TOWARD AN UNDERSTANDING OF THE EXPERIENCE OF SUPPORT FOR RECUPERATING MYOCARDIAL INFARCTION PATIENTS

A PHENOMENOLOGICAL STUDY

by

MARION JOAN HEALEY-OGDEN

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[redacted]

Donald W. Knowles, Ph.D.

[redacted]

Ted T. Aoki, Ph.D.

[redacted]

J. Isobel Dawson, Ph.D.

[redacted]

Barbara Whittington, M.S.W.

University of Victoria

Supervisor: Professor Donald W. Knowles

Abstract

This thesis examined the experience of support for Myocardial Infarction patients. Phenomenological inquiry was used in order to reach the essence of support. Data were drawn from a vast array of sources to help answer the research question: what is it about the experience of support which gives possibility to recuperation?

A pilot support program for five Myocardial Infarction patients was the primary focus of this study. These patients were chosen according to the following criteria:

1. first five Myocardial Infarction patients admitted to Prince George Regional Hospital, Intensive Care Unit, beginning January 19, 1987.
2. residing in the city of Prince George, B.C..
3. willing and able to participate in the program.
4. internist's and general practitioner's consent.

The main program activity was communication sessions which declined in frequency from the date each patient began the program until October, 1988. Data from this pilot support program were obtained from observations and fieldnotes during communication sessions, document review, one questionnaire and three structured interviews. Data

for this thesis were also gathered from my personal experiences, etymological sources, idiomatic phrases, word couplets, phenomenological literature and nonfiction descriptions of the recuperation experiences of Myocardial Infarction patients and their families.

Patients felt it is crucial that they be in control of their own recuperation. To facilitate this sense of control the patient's nurse should be in control of how he or she empowers the patient. Three catalysts emerged as important ingredients in the control the patient achieves (a) being given hope as a way of being strengthened, (b) being given information as a way of receiving guidance, and (c) being given permission to struggle as a way of being set free to be in control of one's own recuperation. As well as being in control of their recuperation, patients felt that the struggle itself was necessary, that they be allowed to struggle toward recuperation according to that which is meaningful to him or her. Altogether, these supportive factors move the Myocardial Infarction patient toward the possibility of recuperation.

Examiners:

[redacted]

Donald W. Knowles, Ph.D.

[redacted]

Ted T. Aoki, Ph.D.

[redacted]

J. Isobel Dawson, Ph.D.

[redacted]

Barbara Whittington, M.S.W.

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Thank-you, too, to the five MI patients who formed the Pilot Support Program. You gave of your time, of your energy and of yourselves, such that I may better understand your experience of support during your recuperation.

I extend a special thank-you to those who cared for me in 1963 while I struggled through my critical illness --

Guillain-Barre Syndrome. Though I indicate in this thesis that I needed a different kind of support during my recuperation, you did support me in the best way you knew how and that support was very special. Thank-you, too, to my cousin Brent, whose personal struggle with Guillain-Barre Syndrome was a catalyst in my awareness that there is a definite need for research on the relationship between support and recuperation.

Dedication

This thesis is dedicated to my husband, Gerry, and our children, Kyle and Angela, who "supported" me in my work at home and, as well, when we had to go our separate ways while I was at university. I also dedicate this thesis to my parents, who understood when visits were few and far between, and to my mother-in-law, father-in-law and sister-in-law who cared for our children through three long summers.

Chapter 1

Introduction

Throughout my life I have experienced critical illness from three perspectives. I was (a) a critically ill patient, (b) a nurse in the Intensive Care Unit (from this point on referred to as ICU), and (c) a family member of critically ill relatives. I have struggled and continue to struggle with the notion of support. Support, in this study, is taken to mean an upholding of the patient through psychosocial and material means, in order to assist the patient to work toward adaptation. It involves the coupling of the patient's resources with the resources of others in order to nurture the patient's coping processes and to strengthen the patient's overall coping ability.

Though I can identify supportive acts which are positive I can also identify lack of support. It is that lack of support that originally caused me to struggle. That struggle helped me to come to the realization that there is a vital piece of knowledge about support which seems important to understand, before a concerted effort can be made to improve and maintain the fit between support needs and support provided. That struggle also makes me aware that there is something more to support than I could

readily describe or than I could identify in literature. This study was concerned with this elusive nature of support.

Purpose of the Study

The purpose of this research was to determine what it is about support which assists the patient toward recuperation. Recuperation, in this study, was taken to mean the regaining of balance and control following any loss, for example the loss of one's health.

The notion of support is tied very closely with those of care and empowerment. In this study I will not be seeking to distinguish support from care and empowerment but, rather, I will allow care and empowerment to surface within the focus of support.

All patients coping with illness seem to have a need for some degree of support; those patients coping with critical illness are faced with a high level crisis situation. According to West in Hardovanic, et al (1984),

> An illness of any nature produces stress. When the illness is severe enough to warrant intensive care, it is obviously life threatening and produces severe emotional stress. The ill person and family feel the impact of this situation and crisis often ensues (p. 243).

When coping with crisis, patients seem to have a need for a high level of support.

I have focused this study specifically on the support experienced by heart attack (from this point on, referred to as MI or Myocardial Infarction) patients. I chose this focus because I have been working with five MI patients within a Pilot Support Program. Thus, I have been able to gather data from a select group. Each patient experienced a critical illness, variations of support, and individual recuperation.

In the literature, support is most often discussed from an outside perspective, from the family, friends and health care personnel's perceptions of how patients are best supported. I chose, instead, to examine the nature of support from an inside perspective, to glean an understanding of support generally, from those who have experienced critical illness, and more specifically from the MI patient's perception of his or her experience.

Research Question

The research question was: what is it about the experience of support that gives possibility to recuperation? The word, possibility, in this study, means that there exists a future which includes an improvement in the present illness state. As the experience of illness can differ from patient to patient so, too, can the experience of recuperation. Support seems to be a vital

link between illness and recuperation. The relationship between support and recuperation was of key interest in this study. Etymologically, both support and recuperation involve a positive tone surrounding the movement from illness toward health, the possibility that an element of health can be achieved.

Scope of the Study

There seems to be little research available which provides an understanding of the experience of support in a general way, or seeks to understand the experience of support specifically for recuperating MI patients. The scope of this study included the acquisition of data from a variety of sources in order to begin an examination of support from the patient's perspective. This study was intended to yield a base from which to conceptualize a model of meaningful support.

Limitations of the Study

It was important to choose a research methodology which allowed for a thorough examination of the essential nature of an experience. I chose the phenomenological research approach because its foundation is a process of "methodically seeking the essence of phenomena, as they truly appear to human consciousness" (Colaizzi, 1973, p.

32). This methodology also allowed me to utilize data from a range of sources, all intended to deepen my understanding of the experience of support.

I described the nature of support for the five patients in the pilot support program, using additional data served to enrich this description. The results of this study were intended to illuminate an aspect of the nature of support for recuperating MI patients and, in turn, to provide nurses and other health care professionals with further knowledge to apply to patients in general. It would be important to complement this study with further research as this study examines only one component of the concept of support.

I was unable to locate phenomenological research articles related specifically to MI patients and more specifically related to the experience of support for recuperating MI patients. This factor may have created limitations for analysis and, thus, for the end result of this study. In lieu of this gap in research literature, I have utilized phenomenological research literature which focuses on related aspects of health and illness. As well, I have purposely chosen a broad range of data to provide the richest data base possible.

CHAPTER 2

Literature Review

Contributions of Literature to This Study

Before examining the literature directly related to important ingredients of support I will first review literature which discusses the need for support. Critical illness is only one of many crisis situations which can occur in a person's life. The significance of a crisis situation to each individual patient is the key in judging the impact of that situation on the patient (Byrne, White, 1980: Byrne, 1982). Thus, it is the meaning of illness to a patient that determines the degree of support required (Schoenhofer,1984; Roberts, 1976; Krantz, 1980). Gray-Toft and Anderson (1983) determined that for hospital employees, job satisfaction increased and stress declined following support program discussions of stressful situations.

Once the need for support is determined the next step is to allow the patient to enter the struggle of recuperation. Campbell (1986) describes the importance of enduring a struggle rather than taking measures to avoid suffering. It is the struggle itself which moves a patient toward recuperation (Stearns, 1984; Kelpin, 1984). Vaillot (1972) referred to this struggle as a trial and

concluded that this trial possibly reaches a breaking point through which inner growth is achieved.

It is apparent that with advances in technology, nurses divide their time between concentrating on equipment and between concentrating on the emotional needs of patients and their families. Thus, it is important that the time spent in supporting patients must be quality support. Sometimes, in busy areas such as Emergency Departments, the support given by bedside nurses can best be supplemented by specific support nurses (O'Brien, 1985). But, regardless of how support is carried out, Shaver (1986) pointed out that the patient rather than the equipment must be the focus of all nursing.

A patient's need to be in control of his or her recovery process, is a strong focus in the literature. Not to be in control is to deal with feelings of powerlessness which can be incapacitating to any patient who is involved in recuperation (Krantz, 1980; Agee, 1980; Frain & Valiga, 1982). A study by Dennis (1987) concluded that patients needed to be supported in dealing with life changes in a way which is meaningful to each patient. The control that patients call out for is not uniform, one to another, but, rather, control that is very individual and that, in itself, is the ultimate of control. As a patient identifies with this need to be in control, an underlying

message also exists. Not to be in control is to have others take over control of the patient's recuperation and, in so doing, shifts the focus of this struggle to the controlling person or persons rather than to the patient (Delaney-Naumoff 1980). This shift of focus only serves to compound the patient's feelings of loss as he or she then faces the loss of health as well as independence.

A sense of powerlessness creeps into this scenario. When faced with loss of control the patient often feels he or she is powerless to shift the emphasis of control back to him or herself thus, in effect, relinquishing even more control to others. The patient, then, seldom seeks information and may even recoil from sharing information (Miller, 1983b). Lack of control and powerlessness combines with feelings of helplessness and hopelessness, as recuperation from illness can seem impossible. Degre-Coustry & Grevisse (1982) described how overprotection by family and even by the health institution, can lead to difficulties in returning to previous roles at home and work. These difficulties are exhibited by various degrees of anxiety, depression and even death (Seligman, 1975).

MIller (1983a) examined the possibility of recuperation by describing enabling factors which help promote the patient's sense of power and, thus, control and

hope. She outlined seven power resources for coping with chronic illness: (a) physical strength and reserve, (b) psychologic stamina and support network, (c) positive self-concept (self-esteem), (d) energy, (e) knowledge, (f) motivation, and (g) belief system (hope) (p. 6). These power resources can enhance a patient's control over the illness situation and subsequently build the patient's hope for recuperation. It is also emphasized that there is value in instilling hope in a patient, as an empowering force during recuperation (Vaillot, 1970; Werner-Beland, 1980; Gates, 1985; Miller, 1983c). Miller(1983c) adds that hope is achieved with another person or persons and that the needed presence of another can be achieved through hoping in God. The importance of hope is akin to the positive effect of encouragement (Cay, 1982).

Information is another aspect of support that empowers a patient to achieve recuperation. MIller (1983a) associated a patient's knowledge of his or her illness situation with his or her control of recuperation. A study by Hentinen, 1983, found that wives of heart attack patients wanted more information than they had received, about caring for their husbands at home. These wives also felt that they were supported by relatives but had received inadequate support from nursing staff.

Kelpin (1984) questioned whether medication is

provided as the only support when a patient is totally helpless. She suggests that if it is the only support offered, perhaps women accept medication with the understanding that it is the only choice besides that of suffering. Kelpin described support as something which must be freely given without request. Leiske (1984) discussed a support program for recently graduated nurse employees, where they were helped to resolve stress-producing conflicts for themselves. They shared their role transition experiences and, as well, were accepted in this supportive environment regardless of the conflict. In a similar fashion Epperson's (1977) study of families in sudden crisis showed that it was crucial for families to know that their feelings were accepted regardless of the nature of the feelings. They also needed to know that, as people, they were okay, regardless of the cause of the crisis. Often this support is most empowering when it is silent, when the supporting person listens to the one in crisis (Epperson, 1977; Kennedy, 1981). Supporting a patient through one's presence is a way of giving energy to the patient so he or she is strengthened to cope with the crisis. In other words, the goal of the nurse should not be to struggle for the patient but, rather, empower the patient within his or her struggle.

Campbell (1986) described patients' feelings about

their illness, identifying that those feelings are often focused on fear of the unknown. It seems that a fine line exists between success and failure, where fear becomes the intervening factor. Yet a certain amount of fear seems warranted in order to make the struggle possible (Campbell, 1986).

The process of moving through an experience is described as an independent venture, a lonely venture. A dichotomy exists where solitude is a means of coming to terms with one's experience, of experiencing the possibility of growth (Kelpin, 1984). Yet, the loneliness of the venture causes a cry for others to be present in the patient's journey. This presence of others takes various forms, but altogether, a nourishing component exists within an attitude of care and support (Kort, 1984 & Kelpin, 1984). Care is much like a means by which to make the unknown less threatening. Campbell (1986) describes the nourishing, spiritual nature of being with others who have experienced a like illness.

