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THE IMPACT OF SOCIAL SUPPORT ON LIVING WITH HEART FAILURE

by

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Abstract

This descriptive correlational study explored the relationship between perceived social support and perceptions of illness for individuals living with New York Heart Association Class Two or Class Three congestive heart failure. A total of 34 participants were interviewed at the University of Ottawa Heart Institute, Ambulatory Heart Failure Clinic. Participants completed three questionnaires, which included a demographic questionnaire, a social support questionnaire (PRQ-85/Part Two), and the Meaning of Illness Questionnaire (MOIQ). They responded to two open-ended questions that elicited information about how heart failure had affected their lives and about the resources that had been most helpful to them in coping with their illness. This data was collected in the clinic during a routine follow-up visit, with the researcher present. The responses to the two open-ended questions were tape-recorded.

Results indicated that subjects perceived their social support to be high. Perceptions or cognitive appraisals of illness were generally positive with respect to MOIQ Factor 4 (positive attitude toward illness as challenge, hope, motivation, and control). Results for MOIQ Factor 3 (degree of stress, change in commitments, and secondary coping resources to deal with it) revealed moderate mean scores. The negative impact of the illness on everyday living patterns was evident by the low mean scores seen in the other factors that reflected a concern for the unpredictability, controllability and vulnerability of the disease.

Perceived social support was seen to account for 24% of the variance in MOIQ Factor 3 (degree of stress, change in commitments, and secondary coping resources to deal with it), and 11% of the variance in MOIQ Factor 2 (type of stress, negative attitude of harm, loss or threat, and viewing the illness as disabling, disfiguring, and deteriorating).

Content analysis revealed six major themes which described the subjects' feelings about how heart failure had affected their lives. The themes that were elicited were: physical limitations, surprise and disbelief, a need for knowledge, adjustment, support from significant others, and getting in touch with one's spirituality.

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Chapter One

INTRODUCTION

1.1 Background to the Problem

Chronic heart failure is the final common pathway of all heart diseases. It is a long-term illness, often associated with disability and characterised by life-threatening exacerbations.

Heart failure is defined as a complex clinical syndrome that can result from any cardiac disorder that impairs the ability of the ventricles to eject blood. The cardinal manifestations of heart failure are dyspnea and fatigue (which may limit exercise tolerance), and fluid retention (which may lead to pulmonary and peripheral edema). Both abnormalities can impair the functional capacity and quality of life of affected individuals. In addition, heart failure is a progressive disorder for most patients. With time, the symptoms of the disease and their functional consequences become increasingly severe, such that patients may experience symptoms even at rest or on minimal exertion. Such progression is directly related to the inevitable deterioration of cardiac structure and function, which may occur without further insult to the heart. This disease progression leads to a recurrent need for medical care and hospitalisation, and finally to the demise of the patient. Sudden death may interrupt the evolution and progression of heart failure at any time (Packer & Cohn, 1999).

The goals of treating heart failure are not only to improve symptoms and quality of life, but also to slow the progression of the disease, and thereby decrease the need for rehospitalisation, along with the rising costs of treatment. Early identification and appropriate

treatment of patients with heart failure are critical to achieve the greatest impact on the population at large (Packer & Cohn, 1999).

Heart failure is the only major cardiovascular disorder that is increasing in incidence and prevalence today. This is a reflection of the ageing population and the effective medical therapies available (Heffernan & Langer, 2000). According to the Heart and Stroke Foundation of Canada, an estimated 420,000 Canadians were living with heart failure in 1997. In that same year, 48,000 deaths were attributed to CHF in Canada. These values reflect a prevalence of 1-2% in the general population, with an increase to 6-10% in patients older than 65 years. Medical therapy is effective at improving the quality of life of patients with CHF and has achieved limited success in extending the lives of these individuals. Unfortunately, many ultimately succumb to the disease. The median survival after diagnosis is 1.7 years in men and 3.2 years in women, with less than 50% of individuals surviving more than five years (Heffernan & Langer, 2000).

