the convalescence period and the longer term recovery period. Older adults and women have been excluded from most of the research pertaining to myocardial infarction survivors (Conn, Taylor & Wiman, 1991).

Several studies of random samples of communities (Berkman & Syme, 1979; House et al., 1982; Welin et al., 1985; Orth-Gormer & Johnson, 1987) found that the more social contacts individuals have, the more likely they are to survive the follow-up period of their first myocardial infarction. Orth-Gomer and Unden (1990) found that a combination of a poor social network and type A behaviour among Swedish men (n=150) was a powerful predictor of cardiovascular death risk during their 10-year follow-up period. Long-term psychosocial adaptation to cardiac illness was better in married men in high-intimacy marriages in contrast with low-intimacy marriages (Waltz et al., 1988).

Most research has focused on spousal support, however psychosocial adjustment during cardiac rehabilitation derives from various sources of social support such as the family, workplace, and broader social networks (Davidson, 1987).

In the early years of coronary rehabilitation, patients had to conform to highly structured, rigid, rather impersonal regimens. More recently, a major shift has occurred that is characterized by a trend to simplify rehabilitative services to meet individual patient's characteristics, requirements, and preferences (Wenger, 1992). This approach to individualized care may prove ideal to address the diverse populations of coronary patients with respect to age, gender, severity of illness, and expectations of outcome.

Considerable variation in patient characteristics may influence the impact of a myocardial infarction on quality of life. Some patients have a high risk for morbidity and mortality early and late after acute myocardial infarction, e.g., a person with residual myocardial ischemia, and demand close clinical observation. While other patients, at lower risk, are free from complications that may indicate a poor prognosis in the postinfarction period, and proceed with a relatively unaltered lifestyle and early resumption of normal activities (Henning, 1990). A low risk status implies a less than 2% risk of cardiac death during the first year after myocardial infarction and a reduced probability of recurrent infarction (Madsen, Hougaard, Gilpin, & Pedersen, 1983). The major need for this patient is education and skill-building required for secondary prevention and a healthy life-style (Henning, 1990). Wenger (1992) stated that the challenge of the 21st century will be to select appropriate coronary care strategies, from the rehabilitation services available, and implement them in a manner appropriate to the individual. She argued that these selections should be based on medical recommendations and personal preferences of the patient to encourage progressive independence and long-term comprehensive care.

Caregiving and Chronic Illness

The caregiving paradigm is complex (Young & Kahana, 1989). Caregiving due to chronic illness and disability represents the increment of extraordinary care that extends beyond the bounds of traditional tasks and activities rendered to family members. Such extraordinary care can be burdensome (Biegel et al., 1991). The role of social and psychological factors in chronic illness is important given that the time and energy commitment potentially stretches over several years. Family caregivers often shoulder the principal, multifaceted responsibilities of chronic illness management (Shillitoe & Christie, 1990).

Anderson and Bury (1988) stated that chronic illness may fall as heavily on the family as on the patient, in terms of the problems created for daily living and family life and through the search by the family for adequate responses to these problems" (p. 7-8). Delbanco (1993) agreed that family members are "very expert witnesses" (p. 17), to what these patients are experiencing, and there are many concerns in the family, "that we're often blind to because we never hear about them" (p. 18).

Chronic illness can create objective stress in families and their members. Families differ in their capacity to cope with these internal and external stressors (Rolland, 1988). The existing literature supports the relationship between patient status and caregiver outcomes. Illness factors that are likely to affect impact on caregivers include the level of physical and cognitive disability, the nature of illness onset and prognosis, the stage of illness in which patients are located, stigmatization, and illness trajectories (Biegel et al., 1991).

Illness severity is a strong and consistent predictor of the amount of stress experienced by caregivers, both during their partners' initial hospitalization after the myocardial infarction, and later in its aftermath (Dhooper, 1983). Caregivers' stress was found to be greater when the patient had been previously hospitalized. Premature or delayed return to normal roles, by patients, may also contribute to caregiver strain.

Suddenness of onset is also a source of caregivers' stress related to myocardial infarction. In the acute stage of illness, individuals experience disequilibrium and disruption as they struggle to cope with the diagnosis of a heart attack and its life-altering implications. Some distress of families may be attributable to personality or behavioral changes in the patient associated with the heart attack. Those who care for the patient may experience confusion and uncertainty or feel overwhelmed by their circumstances not knowing how to respond to the patients needs (Biegel et al., 1991).

Perceived stress or burden appears to be the cornerstone of a complex network of caregiving consequences. A universally acceptable definition of psychological stress has never evolved due to an abundance of diverse and contradictory theoretical interpretations (Burchfield, 1979; Hamberger & Lohr, 1984). Researchers have failed to develop a unified theory of stress which enables one to fully comprehend the dynamics of the stress process. Numerous conceptualizations of stress have resulted in terminological confusions in the stress literature because this word is used to refer to either stimulus, response, or intervening variable or any combination of these factors. Therefore, stress is being perceived as both an independent and a dependent variable (Cox, 1978; Meister, 1981).

Contemporary studies in psychological stress view it as the product of complex adaptive transactions between the person and the environment. The latter can be judged as either damaging, threatening, challenging, or conducive to positive well-being (Lazarus, Averill, & Opton, 1970). The stress responses are thought to be self-initiated and self-propagated. This is due to the fact that the same stimulus configuration will produce quite different patterns of stress response in different individuals and groups (Everly and Rosenfeld, 1981).

People depend on this perceptual-cognitive warning system for survival and growth. Subtle and complex distinctions are required between benign and harmful stimulus configurations to achieve satisfactory adaptation. This dynamic process depends upon cognitive appraisal and reappraisal of divergent situational demands and the individual's resources and coping abilities. The coping activities are crucial mediating processes that may involve a series of physical and/or cognitive responses that function to regulate the environment and restore psychological equilibrium (Lazarus & Folkman, 1984). The recognition of the crucial role of cognition in the stress response has important implications for caregiving.

Researchers (e.g., Biegal et al., 1991; Fontana, Kerns, Rosenberg, and Colonese, 1989) have studied a number of contextual variables that mediate the caregiver's response to CHD. Demographic factors, preexisting caregiver psychosocial status, quality of the caregiver/patient relationship, family life stage, and social support are the variables most frequently discussed.

Young and Kahana (1989) proposed a caregiving-outcomes model that suggests several variables contribute to the burden and stress experienced by the patient and primary caregiver and influence outcomes of a caregiving situation. These variables include attitudinal, behavioral, and socio-demographic factors. In a study of elderly recovering heart patients (n=183), these researchers explored how the role of gender and relationship to the patient would differentially affect caregiver well-being and caregiving outcomes, six weeks and one year after discharge.

These findings also indicated that caregiving stress, involving physical and mental symptoms and social impact, and effort was greatest among wives, particularly younger wives, and daughters, rather than husbands. Wives typically experienced less problems than daughters. Poor health has been found to predict worse caregiver reactions in cancer and stroke, but has not been established in heart disease. Stern (1984) suggested, in an extensive literature review, that 25% of spouses may experience depression or anxiety. There is no conclusive evidence from coronary research that caregivers with higher psychological adjustment scores, prior to the myocardial infarction, adapt better than those scoring lower.

Traditional caregivers have been women (wives, daughters, sisters) due to the social expectation of women as nurturers. The increasing numbers of women, whether by choice or economic necessity, are entering or returning to the work-force (Biegel et al., 1991; Facione, 1994; Pohl, Gwen, Collins, & Given, 1994). It is not known how this trend will affect the quality of life of patients and their families managing and living with their illnesses. Is it possible for an individual to have multiple role responsibilities, such as spouse, parent, caregiver, worker, and housekeeper, and maintain as high a quality of life as possible for both the person with CHD and the family that share that experience?

Considerable evidence supports the beneficial aspects of supportive relationships in facilitating recovery from physical illness (e.g., Cohen & Syme, 1985; Wortman, 1984). There is growing consensus that social support is a multidimensional concept. Despite the lack of a multidimensional definition of social support (Cohen, 1988; Heitzmann and Kaplan, 1988) several broad classifications have emerged (King, Reis, Porter, & Norsen. 1993). Many researchers have emphasized the need to identify specific types of support that may be helpful in different contexts or situations. The types of support found in the caregiving literature include: appraisal support, tangible support, self-esteem support, emotional closeness support, and group-belonging support (King et al., 1993).

Fontana et al. (1989) suggested that social support counterbalances psychological stress and acts to both reduce distress and enhance physical recovery. For Lazarus and Folkman (1984) the critical feature that distinguishes psychological stress from other types of stress is the appraisal of harm, loss, or threat that people apply to a noxious stimulus. In his approach, Lazarus conceptualized support as perceived support, that is as the perception that some aspects of social contacts are helpful. In the same manner, psychological distress can be conceptualized as subjectively experienced cognitive and emotional discomfort (Fontana et al., 1989).

Derenowski (1988) stated that social support may be viewed as the extent to which basic social needs are met through interaction and communication with others. A general viewpoint from the literature on support is that illness, distress, and stress mobilize others to come to a person's aid (e.g., Cutrona, 1986; Gore, 1981), particularly the spouse. However, much ambiguity regarding the impact of social support on health still exists within the literature (Leppin & Schwarzer, 1990).

Stanley and Frantz (1988) stated that for an individual with chronic illness and the spouse, the marital situation is of particular importance, for it is within the social context of the family that such illness occurs and is managed. Burke and Weir (1984) reported that of all possible social contacts, both men and women choose their spouse as the person they would likely turn to for help with their problems.

Perceived spousal support is an essential resource for positive psychosocial adjustment and adaptation during recovery from myocardial infarction (Mayou, 1984; McIvor, Riklan, & Reznifoff, 1984). Spouses seem to impact psychosocial adjustment indirectly by influencing patients' experiences of dysphoria or emotional distress (Brecht et al, 1994). Badger (1992) examined the coping responses, lifestyle changes health perceptions, and marital adjustment of middle-aged women and men with cardiovascular disease and their spouses. Findings indicated that gender differences exist in coping and adjustment to CHD. Female patients minimized the impact of CHD on their lives, reported less lifestyle change, better health perceptions and greater marital adjustment than male patients. Husbands of women with CHD reported that the illness exacerbated existing martial distress.

Blood and Wolfe (1960) stated that the spousal system is a resource for affection, companionship, and ego strength in times of social and psychological crisis. Patients with a supportive partner may appraise their resources as adequate and respond with less depression, anxiety and anger in the illness context (Brecht et al., 1994; Lazarus & Folkman, 1984). Consequently, the reactions of spouses are an important consideration because their attitudes towards the chronically ill person may determine how effectively the latter utilize their remaining capacities (Grant & Alves, 1987).

Those couples with better preexisting relationships, greater marital cohesion and more effective communication skills withstand the onslaught of heart attack better than those in poorer marriages (Mayou, 1984; Waltz, 1986). Elderly wives caring for disabled husbands experienced drastic changes in the marital bond that caused disintegration and disruption of the marital relationship (Croog & Fitzgerald, 1978; Wilson, 1970). Riegal (1989) concluded that emotional isolation and long-standing marital difficulties would make changes required for adjustment and adaptation more difficult. In summary, the relationship between marital quality and dysphoria appears to be reciprocal, so these constructs may demand equal attention during intervention (Brecht et al., 1994).

Overview of Quality of Life Research

Quality of life has emerged as an important attribute of clinical investigation and patient care (Cella, 1992; Gill & Feinstein, 1994). Researchers have employed multiple frameworks, methods, and instruments to examine a diverse array of populations (Testa & Nackley, 1994), to predict patient outcomes (Ganz, Lee & Siau, 1991; Jenkins, Jono, Stanton, & Stroup-Benham, 1990), and to evaluate pharmacological agents in clinical trials (Rosenblum, Rosen, Pine, Rosen, & Borg-Stein, 1993; Testa et al., 1993).

Despite the proliferation of instruments (Spilker, Monlinek, Johnson, Simpson, & Tilson, 1990) and the burgeoning literature (Guyatt, Feeny, & Patrick, 1993) little agreement has been attained about existing definitions, and no unified approach has been devised to measure quality of life (Gill & Feinstein, 1994). Arguably it is not easy to achieve integration or synthesis of perspectives or methods in all related fields of health, behavioral, social, and therapeutic research. In contrast, relying upon a singular approach could limit our understanding of this complex phenomenon at our present state of knowledge (Levine, 1995). Three major issues arose from examination of the clinical research that assesses quality of life: conceptualization of the construct, the need for and value of a "gold standard" of measurement, and practical administration. (Bergner, 1989). These issues will be discussed in the following sections.

Definitions of Quality of Life: A Historical Perspective

Quality of life research has not moved beyond the struggle with definition. The term "quality of life" is often used interchangeably with other terms intended to describe a patient's health, such as "health status", "life satisfaction", "well-being", or "functional ability" (Day, 1993; Gill & Feinstein, 1994). Van Dame, Somers, and van Beck-Couzijn (1981) found that from a literature survey of about 100 scientific publications, in which this concept was used, it appeared that rarely was a definition of this term given. Similarly, Gill and Feinstein (1994) randomly selected 75 articles from 579 referenced in a recent Quality-of-life Bibliography, and found that more than half the citations did not mention the term "quality of life".

Historically, the term was briefly mentioned by Pigou (1920) who explored the consequences of working conditions on the welfare of workers. It was not until several decades later that the term quality of life resurfaced in the 1960s in the "Report of the President's Commission on National Goals in the United States". President Johnson stated that:

> the Great Society is concerned not with how much, but with how good - not with the quantity of goods, but with the quality of our lives. (Schuessler & Fisher, 1985, p. 130)

In the 1960s the study of quality of life was pioneered in survey research with the general population. In one of the first attempts, Cantril (1965) devised the Self-Anchoring Ladder Scale which required individuals to identify their satisfaction with life, based on one of ten "rungs" ranging from "absolutely rotten" to "perfect". In the 1970s, social researchers (Andrews & Withey, 1976; Campbell, Converse, & Rodgers, 1976; Lui, 1975) began to focus on the well-being of individuals. Various components of life satisfaction were examined, such as job, financial circumstances, family, marriage, friends, recreational pursuits and the environment (Hawthorn, 1993).

As early as the 1980s, quality of life research had arrived at a juncture. Many investigators became interested in the concept, and different avenues were created (Day, 1993). Two primary dimensions that developed in parallel involved objective and subjective indicators. Attempts to delineate the main components of quality of life included subjective and objective indicators of both physical and psychological phenomena (Ferrans & Powers, 1985; Jones, Fayers, & Simons, 1987; Krupinski, 1980; Lubkin, 1986; Najman & Levine, 1981; Testa & Simonson, 1996; Wenger et al., 1984).

Sociologists were interested in external, objective indicators such as income, housing, level of education and pollution at the societal level. Indices were constructed by researchers using one or more domains to assess the utility of social policies prior to and after an intervention e.g., election. During the same period, the broader cultural appreciation for quality of life exerted pressure on the medical profession to include the term as an outcome measure in clinical trials. Indeed quality of life outcome measures became a popular way of assessing the impact of medical technology and interventions. Medical practitioners preferred to use the term "health-related quality of life" to refer to the impact of health conditions upon function. This definition may be independent of non-health-related components (Kaplan, 1994; Rice, 1984).

In more recent years, strong counterpressures against quantification have emerged. Interest in alternative paradigms were stimulated by a growing dissatisfaction with the patent overemphasis on quantitative methodologies (Guba & Lincoln, 1994). Qualitative research gained momentum, and new attempts were made to clarify and critique the fundamental assumptions regarding quality of life.

Some investigators (Benner, 1985; Briscoe, 1985; Campbell, 1981; Oleson, 1990) subscribed to transcendental phenomenological approaches in efforts to define quality of life. They acknowledged that individuals differ in how they perceive and experience their lives. They argued that an individual's quality of life cannot be determined adequately by only objective indicators in nature. Brentano (1973) and Schutz (1973) expressed a similar conviction that progress cannot occur without the strict consideration of actual lived experience. Assumptions associated with Husserl's (1970) theory of the phenomenological method were applied to the analysis of the concept of "subjectively perceived quality of life". Benner (1985) suggested that phenomenology could indicate how:

> quality of life can be approached from the perspective of quality of being, and does not need to be approached merely from the perspective of doing and achieving. (p. 5)

Many researchers have attempted to estimate quality of life by rating overt patient behaviour. Such efforts neglect the patients' perspective. Subjectivity refers to patients' appraisal of and satisfaction with their current level of functioning compared to what they perceive to be possible or ideal (Cella & Cherin, 1988). Patient perceptions of their illness and treatment involve dynamic interplay between expectation, adaptation, and self-report of well-being, variable across time and situations. The fundamental component of subjectivity is particularly important when quality of life concerns drive treatment decisions.

To date, no quality of life measurement approach has succeeded in obtaining the patient's appraisals of quality of life by occluding premorbid characteristics from disease and treatment morbidity. Many would argue that this dilemma is irrelevant because a patient's perspective is valuable, regardless of etiology. Testa and Nackley (1994) stated that three properties of quality-of-life measures influence how and how well the hypothetical constructs are assessed. These constructs and the corresponding measurement scales are multidimensional, multilayered and often measured indirectly.

There is a clear consensus that quality of life is a multidimensional construct. There is, however, considerable debate as to the specific nature of these dimensions (Kaplan, 1994). Flanagen (1978, 1982) attempted to delineate the main components of quality of life. He identified physical and material well-being, interpersonal relationships, social and recreational activities, and personal development and fulfilment as domains. Quality of life has also been portrayed as a personal and global evaluation of the good or satisfactory life characteristics (Szalai, 1980), or the degree to which a person's physical, psychological, social, activity, structural and material needs are met (Hornquist, 1982).

In a review of selected definitions (Oleson, 1990), the perceived levels of “satisfaction” and “happiness” were the two critical attributes most frequently identified as manifestations of subjectively or positively perceived quality of life. The conclusive construct incorporated a cognitive experience manifested by satisfaction with life domains of importance to individuals, and an affective experience manifested by happiness with these important aspects of life.

Specific life domain antecedents elucidate the why and with what individuals are satisfied and happy. Four broad dimensions, identified by Ferrins and Powers (1985) as a result of an extensive literature review, have been shown to influence subjectively perceived quality of life: socioeconomic, family, health and functioning, and psychological/spiritual indicators. The positive consequences of subjectively perceived quality of life are uniquely described and individually interpreted as an opportunity for personal growth and self actualization (Gillingham, 1982). Patrick and Erickson (1988) conceptualized "health-related quality of life" to include functional status, social opportunities, health perceptions, impairments, and life duration. Bergner (1989) cited a similar multidimensional definition which included symptoms, functional status, role activities, social functioning, emotional status, cognition, sleep and rest, energy and vitality, health perceptions and general life satisfaction.

Küchler (1989) devised a multidimensional pictorial representation that incorporated three primary dimensions: reference, time and experience in a grid format. Each dimension was comprised of subjective experiences and objective factors. The reference dimension provided the individual's context as either family, social group, or a cultural/political framework. The dimension of experience included physical status, in terms or functional capabilities and disease or treatment symptoms, psychological status , involving both cognitive and emotional aspects, and interpersonal relationships. The socioeconomic domain included financial situation, environment, leisure pursuits, and work performance. Spirituality consisted of religious faith, meaning of life, and other ethically motivated beliefs. Finally, the time dimension added a temporal component whereby quality of life was perceived as the compilation of past and present experiences as well as future goals and expectations. Küchler (1989) proposed that the interaction of the three dimensions portrays an individual's quality of life at a particular point in time. Wood-Dauphineé and Küchler (1992) stated that this representational model has limited practical use due to it's diversity, but may be useful as an organizing framework for discussion of quality of life in rehabilitation research.

Jenkins et al. (1990) identified five major dimensions, by factor analysis, of health-related quality of life of individuals in recovery from coronary artery bypass or cardiac valve surgery. These dimensions were low morale, symptoms of illness, neuropsychological function, interpersonal relationships and economic employment.

In an assessment of quality of life in clinical trials of cardiovascular therapies, Wenger et al. (1984) stated that quality of life,

> denotes a wide range of capabilities, limitations, symptoms, and psychosocial characteristics that describe an individual's ability to function and derive satisfaction from a variety of roles. (p.908)

They defined three major components of quality of life as functional capacity, perceptions, and symptoms and their consequences. Functional capacity involved the capabilities to carry out daily life activities, social function, intellectual function, emotional function and economic status. Each of these five subcomponents had further subscales. Changes in the patient's subjective appraisal of functional capacities along with perceptions of general health status, level of well-being and life satisfaction was the second component. The third major component explores how quality of life may be altered by symptoms of disease, impairment, recurrent clinical events or drug therapy.

Recently, Testa and Simonson (1996) proposed that the distinct domains of "health-related quality of life" are physical, psychological and social areas, with each containing many components. These researchers stated that measurement of quality of life should address both objective assessments of functioning and subjective perceptions and expectations, perceived as important by the respondent, and susceptible to being positively or negatively influenced by disease and interventions.

Their conceptual scheme suggested that the objective assessments (on the *y* axis), defines the person's degree of health, while the individual's subjective perceptions (on the *x* axis) translate the objective assessment into the actual quality of life experienced (*Q*). Hence, two people with the same objective health status and different expectations may have very different qualities of life. Testa and Simonson (1996) concluded that questions formulated from each domain and statistically analysed to yield scale scores may result in a measurement scale (*Z*) corresponding to the true *Q* value.

Despite advocating the importance of the patient's perceptions in quality-of-life assessment, Testa and Simonson (1996) appeared to continue to rely on more objective measures to assess changes in quality of life, because they are "easier to interpret" (p. 838). A hypothetical model provided in the article, describing the role of quality of life in determining the net benefit of therapy for a chronic disease, paradoxically reduced patient characteristics to simply "compliance" to various treatments.

It is evident that efforts to demonstrate the links among medical interventions, clinical and physiological changes, and quality of life continue to present researchers with a formidable task. Nevertheless, the difficulty of investigating the complex impact of illness and their medical regimens on quality of life of individuals and families should not deter them from attempting to answer clinicians' questions, while upholding the integrity of the people who face the daily challenge of chronic illness.

Disease-Specific vs. General Approaches

The study of quality of life was pioneered in survey research with the general population. Since 1965, a proliferation of scales measuring global and specific indicators of quality of life has evolved. Typically, the development of such scales has relied upon those domains specified by the investigators using a variety of approaches such as surveys (e.g., Andrews &Withey,1976; Campbell, Converse, &Rodgers, 1976), literature reviews (e.g., Ferrans & Powers, 1985), and critical incident techniques (e.g., Flanagan, 1978).

Most investigators have designed global or generic quality of life measures for use with any population or condition. Kaplan (1994) argued that the purpose of quality of life measures is to determine the impact of disease on general function (physical, social and emotion). Examples of some of the more commonly used measures include the Index of Activities of Daily Living (ADL) (Katz et al., 1963), the Nottingham Health Profile (Hunt & McEwan, 1983), The Quality of Well-being Scale (Bush, 1984), and the Sickness Impact Profile (SIP) (Bergner et al., 1981). Kaplan (1994) believed that general quality of life measures adequately capture many different dysfunctions associated with cardiovascular disease, so a generalized approach is sufficient. In contrast, Testa and Simonson (1996) stated that global assessment is "useful" but often leaves quality of life ambiguously defined and makes interpretation difficult.

Some researchers (Wenger & Furberg, 1990) argued that there are clinical advantages to using disease-specific measures. These instruments can focus on the domains most relevant to the condition and address changes that are unique to an identified population or illness. For example, the New York Heart Association functional classification can assess physical activity limitations in a variety of cardiovascular diseases. Researchers who prefer disease-specific approaches need to refrain from using only clinical indicators of a specific disease (Kaplan, 1994). Many domains of interest may also vary with , for example, the stage or severity of that illness. Another major problem of disease-specific measures is that one cannot compare quality of life outcomes across populations with different diseases (Wenger & Furberg, 1990).

Researchers in oncology and palliative care have proposed various dimensions that may contribute to the construct of quality of life. Schipper and Levitt (1985) identified four dominant contributors in relation to the quality of life composite: physical/occupational function; logical state (e.g., freedom from depression, anxiety); sociability (ability to maintain social interactions); and somatic comfort (freedom from discomfort). Aaronson (1986) presented a taxonomony of dimensions of quality of life that included disease symptoms and treatment side effects, functional status, psychological distress, social interaction, sexuality and body image, and treatment satisfaction.

In cancer research, factor analyses and scale aggregated studies have generally concluded that health-related quality of life can be grouped into one of four correlated but distinct dimensions: physical, functional, emotional , and social (e.g., Aaronson & Beckman, 1987; Hays & Stewart, 1990; Aaronson, 1986; Cella, 1991; Schipper, Clinch, McMurray, & Levitt, 1984). Cella (1992) described each of these dimensions. Physical well-being referred to perceived and observed bodily function disruption, such as pain, nausea and fatigue. Physical well-being incorporated the patient's perception of disease symptoms, treatment side effects, and general well-being. Functional well-being referred to one's ability to perform daily activities related to personal needs, ambitions, and social role, such as partner, friend or parent. Emotional well-being was bipolar and reflected both well-being (+ve) and distress (-ve) . The fourth major quality of life dimension was social-well being. The content of this dimension was difficult to define due to its ambiguity and diversity. Social indicators of cancer patients ranged from perceived social support, maintenance of leisure activities, and family functioning to intimacy and sexuality.

Several researchers (e.g., Hays & Stewart, 1990; Aaronson, 1986) found that aspects of the four primary dimensions were related to other dimensions. The functional dimension was correlated but distinct from the physical dimension, while emotional well-being was correlated but distinct from physical well-being. Sexuality was an aspect of the cancer experience that linked all four dimensions.

Measurement Issues

Many researchers have stipulated that a major problem has been the lack of an objective "gold standard" against which to measure the validity of patients' self-reports of their quality of life. Investigators have often embarked on a futile search for the measure that everyone will find appropriate and credible. There is unlikely to be a gold standard, and it may not be desirable to have one (Bergner, 1989; Ferrans, 1992). For example, there is no gold standard for intelligence, yet many psychometrically sound tests exist. In essence, individuals' statements about how they feel about the quality of their lives could in itself be the gold standard. Researchers have questioned whether people can perceive that they have a good quality of life and be wrong (Bergner, 1989; Hadorn, Sorensen & Holte, 1995).

Rigorous evaluation of therapeutic interventions such as pharmacologic treatment, surgery, and preventive strategies depends entirely upon the adequacy and appropriateness of the methodologies employed and the manner in which analytical models are used in interpretation of results (Testa & Nackley, 1994). There is considerable debate about whether outcome measures must necessarily reflect the multidimensional and multilayered structure of quality of life. Two major approaches have contributed to our current understanding of quality of life assessment: the psychometric approach, and the decision theory approach (Kaplan, 1994).

The psychometric approach generates separate measures for each of the many dimensions of quality of life. One of the best-known and widely used examples of the psychometric tradition is the Sickness Impact Profile (SIP) (Gill & Feinstein, 1994; Kaplan, 1994). The SIP has 136 items describing the effect of sickness upon behavioral function. The items are subdivided into three groups of twelve categories: independent, physical, and psychosocial. Categories contained in the independent group include home management, work, eating, sleep/rest, and recreation/pastimes. The physical categories are mobility, ambulation, and body and movement. Psychosocial categories include social interaction, alert behaviour, emotional behaviour, and communication. Percentage scores are obtained for each category and can be plotted graphically to create a profile.

This profile approach is popular with investigators assessing the side effects of medications. Measures such as the SIP or the Nottingham Health Profile (Hunt & McEwan, 1983) indicate how some aspects of quality of life improve while others get worse. For example, patients with cardiovascular disease may show minor improvements in aspects of mobility and role performance, but experience side-effects such as confusion and nausea. Bush (1984) stated that the psychometric approach fails to consider that different health concerns are not of equal value to the patient, such as a runny nose compared to severe chest pains. Gill and Feinstein (1994) agreed that reporting a profile of the scores of individual items or domains may provide rich descriptive information but does not effectively characterize quality of life.

The decision theory or aggregate approach, on the other hand, attempts to weigh the different dimensions of health in order to provide a single aggregate or composite rating. An aggregate quality score attempts to summarize the results of multiple items or domains into a single account of whatever is used as the construct of quality of life. Gill and Feinstein (1994) stated that a composite score serves two useful purposes. First, it enhances the communication of results. Second, it may encourage researchers to establish explicit criteria or "weightings" for the constellation of dimensions, and subsequently culminate in an underlying construct for quality of life. Ware et al. (1981) disputed this contention, stating that "any aggregate measure of health status is like adding apples to oranges".

Bush (1984) argued that the constituent elements of quality of life measures are analogous to different pieces of fruit in a basket. The contents of various baskets may differ and thus some baskets will be valued more than others. A full basket of fresh fruit would be preferable to one which has some pieces either missing or decayed. Bush concluded that the aggregate approach allows clinicians to determine comprehensively whether a treatment makes a person feel better or worse. Wenger et al. (1984) stated that use of a battery of measures, or multidimensional indexes with separate subscales for each dimension, rather than one aggregate measure, may be more prudent. Indeed, the latter approach to assessment would seem more expedient, at least until greater consensus is achieved among researchers about a "core" measurement model.

Gill and Feinstein (1994) conducted a comprehensive literature review , of quality-of-life articles (n=75) published from 1987 to 1991, to evaluate how well quality of life is being measured in the medical literature. The instrument(s) used to evaluate quality of life in each article were also evaluated. The results of this study indicated that only 15% of the investigators in the sample conceptually defined quality of life. Fewer than half the researchers identified the target domains (47%) or gave reasons for selecting the chosen quality-of-life instruments (36%) in their studies.

No attempts were made to distinguish global quality of life from health-related quality of life. Very few patients (17%) were asked to globally rate their quality of life, personally rate the importance of individual items (8.5%), or supplement the stipulated items, previously selected by "experts", with personal responses (13%). The most commonly employed instruments, from a total of 159 instruments, were the SIP (10 times), the Functional Living Index-Cancer (7 times), the Karnofsky Performance Index (6 times), and the Bradburn Affect-Balance Scale (5 times). One hundred and thirty-six instruments were used only once. These findings reiterated the importance of giving individuals the opportunity to "voice" their unique perceptions of their quality of life, and supplement or replace measures developed by "experts" using quantitative models (Gill & Feinstein, 1994).

Measuring patient quality of life. Few instruments exist that were specifically developed within the context of CHD. For example, McGirr, Rukholm, Salmoni, O'Sullivan, and Koren (1991) adapted the Quality of Life Instrument developed by Padilla and Grant (1985) for cancer patients for use with a cardiac rehabilitation program. Wiklund, Herlitz and Hjalarson (1989) employed the Nottingham Health Profile to assess the quality of life and factors influencing quality of life five years after myocardial infarction. Patients reported a relatively high quality of life and seemed well-adjusted. Patients who experienced angina pectoris, dyspnoea and emotional distress reported decreases in health-related quality of life.

Oldridge et al. (1991) developed a disease-specific, health-related Quality-of-Life after Myocardial Infarction (QLMI) questionnaire to determine the effects on quality of life with comprehensive rehabilitation after acute myocardial infarction who showed evidence of anxiety or depression. The QLMI had five factors aggregated into two dimensions: limitations (including symptoms and restrictions) and emotions (including emotional function, confidence and self-esteem). Responses to items were presented as a 7-point scale ranging from "none of the time" to "all of the time".

Hillers et al. (1994) revised the QLMI on the basis of the most frequently identified and important problems, reported by patients, following acute myocardial infarction. Five domains were identified in the 26-item QLMI: symptoms, restriction, confidence, self-esteem, and emotions. The QLMI demonstrated a high degree of reliability and moderate responsiveness when compared to other instruments.

Lim et al. (1993) devised a slightly modified version of the QLMI questionnaire so that it could be self-administered to patients with suspected acute myocardial infarction in a randomized controlled trial of secondary prevention. Factor analysis resulted in three quality-of-life dimensions: emotional, physical, and social, which differed from the original dimensions proposed by Oldridge and his colleagues. Lim et al. (1993) concluded that the revised QLMI could be successfully self-administered and had "good potential" as a quality-of-life instrument. In contrast to Oldridge et al. (1991) and Hillers et al. (1994), Lim and her colleagues rejected a single global index of quality of life. They argued that since quality of life is a multidimensional construct, "the simplicity of such an index merits further consideration" within the context of quality of life following myocardial infarction. These conflicting approaches to quality-of-life assessment mirrored the state of the general quality-of-life assessment literature.

Measuring partner quality of life. Most researchers have used general measurement tools to assess the quality of life, psychosocial adjustment or coping patterns of spouses. For example, the Ways of Coping Questionnaire, the Dyadic Adjustment Scale (DAS), the Social Support Inventory and the General Health Ratings Index are commonly used to assess spouses of CHD patients (Badger, 1990, 1992; Beach et al., 1992; Brecht et al., 1994).

Ebbeson, Guyatt, McCartney, and Oldridge (1990) developed the Quality of Life Questionnaire for Cardiac Spouses (QL-SP) as an objective measure of changes in quality of life of spouses of postmyocardial infarction patients. The 26 items on the QL-SP were categorized into two dimensions: the Emotional Function (EFD) or affective component, and the Physical and Social Function (PSFD) or lifestyle pattern component. The QL-SP was developed through a combination of a literature review and unstructured interviews with cardiac health care providers, cardiac patients and their spouses. An interesting finding occurred during development of the QL-SP when spouses were asked to rate the importance of all the items identified as problems. Those items (78.2%) that were identified spontaneously during the interview were higher in importance than interviewer elicited responses. This evidence reiterates the importance of tapping the "lived experience" in health psychology research.

In summary, the multidimensional, multilayered way in which quality of life is conceptualized will influence the way it is measured and the complexity of the instruments. The problem of defining quality of life and specifying its appropriate indicators is far from resolution (Jenkins et al., 1990). Most measurements of quality of life in the medical literature appear to be aimed at the wrong target (Gill & Feinstein, 1994). Researchers must be cognizant of the specific population and the purposes of their study as they make assessment decisions and implement therapeutic interventions. Development of quality-of-life methodologies should be built on the strong foundations established in clinical research, epidemiology, biostatistics, economics and behavioral science (Testa & Nackley, 1994; Testa & Simonson, 1996), while striving to maintain the integrity of the patient's lived experience. Quality-of-life data may be particularly useful within the context of chronic illness. For example, different treatment regimens may have marginal differences on survival rate of patients, or a highly effective treatment may reduce mortality but be toxic, with resultant morbidity. It may be beneficial to determine how such scenarios impact quality of life and hence therapeutic decision-making.

In the future, low risk coronary patients are unlikely to demonstrate an improvement in survival or a lessening of reinfarction as an outcome of medical care. In this population, morbidity and mortality outcomes are considered insensitive measures of intervention efficacy. Quality of life outcome measures are likely to receive greater consideration in coronary rehabilitative care and may determine the therapy of choice (Testa & Nackley, 1994; Wenger, 1992; Wenger et al., 1984).

Concept Mapping

Concept mapping is a methodological approach that is used to clarify the domain, constituent elements, and underlying structure of a particular phenomenon. The impact on quality of life of patients and partners after a myocardial infarction was examined in this study using concept mapping techniques.

Concept mapping was used extensively, at first, in the area of program planning and evaluation by group and committees (Trochim, 1989a). In psychology, the process of concept mapping was initially used to gain a better understanding of the perceptual themes underlying psychological disorders (Daughtry & Kunkel, 1991). Recent research has included conceptually mapping the dysfunctional beliefs of battered women (Deby, 1993), problems of remarried families (Philips, 1993), staff members' views of a supported employment program for individuals with severe mental illness (Trochim, Cook & Setze, 1994) and the areas of clergy vocational stress (Millar, 1996).

Method

There are three main components in this structured conceptualization process: a) a specified group of subjects use a specified research question to generate ideas, experiences, or thoughts; b) commonalities between participants' responses are grouped together according to common themes using an unstructured card sort procedure; and c) a multidimensional scaling (MDS) analysis is conducted on the card sort data to determine underlying themes. Finally, the results of the MDS analysis are depicted in a spatial configuration or "map" format representing the ideas of interest.

The process of concept mapping allows for careful evaluation of the participant's perspective regarding a phenomenon, in a number of ways. First, it allows one to objectively categorize items into themes using statistical techniques. Typically, qualitative type data is analysed by researchers using subjective judgements without the use of quantitative methodology, such as statistics (Trochim, 1989a). Concept mapping allows one to cluster the qualitative data into underlying themes in a substantively meaningful way, as the experiences are spontaneously reported by patients rather than elicited and interpreted by researchers (Daughtry & Kunkel, 1991; Fitzgerald & Hubert, 1987; Trochim, 1989a). Consequently, this approach allows for a careful evaluation of participants' perspectives regarding a specified phenomenon.