Support is a crucial ingredient in recuperation. Haase (1987), in a study of courage in critically ill adolescents, found that adolescents experienced significant courage when supported by one or more people. Dhooper (1984) described the results of a study of social networks and support during the crisis of heart attack, where

patients received almost all support from outside resources while in hospital. Little support was received from health professionals. In conclusion, Dhooper suggested that health professionals can provide valuable support by enhancing network support which does exist for a patient. Kalish (1981) described a study by Koenig, where terminally ill cancer patients indicated they wanted help to deal with numerous areas of concern: (a) difficulties at the hospital, including erratic nursing attention, (b) inadequate information about their condition, and (c) impersonal treatment (p. 283). Smith (1985) states that greatest possibility of success for a burn patient to regain a productive life, is related to the degree of understanding and acceptance by the patient's family and spouse. Hodovanic, Reardon, Reese & Hedges (1984) described a crisis intervention program for families of ICU patients. This program was started because of the recognition that the crisis that the family feels can affect the patient's recuperation. Kort (1984) also refers to the importance of being objective and accepting of the patient in his or her individual struggle as well as keeping support focused on the goal of life style changes.

To return to the concept of control, not only is it important that the patient be in control of his or her recuperation but, in order to achieve this control, the

nurse must first be in control of his or her nursing. Tisdale (1986) reminded nurses of the amnesia that has crept into nursing as the age of technology has coloured the face of patient care. Nurses tend to forget the closeness between wellness and illness. It is common for nurses to focus their care on equipment and procedures rather than on the patient. Upon examining illness, Tisdale questioned why nurses move away from the pain of illness. She suggested that the pain caused by modern medical techniques actually heightens our sense of powerlessness. Increasing our awareness of the nature of being sick and ways to help patients cope with illness, in turn can increase our power and consequently our control in guiding the patient toward his or her own recovery.

Holderby & McNulty (1982) referred to the dehumanized effect of technology on patient care. Shaver (1986) also brings to attention, the swing of emphasis toward technology rather than toward the people to whom technology is directed. A thought then emerges in the literature: perhaps the mechanization and dehumanization of health care is an underlying reason why many patients require support over and above that which is already being delivered.

Differences Between Literature and This Study

Much of the available literature describes support

from an outside perspective rather that from the perspective of the patient. We learn about the support needs of patients. We learn about how nurses can best support patients and family dealing with a stressful situation. Seldom, in the literature, are we provided with information which looks below the support needs of patients to underlying workings of support, to the reason why support is meaningful. Seldom, in the literature, are we provided with an examination of the true nature of support.

Phenomenological Approach

A few phenomenological studies exist which examine various aspects of illness and support. The study by Haase (1987) identified faith and hope for the critically ill adolescent as the essence of the experience of support. It was important for the participants in Haase's study to have the opportunity to express both faith and hope, in order to cope with their situation.

In the study by Campbell (1986) the meaning of the breast cancer/mastectomy experience was examined. It was determined that suffering occurs with an accompanying spiritual growth experience. The breakings involved in a struggle become the very centre which leads to recovery.

Kelpin (1984) examined the nature of the pain experienced in childbirth. She described the pain

experience as a reflection of the relationship a woman has with that pain. Kelpin indicated that to dull the pain can remove the work experience; that removal may possibly be a sign to the patient of giving up the experience and of giving up the struggle. Kelpin focused on the importance of supporting the birthing patient through voluntary actions such as backrubs, in order to empower the patient to complete the birthing task and to endure the pain. She also focused on the importance of the caring presence of another person.

Zaner (1982) described the experience of the end stage renal dialysis patient as one of being unchosen. Rawlinson (1982) described the narrow focus of the patient, which is centred about his or her illness, and which seldom allows other life concerns to bear any importance. Pelligrino (1982) expanded on the importance of allowing the patient to make choices according to his or her wishes and, as well, of imparting specific information so the patient is enabled in making those choices. Koestenbaum (1971) also referred to the importance of allowing the patient a choice. This choice is focused on the way he or she makes sense out of his life following a loss. This choice is a way for the patient to examine his or her future.

In summary, the literature related to support as well as to illness. covers a broad spectrum of important areas

to be considered. The difference in the literature compared with this study is primarily related to the perspective from which support is viewed. The authors of the literature which examine support from the patient's perspective highlight the experience of illness as well as the need for support. This examination is carried out from a deep level and, thus, begins to unveil the essence of support.

CHAPTER 3

Methodology

Phenomenological Enquiry

It is through a descriptive study that the appearance of something is made apparent. Phenomenology is a science which takes that description one step farther, namely to portray the deeper level meaning underlying the appearance of the lived experience. The goal of phenomenology is not the development of theories or explanations. Van Manen (1984) states that phenomenology "offers us the possibility of plausible insights which bring us in more direct contact with the world" (p. 1).

The phenomenological method is such that the description that is offered moves to the very core of the lived experience. Until that full description is reached, the writing is a gradual moving toward greater awareness of that inner core. It is a process of becoming more and more alert to the nature of the lived experience and to the essence of the phenomena.

Phenomenology can be related to art. In describing the work of art, Gadamer (1976) states that "its truth is not its simple manifestation of meaning, but rather the unfathomableness and depth of its meaning" (p. 226).

The methodology I employed in this study follows that which is described by Van Manen (1984):

> Phenomenological research may be seen as a dynamic interplay among four procedural activities:
>
> a) turning to a phenomenon which seriously interests us and commits us to the world;
>
> b) investigating experience as we live it rather than as we conceptualize it;
>
> c) reflecting on the essential themes which characterize the phenomenon;
>
> d) describing the phenomenon through the art of writing and rewriting (p. 2).

In carrying out this thesis research I experienced this interplay as I walked back and forth through the data in a sense-making manner. "It is all too possible to discern features that in their context and dimension are clear enough, but upon further investigation turn out to be related to a wider context and deeper levels of phenomena so that what is initially taken as 'apodictic' turns out to be relatively 'inadequate'" (Ihde, 1973, p. 18). This sense-making is not only a grasping of the descriptive threads but a slowing of the motion of descriptive activity until the picture stands still and until the core is apparent.

Turning to the Nature of Lived Experience

Before beginning a phenomenological study there is need to question an aspect of lived experience. Further to this questioning must be the presence of an inner drive to seek an answer to this concern. A phenomenological question is then posed. Van Manen (1984) stated that "even minor phenomenological research projects require that we not simply raise a question and possibly soon drop it again, but rather that we 'live' this question or, better, that we 'become' this question" (p. 8). And so it was throughout the course of this thesis, that the question became the thesis and I, as researcher, lived the question and in turn the thesis itself.

It is important, too, to set my initial viewpoint of an experience in full view prior to phenomenological inquiry. Van Manen (1984) explained that it is important to bracket one's "understandings, beliefs, biases, assumptions, presuppositions and theories" (p. 9). Spiegelberg (1975) described this approach as being "as free as possible from conceptual presuppositions, and an attempt to describe them as faithfully as possible" (p. 10). By so doing, both the reader and myself as researcher became aware of the clouded window through which I began to perceive the nature of the experience in question. Bracketing my original stance became a way of placing this

stance on one side of a clouded window as my reflections took me through the window and onward toward a clear perspective point in the distance. It is not a covering over of the window which is called for in phenomenology but, rather, an awareness of the clouded nature of the window through which I first began to focus. Further focusing was intended, then, to be movement away from the clouding influence of that window.

Existential Investigation

Data gathering provides a possibility for coming to an understanding of the essence of an experience.

> The challenge of this exploratory work is that, while interpretive material is located (or stumbled upon), the researcher is sensitive to the ways in which this material begins to speak, as it were, and yet all the while remaining open to new material and to other interpretive possibilities (van Manen, 1984, p. 12).

Data are collected from a vast array of sources such as personal experience; etymological sources; idiomatic phrases; experiential descriptions from others; experiential descriptions in, for example literature and art; and in phenomenological literature. Collectively, these data provide examples for the description of the experience in question. Spiegelberg (1982) stated that

> most adherents to phenomenology will hold that it is possible to obtain insights into the essential structures and the essential relationships among these phenomena on the basis of the careful study of concrete examples supplied by experience or imagination and by systematic variation of these examples in the imagination. (p. 10).

Phenomenological Reflection

"Phenomenological themes are the structure of experience" (van Manen, 1984, p. 20). It is through themes, extracted from the experiential data, that I wrote myself toward the focus of this experience. It is much like an increasing awareness through becoming more and more attuned to the fundamental core. I moved closer to the essence of this experience through constant reflection. Van Manen (1984), explained the importance of "dialogic conversations where both the researcher and the interviewee collaborate in the attempt to interpret the significance of the preliminary themes in the light of the original phenomenological question"(p. 24).

Phenomenological Writing

Writing and rewriting is a way of illuminating the essential nature of the experience, providing sensitization

to the meaning structures which are present in the examples which make up a phenomenological description. It is important, too, to vary the examples within phenomenological writing in order to view the experience from numerous vantage points, filling out the description and providing greater sensitivity to the fundamental core of the experience. Gadamer (1976) states that, "the very truth of the thing is implied if this truth is still capable of coming forth in the work of art " (p. 227). Hence, writing once is not enough. Ongoing reflection with continued thoughtfulness is the attuning to the nature of a lived experience.

Appropriateness To This Study

To understand what it is that gives possibility to recuperation is to understand more than the mere appearances of support and recuperation. It is "looking for what makes that experience possible instead of looking for what it is" (Merleau-Ponty, 1962, p. xvi). To answer the research question is to understand the essence of support, the essential nature of the lived experience of support within recuperation. The phenomenological research methodology allowed for responsive, reflective writing in order to grasp, in this study, the essential nature of the experience of support for recuperating MI patients.

Sources of Data

Data sources varied. The personal experiences I used are my past roles in the critical care setting as patient, nurse and family member. I used etymological sources to help fill out both the range of data as well as to enrich the data with a deeper dimension than is readily obtained from general definitive sources. I also examined idiomatic phrases and word couplets, to add a further dimension to the descriptive picture.

The experiential descriptions from others were taken from the five patients in the pilot support program which I implemented for MI patients. Experiential descriptions were also derived from literature. I found nonfiction descriptions of MI patients, and their family's experiences, to be rich sources of data for this study. Data from phenomenological literature also allowed me to be sensitized further to the essential meaning of the lived experience of support during recuperation.

Means of Obtaining Data

I used a variety of means to obtain data for this study. I used the power of recall to describe my personal experiences of being a patient, a nurse and a family member in the critical care setting. As well, I used both regular

English and etymology dictionaries to determine the literal sense of words and phrases. I read and reread books, newspapers and journal articles. The five MI patients who were in the pilot support program consented to my visits. I interviewed them in hospital and in their homes. Those visits included time for discussion of their MI experience, as well as time to focus on problems which they were encountering in dealing with this experience. Within two to thirty-six hours of those visits I wrote a detailed account of those visits, including as many quotes as I could recall. Four to five months following each patient's MI, two separate interviews were scheduled about one to two weeks apart. On the day of the first interview I left a questionnaire for the patients to complete and on the day of the second interview I collected the questionnaire. Each question and answer was discussed with each patient, (a) to ensure that I understood their statements, and (b) to gather any further data which they added to their original response. As well, I discussed, with each patient, possible themes which were beginning to make up six beginning themes. It was following these discussions that I clarified those six beginning themes and continued, afterward, to reflect on what each of the patients had said. Upon identifying what I thought were the core themes, the themes identified as the essence of support, I

again discussed this core message with four of the five support group members. Those four people confirmed the core message which I had identified.

Limitations of This Methodology

Van Manen (1984) stated that "every phenomenological description is in a sense only an example, an icon that points at the 'thing' which we attempt to describe" (p. 25). Thus, a limitation of this methodology is that it does not offer the only picture but, rather, a way of looking at an experience. Also that "way" is an isolated example where numerous other examples may also be apparent.

> For Heidegger, the manner in which one relates to the function which first constitutes one's world and the manner in which one is aware of one's world itself determines the way in which entities within one's world are experienced. In short, they determine how entities are determined. (Erickson, 1970, p. 161).

It is important to remember that any illumination is good when it focuses attention on the meaning of an experience, either adding to past research or being the pioneer of new ground.

Another limitation of this study rests with the interviews and questionnaires. The initial interview was carried out without difficulty but I encountered problems

in getting the patients to complete the questionnaire. Lack of time seemed to be a factor for some patients, whereas others found either the questions were unclear or they had difficulty putting their thoughts down on paper. It took about three weeks longer to collect the questionnaires than I had anticipated. This delay also affected the second interview in that some patients did not seem to have the desire or want to take the time to go over the questionnaire and theme threads. They each cooperated in this second interview though in some cases I rushed through some of the questions because of a seeming one-sided interest on my part. I interviewed one patient on the phone as our time schedules did not allow for a face-to-face meeting. For the final discussion of the core message I was able to locate and talk via the phone, with only four of the five patients.

The final limitation was in the area of research literature. I found no phenomenological study directly related to MI patients' experience with support. I did access a couple phenomenological studies on related topics, which supplemented the dearth of literature on this thesis topic.

Reaching a Conclusion

Despite limitations within this study, the data I

collected were immense. I followed the methodology set out by van Manen (1984) and I allowed the data to speak for themselves. As the picture was unfolding it seemed to gather momentum until suddenly it stood still. At one point in this process I thought this motion would never end. As I practiced reflexive and responsive writing, each new illumination became less and less stable. Suddenly, when I reached the core, all movement stopped. I was very aware of walking back and forth within the data. As I wrote, clarification and illumination grew. A fit emerged within the final description. The nature of the lived experience of support during recuperation became clear.

Chapter 4

Turning to The Nature of Lived Experience

To begin this phenomenological journey I portrayed my initial ideas in relation to the concept of support and its relationship to recuperation so that they were obvious when I proceeded to examine the data for this study.

Explicating Assumptions and Pre-Understandings

Health

This is a state of well-being where there is absence of disease, as in a sound mind and body. To be healthy implies that one is in physical and mental balance and that there exists a sense of harmony in a person's life.