In the United States, heart failure afflicts 4.8 million people, with 400,000 to 700,000 new cases developing each year. Approximately 1.5-2.0% of the population has heart failure, and the prevalence increases to 6-10% in patients greater than 65 years old (American Heart Association Statistical Update, 1998; Massie & Shah, 1997). Heart failure is responsible for more than 11 million physician office visits, and causes or contributes to over 3.5 million hospitalisations annually. Approximately one-third of heart patients hospitalised for heart failure are readmitted to the hospital within 90 days, and 29-47% are readmitted within three to six months (Packer & Cohn, 1999). The annual direct expenditures for heart failure in the United States have been estimated at \$20-40 billion. The cost of hospitalisation for heart failure is twice that for all forms of cancer (O'Connell & Bristow, 1994).

Successful management of heart failure often requires major lifestyle adjustment by patients and their families. Symptoms of heart failure must be monitored so that prompt treatment is obtained and severe deterioration requiring hospitalisation is prevented. There must also be an adjustment to the psychological burden of living with new limitations and the knowledge that life expectancy may be shortened (Dracup, Baker, Dunbar et al., 1994). Many studies have concluded that readmissions could have been avoided in 40-59% of the patients if there had been better assessments, if rehabilitation had been more adequate, and if discharge had been more carefully planned. Poor compliance with medication and diet regimens were also cited as difficulties for patients, as well as lack of education and social isolation (Graham & Livesley, 1983; Vinson, Rich, Shaw & Sperry, 1990; Rich et al., 1995; Shah, Der, Ruggiero, Heidenreich & Massie, 1998).

There is considerable theoretical evidence of the paramount role of social support in adjustment to chronic illnesses such as heart failure (Cronkite & Moos, 1984; Cohen & Syme, 1985; Sarason & Sarason, 1985; Markle-Reid, 1989; Rideout, 1992; Moser, 1994; Stewart et al., 1997a; Stewart, Hirth, Klassen, Makrides & Wolf, 1997b). Some researchers have suggested that the evidence linking insufficient social support and vulnerability to poor physical and mental health during recovery is strong enough to warrant the consideration of inadequate social support as a potent risk factor for increased morbidity and mortality (Moser, 1994; Gliksman, Lazarus, Wilson & Leeder, 1995; Stewart et al., 1997a & b; Stewart et al., 2000). Nurses need to assess the current sources of support from family, friends, and health care professionals in order to determine any discrepancies between available and desired levels of support when planning interventions with patients and their families. This assessment can help identify patients at potential risk for difficulties in managing a chronic illness such as heart failure.

It is important to determine each client's perception of the illness. Some patients perceive heart failure as a hopeless situation, viewing themselves as powerless to alter the course of the illness as they wait to die. Others take on living with a chronic illness as another of life's challenges to be mastered (Waller, 1991). This knowledge of illness perception can impact on how support may be tailored to meet the identified needs.

There is evidence to suggest that perception of one's illness is a factor that could influence psycho-social adjustment to chronic illness (Craig, 1983; Lazarus & Folkman, 1984; Viney & Westbrook, 1984; Browne et al., 1988; Waller, 1991; Rideout, 1992; Weir, Browne, Roberts, Tunks & Gafni, 1994; Riegel, Carlson & Glaser, 2000). Research has shown that patients who are better adjusted to heart failure tend to be more involved with their own care. For example, patients who take an active role in caring for themselves perceive less helplessness, feel more able to influence their disease, and experience better psychological outcomes (Price, 1993; Baas, Fontana & Bhat, 1997). A patient's perception of an illness may affect the way an individual manages on a daily basis. One of the factors that has been shown to influence both perception and adjustment to illness is social support (Markle-Reid, 1989; Weir et al., 1994).

A study which determines the influence of perceived social support on perception of illness in patients with heart failure may improve care through development of strategies which would help both patients and families live with the disease.

1.2 Purpose of the Study

The purpose of this study is to determine the nature of the relationship between perceived social support and perceptions of illness in individuals with chronic congestive heart failure.

1.3 Research Objectives

1. To determine the perception of social support for patients with NYHA Class Two or Class Three congestive heart failure.
2. To determine the perception of illness for patients experiencing NYHA Class Two or Class Three congestive heart failure.
3. To determine the strength of the relationship between perceptions of social support and perceptions of illness for patients experiencing NYHA Class Two or Class Three congestive heart failure.