The potential for bias and subjective variability is reduced because the data set is grouped by different sorters rather than a single researcher. The MDS analysis performed on the card-sort data also reduces researcher bias, by suggesting statistically and visually the organizational principles implicit in participants' sorting (Davidson, Richards, Rounds, 1986). This method of identifying the underlying dimensions leaves the respondents' judgements uncontaminated by the investigator's preconceptions (Rosenberg & Kim, 1975). The final concept map graphically displays the interrelationships among the ideas as reflected through the original set of groupings or proximities (Fitzgerald & Hubert, 1987).

In conclusion, concept mapping represents a triangulated combination (Hoshmand, 1989), of thought listing and guided inquiry, multidimensional scaling and cluster analysis, in which qualitative and quantitative analyses are used dialectically (Daughtry & Kunkel, 1993). This approach seemed a valuable way of detecting the themes that constitute the impact of myocardial infarction on the quality of life of patients and partners.

Six specific steps are involved in the development of concept maps (Trochim, 1989b): 1) preparation ; 2) generation of statements; 3) structuring of statements; 4) representation of statements; 5) interpretation of maps; and 6) utilization of maps.

Preparation. Two major tasks must be undertaken before the concept mapping process is begun. First, participants must be chosen and then the specific focus for the conceptualization must be decided (Trochim, 1989b). Concept maps have been developed using a wide variety of participants relevant to the research question, using small homogeneous groups or random sampling methods. A maximum limit for the number of participants was not established , and although groups as large as 80 people have been used (e.g., Daughtry & Kunkel, 1993), typically 10 to 20 individuals is sufficient (Trochim, 1989b). Next, the domain or specific focus of the research must be carefully defined. The open-ended research question must be clearly and simply worded, and have a single focus in order to avoid confusion or ambiguity.

Generation of Statements. Once the participants have been chosen and the focus statement for the conceptualization established, the concept mapping process begins with the generation of a set of statements based on participants' perceptions about the research question. A brainstorming process can be used to generate the statements where the subjects are asked to respond, with written phrases or short sentences, about their perspectives on the ways in which they experience the phenomenon (Trochim, 1989b).

Participants' written responses are collected, combined, and redundancies are removed. The intent of this process is to distill from participants' statements an inclusive subset of meaningful items that captured the essence of the phenomena while retaining participants' language and reflected the domain of experience (Daughtry & Kunkel, 1993). For the sorting process, it has been found that no more than 100 statements should be included in the final, edited list of statements (Trochim, 1989b).

Categorization of Statements. A card sorting procedure is performed on the edited list of statements to identify the interrelationships between statements. For the sorting task, each statement is printed in a mailing label format and arranged in random order. Next, a group of participants is chosen for the sorting task, who may or may not, be the same individuals who participated in the initial statement generation. A complete set of statements is given to each sorter, who is asked to place the cards in piles according to "how they seem to go together" as a theme or idea. No restrictions are placed on the participants' sorting strategies other than that they not place each item card alone in a pile or place all cards in one pile. Also each statement can only be placed in one pile.

There are several advantages to this unstructured sorting procedure. The pile sort task can accommodate a larger number of items. Weller and Romney (1988) stated that they knew of no other method of collecting over 100 items of judged similarity data.

Other applications , such as triads or paired comparison ratings, become impaired with large similarity data sets. This sorting procedure can be completed quickly and is easy for subjects to understand.

Multidimensional scaling is conducted on the returned card-sort data to statistically and graphically represent the structure of the data and to interpret this structure, and possibly the implicit underlying dimensions, in a substantively meaningful way (Fitzgerald & Hubert, 1987). Finally, hierarchial cluster analysis is used to uncover conceptually similarity among groups of sorted items (Borgen & Barnett, 1987). Ward's (1963) minimum variance method is used to optimize distinctiveness across clusters.

Representation of Statements. The concept mapping analysis begins with the structuring of the returned sorts. First, a N x N binary similarity matrix (X_{ij}), or square table, is constructed by assigning values of either zero or one using each person's sorting results. Second, a total N x N group similarity matrix (T_{ij}) is obtained by summing across the individual X_{ij} matrices. Any cell in this matrix may have integer values between zero and the total number of people who sorted the statements. This value represents the number of people who placed an item *(ij)* pair in the same pile.

Three steps are involved in the representation of the conceptual domain. The total similarity matrix T_{ij} is analysed using nonmetric (MDS) analysis with a two-dimension solution. This analysis yields a two-dimensional *(xy)* configuration of the data set, which locates each statement as a separate point on a map. Those statements sorted together more frequently are located more proximately in two-dimensional space. Second, the MDS configuration of the statements is partitioned into nonoverlapping hierarchial clusters. Finally, concept maps are generated as either "point maps" or "cluster maps" where the points are enclosed in boundaries (Trochim, Cook, & Setze, 1994).

Interpretation of Maps. This step involves interpretation of the results of the concept mapping analysis. It involves informed conjecture about the possible structure participants' imposed on the items in the sorting task (Daughtry & Kunkel, 1993). Each cluster or theme grouping is visually examined and is given a title which seems to contribute most to the uniqueness of that cluster. This labelling process can be completed by the sorters or by the researcher (Trochim, 1989b). The ideas can be qualitatively classified into hierarchial concepts after initial articulation of the constructs, which can be useful with some data sets (Novak & Gowin, 1984). Finally, a concept map can be constructed which is simply a visual portrayal of the cluster list and the conceptualization process.

Utilization of Maps. The results of a concept mapping process can be used to gain a better understanding of the participants' perspective on a specified phenomenon, and plan or evaluate intervention programs. Trochim (1989b) stated that each grouping can be viewed as a measurement construct to guide future research. The concept map could be also used for communication and educational purposes because the visual representation of the constructs facilitates greater understanding of the essential ideas.

In conclusion, the purpose of this study is to attempt to answer two research questions: 1. What are the reported experiences of individuals who have had at least one myocardial infarction and of their partners? 2. What are the themes or categories underlying their identified experiences? It is hoped that this research will provide valuable information to health-care providers counselling patients and partners, dealing with the impact of a myocardial infarction, so that they might improve their quality of life.

CHAPTER III

Methodology

A review of the quality of life literature demonstrated a need for examining the personal experiences of post-myocardial infarction patients and their partners, from participants' own unique perspectives. As a result, multidimensional scaling and hierarchial cluster analysis were used to develop a graphic conceptual framework of the perceptions of the impact on quality of life of patients and partners following myocardial infarction. Specific research questions addressed in this study included: 1) What were the reported experiences of individuals who have had at least one myocardial infarction and of their partners?; 2) What were the themes or categories underlying their identified experiences?

This study comprised of two distinct parts. Phase One involved the collection and identification of experiential data as reported by both patients and their partners. Phase Two involved representing the generated statements as they relate to themes, depicted graphically in concept maps. This study received ethical reviews by committees in the Department of Educational Psychology and at the University of Alberta Hospital.

Phase One: Generation of Statements

The following section is a detailed explanation of how statements were collected.

Participants

Phase One of the study required statements from a sufficient number of patients and their partners to ensure the saturation point for reported experiences was attained. Participants in all phases of this study were recruited, with the cooperation of their specific cardiologists, from a registry of post-myocardial infarction patients in the Division of Cardiology at the University of Alberta Hospital, Edmonton. Participants were solicited from a list of patients (n = 70) who had attended the hospital for stress tests. Participants had to have experienced at least one heart attack within the last 36 months to be included in this sample.

Procedure

Prospective participants were randomly selected from lists provided by their cardiologists, of patients who have had a myocardial infarction. A package of forms was mailed seperately to both the patient and their partner. Each package contained an introductory cover letter explaining the nature of the study and detailed instructions for generating statements experienced by 1) the patient, and 2) the partner (see Appendix A), a response sheet for completing demographic information and for answering the research question (see Appendix B - patient and Appendix C - partner), and finally, a form to agree to participate in the sorting task (see Appendix D).

Potential participants were informed that permission to contact them had been obtained from their cardiologist and that their involvement in this research was voluntary. Participants were informed that refusal to participate in the study would in no way influence their or their partner's medical treatment. It was indicated that all their responses would be completely confidential. Participants were instructed that the return of the questionnaire was viewed as consent to participate in the study. To ensure anonymity, participants were instructed not to sign their name on the response sheet. If participants were willing to take part in Phase Two of the study they were asked to also complete the

Agreement to Participate in Sorting Task form. A seperate envelope was provided and participants were instructed to return all completed forms by self-addressed, pre-paid post.

Participants generated statements using an open-ended questionnaire format that was guided by a specific prompt. This open-ended method encourages participants to express themselves in a context of neutrality and anonymity, and allows respondents sufficient time to consider their answers (Kidder, 1981). The focus statements for generating the response for patients read: a) "Describe how having had a heart attack has affected your quality of life", and for partners read: b) "Describe how having a partner who has had a heart attack has affected you". This open-ended prompt was designed to elicit participants' perspective on the phenomenon without overly constraining their response (Daughtry & Kunkel, 1993).

Seven of the seventy packages sent out were returned unopened due to incorrect addresses. Initially, a total of 9 patient response forms (12%) and 6 partner response forms (9%) were completed and returned within the one month cut-off. As a result of this poor response rate, telephone interviews were conducted to determine a) if participants had received the questionnaire, b) if they intended to complete it and return it, and c) whether they would prefer to have a telephone interview instead. Nine additional patients chose to complete the questionnaire and return it. Nine patients and their partners preferred to have a telephone interview. A telephone script, paralleling the mail-out format, was used to conduct the telephone interviews (see Appendix E). Once all of the forms were returned and the telephone interviews were completed, descriptive statistics

Table 1

Demographic Characteristics of Statement Generation and Sorting Participants

Variable	Patients (n = 27)		Partners (n = 23)	
	Mean	Range	Mean	Range
Age (yrs)	64	46-83	51	46-80
Male	22		4	
Female	5		19	
Married (yrs)	34	1-55	26	1-55
Heart Attack	1.6	1-6		
Last Heart Attack (mths)	18	1-36		
Initial Diagnosis (mths)	29	5-136		

	Patients (n = 27)			
	%Yes	%No	M (mths)*	Range (mths)
Symptoms	51	49		
Bypass Surgery	34	66	19.3	2-32
Angioplasty	40	60	15.7	2-36
Rehab. Program	34	66	15.6	1-25

* Mean number of months since bypass surgery, angioplasty, or participation in rehabilitation program.

on the patients (n=27) and their partners (n=23) were computed and summarized (see Table 1). No differences were noted in the interview vs. the mail out data. Data was collected and analyzed seperately for each member of the dyad.

Two master lists of patient and partner statements of their post-myocardial experience were compiled. As each response form of patient and partner statements was returned, the specific statements were compiled to formulate the patient master list and the partner master list. A total of 162 statements were generated by 27 patients (see

Appendix F). A total number of 103 statements were generated by 23 partners (see Appendix G).

Each entire statement list was edited to remove any specific reference to persons, gender or positions, to correct errors in grammar and spelling, to eliminate statements not related to the research questions, e.g., "We moved from Vancouver to Whistler", or that seemed ambiguous or vague, and to split up phrases that had more than one response. The essential meaning of each statement was retained using the participant's wording of the statement. The intent of this editing process was to ensure that the statements were clear, concise, and precise to facilitate their use in the next phase of the study. After the first editing process, there were 188 statements in the patient master list (see Appendix H) and 114 statements in the partner master list (see Appendix I).

A second edit was conducted, by the investigator, on the patient and partner lists to remove redundant statements. The process of compiling a final master list commenced by reviewing the statement list of the second participant and comparing it to the statement list of the first participant. Any statements that had not been previously stated were added to the new master list. Then, the third participant's responses were reviewed and again any new statements were added to the master list. Any duplicated areas were eliminated. This process was repeated with each person's statement list until all areas of the experience of having had a heart attack or being a partner of some-one who has had a heart attack, that were reported, were represented in the edited master lists for patients and partners and all redundancies were eliminated. Redundancy or saturation was judged to be reached when no new statements were presented by participants. Patients' reported experiences were judged to be redundant after the 16th patient (see Appendix J) and the final list of 66 patient statements was considered complete. Partners' reported experiences were judged to be redundant after the 18th participant and the list of partners' experiences was considered complete (see Appendix K).

The master lists of statements comprised of items from both male and female participants. Comparisons of the statements in the lists by gender found no differences in items, so the statements were collapsed together. The final listing of partner statements contained 66 statements. The final lists of patient and partner statements were each randomly numbered to safeguard confidentiality and ensure that one respondent's statements were not grouped together in the presentation of the data set.

The validity of this editing process was increased by submitting the original master lists and the first and second edited lists for evaluation by a chartered psychologist and a graduate student. They were instructed to see if the statements in the final lists captured the essence of the original statements, so no key ideas had been ommitted. They were asked to make suggestions that would clarify and simpify statements, yet retain participants' language. Finally, they were to examine the lists and verify that deleted statements duplicated earlier responses in the set. They were also asked to determine if any duplicated statements remained in the final patient and partner lists. Recommendations made to change statements were considered and incorporated when deemed appropriate.

Phase Two: Structuring of Statements

Phase Two involved two distinct tasks, the sorting of the statements by theme into categories and then analyzing the thematic groupings using a concept mapping procedure. The sorting task was completed by those volunteers from Phase One who agreed to sort. Twenty patients and 17 partners volunteered to participate in the sorting task. Patient volunteers were asked to sort only those statements on the final list generated by patients, while partners were given only statements on the final list of partners. Each of the statements were put on an individual index card. A sorting package was mailed to patients and partners that contained a complete set of statements (either patient or partner) with a cover letter (see Appendix L) and instructions to group the statements into piles which contained common themes (Appendix M - patient; Appendix N - partner).

The cover letter was used to inform the sorters about the purpose and nature of the research. Participants were reminded that they could withdraw from the study at any time and that their anonymity would be ensured. Participants were also reminded that if they decided to withdraw, their decison would not affect their or their partner's medical treatment. A response time of one month was allowed. A total of 15 sorts were returned by patients and 12 sorts by partners within the allotted time. This response represented a 75% return rate for patient sorters and a 71% return rate for partner sorters.

The sorters were instructed to group their set of statements into themes based on similarity of content and meaning using their personal judgements. There were several restrictions in this sorting task. The statements could not be placed in 66 piles of one item each, or one pile consisting of 66 items. Each statement could be placed in only one pile.

The sorters were told to make as many groups as they wished. Statements could be kept separate if they did not fit into any group. The participants were encouraged to label each of their groupings. An example of how to sort some statements into themes and label the groups was provided at the end of the written instructions.

Weller and Romney (1988) pointed out that the outstanding strength of such unstructured sorting in this "pile sort method" is that it can accommodate a large number of items. They stated that it is the method of choice when it is necessary to collect judged similarity data of over 100 items. These researchers also suggested that any sort that had a single pile ("lumper") including more than one third of the brainstormed statements, or smaller categories with finer distinctions ("splitters")should be eliminated from the final analysis. The inclusion of sort data from extreme lumpers, with a small overall sample size, could lessen the interpretability of the maps. As such, two patients' sorts and one partner sort were eliminated.

Data Analysis. The data analysis was conducted and concept maps produced using the Concept System computer software designed by Trochim (1989b) to implement the concept mapping procedure. The analysis began with construction of individual matrices, called binary symmetric similarity matrices, for each of the sorted items. Next, the results from all the sorters were aggregated to obtain a combined group similarity matrix. The data from the group similarity matrix was analyzed using a nonmetric multidimensional scaling (MDS) procedure with a two-dimensional solution. Krushal and Wish (1978) stated that when an MDS configuration is required as the basis on which to display clustering results, a two-dimensional configuration is easier to work with and far more useful than one involving three or more dimensions.

This analysis created a point map representing an X-Y coordinate for each statement. This configuration was based on the criterion that statements piled together most often are located more proximately in two-dimensional space, whereas those sorted together less frequently are further apart (Trochim, Cook, & Setze, 1994). This statistical method has successfully described the latent relationships among variables by spatial representation of proximities, particularly when the underlying relations are not well developed or are not known (Fitzgerald & Hubert, 1987; Krushal & Wish, 1978; Schiffman, Reynolds, & Young, 1981).

A final stress value was computed for the two-dimensional solution of the MDS analysis. The stress value is a numerical index of the stability of an MDS solution and ranges from zero (perfectly stable) to one (perfectly unstable) (Daughtry & Kunkel, 1993). Stress denotes the degree of departure of the observed or calculated similarity from the true or judged similarity among items taken two at a time. A two-dimensional MDS solution was selected because it is more consistent with the concept mapping approach than one involving three or more dimensions. This MDS configuration is desired primarily as the basis on which to display clustering results (Krushal & Wish, 1978).

In the next stage of the data analysis, a hierarchial cluster analysis with Ward's (1963) algorithm was used to define the conceptual domain. The data obtained from the MDS configuration was input into the cluster analysis to group sorted items into internally consistent clusters. The resultant cluster solution was partitioned into any number of clusters and superimposed on the MDS point map. No simple mathematical criterion exists to faciliate selection of the final number of clusters. Consequently, the procedure followed here was to examine an initial cluster solution, that averaged about five statements in each cluster. Then, successively lower and higher cluster solutions were explored with the goal to maintain the integrity of the MDS results through the absence of overlapping clusters. This resulted in acceptance of a cluster solution that preserved the most detail and yielded substantively interpretable clusters of both patient and partner statements (Trochim, Cook, Setze, 1994).

Finally, the MDS configurations of the 66 points for both patients and partners were graphed in two dimensions. These "point maps" illustrated the location of all the statements, with statements closer to each other expected to be more similar in meaning. "Cluster maps" were also created that displayed the original 66 points enclosed by boundaries to form clusters.

Description of the Sample. The average age of patients was approximately 64 years old with a range of 46 to 83 years old. The partners ranged from 46 to 80 years, with an average of about 51 years. Patients stated that they have been married or living with their partners an average of 34 years with a range of 1 to 55 years. The average number of married years for partners was 26 with a range of 1 to 55 years. There were 22 male patients and 5 female patients, and 4 male partners and 19 female partners. The sample was somewhat skewed toward male patients, female partners, and individuals who have been married or living with partners for over 25 years (see Table 1).

The patient data also indicated that 51% of individuals experience symptoms of CHD. Thirty-four percent of patients reported that they had bypass surgery ranging from

2 to 32 months ago (M = 19 mths.), and 40% stated that they previously had angioplasty ranging from 2 to 36 months (M = 16 mths.). Thirty-four percent of patients had participated in a rehabilitation program ranging from 1 to 25 months (M = 16 months).

In chapter IV, the results obtained from Phase One and Phase Two of the study will be reported and discussed. This chapter will include a separate description and discussion of each of the statements and clusters contained in the patient and partner concept maps, along with participant incidence survey findings, and validation interviews of the conceptual themes.

CHAPTER IV

Results and Discussion

Introduction

In this study, the application of a methodological approach, concept mapping, is used to gain an understanding the impact of a myocardial infarction on the quality of life of patients and partners. The intent of this investigation was to obtain a description of the ways in which patients and partners, themselves, construed and experienced a myocardial infarction and identify the underlying themes. Participants' collaboration was sought in clarifying the organization and salience of the various elements of their experiences, rather than adhere to conceptually or diagnostically based a priori formulations. The intent was to minimize investigator bias. In particular, this research was designed in two main phases to answer the following research questions:

1. What are the reported experiences of patients who have had a myocardial infarction and partners of individuals who have had a myocardial infarction?
2. What are the themes underlying the experiences identified by patients who have had a myocardial infarction and partners of individuals who have had a myocardial infarction?

The results of these two phases will be reported and discussed in this chapter.

Phase One

In Phase One, patients (n = 27) and partners (n = 23) were asked to generate statements using a specific opened-ended prompt: "Describe how having (a partner who has) had a heart attack has affected your quality of life", to elicit their individual perspectives on the impact of a myocardial infarction. This process generated 188 patient statements and 114 partner statements. Each master list was edited to remove redundant, irrelevant, or ambiguous statements. The reported experiences of patients were judged to be redundant after the 16th participant. Partners' experiences were judged to be redundant after the 18th respondent. The two resultant master lists consisted of 66 statements for patients and also partners. These lists of statements are presented in Table 2 and Table 3 respectively. These statements were used to develop the concept maps in Phase Two of the study, to determine if the perceived experiences identified by the participants fell into underlying themes or categories.

Phase Two

In Phase Two, the conceptual structuring process commenced with a sorting task where the 66 patient statements were sorted by 15 patients and the 66 partner statements were sorted by 12 partners. The multidimensional scaling analysis (MDS) and hierarchial cluster analysis were conducted on the returned similarity data. Finally, two-dimensional concept maps were constructed to graphically display the patients and partners statements.

The two-dimensional solution of the MDS analysis resulted in a final stress value of .29 for patients and .32 for partners. These stress values, 0.29 and 0.32, represent

Table 2

Final Master List of Patient Statements

Number	Statement
1	I can't drink alcohol any more.
2	It takes me longer to complete simple tasks.
3	I am reluctant to accept any long-term work.
4	My business income has been seriously curtailed.
5	I am unable to do my hobbies.
6	I cannot do yard work.
7	My social life is very limited.
8	I can't travel.
9	The heart attack has virtually cut out my sex life.
10	I am losing my physical fitness.
11	I have heart palpitations.
12	I experience dizziness.
13	I suffer intermittent weak feelings.
14	I suffer pain daily.
15	I am no longer employed.
16	I have **not** tried to maintain the lifestyle changes, suggested by my doctors.
17	My partner has pulled me through the worst times.
18	I want to contribute more to my community but I can't.
19	I have less energy.
20	I find it difficult to concentrate.
21	I am no longer a"go-getter".
22	I feel better and eat better and take vitamin supplements.
23	If anything my life has improved.
24	I seem to want to stay at home more.
25	I worry about my partner.
26	I cannot remember things as well.
27	I appreciate life more.
28	I am generally more relaxed.
29	I worry about my future health.
30	I have more time to socialize with friends.
31	I lack motivation to look for another job.
32	My partner financially supports us.
33	I try to forget about my heart condition and get on with life.
34	Our children are good support.
35	My partner does not go out as much these days.
36	I enjoy being outside and going for walks with my partner.
37	My partner and I take it day to day.
38	I have lost my self-confidence.
39	I worry the hospital cutbacks will affect our quality of life.
40	I am very bored at home.
41	I feel like a burden to my family and friends.

Table 2 (continued)

Number	Statement
42	I am afraid of dying.
43	I take more care of what I eat.
44	It takes much fun out of life.
45	I lost many of my friends.
46	We have survived wonderfully together.
47	I am careful not to over-exert my heart.
48	I am not always consistent with my exercise.
49	I am scared to drive.
50	I have had no problems at all since my heart attack.
51	I have returned to work and feel great.
52	I have not noticed any changes in my quality of life.
53	I can't smoke.
54	I exercise to keep my partner happy.
55	I feel a little depressed some days.
56	Hot or cold weather has a lot of effect on my way of life
57	I seem to be very short of breath at times.
58	I am more aware of minor pains in muscles or indigestion
59	I have to slow down and take rest breaks.
60	I have to leave heavy work to others.
61	I can't go anywhere by myself.
62	I no longer enjoy eating out.
63	I am having a difficult time sleeping.
64	I have more time to indulge in leisure pursuits.
65	I shifted focus away from my job to the home.
66	I can't stand much noise.

Table 3

Final Master List of Partner Statements

Number	Statements
1	My partner and I continue to talk about the heart attack.
2	My partner worries about me, when I don't take care of myself.
3	The heart attack is a continuous subject of conversation with friends.
4	My partner thinks I never worry about him/her.
5	I must not talk about anything when I feel bad.
6	I feel hopeful my partner will get help coping with stressful work situations.
7	My partner shares more of the household chores.
8	I have reduced stressful situations in the home.
9	More time to enjoy the company of friends.
10	I am spending lots of time reading food labels in the stores.
11	I am finding it difficult to find interesting food for my partner's daily needs.
12	I try not to upset my partner.
13	My partner refuses to eat food I prepare.
14	My partner has a shorter fuse.
15	I am often more worried than my partner is.
16	I ensure that my partner takes rest breaks.
17	My partner has sleeping problems that affects my sleep as well.
18	I always watch out for signs of problems.
19	I fear the end could come suddenly.
20	I feel anxious due to health cuts and long waiting lists.
21	I am happy nobody smokes in our home now.
22	I never drink alcohol anymore.
23	I have been experiencing some depression.
24	There are a lot of things we can't do anymore.
25	I have to encourage my partner to exercise.
26	We have to walk to places because he/she can't drive.
27	I get tired looking after my partner.
28	I enjoy spending time with my partner.
29	I don't go out socially as much as I did prior to the attack.
30	I am pleased my partner has more time for our family.
31	I can't drive the car so we stay closer to home these days.
32	I have to do all the physical work.
33	Our quality of life has deteriorated.
34	I had to learn how to care for my partner.
35	It is hard to continue the relaxation exercises we were taught.
36	I can't drive the car so we stay closer to home these days.
37	I felt overwhelmed by the amount of information the hospital staff gave us.
38	I am frustrated because my partner doesn't make an effort to take care of him/herself.
39	My quality of life is unaffected by the heart attack.

Table 3 (continued)

Number	Statements
40	I become concerned if he/she complains of discomfort in his/her chest.
41	I worry about the possibility of my partner having another heart attack.
42	My partner no longer works so income is a big stressor.
43	I take it day to day.
44	Anxiety - for first few months, then I was okay
45	We have lost many of our friends.
46	My partner is willing to help me but is unable to.
47	It is hard to accept the changes in my lifestyle.
48	I make sure that he has taken his medication.
49	I have lost my independence.
50	Social activities are almost zero.
51	I had to take over my partner's chores.
52	I have increased my exercise as a personal preventive measure
53	My partner has not increased his/her exercise.
54	I feel lonely at times because he sleeps a lot.
55	I don't like the restrictions.
56	Overall quality of life has improved.
57	I can't keep up with my partner.
58	I have had to manage more on my own.
59	Switch to cooking with low fat recipes - I enjoy doing this.
60	I get anxious about keeping appointments.
61	If a person isn't on time you think "What has happened?".
62	I have become more watchful.
63	I try to not nag.
64	I had to stop work to take care of my partner.
65	My life is hectic and busy.
66	I would love to travel more, but it would be too difficult for my partner.

reasonably stable solutions. In a study exploring the experience of depression in college students, Daughtry and Kunkel (1993) obtained a final stress value of .27 for a two-dimensional solution. Trochim, Cook, and Setze (1994) examined staff views of a program of supported employment for individuals with severe mental illness, using the concept mapping approach, and accepted a final stress value of 0.31 for a two-dimensional solution of the MDS analysis.

The two-dimensional configuration or "point map" of the 66 patient statements is presented in Figure 1, while the 66 partner statements are displayed in Figure 2. A detailed explanation of the concept maps is provided, as follows, since this way of presenting data may be unfamiliar to many. Each statement produced by participants is represented by a dot or "point" with the number identifying the statement beside it. The placement of points is derived from the MDS solution which spatially represents a matrix of proximities, judged to be similar or dissimilar among other items (Krushal, 1981). The distance between the points reflected the frequency with which the items were sorted together by participants. Hence, points relatively close together on the map represented items often placed together in participants' sorts than items represented by points more distant from one another.

Several pairs of statements fell virtually in the same place on the maps. The premises underlying the analysis assume that these items should be located in close proximity of each other. For example, at the top of the patient map (see Figure 1), statements #23 (If anything my life has improved) and #33 (I try to forget about my heart condition and get on with my life) were located closely together, as expected given their

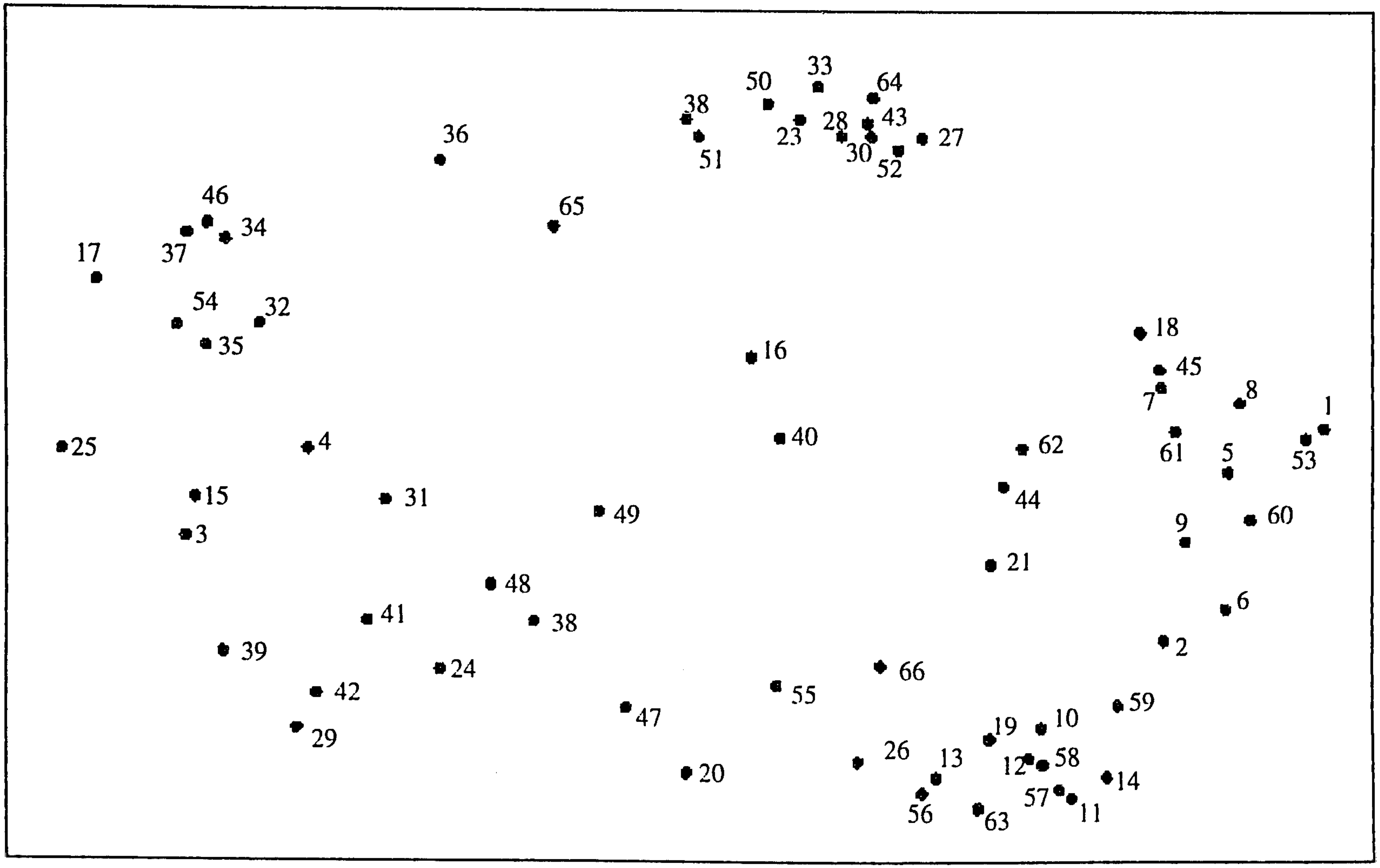

Figure 1: Point map of 66 patient statements

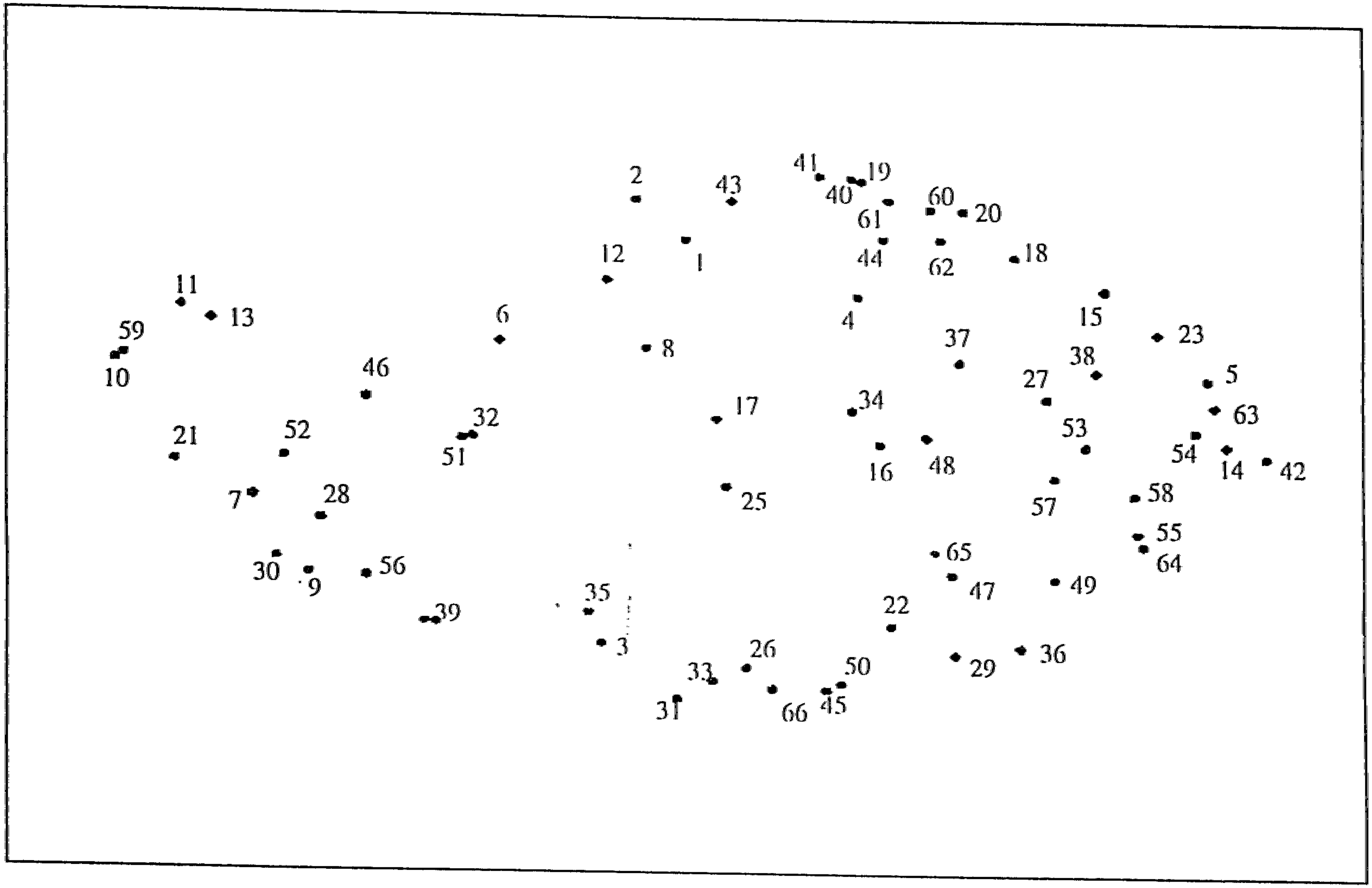

Figure 2: Point map of 66 partner statements

high conceptual similarity. While statement #21 (I am happy nobody smokes in our home now) on the far left of the partner map (see Figure 2) lacks conceptual similarity to statement #42 (My partner no longer works so income is a big stressor) on the extreme right.

A hierarchial cluster analysis with Ward's (1963) algorithm was conducted on the MDS solution as the basis for defining the conceptual domain of both patients' and partners' experiences of how a myocardial infarction affected their quality of life. Ward's algorithm is a minimum variance clustering technique found to give more sensible and interpretable solutions than other approaches (Trochim, 1989b). Lastly, clusters of individual statements were enclosed in polygons and numbered.

The cluster analysis partitioned the MDS configuration, for both patients and partners, into a thirteen cluster solution (one fifth of the total number of statements). There is no simple mathematical criterion for selecting the number of clusters for the final concept maps. Initially, one must use discretion in examining different cluster solutions to prevent fragmentation or over generalization of the statements. The aim of this decision-making process is to arrive at a true partitioning of the space, where there are no overlapping clusters. (Trochim, 1989b; Trochim, Cook, & Setze, 1994).

Interpretation of the results of the concept mapping analysis followed a structured process which occurred in two phases. In the first phase, the initial 13-solution cluster map for patients (see Appendix O) was examined along with a higher (15) and successively lower (12, 10, 9, 8, 7, 6, 5) cluster solutions to arrive at a final cluster solution. In phase two, the initial 13-cluster map for partners (see Appendix P) was evaluated along with successively lower (12, 10, 9, 8, 7, 6, 5) and a higher cluster (15) solutions to determine a final partner map. A judgement was made at each level, for both patient and partner maps, about whether the merger or split seemed substantively reasonable.

The integrity of the multidimensional scaling was maintained by using computed "bridging indexes" to determine the number of clusters. A bridging index is calculated for each statement and ranged from 0.0 to 1.0. Lower values represented statements sorted together often. Higher values represented statements frequently sorted with items farther away on the map. Thus, an item with a higher value was more likely to be a "bridge" or "linking" item having been sorted with various statements. In contrast, a lower bridging index denoted statements more central to the meaning of a cluster (Trochim, 1993).