Health is on the opposite end of a continuum from illness. So too, harmony and disharmony sit opposite each other on a similar continuum. Health and harmony are as much a couple as are illness and disharmony.

Physical and mental imperfections are a natural part of human life. Throughout healthy coping and while drawing on supportive resources to assist in that coping, a person retains a certain degree of equilibrium, a certain degree of health. The nature of available support is fundamental to the direction one progresses along this health-illness

continuum.

Illness and Recuperation

Taking a look at illness, in general, presents a picture that the patient is in an unchosen situation where routine is altered or shattered, and that there is the prospect that life as the patient knows it may change. We don't choose illness as we choose most everything else in life, nor do we choose the time or place that illness will strike. Illness is a breaking point which begs repair. Repair can take place visibly or invisibly as recuperation following the break.

Illness is a loss of health. To work toward recuperation involves the process of recovering one's lost health. Within that process a struggle exists as the patient moves through the grieving process. Kubler-Ross (1969) describes five stages which patients may work through in coming to terms with their death, (a) denial, (b) anger, (c) bargaining, (d) depression, and (e) acceptance. These five stages also form part of the struggle of recovering one's health.

Illness is a state of disharmony. It is a state where balance and harmony within one's life is altered, depleted or destroyed. As illness takes hold, the shattering of the taken-for-granted aspects of one's life is a break which

varies in intensity and varies in significance according to the meaning of the illness to the patient. Depending on one's experience, illness can be a monumental struggle within a foreign environment or, for some, it can be a coping with unknown aspects of one's life.

Throughout our individual lives we also struggle with a series of actual breaking points, our reaction to each, varying according to the meaning of each break. It seems that some breaks occur without significant change. Conversely, other breaks are motivations toward change, as the breaking point presents a challenge which the person can accept or not accept. Despite the possibility of change, nothing removes the struggle that occurs within the existence of a break. The struggle is the movement through illness to any point in recuperation where balance and harmony are once again restored, where the struggle dissipates, and where health is regained. The struggle itself is a solitary venture toward recovery. This struggle exists but can be ignored, delayed or accepted.

Illness and Recuperation in the MI patient

For the MI patient, illness usually occurs suddenly. Sometimes the patient will have prior warning of the possibility of an MI but for such patients, the actual occurrence of the MI is still unexpected at that particular

time. The MI patient is cast into an unchosen situation. He or she experiences a breaking point where routine is shattered, not just for a day or a week but upwards of two to three months or even much longer. This disruption presents numerous problems which are part of the struggle of illness. Often, the patient's financial situation looms paramount as he or she attempts to maintain control of his or her financial affairs, all the while struggling to cope with the illness itself.

The MI patient works through the grieving process as he or she experiences the loss of health, as well as the loss of factors such as financial security, control of routine activities and role. Throughout the grieving process a struggle ensues. The MI patient seeks to restore balance and harmony in his or her life. The significance of both the illness and the struggle is associated with the meaning each MI patient places on the entire experience of having both an MI and the struggle to achieve a state of health.

Support

To be supported in illness is to be upheld in the movement toward health. Support includes a positive connotation in that support encourages success in the process of achieving health. When I consider the word

support, I am at first inclined toward the thought that someone is going to be assisted to get through a trial, large or small. But regardless of the support the one who has to face the trial is responsible for his or her actions within that situation. A trial conjures up the notion of a struggle to be free. During illness a trial would be whatever struggle is involved in becoming free of the restraints of one's illness. Within a struggle it is important to guide as well as strengthen the recuperating person. But guiding and strengthening seem to be actions which are elusive.

How does someone guide when that someone is not walking in the ill person's shoes and not experiencing the ill person's trial? My immediate bias, here, is that guidance seems to be readily offered from an outside perspective. I doubt that the supporting person can ever fully enter another person's struggle. The greatest exception is possible, when a supporting person has experienced a similar struggle. In nursing, I consider it possible, that even if the nurse has not experienced a similar struggle, he or she can move toward an understanding of a patient's struggle and thus guide him or her in the direction of recuperation.

Even more elusive is the question of how someone gives strength to another human being. How does someone

strengthen a patient when strength seems to be an invisible force? Perhaps strength in support is manifest when the desire to support and the understanding of the empowering nature of support is paramount for the supporting person. Perhaps, too, there is the need for the patient to be ready to receive strength from another person.

It becomes, then, the responsibility of both the nurse as well as the patient who needs support, to work together to move the patient toward a dimension of health. The nurse can move only as close as the patient will allow. Patients differ in their need for support as well as in their readiness to accept support. The elusive nature of support, again, is evident as it is difficult to capture both a patient's need for and readiness to accept support.

As to how close the nurse can move to the focus of the patient's experience, I sense, also depends upon the nurse's ability and desire to enter the meaning structure of the patient's world, to begin to feel what the patient's experience is really like for him or for her. It seems that the closer the nurse moves toward the patient's experience focus, the more meaningful and precise the support becomes.

The fact that patients often suggest they are not being supported in a meaningful way is an indication that those involved in health care need to look closely at what

makes support meaningful to patients and what it is about support that leads to recuperation. Nurses are in a critical position as they are often with patients twenty-four hours a day. During that concentrated time it is possible for the nurse to work with the patient in getting to know what illness and the subsequent recuperation struggle mean to the patient. It is then possible for the nurse to support the patient from an inside perspective, presenting the patient with the possibility of recuperation?

Conclusion

I placed, in full view, my beginning stance on support and its relationship to recuperation. There seems to be a definite tie between health and illness as a person fluctuates along the continuum which connects these opposing concepts. Health is on one end of the continuum, representing one way of being whereas illness, on the opposite end of the same continuum, represents another way of being. The recuperation process, which moves one from illness toward health, involves a struggle. For a patient to be supported in that struggle is for him or her to be sustained in moving toward health. The meaning the patient places on his illness and recuperation process is a measuring stick by which to adapt support to the individual

patient. For a nurse to provide support for the patient, is to move toward closing the gap between how the patient perceives he or she should be supported and what a nurse identifies as meaningful support.

Chapter 5

Opening up to Patient's Experienced World

Existential Investigation

This section involves an examination of the data which describes the lived experience of support and recuperation from illness. This closer look is a move to a deeper level of understanding in order to help reach the essence of the phenomenon of support which gives possibility to recuperation.

Personal Experience

I have not experienced an MI but have had personal experience with critical illness, Guillain-Barre Syndrome, when I was a teenager. I was paralyzed from my toes to the top of my head, unable to see or hear for a short interval, and on a respirator. I felt supported by the presence and reassurance of family, friends, and health care professionals, but I felt the need for a different kind of support.

In the initial stage of my illness I felt quite numbed by the experience. My respirator became a type of lifeline. It also became my friend as I could not trust an enemy with my life. My respirator supported my life but,

even as a friend, it did not support my inner struggle to recuperate. Many times I felt that my illness, as well as technology were honing in on me. Certainly, aspects of humanness were present but there were times when I felt as if I were a thing. I was not in control. My lifeline allowed me some freedom to fly but my wings were clipped by my illness. I could not talk or even move a finger. At one point my struggle came only from my thoughts and imagination and, there was my only place of control.

Though I could do little to look after myself, that seemed tolerable to me at first, but where and when I was able to function I hesitantly stepped out toward taking on more and more activities. I wanted control of those activities and, at the same time, I wanted control of my struggle. I wanted to make my own decisions regarding my readiness to struggle and how far into the struggle I would go. It was a way for me to be in control, to be allowed the decision to be powerful or powerless.

My struggle involved feeling the effects of a changed role, as a patient recuperating from a critical illness compared with the role of a healthy teenager. It involved grappling with the pain of grief as I felt the loss of my prior role, my previous healthy self, and the experience of being close to death. My struggle also involved placing into perspective my uniqueness of having gone through a

rather rare illness and being viewed as different, vulnerable and almost fragile. Yet, within that uniqueness I did not want to be considered different or vulnerable to breaking but, rather, capable of power and control of my own self. I needed to struggle with my fragile emotions to emerge strengthened by my experience, in order to achieve recovery.

As I began to feel the emotions of my experience I needed permission to continue to feel and to work through those emotions but I felt I could not ask for support in that regard. I also needed to know that it was truly okay to struggle, to feel pain and to show that pain. I did not discern that permission.

I also needed to know that the struggle was an accepted part of recuperation and that I would survive the effects of that struggle. I needed to know that there would be new life after bearing pain and that the struggle was worth the pain and would actually give me freedom from the weight of my experience. I needed to know that when I no longer needed the security of a lifeline in the form of a respirator, I would still have the security of a lifeline of people who would recognize that my wings were growing and allow me the beginning of new flight.

I needed someone or others to be with me in that struggle as a silent strength and guide. I could not

struggle alone and yet my struggle was solitary. The presence of others was important as a source from which I could tap energy, but I did not feel this energy. The presence of others was important as a guide, but I did not sense that guidance.

I needed someone to recognize my grief then allow me to feel the pain of that grief and, as well, to listen as I sorted through that turmoil. Instead, my pain seemed camouflaged by others and, without focused support, was camouflaged as well, by myself. It was as if I had to avoid the possibility of being engulfed by the struggle of recuperation and in order to survive, I had to deny the struggle. Yet, deep inside I knew a powerful need to work through that struggle despite knowing that any fight is solitary. Regardless of this knowledge I could not risk entering that battleground alone. I could feel the sharp edge of that pain. I reached a point of feeling the need to cry and talk and cry some more. When I was then asked if I was okay, I denied that anything was wrong because instead I needed someone who recognized that something <u>was</u> wrong and then would allow me to struggle. I needed someone to confront me with my emotions and then remain as a strength and listen to me make the decision of how far to enter my battleground, how much to feel my pain and to decide on my own readiness to fight. Likely, I would have

only looked at the battle and would not have been totally surrounded by it during the early stages of my recuperation. I was seeing some daylight merely through physical recovery; therefore, I would have needed only to acknowledge my feelings, situation, experience and illness in order to feel in control of my struggle. Inside I was silently crying out for a special supportive person. I wept inwardly with grief that was not recognized. This was the only measure of control I could achieve.

I struggled to a point of partial balance but my struggle was not complete. A sense of harmony was missing from my life. It was many years later when that disharmony again surfaced. I cried out for a special kind of support and to be given control of my struggle. It was at that time that I felt I could pursue the struggle. Not only did I receive a silent strength, direction and permission to feel and work through that feeling of disharmony but I allowed the struggle to occur. It was as if I had permission to venture into the unknown and it was also a time when I felt ready to accept the challenge of that struggle. The struggle was my choice and at the same time it engulfed me naturally. In the course of the struggle I felt encapsulated in darkness and rid with a heavy weight of despair. My heart felt as if it would break into a million pieces. I felt totally unable to sense direction

toward recovery, and too weak to move toward recovery on my own. The support I received represented the direction toward recuperation and the energy source to work through the struggle, as well as the presence of viability within the struggle. I could feel a human concern that was a silent energy and which allowed me full control of my struggle. I could feel that I was not alone though my struggle remained solitary.

I battled to make sense of my illness and to understand my grief. As the weight of my grief lifted, it was as if light shone once again. I felt a definite relief, a definite new life. I sensed a balance and harmony which had been missing. The frayed emotions of my experience became an emotional tapestry as I can now recall the experience but without the pain. I needed to experience that pain before the tapestry was complete.

When my dad had his MI in 1984, he had one nurse who seemed to make a positive difference to his recovery. Though he was the one experiencing the MI, I recall agreeing with his stated feelings about that particular nurse. She was always pleasant, though not artificially cheerful, giving us the impression that she was truly interested in his well-being. She also provided him with information related to his MI.

The most memorable supportive action that I recall she provided was after my dad had been moved from ICU to the ward. That nurse had come from ICU to check the telemetry (long-distance monitoring system) of another patient. She greeted my dad as if she was still his nurse and upon noting his need for more rest and quiet, she shared her concern with him and was direct in explaining its importance in his recovery. She then discussed the matter with the nurses on the ward, who, up to that point, had not responded to that need. Afterwards he talked of that nurse's concern and how important that made him feel. As family, both my mom and I were experiencing that same sense of gratitude. I not only felt comforted that my dad was supported in his recuperation by a nurse who showed a genuine and ongoing interest in his well-being, but also that we, as a family were in turn supported.

Etymological Sources

The concept of support pulls much of its meaning from the concepts involved within recuperation. Here I will examine, etymologically, support, recuperation and associated words.

Support involves both the concepts of upholding and approval. The Latin word for support, "supportare," means to carry, bring or convey to a place, bear or endure and

give approval to (Skeat, 1968, p. 618; Klein, 1966, p. 1545; Guralnick, 1974, p. 1431). To bear a child is to go through pain prior to new life being born. This same concept can be linked to support where one is assisted to bear the pain of any struggle prior to the beginning of a new release on life. Within any struggle where support is involved, to have approval to carry out that task is crucial. For many people a struggle is not necessarily seen as an envied position nor necessary to our existence. Therefore it is common not to receive approval to engage in such an action. The Latin word for approval comes from the word "probare," meaning, to try (Guralnick, 1974, p. 68). That meaning connotes an element of consent to carry out a task which, in turn, highlights the concept of permission. To have permission to struggle is akin to setting one up rather than putting one down in that the possibility of success enters the picture. One is upheld within the realm of possible success.

The Latin word for pain, "poena", refers to punishment or penalty (Klein, 1966, p. 1112). Skeat (1968) defines pain as bodily suffering or anguish (p. 423). A struggle is painful. To feel excruciating pain over time would be difficult to bear, but as for a woman bearing a child, the pain dies away as new life is visible.