Chapter Two

LITERATURE REVIEW AND CONCEPTUAL MODEL

This chapter is divided into two major areas of discussion. A review of the literature will be presented with respect to social support and chronic illness and, more specifically, for cardiovascular diseases such as chronic congestive heart failure. This will be followed by an examination of the underpinnings of perceived social support and perception of illness, and the relationship of these variables to psycho-social adjustment to living with a chronic illness. Finally, the theoretical framework for the present study will be outlined.

2.1 Literature Review

2.1.1 Social support and chronic illness

Chronic illness is permanent and progressive, requires ongoing adaptation on the part of the individual and network, and necessitates long-term monitoring by health professionals, patients, and their families (Dimond & Jones, 1983; Rolland, 1984; Corbin & Strauss, 1988; White, Richter & Fry, 1992; Pollock, 1993; Gliksman et al., 1995; Stewart et al., 1997a & b).

Individuals experiencing chronic illness are influenced not only by normative changes and life events, but also by the stressors produced by the uncertainties of disease progression and the changing demands required to manage the illness (White et al., 1992). Coping resources such as social support may be important predictors of successful adaptation in the chronically ill (White et al., 1992; Pollock, 1993; Weir et al., 1994; Gliksman et al., 1995; Stewart et al., 1997a & b).

A multi-stage project that included examination of life-stage transitions of chronically ill women with diabetes mellitus was carried out by White et al. (1992). Perceived social support was found to diminish with failing health in these individuals with diabetes. It was further noted that social isolation was commonly experienced by these chronically-ill individuals as well as their significant others, and that lack of social support seemed to contribute to deterioration in health and brought poorer physical outcomes. Poor health status may limit the opportunity for the chronically ill to develop and maintain social networks.

A nursing research program was conducted by Stewart et al. (1997a) which studied social support for individuals with a variety of chronic illnesses. Specific interventions were used on different groups of patients to determine sources, links and impact of support on health, health behaviours, and use of health services. Some of the interventions included: telephone and computer support, peer home visits, and face-to-face support groups. The authors reported that most support was provided by family members and/or close relationships. A variety of support interventions for haemophiliacs with AIDS, myocardial infarction survivors, or stroke survivors and their respective family caregivers were shown to help them cope with the demands of a chronic condition. Those living with AIDS reported increased problem-focused coping and actions, particularly information seeking and advocacy. Peer visitors explained about coping strategies to caregivers of stroke survivors; caregivers noted improved information-seeking and distraction from stress. The couples coping with myocardial infarction reported enhanced problem-focused and relationship-focused coping. In close support relationships, the coping of one partner influenced the coping behaviours of the other.

Further studies are needed to examine the sources and types of social support that would benefit the recipient from the time of diagnosis throughout the course of the chronic illness. As

well, nursing research directed toward understanding the role of the partner and family in easing adaptation to chronic illness will provide critical information on how best to enhance and mobilise these support systems (Stewart, 1997a).

2.1.2 Social support and cardiovascular illness/heart failure

Coronary artery disease accounts for the most significant mortality and morbidity statistics (Johnstone et al., 1994; American Heart Association Statistical Update, 1998; Packer & Cohn, 1999; Heffernan & Langer, 2000). Sixty to seventy percent of persons experiencing a myocardial infarction develop heart failure or, as it is otherwise termed, end-stage cardiac disease (Johnstone et al., 1994; Meagher-Stewart, 1994; AHA Statistical Update, 1998; Packer & Cohn, 1999; Heffernan & Langer, 2000).

The New York Heart Association (NYHA) classification of heart failure is widely used to grade the degree of symptoms of adult heart failure patients, and is outlined below:

- Class 1: No symptoms
- Class 2: Symptoms with ordinary activity
- Class 3: Symptoms with less than ordinary activity
- Class 4: Symptoms at rest (Konstam et al., 1994)

From clinical experience and a review of the literature, survival and quality of life are two of the major issues that cardiac patients and their families confront. The links between social support, survival, quality of life and cardiovascular illness have been researched extensively in the last two decades (Sirles & Selleck, 1989; Meagher-Stewart, 1994; Moser, 1994; Yates, Skaggs & Parker, 1994; Gliksman et al., 1995; McCauley, 1995; Harrison, Juniper & Mitchell-DiCenso, 1996; Stewart et al., 1997a).