Similarily, the computer program also provided an average bridging index for each cluster. Statements were judged to be more coherent if the cluster had a low average bridging index. Clusters with higher bridging averages were typically "linking" clusters between adjacent clusters (Trochim, 1993). The appropriate number of clusters, for both patient and partner maps, were determined after careful examination of cluster solutions ranging from 15 to 5. A detailed discussion of the evaluation process used to determine the final cluster solutions, for the patient and then the partner map, will now follow, along with descriptions of each cluster of the final maps. It is important to note that no attempt was made to compare patient and partner statements or their possible interrelationships. Each set of statements for these participants was regarded as separate data sets. The exception was when some respondents made reference to their partners within the context of an item. For example, "we enjoy spending time together" would be an instance where an interrelationship may be discussed during interpretation of the findings.

The Patient Concept Map

Each clustering of the statements was examined in a clockwise direction, commencing in the upper right quadrant of the map, and proceeding down and across the configuration. It was immediately apparent that the 13 and 15-cluster solutions of the patient map were much too discrete. In both cases, clusters contained too few items and appeared to conceptually overlap. Thus, further reduction of the cluster solutions was considered appropriate due to the difficulty encountered during interpretation.

Next, the 5-cluster solution was examined. These clusters were very general and contained more than one theme. For example, cluster #3 included financial constraints, future health concerns and confinement issues. Consequently, this solution was also rejected in favour of a more sensible and interpretable partition of the multidimensional space. It was now evident that the final cluster solution was between 5 and 12 clusters for patients.

The next choice was a 10-cluster solution. This solution was an improvement over the 5-cluster solution because some clear and consistent themes were emerging. For example, in the lower left portion, financial constraints (cluster #5) was now seperated from future health concerns (cluster #6) and confinement issues (cluster #7). The cluster bridging index for these clusters (0.80, 0.82 and 0.76 respectively) remained close to their merged value of 0.80. However, in the lower right section problems persisted with the overlapping of cluster 1 and 2. Clusters #1 and #2 seemed to be closely related. Statements like #7 in cluster 1: "My social life is very limited" appeared to be conceptually similar to #44 in cluster #2: "It takes much fun out of life". Evaluation of cluster solutions ranging from 5 to 9 confirmed that these two clusters were consistently merged as the distinct theme of lifestyle changes encountered by patients who have had a heart attack. Thus, further reduction of the cluster solution was considered appropriate.

Successive cluster solutions were examined and cross-referenced to determine the most appropriate number of clusters. The 6-cluster solution was an improvement over the 5-cluster solution. Confinement issues (cluster #4) emerged as a cluster in the centre of the map, and was now seperated from financial constraints and future health concerns in cluster #3. Further clarification occurred in the lower left corner of the map when cluster 3 was split in the 7-cluster solution. Financial constraints (cluster #3) and future health concerns (cluster #4) emerged once again as seperate clusters as they had done in the 10 cluster solution.

The left side of the map was now regarded as relatively stable since the visual structure of the themes, financial constraints, future health concerns and partner support, was distinct and remained unchanged across the remaining cluster solutions (7 to 10). The difficulty in evaluating the lower quadrant of the map was resolved in the 8-cluster solution (see Figure 3). Two additional clusters emerged that reflected the themes of physiological symptoms (cluster 2) and depression (cluster 3). This seperation improved the bridging index of cluster 2, reducing it from 0.30 down to 0.19.

Inspection of the 9-cluster solution suggested the two new clusters that emerged at the top of the map were both related to improvements in patient quality of life as a result of a myocardial infarction. For example, statements #23: "If anything my life has improved" was similar to statement #33 "I have more time to socialize with my friends" so it seemed more meaningful to include them in the same cluster. Furthermore, the combination of these two clusters in solution 8 resulted in a respectable average bridging index of 0.34. It was concluded that further increases in the cluster solution failed to improve the structure of the configuration. Consequently, this decison resulted in the acceptance of the 8-cluster solution as the one that provided the most clear and concise description of the patient data set. The 8-cluster solution concept map for patients is displayed in Figure 3.

Description of the Patient Cluster Map

Interpretation of the concept map and each cluster involves informed conjecture about how items were sorted by participants. Initial examination of the map involves an attempt to identify implicit dimensional axes around which points may be configured (see Buser, 1989). It appeared that the map was divided diagonally along two dimensions. On the lower right side of the map, the clusters (#1, #2, and #3) seemed to be related to the personal impact of a myocardial infarction on patients' quality of life: lifestyle changes, physiological symptoms, and depression. The upper left portion of the map seemed to identify interpersonal issues, where the myocardial infarction was perceived to influence other lives as well as the patient's own, not only now but in the

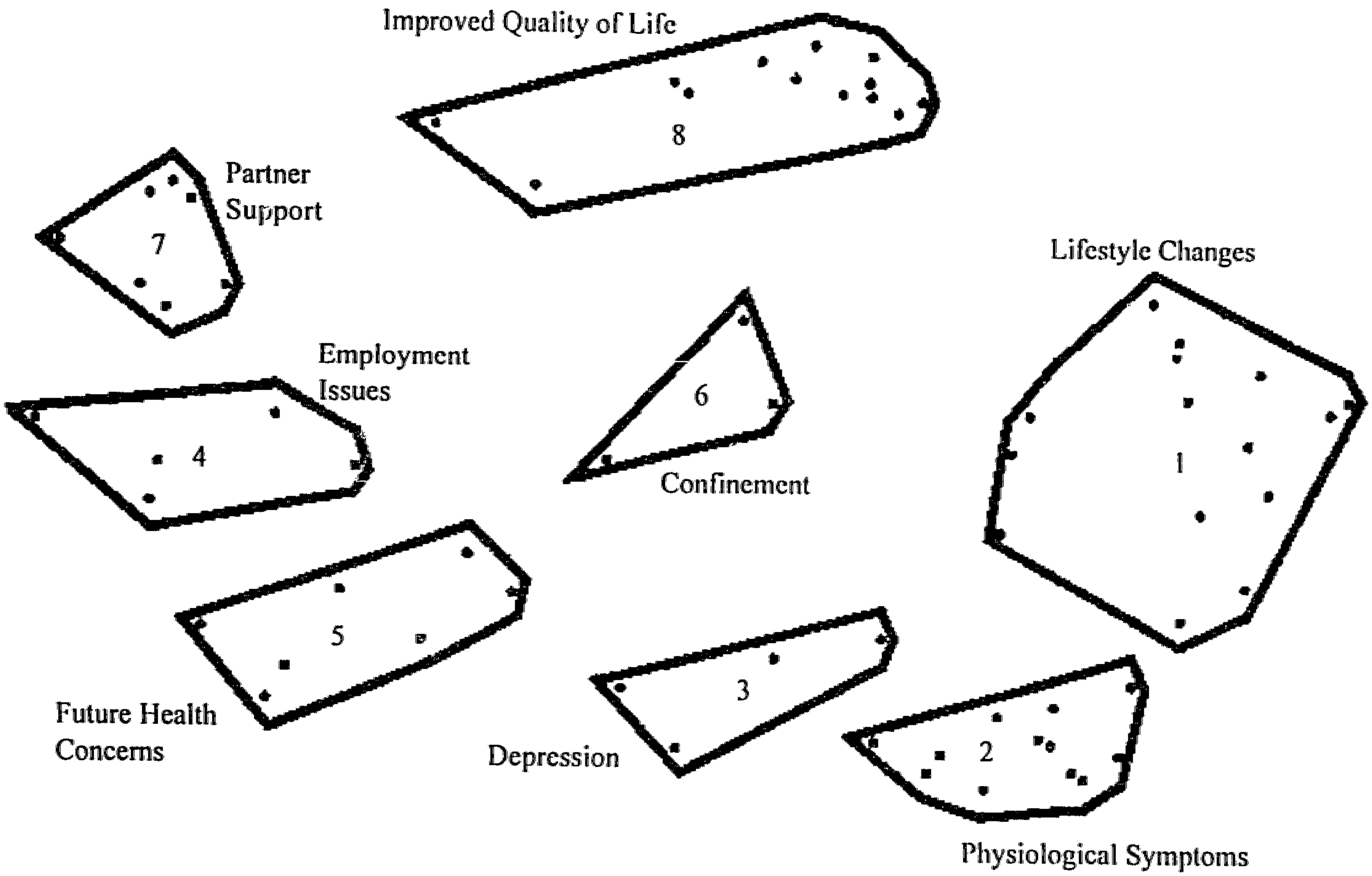

Figure 3: Eight solution concept map of 66 patient statements

future: future health concerns, employment issues, partner support, and improvements in quality of life (#4, #5, #7, and #8 respectively). Constrasting the most dissimilar items in each of these domains illustrated how they were thematically distinct. For example, "I cannot do yard work" (#6) and "I have to slow down and take rest breaks" (#59) were located on the extreme right side, while in constrast "I worry about my partner" (#25) and "My partner has pulled me through the worst times" (#17) were items on the far left side of the map.

Cluster #6 "Confinement" was positioned centrally on the concept map. Confinement may be related to other clusters as a negative consequence of a myocardial infarction on quality of life. It may have reflected resistance to change or rigidity within the patient in relation to self and others. Each cluster was assigned a descriptive label.

The procedure followed to name each cluster was somewhat subjective, but also statistically and conceptually based. Patients were asked to provide labels for their groupings during the sorting task. The bridging index of each item making up the cluster was also considered. The items in each cluster were arranged in ascending order from lowest to highest bridging index. The item or items that contributed most to the uniqueness of the theme of that cluster had the lowest index.

Subsequent items were considered moving systematically from more central (low bridging index) to less similar items (high bridging index). An attempt was also made to use key words from the statements in the actual cluster label. The chosen cluster names reflected the central items as much as possible. The items of each cluster in the 8-solution patient concept map, along with their accompanying bridging indexes and labels, are displayed in Table 4. A detailed interpretation of each cluster of the patient map and their interrelationships follows.

Cluster #1 - Lifestyle Changes. Cluster #1 was located on the far right side of the concept map and contained the most items (23%) of this solution. The statements were related to the lifestyle changes experienced by patients up to 36 months after a myocardial infarction. Some statements presented general limitations imposed by the impact of the myocardial infarction, while others were quite specific. Generally, patients recognized that they were physically restricted to simple tasks (#2), do yard work (#6) or any "heavy work has to be left to others" (#60). Changes in patients' social activities were also evident where their "social life is very limited" (#7), they had "lost many of their friends" (#45), and they "no longer enjoy eating out" (#62). Associated with this theme was not being able to travel (#8) or to go anywhere by themselves (#61).

Individuals expressed generally how the heart attack "takes much fun out of life" (#44). Specific ramifications were also identified. These included not being able to "drink alcohol anymore" (#1), cessation of smoking (#53), and reduction in their sex life (#9). Dissatisfaction was evident in statements such as "I am no longer a go-getter" (#21), "I am unable to do my hobbies", and wanting to contribute more to their community but being unable to (#18). This cluster was labelled "lifestyle changes".

Cluster #2 - Physiological Symptoms. Cluster #2 is adjacent to Cluster #1. This theme seemed to reflect the specific physiological symptoms experienced by patients with CHD and their consequences. Shortness of breath (#57), a lack of energy (#19), dizziness (#12) and intermittent weak feelings (#13) seemed to contribute to a loss of

Table 4

Cluster Items and Bridging Indexes for Eight Solution Concept Map of Patients Who have had a Myocardial Infarction

Cluster	**Statements (#)**	**Bridging Index**
	Lifestyle Changes	
One	It takes me longer to complete simple tasks (#2)	0.40
	I can't drink alcohol anymore (#1)	0.47
	I cannot do yard work (#6)	0.47
	I am unable to do my hobbies (#5)	0.48
	I can't smoke (#53)	0.49
	I no longer enjoy eating out [illegible]	0.52
	I can't travel (#8)	0.56
	It takes much fun out of life (#44)	0.58
	I am no longer a "go-getter"(#21)	0.59
	My social life is very limited (#7)	0.61
	I can't go anywhere by myself (#61)	0.61
	I lost many of my friends (#45)	0.62
	The heart attack virtually has cut out my sex life (#9)	0.64
	I have to leave heavy work to others (#60)	0.64
	I want to contribute more to my community but I can't (#18)	0.80
	Cluster Average	0.57
	Physiological Factors	
Two	I seem to be very short of breath at times (#57)	0.00
	I have heart palpitations (#11)	0.08
	I suffer pain daily (#14)	0.10

Cluster	Statements (#)	Bridging Index
Two	I experience dizziness (#12)	0.16
(cont'd)	I have less energy (#19)	0.18
	I am having a difficult time sleeping (#63)	0.18
	I am more aware of minor pains in muscles or indigestion (#58)	0.20
	I suffer intermittent weak feelings (#13)	0.23
	Hot or cold weather has a lot of effect on my way of life (#56)	0.25
	I am losing my physical fitness (#10)	0.26
	I have to slow down and take rest breaks (#59)	0.28
	I cannot remember things as well (#26)	0.36
	Cluster Average	0.19
	Depression	
Three	I feel a little depressed some days (#55)	0.51
	I can't stand much noise (#66)	0.54
	I find it difficult to concentrate (#20)	0.57
	I am careful not to over-exert my heart (#47)	0.92
	Cluster Average	0.63
	Employment Issues	
Four	I lack motivation to look for another job (#31)	0.73
	I worry about my partner (#25)	0.76
	My business income has been serious curtailed (#4)	0.81
	I am reluctant to accept any long-term work (#3)	0.83
	I am no longer employed (#15)	0.89
	Cluster Average	0.80

Cluster	Statements (#)	Bridging Index
	Future Health Concerns	
Five	I have lost my self-confidence (#38)	0.62
	I worry the hospital cutbacks will affect our quality of life (#39)	0.76
	I worry about my future health (#29)	0.79
	I feel like a burden to my family and friends (#41)	0.82
	I am afraid of dying (#42)	0.86
	I seem to want to stay at home more (#24)	0.87
	I am not alway consistent with my exercise (#48)	1.00
	Cluster Average	0.82
	Confinement	
Six	I am very bored at home (#40)	0.71
	I am scared to drive (#49)	0.79
	I have not tried to maintain the lifestyle changes, suggested by my doctors (#16)	0.80
	Cluster Average	0.76
	Partner Support	
Seven	My partner has pulled me through the worst times (#17)	0.19
	My partner and I take it day to day (#37)	0.27
	We have survived wonderfully together (#46)	0.29
	Our children our good support (#34)	0.41
	My partner financially supports us (#32)	0.59
	I exercise to keep my partner happy (#54)	0.72
	My partner does not go out as much these days (#35)	0.76
	Cluster Average	0.46

Cluster	Statements (#)	Bridging Index
	Improved Quality of Life	
Eight	If anything my life has improved (#23)	0.14
	I try to forget about my heart condition and get on with life (#33)	0.21
	I have more time to indulge in leisure pursuits (#64)	0.22
	I am generally more relaxed (#28)	0.23
	I feel better and eat better and take vitamin supplements (#22)	0.23
	I have not noticed any changes in my quality of life (#52)	0.29
	I take more care of what I eat (#43)	0.29
	I have more time to socialize with my friends (#30)	0.33
	I have returned to work and feel great (#51)	0.34
	I have had no problems at all since my heart attack (#50)	0.35
	I appreciate life more (#27)	0.45
	I enjoy being outside and going for walks with my partner (#36)	0.59
	I shifted focus away from my job to the home (#65)	0.78
	Cluster Average	0.34

physical fitness (#10), difficulty sleeping (#63), and the need for patients to "slow down and take rest breaks" (#59). Heart palpitations (#11) and loss of memory (#26) were also included in this theme. Individuals reported experience pain daily (#14) or were "more aware of minor pains in muscles or indigestion" (#58). Sensitivities to extreme weather conditions, either hot or cold, seemed to have "a lot of effect" on patients' way of life (#56). This cluster, entitled "physiological symptoms", had the lowest cluster average (0.19) of the eight clusters on this map. This value indicated that these items were perceived to have a high degree of similarity and thus, formed a discrete, coherent cluster in this region of the map.

Cluster #3 - Depression. The close placement of items representative of affective elements of depressive experience to those reflecting the physiological symptoms of myocardial infarction suggests that these categories were percieved as similar by participants. The items with the lowest bridging values and likely those most representative of this cluster were: "I feel a little depressed some days" (#55) , "I can't stand noise" (#66), and "I find it difficult to concentrate" (#20). This cluster contained an item with a particularly high bridging index of 0.92. It appeared that the need to be "careful not to over-exert my heart" was linked to patients' concerns about their future health, in the adjacent cluster #5. This cluster was labelled "depression".

In summary, the right section of the patients' concept map was dominated by items related to how a myocardial infarction impacted the intrapersonal (physical, social, and affective) domains of patients' lives.

Cluster #4 - Employment Issues. Items in this cluster were located on the far left portion of the concept map. Items appeared to be related to work-related outcomes of myocardial infarction. This theme reflected how patients lacked motivation to look for work, or if they had a job they were "reluctant to accept any long-term work" (#31). The statement "I worry about my partner" seemed to reflect the result of business income being "seriously curtailed" (#4) or being "no longer employed" (#15). This cluster was labelled "employment issues".

Cluster #5 - Future Health Concerns. Cluster #5 is located in the lower left corner of the map. Patients reported a loss of self-confidence (#38) and that they felt like "a burden to my family and friends" and were "afraid of dying" (#42). Statements also reflected that they are worried about their "future health" (#29) and how "the hospital cutbacks will affect our quality of life" (#39). One item expressed a preference "to stay at home more" (#24) and another, reported inconsistency with their exercise regime (#48).

Items in this cluster were sorted adjacent to those within the depression and employment clusters. Some degree of perceived similarity existed between future health concerns, depression and employment issues. However, it is important to note that this cluster had the highest average bridging index of the eight clusters (0.82). Statements with high bridging values were "I am not always consistent with my exercise" (#48), "I seem to want to stay at home more" (#24), and "I am afraid of dying" (#42) (1.00, 0.87, 0.86 respectively). These values indicated that these statements were linking items frequently sorted into different clusters. This cluster was titled "future health concerns".

Cluster #6 - Confinement. Cluster #6 was located in the centre of the map. It contained only three statements with, it seemed, little conceptual similarity. It was difficult to assign a label to this cluster. The statements "I am very bored at home", "I am scared to drive" and "I have not tried to maintain the lifestyle changes, suggested by my doctors" (0.71, 0.79, and 0.80 respectively) appeared to also be bridging statements. Alternatively, these items may have been sorted frequently into other clusters because they were not commonly perceived as an impact of myocardial infarction on quality of life by many of the sorters. As such, this cluster, labelled "confinement", was judged to be the weakest of the concept map.

The next two clusters represented concepts that illustrated relatively positive perceptions of the impact of myocardial infarction on quality of life.

Cluster #7 - Partner Support. The upper left corner of the map contains items sorted together related to partner support following a myocardial infarction. The essence of this cluster is captured in the statement "We have survived wonderfully together" (#46). Mutual support was also exemplified in the statement "My partner and I take it day to day" (# 37). The couple seemed to also receive "good support" from their children (#34). Patients recognized that their partners had pulled them through the "worst times" (# 17). Role demands were identified in the statement "my partner financially supports us" (#32) and "my partner does not go out as much these days" (#35). One item described the influence of the partner on the patient's exercise compliance "I exercise to keep my parner happy" (#35).

Cluster #8 - Improved in Quality of Life. Cluster #8 contained 13 statements which described improvements in patients' quality of life after a myocardial infarction. This cluster had the second lowest average bridging index (0.34) of the eight clusters in this map. Some patients reported that "If anything my life has improved" (#23) since their heart attack, while others stated that "I have not noticed any changes in my quality of life" (#52) or "I have had no problems at all since my heart attack" (#50).

Statements identified how patients responded to the heart attack by "trying to forget about my heart condition and get on with life" (#33), becoming "generally more relaxed" (#28), and appreciating life more (#27). Attention to proper nutrition was also reflected in this theme in the statements "I feel better and eat better and take vitamin supplements" (#22) and "I take more care of what I eat" (#43).

As a result of the myocardial infarction, some patients appeared to have more time "to socialize with my friends" (#30) and "to indulge in leisure pursuits" (#64), like "being outside and going for walks with my partner (#36). Two final statements indicated that participants had returned to work and felt great (#51), but their focus had shifted away from work to life at home (#65).

Discussion of Patient Concept Map

The patient concept map consisted of eight themes: 1) lifestyle changes, 2) physiological symptoms, 3) depression, 4) employment issues, 5) future health concerns, 6) confinement, 7) partner support and 8) improved quality of life. The patient concept map supported findings in the existing research literature. The map also described some concepts that have received little attention in the literature regarding quality of life after a myocardial infarction.

The theme of physiological symptoms associated with myocardial infarction was the tightest cluster on the map, because it had the lowest average bridging index of the concept map (0.19). Wenger et al. (1984) identified symptoms and their consequences as a major component of quality of life in cardiovascular disease. Hillers et al. (1994) also formulated a distinct category of "symptoms" when they developed the QLMI instrument. Items in the symptom domain of the QLMI were similar to some of the items found in cluster #2. For example, "How often in the last two weeks have you felt worn out or low in energy?" and "How much shortness of breath have you experienced during the last two weeks while doing your day-to-day activities?" of the QLMI compared to "I seem to be very short of breath at times" (#57) and "I have less energy" (#19) in cluster #2.

Lim et al. (1993) modified the QLMI developed by Olderidge and colleagues. Their factor analysis suggested three quality-of-life dimensions: physical, emotional, and social. The symptoms theme was now incorporated into the physical domain. Testa and Simonson (1996) conceptualized three health domains: social, psychological, and physical. Again, symptoms were included as a variable of the physical domain in quality-of-life assessment. It is interesting to note that this theme was the only cluster on the map that dealt specifically with medical factors of a myocardial infarction that may impact quality of life.

Lifestyle changes (cluster #1) is adjacent to physiological symptoms (cluster #2) on the map. The items that represented this theme appeared to refer to how the myocardial infarction had affected patients' ability and energy to perform daily activities e.g., yard work or hobbies, to participate in social activities, and changes associated with risk factors. This theme has been conceptualized in different ways in the literature. Wenger et al. (1984) included such lifestyle changes within the domain of "functional capacity" as one of five subcomponents. In contrast, Oldridge et al. (1991) and Hillers et al. (1994) included items similar to those in cluster #2 in a distinct domain entitled "restrictions" within the QLMI instrument. Lim et al. (1993), and more recently, Testa and Simonson (1996) proposed that such items should be included in the physical domain along with items related to symptoms and disability. Several oncology researchers (e.g., Hays & Stewart, 1990; Aaronson, 1986) found that the functional dimension of quality of life was correlated but distinct from the physical dimension.

The experience of depression was reflected in the concept map as an outcome of myocardial infarction. It may be helpful to consider the conceptual adjacency of depression to other items on the map. The map shows that items related to physiological symptoms (cluster #2), future health concerns (cluster #5), and confinement (cluster #6) were linked to patients' depressive experience. Frasure-Smith, Lespérance and Talajic (1995) recognized potential behavioural and physiological mechanisms linking psychological variables and outcomes, that may influence prognosis following myocardial infarction. They stated that the possible interrelationships of these variables are "enormously complex", but their data indicated a "good degree of independence in their impact on prognosis".

With regard to behavioural mechanisms, there is some evidence that worse outcomes in depressed and anxious patients may be attributable, in part, to reduced compliance with treatment regimes (Blumenthal, Williams, Wallace Williams, & Needles, 1982) and failure to adhere to physician's recommendations (Frasure-Smith, Lespérance and Talajic, 1995). Thus, items like "I have not tried to maintain the lifestyle changes, suggested by my doctors" (#16 in cluster 6), and "I am not always consistent with my exercise" (#48 in cluster 5) may be conceptually linked to depression experienced by patients. Each of these latter items have high bridging indexes which would confirm the interrelatedness of these clusters.

There is also evidence in the literature to suggest that psychological variables are linked to potential pathophysiological mechanisms, such as thrombogenesis or arrhythmogenesis (Frasure-Smith, Lespérance and Talajic, 1995). The close relationship between physiological symptoms and depression is important given that the fearful, anxious, or depressed patients recovering from a heart attack would probably have a better quality of life if clinical symptoms are not exacerbated.

Daughtry and Kunkel (1993) examined the experience of depression in college students using concept mapping. Several of the clusters and items from the students' concept map described similar themes to those experienced by post myocardial infarction patients. For example, internal affective elements of depression contained in the students' burdened cluster, such as "felt scared about the future" and "felt like there was a huge weight" were reflected in the patients' future health concerns cluster (#5), with items like "I worry about my future health" (#29) and "I feel like a burden to my family and friends" (#41).

The students' vegatative cluster contained items like "felt it was difficult to concentrate", "felt bored", "felt like I couldn't sleep" and "felt like something was wrong". The close placement of the following items on the map, "I am very bored at home" (#40 in cluster #6), "I seem to want to stay at home more", (#24 in cluster #5), "I find it difficult to concentrate" (#20 in cluster #3) and "I have a difficult time sleeping" (#63 in cluster #2) suggest they were perceived as similar by participants. It is possible the impact of negative emotions on post-myocardial patients elicits a "vegatative" or "static" maladaptive response to the cardiac event.

Several items in the QLMI questionnaires (Hillers et al., 1994; Lim et al., 1993; Oldridge et al., 1991) appeared to relate to negative affect and were in the "emotions domain". Wenger et al. (1984) included described emotional function as a subcomponent of functional capacity that encompassed such factors as mood changes, depression, hostility, helpelssness and satisfactions. A "psychological" domain was conceptualized by Testa and Simonson (1996) containing three variables: positive affect, negative affect and behaviour.

The concept map showed employment issues (cluster #4) as a distinct theme from lifestyle changes (cluster #1) or symptoms (cluster #2). Cluster #4 is positioned on the far left side of the map, while clusters 1 and 2 are on the far right side. Items revealed that patients perceived that myocardial infarction could cause job loss, restrict work capacity or result in negative affect. Croog and Levine (1982) found that patients with lower occupational status and with greater depressive symptoms have worse health outcomes.

Wenger et al. (1984) included work as a subcomponent of functional capacity. The QLMI questionnaires (Hillers et al., 1994; Lim et al., 1993; Oldridge et al., 1991) did not contain any items that made specific reference to employment problems. Testa and Simonson (1996) incorporated work issues within the "social" domain of their quality-of-life assessment model. The map provided evidence that patients perceived employment issues to be related to future health concerns (cluster #5) and partner support (cluster #7) due to the close proximity of these clusters. This finding appeared to corroborate with Testa and Simonson's conceptual scheme.

Cardiac rehabilitation is a social process that can be facilitated or impeded by the attitudes and behaviours of patients, spouses, and other family members (Gorkin, Follick, Wilkin, & Niaura, 1994). These results are consistent with earlier research indicating that perceptions of support provided by a caring individual relate to successful psychosocial adjustment during cardiac rehabilitation (e.g., Brecht et al., 1994; Ell & Dunkel-Schetter, 1994; Fletcher et al., 1987; Holahan et al., 1995). The theme of partner support (cluster #7) clearly outlined the important role that partners play following a myocardial infarction. It was evident that a sense of "togetherness" and intimacy buffered the impact of the acute cardiac episode and may have facilitated adaptive coping strategies.

The concept map contained a final theme (cluster #8) that identified patients' perceptions of improvements in their quality of life since the myocardial infarction The primary focus of many assessments of quality-of-life outcomes is the negative impact of a cardiac event. In contrast, this theme is characterized by items that express changes that have benefited patients' psychological, social and functional status. General changes included "if anything life has improved" (#23), "generally more relaxed"(#28), and "I appreciate life more" (#27). Stern (1984) found that as many as 75% of patients viewed their heart attacks as having enhanced their perspectives and given them a new appreciation of their lives.

Life-style behavioural changes identified were eating better (#22 & #43), and shifting "focus away from my job to the home" (#65). Indeed, interpersonal relationships appeared to take precidence in patients' lives following the heart attack. Patients had more time to spend with their partners (#36), socializing with friends (#30), or indulging in leisure pursuits (#64). This finding warrants further systematic investigation to confirm and clarify the influence of such variables on patient quality of life.

Incidence Survey

Concept mapping, like many alternative research approaches, involves a compromise between breadth and depth of understanding (Daughtry & Kunkel, 1993). There is reasonable confidence that the perceived impact of a myocardial infarction on patient quality of life has been captured, organized and interpreted.

A limitation of this methodology is that the incidence of each statement or item is not determined for the entire sample of patients. Thus, an incidence survey was developed from the patient statements (see Appendix Q) and distributed to patients (n=35) to determine those items most frequently endorsed as prevalent to their experiences following heart attack and how it impacted their quality of life.

Participants were asked to rate each item on a 5-point Likert response scale to determine how relevant the statement was to their personal experience of having a heart attack. The five points were: 1= strongly disagree, 2 = disagree, 3 = neutral/not applicable, 4 = agree, and 5 = strongly agree. Respondents were also asked to answer two questions. The first question asked patients to rate their present quality of life as the value of a number from 1 to 100 (where 1 = poor and 100 = excellent). The second question asked respondents to rate the change in their quality of life since the heart attack by circling one of the following; very deteriorated, somewhat deteriorated, no change, somewhat improved, or very improved. Frequencies were calculated for each of the patient statements (see Appendix R).

The data from this initial analysis was summarized as means, standard deviations and three percentage values (1. strongly disagree/disagree, 2. neutral/not applicable, and

Table 5

Item Means and Percentages of Patient-Endorsed Statements

Rank	Statement	% Patient-Endorsed Items*			
		Mean	SD/D	N/A	A/SA
1	I appreciate life more (#27)	4.2	18	9	73
2	I try to forget about my heart condition and get on with life (#33)	4.0	17	6	77
3	Our children are good support (#34)	3.9	6	17	77
4	We have survived wonderfully together (#46)	3.8	9	17	74
5	My partner and I take it day to day (#37)	3.7	11	20	69
6	I enjoy being outside and going for walks with my partner (#36)	3.7	9	22	69
7	I have to leave heavy work to others (#60)	3.7	17	11	72
8	My partner has pulled me through the worst times (#17)	3.7	17	9	74
9	I am careful not to over-exert my heart (#47)	3.6	20	9	71
10	I have to slow down and take rest breaks (#59)	3.5	23	6	71
11	Hot or cold weather has alot of effect on way of life (#56)	3.5	28	6	66
12	I can't smoke (#53)	3.4	9	57	34
13	I am more aware of minor pains in muscles or indigestion (#58)	3.4	26	11	63
14	I worry about my future health (#29)	3.4	31	9	60
15	I worry the hospital cutbacks will affect our quality of life (#39)	3.4	31	6	63
16	I have more time to indulge in leisure pursuits (#64)	3.4	29	14	57
17	I feel better and eat better and take vitamin supplements (#22)	3.3	34	14	52
18	I cannot remember things as well (#26)	3.3	34	9	57
19	I have less energy (#19)	3.3	31	9	60
20	I feel a little depressed some days (#55)	3.2	36	9	55

* SD = strongly disagree, D = disagree, N/A = not applicable, A = agree, SA = strongly agree

Rank	Statement	% Patient-Endorsed Items*			
		Mean	SD/D	N/A	A/SA
21	I can't stand much noise (# 66)	3.2	34	14	51
22	I have returned to work and feel great (#51)	3.2	20	49	31
23	I have heart palpitations (#11)	3.2	43	17	40
24	I have more time to socialize with friends (#30)	3.1	26	37	37
25	I worry about my partner (#25)	3.1	31	29	40
26	I shifted my focus away from my job to the home (#65)	3.1	26	43	31
	Patient-endorsed items with means less than 2.5				
1	I can't go anywhere by myself (#61)	1.7	80	11	9
2	I am scared to drive (#49)	1.8	75	14	11
3	I am afraid of dying (#42)	2.0	74	9	17
4	I suffer pain daily (#14)	2.0	74	9	17
5	I can't travel (#8)	2.1	71	9	20
6	I no longer enjoy eating out (#62)	2.1	77	6	17
7	I lost many of my friends (#45)	2.1	74	9	17
8	I am very bored at home (#40)	2.1	77	6	17
9	I feel like a burden to my family and friends (#41)	2.2	69	14	17
10	I have **not** tried to maintain the lifestyle changes, suggested by my doctors (#16)	2.3	74	6	20
11	I exercise to keep my partner happy (#54)	2.4	66	11	23
	Neutral or non applicable items				
1	I lack motivation to look for another job (#31)	2.6	26	69	5
2	My business income has been seriously curtailed (#4)	2.6	28	66	6

* SD = strongly disagree, D = disagree, N/A = not applicable, A = agree, SA = strongly agree

3. agree/strongly agree) to determine how statements were endorsed by patients. Those statements that had means greater than 3.00 and less than 2.5 were chosen for further interpretation. This data is presented in Table 5.

The statement most frequently endorsed by patients was "I appreciate life more" (73%). Eight of the top ten statements were positive and adaptative perceived outcomes of the experience of a myocardial infarction. For example, "I try to forget about my heart condition and get on with life" (77%), "Our children are good support" (77%), "We have survived wonderfully together" (74%) and "My partner and I take it day to day" (69%). A total of 26 statements had means greater than 3.00.

Statements that received the least frequent agreement were: "I can't go anywhere by myself" (9%), "I am scared to drive" (11%), "I can't travel" (20%), "I am afraid of dying" (17%), "I suffer pain daily" (17%), and "I no longer enjoy eating out" (17%). A total number of 11 statements had a mean less than 2.5. Three statements perceived as neutral or not applicable were: "I lack motivation to look for another job" (69%), "My business income has been seriously curtailed" (67%) and "I can't smoke" (57%).

The data was also organized by cluster to determine how patients had endorsed particular categories of items. Table 6 contains a listing of the means and standard deviations of each item by cluster as well as computed cluster means. The results indicated that cluster #8 (improved quality of life) had the most number of patient-endorsed statements with means greater than 3.00 (agree/strongly agree) in the concept map. This cluster contained eight of the top 26 statements.