An element of darkness is also apparent when examining

the word grieve. Klein (1966) identifies that the Latin word for grieve, "gravare", means to weigh down with a burden or load (p. 680). When someone is struggling with the pressure of a load they are more likely to feel trapped by that burden and, thus, to be surrounded by darkness. To be free of that load allows that person to emerge from the darkness that weighed upon them.

The Middle Latin word for important is "importans" which derives from the word "importare," meaning, to imply or be of importance. The Latin meaning of "importare" means to bring in or introduce, with "portare" meaning to carry. "Importans" refers to having much significance in the sense of having power and authority (Guralnick, 1984, p. 705) To be carried through a struggle is like being upheld to a level of importance where not only the struggle is significant but the person directly involved in the struggle feels a sense of power and authority within his or her recuperation.

The Old French word for control is "contrerole" which means the "power to direct or regulate" (Guralnick, 1984, p. 309). Not only is the sense of power and authority within a person's struggle, vital to the recuperation process, but to have the power to direct or regulate one's struggle seems crucial to the positive effects of recovery.

In all of this, to be upheld to a level of importance,

where the struggle is also important, and to be given permission to struggle and control the struggle, there is also the essence of a presence of someone, a strength within the struggle. This is an enabling factor which is necessary to actually carry out the struggle. This enabling factor seems to point to an empowerment which adds a source of energy to the possibility of recuperation. The French meaning for empower refers to a power from another source (Skeat, 1968, p. 193). The Middle French word for power is "possibilite" (Partridge, 1966, p. 517). To be empowered toward recovery is to know the possibility of recuperation.

The reason for the struggle in illness, is to yield recuperation, to recover a loss of health. To recuperate is akin to the Latin word "recipere," to bring back or receive (Guralnick, 1984, p. 1188). To recover refers to returning to a state of balance and control (Guralnick, 1984, p. 1188). To regain one's health is to recover one's balance and control. To achieve balance includes an element of harmony where the struggle subsides. To achieve control includes the power and the choice to direct or regulate one's abilities. To achieve balance and control includes a time when one's support needs diminish and where one maintains his or her own balance and control. Support needs still exist in daily life but wax and wane according

to the breakings in one's life.

Etymologically, the word lifeline, is examined in separate parts. The word, life, comes form the Greek word, "leib," meaning body, continuance, perseverance (Klein, 1967, pp. 887-888) The word line comes from the Latin word, "linea," meaning a linen thread, string, or cord (Klein, 1967, p. 892). A lifeline, then, refers to a sustained connection to vitality. The possibility of life echoes within this definition.

Idiomatic Phrases

I identified both word couplets as well as idiomatic phrases which add further understanding to the concept of support for MI patients. The first word couplet is the term "heart attack". I am caught by the harmful nature that those words connote, on a body organ which represents life or death depending on its level of functioning. During recuperation, following a heart attack, the patient may struggle with this negative image, of the insult that was directed toward his or her source of life. Having a heart attack, then, could pose negative thoughts for the possibility of recuperation.

The medical term, "myocardial infarction", refers to the process of death of a region of heart muscle. This term promotes the concept of even greater harm than the

term "heart attack" as the concept of death is truly present. How close to death can one person get before death is inevitable? An element of fear seems part of this critical picture, fear for one's life.

The phrase "depth of despair", indicates that despair has distance and that at its depth one is experiencing the extreme pain of despair. Darkness seems to accompany the extreme of most any depth as it also does with the hopeless quality of despair. To be enclosed in a hopeless darkness again seems to indicate an element of fear and, as well, the need for some kind of outside assistance to see both light and hope.

The phrase, "throw out a lifeline" is used at times when a person is in danger and needs the strength and direction offered by a visible or an invisible line which leads to safety or to a place of rescue. An element of fear for one's life also seems part of this critical picture, as does the presence of outside assistance. It includes the additional concept that the person toward whom the line is thrown has permission to grasp that lifeline. Another dimension exists, too, in that the person grasping the lifeline has a choice, as to: if or when he grasps or lets go of the strength in that lifeline and of the lifeline itself. This choice represents a form of control over one's own recovery from danger.

Altogether, these etymological words and phrases describe the notion that support is an energizing source provided by others to allow the supported person to be in control of his or her recuperation struggle. To be a healthy struggle it eventually yields a harmonious equilibrium.

Experiential Descriptions From Others

The five patients who were part of the Pilot Support Program which I instituted at Prince George Regional Hospital in January 1987, presented with individual profiles which exhibited aspects of the experience of support. Upon first meeting with each patient I explained that the emphasis of the program was not so much teaching about their MI but, rather, assisting them to cope with the experience of the MI and assisting them in the change process. Throughout the course of the program and during an interview and within one questionnaire, each patient talked about what it is like to be supported, what it is like not to be supported, as well as how those aspects of support have affected their recuperation.

In general the patients often asked me questions related either to how to make life style changes or to understanding the MI process and associated effects of both previous or advocated life styles. Though I answered their

questions during the process of assisting them to both cope with their MI experience and to make life style change, there seemed to be present a need for something over and above the support which they experienced.

The following are the five individual patient profiles with names being fictitious:

Albert

This was Albert's first MI. He was 37 years old at the time of his MI, and at that same time his wife was due with their third child. He was a self-employed manual labourer with work being available on a seasonal basis. When his MI occurred it was of a transient nature in that he went to the Emergency Department of the hospital complaining of severe indigestion. Though his cardiac status was checked, he managed to convince the doctor that the problem was gastric. He went home feeling improved and went out to work the next day. It was not until a few days later that blood work results were available, indicating the occurrence of an MI. His wife was notified so that she might inform him of his condition and the importance of his return to the hospital.

Upon first meeting Albert he was anxious to be part of the support program. In the hospital Albert talked much

about how he and his wife and family would manage financially until he could return to work. He continued with these discussions in an ever evolving manner. Rather than ask me many questions in regard to what he should do, work wise, he discussed ever so many alternatives regarding what might or might not be feasible. Once their baby arrived he also talked of how they shared feeding times and also the negative effects of broken sleep.

He talked of how helpful it was that his wife changed the family's diet, insisted he go on his walks and insisted he quit smoking. He referred to his wife's sudden change in life style, such as herself quitting smoking as a support during his recovery. His wife supported him, too, when she helped him to work toward solutions regarding their situation.

Albert showed me books and other sources of information which he found useful in his understanding of his MI. In his view information made important contributions:

> It helped me to make sense of this heart attack. It helped me to put things together. Going over this material has helped me to sort out what to do, it has helped me make the necessary changes.

The material he read, which he obtained mostly from friends and relatives, helped him to understand, as he said, "why these things happen, what atherosclerosis is and why it

occurs." He stated that he would have liked to have more information "right off the bat" as well as to be "shown the X-rays, to understand just how serious the heart attack was and what stage of the heart attack I was in." He also felt a need for information which would be a guideline as to how far he should walk and what kind of work he could or should engage in. At one point he said, "I couldn't wait to get down to the dietician's office to find out what I could eat." During one visit I wrote his various problems out on paper. He said that it is "easier to see how they all relate when on paper." The books and other written material he read were a form of "moral support" during this recuperation time.

He also described that it was important that he have someone to believe that

> my health would be restored. It helped me to concentrate on the end result. I needed to know that I was on the right track and that I would recover. I needed people to be positive in their thinking. I needed to quickly find solutions to problems.

People, themselves, also seemed to be a support for Albert. He said he felt supported when others

> were concerned about my well-being; were behind me in providing information, changing my diet and checking things for me; reminded me of my bad habits; encouraged change; helped me to change; available to ask questions of; followed up on my progress.

The people who were specifically mentioned for their

contributions of support were his wife; friends of his parents, one of whom had had an MI; his sister-in-law who is a nurse, and myself.

Albert identified lack of support upon receiving conflicting, unclear messages about the direction he should follow to make change, for example, what aspects of work he should restrict. Also he said he felt helpless when "I didn't know how long I would be ill and I was concerned about my family, my business and and my health."

In regard to change, he said, "I found it very difficult to quit smoking when I was dealing with other stresses." His mother expressed a lack of understanding about why "he can't just quit smoking like his father."

He counts his MI as being "a lifesaver. If I had continued on my regular diet a year or two longer I would have had a major heart attack."

Barney

This was Barney's first MI. He was 41 years old at the time of his MI and lived with his wife and two children. He was working at a desk job by day and was working on similar work at home on many evenings. When his MI occurred he was skating. A friend immediately brought him to hospital. He received a medication which essentially "aborted" his MI. He was the first patient on

which this medication was effective at Prince George Regional Hospital. There was uncertainty about whether or not Barney's heart had actually been damaged. Immediate plans were made for him to go to Vancouver for an angiogram x-ray.

Throughout hospital and home visits Barney insisted that he have more information so that he could make plans and also so that he could understand what had happened. Though he was given information by various people throughout his recuperation, he continued to feel that,

> I need direct answers and uniform explanations so that I can understand exactly how serious it is, how much damage there is , why I had a heart attack, why I am going to Vancouver, what the doctor suspected, and what is being done for my condition. It's difficult planning around this pending trip to Vancouver. I need black and white answers. Even if the doctor does not know, I need to know that.

In regard to his visitors he said:

> I kept getting tired explaining what had happened. They would ask things like °I guess you have to walk?' Friends who had had a heart attack were most supporting because they would give me books about heart attacks, which were helpful, and they would say °I guess you are walking'. In the Vancouver hospital my roommate and I discussed our lack of knowledge. I explained this need to a nurse, then the nurses and doctor began explaining. How good this was; it made me feel more comfortable.

He talked of being supported when the nurses "got rid of my pain." But he referred to not being supported when in the Vancouver hospital:

> I could look down the long hall at night and never see a nurse. It made me wonder what would happen if two or three patients were seriously ill at the same time.
>
> It was encouraging to hear about other (MI) patient's successful recovery. They would not ask me what I was doing but would, rather, state what I was probably doing and would explain their experience.
>
> Since my heart attack we do more things together as a family. Our diet has changed and we go on long bike rides together. Before, we each used to do our individual thing.

Barney talked about his ICU experience, where he felt helpless when he was "all wired up with no where to go." He talked at length about wanting to make his

> own decisions--what I feel comfortable with. Let me do it my way. I want to be treated like an individual. I don't like being treated like a child being told what to do. I don't want to be bugged about making changes. I do not receive full encouragement because I have not made full changes.

In discussing his MI experience Barney said it was "frightening, scary and painful but it was a warning to get healthy again."

Charles

This was Charles' first MI. He was 59 years old and unmarried. He was working in a "low stress job" which included little manual labour. He had contemplated retirement throughout his recuperation process, a decision which he was not forced to make at that time. When his MI occurred he was skiing on a local mountain. He talked

about the expertise and the speed at which he was assisted by the ski patrol and the ambulance team.

Charles is quite positive in his descriptions of the support he received.

> When the doctor told me what kind of heart attack I had - acute myocardial infarction - I knew it was serious. Information helped me to understand what to do. Its helpful to talk to others who have had a heart attack, and about their different experiences. I got information from everyone but I sieved out what was best for me.

He talked of feeling comforted when he was

> wired up right away. The nurses were there twenty-four hours per day. Their just being there helped. At work they were concerned that I don't return too soon. Without support I'd be nothing. I couldn't do it.

He stayed with his sister and brother-in-law for about eight weeks after discharge.

> It helped when my sister would control my diet by cooking for me and telling me what I could and could not eat. My brother-in-law became my walking partner. That helped me to pace my speed.

Charles discussed his feelings about being discharged from ICU to the ward.

> There were not any windows by my bed and I did not have the same privacy. In the ICU I was treated like a king. I was catered to. I did not get the same attention on the ward. When I was transferred from ICU I felt like an old tire, thrown aside.

He also described feeling powerless: "Sometimes I could not sleep because of the other patients. I also felt powerless to help other patients. Sometimes I can't bring back

words. I have trouble remembering dates and names."

Charles discussed his MI as being "surprising and different. °He' gave me a warning this time but maybe it will not be a warning next time. If this is the way it is going to be, that is okay." When referring to guilt feelings, he said, "I spend a lot of time thinking about that one but I can't change things. I'm lucky, it could have been a stroke. It was a good warning."

David

This was David's second MI, his first occurring about four months previous. He was 51 years old and lived with his wife and two children. He had a desk job which involved some travel. His first MI occurred while he was working in another city. This second MI occurred when he was at home.

David felt most supported when he was "not being talked to as a cripple." He feels that the one thing about support that can assist heart attack patients to recover is "not to treat them as invalids with one foot in the grave, to treat them as normal and not totally incapacitated." He described that when he received cards and phone calls he was "pleased by everyone's concern; it was a good feeling though I could have existed without them." He said his recuperation process was "helped by family members simply

by their presence. They were concerned about how I was doing but they didn't do everything for me." It was important to him that others were available when needed and that others did what he could not do for himself.

> When at a steady level there's no need to keep touching on the subject, no sense going over the subject after its over. After talking to the patient about his heart attack, try to convince the patient of his problem but don't harp on it. Self-realization of the problem is the best way to face it.

David found that he would have been more supported

> if the doctors had explained the causes of his MI more fully, the mechanics of it. It helps to know the mechanism of what will happen if I don't make changes. I would have liked the blood tests explained, to know why the tests are being done and to know the results of the tests.

He would have liked to know his "state of general health." During this second MI it was helpful to be able "to phone home" and "have visitors." In describing his feelings upon meeting one of his nurses while shopping, he said, "in ICU she would have done anything for me, yet when I met her in the store she didn't really have the time of day for me. I was rather hurt."

He talked of friends who visited and who said "I didn't do this heart attack right, I should be flat on my back." He referred to a previous accident where friends "didn't even think I broke my arm right."

When talking about recuperation he refers to it as

"trying to regain full recovery." David talks about the life style changes following an MI as

> taking the fun out of life when I can't do the things I enjoy. I sometimes wonder if its worth living ten years unhappy when I could live five years happy, doing the things I most enjoy. I'm going to die anyway.

He describes his most crucial concern as follows:

> ...trying to get as well as possible in the quickest possible time, to get out of hospital as fast as possible. I want to make my own decisions. Its up to me how I recuperate." After one home visit he said, "Its good to hear myself talk about all those things.

David talked of his MI experience as being "a surprise, not expected, I couldn't plan for it. It was quite interesting as it resulted in quite a change in life style."

Edward

This was Edward's first MI. He was a 39 years old and lived with his wife and two children. About six months prior to his MI he made positive life style changes in diet and exercise following his thirty-five year old sister's death from an MI, one year before. When Edward's MI occurred he was playing racquetball.

Much of his MI experience has included a concentrated effort to try to understand why he had an MI after making life style changes. He constantly looked for answers to

questions such as: "what didn't I do? Wasn't I doing the right thing? How do I prevent another heart attack?"

Information which he has read or heard, he says, "has helped me to understand what is happening. It makes it easier to accept what has happened. Since one doesn't plan a heart attack one doesn't plan to learn about it first."

He stated that he needed repetition in the reading material but he also had difficulty concentrating on what he read. He thought pamphlets would be helpful. But Edward also talked about receiving conflicting information from most everyone and even from reading material. That made him wonder, "can I depend on the information? Is it the full truth? He stated that he "wished that the doctors would have told him the whole truth." Also, he felt he needed more explanation. He explained, "the doctor says °take it easy' but what does that mean?" I could have been helped by my doctor with more reassuring information."

> Edward stated that he felt supported when he was treated like an individual. I like people to be cheerful and positive, not morbid. Friends and family cared, through their presence." In the Emergency Department he wished that "they would have asked my family the questions instead of me.

His family joined in with life style change; "that is good." He is most comfortable when he is left to do things on his own time, to come up with his own answers.

> I want a choice of what to do with the information. A person must know exactly his condition so that he can decide for himself how much he can do. Support means to be able to put my life back together without anyone putting pressure on me. In the hospital I felt I was expected to get better fast but at home I felt more relaxed and I was able to get better easier. Talking about my MI was not helpful because I had to relive a painful experience over and over.

In describing his MI experience Edward stated that "it was probably the best thing that could have happened because it made me reevaluate my health."

Beginning themes

Though these five experiential descriptions are each different, common threads exist which help give meaning to the nature of support. These patients definitely described occasions, as well as the feeling of being supported. They also described times when they felt they needed a different kind of support.

Six beginning themes emerge in the material discussed to this point: (a) provision of information, (b) presence of others, (c) others joining life style change, (d) reassurance of recovery, (e) control of own recovery process, and (f) meaning of the MI experience. I will briefly discuss these six beginning themes and use them as the framework to draw data for ongoing analysis. As additional data are presented these beginning themes will become more focused as I work to capture the essence of

support.

Provision Of Information

To have information seems to be a factor which provides a way to cope with the unknown. When suddenly thrust into a situation where the answers seen elusive, information helps patients put the puzzle pieces together in order to create a possible picture of recovery, to understand what has happened, why the MI has occurred, how serious it is, what treatment will be done, and what and how to recover. It is as if information allows access to and movement in a problem solving direction. Like one of the keys to recovery it seems to open the doors of possibility to recuperation, a way to resolve the immediate situation. It is a way of providing control for the patient, a way of including him as an important member in his recuperation.

Without information the way seems blocked or hidden or at least, very obscure. To be unable to make plans for change seems to detract from attempting to or being able to make those changes. Frustration and stress are two factors which often exist because of the traumatic nature and unchosen circumstances related to the occurrence of an MI. Questions about whether or not one is being told the full

truth can negatively affect the trust relationship between the patient and the health professional. When the trust relationship is affected, there exists the possibility of decreased motivation to struggle with change.

Presence Of Others

There is a mysterious quality surrounding the presence of certain people in other people's lives. It can be an enriching quality, an energizing source which carries a person onward. In the case of the MI patient it is a factor which seems very valuable, a support which helps move each patient toward recuperation.

There seems to be a special understanding by the people who create that energy. They genuinely care for the patient and his well-being. It is as if they are walking in the patient's shoes yet have left control of the situation to the patient. Whenever the patient needs a boost or even guidance, the supporting person is always present? Yet concern for the patient is such that he or she does not smother the patient's progress, does not smother the little spark of assurance which may be present. It is an upholding quality and akin to being given permission and approval to carry out the recuperation process.

The negative side of this factor exists when the

patient experiences feelings of being alone in his struggle or being truly alone with no one physically present. This situation suggests that energy to recuperate, comes from within the patient, a difficult situation when the illness itself uses up much of the patient's energy resources. Supporting persons can also detract from the MI patient's recuperation, when their presence saps the patient's energy. It is almost as if this negative support places the focus of attention on the supporting person rather than on the patient. When this occurs, the importance of the patient is lost, and also lost is the importance of allowing the patient to recuperate in a way which is meaningful to him or her. The importance of the patient as an individual provides an energy source for recuperation.

Others Joining Life Style Change

It seems that when significant others join the patient in making life style change, there exists a camaraderie, a strength of sameness of purpose, of sameness of struggle. It is like saying to the patient that if his or her changes are important for him or her they are also important for the rest of the family. It is also an encouragement to make a change, when significant others also work toward change.

A defeated attitude can build in the patient when the

family completes changes but the patient is still making or struggling to make those same changes. It is almost as if control of life style change is removed from the patient's grasp when he or she is unsuccessful in that change. As with the previous theme, the focus of attention seems to move from the patient to the family. Instead of diminishing support of the patient when he or she is slow to succeed, it seems important to keep support focused on the patient. The patient needs to feel in control of recuperation regardless of the choices made.

Reassurance Of Recovery

This seems to be another energizing factor which is necessary for recuperation. It is akin to providing some light at the end of a dark tunnel. Rather than just spending time talking to the patient specifically about his experience, it seems of greater importance to identify what the patient's struggle means to him or her, and within that individual meaning to focus on assisting the patient to understand his experience, to understand what happened, and to assist him to look at the possibility of recuperation. The idea that recuperation is possible is important in giving the patient a reason to struggle. Without that reason it seems unlikely that any person would endure such a trial. That reason, then, becomes an aspect of hope

which is crucial in any struggle. Hope has a positive connotation, suggesting an element of success for recuperation.

Control Of Own Recovery

The fact that an MI is usually a very sudden occurrence, is an uncontrollable factor. To have someone, then, laying out ground rules for change in the life one has known is much like an invasion of privacy. A natural defense seems to emerge, in order to hold on to as much control as possible, of his or her own body. It seems to be accepted and even expected that anything a patient can not do will be done for him. But even when a patient is critically ill, he or she still calls out to be allowed to be in control of as much as possible, even if that control be through thought alone. This control is often difficult to achieve unless it is accompanied by the patient's understanding of his or her illness. This is possible through the provision of information in conjunction with the patient's individual need for information.

Meaning Of MI Experience

This theme offers a sense of vitality in, and purpose for, carrying through with the agony involved in the struggle. Despite both negative and positive support these

patients seem to have experienced a sense of relief and a sense of direction for the ongoing struggle. It seems to be an acceptable learning process in which to view life through brand new lenses. The warning that their MI presented them with, was a motivating factor which seems to contribute to life style change. Though many patients do not feel they achieved balance or harmony during their recuperation, they generally agree that balance and harmony is an achievable state upon recovery.

This theme is tied closely to that of: Control of Own Recovery Process. The meaning of the MI experience is a major catalyst for recuperation but without a sense of control of one's recovery this catalyst easily loses its positive effect. Instead, this catalyst can add an element of bitterness to the struggle, upsetting the possibility of balance and harmony. Without control, the patient is deemed helpless in his recovery. Consequently, the true meaning of the patient's MI experience is altered. The struggle can become one of fighting to retain this meaning, or of rebelling against diminished control. The struggle yields more possibility when experiential meaning is allowed to shape how one controls one's own recuperation. Thus the meaning of the MI experience becomes a guideline by which support is provided rather than being a form of support received from a supporting person.

Experiential Descriptions in Literature

I find it interesting to note that the previous six beginning themes which emerged from the experiential descriptions of others also emerged in literature. The literature I examined contained personal accounts of patient's and family's experiences of recuperation from an MI.

Provision Of Information

This was consistently revealed as a crucial factor in being able to put order back into a shattered life. Lear (1980) describes the following feelings in relation to her husband's and her experience during his MI experience:

"I need to know these things" (p. 55).

"Why don't doctors give you straight answers" (p. 105)?

"Not out of any macabre self-interest but because he simply had to know" (p. 104).

"I could not make much sense of his doodles and no sense at all of his technical talk, but it soothed me" (p. 122).

"Please try again. Please try to explain it to me" (p. 156).

"It was the first time that any clinician had spoken to him reasonably of the mind-body connection and he was comforted" (p. 200).

"I don't care what I find out, but I've got to know" (p. 199).

"The truth would have been easier" (p. 267).

"What I care about...is that he get consistent instructions at a time when contradictory instructions would be very confusing and demoralizing" (p. 306).

"One doctor says he's in danger, one doctor says he'll be all right. It's crazy, isn't it" (p. 334)?

"Well, that's good news. That makes me feel better" (p. 381).

"Don't give me options. Give me guidance" (p. 291).

Weiss (1980) describes the following feelings that patients and their families have, in relation to the MI experience:

"They want to know what a heart attack is, why it happened and what they can do in the future to preserve health and life" (p. xii).

"They want the complete facts. It is the half-truths, myths, and most of all the unknown that is really frightening and depressing" (p. xii).

"I wanted books. He (the doctor) just said °go to the bookstore', but he didn't have any specific suggestions" (p. 73).

Lair (1973), focuses on the importance of providing information in a way which includes an understanding of how difficult life style changes can be for each patient.

"I noticed that a lot of the advice to heart patients tells them to stop rushing without any sense of how hard it is" (p. 83).

Effective communication was important for the patient to understand the information given to him or her.

"°Well, there's no question about your having a heart attack'. What a dumb way to put it, he thought. I don't

know what he's saying. What do you mean, °no question'? Did I or didn't I" (Lear, 1980, p. 14)?

It seems that, regardless how negative the truth about an illness may be, the MI patient had a tremendously strong desire to know that truth, to receive straight answers in order to assist in sorting out his or her life. The information also must be consistent because without consistency, mistrust erupts. Straight forward answers with an ingredient of understanding of the individual and his situation created a soothing, comforting feeling of being supported. It was important, too, that the information be a guide for the patient to help him or her sort out his present and future situations. It was like a strength to work toward recuperation rather than a sapping of that strength as the patient was left to hunt for specific guidelines in the literature.

Presence Of Others

To have the presence of another in one's struggle to recuperate from an MI seems to empower the patient toward recuperation, but it is important that that presence be accompanied by a sense of caring. The caring seems to take away some of the loneliness of the struggle but the experience is still solitary. Lear (1980) describes an article he read during his recuperation, which was written

by a husband, whose wife suffered tremendous physical and emotional anguish prior to her death. Lear identified so fully with that anguish which seemed tied to the fact that there was "nobody, anywhere, to understand" (p. 196). Lair (1973) discusses his and his wife's experience throughout his MI recuperation:

"The days went by very well and my fear didn't get too bad except sometimes in the early mornings when I would wake up and no one was around. There was a nurse on the night shift who made those times much easier just because she was there" (p. 141).

"The nurse wheeled my cart up to the door of the surgery suite and then turned and walked away. I suppose she had something important to do. I sure hope so because I know I needed her bad just then" (p. 142).

That last quotation includes the concept of abandonment along with the feeling of loneliness in the struggle of recuperation. This abandonment is described in a pronounced manner when it accompanies the feeling that no one understands the struggle the patient is experiencing. Burnside, (1972), described that "touch somehow closed the distance I felt between myself and others; the distance, though part of the experience, adds to the bereftness and loneliness of it all" (p. 120).

Gratitude, as a result of a caring response by nurses and doctors seemed obvious too. Lear (1980) describes the following situations:

"For the most part they were deeply caring....So gentle...so regretful for the pain they had to cause

him....he felt an overwhelming gratitude" (p. 142).

[He] "managed somehow never to cut the human connection" (p. 121).

"Friends called and were caring" (p. 157).

It seemed important too that an attitude of cheerfulness and optimism exist. Weiss (1980) stated:

"She acted °up' and it helped" (p. 51).

There is the suggestion that something specific is important in supporting patients through a struggle. There are a few references to lifelines which seem to foster the picture of an energy system which is directional and which the patient can tap at any time. Lear (1980) describes this situation:

"The CCU people have been our lifeline. I am so frightened to leave them" (to go to the ward) (p. 364).

"They (the nurses) touched him with their hands, flesh to flesh. His succor. His lifesavers. His lifelines" (p. 40).

Though wires and tubes can be extremely limiting, they too can act like a lifeline, taking on caring qualities.

"Gradually he became aware of his connection to things. There was his old friend the monitor" (Lear, 1980, p. 133).

The lifeline itself seems to encompass much of the experience of support for recuperating MI patients. Information is a lifeline, in that it allows the patient to find his way, and be strengthened through his struggle with

recuperation. The presence of others, too, seems to provide a lifeline when supportive qualities are present.