Seventy-four percent of patients indicated that since their myocardial infarction they appreciated life more (#27) and 77% tried to forget about their heart condition and get on with life (#33). About 69% of patients stated that they enjoyed walking outside

Table 6

Item Means and Percentages of Patient-Endorsed Statements by Cluster

Statement	% Patient-Endorsed Items*			
	Mean	SD/D	N/A	A/AS
Cluster #1- Lifestyle Changes				
It takes me longer to complete simple tasks (#2)	2.8	57	3	40
I can't drink alcohol anymore (#1)	2.6	49	34	17
I cannot do yard work (#6)	3.0	46	11	43
I am unable to do my hobbies (#5)	2.5	60	11	29
I can't smoke (#53)	3.4	9	57	34
I no longer enjoy eating out (#62)	2.1	77	6	17
I can't travel (#8)	2.1	71	9	20
It takes much fun out of life (#44)	2.5	60	14	26
I am no longer a "go-getter" (#21)	2.9	37	20	43
My social life is very limited (#7)	2.6	57	20	23
I can't go anywhere by myself (#61)	1.7	80	11	9
I lost many of my friends (#45)	2.1	74	9	17
The heart attack has virtually cut out my sex life (#9)	2.8	63	14	23
I have to leave heavy work to others (#60)	3.7	17	11	72
I want to contribute to my community but I can't (#18)	2.9	34	43	23
Cluster Mean	2.6	53	43	29
Cluster #2 - Physiological Symptoms				
I seem to be very short of breath at times (#57)	2.8	49	17	34
I have heart palpitations (#11)	3.2	43	17	40
I suffer pain daily (#14)	2.0	75	8	17
I experience dizziness (#12)	2.7	51	14	34
I have less energy (#19)	3.3	31	9	60

* SD = strongly disagree, D = disagree, N/A = not applicable, A = agree, SA = strongly agree

Statement	% Patient-Endorsed Items			
	Mean	SD/D	N/A	A/SA
Cluster #2 - Physiological Symptoms (continued)				
I am having a difficult time sleeping (#63)	2.5	57	14	29
I am more aware of minor pains in muscles or indigestion (#58)	3.4	26	11	63
I suffer intermittent weak feelings (#13)	2.8	49	17	34
Hot or cold weather has alot of effect on my way of life (#56)	3.5	28	6	66
I am losing my physical fitness (#10)	2.8	54	9	37
I have to slow down and take rest breaks (#59)	3.5	23	6	71
I cannot remember things as well (#26)	3.3	34	9	57
Cluster Mean	3.0	43	10	45
Cluster #3 - Depression				
I feel a little depressed some days (#55)	3.2	37	8	55
I can't stand much noise (#66)	3.2	34	14	52
I find it difficult to concentrate (#20)	2.8	43	14	43
I am careful not to over-exert my heart (#47)	3.6	20	9	71
Cluster Mean	3.2	33	11	56
Cluster #4 - Employment Issues				
I lack motivation to look for another job (#31)	2.6	26	69	5
I worry about my partner (#25)	3.1	31	29	40
My business income has been seriously curtailed (#4)	2.6	28	66	6
I am reluctant to accept any long-term work (#3)	2.8	37	40	23
I am no longer employed (#15)	2.6	43	37	20
Cluster Mean	2.7	33	48	19

* SD = strongly disagree, D = disagree, N/A = not applicable, A = agree, SA = strongly agree

Statement	% Patient-Endorsed Items			
	Mean	SD/D	N/A	A/SA
Cluster #5- Future Health Concerns				
I have lost my self-confidence (#38)	2.5	57	11	32
I worry the hospital cutbacks will affect our quality of life (#39)	3.4	31	6	63
I worry about my future health (#29)	3.4	31	9	60
I feel like a burden to my family and friends (#41)	2.2	69	14	17
I am afraid of dying (#42)	2.0	74	9	17
I seem to want to stay at home more (#24)	2.9	49	11	40
I am not always consistent with my exercise (#48)	2.7	55	11	34
Cluster Mean	2.7	53	10	37
Cluster #6 - Confinement				
I am very bored at home (#40)	2.1	77	6	17
I am scared to drive (#49)	1.8	75	14	11
I have **not** tried to maintain the lifestyle changes, suggested by my doctors (#16)	2.3	74	6	20
Cluster Mean	1.2	75	9	16
Cluster #7 - Partner Support				
My partner has pulled me through the worst times (#17)	3.7	17	9	74
My partner and I take it day to day (#37)	3.7	11	20	69
We have survived wonderfully together (#46)	3.8	9	17	74
Our children are good support (#34)	3.9	6	17	77
My partner financially supports us (#32)	2.5	46	34	20
I exercise to keep my partner happy (#54)	2.4	66	11	23
My partner does not go out as much these days (#35)	2.8	43	20	37
Cluster Mean	3.2	28	18	53

* SD = strongly disagree, D = disagree, N/A = not applicable, A = agree, SA = strongly agree

Statement	% Patient-Endorsed Items			
	Mean	SD/D	N/A	A/SA
Cluster #8 - Improved Quality of Life				
If anything my life has improved (#23)	2.8	51	9	40
I try to forget about my heart condition and get on with life (#33)	4.0	17	5	77
I feel better and eat better and take vitamin supplements (#22)	3.3	34	14	51
I have more time to indulge in leisure pursuits (#64)	3.4	29	14	57
I am generally more relaxed (#28)	3.0	40	11	49
I have not noticed any changes in my quality of life (#52)	2.8	51	9	40
I take more care of what I eat (#43)	3.3	20	26	54
I have more time to socialize with my friends (#30)	3.1	26	37	37
I have returned to work and feel great (#51)	3.2	20	49	31
I have had no problems at all since my heart attack (#50)	2.7	54	6	40
I appreciate life more (#27)	4.2	17	9	74
I enjoy being outside and going for walks with my partner (#36)	3.7	9	23	68
I shifted my focus away from my job to the home (#65)	3.1	26	43	31
Cluster Mean	3.2	30	20	50

* SD = strongly disagree, D = disagree, N/A = not applicable, A = agree, SA = strongly agree

with their partners (#36), while approximately half the repondents (57% and 52% respectively) had more time to indulge in leisure pursuits (#64), and ate better and took vitamin supplements (#22). Thirty-one percent of patients had returned to work and felt great (#51) and also 31% had shifted their focus away from their job to home life (#65). Finally in this cluster, 37% of individuals had more time to socialize with friends (#30).

Cluster #2 (physiological symptoms) was endorsed second by patients with six statements. The main concerns patients had were changes associated with the clinical manifestations of a heart attack. Seventy-one percent of patients stated that they had to slow down and take rest breaks (#59), while 66% found that hot or cold weather has a considerable impact on their way of life (#56). Some individuals (63%) had a heightened awareness of minor pains in muscles or indigestion (#58). Other respondents (57%) stated that they cannot remember things as well (#26). Loss of energy (#19) was experienced by 60% of patients, while 40% had heart palpitations.

Cluster #7 (partner support) was the third ranked category with four items in the top eight statements. Patients (77%) indicated that their children were a good source of support (#34%). Seventy-four percent of respondents stated that they and their partners have survived wonderfully together (#46) and 69% coped by taking it day to day (#37). Seventy-four percent of patients admitted that their partner had pulled them through the worst times (#17). These findings reiterated that social support received from family is a major component of patients' adjustment post myocardial infarction.

Cluster #3 (depression) had three statements endorsed by patients. Seventy-one percent of respondents indicated that they were careful not to over-exert their heart (#47). About half of the participants (55% and 51% respectively) stated that they feel a little depressed some days (#55), and that they can't stand much noise (#66) since the acute cardiac episode.

Two clusters contained two statements that were ranked in the top 26 items. First, from cluster #1(lifestyle changes), 72% of patients leave heavy work to others (#60) and 34% no longer smoke (#53). Second, from cluster #5 (future health concerns), 60% of patients worry about their future health, while 63% stated they worry how the hospital cutbacks will affect their quality of life (#39). Cluster #4 (employment issues) contained one statement that was ranked in the top 26 items, that indicated 40% of patients worry about their partners (#25) in regards to work-related issues.

Several statments were also notable for how infrequently they were endorsed. Eleven items were endorsed as less than 2.5 (disagree/strongly disagree). Cluster #1 (lifestyle changes) contained four items with the lowest endorsement. Only 9% of patients felt they couldn't go anywhere by themselves (#61) and only 20% felt they couldn't travel (#8). Seventeen percent indicated that they no longer enjoyed eating out (#62) and had lost many of their friends (#45).

All the items of cluster #6 (confinement) were negatively endorsed by patients. Only 11% of respondents were scared to drive (#49), 17% were bored at home (#40), and 20% had not tried to maintain the lifestyle changes suggested by their physicians. Cluster #5 (future health concerns) contained two statements with the lowest average ratings. It appeared that only 17% of patients were afraid of dying (#42) and felt like a burden to family and friends (#41). Two final items completed the list of least endorsed statements. In cluster #2 (physiological symptoms) only 17% of respondents indicated that they suffered pain daily (#14). In cluster #7 (partner support) only 23% of patients exercised to keep their partner happy (#54).

Two items in cluster #4 (employment issues) were also notable because patients indicated that they were not applicable to them. Sixty-nine percent of respondents stated that lacking motivation to look for another job (#31) was not applicable to them, and 66% indicated neither was the item referring to business income being seriously curtailed (#4).

It was evident from the demographic data that the average age of patients was about 64 years old, so it could be assumed that many are retired from work, which may explain these ratings.

Patients were asked to rate their present quality of life and their percieved change in quality of life since their myocardial infarction. Forty-nine percent of patients rated their overall present quality of life as very good with values ranging from 25 to 100. The mean quality of life rating for patients was 73.2 (SD = 19.2). The perceived changes in quality of life scores following a heart attack suggested 46% of patients felt their quality of life had somewhat to greatly deteriorated. Twenty percent of respondents reported no changes, and 34 % of patients perceived somewhat to greatly improved quality of life. It seems that the impact of a myocardial infarction is quite variable across the patient sample, with no significant impact either positive or negative evident. Patrick, Danis, Southerland and Hong (1988) stated that patients, with various chronic illnesses, frequently rated their health as poor and reported considerable dysfunction in their physical, mental and social lives. However, these same individuals reported high levels of general well-being and satisfaction regardless of their physical status and behavioural dysfunction.

In summary, a total of 26 statements had an item average above 3.00. The remaining 40 statements in this survey were rated with an item average at the scale mid-point or below. Cluster #6 (confinement) received the lowest average rating of 1.2 and clusters #3 (depression), #7 (partner support), and #8 (improved quality of life) had equally the highest average rating of 3.2 The grand mean for all 66 statements was 2.39 on the 5 point Likert scale. Considerable variation in item averages were evident within clusters across patients. The findings confirmed that it is necessary to assess perceptions of the impact on life quality of myocardial infarction. The delivery of patient-centred care demands that physicians' assessments of the benefits of care include global aspects of patients' quality of life in addition to survival, chronic disease, and functional status.

The Partner Concept Map

Each statement cluster was examined in a clockwise direction commencing in the upper right quadrant of the map and proceeding down and across the configuration. It was apparent that the 13 and 15-cluster solutions of the partner map were much too conceptually discrete and visually fragmented. In both cases, clusters contained too few items and appeared to conceptually overlap. Thus, further reduction of the cluster solutions was considered appropriate due to interpretation difficulty.

Next, the 5-cluster solution was examined. These clusters were very general and contained more than one theme. For example, cluster #3 included both negative consequences of having a partner who has had myocardial infarction and changes in the pace of life. Consequently, this solution was also rejected in favour of a more sensible and interpretable partition of the multidimensional space. It was now evident that the final cluster solution was between 5 and 12 clusters for partners.

The next choice was a 10-cluster solution. This solution was an improvement over the 5-cluster solution because some clear and consistent themes were emerging. For example, on the left hand side of the map, improvements in quality of life (cluster #9) was now seperated from nutritional concerns (cluster #10). The cluster bridging index for these clusters (0.54 and 0.46 respectively) remained close to their merged value of 0.51.

Problems persisted with the overlapping of clusters 2 and 3, each seemed to be closely related. Statements like #27 in cluster #2: "I get tired looking after my partner" appeared to be conceptually similar to #58 in cluster #3: "I have to manage more on my own". Evaluation of across cluster solutions 5, 6 and 7 confirmed that these two clusters were consistently merged as the distinct theme of caregiver stress experienced by partners with a bridging index of 0.53. Fear of reoccurrence (cluster #1) emerged on the upper right side of the map, and remained stable from cluster solution 10 through to 5. Thus, further reduction of the cluster solution was considered appropriate.

Successive cluster solutions were examined and cross-referenced to determine the most appropriate number of clusters. The 9-cluster solution was an improvement over the 10-cluster solution. Further clarification occurred, in the right hand portion of the map, when negative social consequences (cluster# 2) emerged in the 8-cluster solution. Changes in the partners' pace of life (cluster #4) was interpreted as one of the more stable themes, remaining unchanged between cluster solutions 7 and 15.

The outer, left-hand side of the map was now regarded as relatively stable since the visual structure of the themes, negative social consequences, improvements in partner quality of life and nutritional concerns, was distinct and remained unchanged across the remaining cluster solutions (7 to 5). The difficulty in evaluating the centre of the map was resolved in the 7-cluster solution (see Figure 4). Clusters 5 emerged to reflect the theme of vigilance. This cluster had a bridging index of 0.62 and seemed to be a pivotal, linking statement cluster in the final partner map.

Inspection of the remaining cluster solutions concluded that further reductions in the cluster solution failed to improve the structure of the configuration. Consequently, this decison resulted in acceptance of the 7-cluster solution as the one that provided the most clear and concise description of the partner data set.

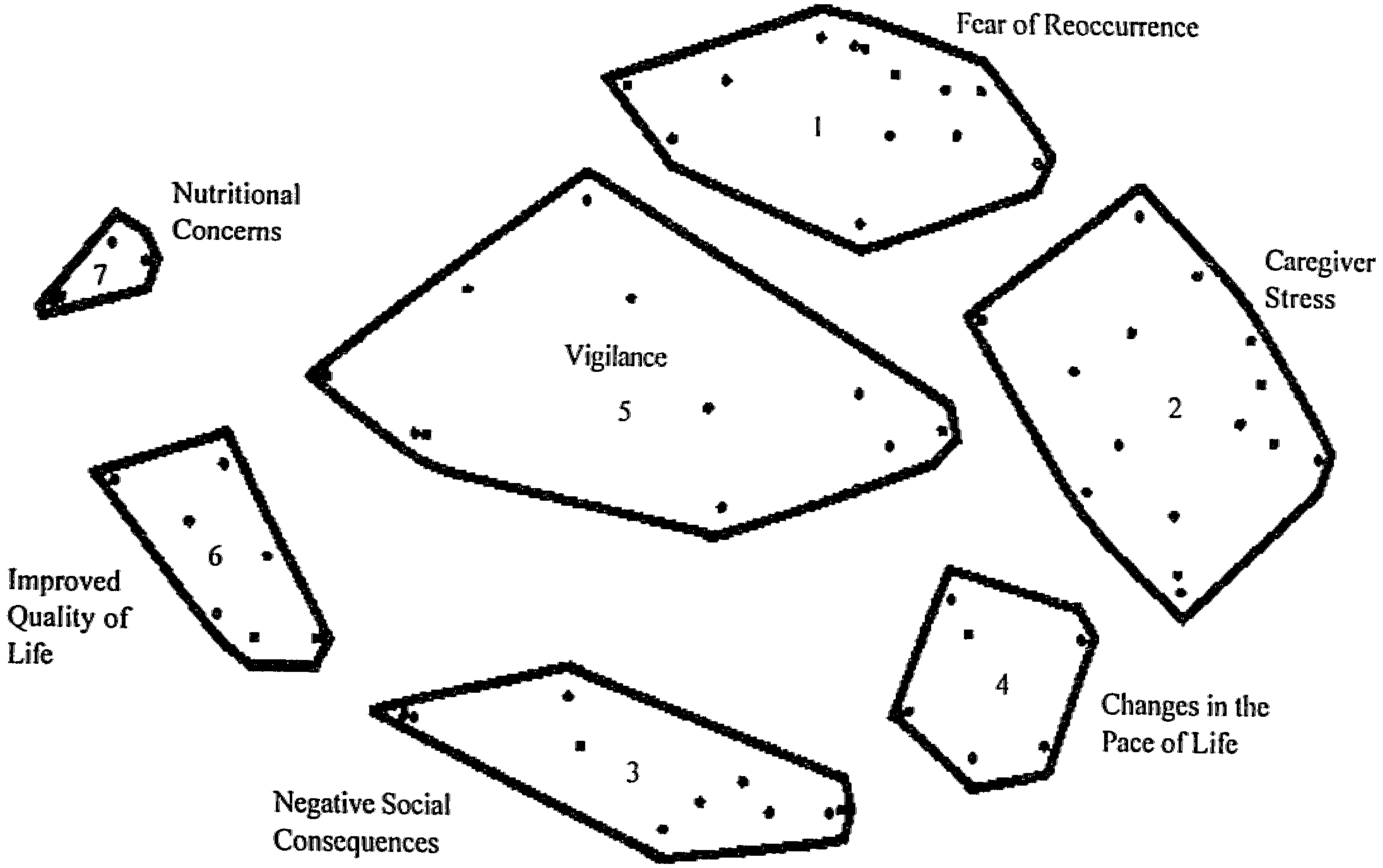

Figure 4: Seven solution concept map of 66 partner statements

Description of the Partner Cluster Map

Initial examination of the partner concept map attempted to identify implicit dimensional axes around which points may be configured. In the centre of the map, cluster 5, labelled "vigilance" , assumed a dominant position. It may represent a pivotal cluster around which other partner themes revolved. The map showed a progression of the negative influences of a myocardial infarction moving from the upper right quadrant clockwise along the perimeter toward the lower left side.

The sequence began with partners' fear of reoccurrence (#1) and moved to specific caregiver stressors associated with a myocardial infarction (#2). Next, changes in the partners' pace of life (#4) appeared adjacent to negative social consequences (#5), that affected both patients and partners, after a myocardial infarction. In contrast, the far left side of the map contained items that represented more positive aspects of the impact of a heart attack on partner quality of life: improved quality of life (#6) and nutritional concerns (#7).

The procedure previously described for labelling each patient cluster was repeated for the partner clusters. Bridging indexes of the items were used to systematically interpret the concept map of partners' of patients who have had a myocardial infarction within the last 36 months. The statements in each cluster of the 7-solution partner concept map, along with their accompanying bridging indexes and names, are displayed in Table 7. A detailed interpretation of each cluster of the partner map and their interrelationships follows.

Table 7

Cluster Items and Bridging Indexes for Seven Solution Concept Map of Partners of Patients Who have had a Heart Attack

Cluster	**Statements (#)**	**Bridging Index**
	Fear of Reoccurrence	
One	I fear the end could come suddenly (#19)	0.00
	I become concerned if he/she complains of discomfort (#40)	0.00
	I worry about the possibility of my partner having another heart attack (#41)	0.08
	I feel anxious due to health cuts and long waiting lists (#20)	0.15
	I feel anxious about keeping appointments (#60)	0.15
	If a person isn't on time you think "What has happened?" (#61)	0.22
	I always watch out for signs of problems (#18)	0.32
	I have become more watchful (#62)	0.36
	I take it day to day (#43)	0.41
	Anxiety - for the first few months then I was okay (#44)	0.43
	My partner thinks I never worry about him/her (#4)	0.54
	My partner worries about me when I don't take care of myself (#2)	0.55
	My partner and I continue to talk about the heart attack (#1)	0.71
	Cluster Average	0.30
	Caregiver Stress	
Two	I am often more worried than my partner is (#15)	0.40
	I get tired looking after my partner (#27)	0.40
	I felt overwhelmed by the amount of information the hospital gave us (#37)	0.43

Cluster	Statements (#)	Bridging Index
Two	I have been experiencing some depression (#23)	0.44
(contd.)	I must not talk about anything when I feel bad (#5)	0.45
	I try not to nag (#63)	0.46
	I feel lonely at times because my partner sleeps a lot (#54)	0.48
	My partner has not maintained his/her exercise program (#53)	0.49
	I am frustrated because my partner doesn't make an effort to take care of him/herself (#38)	0.50
	I have had to manage more on my own (#58)	0.53
	My partner has a negative attitude towards life now (#14)	0.63
	I have had to stop work to take care of my partner (#64)	0.64
	I don't like restrictions (#55)	0.65
	I can't keep up with my partner (#57)	0.69
	My partner no longer works so income is a big stressor (#42)	0.72
	Cluster Average	0.53
	Negative Social Consequences	
Three	We have lost many of our friends (#45)	0.18
	I would love to travel more, but it would be too difficult for my partner (#66)	0.18
	Social activities are almost zero (#50)	0.19
	There are a lot of things we can't do anymore (#24)	0.19
	We have to walk to places because he/she can't drive (#26)	0.32
	Our quality of life has deteriorated (#33)	0.36
	I can't drive the car so we stay closer to home these days (#31)	0.46
	My quality of life is unaffected by the heart attack (#39)	0.64

Cluster	Statements (#)	Bridging Index
Three	It is hard to continue the relaxation exercises (#35)	0.68
(contd.)	Heart attack is a continuous subject of conversation with friends (#3)	0.84
	Cluster Average	0.40
	Changes in the Pace of Life	
Four	I don't go out socially as much as I did prior to the attack (#29)	0.39
	I have lost my independence (#49)	0.55
	We participate in less outdoor activities since the heart attack (#36)	0.57
	My life is hectic and busy (#65)	0.59
	It is hard to accept the changes in my lifestyle (#47)	0.63
	I never drink alcohol anymore (#22)	0.72
	Cluster Average	0.57
	Vigilance	
Five	I ensure that my partner takes rest breaks (#16)	0.33
	I make sure that my partner has taken his/her medication (#48)	0.33
	I had to learn how to care for my partner (#34)	0.39
	My partner has sleeping problems that affect my sleep (#17)	0.60
	I have to encourage my partner to exercise (#25)	0.64
	I have to do all the physical work (#32)	0.60
	I had to take over my partner's chores (#51)	0.60
	I try not to upset my partner (#12)	0.74
	I have reduced stressful situations in the home (#8)	0.77
	My partner is willing to help me but is unable to (#46)	0.80

Cluster	**Statements (#)**	**Bridging Index**
Five (contd.)	I feel hopeful my partner will get help coping with stressful work situations (#6)	1.00
	Cluster Average	0.62
	Improved Quality of Life	
Six	I am pleased my partner has more time for our family (#30)	0.38
	My partner shares more of the household chores (#7)	0.42
	More time to enjoy the company of friends (#9)	0.44
	Overall quality of life has improved (#56)	0.56
	I enjoy spending time with my partner (#28)	0.59
	I am happy nobody smokes in our home now (#21)	0.67
	I have increased my exercise as a personal preventative measure (#52)	0.75
	Cluster Average	0.54
	Nutritional Concerns	
Seven	I am spending lots of time reading food labels in the store (#10)	0.22
	Switch to cooking with low fat recipes, I enjoy doing this (#59)	0.22
	I am finding it difficult to find interesting food for my partner's daily needs (#11)	0.66
	My partner refuses to eat the food I prepare (#13)	0.75
	Cluster Average	0.46

Cluster #1- Fear of Reoccurrence. Cluster #1 was located in the upper right quadrant of the cluster map. The statements reflected how respondents feared their partners would experience a recurrent myocardial infarction and perhaps die. The items that were most representative of this cluster were "I fear the end could come suddenly" (#19), "I become concerned if he/she complains of discomfort" (#40), "I worry about the possibility of my partner having anothr heart attack" (#41). Statements identified the anxiety partners feel "due to health cuts and long waiting lists" (#20) and "keeping appointments" (#60) with their partners' doctors. Generally, partners' have become "more watchful" (#62) for any "signs of problems" (#18).

Specific statements indicated that partners' are worried "for the first few months" (#44) after the heart attack episode and if "a person isn't on time you think 'What has happened?" (#61). The partners' appeared to try and cope with these stressors by taking "it day to day" (#40) or by continuing "to talking about the heart attack" (#61) with their spouses. In constrast, caregivers may choose to not disclose their concerns to their partners, as seen in the item "My partner thinks I never worry about him/her" (#4). A final item reflected that the patients may also worry about their partners when they do not take care of themselves (# 2). This cluster had the lowest bridging index (0.30) of this 7-solution conept map. This value indicated that these items were sorted together frequently to form a distinct, cohesion grouping.

Cluster #2 - Caregiver Stress. Cluster #2 is adjacent to Cluster #1. This theme seemed to reflect the personal impact of caring for a person who has had a myocardial infarction. The nature of the caregiver stress or burden is reflected in the statements "I am often more worried than my partner is" (#15) and "I get tired looking after my partner" (#27). One somewhat related item was "I can't keep up with my partner" (#57). Individuals reported that they "have been experiencing some depression" (#23), but "must not talk about anything when they feel bad" (#5). As a result, they have had to manage more on their own (#58) and "feel lonely at times " (#54) because their partners sleep alot. In addition, these individuals "felt overwhelmed by the amount of information the hospital gave" them (#37).

Other statements indicated that partners' "try not to nag" (#63) even if they are frustrated because their partners' don't make an effort to take care of themselves" (#38) or fail to maintain their exercise programs (#53). One related statement seemed to be "My partner has a negative attitude towards life now" (#14). Some individuals "don't like the restrictions" (#55) on their lifestyle following the heart attack, such as, having to stop work to take care of their partners (#64) or the financial stressors incurred because their partners can no longer work (#42).

Cluster #3 - Negative Social Consequences. Negative social consequences, in cluster 3, is located at the bottom of the map in the centre. These items identified the interpersonal changes that have occurred in the partners' lives. Partners' reported that "There are alot of things we can't do anymore" (#24) and consequently "We have lost many of our friends" (#45) and "Social activities are almost zero" (#50). Their limited social life seemed to be related to travel restrictons. For example, "We have to walk to places because he/she can't drive" (#26) and "I can't drive the car so we stay closer to home these days" (#31). One partner indicated that "I would love to travel more, but it would be too difficult for my partner" (#66). Perceptions were that their quality of life following their partners' heart attack was either "unaffected" (#39) or had "deteriorated" (# 33). One bridging item (0.84) indicated that "the heart attack is a continuous subject of conversation with friends" (#3). While a final statement reported that the partners found it "hard to continue the relaxation exercises " (#35) they were taught in the hospital.

Cluster #4 - Changes in the Pace of Life. Cluster #4 was positioned between caregiver stress and negative social consequences on the map. The close proximity of these items suggested that partners perceived them as similar to each other. The essence of this theme was captured in the statement "I have lost my independence" (#49). Statements seemed to reflect that some aspects of the caregivers' lives had become "hectic and busy" (#65) while individual social activities (#29) and outdoor activities with their partner had lessened since the heart attack (#36). Partners' reported that "it is hard to accept the changes in my lifestyle" (#47), such as never drinking alcohol anymore (#22).

Cluster #5 - Vigilance. The fifth cluster was located in the centre of the map. Most of the statements were related to the theme of vigilance. Caregivers indicated that they had to learn how to take care of their partners following the heart attack (#34). Specific key statements were "I ensure that my partner takes rest breaks" (#16), and "I make sure that my partner has taken his/her medication" (#48), both with a bridging index of 0.33. Encouraging their partners' to exercise (#25) and feeling hopeful their partners' will get help coping with stressful work situations (#6) were other statements reflecting this theme.

Further statements identified how attempts are made to control the level of stress within the patient's environment by: doing all the physical work (#32); taking over their partners' chores (#51) ; reducing stressful situations in the home (#8); and trying not to upset their partners (#12). One item reported that "my partner is willing to help me but is unable to" (#46).

Two clusters were located on the far left side of the map that dealt with the more positive outcomes of a myocardial infarction on partner quality of life: improved quality of life (Cluster #6) and nutritional concerns (Cluster #7).

Cluster #6 - Improved Quality of Life. Improved quality of life statements were adjacent to vigilance and negative social consquences items. Some partners' felt that their "overall quality of life has improved" (#56) since the heart attack. The primary reasons given for this improvement were that the person who had the heart attack now "has more time for our family" (#30) and "more time to enjoy the company of friends" (#9). Partners' happiness about these lifestyle changes was expressed in the statements "I enjoy spending time with my partner (#28), "I am happy nobody smokes in our home now (#21), and "My partner shares more of the household chores (#7). The statement "I have increased my exercise as a personal preventative measure" (#52) provided an example of a specific lifestyle change made by the partner in response to the myocardial infarction.

Cluster #7 - Nutritional Concerns. The seventh cluster is situated in the upper left quadrant of the map close to improved quality of life and vigilance items. Although it contained the fewest items, this cluster suggested that proper nutrition was an important consideration following a heart attack. These statements were "I am spending lots of time reading food labels in the store" (#10) and enjoying the switch to cooking with low-fat recipes (#59). Some partners' experienced difficulty finding interesting food for their partners' daily needs (#11) or motivating them to eat the low-fat food they prepared (#13).

Discussion of Partner Concept Map

The partner concept map consisted of seven themes: 1) fear of reoccurrence, 2) caregiver stress, 3) negative social consequences, 4) changes in pace of life, 5) vigilance, 6) improved quality of life, 7) nutritional concerns. Early clinical literature emphasized the need to involve the family of individuals with CHD in informational and therapeutic efforts, but little empirical evidence has supported this judgement (Croog, Levine & Lurie, 1968). In recent years, investigation of family caregivers reactions has primarily focused on the ramifications for patients (e.g., Beach et al., 1992; Brecht et al., 1994). Recommendations for family interventions have been justified from the perspective of patient outcome improvement rather than psychosocial adjustment of the caregivers (Biegel et al., 1991). Stern (1984) stated that spouses are frequently forgotten in medical environments devoted to patients. Ell and Dunkel-Schetter (1994) agreed that the lack of extensive research on family responses to patients' acute coronary events is remarkable.

It was evident that coronary caregivers continue to fear the sudden death of their partners even as much as 36 months after the initial myocardial infarction. Partners' statements (cluster #2) also indicated that considerable anxiety and fear is associated with the cognitive appraisal of the threat of reinfarction. Ebbesen et al. (1990) included items in the QL-SP questionnaire that dealt generally with anxiety experienced by cardiac spouses (e.g., "how often have you felt concerned or worried?), but did not make specific reference to fears of sudden death or occurrence of another heart attack.

The personal impact of the heart attack on partners was reported in cluster #2. Several studies attest to the high degree of distress experienced by caregivers of cardiac patients. Skelton and Dominian (1973) stated that after three months more than one third of spouses of post myocardial infarction patients reported sustained feelings of general anxiety and depression. It was evident that partners were experiencing not only emotional strain (e.g., "I have been experiencing some depression" (#23)), but also physical long-term demands (e.g., "I get tired looking after my partner" (#27)).

Partners' attempts to insulate patients from stress by concealing both their feelings and problems was also recognized in earlier investigations (e.g., Gorkin et al., 1994), but not extensively so. Specifically, continued struggles associated with life-style changes and resentment of the perceived restrictions on partners' lives seems unaddressed in previous studies. Distribution of information by hospital staff continues to cause problems. In this study, partners felt overwhelmed by too much information. In contrast, Bramwell (1986) and Thompson and Cordle (1988) found that family members were stressed by a lack of information, especially about patients' optimum general activity levels.

Many investigations have examined the impact of the marital relationship on psychosocial adjustment to heart disease (e.g., Brecht et al., 1994; Fontana et al., 1989). The focus has been primarily the influence of the spouse on the patient's adjustment, spouses have received little attention. The theme of negative social consequences (cluster #3) indicated that partners' social activities appear restricted by the impact of the heart attack. The findings suggest that partners' quality of life may have deteriorated because their social life has diminished as part of a couple, or caregiving role demands may prevent partners participating in individual activities or hobbies. Langeluddecke, Tennante, Fulcher, Barid, and Hughes (1989) suggested that emotional strain may significantly affect a couple's recreational pursuits. It appears that partners' adjustment to the impact of the myocardial infarction may develop from within a mutual context of communication and interaction.

King et al. (1993) found that support to spouses, of patients who had coronary artery surgery, was significantly related to positive patient outcomes, as well as to the spouses' own perceptions of well-being. Also higher levels of spouses' perceived support may enable them to be supportive to patients and result in better psychosocial outcomes (Finlayson & McEwan, 1977). Research (Dhooper, 1984; Finlayson & McEwan, 1977; Nyamathi, 1987) with spouses of myocardial infarction patients has indicated that sources of spousal social support are primarily adult children and along with, in the initial stages of recovery, siblings, friends and neighbours.

The theme related to changes in the pace of partners' lives (cluster #4) decribed the more personal impact of the myocardial infarction. There is the sense that some aspects of partners' lifestyles have become "hectic and busy" (#65) while other spheres of their lives have slowed down. Again, there is little specific reference to this theme in the literature.

The theme of vigilance (cluster #5) contains statements that may address the coping behaviour of partners in response to the threat of reinfarction or cardiac death. Lazarus and Folkman (1984) stated that coping activities are crucial mediating processes that may involve a series of physical and coginitive responses that attempt to regulate the environment and restore psychological equilibrium. It appears that partners continue to monitor patients' activities or assume their role responsibilities within the home up to 36 months after the cardiac episode. This theme may also demonstrate how social support can, in some cases, be detrimentral to recovery.

Spouses may become oversolicitous in their efforts to relieve patients of domestic tasks (Biegel et al., 1991; Gorkin et al., 1994; Levin, 1987) Partners' fears and concerns may result in excessive restrictions being placed on the patients (Taylor, Bandura, Ewart, Millar & DeBusk, 1985). This process often involves policing patients' compliance with recommended regimens or becoming overprotective in general. Levin (1987) suggested that some individuals assume the role of "the good little woman" but their genuine concern to protect patients backfires, and they shift from caring to "caretaking". Levin defined caretaking as calculated, controlling, stemming from perceived helplessness, motivated by insecurities, and often involving conditional behaviour.

Jenkins et al. (1983) suggested that partners' assumption of an overprotective stance towards patients may be due to a lack of adequate and accurate information, or incongruent perceptions between patients and partners of patients' overall health status. Patients may respond with depression and excessive dependancy (Gorkin et al., 1994), which in turn could exacerbate the strain experienced by the caregivers and impair their ability to be supportive (Burch & Brandenburg, 1990). The concept map can be interpreted to suggest that the vigilance theme plays a central role to the rest of the themes that surround it, acting rather like a hub in the centre of a wheel.

The last two themes described in this study have received little specific attention in the literature. Partners' described improvements in their quality of life since the heart attack (cluster #6), that have been only indirectly implied in studies of marital quality and social support (e.g, Brecht et al., 1994). The partners indicated that the myocardial infarction had changed patients' lifestyles in a way that provided them with more quality time to spend with their partner, children and friends. Changes in food consumption to healthier, low-fat recipes appears to be perceived as an important way of reducing risk factors and improving an individual's cardiovascular health. This cluster was adjacent to items related to vigilance on the map. Amick and Ockene (1994) suggested that family and social networks play important roles in the continued maintainence of life-style changes. They stated that social support resources help to minimize interpersonal and environmental stressors, enhance motivation and commitment, and promote relapse prevention skills.

Incidence Survey - Partners

A survey was developed using the partner statements to determine how frequently these items were endorsed by partners as prevalent to their experiences following their partners' heart attack (see Appendix S). Frequencies were calculated for each of the partner statements (see Appendix T). Respondents were asked to rate each item on a 5-point Likert scale as 1 = strongly disagree, 2 = disagree, 3 = neutral/not applicable, 4 = agree, or 5 = strongly agree. Participants were also asked to respond to two questions. First, how did partners rate their present quality of life as a value from 1 to 100 (where 1= poor and 100 = excellent). Second, participants were asked to rate the change in their quality of life since their partners' heart attack by circling one of the following: very deteriorated, somewhat deteriorated, no change, somewhat improved, or very improved.

The raw data was summarized as means, standard deviations and three percentage values (1. strongly agree/disagree, 2. neutral/not applicable, and 3. agree/strongly agree) to determine how statements were endorsed by partners. Those statements that had means greater than 3.00 and less than 2.5 were chosen for further interpretation. This data is presented in Table 8.

The statement most frequently endorsed by partners was "I enjoy spending time with my partner" (88%). Other top ten statements frequently endorsed were: "I always watch out for signs of problems" (88%), "I become concerned if he/she complains of discomfort in his/her chest" (85%), "I have become more watchful" (85%), "My partner worries about me when I don't take care of myself" (81%), and "I worry about the possibility of my partner having another heart attack" (81%).

Statements that were least frequently endorsed by partners included "My partner refuses to eat food I prepare" (12%), "I get tired looking after my partner" (11%), "We have to walk to places because he/she can't drive (0%), and "I had to stop work to take care of my partner" (4%). Statement #35 ("It is hard to continue the relaxation exercises we were taught") appeared to be non-applicable to partners (62%).

The data was then organized by cluster to determine how partners had endorsed particular themes. Table 9 contains a listing of the means and standard deviations of each

Table 8

Item Means and Percentages of Partner-Endorsed Statements

Rank	Statement	% Partner-Endorsed Items*			
		Mean	SD/D	N/A	A/SA
1	I enjoy spending time with my partner (#28)	4.3	4	8	88
2	I always watch out for signs of problems (#18)	4.2	4	8	88
3	I become concerned if he/she complains of discomfort in his/her chest (#40)	4.1	7	8	85
4	I try not to nag (#63)	4.0	0	23	77
5	I have become more watchful (#62)	4.0	7	8	85
6	My partner worries about me, when I don't take care of myself (#2)	4.0	11	8	81
7	I am happy no-one smokes in our house now (#21)	4.0	4	38	58
8	I worry about the possibility of my partner having another heart attack (#41)	4.0	11	8	81
9	My partner and I continue to talk about the heart attack (#1)	3.7	19	8	73
10	If a person isn't on time you think "What has happened?" (#61)	3.6	19	12	69
11	I am often more worried than my partner is (#15)	3.6	19	11	70
12	I am spending lots of time reading food labels in the stores (#10)	3.6	23	15	62
13	I am pleased my partner has more time for our family (#30)	3.5	11	35	54
14	I have reduced stressful situations in the home (#8)	3.5	11	23	66
15	I feel hopeful my partner will get help coping with stressful work situations (#6)	3.5	8	46	46
16	I make sure my partner has taken his/her medication (#48)	3.5	15	31	54
17	My partner has not maintained his/her exercise program (#53)	3.4	23	15	62
18	My partner shares more of the household chores (#7)	3.4	19	19	62

* SD = strongly disagree, D = disagree, N/A = not applicable, A = agree, SA = strongly agree

Rank	Statement	% Partner-Endorsed Items*			
		Mean	SD/D	N/A	A/SA
19	I ensure that my partner takes rest breaks (#16)	3.4	23	11	66
20	I feel anxious due to health cuts and long waiting lists (#20)	3.4	34	8	58
21	Anxiety - for the first few months, then I was okay (#44)	3.3	34	4	62
22	I take it day to day (#43)	3.2	42	4	54
23	I can't keep up with my partner (#57)	3.1	35	19	46
24	More time to enjoy the company of friends (#9)	3.1	31	15	54
	Partner-endorsed items with means less than 2.5				
1	My partner refuses to eat food I prepare (#13)	1.9	73	15	12
2	I get tired looking after my partner (#27)	2	66	23	11
3	We have to walk to places because he/she can't drive (#26)	2.1	58	42	0
4	I can't drive the car so we stay closer to home these days (#31)	2.1	54	46	0
5	My partner thinks I never worry about him/her (#4)	2.1	81	4	15
6	We have lost many of our friends (#45)	2.1	62	23	15
7	Our quality of life has deteriorated (#33)	2.1	77	8	15
8	I had to stop work to take care of my partner (#64)	2.3	42	54	4
9	We participate in less outdoor activities since the heart attack (#36)	2	46	50	4
10	I make sure that my partner has taken his/her medication (#48)	2.3	66	19	15
11	I have to encourage my partner to exercise (#25)	2.3	62	19	19
12	I have to do all the physical work (#32)	2.4	61	8	31
	Neutral or non applicable items				
1	It is hard to continue the relaxation exercises we were taught (#35)	2.9	23	62	15

* SD = strongly disagree, D = disagree, N/A = not applicable, A = agree, SA = strongly agree

item by cluster as well as computed cluster means. The findings indicated that cluster #1 (fear of reoccurrence) had the most number of partner-endorsed statements with a mean greater than 3.00 (agree/strongly agree). This cluster contained ten of the top 24 statements. Eighty-five percent of partners stated that they have become more watchful (#62) and 88% continue to always watch out for signs of problems (#18). The possibility of their partner having another heart attack (#41)is a source of anxiety for 81% of partners, while only 50% are concerned about sudden death (#19).

Respondents (85%) are also concerned if their partners' complain of discomfort (#40), and 88% stated that their partners worry about them when they don't take care of themselves (#2). Seventy-three percent of partners' continue to talk about the heart attack with their spouses (#1). Partners' anxiety was endorsed in three different statements. If patients are not punctual (#61) 69% of partners worry about what might have happened to them. Other respondents (58%) feel anxious about health cuts and long waiting lists (#20). Sixty-two percent of partners' were anxious during the first few months after their partners' heart attack (#44), and finally about half the partners (54%) cope by taking it day to day.

Two clusters contained four statements that were ranked in the top 24 statements. First, from cluster #2 (caregiver stress), 77% of partners stated that they try not to nag (#63). Seventy percent of respondents perceived that they were often more worried than their partners are (#15). Patients lack of compliance in maintaining their exercise programs (#53) was endorsed by 62% of partners. Less than half of the partners (46%) perceived that they can't keep up with their partners (#57).

Table 9

Item Means and Percentages for Partner-Endorsed Statements by Cluster

Statement	% Partner-Endorsed Items*			
	Mean	SD/D	N/A	A/SA
Cluster #1-Fear of Reoccurrence				
I fear the end could come suddenly (#19)	2.8	50	8	42
I become concerned if he/she complains of discomfort (#40)	4.1	7	8	85
I worry about the possiblity of my partner having another heart attack (#41)	4.0	11	8	81
I feel anxious due to health cuts and long waiting lists (#20)	3.4	34	8	58
I feel anxious about keeping appointments (#60)	2.7	42	31	27
If a person isn't on time you think "What has happened?" (#61)	3.6	19	12	69
I always watch out for signs of problems (#18)	4.2	4	8	88
I have become more watchful (#62)	4.0	7	8	85
I take it day to day (#43)	3.2	42	4	54
Anxiety - for the first few months then I was okay (#44)	3.3	34	4	62
My partner thinks I never worry about about him/her (#4)	2.1	81	4	15
My partner worries about me when I don't take care of myself (#2)	4.0	11	8	81
My partner and I continue to talk about heart attack (#1)	3.7	19	8	73
Cluster Mean	3.2	28	8	64
Cluster #2 - Caregiver Stress				
I am often more worried than my partner is (#15)	3.6	19	11	70
I get tired looking after my partner (#27)	2.0	66	23	11
I felt overwhelmed by the amount of information the hospital gave us (#37)	2.7	54	19	27
I have been experiencing some depression (#23)	2.9	46	8	46
I must not talk about anything when I feel bad (#5)	2.5	62	11	27
I try not to nag (#63)	4.0	0.0	23	77

* SD = strongly disagree, D = disagree, N/A = not applicable, A = agree, SA = strongly agree

Statement	**% Partner-Endorsed Items***			
	Mean	**SD/D**	**N/A**	**A/SA**
Cluster #2 - Caregiver Stress (continued)				
I feel lonely at times because my partner sleeps alot (#54)	2.3	69	8	23
My partner has not maintained his/her exercise program (#53)	3.4	23	15	62
I am frustrated because my partner doesn't make an effort to take care of him/herself (#38)	2.4	66	11	23
I have had to manage more on my own (#58)	2.7	46	27	27
My partner has a negative attitude towards life now (#14)	3.0	42	19	39
I had to stop work to take care of my partner (#64)	2.3	42	54	4
I don't like the restrictions (#55)	2.5	54	23	23
I can't keep up with my partner (#57)	3.1	35	19	46
My partner no longer works so income is a big stressor (#42)	2.6	39	50	11
Cluster Mean	2.8	44	21	35
Cluster #3 - Negative Social Consequences				
We have lost many of our friends (#45)	2.1	62	23	15
I would love to travel more, but it would be too difficult for my partner (#66)	2.5	54	27	19
Social activities are almost zero (#50)	2.7	69	19	12
There are alot of things we can't do anymore (#24)	2.7	62	4	34
We have to walk to places because he/she can't drive (#26)	2.1	58	42	0.0
Our quality of life has deteriorated (#33)	2.1	77	8	15
I can't drive the car so we stay closer to home these days (#31)	2.1	54	46	0.0
My quality of life is unaffected by the heart attack (#39)	2.7	50	23	27
It is hard to continue the relaxation exercises (#35)	2.9	23	62	15
Heart attack is a continuous subject of conversation with friends (#3)	2.9	39	15	46
Cluster Mean	2.5	55	27	18

* SD = strongly disagree, D = disagree, N/A = not applicable, A = agree, SA = strongly agree

Statement	% Partner-Endorsed Items*			
	Mean	SD/D	N/A	A/SA
Cluster #4 - Changes in the Pace of Life				
I don't go out socially as much as I did prior to the attack (#29)	2.6	46	35	19
I have lost my independence (#49)	2.3	66	19	15
We participate in less outdoor activities since the heart attack (#36)	2.3	46	50	4
My life is hectic and busy (#65)	3.0	46	15	39
It is hard to accept the changes in my life style (#47)	2.5	58	19	23
I never drink alcohol anymore (#22)	2.7	42	39	19
Cluster Mean	2.6	51	29	20
Cluster #5 - Vigilance				
I ensure that my partner takes rest breaks (#16)	3.4	23	11	66
I make sure that my partner has taken his/her medication (#48)	3.5	11	23	66
I had to learn how to care for my partner (#34)	2.8	42	19	39
My partner has sleeping problems that affect my sleep (#17)	3.0	46	12	42
I have to encourage my partner to exercise (#25)	2.3	62	19	19
I have to do all the physical work (#32)	2.4	61	8	31
I had to take over my partner's chores (#51)	2.7	46	23	31
I try to not upset my partner (#12)	3.5	19	15	66
I have reduced stressful situations in the home (#8)	3.5	11	23	66
My partner is willing to help me but is unable to (#46)	2.5	50	31	19
I feel hopeful my partner will get help coping with stressful work situations (#6)	3.5	8	46	46
Cluster Mean	3.0	34	21	45
Cluster #6 - Improved Quality of Life				
I am pleased my partner has more time for our family (#30)	3.5	11	35	54
My partner shares more of the household chores (#7)	3.4	19	19	62
More time to enjoy the company of friends (#9)	3.1	31	15	54

* SD = strongly disagree, D = disagree, N/A = not applicable, A = agree, SA = strongly agree

Statement	% Partner-Endorsed Items*			
	Mean	SD/D	N/A	A/SA
I enjoy spending time with my partner (#28)	4.3	4	8	88
I am happy nobody smokes in our home now (#21)	4.0	4	38	58
Overall quality of life has improved (#56)	2.6	46	35	19
I have increased my exercise as a personal preventative measure (#52)	2.7	46	23	31
Cluster Mean	3.4	23	25	52
Cluster #7 - Nutritional Concerns				
I am spending lots of time reading food labels in the store (#10)	3.6	23	15	62
Switch to cooking with low fat recipes, I enjoy doing this (#59)	3.0	38	27	35
I am finding it difficult to find interesting food for my partner's daily needs (11)	2.7	50	19	31
My partner refuses to eat the food I prepare (#13)	1.9	73	15	12
Cluster Mean	2.8	46	19	35

* SD = strongly disagree, D = disagree, N/A = not applicable, A = agree, SA = strongly agree

Second, from cluster #5 (vigilance), 66% of partners had reduced stressful situations in the home (#8) and ensure their partners take rest breaks (#16). Fifty-four percent of respondents also make sure patients take their medication (#48). Less than half (46%) feel hopeful their partners will get help coping with stressful work situations (#6). One statement (#10) from cluster #7 was endorsed by 62% of partners who perceived that they spend lots of time reading food labels in the stores.

Eleven statements were also notable for how infrequently they were endorsed by partners (disagree/strongly disagree). Cluster #3 (negative social consequences) contained four items with the lowest endorsement. No partners endorsed the statements (#26 & #31) related to limitations imposed by not being able drive a car. Only 15% of partners stated that their life had deteriorated (#33) and that they had lost many of their friends (#45). It is interesting to note that only half the partners (50%) perceived that their life is unaffected by the heart attack (#39).

Clusters #2 (caregiver stress) and #5 (vigilance) contained two statements that were negatively endorsed by partners. In cluster #2, 11% of partners got tired looking after their partners (#27). Only 4% of respondents had to stop work to take care of their spouses. It was evident that employment is not applicable to over half the partners (54%) in this sample. In cluster #5, only 19% of partners have to encourage their partners to exercise (#25), and 31% endorsed that they have to do all the physical work (#32).

Three clusters had one statement with a mean of less than 2.5. In cluster #1 (fear of reoccurrence) only 15% of respondents thought their partners never worry about them (#4). Twelve percent perceived that their spousess refused to eat food they prepared (#13). Only 4% of partners participated in less outdoor activities since the heart attack (#36), although 50% stated that the item didn't apply to them.

Partners were also asked two questions regarding their overall perception of their quality of life. First, partners rated their present quality of life between 40 and 98, with an average of 74.9 (SD = 14.4). This finding suggested that most respondents perceived their present quality of life to be very good. In response to the second question, 46% of partners stated that their quality of life had somewhat to greatly improved since the heart attack. Twenty seven percent of respondents perceived no change, while 27% also felt their quality of life had somewhat to greatly deteriorated. There was a moderate relationship between partners' present quality of life and the perceived changes in their quality of life since their partners' myocardial infarction ($r = 0.53$, $p < 0.01$).

In summary, a total of 24 statements had an item average of over 3.00. The remaining 42 statements in the survey were rated with an item average at the mid-scale or below. The improved quality of life cluster (#6) had the highest average endorsement by partners. Cluster #3 (negative social consequences) received the lowest average rating of 2.5. The grand mean for all 66 statements was 2.95. Considerable variability was evident among the item means within each cluster. In general, it appears that the longer-term impact of a myocardial infarction is perceived as having variable effects on the quality of life of partners. It is evident that partners continue to experience the aftershocks of the initial cardiac episode as much as 36 months later. In particular, the threat of their partners experiencing a future heart attack seems to be a primary concern. The themes of concept map suggested that many of the partners' cognitive and behavioural responses may be influenced by this stressor.

General Conclusions

In general, it was evident that considerable respondent variability existed at the level of individual items for both patient and partner themes. The clusters organized the statements conceptually based on common groupings, so some of the clusters contained weak items. For example, in cluster #3 (depression) of the patient concept map, statement #47 ("I am careful not to over-exert my heart") appears to be a weak item. In a factor analysis, such an item may have not correlated highly with the factor of depression. It is the belief of this author that, for clinical purposes, these conceptual ratings would have more utility than the correlational ratings of factor analysis. The highest practical, clinical utility remains with individual experiential items that could be administered in a check-list format.

The validity of the master lists was achieved using redundancy. It appeared that redundancy was reached during data collection. Many major items seemed to be representative of the impact of myocardial infarction on quality of life. It could be argued that some themes e.g., spirituality, were not mentioned. Indeed, other unique items might be generated by participants, but the practical utility of more item generation is questionable. A check-list developed from these items would probably not exceed 40 items, otherwise, in a clinical setting, it would be too time-consuming and cumbersome to administer to patients and partners.

With regard to gender issues, statements were collapsed together for male and female participants. Initial observation of items found them to be indistinguishable at the conceptual level for either group. No items were gender specific, although perhaps one gender might support a single item more than others. If such gender differences exist they are more likely to occur at the survey level.

Validation of the Conceptual Themes

The findings of this study were presented to several health-care providers that have worked with cardiac patients and families, on average for 15 years. These individuals were asked to comment on the concept maps and incidence data of the participants in relation to their professional experiences.

A cardiologist stated that the themes "seem to make sense", and that patients and partners had provided feedback that they had enjoyed participating in this type of study. Two nurses with extensive patient contact agreed the themes appeared to be representative of what they have encountered "on the front line"during their interactions and communications with patients and their families. One nurse commented:

> we often make the mistake of thinking that we know what patients need, where their focus is..... I have learned over the years to listen to the patients and get their story, find out what is important to them.....only then do I take care of the 'must do's' as far as the limitations that are imposed on their lives by the myocardial infarction.

She emphasized that patients regard continued interaction as important:

> patients frequently express their appreciation when I make personal contact in follow-up phone calls. One person told told me, "Those phone calls you made to me, you have no idea how much they mattered to me"....but these days time restraints limit this personal touch.

It was reported that many patients perceived the heart attack "as an unwelcome physical insult....as if their bodies have betrayed them". It was stated that some individuals continue to question whither they actually had a heart attack even months after the infarct while others refer to it as "my event" refusing to use the words "heart attack". The nurses stated that they are "not surprised" that few women were willing to participate in the study. In their experience it has always been difficult to elicit the participation of women, both patients and partners, in studies and programs.

In reference to specific items, the respondents agreed that considerable variability exists among patients' experiences of the impact of a myocardial infarction. Items pertaining to short term memory loss.(#26) and the inability to concentrate (#20) were identified as impacting many patients, so much so these factors may warrant neuropsychological assesssment.

The nurses responded that they have limited contact with partners of patients, especially if the partners are employed. However, the themes of caregiver stress (cluster #2), vigilance (cluster #5) and nutritonal concerns (cluster #7) were perceived as key concepts. The experiences of partners were also reported as variable, which added support to the findings. It was noted that:

> ... many couples seem to not connect .... partners appear resentful and angry, at times, towards patients. Often the heart attack occurs prior to retirement when they have planned to travel together. It seems like a non-verbal expression of how they feel the heart attack has ruined their lives.

These comments provided some support for the finding that partner support has the potential to both positively and negatively impact patient quality of life. Caregiver stress was discussed in relation to the increased role demands of caregiving. It was reported that many partners are not able to relinquish the caregiver role, even in older individuals. This impact on partner quality of life was illustrated in the example given:

> You have an older woman, who works part-time to supplement her benefits. She looks after the grandchildren once in a while to give her daughter a break, and also sometimes cares for an elderly parent ....then on top of all that she now has a sick husband. So who looks after her?

The response of some partners, it was stated, is to avoid or deny what is happening by refusing or being reluctant to becoming involved in the rehabilitation process. Caregivers' stress was expressed when they complained that patients "do not listen to them" or fail to comply with the treatment suggestions (#38).

It was reported that one of "the biggest issues" for partners, time and again, is nutritional concerns (#7). Often "the first and most frequently asked questions are concerned with food, before anything is mentioned about exercise or medications" it was stated. It was suggested that this is perhaps one of the few areas of their lives that patients can resume and retain control over throughout the experience of CHD. The health-care providers concluded:

> it would be interesting to use this information to diminish some of the fears and anxieties that patients and families have regarding recovery and returning to normal activities.

In chapter V, a summary and limitations of the study will be provided and future directions for research will be discussed.

CHAPTER V

Summary and Future Directions

Summary

This chapter provides a summary and discussion of the research findings and presents the implications of the results, and recommendations for future research. This study arose from a need within the health-related quality of life literature to return to the basics. The relative inadequacy of most commonly used measures of quality of life, which are based primarily on investigator-specific criteria, has emerged in the literature as an implicit problem. Health practitioners are seeking to use quality of life assessments to measure changes in physical, psychological, and social health in order to evaluate the human and financial costs and benefits of clinical programs and interventions (Testa & Simonson, 1996). Quality of life researchers are confronted with the challenge of deciphering the complexity of this elusive construct to directly answer questions related to therapeutic choices and practical clinical applications.

The purpose of this research was to gain a better understanding of the impact of an acute myocardial infarction on the quality of life of patients and their partners, as defined by the participants themselves. The first intent of this investigation was to identify the experiences of individuals who have had at least one myocardial infarction and their partners. The second objective was to analyse these areas, using concept mapping, to reveal the themes underlying their identified experiences. Two separate lists of 66 statements were identified and subsequently sorted by patients and partners. The sorted data was then statistically analysed using multidimensional scaling and hierarchial cluster analysis (concept mapping) in order to identify potential themes. As a result of this process, a concept map was generated for patients that consisted of eight themes: lifestyle changes, physiological symptoms, depression, employment issues, future health concerns, confinement, partner support, and improved quality of life. The concept map developed separately for partners contained seven themes: fear of reoccurrence, caregiver stress, negative social consequences, changes in the pace of life, vigilance, improved quality of life, and nutritional concerns.

Two incidence surveys were conducted to ascertain the prevalence of the identified items to patients and partners experiences following a myocardial infarction. Surveys developed using participants statements were distributed to a larger sample of randomly selected patients and partners (n = 100). The response rate was 35% and 26% respectively. Hence, the results of the incidence surveys need to be interpreted with caution due to the small sample size of the groups.

These results indicated that there is considerable variation in the experiences of patients as a result of a myocardial infarction. In general, patients were more appreciative of life and tried to forget about their heart condition and get on with life. Support from partners appeared to play a significant role in buffering the impact of the myocardial infarction on patients. A total of 26 statements had means greater than 3.00 (agree/strongly agree).

The theme of improved quality of life (cluster #8) contained the most patient-endorsed statements, with eight of the top 26 items. Physiological symptoms (cluster #2) appeared to have considerable impact on patients' quality of life. This cluster contained six of the top statements, while cluster #7 (partner support) was ranked third with four items in the top eight statements. Three of the four statements from cluster #3 (depression) were endorsed by patients. Clusters #1(lifestyle changes) and #5 (future health concerns) contained two each. The average for most statements was below the mid-point score of 3.00 (disagree/strongly disagree).

Considerable variation in response also existed in the perceived impact on quality of life of partners 18 months, on average, after a myocardial infarction. It was evident that partners continued to fear the reoccurrence of a myocardial infarction and perhaps the sudden death of patients. It was apparent that respondents enjoyed spending more time with their partners, but they also tended to be more vigilant for potential problems that may result in reinfarction. A total of 24 statements had means greater than 3.00 (agree/strongly agree).

The findings indicated that cluster #1 (fear of reoccurrence) had the most number of partner-endorsed statements, with ten of the top-ranked 24 items. Improved quality of life (cluster #6) was ranked second by partners, with five statements. Partners expressed their happiness at the changes in their partners' lives that allowed them more time to spend with family and friends. Clusters #2 (caregiver stress) and #5 (vigilance) each contained four statements. In cluster #7 (nutritional concerns) one statement was endorsed by partners. Again, most items had means less than 3.00 (disagree/strongly disagree).

At the end of the incidence surveys, respondents were asked to cognitively appraise their present quality of life and also the perceived change in their quality of life since the myocardial infarction. In response to the first question, patients' rated their average present quality of life as 73 (where 1 = poor and 100 = excellent), with a range of 25 to 100. Secondly, about 46% of patients rated their quality of life as somewhat to greatly deteriorated. Twenty percent reported no change, and about 34% of patients perceived their quality of life had somewhat to greatly improved. There was a moderate correlation between these simplistic measures of patients' present quality of life and the perceived change in quality of life since their heart attack ($r = 0.42$, $p < 0.05$).

Partners were asked to rate their present quality of life and also the perceived change in their quality of life since their partners' myocardial infarction. First, partners appraised their present quality of life at about 75, with a range of 40 to 98. Most respondents indicated that it was very good. Second, 46% of partners' reported that their quality of life had somewhat to greatly improved since their partners' heart attack. Twenty-seven percent perceived no change, while 27% felt their quality of life had somewhat to greatly deteriorated. Partners' present quality of life was moderately correlated with the perceived change in their quality of life since their partners' heart attack ($r = 0.53$, $p < 0.01$). The reported changes in the respondents' quality of life measure appears to be more applicable to the present study because the focus is on the impact of a myocardial infarction on quality of life, rather than a more static assessment of perceived present quality of life.

Conclusions

The goals of this investigation were to identify the areas of impact on quality of life perceived by post-myocardial infarction patients and their partners and to determine whether these areas reflected underlying themes or categories. Sixty-six statements were identified by both patients and partners. The development and interpretation of the two concept maps created from those statements indicated some themes previously cited in the literature as well as other concepts that were largely unrepresented. The concepts defined by patients seemed to centre on improvements in quality of life and the physiological symptoms of myocardial infarction. The central themes defined by partners included fear of reoccurrence, vigilance and improved quality of life. The survey data concluded that there is considerable variation in the personal experience of the impact on quality of life, on average 18 months, post-myocardial infarction for both patients and partners. Some of the themes contained both positive and negative aspects which may provide a more comprehensive representation of the domains specific to the experience of myocardial infarction. Previous quality of life assessments appear to focus primarily on negative aspects of the impact of an acute cardiac episode. It is evident that quality of life is a dynamic construct, and measures may shift the focus in the directionality of quality of life.

Limitations of the Study

The findings of this study are preliminary and include some limitations. Any interpretations of the findings must be conducted with the following limitations in mind. This study focused on the areas identified by patients and partners that impacted their quality of life following myocardial infarction, but did not investigate other cardiovascular diseases or chronic illnesses. Thus, it does not purport to discuss the entire domain of CHD experience or chronic illness. Furthermore, some of the experiences provided by participants, in phase one, may not have been a function of the impact on quality of life after a myocardial infarction.

The statements compiled in the study must not be understood to be reflective of the entire myocardial infarction domain. Very few female patients responded to the statement generation questionnaire. As a result, some important statements relative to the experiences of female patients and male partners may have been excluded. The low response rate among female patients may have prevented assessment of potentially important gender differences in perceptions of quality of life. Frasure-Smith et al. (1995) encountered a similar problem in their study and stated that, as in other recent cardiac studies, women and older patients are more likely to refuse to participate. This concern was alleviated somewhat, in phase one of this study, in that the statements obtained from female patients were judged to be similar to male patients, and also female partners and male partners, hence the data was amalgamated. The low percentage of respondents to the incidence surveys also suggested that these results should be interpreted carefully.

Other demographic limiting factors in this study were most patients were married, middle-aged males (M = 64 yrs.) who had lived with their partners for about 25 years. The generalizability of the incidence surveys must be carefully evaluated. Most respondents were male patients (88%) and female partners (92%). As a result, the application of these findings to other populations must be done with caution.

Future Research Directions

The findings for this study have implications for future research. Additional research is required to validate the results of this investigation and explore their reliability with different post-myocardial infarction patients and their partners. This study confirmed that it is necessary to evaluate the patients' perspectives of the impact of illness on their quality of life and that of their partners. The findings underscored the importance of continuing, in future research, to integrate the perspectives of these "very expert witnesses" into quality-of-outcome measures as perhaps a key dimension in itself.

Other studies should attempt to gain a higher response rate from female patients and male partners to attempt to bridge the gap in research among female cardiac patients. The sample for this study was obtained from individuals who attended one hospital in a large urban area. It is suggested that research be conducted on a larger national sample of patients who have experienced a myocardial infarction and their partners (n = 500), and then expand this research to include the impact on quality of life of other cardiovascular diseases, such as individuals who have had a heart transplant or perhaps patients waiting for bypass surgery.

Respondent variability can occur due to a variety of factors such as different reporters (e.g, patient, partner, physician, or nurse) or the assessment context (e.g., hospital or home). Previous research (e.g., Packerson, Broadhead, & Chiu-Kit, 1992) has indicated that physicians, patients, and partners perceptions of quality of life differ. Thus, it would be interesting to generate concept maps from each of these groups of individuals, in various chronic illness contexts, to determine how their perceptions differ and where the participants focus their energy. It would also be interesting to have health care professionals sort the patient and partner data to determine if there are any differences in conceptualization. Such comparisons may enhance the effectiveness of clinical programs and simplify therapeutic decision-making.

Researchers have documented transitions in the adaptation of patients and families to myocardial infarction from hospitalization and early convalescence through to longer-term recovery that may stretch up to five years after the initial cardiac episode. It would be interesting to generate concept maps from patients and partners across the trajectory of this chronic illness to determine if changes occur in conceptualization of its impact on their quality of life. Such research may provide key conceptual themes of similarities and differences in experiences of the primary stakeholders, giving a sense of the "big picture" rather than smaller "snapshots".

Despite the prevalence of CHD in older individuals (<50 years), researchers should attempt to investigate the experiences of younger individuals, who may be single and at a different stage of life, to determine how a myocardial infarction impacts their quality of life compared to older patients. Such research is particularly important given that a theme e.g., employment or return to work, may be used as a quality-of-life outcome measure by health practitioners. This factor may be relevant to a younger sample, but may not be perceived as important within an older sample, as observed in this study.

In the absence of a gold or criterion standard of measurement of either individual domains or overall quality of life, evidence of the validity of the conceptual themes cannot come from comparing results to a single criterion measure (Testa & Simonson, 1996). Content validity was established as a result of the manner in which the items were generated. It could be argued that the themes do not reflect all aspects of the comprehensive frameworks of quality of life proposed, for example, by Küchler (1989). The concept map has no items, for example, pertaining to spirituality, which a health practitioner may have thought to be important. However, those items that were generated and then endorsed by patients and partners appeared as themes because they were perceived as important by those individuals who are living with and in spite of chronic illness.

Practical Clinical Implications

The findings of this study have practical clinical implications. It is apparent that care of the patient and partner after myocardial infarction demands striking a balance between the many dimensions of quality of life. Such care is contingent upon not only physical but also psychological and social processes. Initially, it seems important to provide opportunities for enhanced communication between the health-care providers and both the patient and partner. This process helps to reinforce the importance of patient and partner input in the rehabilitation program.

A logical step in future research would be to develop the lists of descriptive data into psychometrically sound instruments that have more practical and clinical utility. The statements obtained from patients and partners could be reduced to 40-item checklists. These instruments could be used in clinical settings, with specific feedback, to familiarize newly diagnosed patients and, in particular, their partners with the themes experienced by other individuals "who have already walked the walk". This approach could provide an opportunity to inform these individuals, investigate their needs and encourage family involvement.

Similar checklists could be developed for various stages of the chronic illness and implemented by health-care providers as a practical tool for organizing distribution of information on the basis of the taxonomomy of issues that appear on the concept maps. In time-limited clinical settings, these checklists could act as organizing devices for discussion, reviews of progress and perhaps may anticipate and usurp future problems. Furthermore, health-care providers could, across time, compile normative data using these checklists and assess patient outcomes associated with new medical interventions or innovative rehabilitation approaches. This may also be a valuable way of identifying high risk caregivers who could benefit from counselling or other support services.

It could be argued, however, that it is not the next step. Instead, it may be advisable to resist the temptation, at this early stage of investigation, to add to the already burgeoning list of inadequate quality-of-life measures. Instead more resolution of the problems at the theoretical level of quality of life research may have more significant implications at the practical clinical level. The decisions that inform and guide the next steps must afford the best avenue for moving toward a responsive and congenial relationship between different theoretical aspects and clinical applications in quality of life research. A resolution of the differences that exist in this area can only occur when a new paradigm emerges that is more informed than any existing one. The present study could be regarded as a blueprint, suggesting the variety and organization of elements of the experience of post-myocardial infarction on quality of life.

This process may demand that researchers return to the basics and adopt more simplistic approaches to the assessment of quality of life that are contextually appropriate. Recent breakthroughs in measurements are enabling researchers and clinicians to obtain and utilize information about the outcomes that matter most to patients and their caregivers, without violation of basic biomedical principles. The primary focus of caring, within the context of chronic illness, must ultimately achieve the goals of alleviating human suffering, minimizing discomfort and contributing to the enhancement of health and quality of life for all those involved.

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APPENDIX A

Cover Letter to Participants in Phase One

Dear participant:

We are conducting a study at the University of Alberta on the quality of life of individuals with coronary heart disease and their partners. It is hoped that through a better understanding of the experiences of cardiac patients and their partners staff will be able to assist individuals more effectively during rehabilitation. We would like to invite you and your partner to participate in our reasearch. Your participation will be strictly voluntary and anonymous. All information collected will be confidential. Your names were obtained from your cardiologist's files and his/her approval was obtained.

The enclosed package contains two forms and two stamped, self-addressed envelopes. We would like you to complete the "Patient's Form". On the top half of this form please fill in the information pertaining to your cardiac history. On the bottom of the form please describe how having had a heart attack has affected your quality of life using statments or short phrases.

Please give the "Partner's Form" to your partner. We would like your partner to describe how having a partner who has had a heart attack has affected his or her quality of life. The completed forms can be returned to us in the self-addressed envelopes provided.

We would like to invite you to also sort statments into groups that have a common theme or idea. This sorting task requires about 30 minutes to complete. If you are willing to participate in this second phrase of the study please provide your name and address on the enclosed form and a sorting package will be mailed to you.

If you have any questions or concerns please feel free to contact Dr. Calder at 492-3696.

Thank you for your time and cooperation.

K. K. Teo, MD, PhD, FRCPC
University of Alberta Hospitals
Edmonton

P. Calder, PhD
Dept. of Educational Psychology
University of Alberta, Edmonton

APPENDIX B

Patient's Form

Please complete the following:

Age ____________ years

Gender Male ☐ Female ☐

Married or living with a partner Yes ☐ No ☐

Number of years with this partner ____________ years

Have you had a heart attack? Yes ☐ No ☐ If so, how many? ______

Number of months since last heart attack ________ months

Number of months since initial diagnosis of a heart attack ________ months

Do you presently experience symptoms of heart disease (e.g. angina, shortness of breath)? Yes ☐ No ☐

Have you ever had bypass surgery? Yes ☐ No ☐ If so, when?_____mths

Have you ever had an angioplasty? Yes ☐ No ☐ If so, when?_____mths

Are you actively involved in a cardiac rehabilitation program? Yes ☐ No ☐
If so, for how long?____mths

Please answer the following:

Describe how having had a heart attack has affected your quality of life.

1. ____
____

2. ____
____

3. ____
____

4. ____
____

Use the back of this form if needed - return in self-addressed envelope. Thank you.

APPENDIX C

Partner's Form

Please complete the following:

Age ________ years

Gender Male ☐ Female ☐

Married or living with a partner Yes ☐ No ☐

Number of years with this partner ________ years

Please answer the following:

Describe how having had a partner who has had a heart attack has affected your quality of life.

1. ____
____

2. ____
____

3. ____
____

4. ____
____

Use the back of this form if needed - return in self-addressed envelope. Thank you.

APPENDIX D

Agreement to Participate in the Sorting Task

I would like to participate in the sorting task, which is a part of the study on the quality of life of patients who have had a heart attack and their partners. I understand that my participation is strictly voluntary and that I can drop out of the study at any time, and that all information collected will be confidential.

Name: ____________________________

Address: ____________________________

____

____

Phone: ____________________________

Signature: ____________________________ Date: ______________________

APPENDIX E

Telephone Script (Guidelines)

Patient Script

Hello, my name is Helen Williamson. I am calling on behalf of Dr. Teo from the Department of Cardiology at the University of Alberta Hospital. We are conducting a survey with patients and their partners regarding their quality of life. Your cardiologist has given us permission to call you. Participation would be strictly voluntary, failure to participate will not in any way impact your medical treatment. Any information you share would be confidential. You are welcome to withdraw from the study at any time, or not answer any particular question I ask you.

Would you be willing to participate? It would require approximately fifteen minutes of your time. Is it convenient for you to answer now? If not, when would be a convenient time to call back?

Time: ________________ Number: __________________

No - Would it be possible to speak to your partner, please? Thank you for your time.

Yes - Thank you.

1. Demographics are collected for patient. (see Appendix B for questions.)
2. Participants were asked to respond to the following question using phrases or short sentences.

Patient Question: **Please describe how having had a heart attack has affected your quality of life?**

Request to participate in Sorting Task

In the second phase of our study, we require patients to sort statements collected from other patients into themes or ideas. It would require sorting the statements into piles that make sense to you. This task will require 20 minutes of your time. I will mail a package with detailed instructions and the statements to you within the next two weeks. You can return them to me using the enclosed stamped-addressed envelope.

Would you like to take part in the second phase of the study? Yes [ ] No [ ]
Would it be possible to speak to your partner, please? Yes [ ] No [ ]

If you have any questions please feel free to call Dr. Calder at 492-3696.
Thank you for your time. Goodbye.

APPENDIX E (continued)

Partner Script

Hello, my name is Helen Williamson. I am calling on behalf of Dr. Teo from the Department of Cardiology at the University of Alberta Hospital. We are conducting a survey with patients and their partners regarding their quality of life. Your partner's cardiologist has given us permission to call you. Participation would be strictly voluntary, failure to participate will not in any way impact your partner's medical treatment. Any information you share would be confidential. You are welcome to withdraw from the study at any time, or not answer a particular question I ask you.

Would you be willing to participate? It would require approximately fifteen minutes of your time. Is it convenient for you to answer now? If not, when would be a convenient time to call back?

Time: ________________ Number: __________________

Yes - Thank you.

1. Demographics are collected for the partner. (see Appendix C for questions.)
2. Participants were asked to respond to the following question using phrases or short sentences.

Partner Question: **Please describe how having a partner who has had a heart attack has affected your quality of life?**

Request to Participate in Sorting Task

In the second phase of our study, we require partners to sort statements collected from other partners into themes or ideas. It would require sorting the statements into piles that make sense to you. This task will require 20 minutes of your time. I will mail a package with detailed instructions and the statements to you within the next two weeks. You can return them to me using the enclosed stamped-addressed envelope.

Would you like to take part in the second phase of the study? Yes [ ] No [ ]

If you have any questions please feel free to call Dr. Calder at 492-3696.
Thank you for your time. Goodbye.

APPENDIX F
Master List of Patient Statements

PAT. # (Gender)	MAIL/ TELE.	#	STATEMENTS
1 (Male)	Mail	1	I suffer pain daily.
		2	I suffer intermittent weak feelings, dizziness and heart palpitations, all of which are controlled by the use of nitro patches and spray.
		3	I can't exercise properly and I am losing my physical fitness.
		4	Virtually cut out my sex life.
		5	I can't travel as I must be within four hours of the hospital.
		6	My diet limits many pleasures and there are few choices on most restaurant menus.
		7	My social life is very limited because I get tired in the evening.
		8	Cleaning walks, gardening, wood and metal working hobbies are greatly curtailed.
		9	With rest breaks and my limited capacity it takes three weeks to do what used to be two days work.
		10	My business has been seriously curtailed with a considerable loss in income.
		11	Profit was lost at my last heart attack when work had to be re-assigned to other companies.
		12	Two or three hours of work per day tires me out, so I am reluctant to accept any long-term work.
		13	I have had to turn down several speaking engagements for 1996-97 as I can't promise that I will be available.
		14	I find it takes me longer to do any task no matter how simple.
2 (Male)	Mail	15	Change in my lifestyle - no smoking, no alcohol, better diet, exercise program.
		16	No other changes or restrictions experienced.
		17	If I can maintain this level of lifestyle, I will be very happy.
3 (Male)	Mail	18	I had to slow down take breaks and leave heavy work to others.
4 (Male)	Mail	19	I'm limited to sitting around the house.
		20	I can't go anywhere by myself.
		21	I have always enjoyed eating out or just lots of home cooked meals with sauces, salt, and fried foods - the food to me isn't the same anymore.
		22	I enjoyed my hobbies within my garage, seemed to give me purpose, unable to currently get involved.
		23	I am having a difficult time resting or sleeping properly at night-time.
		24	My partner and I are starving by no means, but still endure a mortgage, therefore financially unable to travel a lot or enjoy time by a lake lot we own.