Others Joining Life Style Change

This section was minimally addressed in the literature. The closest references describe the importance of a mutual support, those who understand the experience. Weiss (1980) describes this concept:

"I wish I had someone to talk to. The psychologist I'm seeing now hasn't been through it. I'd like to get into a cardiac club" (p. 10).

"People who desperately need help themselves can be very healing for others. Their own needs and hurts don't keep them from healing others. In fact, their own hurts are the very thing that helps them heal others" (Lair, 1973, p. 120)

This concept, too, infers that a lifeline exists when someone understands another's experience. This mutual understanding is like a source of energy which seems to empower the patient toward recovery.

Reassurance Of Recovery

The reassurance of recovery lay in the possibility of recuperation. It is a grasping on to an element of hope. It is empowering to know that despite the struggle of recuperation, there is the possibility that the struggle may lead to a ray of sunshine, to an escape from the enclosing capsule of suffering. This concept, too, holds

an element of energy as well as a sense of direction.

There is the presence of a fluctuating emotional tide which accompanies the entire MI experience. This fluctuation directly affects one's reassurance of recovery. Weiss (1980) describes one aspect of this fluctuating emotional tide:

"I felt like I wasn't there" (p. 4).

"At the time it wasn't a frightening experience" (p. 4).

Numbness seems to give way to both positive and negative reactions. Lear (1980) describes this fluctuation:

"I no longer trusted my doctors....They'd be properly sympathetic and say 'Come back next week.' That wasn't enough. I was on an emotional roller coaster. When I felt good, I was so hopeful. When bad things happened to me, I was depressed and bewildered" (pp. 262-263).

In the literature there is some guidance as to how to reassure patients:

"Positive remarks about progress and possible future plans are also helpful" (Weiss, 1980, p. 58).

Lear (1980), discusses the importance of reading what the patient says, between the lines. When asking,

"What is my prognosis?....What (was) the patient really asking?....To give me encouragement that my life wasn't over" (p. 55).

"He was looking for hope. I wouldn't lie. I would stress the positive" (p. 55).

"It was not yet hopeless. Quite true, it was very bad, but

it was not yet hopeless" (p. 336).

Weiss (1980) states,

"We should give the patient the greatest encouragement to be a vital, active person once again" (p. 59).

Throughout these quotes, again, exists a focus on the positive, a focus on the possibility of recuperation. It is important to focus, as well, on the patient's negative feelings--feelings which exist as a result of negative support but which also exist as a reflection of the nature of being ill.

"I feel that I'm no good anymore" (Weiss, 1980, p. 10).
"The very thought of not being able to work again was intolerable. It engulfed him with guilt" (Lear, 1980, p. 190).
"I feel to be put back in a regular room...is to be cast out into the world" (Lear, 1980, p. 364).

It is almost as if patients lose their sense of being important when they can no longer carry out their previous roles and, as well, when they are moved from a specialty area to a regular ward. This is where it becomes crucial to assist the patient to focus on the positive aspects of the possibility of recuperation rather than on the negative side of illness and the losses involved in recuperation.

Effective communication is also important here, for it can empower the patient toward recuperation. Ineffective communication can destroy any sense of reassurance of recovery and any sense of hope.

"'Could be that one of your bypasses plugged up....Take it easy, now'....Could he really have said that?....this casual conjuring up of a plugged lifeline, shooting dye into the heart again, possibly slitting open the chest again, might be enough to produce another coronary. Oh, he looks so scared" (Lear, 1980, pp. 218-219).

Control of Own Recovery

This factor almost screams from the pages of the literature as the patient quickly moves from a rather numb state upon admission, through what seems to be a growing need to take the reins in his or her recovery. He or she is then at the point of dealing with life style change. Surrendering to life style change seems the first step toward surrendering to the illness itself. Weiss (1980) describes this need for control:

"At home, I wasn't myself. I began to withdraw, to feel I was less than the rest of the world. When I went out, I wouldn't carry my wallet; I wanted to be nonidentifiable" (p. 5).

"What helped me to get out of it (depression)? Working!" (p. 5).

"I also began testing myself by walking around the block twice" (p. 5).

"I hate when people help me....I don't need mothers. I'm a proud person--if I need help, I ask for it....I can't stand people babying me" (p. 9).

Lear (1980), described the reaction of an MI patient to his lack of control within his patient role:

"If I'm having that test (angiogram) done tomorrow, I really should take one last little test of my own tonight.

Just to see if I get pain. He decided to walk the corridor...twenty times. A mile" (p. 110).

"He could do nothing but lie there utterly passively silently choking to death" (133).

"You must keep an active role in your own care...to feel in control of his affairs" (p. 214).

"I want to have more control at the helm of this boat" (p. 266).

"Perhaps because he feels so little control over his own life, he has become overcontrolling with me" (p. 316).

"I'm letting him run the show" (p. 347).

"We hadn't realized how angry he was about feeling helpless....He is in constant communication with that body of his that's letting him down. He is fighting" (p. 347).

The fight is often very difficult, particularly when the fight involves a change in life style on one hand, and on the other hand, experiencing the feelings surrounding the close view of death. Delaney-Naumoff (1980) describes the pre and post MI feelings of a 39 year old patient:

> He stated he felt his body was falling apart; that it was not allowing him to do what was necessary to provide support for his family. Now, with a heart attack plus his business and legal problems, he envisioned his family left without financial security and being held responsible for his investment losses. The patient even said he bargained with God. If he did everything that was therapeutically indicated for his recovery, would God leave him here long enough to see that his family was secure? (p. 95)

In an article by Thompson in the Prince George Citizen (1986), she described her and her family's experience during her father's recuperation following an MI:

> No one told us about the mental changes some heart

> patients go through. It's easy to sit back and say we all know life won't go on forever but it's hard to summarize the feelings people have when death has come so close. When people talked to us about heart disease they talk about physical things like blocked arteries, hardening of the arteries, diet, and exercise. Knowledge about these things is extremely important to understand what Dad was going through. (p. 3)

Control of one's illness and recuperative process is fostered by the existence of a lifeline. To be in control without a lifeline would likely yield a search for energy rather than being guided by the existence of an already present lifeline, in order to move toward recovery.

The unexpectedness of the MI situation is an automatic case for loss of control. Not only does routine life as the patient knows it, suddenly change without occasion for a choice at that point, but the patient is forced to yield some control to professionals who are strangers, on the most part. Within that context there exists an occasion for the patient to trust those strangers and strange environment until he or she can regain control. It seems that control over the situation by the patient can exist in two spheres (a) control by denial of the illness where the patient, in all intensive purposes, still remains under the control of the illness itself and, (b) control of recuperation where the patient makes his or her own choice to surrender his or her previous life style and, instead, adopt a healthy life style which controls the continuation

or recurrence of the illness.

Meaning Of The MI Experience

In examining the literature it is evident that the struggle inherent within the MI experience can yield the possibility of growth. Weiss, (1980) states:

"Most people feel immensely grateful and happy to be alive" (p. 42).

"I found out just how tenuous life can be and I really do enjoy every day with a new sense of reality" (p. 42).

Lair (1973) states,

"Life is a beautiful teacher and if you don't pay attention to her little blows, you'll soon get a bigger blow. In my case, it took a heart attack to get my attention" (p. 78).

But for some people, the will to live is lost and when that happens, death often ensues despite the struggle or the support.

"She didn't seem to want to live...we both wanted to live badly" (Lair, 1973, p. 145).

Phenomenological Literature

The unexpectedness of the occurrence of an MI opens numerous avenues of thought when coming to terms with the patient's meaning of the situation. Zaner (1982), in discussing the plight of the end stage renal dialysis patient describes the experience as "befalling the person, as an un-asked-for and unanticipated 'happening to me,'

falling outside the person's range of possible choice and plans" (p. 50). Being ill involves both, not choosing the illness as well as limitations of choice during the illness. Perhaps those limitations within illness are a result of altered perceptions. "The sick person--in proportion to the severity of the illness--cannot see beyond the pains and concerns of illness" (Rawlinson, 1982, p.75). It is as if his or her illness takes over all importance in the world, limiting his peripheral accounting of previously important aspects in his life. Rawlinson (1982) also identifies the limitation that "illness confounds our capacity to expect" (p. 74). Because the ill person is thrust into a new and strange role, he or she has difficulty looking beyond that situation to consider future action. Thus the ill person not only finds himself or herself in an unchosen environment but is limited in choices within both the present and future environments.

Limitations in choice also create limitations of one's control over life activities. "To be ill is typically to be unable to have immediate control over some of the circumstances of one's life, to be in need of some special care, and depending on the severity of the illness, to be unable to discharge some of one's usual social duties" (Rawlinson, 1982, p. 148). Control can be partially restored to the patient by informing him of various aspects

of his illness.

> The defect in knowledge about the illness--what is wrong; how serious it is; what can be done; what should be done; what it costs in time, discomfort, money; what alternatives are available; the physician's own capability to treat this illness--these must be disclosed. The patient must be assisted, to the extent he wishes, to make conscious choices and thus to act as a human person rather than become the object of technical manipulation (Pelligrino, 1982, p. 161).

Experiencing an MI includes much of the feelings involved with experiencing death. The MI patient not only experiences symbolic death in relation to any unchosen changes in routine and corresponding life style changes, but he or she also comes face to face with the possibility of his or her own death. Koestenbaum (1971) describes symbolic death as "the collapse of the particular world towards which our energies and goals are directed" (p. 14). In facing one's own death, Koestenbaum (1971) describes such an experience as

> "a persistent and nagging reminder that he is coerced to make some sense of his life, and that he is to do it now....adopts a no-nonsense approach to the business of living successfully. Precisely what these goals are is an individual choice (p. 27)

Koestenbaum (1971), uses Heidegger's words to explain the importance of knowing there is a future. "I am my futurity. My self-image, my conception of my real self is an image projected into the future, an image in which the

roles, unfulfilled at present, are fulfilled" (p. 45). Koestenbaum (1971), describes the opposite concern of considering the future unattainable, "The recognition that the role in its ideal state is unattainable....is in effect the destruction of the real personal self" (p. 45).

The MI patient then, who comes face to face with death, works to make sense out of the life he or she now has. But if this new life requires a role which is unattainable according to what is meaningful to him or her, then it seems possible that the will to struggle, the will to live, could be lost. It is necessary, then that the struggle be such that it is in accordance with that which is meaningful to each patient, in order for him or her to more easily make sense out of this new role.

The struggle itself seems necessary in order to work toward change and, in many cases, to view life from a different perspective. "Suffering is a necessary preamble for understanding and fulfillment" (Koestenbaum, 1971, P. 57). Recuperation involves a return to the balance and harmony associated with health.

> We feel healthy when we are in a state of equilibrium between our already experienced shortcomings and our aspirations and thus have adjusted our goals to the gap between them. Health is a state of accommodation, defined in different terms by each person. Illness rudely upsets that equilibrium (Pelligrino, 1982, p. 158).

The breaking point of illness presents the patient with a challenge which he or she either accepts or does not accept. If the patient accepts the challenge he is supported in the ensuing struggle when he can accept that challenge on his own ground, and when he or she is in control of that struggle.

Conclusion

It is apparent that the six beginning themes which I presented in this chapter, establish a beginning framework of support. These six themes, (a) provision of information, (b) presence of others, (c) others joining life style change, (d) reassurance of recovery, (e) control of own recovery process, and (f) meaning of the MI experience, are seen as common threads throughout the experiential descriptions within this chapter. These threads appear when describing support needs of patients and, as well, they are present as support needs of the patient's family. Underlying these basic themes is the presence of an internal struggle which is at the heart of change. Since change is a part of any illness, so too is a struggle. Rather than camouflage the suffering that accompanies a struggle, it is necessary for support to allow suffering to occur in accordance with the meaning of

the struggle for the patient. To be supported in one's struggle is to be allowed to be in control of one's suffering and simultaneously to be upheld through a positive focus toward recuperation.

Chapter 6

Personal Struggle as a Student

Within phenomenological research, it is important to move as close as possible to the fundamental core of an experience by varying the examples. My experience as a student provides yet another vantage point for viewing support related to a struggle. This chapter is a description of the struggle I experienced while attempting to unravel the essential nature of what it is about support which gives possibility to recuperation. The process of moving toward that inner core of understanding, is one in which I experienced overlapping tides of disbelief and longing, frustration and an inner drive to see this challenge to its end. All the while I felt assured that one day I would answer the research question which is addressed in this thesis. My struggle to write this thesis is part of the process I went through to achieve ground, and it is a like process to recuperate from illness.

My Struggle

At first glance, I thought of support as something which every living person is entitled to. I have not

changed that stance but, rather, have come to view support from an inside perspective, to understand that support contains essential ingredients which are catalysts in the recuperation process. My struggle began as I experienced a gap in the area of support and, as well, I heard many patients describe that same gap. I found it very difficult to believe that nursing, with its dedication to care for and treat those who are ill, often moves away from the patient rather than moves forward to meet his or her need for support. I also felt frustrated because though I recognized that technology holds a key role in nursing, I also knew that the carative aspect of nursing was being overstepped by technology. The literature is definite that support is important, and it also holds answers to ways to support patients. I could identify times when supportive effects were obviously amiss even when supportive acts were present. Patients are not always satisfied with the support they receive, nor are they fully assisted with their recuperation.

My personal experience as a patient, and also as a nurse, allowed me to be extremely aware of that gap. My experiences presented me with a challenge which I accepted and consequently felt driven to master. I decided to examine the elusive nature of support, to help fill that knowledge gap and, in turn, to provide a way to build the

supportive qualities in nursing such that carative aspects exist ahead of technology.