PAT. # (Gender)	MAIL/ TELE.	#	STATEMENTS
5 (Male)	Mail	25	Physical restrictions have curtailed my activities considerably, prior to my heart attack I exercised 2/3 times per week.
		26	Sick leave has given me more time to indulge in leisure pursuits.
		27	I shifted my focus away from my job to the home.
		28	I have more time to meet or talk with friends, particularly work colleagues whom previously I had only time to discuss work-related issues.
		29	I worry about my future health and bearing on my family and finances.
		30	I am generally more relaxed.
		31	I appreciate life more.
6 (Female)	Mail	32	I cannot remember things as well.
		33	I don't do as many things.
		34	I worry about my partner all the time.
		35	I am very nervous when my partner drives.
		36	I get very nervous when my partner gets up during the night I get very nervous when my partner is not feeling good.
		37	I seem to want to stay at home more.
7 (Female)	Mail	38	If anything my life has improved. After twenty years of shortness of breath and not being able to do any physical work without nearly collapsing, I finally got the professional help I needed.
		39	I am waiting for a hip replacement and a knee replacement so I'm not sure how much I could do now, physically.
		40	I feel better and eat better and take vitamin supplements.
		41	Since my angioplasty I've had no angina, regardless of how hard I've exerted myself - almost to collapse - I've shovelled a lot of snow at the start of winter.
		42	I must have had only minimal heart damage and scarring.
		43	I've had 40 years of stress - unbelievable stress. many years with as sick, abusive husband, then 7 years as a widow. I've found someone with whom I'm totally compatible, we have a happy stress-free life.
8 (Male)	Mail	44	I am more aware of having a proper lifestyle.
		45	I take more care of what I eat.
		46	My exercise program has dropped off.
		47	I have not tried to maintain the changes in my lifestyle, as suggested by my doctors.
		48	I am not working any longer. I got laid off after my heart attack. I lack motivation to look for another job.
		49	My partner financially supports us, we are able to manage.

PAT. # (Gender)	MAIL/ TELE.	#	STATEMENTS
9 (Male)	Tele.	50	If I go too hard I get tired easily.
		51	I have to pace myself.
		52	I feel tightness and pains in my chest the odd time.
		53	There is not much I can do, so I try to forget about it and get on with my life.
		54	Our children are good support for my partner and I.
		55	One of our children phones us every day to make sure we are okay.
		56	I swim to exercise, but not as often as I used to.
		57	I enjoy going to the hockey games with my friends.
		58	My partner does not go out as much these days.
		59	I enjoy being outside and going for walks with my partner.
		60	I turned my responsibilities for my property over to my son.
		61	I don't like travelling, carrying bags is too difficult for me.
		62	My partner and I take it day to day.
		63	If I am feeling well enough we will go on holiday this year.
10 (Male)	Tele.	64	Having a heart attack is an utter nuisance.
		65	I am not back at work yet. It has slowed down my life, and I resent that.
		66	I would prefer to receive more handouts to gain information rather than be talked at.
		67	You have to do what is necessary to get by. There are not many choices in this situation.
		68	I am very bored at home.
		69	My angioplasty was unsuccessful. I am concerned that I am running out of options and how the cutbacks will affect me.
		70	I feel like a burden to my family and friends sometimes. There is only so much they can do.
11 (Male)	Tele.	71	The heart attack has slowed me down. I don't lead such an active life.
		72	I am absolutely useless. I can't mow the lawn, shovel snow, or even rake leaves.
		73	My doctor says I am not allowed to over-exert myself.
		74	I worry about dying.
		75	I worry about my partner because she has too do all the yard work and chores around the house.
		76	I can't drink or smoke anymore. I used to smoke 3 packs per day. It takes a lot of the fun out of life.
		77	I lost a lot of my friends because they want to drink and party. My partner and I don't drink anymore.
		78	We have survived wonderfully together, there is just the two of us.
		79	I don't know what exercise level is appropriate for my heart. I am afraid of overdoing it.

PAT. # (Gender)	MAIL/ TELE.	#	STATEMENTS
12 (Female)	Tele.	80 81 82 83 84 85	I am more careful about what I eat. I stay away from fried food. I try my best to exercise more. I am not always consistent with my exercise. I feel pretty good most days and rarely experience any pain. I go for a yearly visit to my doctor. It is important for me to keep an eye on things and see how well I'm doing. I am careful when I get excited, because I feel my heart-rate go up. Our children are very supportive. They are right there when we need them.
13 (Male)	Tele.	86 87 88	I have had no problems at all since my heart attack. If I get the odd twinge of pain in my chest, from maybe indigestion, some worries float through the back of my mind for a while. My quality of life is unaffected by the heart attack.
14 (Male)	Tele.	89 90 91 92 93 94	I have returned to work and feel great. You have to take life as it comes and deal with it. What other choice do you have? My wife and kids helped me through the worst of it. I'm glad they were there. It is hard to gage how much exercise to do and how hard? My partner worries when I drive the car. She can't drive. We walk to the mall close by when the weather is good. I don't like walking much even though it is supposed to be good for me. I exercise to keep my partner happy. I have resumed my life and do not notice a change in my quality of life.
15 (Male)	Mail	95 96 97 98 99 100	I feel a little depressed some days, or maybe its stress not being able to do things. I can't do the things I used to do with ease before the heart attack. The hot or cold weather has a lot of effect on my way of life. I sure have to watch my diet and keep weight down. Right now I seem to be very short of breath at times. I must learn to slow down in my activity which I find hard to do. I can't stand much noise. More so since my last heart attack, and I can't understand why.
16 (Male)	Tele.	101 102 103 104 105 106 107 108 109 110 111	I used to be very active, a "go-getter". I find it difficult to relax and concentrate. I have less energy. I can't read or watch T.V. I'm not the same as I used to be. I feel worthless. I want to contribute more to my community but I can't. I miss my old friends and the camaraderie. My partner has pulled me through the worst times. I have lost my self-confidence. I feel the cutbacks will affect our quality of life eventually. Staff are busy and do not take time to listen. I am afraid of dying. I am scared to drive. I am no longer creative.

PAT. # (Gender)	MAIL/ TELE.	#	STATEMENTS
17 (Female)	Tele.	112	It was a really light attack, there was no real effect.
		113	The children helped me afterwards.
		114	I have to be more careful and I don't go so hard.
18 (Male)	Tele.	115	I can't lift anything.
		116	I can't do a lot of things I used to do. Its hard on my partner.
		117	I think about the end sometimes and what would become of my partner.
		118	I can't do much around the house.
		119	I feel like a burden, a"dead weight" around her neck.
		120	I am light-headed when I walk or move too fast.
		121	Short of breath at times.
19 (Female)	Mail	122	Short of air some days when I'm walking.
		123	Slowed down in walking.
		124	Can't do my housework like I used to I get too tired.
		125	Can't do my vacuuming.
		126	Not interested in cooking meals.
		127	Can't drive my car anymore as I do not trust myself.
		128	My son has had to stay home from work as he didn't want to leave me alone.
20 (Male)	Mail	129	Restricted outside activities in cold weather. I can't do things I used to like doing before the heart attack.
21 (Female)	Mail	130	In the beginning restricted my daily activities. Later I experienced angina pain, and I am again experiencing angina pain.
		131	Sometimes I get paranoid, or anxious would be a better way of describe that it could happen again.
		132	I never in my wildest dreams would have thought I would have a heart attack. Makes me enjoy day to day life.
		133	I am coping well I think.
22 (Male)	Mail	134	No real difference, except, for being more aware of minor pains of muscles or indigestion.
		135	More conscious about getting daily exercise, usually 4 to 5 miles walking.
23 (Male)	Mail	136	Reduced eating - less fats, sugar and meat.
		137	Have some interests and hobbies as previous.
		138	Find it difficult to deliberately exercise as I am naturally <u>very</u> lazy.
24 (Male)	Mail	139	My quality of life is now better as a result of the bypass.
		140	I can walk, ski, etc.
		141	I have cut down on my day-to-day workload.
		142	We moved from Vancouver to Whistler.
		143	I live with a fabulous lady.
		144	Life is now a joy. I want to live as good a life as possible and as long as possible.

PAT. # (Gender)	MAIL/ TELE.	#	STATEMENTS
25 (Male)	Mail	145	Angina everyday - lots of medication.
		146	Can't socialize - self confidence lost - feel very vulnerable when in a crowd. Can't do activities other than some walking.
		147	Can't travel.
		148	Can't sit too long - bus, train etc.
		149	The difference in my quality of life is night and day.
		150	Stay at home and confine my routine to small things.
		151	Though all of this I manage with the help of my family and wife.
		152	
26 (Male)	Mail	153	The first four weeks after the heart attack my activities were somewhat restricted, i.e., no driving long distances, no yard work, etc. More hours in bed at night. Take a rest after lunch.
		154	I have now resumed my usual activities. I own an insurance agency business, and am usually at the office during business hours,except that I usually rest for ½ hour after lunch.
		155	We travelled by air to Victoria, BC at the Christmas season, again without incident.
		156	I occasionally feel stressed if I get over tired, and then take some rest and consciously endeavour to relax.
		157	I have modified my diet. No butter or ice cream or pastries.
		158	I am on a low fat diet. I have lost 10 lbs of weight since the incident with my heart.
		159	I use some vitamin supplements.
27 (Male)	Mail	160	Leads to a lack of confidence.
		161	Anxiety due to not knowing what to expect.
		162	Not knowing my limitations leaves me wondering as to what I can do or not do.

APPENDIX G
Master List of Partner Statements

PART. # (Gender)	MAIL/ TELE.	#	STATEMENTS
1 (Male)	Mail	1	My partner and I continue to talk about the heart attack.
		2	My partner and I continue to worry about another heart attack, even though the angiogram shows that there are very little problems.
		3	My partner worries about me, when I don't take care of myself.
		4	The heart attack is a continuous subject of conversation with friends.
		5	My partner thinks I never worry about him/her.
		6	I must not talk about anything when I don't feel good - my partner gets nervous.
		7	My partner's big problem is her nerves.
2 (Female)	Mail	8	A sense of relief - The heart attack changed the pace of life for my partner and will probably extend his/her life.
		9	A sense of hope that finally my partner will receive support and guidance to help him cope with a very stressful work situation.
		10	Anxiety due to health cuts and the subsequent long waiting lists for angiograms and angioplasty which my partner needs.
		11	Pleasure - my partner has more time for his/her family.
3 (Female)	Mail	12	My partner helps his child in a way that he never had time or energy to do before.
		13	More sharing of doing household routines - e.g., dish-washing, making supper.
		14	A reduction of stressful situations in the home.
		15	More time to enjoy the company of friends.
4 (Female)	Mail	16	I am spending lots of time reading food labels in the stores.
		17	I am finding it difficult to find interesting food for my partner's daily needs.
		18	I experience difficult moments with my partner, but do not want to upset him.
		19	I have been experiencing some depression.
		20	My partner hates going for a walk.
		21	My partner criticizes my cooking or refuses to eat his/her food.
		22	My partner has a negative attitude because life is now so different.
		23	My partner was well-known for his good nature.
		24	My partner has a shorter fuse.
5 (Female)	Mail	25	I am often more worried than my partner is.
		26	I make sure that my partner does not work too hard or too long, and that he/she takes breaks.
		27	My partner has sleeping problems and this affects my sleep as well.
		28	I always watch out for signs of problems.
		29	We are very lucky, my partner only had a light attack.

PART. # (Gender)	MAIL/ TELE.	#	STATEMENTS
6 (Male)	Mail	30	An increase in anxiety knowing there is a real possibility the end could suddenly come.
7 (Female)	Tele.	31	I have not noticed any changes in my life at all.
		32	I have to work, he does not.
		33	I had to learn how to care for my partner without much help from the hospital. The first heart attack was unexpected because he did not have any symptoms.
		34	We went to relaxation classes together. It is hard to sustain the relaxation exercises we were taught.
8 (Female)	Mail	35	I am happy for the change in lifestyle, nobody smokes in our home now.
		36	No alcohol, I never drink.
9 (Female)	Tele.	37	There are a lot of things we can't do anymore.
		38	I can't drive the car so we stay closer to home these days.
		39	I worry when my partner drives the car in case he has another heart attack.
		40	He is a miracle case.
		41	I have to do a lot of yard work myself.
		42	I have to encourage my partner to exercise.
		43	We have to walk to the mall because he can't always drive.
10 (Female)	Tele.	44	I get tired looking after my partner.
		45	I enjoy spending time with my partner doing crossword puzzles.
		46	We enjoy walking together for short periods of time.
		47	I don't go out socially as much as I did prior to the attack.
11 (Female)	Mail	48	Complete change in cooking - switch to low fat recipes - I enjoy doing this.
		49	Anxiety - for first few month then I was okay.
		50	I make sure that he has taken his medication.
		51	I get anxious about keeping prearranged schedule or appointments. If a person isn't on time you think "What has happened".
		52	Become more watchful and try to not nag.
12 (Female)	Tele.	53	I think our quality of life could have been improved if the hospital staff had taught us how to manage more. There was too much information and not enough teaching by them. I felt overwhelmed by the amount of information.
		54	I am frustrated because my husband doesn't make an effort to take care of himself. He has not maintained his exercise program.

PART. # (Gender)	MAIL/ TELE.	#	STATEMENTS
13 (Male)	Tele.	55 56 57	My quality of life is unaffected by the heart attack. After coping with the initial shock of the heart attack I was okay. My partner has indigestion sometimes and I become concerned if she complains of discomfort in her chest.
14 (Female)	Tele.	58 59 60	My partner no longer works so income is a big stressor. I have had to manage more on my own. I am always wondering what might happen today. I try to forget about the possibility of my partner having another attack and take it day to day.
15 (Female)	Tele	61 62 63 64 65 66 67 68 69 70 71 72	I had to stop work to take care of my partner. I have to do all the physical work on the acreage. Our quality of life has deteriorated. We have lost our friends due to my partner's health. We are more isolated and [illegible] My partner is willing to [illegible] but is unable to. My life is hectic and busy. I feel very angry about the changes in my lifestyle. It is hard to accept the changes. I would love to travel more, but it would be too difficult for my partner. I prefer my husband to drive, now I have to do it. I have lost my independence.
16 (Female)	Mail	73 74 75 76	Vacation trips are restricted to short distances. Social activities are almost zero. I had to take over my partner's chores, e.g., snow shovelling, driving the car. I feel lonely at times because he sleeps a lot.
17 (Female)	Mail	77 78 79 80 81	I have changed many cooking/eating patterns to cut back on fats, sugars etc. that my partner loves. I don't like the restrictions. I have increased my exercise (walking mostly) as a personal preventive measure, although my partner has not. We have done less outdoor activities, travel etc. than previously as my partner shows less interest. I spend more time by myself due to his cat naps.
18 (Female)	Mail	82 83	A little cautious, but overall quality of life has improved since my partner's surgery. I can't keep up with him.

PART. # (Gender)	MAIL/ TELE.	#	STATEMENTS
19 (Female)	Mail	84	Have feelings of anxiety and helplessness over government health funding cuts - closures, lay-offs. Will transplant come in time?
		85	We make no long term plans just do one day at a time.
		86	Very quiet social life. An occasional evening out is very tiring for my husband.
		87	Cannot count on any help with chores - carry groceries, clean walks, yard work myself.
		88	Positive note - Healthy adjustment to lifestyle re: choice of food and food preparation.
		89	Daily walks with husband are one of our most pleasant times together.
20 (Female)	Mail	90	Increase in physical activity - daily walks, snow shovelling, carrying groceries.
		91	Slightly more vigilant to cholesterol/fat content of diet.
21 (Male)	Mail	92	My partner and I compliment each other. We eat the same food and maintain the same lifestyle.
		93	We support one another.
		94	Life is worth living with a caring partner.
22 (Female)	Mail	95	I have had to look honestly at my own behaviour and keep a positive attitude since my husband's heart attack.
		96	I have had to realize that stress affects him.
		97	We are doing well sharing and balancing responsibilities - but it has always come naturally for him, so that is easy for me.
		98	I feel so hopeful, now , that he is recovering with the help of exercise and medication.
23 (Female)	Mail	99	I have become the sole "breadwinner" in our household.
		100	He goes into depressions where he won't do anything.
		101	He doesn't talk about how he is feeling so there are times when I worry a lot.
		102	We are very restricted as to where we can go and what we can do on holidays.
		103	There isn't the "disposable" cash that there was before.

APPENDIX H
Edit #1- Patient Statements

PAT. # (Gender)	MAIL/ TELE.	#	STATEMENTS
1 (Male)	Mail	1	I suffer pain daily.
		2	I suffer intermittent weak feelings.
		2a	I experience dizziness
		2b	I have heart palpitations.
		3	I can't exercise properly.
		3a	I am losing my physical fitness.
		4	The heart attack has virtually cut out my sex life.
		5	I can't travel.
		6	My diet limits many pleasures.
		6a	There are few choices on most restaurant menus.
		7	My social life is very limited.
		8	I cannot do yard work.
		8a	I am unable to do my hobbies.
		9	With rest breaks and my limited capacity it takes longer to complete tasks.
		10	My business income has been seriously curtailed.
		11	Profit was lost at my last heart attack when work had to be re-assigned to other companies.
		12	I am reluctant to accept any long-term work.
		13	I have had to turn down several speaking engagements for 1996-97 as I can't promise that I will be available.
		14	It takes me longer to complete simple tasks.
2 (Male)	Mail	15	Change in my lifestyle - no smoking, no alcohol, better diet, exercise program.
		16	No other changes or restrictions experienced.
		17	If I can maintain this level of lifestyle, I will be very happy.
3 (Male)	Mail	18	I had to slow down take breaks
		18a	I leave heavy work to others.
4 (Male)	Mail	19	I'm limited to sitting around the house.
		20	I can't go anywhere by myself.
		21	I no longer enjoy eating out.
		22	I am unable to currently get involved in my hobbies.
		23	I am having a difficult time sleeping .
		24	My partner and I are financially unable to travel a lot.

PAT. # (Gender)	MAIL/ TELE.	#	STATEMENTS
5 (Male)	Mail	25	Physical restrictions have curtailed my activities considerably.
		26	I have more time to indulge in leisure pursuits.
		27	I shifted my focus away from my job to the home.
		28	I have more time to socialize with friends.
		29	I worry about my future health.
		30	I am generally more relaxed.
		31	I appreciate life more.
6 (Female)	Mail	32	I cannot remember things as well.
		33	I don't do as many things.
		34	I worry about my partner.
		35	I am very nervous when my partner drives.
		36	I get very nervous when my partner gets up during the night.
		36a	I get very nervous when my partner is not feeling good.
		37	I seem to want to stay at home more.
7 (Female)	Mail	38	If anything my life has improved.
		39	I am waiting for a hip replacement and a knee replacement so I'm not sure how much I could do now, physically.
		40	I feel better and eat better and take vitamin supplements.
		41	Since my angioplasty I've had no angina.
		42	I must have had only minimal heart damage and scarring.
		43	We have a happy stress-free life.
8 (Male)	Mail	44	I am more aware of having a proper lifestyle.
		45	I take more care of what I eat.
		46	My exercise program has dropped off.
		47	I have not tried to maintain the changes in my lifestyle, as suggested by my doctors.
		48	I am no longer employed.
		48a	I lack motivation to look for another job.
		49	My partner financially supports us.

PAT. # (Gender)	MAIL/ TELE.	#	STATEMENTS
9 (Male)	Tele.	50	If I go too hard I get tired easily.
		51	I have to pace myself.
		52	I feel tightness and pains in my chest the odd time.
		53	I try to forget about my heart condition and get on with my life.
		54	Our children are good support.
		55	One of our children phones us every day to make sure we are okay.
		56	I swim to exercise, but not as often as I used to.
		57	I enjoy going to the hockey games with my friends.
		58	My partner does not go out as much these days.
		59	I enjoy being outside and going for walks with my partner.
		60	I turned my responsibilities for my property over to my son.
		61	I don't like travelling, carrying bags is too difficult for me.
		62	My partner and I take it day to day.
		63	If I am feeling well enough we will go on holiday this year.
10 (Male)	Tele.	64	Having a heart attack is an utter nuisance.
		65	I am not back at work yet.
		65a	It has slowed down my life, and I resent that.
		66	I would prefer to receive more handouts to gain information rather than be talked at.
		67	You have to do what is necessary to get by.
		68	I am very bored at home.
		69	I am concerned that I am running out of options.
		69a	I am concerned about the health care cutbacks.
		70	I feel like a burden to my family and friends.
11 (Male)	Tele.	71	The heart attack has slowed me down.
		71a	I don't lead such an active life.
		72	I can do no work in the yard.
		73	I am careful not to over-exert my heart.
		74	I worry about dying.
		75	I worry about my partner.
		76	I can't drink anymore.
		76a	It takes a lot of the fun out of life.
		76b	I can't smoke.
		77	I lost a lot of my friends.
		78	I am afraid of overdoing it when I exercise.
		79	We have survived wonderfully together.
12 (Female)	Tele.	80	I am more careful about what I eat.
		81	I am not always consistent with my exercise.
		82	I feel pretty good most days.
		82a	I rarely experience any pain.
		83	It is important for me to know how I'm doing.
		84	I am careful when I get excited, because I feel my heart-rate go up.
		85	Our children are very supportive.

PAT. # (Gender)	MAIL/ TELE.	#	STATEMENTS
13 (Male)	Tele.	86	I have had no problems at all since my heart attack.
		87	I worry if I get the odd twinge of pain in my chest, from maybe indigestion.
		88	My quality of life is unaffected by the heart attack.
14 (Male)	Tele.	89	I have returned to work and feel great.
		90	You have to take life as it comes and deal with it.
		91	My family helped me through the worst of it.
		92	It is hard to gage how much exercise to do and how hard?
		93	My partner worries when I drive the car.
		93a	I don't like walking much even though it is supposed to be good for me.
		93b	I exercise to keep my partner happy.
		94	I have not noticed any changes in my quality of life.
15 (Male)	Mail	95	I feel a little depressed some days.
		96	I can't do the things I used to do with ease before the heart attack.
		96a	Hot or cold weather has a lot of effect on my way of life.
		97	I have to watch my diet and keep weight down.
		98	I seem to be very short of breath at times.
		99	I must learn to slow down in my activity which I find hard to do.
		100	I can't stand much noise.
16 (Male)	Tele.	101	I used to be very active, a "go-getter".
		102	I find it difficult to relax.
		102a	I find it difficult to concentrate.
		103	I have less energy.
		103a	I can't read or watch T.V.
		104	I want to contribute more to my community but I can't.
		105	I miss my old friends and the camaraderie.
		106	My partner has pulled me through the worst times.
		107	I have lost my self-confidence.
		108	I worry the hospital cutbacks will affect our quality of life.
		109	I am afraid of dying.
		110	I am scared to drive.
		111	I am no longer creative.
17 (Female)	Tele.	112	It was a really light attack, there was no real effect.
		113	The children helped me afterwards.
		114	I have to be more careful.
		114a	I don't go so hard.

PAT. # (Gender)	MAIL/ TELE.	#	STATEMENTS
18 (Male)	Tele.	115	I can't lift anything.
		116	I can't do a lot of things I used to do.
		116a	Its hard on my partner.
		117	I think about the end sometimes.
		118	I can't do much around the house.
		119	I feel like a burden, a "dead weight" around his/her neck.
		120	I am light-headed when I walk or move too fast.
		121	Short of air some days when I'm walking.
19 (Female)	Mail	122	I am short of breath at times.
		123	Slowed down in walking.
		124	Can't do my housework like I used to I get too tired.
		125	Can't do my vacuuming.
		126	Not interested in cooking meals.
		127	Can't drive my car anymore as I do not trust myself.
		128	My son has had to stay home from work as he didn't want to leave me alone.
20 (Male)	Mail	129	Restricted outside activities in cold weather.
		129a	I can't do things I used to like doing before the heart attack.
21 (Female)	Mail	130	Restricted my daily activities.
		130a	I am again experiencing angina pain.
		131	I get anxious that a heart attack could happen again.
		132	Makes me enjoy day to day life.
		133	I am coping well I think.
22 (Male)	Mail	134	No real difference in my quality of life.
		135	More conscious about getting daily exercise.
23 (Male)	Mail	136	Reduced eating - less fats, sugar and meat.
		137	Have some interests and hobbies as previous.
		138	I find it difficult to deliberately exercise.
24 (Male)	Mail	139	My quality of life is now better.
		140	I can walk, ski, etc.
		141	I have cut down on my day-to-day workload.
		142	We moved from Vancouver to Whistler.
		143	I live with a fabulous lady.
		144	Life is now a joy.
		144a	I want to live as long and good a life as possible.

PAT. # (Gender)	MAIL/ TELE.	#	STATEMENTS
25 (Male)	Mail	145	Angina everyday - lots of medication.
		146	I can't socialize.
		146a	My self confidence lost.
		147	I can't do activities other than some walking.
		148	I can't travel.
		149	I can't sit too long - bus, train etc.
		150	The difference in my quality of life is night and day.
		151	Stay at home and confine my routine to small things.
		152	I manage with the help of my family and partner.
26 (Male)	Mail	153	The first four weeks after the heart attack my activities were somewhat restricted.
		154	I have now resumed my usual activities.
		154a	I usually rest for ½ hour after lunch.
		155	My partner and I travelled without incident.
		156	I feel stressed if I get over tired.
		156a	I take some rest and consciously endeavour to relax.
		157	I have modified my diet - no butter or ice cream or pastries.
		158	I am on a low fat diet to maintain my weight loss.
		159	I use some vitamin supplements.
27 (Male)	Mail	160	Leads to a lack of confidence.
		161	Anxiety due to not knowing what to expect.
		162	Not knowing my limitations leaves me wondering as to what I can do or not do.

APPENDIX I
Edit #1- Partner Statements

PART. # (Gender)	MAIL/ TELE.	#	STATEMENTS
1 (Male)	Mail	1	My partner and I continue to talk about the heart attack.
		2	My partner and I continue to worry about another heart attack
		3	My partner worries about me, when I don't take care of myself.
		4	The heart attack is a continuous subject of conversation with friends.
		5	My partner thinks I never worry about him/her.
		6	I must not talk about anything when I feel bad.
		7	My partner's big problem is her nerves.
2 (Female)	Mail	8	The heart attack changed the pace of life for my partner.
		9	I feel hopeful my partner will get help him dealing with stressful work situations.
		10	I feel anxious due to health cuts and the long waiting lists.
		11	I am pleased my partner has more time for our family.
3 (Female)	Mail	12	My partner helps his child in a way that he never had time or energy to do before.
		13	My partner shares more of the household chores.
		14	I have reduced stressful situations in the home.
		15	More time to enjoy the company of friends.
4 (Female)	Mail	16	I am spending lots of time reading food labels in the stores.
		17	I am finding it difficult to find interesting food for my partner's daily needs.
		18	I try not to upset my partner.
		19	I have been experiencing some depression.
		20	My partner hates going for a walk.
		21	My partner criticizes my cooking
		21a	My partner refuses to eat food I prepare.
			My partner has a negative attitude towards life now.
		22	My partner was well-known for his/her good nature.
		23	My partner has a shorter fuse.
		24	
5 (Female)	Mail	25	I am often more worried than my partner is.
		26	I make sure that my partner does not work too hard or too long.
		26a	I ensure my partner takes breaks.
		27	My partner has sleeping problems that affect my sleep as well.
		28	I always watch out for signs of problems.
		29	We are very lucky, my partner only had a light attack.
6 (Male)	Mail	30	There is an increase in my anxiety levels.
		30a	I fear the end could come suddenly.

PART. # (Gender)	MAIL/ TELE.	#	STATEMENTS
7 (Female)	Tele.	31	I have not noticed any changes in my life at all.
		32	I have to work, he/she does not.
		33	I had to learn how to care for my partner.
		34	It is hard to continue the relaxation exercises we were taught.
8 (Female)	Mail	35	I am happy nobody smokes in our home now.
		36	I never drink alcohol anymore.
9 (Female)	Tele.	37	There are a lot of things we can't do anymore.
		38	I can't drive the car so we stay closer to home these days.
		39	I worry when my partner drives the car in case he has another heart attack.
		40	He is a miracle case.
		41	I have to do a lot of yard work myself.
		42	I have to encourage my partner to exercise
		43	We have to walk to places because he/she can't always drive.
10 (Female)	Tele.	44	I get tired looking after my partner.
		45	I enjoy spending time with my partner.
		46	We enjoy walking together for short periods of time.
		47	I don't go out socially as much as I did prior to the attack.
11 (Female)	Mail	48	Switch to cooking low-fat recipes - I enjoy doing this.
		49	Anxiety - for first few month then I was okay.
		50	I make sure that my partner has taken his/her medication.
		51	I get anxious about keeping appointments.
		51a	If a person isn't on time you think "What has happened".
		52	I have become more watchful.
		52a	I try to not nag.
12 (Female)	Tele.	53	Hospital staff should have taught us how to manage more.
		53a	I felt overwhelmed by the amount of information the hospital staff gave us.
		54	I am frustrated because my partner doesn't make an effort to take care of him/herself.
		54a	My partner has not maintained his/her exercise program.

PART. # (Gender)	MAIL/ TELE.	#	STATEMENTS
13 (Male)	Tele.	55 56 57	My quality of life is unaffected by the heart attack. After coping with the initial shock of the heart attack I was okay. I become concerned if my partner complains of discomfort in his/her chest.
14 (Female)	Tele.	58 59 60 60a	My partner no longer works so income is a big stressor. I have had to manage more on my own. I worry about the possibility of my partner having another heart attack. I take it day to day.
15 (Female)	Tele	61 62 63 64 65 66 67 68 69 70 71 72	I had to stop work to take care of my partner. I have to do all the physical work. Our quality of life has deteriorated. We have lost many of our friends. We are more isolated and alone. My partner is willing to help me but is unable to. My life is hectic and busy. I feel very angry about the changes in my lifestyle. It is hard to accept the changes in my lifestyle. I would love to travel more, but it would be too difficult for my partner. I prefer my husband to drive, now I have to do it. I have lost my independence.
16 (Female)	Mail	73 74 75 76	Vacation trips are restricted to short distances. Social activities are almost zero. I had to take over my partner's chores. I feel lonely at times because my partner sleeps a lot.
17 (Female)	Mail	77 78 79 80 81	I have changed many cooking/eating patterns to cut back on fats, sugars etc. that my partner loves. I don't like the restrictions. I have increased my exercise as a personal preventive measure. We participate in less outdoor activities since the heart attack. I spend more time by myself due to his/her cat naps.
18 (Female)	Mail	82 82a 83	I am more cautious. Overall quality of life has improved. I can't keep up with my partner.

PART. # (Gender)	MAIL/ TELE.	#	STATEMENTS
19 (Female)	Mail	84	Have feelings of anxiety and helplessness over health cuts.
		84a	I worry about whither a transplant will come in time.
		85	We make no long term plans just do one day at a time.
		86	Very quiet social life.
		86a	An occasional evening out is very tiring for my partner
		87	Cannot count on any help with chores - carry groceries, clean walks, yard work myself.
		88	Healthy adjustment to lifestyle.
		89	Daily walks with my partner are one of our most pleasant times together.
20 (Female)	Mail	90	There is an increase in my physical activity.
		91	Slightly more vigilant of cholesterol/fat content of diet.
21 (Male)	Mail	92	My partner and I compliment each other.
		93	We support one another.
		94	Life is worth living with a caring partner.
22 (Female)	Mail	95	I try to maintain a positive attitude.
		96	I have had to realize that stress affects my partner.
		97	We are doing well sharing and balancing responsibilities.
		98	I feel hopeful, now my partner is recovering.
23 (Female)	Mail	99	I have become the sole "breadwinner" in our household.
		100	My partner goes into depressions where he/she won't do anything.
		101	There are times when I worry a lot.
		102	We are very restricted as to where we can go and what we can do on holidays.
		103	There isn't the "disposable" cash that there was before.

APPENDIX J

Edit #2 - Patient Statements

PAT. # (Gender)	MAIL/ TELE.	#	STATEMENTS
1 (Male)	Mail	1	I suffer pain daily. ✔
		2	I suffer intermittent weak feelings. ✔
		2a	I experience dizziness. ✔
		2b	I have heart palpitations. ✔
		3	I can't exercise properly. ✗
		3a	I am losing my physical fitness.✔
		4	The heart attack has virtually cut out my sex life. ✔
		5	I can't travel. ✔
		6	My diet limits many pleasures. ✔
		6a	There are few choices on most restaurant menus. ✗
		7	My social life is very limited. ✔
		8	I cannot do yard work. ✔
		8a	I am unable to do my hobbies. ✔
		9	With rest breaks and my limited capacity it takes longer to complete tasks.✔
		10	My business income has been seriously curtailed. ✔
		11	Profit was lost at my last heart attack when work had to be re-assigned to other companies. ✗
		12	I am reluctant to accept any long-term work. ✔
		13	I have had to turn down several speaking engagements for 1996-97 as I can't promise that I will be available. ✗
		14	It takes me longer to complete simple tasks. ✔
2 (Male)	Mail	15	Change in my lifestyle - no smoking, no alcohol, better diet, exercise program. ✗
		16	No other changes or restrictions experienced. ✗
		17	If I can maintain this level of lifestyle, I will be very happy. ◘
3 (Male)	Mail	18	I have to slow down and take rest breaks. ✔
		18a	I have to leave heavy work to others. ✔
4 (Male)	Mail	19	I'm limited to sitting around the house. ✗
		20	I can't go anywhere by myself. ✔
		21	I no longer enjoy eating out . ✔
		22	I am unable to currently get involved in my hobbies. ✗
		23	I am having a difficult time sleeping . ✔
		24	My partner and I are financially unable to travel a lot. ✗

Note. ✔ denotes statements included in final list, ✗ denotes redundant statements removed, and ◘ denotes ambiguous or vague statements.

PAT. # (Gender)	MAIL/ TELE.	#	STATEMENTS
5 (Male)	Mail	25	Physical restrictions have curtailed my activities considerably. ✗
		26	I have more time to indulge in leisure pursuits. ✓
		27	I shifted my focus away from my job to the home. ✓
		28	I have more time to socialize with friends. ✓
		29	I worry about my future health. ✓
		30	I am generally more relaxed. ✓
		31	I appreciate life more. ✓
6 (Female)	Mail	32	I cannot remember things as well. ✓
		33	I don't do as many things. ✗
		34	I worry about my partner. ✓
		35	I am very nervous when my partner drives. ✗
		36	I get very nervous when my partner gets up during the night. ✗
		36a	I get very nervous when my partner is not feeling good. ✗
		37	I seem to want to stay at home more. ✓
7 (Female)	Mail	38	If anything my life has improved. ✓
		39	I am waiting for a hip replacement and a knee replacement so I'm not sure how much I could do now, physically. ◘
		40	I feel better and eat better and take vitamin supplements. ✓
		41	Since my angioplasty I've had no angina. ✗
		42	I must have had only minimal heart damage and scarring. ◘
		43	We have a happy stress-free life. ◘
8 (Male)	Mail	44	I am more aware of having a proper lifestyle. ✗
		45	I take more care of what I eat. ✓
		46	My exercise program has dropped off. ✓
		47	I have not tried to maintain the changes in my lifestyle, as suggested by my doctors. ✓
		48	I am no longer employed. ✓
		48a	I lack motivation to look for another job. ✓
		49	My partner financially supports us. ✓

PAT. # (Gender)	MAIL/ TELE.	#	STATEMENTS
9 (Male)	Tele.	50	If I go too hard I get tired easily. ✗
		51	I have to pace myself. ✗
		52	I feel tightness and pains in my chest the odd time. ✗
		53	I try to forget about my heart condition and get on with my life. ✓
		54	Our children are good support . ✓
		55	One of our children phones us every day to make sure we are okay. ✗
		56	I swim to exercise, but not as often as I used to. ✗
		57	I enjoy going to the hockey games with my friends. ✗
		58	My partner does not go out as much these days. ✓
		59	I enjoy being outside and going for walks with my partner. ✓
		60	I turned my responsibilities for my property over to my son. ✗
		61	I don't like travelling, carrying bags is too difficult for me. ✗
		62	My partner and I take it day to day. ✓
		63	If I am feeling well enough we will go on holiday this year. ✗
10 (Male)	Tele.	64	Having a heart attack is an utter nuisance. ◘
		65	I am not back at work yet. ✗
		65a	It has slowed down my life, and I resent that. ✗
		66	I would prefer to receive more handouts to gain information rather than be talked at. ◘
		67	You have to do what is necessary to get by. ✗
		68	I am very bored at home. ✓
		69	I am concerned that I am running out of options. ✗
		69a	I'm concerned about the health care cutbacks. ✗
		70	I feel like a burden to my family and friends. ✓
11 (Male)	Tele.	71	The heart attack has slowed me down. ✗
		71a	I don't lead such an active life. ✗
		72	I can do no work in the yard. ✗
		73	I am careful not to over-exert my heart. ✓
		74	I worry about dying. ✗
		75	I worry about my partner. ✗
		76	I can't drink alcohol anymore. ✓
		76a	It takes a lot of fun out of life. ✓
		76b	I can't smoke. ✓
		77	I lost many of my friends. ✓
		78	I am afraid of overdoing it when I exercise. ✗
		79	We have survived wonderfully together. ✓
12 (Female)	Tele.	80	I am more careful about what I eat. ✗
		81	I am not always consistent with my exercise. ✗
		82	I feel pretty good most days. ◘
		82a	I rarely experience pain. ✗ .
		83	It is important for me to know how I'm doing. ✗
		84	I am careful when I get excited, because I feel my heart-rate go up. ✗
		85	Our children are very supportive. ✗

PNT. # (Gender)	MAIL/ TELE.	#	STATEMENTS
13 (Male)	Tele.	86	I have had no problems at all since my heart attack. ✔
		87	I worry if I get the odd twinge of pain in my chest, from maybe indigestion ✗
		88	My quality of life is unaffected by the heart attack. ✗
14 (Male)	Tele.	89	I have returned to work and feel great. ✔
		90	You have to take life as it comes and deal with it. ✗
		91	My family helped me through the worst of it. ✗
		92	It is hard to gage how much exercise to do and how hard? ✗
		93	My partner worries when I drive the car. ✔
		93a	I don't like walking much even though it is supposed to be good for me.✗
		93b	I exercise to keep my partner happy. ✔
		94	I have not noticed any changes in my quality of life. ✔
15 (Male)	Mail	95	I feel a little depressed some days. ✔
		96	I can't do the things I used to do with ease before my heart attack. ✗
		96a	Hot or cold weather has a lot of affect on my way of life. ✔
		97	I have to watch my diet and keep my weight down. ✗
		98	I seem to be very short of breath at times. ✔
		99	I must learn to slow down in my activity which I find hard to do. ✗
		100	I cant stand much noise. ✔
16 (Male)	Tele.	101	I used to be very active, a"go-getter". ✔
		102	I find it difficult to relax. ✗
		102a	I find it difficult to concentrate. ✔
		103	I have less energy. ✔
		103a	I can't read or watch T.V.
		104	I want to contribute more to my community but I can't. ✔
		105	I miss my old friends and the camaraderie. ✗
		106	My partner has pulled me through the worst times. ✔
		107	I have lost my self-confidence. ✔
		108	I worry the hospital cutbacks will affect our quality of life. ✔
		109	I am afraid of dying. ✔
		110	I am scared to drive. ✔
		111	I am no longer creative. ◘
********	*****	***	** *REDUNDANCY WAS JUDGED TO BE REACHED AT THIS POINT.*
17 (Female)	Tele.	112	It was a really light attack, there was no real effect. ✗
		113	The children helped me afterwards. ✗
		114	I have to be more careful. ✗
		114a	I don't go so hard. ✗

PAT. # (Gender)	MAIL/ TELE.	#	STATEMENTS
18 (Male)	Tele.	115	I can't lift anything. ✗
		116	I can't do a lot of things I used to do. ✗
		116a	Its hard on my partner. ✗
		117	I think about the end sometimes. ✗
		118	I can't do much around the house. ✗
		119	I feel like a burden, a"dead weight" around his/her neck. ✗
		120	I am light-headed when I walk or move too fast. ✗
		121	Short of air some days when I'm walking. ✗
19 (Female)	Mail	122	I am short of breath at times. ✗
		123	Slowed down in walking. ✗
		124	Can't do my housework like I used to I get too tired. ✗
		125	Can't do my vacuuming. ✗
		126	Not interested in cooking meals. ✗
		127	Can't drive my car anymore as I do not trust myself. ✗
		128	My son has had to stay home from work as he didn't want to leave me alone. ✗
20 (Male)	Mail	129	Restricted outside activities in cold weather. ✗
		129a	I can't do things I used to like doing before the heart attack. ✗
21 (Female)	Mail	130	Restricted my daily activities. ✗
		130a	I am again experiencing angina pain. ✗
		131	I get anxious that a heart attack could happen again. ✗
		132	Makes me enjoy day to day life. ✗
		133	I am coping well I think. ✗
22 (Male)	Mail	134	No real difference in my quality of life. ✗
		135	I am more conscious about getting daily exercise. ✗
23 (Male)	Mail	136	Reduced eating - less fats, sugar and meat. ✗
		137	I have some interests and hobbies as previous. ✗
		138	I find it difficult to deliberately exercise. ✗
24 (Male)	Mail	139	My quality of life is now better. ✗
		140	I can walk, ski, etc. ✗
		141	I have cut down on my day-to-day workload. ✗
		142	We moved from Vancouver to Whistler. ▣
		143	I live with a fabulous lady. ▣
		144	Life is now a joy. ▣
		144a	I want to live as long and good a life as possible. ✗

PAT. # (Gender)	MAIL/ TELE.	#	STATEMENTS
25 (Male)	Mail	145 146 146a 147 148 149 150 151 152	Angina everyday - lots of medication. ✗ I can't socialize. ✗ My self confidence is lost. ✗ I can't do activities other than some walking. ✗ I can't travel. ✗ I can't sit too long - bus, train etc. ✗ The difference in my quality of life is night and day. ◘ Stay at home and confine my routine to small things. ✗ I manage with the help of my family and partner. ✗
26 (Male)	Mail	153 154 154a 155 156 156a 157 158 159	The first four weeks after the heart attack my activities were somewhat restricted. ✗ I have now resumed my usual activities. ✗ I usually rest for ½ hour after lunch. ✗ My partner and I travelled without incident. ✗ I feel stressed if I get over tired. ✗ I take some rest breaks and consciously endeavour to relax. ✗ I have modified my diet. No butter or ice cream or pastries. ✗ I am on a low fat diet to maintain my weight loss. ✗ I use some vitamin supplements. ✗
27 (Male)	Mail	160 161 162	Leads to a lack of confidence. ✗ Anxiety due to not knowing what to expect. ✗ Not knowing my limitations leaves me wondering as to what I can do or not do. ✗

#	DUPLICATED STATEMENTS	REDUNDANT STATEMENTS REMOVED (✗)
3	3a, 25, 46, 56, 81	I can't exercise properly.
6	21, 136	My diet limits many pleasures.
6a	21, 62	There are few choices on most restaurant menus.
9	14, 18, 65a, 71, 96, 100, 156a	With rest breaks and my limited capacity it takes longer to complete tasks.
11	10	Profit was lost at my last heart attack when work had to be re-assigned to other companies.
13	12	I have had to turn down several speaking engagements for 1996-97 as I can't promise that I will be available.

#	DUPLICATED STATEMENTS	REDUNDANT STATEMENTS REMOVED (✗)
15	16, 38, 40, 44, 76, 77, 78, 80, 98, 135, 157	Change in lifestyle - no smoking, no alcohol, better diet, exercise program.
16	86, 112, 134	No other changes or restrictions experienced.
19	68, 151	I am limited to sitting around the house.
22	8a, 137	I unable to currently get involved in my hobbies.
24	5, 119	My partner and I are financially unable to travel a lot.
25	3, 33	Physical restrictions have curtailed my activities considerably.
33	101, 103, 104, 111, 116, 130, 147	I don't do as many things.
35	34, 75	I am very nervous when my partner drives.
36	34, 75	I get very nervous when my partner gets up during the night.
36a	34, 75	I get very nervous when my partner is not feeling good.
41	86, 139	Since my angioplasty I've had no pain.
44	29, 45, 76,77, 80, 135,157	I am more aware of having a proper lifestyle.
50	25, 51, 103, 114a,124, 156	If I go too hard I get tired easily.
51	114, 141, 151, 153, 154a	I have to pace myself.
52	1, 87,130a	I feel tightness and pains in my chest the odd time.
54	55, 85, 113, 128	One of our children phones us every day to make sure we are okay.
56	3, 3a, 25, 46, 81	I swim to exercise, but not as often as I used to.
57	28	I enjoy going to the hockey games with my friends.
60	54, 128	I turned my responsibilities for my property over to my son.
61	5	I don't like travelling, carrying bags is to difficult for me.
63	5,	If I am feeling well enough we will go on holiday this year.
65	48	I am not back at work yet.
65a	14, 18, 25, 71, 96, 100,	It has slowed down my life, and I resent that.

#	DUPLICATED STATEMENTS	REDUNDANT STATEMENTS REMOVED (✗)
67	62, 90, 144a	You have to do what is necessary to get by.
69	74, 109, 117	I am concerned that I am running out of options
69a	108	I'm concerned about the health care cutbacks.
71	9, 14, 18, 65a, 96, 100	The heart attack has slowed me down.
71a	25, 56	I don't lead such an active life.
72	8	I can do no work in the yard.
74	109	I worry about dying.
75	34	I worry about my partner.
78	76a	My partner and I don't drink anymore.
80	40, 45, 98, 157	I am more careful about what I eat.
81	93a	I am not always consistent with my exercise.
82a	52, 87	I rarely experience pain.
83	29	It is important for me to know how I'm doing.
84	73, 114	I am careful when I get excited, because I feel my heart-rate go up.
85	54, 113	Our children are very supportive.
87	52, 134a	I worry if I get the odd twinge of pain in my chest, from maybe indigestion.
88	94	My quality of life is unaffected by the heart attack.
90	62	You have to take life as it comes and deal with it.
91	106, 113	My family helped me through the worst of it.
92	73, 114, 162	It is hard to gage how much exercise to do and how hard?
93a	81	I don't like walking much even though it is supposed to be good for me.
96	14, 25	I can't do the things I used to do with ease before the heart attack.
98	15	I sure have to watch my diet and keep weight down.
99	121	I seem to be very short of breath at times.
100	18, 65a, 71	I must learn to slow down in my activity which I find hard to do.
102	23	I find it difficult to relax.
105	7, 77a, 146	I miss my old friends and the camaraderie.

#	DUPLICATED STATEMENTS	REDUNDANT STATEMENTS REMOVED (✗)
112	134	It was a really light attack, there was no real effect.
113	54, 85	The children helped me afterwards.
114	18a, 51	I have to be more careful.
114a	18, 73	I don't go so hard.
115	8, 18a,	I can't lift anything.
116	33, 130, 147	I can't do a lot of things I used to do.
116a	34, 49, 62, 75	Its hard on my partner.
117	74, 109	I think about the end sometimes.
118	8, 124, 125, 126	I can't do much around the house.
119	70	I feel like a burden, a "dead weight" around his/her neck.
120	2a	I am light-headed when I walk or move too fast.
121	122	Short of air some days when I'm walking.
123	3a, 18, 71	Slowed down in walking.
124	14, 103	Can't do my housework like I used to I get too tired.
125	14,124	Can't do my vacuuming.
126	6, 95	Not interested in cooking meals.
127	5, 110	Can't drive my car anymore as I do not trust myself.
128	54, 85, 113	My son has had to stay home from work as he didn't want to leave me alone.
129	97	Restricted outside activities in cold weather.
129a	8a,14,25	I can't do things I used to like doing before the heart attack.
130	8, 8a, 25	Restricted my daily activities.
130a	1, 145	I am again experiencing angina pain.
131	29	I get anxious that a heart attack could happen again.
132	31, 62	Makes me enjoy day to day life.
133	17, 82	I am coping well I think.
134	16, 86, 88,112	No real difference.
135	44, 59	More conscious about getting daily exercise.

#	DUPLICATED STATEMENTS	REDUNDANT STATEMENTS REMOVED (✗)
136	15, 44,157	Reduced eating - less fats, sugar and meat.
137	8a, 22	Have some interests and hobbies as previous.
138	46, 81	I find it difficult to deliberately exercise.
139	38,	My quality of life is now better.
140	56, 59	I can walk, ski, etc.
144a	62, 132	I want to live as good a life as possible and as long as possible.
145	1, 130a	Angina everyday - lots of medication.
146	7, 77a, 105	I can't socialize.
146a	107, 160	My self confidence is lost.
147	25, 46	I can't do activities other than some walking.
148	5, 24,	I can't travel.
149	5, 24, 149	I can't sit too long - bus, train etc.
151	27, 33, 37,	Stay at home and confine my routine to small things.
152	91, 106, 113	I manage with the help of my family and partner.
153	25, 130	The first four weeks after the heart attack my activities were somewhat restricted.
154	86, 89, 112	I have now resumed my usual activities.
154a	18	I usually rest for ½ hour after lunch.
155	86	My partner and I travelled without incident.
156	50, 65a	I feel stressed if I get over tired.
156a	18, 30, 114a	I take some rest breaks and consciously endeavour to relax.
157	45, 80	I have modified my diet. No butter or ice cream or pastries.
158	15, 98	I am on a low fat diet to maintain my weight loss.
159	40	I use some vitamin supplements.
160	107, 146a	Leads to a lack of confidence.
161	29, 69, 83,131	Anxiety due to not knowing what to expect.
162	4, 25, 84, 92	Not knowing my limitations leaves me wondering as to what I can do or not do.

#	AMBIGUOUS, VAGUE OR IRRELEVANT STATEMENTS REMOVED (◘)
17	If I can maintain this level of lifestyle, I will be very happy.
39	I am waiting for a hip replacement and a knee replacement so I'm not sure how much I could do now, physically.
42	I must have only minimal heart damage and scarring.
43	We have a happy stress-free life. (referring to previous abusive marriage)
64	Having a heart attack is an utter nuisance.
66	I would prefer to receive more handouts to gain information rather than be talked at.
82	I feel pretty good most days.
103a	I can't read or watch T.V.
111	I am no longer creative.
142	We moved from Vancouver to Whistler.
143	I live with a fabulous partner.
144	Life is now a joy.
150	The difference in my quality of life is night and day.

APPENDIX K
Edit # 2 - Partner Statements

PART. # (Gender)	MAIL/ TELE.	#	STATEMENTS
1 (Male)	Mail	1	My partner and I continue to talk about the heart attack. ✔
		2	My partner and I continue to worry about another heart attack. ✕
		3	My partner worries about me, when I don't take care of myself. ✔
		4	The heart attack is a continuous subject of conversation with friends.✔
		5	My partner thinks I never worry about him/her. ✔
		6	I must not talk about anything when I feel bad. ✔
		7	My partner's big problem is his/her nerves. ◘
2 (Female)	Mail	8	The heart attack changed the pace of life for my partner. ◘
		9	I feel hopeful my partner will get help dealing with stressful work situations. ✔
		10	I feel anxious due to the health cuts and long waiting lists. ✔
		11	I am pleased my partner has more time for our family. ✔
3 (Female)	Mail	12	My partner helps his/her child in a way that he/she never had time or energy to do before. ✗
		13	My partner shares more of the household chores. ✔
		14	I have reduced stressful situations in the home. ✔
		15	More time to enjoy the company of friends. ✔
4 (Female)	Mail	16	I am spending lots of time reading food labels in the stores. ✔
		17	I am finding it difficult to find interesting food for my partner's daily needs. ✔
		18	I try not to upset my partner. ✔
		19	I have been experiencing some depression. ✔
		20	My partner hates going for a walk. ✗
		21	My partner criticizes my cooking . ✗
		21a	My partner refuses to eat food I prepare. ✔
		22	My partner has a negative attitude towards life now. ✔
		23	My partner was well-known for his/her good nature. ◘
		24	My partner has a shorter fuse. ✔
5 (Female)	Mail	25	I am often more worried than my partner is. ✔
		26	I make sure that my partner does not work too hard or too long. ✗
		26a	I ensure my partner takes rest breaks. ✔
		27	My partner has sleeping problems that affect my sleep as well. ✔
		28	I always watch out for signs of problems. ✔
		29	We are <u>very lucky</u>, my partner only had a light attack. ◘
6 (Male)	Mail	30	There is an increase in my anxiety levels. ✗
		30a	I fear that the end could come suddenly. ✔

Note. ✔ denotes statements included in final list, ✗ denotes redundant statements removed, and ◘ denotes ambiguous or vague statements.

PART. # (Gender)	MAIL/ TELE.	#	STATEMENTS
7 (Female)	Tele.	31	I have not noticed any changes in my life at all. ✗
		32	I have to work, he/she does not. ✗
		33	I had to learn how to care for my partner. ✔
		34	It is hard to continue the relaxation exercises we were taught. ✔
8 (Female)	Mail	35	I am happy nobody smokes in our home now. ✔
		36	I never drink alcohol anymore. ✔
9 (Female)	Tele.	37	There are a lot of things we can't do anymore. ✔
		38	I can't drive the car so we stay closer to home these days. ✔
		39	I worry when my partner drives the car in case he has another heart attack. ✗
		40	He is a miracle case. ▣
		41	I have to do a lot of yard work myself. ✗
		42	I have to encourage my partner to exercise. ✔
		43	We have to walk to places because he/she can't drive. ✔
10 (Female)	Tele.	44	I get tired looking after my partner. ✔
		45	I enjoy spending time with my partner. ✔
		46	We enjoy walking together for short periods of time. ✗
		47	I don't go out socially as much as I did prior to the attack. ✔
11 (Female)	Mail	48	Switch to cooking with low-fat recipes - I enjoy doing this. ✔
		49	Anxiety - for first few months, then I was okay. ✔
		50	I make sure that my partner has taken his/her medication. ✔
		51	I get anxious about keeping appointments. ✔
		51a	If a person isn't on time you think "What has happened?". ✔
		52	I have become more watchful. ✔
		52a	I try to not nag. ✔
12 (Female)	Tele.	53	Hospital staff should have taught us how to manage more. ▣
		53a	I felt overwhelmed by the amount of information the hospital staff gave us. ✔
		54	I am frustrated because my partner doesn't make an effort to take care of him/herself. ✔
		54a	My partner has not maintained his/her exercise program. ✔

PART. # (Gender)	MAIL/ PHONE	#	STATEMENTS
13 (Male)	Tele.	55	My quality of life is unaffected by the heart attack. ✔
		56	After coping with the initial shock of the heart attack I was okay. ✗
		57	I become concerned if my partner complains of discomfort in his/her chest. ✔
14 (Female)	Tele.	58	My partner no longer works so income is a big stressor. ✔
		59	I have had to manage more on my own. ✔
		60	I worry about the possibility of my partner having another heart attack. ✔
		60a	I take it day to day. ✔
15 (Female)	Tele.	61	I had to stop work to take care of my partner. ✔
		62	I have to do all the physical work. ✔
		63	Our quality of life has deteriorated. ✔
		64	We have lost many of our friends. ✔
		65	We are more isolated and alone. ✗
		66	My partner is willing to help me but is unable to. ✔
		67	My life is hectic and busy. ✔
		68	I feel very angry about the changes in my lifestyle. ✗
		69	It is hard to accept the changes in my lifestyle. ✔
		70	I would love to travel more, but it would be too difficult for my partner ✔
		71	I prefer my husband to drive, now I have to do it. ✗
		72	I have lost my independence. ✔
16 (Female)	Mail	73	Vacation trips are restricted to short distances. ✗
		74	Social activities are almost zero. ✔
		75	I had to take over my partner's chores. ✔
		76	I feel lonely at times because my partner sleeps a lot. ✔
17 (Female)	Mail	77	I have changed many cooking/eating patterns to cut back on fats, sugars etc. that my partner loves. ✗
		78	I don't like the restrictions. ✔
		79	I have increased my exercise as a personal preventive measure. ✔
		80	We participate in less outdoor activities since the heart attack. ✔
		81	I spend more time by myself due to his/her cat naps. ✗
18 (Female)	Mail	82	I am more cautious. ✗
		82a	Overall quality of life has improved. ✔
		83	I can't keep up with my partner. ✔
*********	*******	****	***
			REDUNDANCY WAS JUDGED TO BE REACHED AT THIS POINT

PART. # (Gender)	MAIL/ TELE.	#	STATEMENTS
19 (Female)	Mail	84	Have feelings of anxiety and helplessness over health cuts. ✗
		84a	I worry about whither transplant will come in time? ✗
		85	We make no long term plans just do one day at a time. ✗
		86	Very quiet social life. ✗
		86a	An occasional evening out is very tiring for my partner. ✗
		87	Cannot count on any help with chores - carry groceries, clean walks, yard work myself. ✗
		88	Healthy adjustments to our lifestyle. ✗
		89	Daily walks with my partner are one of our most pleasant times together. ✗
20 (Female)	Mail	90	There is an increase in my physical activity. ✗
		91	Slightly more vigilant to cholesterol/fat content of diet. ✗
21 (Male)	Mail	92	My partner and I compliment each other. ✗
		93	We support one another. ✗
		94	Life is worth living with a caring partner. ◘
22 (Female)	Mail	95	I try to maintain a positive attitude. ✗
		96	I have had to realize that stress affects my partner. ✗
		97	We are doing well sharing and balancing responsibilities. ✗
		98	I feel hopeful now my partner is recovering. ✗
23 (Female)	Mail	99	I have become the sole "breadwinner" in our household. ✗
		100	My partner goes into depressions where he/she won't do anything. ✗
		101	There are times when I worry a lot. ✗
		102	We are very restricted as to where we can go and what we can do on holidays. ✗
		103	There isn't the "disposable" cash that there was before. ✗

#	DUPLICATED STATEMENT	REDUNDANT STATEMENTS REMOVED (✗)
12	11	My partner helps his/her child in a way that he/she never had time or energy to do before.
20	42, 54, 54a	My partner hates going for a walk.
21	17, 21a	My partner criticizes my cooking.
26a	26	I make sure that my partner does not work too hard or too long.
30	10, 25	There is an increase in my anxiety levels.
31	55	I have not noticed any changes in my life at all.
32	58, 96	I have to work, he/she does not.

#	DUPLICATED STATEMENT	REDUNDANT STATEMENTS REMOVED (✗)
39	2, 60	I worry when my partner drives the car in case he has another heart attack.
41	62, 75, 87	I have to do a lot of yard work myself.
46	45, 89	We enjoy walking together for short periods of time.
56	49	After coping with the initial shock of the heart attack I was okay.
65	47, 64, 74	We are more isolated and alone.
69	68, 78	It is hard to accept the changes.
71	75	I prefer my husband to drive, now I have to do it.
73	70, 80, 102	Vacation trips are restricted to short distances.
75	41, 62, 87	I had to take over my partner's chores, e.g., snow shovelling, driving the car.
77	16, 48, 88, 91	I have changed many cooking/eating patterns to cut back on fats, sugars etc. that my partner loves.
81	59, 81	I spend more time by myself due to his cat naps.
82	28	I am more cautious.
84	10	Have feelings of anxiety and helplessness over health cuts.
84a	10, 60	I worry about whither transplant will come in time?
85	60a	We make no long term plans just do one day at a time.
86	47, 74	Very quiet social life.
86a	8	An occasional evening out is very tiring for my husband.
87	41, 62, 75	Cannot count on any help with chores - carry groceries, clean walks, yard work myself.
88	16, 35, 36, 48, 77	Healthy adjustments to our lifestyle.
89	46	Daily walks with husband are one of our most pleasant times together.
90	41, 62, 75, 87	Increase in my physical activity.
91	48, 77	Slightly more vigilant to cholesterol/fat content of diet.
92	13, 46, 97	My partner and I compliment each other.
93	13, 45, 46	We support one another.
95	60a	I try to maintain a positive attitude.
96	9, 14	I have had to realize that stress affects him.

#	DUPLICATED STATEMENT	REDUNDANT STATEMENTS REMOVED (✗)
97	13, 46, 92	We are doing well sharing and balancing responsibilities.
98	49	I feel hopeful now my partner is recovering.
99	32	I have become the sole "breadwinner" in our household.
100	42, 54	He goes into depressions where he won't do anything.
101	25, 84a	There are times when I worry a lot.
102	38, 70, 73, 80	We are very restricted as to where we can go and what we can do on holidays.
103	58	There isn't the "disposable" cash that there was before.

#	AMBIGUOUS, VAGUE OR IRRELEVANT STATEMENTS REMOVED (◘)
7	My partner's big problem is his/her nerves.
8	The heart attack changed the pace of life for my partner.
23	My partner was well-known for his/her good nature.
29	We are very lucky, my partner only had a light attack.
40	He is a miracle case.
53	Hospital staff should have taught us how to manage more.
94	Life is worth living with a caring partner.

APPENDIX L

Cover Letter for Sorting Task in Phase Two

Dear participant:

We would like to thank you for agreeing to participate in the second phase of our research. We would like to remind you that your participation is strictly voluntary and you may drop-out at any time. All information will be confidential.

The enclosed package contains descriptive statements, a recording sheet, and instructions for the sorting task. We would like you to sort the statements into common themes. Detailed, step-by-step instructions are provided. This task requires about 20 minutes to complete. A **stamped, self-addressed envelope** is also enclosed so that you can conveniently return your completed record sheet to us. This distribution procedure ensures your confidentiality.

The sorted statements will be used to create concept maps that reflect the common experiences and themes of individuals who have had a heart attack and their partners. It is hoped this information will contribute to a greater understanding of these individuals' quality of life.

If you have any questions or concerns please feel free to contact Dr. Calder at 492-3696.

Thank you for your time and cooperation.

K. K. Teo, MD, PhD, FRCPC
University of Alberta Hospitals
Edmonton

P. Calder, PhD
Dept. of Educational Psychology
University of Alberta, Edmonton

APPENDIX M

Sorting Task - Patient Statements

Instructions:

In this task we are going to ask you to sort statements, obtained from cardiac patients, into groups that have a common theme or idea. This will reflect how you perceive and categorize this experience. This task should take approximately 30 minutes.

Enclosed in this package are a set of small cards in an envelope. Each card contains a statement that cardiac patients made. Each card is numbered randomly. Please follow these instructions:

a) Read through **all** the statements.

b) Sort the statements into groups that ***make sense to you.*** You can create as many groups as you like. (Please do not put all statements in one pile or 66 piles.)

c) Once you have created groupings of statements, put the statement numbers for each of your groups on the record sheet.

d) If possible, select a title or label for each of your groups of statements.

e) Place the completed record sheet in the self-addressed envelope and return it to me. Thank you.

NOTE: THERE ARE NO RIGHT OR WRONG GROUPINGS.

EXAMPLE

#2 I enjoy reading.
#6 Reading is pleasurable ---------------------------- Group #1
#9 I relax when I read

#1 Reading improves my vocabulary
#4 Reading expands my knowledge ------------------ Group #2

Group Number	Statement Numbers	Title
1	2, 6, 9.	Enjoyment
2	1, 4.	Learning

If you have any questions about how to complete this task please contact Dr. Calder at 492-3696. We would appreciate receiving the sorts within 2 weeks. Thank you.

APPENDIX N

Sorting Task - Partner Statements

Instructions:

In this task we are going to ask you to sort statements, obtained from partners of cardiac patients, into groups that have a common theme or idea. This will reflect how you perceive and categorize this experience. This task should take approximately 30 minutes.

Enclosed in this package are a set of small cards in an envelope. Each card contains a statement that partners of cardiac patients made. Each card is numbered randomly. Please follow these instructions:

a) Read through **all** the statements.

b) Sort the statements into groups that ***make sense to you.*** You can create as many groups as you like. (Please do not put all statements in one pile or 66 piles.)

c) Once you have created groupings of statements, put the statement numbers for each of your groups on the record sheet.

d) If possible, select a title or label for each of your groups of statements.

e) Place the completed record sheet in the self-addressed envelope and return it to me. Thank you.

NOTE: THERE ARE NO RIGHT OR WRONG GROUPINGS.

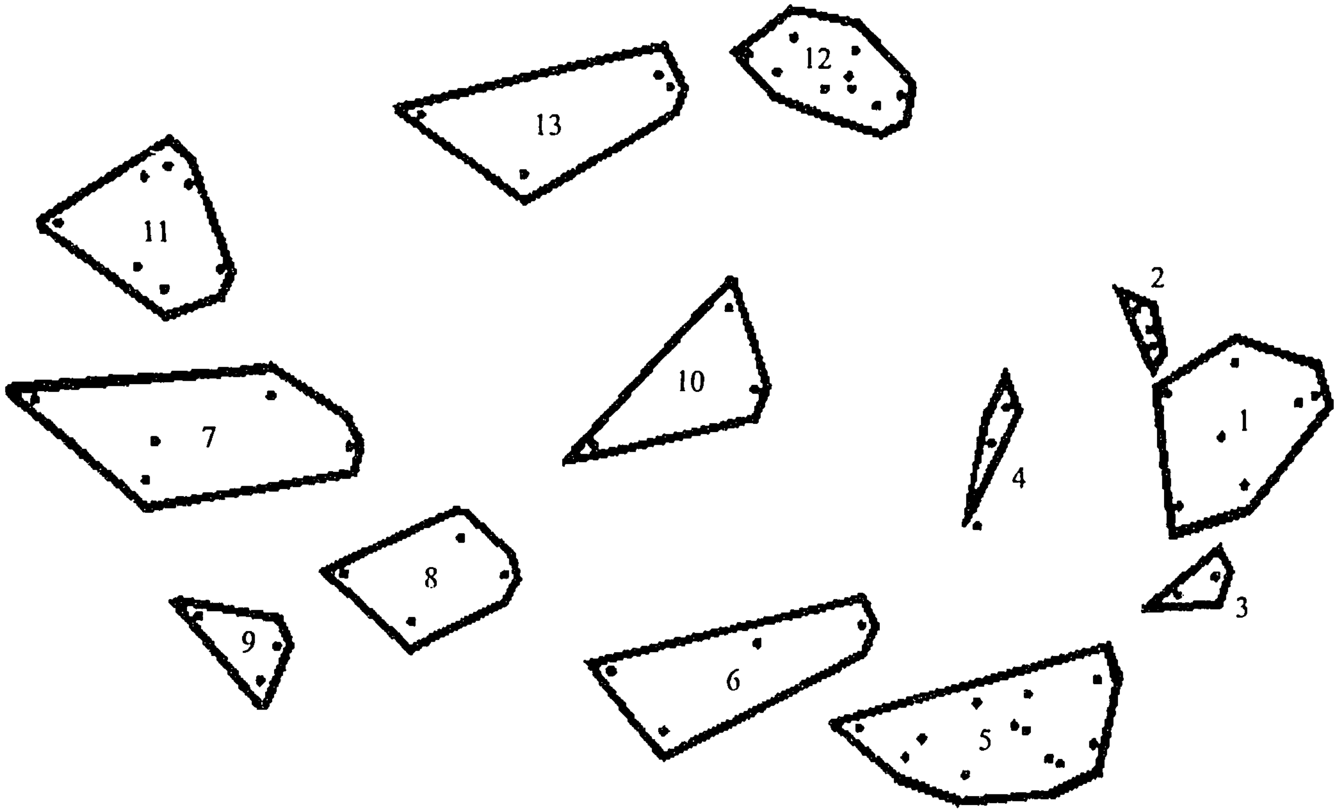
EXAMPLE

#2 I enjoy reading.
#6 Reading is pleasurable ---------------------------- Group #1
#9 I relax when I read

#1 Reading improves my vocabulary
#4 Reading expands my knowledge ------------------- Group #2

Group Number	Statement Numbers	Title
1	2, 6, 9.	Enjoyment
2	1, 4.	Learning

If you have any questions about how to complete this task please contact Dr. Calder at 492-3696. We would appreciate receiving the sorts within 2 weeks. Thank you.



APPENDIX O: 13 solution concept map of 66 patient statements

APPENDIX O

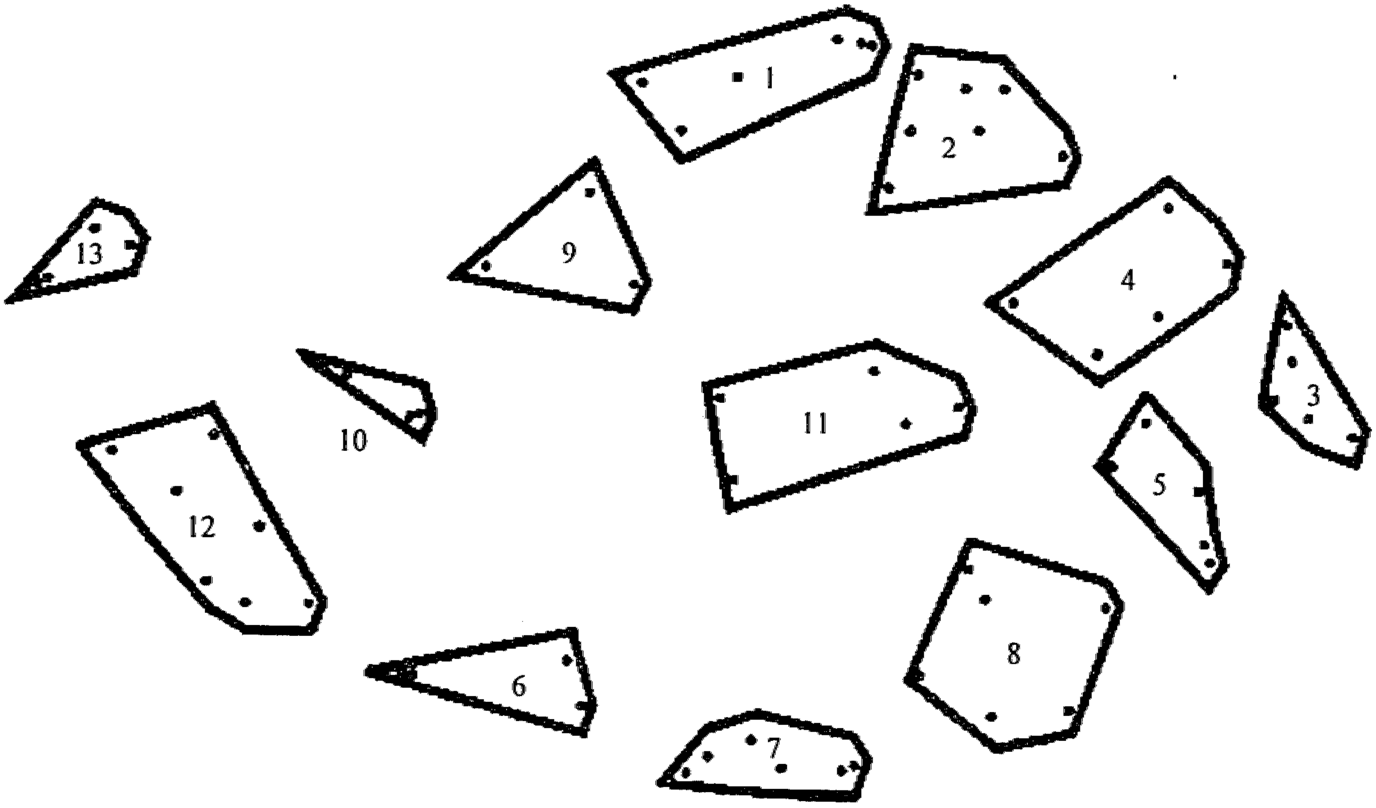
Cluster Items and Bridging Indexes for 13 Solution Concept Map of Patients Who have had a Myocardial Infarction

Cluster	Statements (#)	Bridging Index
One	I can't drink alcohol anymore (#1)	0.47
	I can't smoke (#53)	0.49
	I can't travel (#8)	0.56
	I can't go anywhere by myself (#61)	0.61
	I am unable to do my hobbies (#5)	0.48
	The heart attack virtually has cut out my sex life (#9)	0.64
	I have to leave heavy work to others (#60)	0.64
	Cluster Average	0.56
Two	My social life is very limited (#45)	0.61
	I lost many of my friends (#45)	0.62
	I want to contribute more to my community but I can't (#18)	0.80
	Cluster Average	0.68
Three	It takes me longer to complete simple tasks (#2)	0.40
	I cannot do yard work (#6)	0.47
	Cluster Average	0.43
Four	I am no longer a "go-getter" (#21)	0.59
	It takes much fun out of life (#44)	0.58
	I no longer enjoy eating out (#62)	0.52
	Cluster Average	0.56
Five	I am losing my physical fitness (#10)	0.26
	I have less energy (#19)	0.18
	I experience dizziness (#12)	0.16

Cluster	Statements (#)	Bridging Index
Five	I am more aware of minor pains in muscles or indigestion (#58)	0.20
	I have to slow down and take rest breaks (#59)	0.28
	I have heart palpitations (#11)	0.08
	I seem to be very short of breath at times (#57)	0.00
	I suffer pain daily (#14)	0.10
	I suffer intermittent weak feelings (#13)	0.23
	Hot or cold weather has a lot of effect on my way of life (#56)	0.25
	I am having a difficult time sleeping (#63)	0.18
	I cannot remember things as well (#26)	0.36
	Cluster Average	0.19
Six	I find it difficult to concentrate (#20)	0.57
	I am careful not to over-exert my heart (#47)	0.92
	I feel a little depressed some days (#55)	0.51
	I can't stand much noise (#66)	0.54
	Cluster Average	0.63
Seven	I am reluctant to accept any long-term work (#3)	0.83
	I am no longer employed (#15)	0.89
	I worry about my partner (#25)	0.76
	My business income has been serious curtailed (#4)	0.81
	I lack motivation to look for another job (#31)	0.73
	Cluster Average	0.80
Eight	I seem to want to stay at home more (#24)	0.87
	I feel like a burden to my family and friends (#41)	0.82
	I have lost my self-confidence (#38)	0.62