At first I thought I could merely develop a workshop for nurses, on how to support patients. As I worked with this concept I realized that I was struggling with a much more complicated subject than I had at first envisioned. Before I could develop a workshop I had to move to the very core of any struggle. Therefore, a workshop given to nurses on how to support patients would have to be developed around the same concept as I would have to employ to support these very same nurses in their own struggles to learn.

It was then that I decided to develop and implement the Pilot Support Program. Though the intention of the program was to assist me to gain data to understand support needs of MI patients, again I felt frustrated in my endeavours. These patients described times when they experienced support but they also described times when they definitely experienced lack of support. I felt caught in a fluctuating emotional tide, between frustration at failing to support the patients within this Support Program and, a longing, enhanced by an inner drive to eventually understand what it is about support which gives possibility to recuperation. My struggle related to this Support Program was inadvertently also related to this thesis. My

struggle seemed ongoing and seemed to be present each time I was involved with, or these patients were involved with, a challenge. It seemed an unending struggle and, yet, at the same time I could see and feel myself moving to a deeper level and, thus, closer to capturing the essence of support. My struggle became the way to understand the core involved in support.

At the same time that I was developing and implementing this Support Program, I was struggling with the concept of how and why some failures in education seem to be the key to success whereas other failures continue to be failing situations. From this concept I wrote a paper entitled "Toward an Understanding of the Experience of Grief". In that paper I examined the experience of grief, reflected on the writing of that experience, tied that reflection into curriculum development and, then, reflected on the experience of putting grief into words. The writing of that paper was an ongoing struggle for myself, as this time I worked to capture the essence of the struggle involved in grief as it affects both recuperation and learning. I recall times when I wondered if I would ever be able to identify the fundamental nature of grieving. I also recall times when I wondered if perhaps it was best if I changed the focus of the paper, altogether.

That paper was being written as an assignment for one

of my Masters courses. As I struggled with that paper I kept returning, in my mind, to both verbal and written comments made by the instructor of the course. They were comments which inspired me to carry on and that reassured me that what I was trying to achieve held possibilities for success. I was never told in a direct manner that I had permission to write that paper nor that I would certainly achieve positive results. Rather, I was encouraged to write that paper by an instructor who empowered my ideas and who, in so doing, allowed me to know for certain that I would experience even a small measure of success. He listened to my ideas, responded to some underlying meanings in my statements, expressed positive statements about my work and when I was not clear in either verbal or written statements, would guide me to look at those statements in a new light. Throughout my struggle with that paper that instructor was in control of how he empowered me to continue to work. He allowed me to be in control of both my struggle and of what I wrote.

As that paper drew to a conclusion I realized that I had described very similar themes as were emerging both from the Pilot Support Program I had already carried out, and in subsequent thesis work. Again, another struggle, or likely a continuation of the same struggle, ensued as I began to write this thesis. During the process of reaching

ground there have been times when I felt lost on some unfamiliar road as the data led me in circles rather than toward an ever deepening understanding. Those were the times that I felt frustrated, that I might never succeed. It was only through support that I have felt that I could achieve ground. I was given indirect permission from a variety of people to struggle with those data. I was never told this was an impossible feat, difficult, but not impossible. It was as if I was presented with a challenge to master that difficulty if I so chose. It was apparent that the struggle was necessary to achieve positive results and that success was possible. I was strengthened by those who listened to my rambling, spoke with me about underlying meanings of some of my statements and concepts and helped me to explore new avenues of thought. I was guided out of ever-threatening circles through, both, provision of information and assistance in focusing on where I was going with this thesis. I was bound by a strong desire to answer my research question. All the while I was left in control of this struggle so that I might achieve a success that was measured by the meaning of this struggle for me. Again, those who supported me in my struggle were in control of their empowering forces. Through their own control they allowed me to remain in control of my own struggle.

Times when I have felt that my energies have been

sapped were whenever I spoke to anyone who could not see possibilities in my struggle and who were not interested in listening to, or in guiding me in my struggle. This situation created a struggle of its own that revolved around the concept of survival. To have my energy sapped by a non-supportive person meant that I was presented with a choice. On the one hand, I could abandon my struggle, or at the least, camouflage it such that I would take an easier route and at the same time receive a form of support from the ensuing artificial peace. Inwardly, though, I knew that an artificial peace would not last and eventually the original struggle would return. On the other hand, I could choose to carry on with my struggle, suffer the loss of a supportive person and hope inwardly for support to come from someone else.

I chose this second alternative because of the strong drive within me to understand the fundamental nature of support. Whenever I suffered the loss of a supportive person I felt the pain, as one does with any loss. But that pain was not lingering likely because I received support from others, over time. These supportive people empowered my movement toward completion of this thesis by nurturing my own control.

Conclusion

Each time I struggled to make sense of an aspect of recuperation or learning, I was supported in that struggle when I was allowed to remain in control. Sometimes that control felt shaky but because there was always a spark of control I never felt the hopeless feeling which can accompany loss of control. At times I felt I needed more support than at other times, but as long as I was being empowered I was able to grow within the struggles I experienced. I learned by being allowed to be in control of my struggle.

CHAPTER 7

Phenomenological Reflection and Writing

A variety of data have been examined up to this point, with six beginning themes having emerged as a framework for providing support. As additional data were presented, a more focused understanding has unfolded which has allowed a deeper meaning of support to show through. Here I will describe these focused themes, the essential themes of support, and then continue to make visible the meaning structure of the lived experience of support.

Essential Themes

The most fundamental theme which appeared in supporting a patient toward recovery is a double theme: that of the nurse being in control of patient centered support methods and allowing the patient to be in control of his or her own recuperation. Three additional themes, (a) being given hope as a way for a patient to be strengthened within recuperation; (b) being given information as a way for a patient to be guided toward recuperation; (c) being given permission to struggle as a way for the patient to be given freedom to recuperate, have a catalytic effect on the pivotal theme, control. As a

consequence, these three additional themes also affect recuperation. Along with control exists an important underlying theme: that of the patient being allowed to struggle to recuperate according to that which is meaningful to him or her. This theme is present as a vehicle which enables the two facets of control to exist. It follows that these five themes are important in total, each carrying a key role in supporting a patient toward recuperation. This entire recuperation experience centres around the meaning of this struggle to the patient. The patient, then, is the focus of recuperation.

It is apparent that to be supported in recuperation requires that the patient be permitted to struggle if that be his or her choice. That choice is presented in a silent caring manner so the patient feels, through a special rapport with the nurse, that he or she has full control. That choice is the empowering means to recuperate. Also, the possibility of recuperation is enhanced once the way is made available. These two concepts work in concert for one cannot exist without the other.

It is important, too, that the patient's struggle not be removed or made easy, rather, that he or she be nurtured within that struggle, in order to grow from the experience, in order to gain meaning from the experience. For the struggle to be removed from the patient is akin to stunting

the patient's growth and removing the opportunity for him or her to gain meaning from that experience. It is important not to facilitate the patient's struggle, for to facilitate means to make a struggle easy. It is necessary, instead, to nurture the patient in his or her struggle.

The way to recuperation requires nurturing through empowerment but the mere act of choosing to struggle will not provide full control of recuperation. An inner awareness by the patient that there is the possibility that a new life can exist beyond the struggle involved in illness gives the patient a reason to struggle. It is a hope for recovery. This reason, in turn, enhances the patient's control as the patient attempts to complete his or her struggle. It is this strong desire to fulfill the possibility of recuperation which gives power to control, which gives control to recuperation and consequently which gives meaning to the patient's own struggle. This profound drive is surrounded by hope for a time when the struggle of illness subsides. To know that the struggle is a means to recuperate is to know a sense of assuredness and courage. Through encouragement, empathy and the strength of human presence, the nurse expresses to the patient that the recuperation struggle is normal, that the patient will emerge from that darkened stage to a world with light. This light depicts hope and to a struggling patient this

light represents balance in recuperation.

The way to recuperation is not set out in neon lights. In fact, the way varies from person to person. The struggle of recuperation is a struggle to find the way. In a groping, grasping manner it is each patient's solitary fight to survive the turmoil inside oneself. The patient copes with this turmoil in three stages. The first stage is a sorting process where all aspects of one's illness as well as one's life before the illness and the future life the patient faces are put into place. The second stage involves a time of trying to make sense of the struggle. The third stage is the process of making the struggle meaningful. Time is an important factor in allowing the patient to achieve these three stages. As well, the presence of the five previously mentioned themes is also important in enhancing the patient's movement through these stages. But the way is never certain. Rather than struggling toward a signal in the distance, it is much akin to suffering through a storm where the way is blackened. "How will I ever survive?", is the nature of the call in the dark.

Thus, it is apparent that that call asks for a guiding hand. That hand cannot pull a patient to safety but it can be a strength in providing stepping-stones by which to feel one's way. Those stepping-stones are, in a small manner,

packages of information which give direction to the patient's struggle. It is important to allow the patient to be in control of the use of this information. To be in control is an empowering force, but to be told to use the information is to remove the patient's control and, thus, the patient's internal power and desire to move toward recuperation.

Though a struggle is a conflict, in itself, it is important that guidance within a struggle is not a conflict. Nonconflicting guidance is empowering. Conflicting guidance lacks strength and saps energy from struggling patients. Consider, for a moment, that information given to patients might actually be conflicting. How then might the struggling patient find his or her way before getting too tired and giving up the fight, or choosing instead to camouflage the struggle? A camouflaged struggle allows the patient to move toward recuperation, but, the patient misses out on the peace that is felt when the struggle subsides. This patient likely will not experience the full possibility of recuperation.

The reason for providing nonconflicting information is not to make the struggle easy but, rather, to allow the struggle to occur. Instead of offering conflicting information, the information must be presented in a simple, clear and uniform manner and be presented in that same way

as often as the patient needs, in order for him or her to follow those stepping-stones toward the light of recuperation.

The presence of a camouflaged struggle is also possible when a patient does not sense that he or she has permission to struggle and consequently that he or she does not have control of that struggle. Again, it is likely that a camouflaged struggle will yield an incomplete recuperation, one void of its natural tranquillity. To give one permission to struggle is not as straight forward as it might first sound. It is a permission that comes not so much from what is said but, rather, from what is unsaid. The nurse displays a human concern that becomes a silent energy. Support can exist through human presence and contact. It is much like the strength that can be felt through touch. The nonverbal acceptance of the patient and the trial he or she is facing can be a powerfully loud catalyst in moving a patient toward recuperation. When verbal and nonverbal communication is employed it is paramount that what is said and how it is said be empowering to the patient. For the patient to receive mixed messages is akin to not receiving any permission at all.

It is important for the patient to know that it is okay to experience the emotional roller coaster of illness,

that it is okay to cry and that it is okay to feel as low as he or she might feel, and at the same time that there remains an element of hope. It is also crucial for the patient to know it is okay to falter, and perhaps fall along that unlighted way and that it is okay, then, to get back up and move forward or even backward.

Using the analogy of acting and with the nurse being in the role of supporting cast, it is important that this permission be granted, so the focus be on the patient rather than on the nurse. Permission is granted by being with the patient, by listening to not only what the patient says but also to the meaning of that which he or she says. If the patient feels important in his or her struggle, he or she will know that the way the struggle is expressed is important as well as acceptable. Acceptance is a way of saying there is a future and that the future is possible.

When recuperation is presented as possible no matter what the roadblocks, no matter how difficult the course, it is a truly empowering feeling for a patient who is scrambling through the darkness. The feeling of knowing that a success of some stature is achievable is, for the patient, knowledge that it is okay for him or her to be in control and that he or she is capable of achieving recuperation in his or her own unique manner.

The nurse's meaning structure is not the focal point

in this drama. It is the patient's meaning structure that this entire labour revolves around. It is the patient's struggle. It is the patient who, only through his or her own control, can choose to bear the pain of this experience. It is the patient who is to be nurtured through this experience and that can only be achieved when the focus is on what is important to that patient.

Nurses, then, to be able to support patients, could move toward accepting a conceptual framework which allows all communication to be responsive to the patient's experience. A nurse would respond in a caring and controlled manner. The nurse would relinquish control of recuperation to the patient through controlled support.

Control for the patient is only limited when he or she is unable to communicate in any manner. But the moment there is a flicker of communication that spark indicates a measure of control. As the patient gradually recuperates he or she draws less and less from the nurturing lifeline available from the nurse. He or she moves from the imbalance of illness through to the balance of recuperation. Sometimes a patient never achieves full recovery but it is possible to achieve balance within chronic illness.

A final factor exists in the nurturing of a patient in his or her struggle. A nurse is one of the members of the

health team. But all the members of the team must work together to foster the patient's growth within his or her recuperation struggle. If it is apparent that the patient's struggle could be further nurtured by a change in the support offered by the team as a whole, it is the ethical responsibility, then, of the individual team members, to work together to create a fully supportive environment. The higher the quality of support offered by the health team, the more powerful is the supportive lifeline which is created. To offer support in this manner, then, is to offer support from an inner perspective, from the patient's perspective. This is the nurturing nature of support and that which gives possibility to recuperation.

Allow me to return for a moment to the analogy of acting. It is the patient who is the primary actor or actress. Regardless of the number of times a patient begins the role of recuperating, he or she is a novice in each struggle. It is important, then, that nurses set the stage for the possibility of recuperation and allow the curtains to be opened to that reality play. Simultaneously, the patient gradually assumes control of recovery. The patient then grows in and from participation in whatever aspect of the play is meaningful to his or her movement within recuperation. The patient remains the

central figure in this drama, whether he or she takes on the role of audience or star. Nurses take on the role of supporting cast, seldom acting, but staying ready behind the scenes, nurturing the patient through prompts, encouragement, and being ever present.