Cluster	Statements (#)	Bridging Index
Eight	I am not always consistent with my exercise (#48)	1.00
	Cluster Average	0.83
Nine	I worry about my health (#29)	0.79
	I am afraid of dying (#42)	0.86
	I worry the hospital cutbacks will affect our quality of life (#39)	0.76
	Cluster Average	0.80
Ten	I have not tried to maintain the lifestyle changes, suggested by my doctors (#16)	0.80
	I am very bored at home (#40)	0.71
	I am scared to drive (#49)	0.79
	Cluster Average	0.76
Eleven	My partner has pulled me through the worst times (#17)	0.19
	My partner financially supports us (#32)	0.59
	My partner does not go out as much these days (#35)	0.76
	I exercise to keep my partner happy (#54)	0.72
	Our children our good support (#34)	0.41
	My partner and I take it day to day (#37)	0.27
	We have survived wonderfully together (#46)	0.29
	Cluster Average	0.46
Twelve	I feel better and eat better and take vitamin supplements (#22)	0.23
	I take more care of what I eat (#43)	0.29
	I am generally more relaxed (#28)	0.23
	I appreciate life more (#27)	0.45
	I have not noticed any changes in my quality of life (#52)	0.29
	If anything my life has improved (#23)	0.14

Cluster	Statements (#)	Bridging Index
Twelve	I have had no problems at all since my heart attack (#50)	0.35
	I try to forget about my heart condition and get on with life (#33)	0.21
	I have more time to indulge in leisure pursuits (#64)	0.22
	Cluster Average	0.27
Thirteen	I have more time to socialize with friends (#30)	0.33
	I have returned to work and feel great (#51)	0.34
	I enjoy being outside and going for walks with my partner (#36)	0.59
	I shifted focus away from my job to the home (#65)	0.78
	Cluster Average	0.51



Appendix P: 13 solution concept map of 66 partner statements

APPENDIX P

Cluster Items and Bridging Indexes for 13 Solution Concept Map of Partners of Patients Who have had a Myocardial Infarction

Cluster	Statements (#)	Bridging Index
One	My partner and I continue to talk about the heart attack (#1)	0.71
	My partner worries about me when I don't take care of myself (#2)	0.55
	I take it day to day (#43)	0.41
	I fear the end could come suddenly (#19)	0.00
	I become concerned if he/she complains of discomfort (#40)	0.00
	I worry about the possibility of my partner having another heart attack (#41)	0.08
	Cluster Average	0.29
Two	My partner thinks I never worry about him/her. (#4)	0.54
	I always watch out for signs of problems (#18)	0.32
	I feel anxious due to health cuts and long waiting lists (#20)	0.18
	I get anxious about keeping appointments (#60)	0.15
	If a person isn't on time you think "What has happened?" (#61)	0.22
	Anxiety - for the first few months, then I was okay (#44)	0.43
	I have become more watchful (#62)	0.36
	Cluster Average	0.31
Three	I must not talk about anything when I feel bad (#5)	0.45
	I try not to nag (#63)	0.46
	My partner has a negative attitude towards life now (#14)	0.63
	I feel lonely at times because my partner sleeps a lot (#54)	0.48
	My partner no longer works so income is a big stressor (#42)	0.72
	Cluster Average	0.55

Cluster	Statements (#)	Bridging Index
Four	I am often more worried than my partner is (#15)	0.4
	I have been experiencing some depression (#23)	0.44
	I get tired looking after my partner (#27)	0.40
	I am frustrated because my partner doesn't make an effort to take care of him/herself (#38)	0.50
	I felt overwhelmed by the amount of information the hospital gave us (#37)	0.43
	Cluster Average	0.43
Five	My partner has not maintained his/her exercise program (#53)	0.49
	I have had to manage more on my own (#58)	0.53
	I can't keep up with my partner (#57)	0.69
	I don't like restrictions (#55)	0.65
	I have had to stop work to take care of my partner (#64)	0.64
	Cluster Average	0.60
Six	The heart attack is a continuous subject of conversation with friends (#3)	0.84
	It is hard to continue the relaxation exercises (#35)	0.68
	My quality of life is unaffected by the heart attack (#39)	0.64
	Cluster Average	0.72
Seven	There are a lot of things we can't do anymore (#24)	0.19
	Social activities are almost zero (#50)	0.19
	We have lost many of our friends (#45)	0.18
	We have to walk to places because he/she can't drive (#26)	0.32
	Our quality of life has deteriorated (#33)	0.36
	I would love to travel more, but it would be too difficult for my partner (#66)	0.18

Cluster	Statements (#)	Bridging Index
Seven	I can't drive the car so we stay closer to home these days (#31)	0.46
	Cluster Average	0.27
Eight	I never drink alcohol anymore (#22)	0.72
	I don't go out socially as much as I did prior to the attack (#29)	0.39
	We participate in less outdoor activities since the heart attack (#36)	0.57
	It is hard to accept the changes in my lifestyle (#47)	0.63
	My life is hectic and busy (#65)	0.59
	I have lost my independence (#49)	0.55
	Cluster Average	0.57
Nine	I feel hopeful my partner will get help coping with stress work situations (#6)	1.00
	I have reduced stressful situations in the home (#8)	0.77
	I try not to upset my partner (#12)	0.74
	Cluster Average	0.83
Ten	I have to do all the physical work (#32)	0.60
	I had to take over my partner's chores (#51)	0.60
	My partner is willing to help me but is unable to (#46)	0.80
	Cluster Average	0.75
Eleven	I ensure that my partner takes rest breaks (#16)	0.33
	I make sure that my partner has taken his/her medication (#48)	0.33
	I had to learn how to care for my partner (#34)	0.39
	My partner has sleeping problems that affect my sleep (#17)	0.60
	I have to encourage my partner to exercise (#25)	0.64
	Cluster Average	0.46

Cluster	Statements (#)	Bridging Index
Twelve	My partner shares more of the household chores (#7)	0.42
	I enjoy spending time with my partner (#28)	0.59
	I am happy nobody smokes in our home now (#21)	0.67
	I have increased my exercise as a personal preventative measure (#52)	0.75
	More time to enjoy the company of friends (#9)	0.44
	I am pleased my partner has more time for our family (#30)	0.38
	Overall quality of life has improved (#56)	0.56
	Cluster Average	0.54
Thirteen	I am spending lots of time reading food labels in the store (#10)	0.22
	Switch to cooking with low fat recipes I enjoy doing this (#59)	0.22
	I am finding it difficult to find interesting food for my partner's daily needs (#11)	0.66
	My partner refuses to eat the food I prepare (#13)	0.75
	Cluster Average	0.46

APPENDIX Q
Patient Incidence Survey

Have you ever had a heart attack, if so how many? Yes_____ No _____ # _____

Statements	Strongly Disagree		Neutral / Not Applicable		Strongly Agree
1. I can't drink alcohol any more.	1	2	3	4	5
2. It takes me longer to complete simple tasks.	1	2	3	4	5
3. I am reluctant to accept any long-term work.	1	2	3	4	5
4. My business income has been seriously curtailed.	1	2	3	4	5
5. I am unable to do my hobbies.	1	2	3	4	5
6. I cannot do yard work.	1	2	3	4	5
7. My social life is very limited.	1	2	3	4	5
8. I can't travel.	1	2	3	4	5
9. The heart attack has virtually cut out my sex life.	1	2	3	4	5
10. I am losing my physical fitness.	1	2	3	4	5
11. I have heart palpitations.	1	2	3	4	5
12. I experience dizziness.	1	2	3	4	5
13. I suffer intermittent weak feelings.	1	2	3	4	5
14. I suffer pain daily.	1	2	3	4	5
15. I am no longer employed.	1	2	3	4	5
16. I have **not** tried to maintain the lifestyle changes, suggested by my doctors.	1	2	3	4	5
17. My partner has pulled me through the worst times.	1	2	3	4	5
18. I want to contribute more to my community but I can't.	1	2	3	4	5
19. I have less energy.	1	2	3	4	5
20. I find it difficult to concentrate.	1	2	3	4	5
21. I am no longer a "go-getter".	1	2	3	4	5
22. I feel better and eat better and take vitamin supplements.	1	2	3	4	5
23. If anything my life has improved.	1	2	3	4	5
24. I seem to want to stay at home more.	1	2	3	4	5
25. I worry about my partner.	1	2	3	4	5
26. I cannot remember things as well.	1	2	3	4	5
27. I appreciate life more.	1	2	3	4	5
28. I am generally more relaxed.	1	2	3	4	5
29. I worry about my future health.	1	2	3	4	5
30. I have more time to socialize with friends.	1	2	3	4	5
31. I lack motivation to look for another job.	1	2	3	4	5
32. My partner financially supports us.	1	2	3	4	5
33. I try to forget about my heart condition and get on with life.	1	2	3	4	5
34. Our children are good support.	1	2	3	4	5
35. My partner does not go out as much these days.	1	2	3	4	5
36. I enjoy being outside and going for walks with my partner.	1	2	3	4	5
37. My partner and I take it day to day.	1	2	3	4	5

Appendix Q (continued)

Statements	Strongly Disagree		Neutral / Not Applicable		Strongly Agree
38. I have lost my self-confidence.	1	2	3	4	5
39. I worry the hospital cutbacks will affect our quality of life.	1	2	3	4	5
40. I am very bored at home.	1	2	3	4	5
41. I feel like a burden to my family and friends.	1	2	3	4	5
42. I am afraid of dying.	1	2	3	4	5
43. I take more care of what I eat.	1	2	3	4	5
44. It takes much fun out of life.	1	2	3	4	5
45. I lost many of my friends.	1	2	3	4	5
46. We have survived wonderfully together.	1	2	3	4	5
47. I am careful not to over-exert my heart.	1	2	3	4	5
48. I am not always consistent with my exercise.	1	2	3	4	5
49. I am scared to drive.	1	2	3	4	5
50. I have had no problems at all since my heart attack.	1	2	3	4	5
51. I have returned to work and feel great.	1	2	3	4	5
52. I have not noticed any changes in my quality of life.	1	2	3	4	5
53. I can't smoke.	1	2	3	4	5
54. I exercise to keep my partner happy.	1	2	3	4	5
55. I feel a little depressed some days.	1	2	3	4	5
56. Hot or cold weather has a lot of effect on my way of life.	1	2	3	4	5
57. I seem to be very short of breath at times.	1	2	3	4	5
58. I am more aware of minor pains in muscles or indigestion.	1	2	3	4	5
59. I have to slow down and take rest breaks.	1	2	3	4	5
60. I have to leave heavy work to others.	1	2	3	4	5
61. I can't go anywhere by myself.	1	2	3	4	5
62. I no longer enjoy eating out.	1	2	3	4	5
63. I am having a difficult time sleeping.	1	2	3	4	5
64. I have more time to indulge in leisure pursuits.	1	2	3	4	5
65. I shifted focus away from my job to the home.	1	2	3	4	5
66. I can't stand much noise.	1	2	3	4	5

On a scale of **1 to 100** where 1 = poor and 100 = excellent, where would you rate your present quality of life? **Answer:** ____________

How would you rate your quality of life since having had your heart attack? (Circle one).

Greatly Deteriorated	Somewhat Deteriorated	No Change	Somewhat Improved	Greatly Improved

APPENDIX R: Frequencies, Percentages, Means, and Standard Deviations for Patient Incidence Survey

INCIDENCE SURVEY- PATIENT

STATEMENTS	Likert-Scale 1		2		3		4		5		M	SD
	f	%	f	%	f	%	f	%	f	%		
1. I can't drink alcohol any more.	6	17.1	11	31.4	12	34.3	3	8.6	3	8.6	2.6	1.1
2. It takes me longer to complete simple tasks.	8	22.9	12	34.3	1	2.9	6	17.1	8	22.9	2.8	1.5
3. I am reluctant to accept any long-term work.	5	14.3	8	22.9	14	40.0	3	8.6	5	14.3	2.8	1.2
4. My business income has been seriously curtailed.	6	17.1	4	11.4	23	65.7	1	2.9	1	2.9	2.6	0.9
5. I am unable to do my hobbies.	11	31.4	10	28.6	4	11.4	5	14.3	5	14.3	2.5	1.4
6. I cannot do yard work.	7	20.0	9	25.7	4	11.4	8	22.9	7	20.0	3.0	1.4
7. My social life is very limited.	7	20.0	13	37.1	7	20.0	4	11.4	4	11.4	2.6	1.3
8. I can't travel.	15	42.9	10	28.6	3	8.6	4	11.4	3	8.6	2.1	1.3
9. The heart attack has virtually cut out my sex life.	6	17.1	16	45.7	5	14.3	3	8.6	5	14.3	2.8	1.3
10. I am losing my physical fitness.	5	14.3	14	40.0	3	8.6	8	22.9	5	14.3	2.8	1.4
11. I have heart palpitations.	7	20.0	8	22.9	6	17.1	8	22.9	6	17.2	3.2	2.0
12. I experience dizziness.	7	20.0	11	31.4	5	14.3	10	28.6	2	5.7	2.7	1.2
13. I suffer intermittent weak feelings.	5	14.3	12	34.3	6	17.1	10	28.6	2	5.7	2.8	1.2
14. I suffer pain daily.	15	42.9	11	31.4	3	8.6	5	14.3	1	2.9	2.0	1.2

Note: 1 = Strongly Disagree, 2 = Disagree, 3 = Neutral/Not Applicable, 4 = Agree, 5 = Strongly Agree

APPENDIX R: Frequencies, Percentages, Means, and Standard Deviations for Patient Incidence Survey (continued)

INCIDENCE SURVEY-PATIENT												
	Likert-Scale											
STATEMENTS	1		2		3		4		5		M	SD
	f	%	f	%	f	%	f	%	f	%		
15. I am no longer employed.	11	31.4	4	11.4	13	37.1	3	8.6	4	11.4	2.6	1.3
16. I have **not** tried to maintain the lifestyle changes, suggested by my doctors.	11	31.4	15	42.9	2	5.7	3	8.6	4	11.4	2.3	1.3
17. My partner has pulled me through the worst times.	3	8.6	3	8.6	3	8.6	17	48.6	9	25.7	3.7	1.2
18. I want to contribute more to my community but I can't.	2	5.7	10	28.6	15	42.9	6	17.1	2	5.7	2.9	0.9
19. I have less energy.	4	11.4	7	20.0	3	8.6	15	42.9	6	17.1	3.3	1.3
20. I find it difficult to concentrate.	9	25.7	6	17.1	5	14.3	12	34.3	3	8.6	2.8	1.4
21. I am no longer a "go-getter".	7	20.0	6	17.1	7	20.0	14	40.0	1	2.9	2.9	1.2
22. I feel better and eat better and take vitamin supplements.	2	5.7	10	28.6	5	14.3	11	31.4	7	20.0	3.3	1.2
23. If anything my life has improved.	5	14.3	13	37.1	3	8.6	11	31.4	3	8.6	2.8	1.2
24. I seem to want to stay at home more.	5	14.3	12	34.3	4	11.4	10	28.6	4	11.4	2.9	1.3
25. I worry about my partner.	1	2.9	10	28.6	10	28.6	10	28.6	4	11.4	3.1	1.0
26. I cannot remember things as well.	2	5.7	10	28.6	3	8.6	15	42.9	5	14.3	3.3	1.2
27. I appreciate life more.	1	2.9	5	14.3	3	8.6	19	54.3	6	17.1	4.2	3.1

Note: 1 = Strongly Disagree, 2 = Disagree, 3 = Neutral/Not Applicable, 4 = Agree, 5 = Strongly Agree

APPENDIX R: Frequencies, Percentages, Means, and Standard Deviations for Patient Incidence Survey (continued)

INCIDENCE SURVEY- PATIENT

STATEMENTS	Likert-Scale										M	SD
	1		2		3		4		5			
	f	%	f	%	f	%	f	%	f	%		
28. I am generally more relaxed.	3	8.6	11	31.4	4	11.4	16	45.7	1	2.9	3.0	1.1
29. I worry about my future health.	1	2.9	10	28.6	3	8.6	14	40.0	7	20.0	3.4	1.2
30. I have more time to socialize with friends.	1	2.9	8	22.9	13	37.1	12	34.3	1	2.9	3.1	0.9
31. I lack motivation to look for another job.	5	14.3	4	11.4	24	68.6	2	5.7	-	-	2.6	0.8
32. My partner financially supports us.	9	25.7	7	20.0	12	34.3	5	14.3	2	5.7	2.5	1.2
33. I try to forget about my heart condition and get on with life.	-	-	6	17.1	2	5.7	15	42.9	12	34.2	4.0	1.0
34. Our children are good support.	1	2.9	1	2.9	6	17.1	20	57.1	7	20.0	3.9	0.9
35. My partner does not go out as much these days.	4	11.4	11	31.4	7	20.0	12	34.3	1	2.9	2.8	1.1
36. I enjoy being outside and going for walks with my partner.	1	2.9	2	5.7	8	22.9	20	57.1	4	11.4	3.7	0.9
37. My partner and I take it day to day.	1	2.9	3	8.6	7	20.0	18	51.4	6	17.1	3.7	0.9
38. I have lost my self-confidence.	10	28.6	10	28.6	4	11.4	10	28.6	1	2.9	2.5	1.3
39. I worry the hospital cutbacks will affect our quality of life.	6	17.1	5	14.3	2	5.7	14	40.0	8	22.9	3.4	1.4
40. I am very bored at home.	12	34.3	15	42.9	2	5.7	4	11.4	2	5.7	2.1	1.2
41. I feel like a burden to my family and friends.	12	34.3	12	34.3	5	14.3	4	11.4	2	5.7	2.2	1.2

Note: 1 = Strongly Disagree, 2 = Disagree, 3 = Neutral/Not Applicable, 4 = Agree, 5 = Strongly Agree

APPENDIX R: Frequencies, Percentages, Means, and Standard Deviations for Patient Incidence Survey (continued)

INCIDENCE SURVEY- PATIENT

STATEMENTS	Likert-Scale											
	1		2		3		4		5		M	SD
	f	%	f	%	f	%	f	%	f	%		
42. I am afraid of dying.	13	37.1	13	37.1	3	8.6	6	17.1	--	-	2.0	1.1
43. I take more care of what I eat.	3	8.6	4	11.4	9	25.7	16	45.7	3	8.6	3.3	1.1
44. It takes much fun out of life.	7	20.0	14	40.0	5	14.3	7	20.0	2	5.7	2.5	1.2
45. I lost many of my friends.	13	37.1	13	37.1	3	8.6	5	14.3	1	2.9	2.1	1.1
46. We have survived wonderfully together.	1	2.9	2	5.7	6	17.1	18	51.4	8	22.9	3.8	0.9
47. I am careful not to over-exert my heart.	2	5.7	5	14.3	3	8.6	19	54.3	6	17.1	3.6	1.1
48. I am not always consistent with my exercise.	5	14.3	14	40.0	4	11.4	10	28.6	2	5.7	2.7	1.2
49. I am scared to drive.	20	57.1	6	17.1	5	14.3	2	5.7	2	5.7	1.8	1.2
50. I have had no problems at all since my heart attack.	8	22.9	11	31.4	2	5.7	10	28.6	4	11.4	2.7	1.4
51. I have returned to work and feel great.	4	11.4	3	8.6	17	48.6	5	14.3	6	17.1	3.2	1.2
52. I have not noticed any changes in my quality of life.	6	17	12	34	3	8.6	9	26	5	14	3	1
53. I can't smoke.	2	5.7	1	2.9	20	57	3	8.6	9	26	3	1
54 I exercise to keep my partner happy.	6	17	17	49	4	11	8	23	-	-	2	1
55. I feel a little depressed some days.	4	11	9	26	3	8.6	15	43	4	12	3	1

Note: 1 = Strongly Disagree, 2 = Disagree, 3 = Neutral/Not Applicable, 4 = Agree, 5 = Strongly Agree

APPENDIX R: Frequencies, Percentages, Means, and Standard Deviations for Patient Incidence Survey (continued)

INCIDENCE SURVEY- PATIENT

STATEMENTS	Likert-Scale											
	1		2		3		4		5		M	SD
	f	%	f	%	f	%	f	%	f	%		
56. Hot or cold weather has a lot of effect on my way of life.	1	2.9	9	26	2	5.7	17	49	6	17	4	1
57. I seem to be very short of breath at times.	6	17	11	31	6	17	9	26	3	8.6	3	1
58. I am more aware of minor pains in muscles or indigestion.	2	5.7	7	20	4	11	17	49	5	14	3	1
59. I have to slow down and take rest breaks.	3	8.6	5	14	2	5.7	21	60	4	11	4	1
60. I have to leave heavy work to others.	2	5.7	4	11	4	11	16	46	9	26	4	1
61. I can't go anywhere by myself.	20	57	8	23	4	11	2	5.7	1	2.9	2	1
62. I no longer enjoy eating out.	11	31	16	46	2	5.7	5	14	1	2.9	2	1
63. I am having a difficult time sleeping.	9	26	11	31	5	14	8	23	2	5.7	3	1
64. I have more time to indulge in leisure pursuits.	3	8.6	7	20	5	14	15	43	5	14	3	1
65. I shifted focus away from my job to the home.	3	8.6	6	17	15	43	7	20	4	11	3	1
66. I can't stand much noise.	2	5.7	10	29	5	14	15	43	3	8.6	3	1

Note: 1 = Strongly Disagree, 2 = Disagree, 3 = Neutral/Not Applicable, 4 = Agree, 5 = Strongly Agree

APPENDIX S
Partner Incidence Survey

STATEMENTS	Strongly Disagree		Neutral / Not Applicable		Strongly Agree
1. My partner and I continue to talk about the heart attack.	1	2	3	4	5
2. My partner worries about me, when I don't take care of myself.	1	2	3	4	5
3. The heart attack is a continuous subject of conversation with friends.	1	2	3	4	5
4. My partner thinks I never worry about him/her.	1	2	3	4	5
5. I must not talk about anything when I feel bad.	1	2	3	4	5
6. I feel hopeful my partner will get help coping with stressful work situations.	1	2	3	4	5
7. My partner shares more of the household chores.	1	2	3	4	5
8. I have reduced stressful situations in the home.	1	2	3	4	5
9. More time to enjoy the company of friends.	1	2	3	4	5
10. I am spending lots of time reading food labels in the stores.	1	2	3	4	5
11. I am finding it difficult to find interesting food for my partner's daily needs.	1	2	3	4	5
12. I try not to upset my partner.	1	2	3	4	5
13. My partner refuses to eat food I prepare.	1	2	3	4	5
14. My partner has a negative attitude towards life now.	1	2	3	4	5
15. I am often more worried than my partner is.	1	2	3	4	5
16. I ensure that my partner takes rest breaks.	1	2	3	4	5
17. My partner has sleeping problems that affects my sleep as well.	1	2	3	4	5
18. I always watch out for signs of problems.	1	2	3	4	5
19. I fear the end could come suddenly.	1	2	3	4	5
20. I feel anxious due to health cuts and long waiting lists.	1	2	3	4	5
21. I am happy nobody smokes in our home now.	1	2	3	4	5
22. I never drink alcohol anymore.	1	2	3	4	5
23. I have been experiencing some depression.	1	2	3	4	5
24. There are a lot of things we can't do anymore.	1	2	3	4	5
25. I have to encourage my partner to exercise.	1	2	3	4	5
26. We have to walk to places because he/she can't drive.	1	2	3	4	5
27. I get tired looking after my partner.	1	2	3	4	5
28. I enjoy spending time with my partner.	1	2	3	4	5
29. I don't go out socially as much as I did prior to the attack.	1	2	3	4	5
30. I am pleased my partner has more time for our family.	1	2	3	4	5
31. I can't drive the car so we stay closer to home these days.	1	2	3	4	5
32. I have to do all the physical work.	1	2	3	4	5
33. Our quality of life has deteriorated.	1	2	3	4	5
34. I had to learn how to care for my partner.	1	2	3	4	5
35. It is hard to continue the relaxation exercises we were taught.	1	2	3	4	5
36. We participate in less outdoor activities since the heart attack.	1	2	3	4	5

APPENDIX S (continued)

STATEMENTS	Strongly Disagree		Neutral / Not Applicable		Strongly Agree
37. I felt overwhelmed by the amount of information the hospital staff gave us.	1	2	3	4	5
38. I am frustrated because my partner doesn't make an effort to take care of him/herself.	1	2	3	4	5
39. My quality of life is unaffected by the heart attack.	1	2	3	4	5
40. I become concerned if he/she complains of discomfort in his/her chest.	1	2	3	4	5
41. I worry about the possibility of my partner having another heart attack.	1	2	3	4	5
42. My partner no longer works so income is a big stressor.	1	2	3	4	5
43. I take it day to day.	1	2	3	4	5
44. Anxiety - for first few months, then I was okay.	1	2	3	4	5
45. We have lost many of our friends.	1	2	3	4	5
46. My partner is willing to help me but is unable to.	1	2	3	4	5
47. It is hard to accept the changes in my lifestyle.	1	2	3	4	5
48. I make sure that he has taken his medication.	1	2	3	4	5
49. I have lost my independence.	1	2	3	4	5
50. Social activities are almost zero.	1	2	3	4	5
51. I had to take over my partner's chores.	1	2	3	4	5
52. I have increased my exercise as a personal preventive measure.	1	2	3	4	5
53. My partner has not maintained his/her exercise program.	1	2	3	4	5
54. I feel lonely at times because he sleeps a lot.	1	2	3	4	5
55. I don't like the restrictions.	1	2	3	4	5
56. Overall quality of life has improved.	1	2	3	4	5
57. I can't keep up with my partner.	1	2	3	4	5
58. I have had to manage more on my own.	1	2	3	4	5
59. Switch to cooking with low fat recipes - I enjoy doing this.	1	2	3	4	5
60. I get anxious about keeping appointments.	1	2	3	4	5
61. If a person isn't on time you think "What has happened?".	1	2	3	4	5
62. I have become more watchful.	1	2	3	4	5
63. I try to not nag.	1	2	3	4	5
64. I had to stop work to take care of my partner.	1	2	3	4	5
65. My life is hectic and busy.	1	2	3	4	5
66. I would love to travel more, but it would be too difficult for my partner.	1	2	3	4	5

On a scale of **1 to 100** where 1= poor and 100 = excellent, where would you rate your present quality of life? **Answer:** ____________

How would you rate your quality of life since your partner's heart attack? (Circle one).

Greatly Deteriorated	Somewhat Deteriorated	No Change	Somewhat Improved	Greatly Improved

APPENDIX T: Frequencies, Percentages, Means, and Standard Deviations for Partners Survey

INCIDENCE SURVEY- PARTNER

STATEMENTS	Likert-Scale										M	SD
	1		2		3		4		5			
	f	%	f	%	f	%	f	%	f	%		
1. My partner and I continue to talk about the heart attack.	-	-	5	19.2	2	7.7	15	57.7	4	15.4	3.7	0.9
2. My partner worries about me, when I don't take care of myself.	-	-	3	11.5	2	7.7	14	53.8	7	26.9	4.0	0.9
3. The heart attack is a continuous subject of conversation with friends.	5	19.2	5	19.2	4	15.4	11	42.3	1	3.8	2.9	1.3
4. My partner thinks I never worry about him/her.	6	23.1	15	57.7	1	3.8	3	11.5	1	3.8	2.1	1.0
5. I must not talk about anything when I feel bad.	6	23.1	10	38.5	3	11.5	4	15.4	3	11.5	2.5	1.3
6. I feel hopeful my partner will get help coping with stressful work situations.	1	3.8	1	3.8	12	46.2	8	30.8	4	15.4	3.5	0.9
7. My partner shares more of the household chores.	2	7.7	3	11.5	5	19.2	14	53.8	2	7.7	3.4	1.1
8. I have reduced stressful situations in the home.	2	7.7	1	3.8	6	23.1	15	57.7	2	7.7	3.5	0.9
9. More time to enjoy the company of friends.	3	11.5	5	19.2	4	15.4	12	46.2	2	7.7	3.1	1.2
10. I am spending lots of time reading food labels in the stores.	2	7.7	4	15.4	4	15.4	9	34.6	7	26.9	3.6	1.3
11. I am finding it difficult to find interesting food for my partner's daily needs.	5	19.2	8	30.8	5	19.2	5	19.2	3	11.5	2.7	1.3
12. I try not to upset my partner	1	3.8	4	15.4	4	15.4	14	53.8	3	11.5	3.5	1.0
13. My partner refuses to eat food I prepare.	11	42.3	8	30.8	4	15.4	3	11.5	-	-	1.9	1.0
14. My partner has a negative attitude towards life now.	4	15.4	7	26.9	5	19.2	5	19.2	5	19.2	3.0	1.4

Note: 1 = Strongly Disagree, 2 = Disagree, 3 = Neutral/Not Applicable, 4 = Agree, 5 = Strongly Agree

APPENDIX T: Frequencies, Percentages, Means, and Standard Deviations for Partners Survey (continued)

INCIDENCE SURVEY- PARTNER

STATEMENTS	Likert-Scale										M	SD
	1		2		3		4		5			
	f	%	f	%	f	%	f	%	f	%		
15. I am often more worried than my partner is.	1	3.8	4	15.4	3	11.5	15	57.7	3	11.5	3.6	1.1
16. I ensure that my partner takes rest breaks.	3	11.5	3	11.5	3	11.5	15	57.7	2	7.7	3.4	1.2
17. My partner has sleeping problems that affects my sleep as well.	5	19.2	7	26.9	3	11.5	6	23.1	5	19.2	3.0	1.4
18. I always watch out for signs of problems.	-	-	1	3.8	2	7.7	14	53.8	9	34.6	4.2	0.7
19. I fear the end could come suddenly.	5	19.2	8	30.8	2	7.7	8	30.8	3	11.5	2.8	1.4
20. I feel anxious due to health cuts and long waiting lists.	4	15.4	5	19.2	2	7.7	7	26.9	8	30.8	3.4	1.5
21. I am happy nobody smokes in our home now.	-	-	1	3.8	10	38.5	3	11.5	12	46.2	4.0	1.0
22. I never drink alcohol anymore.	4	15.4	7	26.9	10	38.5	2	7.7	3	11.5	2.7	1.2
23. I have been experiencing some depression	4	15.4	8	30.8	2	7.7	10	38.5	2	7.7	2.9	1.3
24. There are a lot of things we can't do anymore.	4	15.4	12	46.2	1	3.8	6	23.1	3	11.5	2.7	1.3
25. I have to encourage my partner to exercise.	8	30.8	8	30.8	5	19.2	4	15.4	1	3.8	2.3	1.2
26. We have to walk to places because he/she can't drive.	9	34.6	6	23.1	11	42.3	-	-	-	-	2.1	0.9
27. I get tired looking after my partner.	11	42.3	6	23.1	6	23.1	3	11.5	-	-	2.0	1.1
28. I enjoy spending time with my partner.	-	-	1	3.8	2	7.7	12	46.2	11	42.3	4.3	0.8

Note: 1 = Strongly Disagree, 2 = Disagree, 3 = Neutral/Not Applicable, 4 = Agree, 5 = Strongly Agree

APPENDIX T: Frequencies, Percentages, Means, and Standard Deviations for Partners Survey (continued)

INCIDENCE SURVEY- PARTNER

STATEMENTS	Likert-Scale											
	1		2		3		4		5		M	SD
	f	%	f	%	f	%	f	%	f	%		
29. I don't go out socially as much as I did prior to the attack.	5	19.2	7	26.9	9	34.6	4	15.4	1	3.8	2.6	1.1
30. I am pleased my partner has more time for our family.	-	-	3	11.5	9	34.6	11	42.3	3	11.5	3.5	0.8
31. I can't drive the car so we stay closer to home these days.	9	34.6	5	19.2	12	46.2	-	-	-	-	2.1	0.9
32. I have to do all the heavy work.	9	34.6	7	26.9	2	7.7	6	23.1	2	7.7	2.4	1.4
33. Our quality of life has deteriorated.	9	34.6	11	42.3	2	7.7	2	7.7	2	7.7	2.1	1.2
34. I had to learn how to care for my partner.	6	23.1	5	19.2	5	19.2	9	34.6	1	3.8	2.8	1.2
35. It is hard to continue the relaxation exercises we were taught.	1	3.8	5	19.2	16	61.5	3	11.5	1	3.8	2.9	0.7
36. We participate in less outdoor activities since the heart attack.	7	26.9	5	19.2	13	50.0	-	-	1	3.8	2.3	1.0
37. I felt overwhelmed by the amount of information the hospital staff gave us.	5	19.2	9	34.6	5	19.2	3	11.5	4	15.4	2.7	1.3
38. I am frustrated because my partner doesn't make an effort to take care of him/herself.	7	26.9	10	38.5	3	11.5	4	15.4	2	7.7	2.4	1.3
39. My quality of life is unaffected by the heart attack.	3	11.5	10	38.5	6	23.1	6	23.1	1	3.8	2.7	1.1
40. I become concerned if he/she complains of discomfort in his/her chest.	1	3.8	1	3.8	2	7.7	13	50.0	9	34.6	4.1	0.9

Note: 1 = Strongly Disagree, 2 = Disagree, 3 = Neutral/Not Applicable, 4 = Agree, 5 = Strongly Agree

APPENDIX T: Frequencies, Percentages, Means, and Standard Deviations for Partners Survey (continued)

INCIDENCE SURVEY- PARTNER

STATEMENTS	Likert-Scale											
	1		2		3		4		5		M	SD
	f	%	f	%	f	%	f	%	f	%		
41. I worry about the possibility of my partner having another heart attack.	1	3.8	2	7.7	2	7.7	11	42.3	10	38.5	4.0	1.1
42. My partner no longer works so income is a big stressor.	4	15.4	6	23.1	13	50.0	2	7.7	1	3.8	2.6	0.9
43. I take it day to day.	-	-	11	42.3	1	3.8	11	42.3	3	11.5	3.2	1.4
44. Anxiety - for first few months, then I was okay.	3	11.5	6	23.1	1	3.8	12	46.2	4	15.4	3.3	1.3
45. We have lost many of our friends.	11	42.3	5	19.2	6	23.1	4	15.4	-	-	2.1	1.1
46. My partner is willing to help me but is unable to.	6	23.1	7	26.9	8	30.8	3	11.5	2	7.7	2.5	1.2
47. It is hard to accept the changes in my lifestyle.	6	23.1	9	34.6	5	19.2	5	19.2	1	3.8	2.5	1.2
48. I make sure that my partner has taken his/her medication.	2	7.7	2	7.7	8	30.8	9	34.6	5	19.2	3.5	1.1
49. I have lost my independence.	7	26.9	10	38.5	5	19.2	3	11.5	1	3.8	2.3	1.2
50. Social activities are almost zero.	5	19.2	13	50.0	5	19.2	2	7.7	1	3.8	2.7	1.0
51. I had to take over my partner's chores.	5	19.2	7	26.9	6	23.1	6	23.1	2	7.7	2.7	1.2
52. I have increased my exercise as a personal preventative measure.	5	19.2	7	26.9	6	23.1	6	23.1	2	7.7	2.7	1.2
53. My partner has not maintained his/her exercise program.	1	3.8	5	19.2	4	15.4	14	53.8	2	7.7	3.4	1.0

Note: 1 = Strongly Disagree, 2 = Disagree, 3 = Neutral/Not Applicable, 4 = Agree, 5 = Strongly Agree

APPENDIX T: Frequencies, Percentages, Means, and Standard Deviations for Partners Survey (continued)

INCIDENCE SURVEY- PARTNER

STATEMENTS	Likert-Scale											
	1		2		3		4		5		M	SD
	f	%	f	%	f	%	f	%	f	%		
54. I feel lonely at times because he sleeps a lot.	7	26.9	11	42.3	2	7.7	5	19.2	1	3.8	2.3	1.2
55. I don't like the restrictions.	7	26.9	7	26.9	6	23.1	4	15.4	2	7.7	2.5	1.3
56. Overall quality of life has improved.	4	15.4	8	30.8	9	34.6	3	11.5	2	7.7	26	1.1
57. I can't keep up with my partner.	3	11.5	6	23.1	5	19.2	11	42.3	1	3.8	3.1	1.1
58. I have had to manage more on my own.	4	15.4	8	30.8	7	26.9	6	23.1	1	3.8	2.7	1.1
59. Switch to cooking with low fat recipes - I enjoy doing this.	3	11.5	7	26.9	7	26.9	6	23.1	3	11.5	3.0	1.2
60. I get anxious about keeping appointments.	4	15.4	7	26.9	8	30.8	6	23.1	1	3.8	2.7	1.1
61. If a person isn't on time you think "What has happened?".	1	3.8	4	15.4	3	11.5	14	53.8	4	15.4	3.6	1.1
62. I have become more watchful.	-	-	2	7.7	2	7.7	17	65.4	5	19.2	4.0	0.8
63. I try to not nag.	-	-	-	-	6	23.1	15	57.7	5	19.2	4.0	0.6
64. I had to stop work to take care of my partner.	7	26.9	4	15.4	14	53.8	1	3.8	-	-	2.3	0.9
66. I would love to travel more, but it would be too difficult for my partner.	6	23.1	8	30.8	7	26.9	3	11.5	2	7.7	2.5	1.2

Note: 1 = Strongly Disagree, 2 = Disagree, 3 = Neutral/Not Applicable, 4 = Agree, 5 = Strongly Agree