And so it becomes a matter of the emphasis of nursing being: allowing the patient to recuperate rather than nursing the patient to recover. The same can be said about teaching the patient. More can come from allowing the patient to learn than by solely teaching the patient. It is that small shift in emphasis that places the focus on the patient rather than on the nurse. It is the patient, who, as the solitary actor or actress in this reality play, must find his or her way on life's stage. Nurses cannot give the patient strength for this endeavour through acting for the patient. Rather, nurses can give the patient strength by allowing the patient to learn this solitary script, thus allowing the patient to recuperate. It is through the completion of the struggle that the recuperation role is completed. If this reality play were presented as a still life picture or as a woven scene, this tapestry would only be complete upon the completion of the struggle.

A patient's wings can be clipped by one's illness but as the patient is set free to be an important person on

life's stage, he or she is, in a sense, set free to learn to fly again. Sometimes a struggle can only take place through thought and imagination as that may be the patient's only means to fly, but that can be a sense of freedom nonetheless. As the patient is set free to fly away toward new struggles, he or she will return for strength, not like a patient who takes flight to escape, too overburdened by a present struggle that to return could mean the end of flight. The patient who is allowed to grow through his or her role will likely return to be nurtured. The patient who is not allowed to grow and change will likely avoid further struggles in life or seek support elsewhere.

Conclusion

It is apparent that to recuperate from illness is to recuperate from a form of crisis. To recuperate requires energy from a source other than self. For a supporting person to be in control of the power which the patient takes in is, in effect, a sapping of energy from the patient. Rather, the supporting person must be in control of the power available but it is the patient who must be in control of the power used. To empower a patient to recover, the nurse must let go of the patient, allowing the patient full control and in so doing, this letting go

actually strengthens the patient in his or her struggle. In concert with patient control, it is essential that the nurse make an energy source available to the patient. This energy source is the catalyst which allows control to be empowering. It consists of three ingredients: (a) instilling hope as a way to strengthen a patient within recuperation, (b) providing information as a way to guide a patient toward recuperation, (c) giving permission as a way to give freedom to one's recuperation struggle.

In order for control, and its catalysts to exist, a means to allow them to function, must also exist. This vehicle is the struggle involved in the experience of illness and recuperation. When that struggle is the patient's choice and when the entire recuperative process focuses on the meaning of the struggle for the patient, then a truly harmonious support exists.

This struggle occurs in three stages, sorting through the effects of illness, making sense of the struggle and making the struggle meaningful. Patients require time to work through these three stages. As well, those factors previously mentioned, control; the three catalysts and allowing the struggle to occur, are all important in assisting the patient through these three stages.

The patient feels strengthened through both verbal and nonverbal communication. Support is enhanced through human

presence and contact. All these factors, together, describe what it is about the experience of support which gives possibility to recuperation.

Chapter 8

General Conclusions

The purpose of this study was to determine the fundamental factors about support which assist the patient within the process of recuperation. In order to determine these factors I asked the research question: "what is it about the experience of support which gives possibility to recuperation?" To answer this question I chose phenomenological research methodology in order to assist me to move to a deep level of understanding. This understanding became a reflection of patients' experiences of support.

Within the context of phenomenological methodology I conducted reflexive writing. Back and forth I moved through the data as I approached an ever deepening understanding of the nature of support. Themes came into view then were replaced by more meaningful themes. There was the presence of both vitality as well as constant movement of those themes until I reached ground. Upon reaching ground the movement stopped and the vitality of the meaning of the nature of support was illuminated.

To understand what it is about support that gives possibility to recuperation, is to understand the essential

nature of support itself. A lifeline is a sustaining, strength-giving direction for the patient. This strength is given through verbal and nonverbal communication whereby the patient is empowered to struggle. The patient, being in control of his or her tapping of the supportive qualities of the lifeline, is in position to be fully supported according to the meaning of the MI for him or for her. To be supported in this manner is to be supported within the possibility of recuperation.

Patient control was a dominant factor in supporting a patient toward recuperation. Control by the patient was possible when a nurse was in control of his or her nursing. It was important for the nurse to bring into his or her nursing a quality of hope for the patient, hope such that the patient could actually feel the possibility of recuperation and then work with that possibility. Control by the patient also required a knowledge of how and which way to proceed. When a nurse gave information to the patient allowing him or her the means by which to recuperate, the nurse was empowering the patient with the possibility of recuperation. One more ingredient of control was important. The patient needed to know that the struggle he or she experienced during recuperation was acceptable and normal. The patient needed to know that it was okay to feel whatever way he or she felt and that it

was okay to exhibit those feelings. The patient was essentially given permission to go through the experience of recuperation.

Along with all aspects of control was a vehicle by which this control can exist. That vehicle was the presence of a struggle. It was the patient alone who was allowed to decide when and if to enter that struggle. It was through the struggle of recuperation that growth occured and that recuperation was fully possible. Recuperation occured in three stages, sorting through the illness experience, making sense out of the struggle and making the struggle meaningful. The possibility of recuperation occured when these three stages were allowed to exist.

Generally, as society changes, and specifically, as the focus of health care changes, more factors may emerge which may direct the description of the nature of support toward a new ground. Until such time arrives, I feel comfortable with the ground I achieved in this study.

Further research is necessary to further understand the reasons why aspects of support exist as they presently do. To understand what it is about support which gives possibility to recuperation, likely is not the only information necessary to specifically foster changes in nursing and to generally foster changes in the health care

system. The information from this study forms a base from which to contribute to those changes.

I suggest that further qualitative research is necessary in the following areas:

1. Explore the gap between the support that nursing purports to offer and support experienced by patients.

2. Explore nurses' experiences of supporting patients.

3. Explore what it means for nurses to be supported in their work.

4. Explore nurses' need to be in control.

5. Explore the common ground between excellence in nursing and excellence in teaching.

Through this research study, possible implications emerge both for nursing in general and for the development of a support model. A major implication is the narrowing of the gap between support needs of patients and support experienced by patients. A second implication is the development of a model of support with emphasis on the subtle nature of support which gives possibility to recuperation. A third implication is a changed focus of support from an individual health team member approach to an overall team approach.

Understanding the essential nature of support, provides nursing with a measure with which to evaluate

present supportive acts, together with the support needs of patients. Subsequent revision of supportive acts, to bring them in line with support needs of patients is a way of narrowing this gap. A model of support would provide both consistency in and a method by which to provide meaningful support. The quality of support is far superior when the health team as a whole is united in its supportive efforts, than when only certain members of the team provide a high quality of support.

It is essential that the health team, in general, and nurses, specifically, concentrate efforts toward fostering patients' growth, through patients' struggles to recuperate. Each patient is an individual person and thus has a need to be treated as an individual, with rights and responsibilities for the control of his or her own struggle. It is important, then, that nurses' responsibilities be focused on supporting patients within their individual struggles with illness.

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Appendices

Appendix A

January 1987

Re: Pilot Support Program

Dear_____:

I, Marion Healey-Ogden, am a registered nurse with experience working in the Intensive Care Unit at Vancouver General Hospital (VGH) and teaching in the Nursing Dept. at VGH and at the College of New Caledonia (CNC). I am piloting a support program for heart attack patients, as part of the requirements for my Master of Arts (MA) degree at the University of Victoria.

This is a pilot project to assess the effectiveness of a program of support in assisting patients to cope effectively with their heart attack. The data from this program would also be used in thesis format, to portray an aspect of the experience of heart attack patients. Confidentiality would be maintained throughout this program and within thesis work. If you are willing to participate in this program I will visit you for a brief period once each day throughout your hospitalization on 3 West. I will continue to visit you in your home in decreasing frequency over the next year. You would be asked to complete a short (about three (3) pages) questionnaire at about (4) months and one (1) year from now.

If at any time you would wish to withdraw from this support program you would be able to do so.

I, _____, am willing to participate
(Patient's Signature)
in this pilot support program. I understand that I will be able to withdraw from this program before its completion if I so wish.

I, _____, give consent for the
(Internist's Signature)
above-named patient to participate in this pilot support program.

I, _____, give consent for the
(General Practitioner's Signature)
above-named patient to participate in this pilot support program.

Thank-you

Marion Healey-Ogden RN, BSN.

Appendix B

May 1987 Interview Format

1. MI Experience:

   a. Describe your feelings during your heart attack experience.

   b. Describe times when or if you felt:
   helpless / helped
   powerless / empowered
   the situation was hopeless / hopeful

   c. What was the most important thing which made the difference between the negative and positive situations described in #1.b?

   d. Describe what you felt were expectations of you during recuperation.

2. Support in MI Experience:

   a. Describe times when you felt most supported during your heart attack experience, in hospital and at home. Explain why you felt supported at these times, how you were supported and by whom or what.

   b. Describe the best way to be helped through this heart attack experience.

   c. Describe what it means to you to recuperate from your heart attack.

3. Support in Other Experiences:

   a. Describe times when you have felt most supported.

   b. Is there a difference between support that you experienced in other experiences and support you experienced during your heart attack? Is there a similarity?

c. In all situations (described in #3) did you have any support needs which were not met?

4. Meaning of Support:

a. Thinking of the word, "Support", what does it mean to you to be supported through this heart attack experience?

b. What does it mean not to be supported?

c. Describe the relationship you see between:
support and care
support and empower

d. How can support help you make changes?

At the end of this time give the questionnaire to the patient for him to complete for the June interview.

Appendix C

May/June 1987 Questionnaire

The purpose of this questionnaire is to gather information which will help describe "the recovery experience of heart attack patients". It will then be possible for health personnel to establish guidelines for supporting heart attack patients during their recuperation.

Please complete the following statements, in regard to your heart attack:

1. My friends and family supported me by...

2. Health personnel supported me by...

3. The best way to overcome fear is...

4. The best way to overcome helplessness is...

5. I wish that the nurses would have...

6. I wish that the doctors would have...

7. I wish that the_____would have...

8. Talking about my heart attack experience, and possible life style changes, was/is...

9. The best way that heart attack patients could be helped to avoid another heart attack is...

10. This heart attack experience was/is...

Please complete the following in regard to your heart attack:

1. Describe your most crucial concern(s) while in hospital and/or at home. Explain how you were or could have been helped to deal with that (those) concern(s).

2. Describe your need for different kinds of support at different times in your illness/recuperation while (a) at home, (b) in emergency, (c) in ICU, (d) on 3 West, and (e) on return home.

3. Describe the support you received from (a) hospital personnel, and from (b) others. What did that support mean to your ability to recuperate? Explain how you could have been further helped to recuperate.

4. Describe any lack of support which detracted from your ability to work through your illness.

5. What is it about support that, you feel, can assist heart attack patients to recover?

6. Explain any difference in support which you needed during any past crisis situation(s), compared with support which you needed during this heart attack. Please state the past crisis situation(s).

7. Do you feel that support is necessary to fully recover from a heart attack? Why or why not?

8. What is the meaning of "support," for you? What is the meaning of "recuperation," for you?

9. Describe your personal experience of recuperation following this heart attack and give examples to clarify your description.

10. Describe what you felt were expectations of you (a) during your hospitalization and (b) when at home, during recuperation. How did/do you feel about those expectations?

Thank-you for your participation in completing this questionnaire.

Appendix D

June 1987 Interview Format

1. Clarification of Answers:

   a. Clarify with each patient that I understand their meaning for each answer on the questionnaire.

2. Meaning of Support, (related to assisting MI patients):
   a. From what support means to you, suggest ways that health professionals can help patients through their heart attack experience. through any experience.

3. Clarification of Themes:

   It is important for me to keep in mind the (thesis) research question, ("What is it about the experience of support which gives possibility to recuperation?"), when I ask each patient to clarify how closely the following themes describe his MI experience and support during recuperation.

   a. Having someone listen to the sorting process is a form of passive permission which gives credence to, and facilitates the sorting process.

   b. An enabling factor exists in achieving a sense of balance or harmony within recuperation.

   c. To be allowed and given the opportunity to achieve and maintain control of recovery can create a sense of balance and self-worth.

   d. Approval, assistance and interest from family, friends and hospital personnel is important in order to foster the possibility of recuperation.

   e. To receive information as the need arises is a comforting situation, reducing the fear of the unknown.

f. Over time, as others have faith in the patient and in his struggle, a comforting factor exists in response to any self-felt guilt related to the occurence of his heart attack.

Appendix E

October 1988 Interview Format

1. Identify the fit and misfit of the following themes, as these themes relate to what it is about your experience of support which gives possibility to recuperation from your heart attack.

    a. being allowed to be in control of your recuperation.

    b. being given hope as a way to be strengthened within recuperation.

    c. being given information as a way to be guided toward recuperation.

    d. being given permission to struggle as a way to be given freedom to recuperate.

    e. being allowed to struggle according to that which is meaningful for you.

Vita

Surname: Healey-Ogden Given Names: Marion, Joan

Place of Birth: Kamloops, B.C.

Date of Birth: August 10, 1949

Educational Institutions Attended, with Dates of Entering and Leaving:

Vancouver General Hospital, School of Nursing	1968	to 1971
Langara College, Vancouver	1969	to 1972
University of British Columbia, Vancouver	1972	to 1974
University of Victoria, B.C.	1985	to 1989

Degrees, Diplomas, Etc., Awarded, with Dates and Names of Institutions:

Graduate Nurse	1971	Vancouver General Hospital, B.C.
Community Health Nurse	1973	University of British Columbia
BSN	1974	University of British Columbia

Honours and Awards:

The Mrs. W.M. Rose M.B.E. Memorial Award in Public Health Nursing	1975

Publications:

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Author: [redacted]

Marion Joan Healey-Ogden

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