Social support is believed to affect recovery from a cardiac event by two general mechanisms: behavioural and physiologic. Behavioural social support has an impact on recovery by influencing behaviour known to affect cardiac risk. For example, recovering cardiac patients with adequate social support may find it easier to adopt healthy behaviours, such as increasing exercise, smoking cessation, and a “heart healthy” diet. Conversely, socially-isolated patients may lack the support resources necessary to effectively alter risky cardiac behaviour patterns. Consequently, these patients remain at increased risk for subsequent cardiac events (Moser, 1994).

Many of the studies that discuss the role of social support on cardiovascular illness have been done in the post-myocardial infarction and bypass surgery populations. Few studies could be found that measured the impact of social support on living with heart failure.

Martensson, Karlsson & Fridlund (1997) used a qualitative approach to focus on how male patients suffering from congestive heart failure perceived their life situation. Six categories emerged, which described the patients’ view of how their life situations had been affected by heart failure. These included feelings of: (1) a belief in the future (hope), (2) gaining awareness of the illness and its impact on their life and living patterns, (3) support from the environment (perceived support), (4) a sense of limitation, (5) a lack of energy, and (6) resignation. A further study was done by Martensson, Karlsson & Fridlund (1998) with a group of female patients suffering from heart failure. Five themes emerged in these results, namely, feeling: (1) content, (2) a sense of support, (3) a sense of limitation, (4) anxiety, and (5) powerless.

In both studies, Martensson et al. (1997, 1998) elicited the patients’ perceptions of support from their environments. They reported both positive and negative feelings in dealing with day-to-day living activities. Congestive heart failure may produce feelings of alienation and

estrangement from family members and friends because of the considerable amount of fear and anxiety involved with a cardiac event. When the patients are released from the hospital and return home, the families may not be fully equipped to cope with the uncertainties and stresses of the situation (Kaplan, Sallis & Patterson, 1993; Jaarsma, Halfens & Huijer-Abu Saad, 1996). Maintaining intact social support systems and supporting the family which is coping with, caring for, and worrying about their chronically ill family member entails a real challenge for nursing (Miller, 1992). When nursing patients with heart failure, the involvement of a key person or caregiver is often what is needed to enable patients to manage without having to be admitted to the hospital (Bushnell, 1992; Karmilovitch, 1994; English & Mastrean, 1995; Martensson et al., 1998).

Several interventional studies have addressed the problem of readmission in the elderly heart failure population (Cintron et al., 1983; Berkman et al., 1991; Rich et al., 1993; Kostis, Rosen & Cosgrove, 1994; Rich et al., 1995; Jaarsma et al., 1996; Happ, Naylor & Roe-Prior, 1997). Findings from these studies indicated that many of these readmissions were related to premature discharge, medication-related problems, lack of knowledge regarding their symptom management, and non-compliance. These results suggested that adequate discharge planning, education, counselling and follow-up can be effective in preventing readmissions. Another factor that has increasingly appeared in the literature related to hospital readmissions for heart failure is that of failing social support (Kostis et al., 1994; Rich et al., 1995; Jaarsma et al., 1996; Happ et al., 1997). Happ et al. (1997) identified two themes which emerged as preventive factors for rehospitalisation: (1) supportive family or friends, and (2) individual motivation. They noted that although most of the rehospitalised patients lived with others, very few had strong support from family and friends. Conversely, they noted that the patients who were not rehospitalised all had

strong social support. None of these studies examined the patients' perceptions of how to manage their illnesses.

2.1.3 Relationship between perceived social support and psycho-social adjustment to illness

In a review of the earlier literature examining social support and adjustment to illness, Dimond and Jones (1983) found evidence of a relationship between social support and psycho-social adjustment to chronic illness. They concluded that social support: (1) has a direct effect on health and that the presence or absence of it is crucial; (2) provides a buffer against the effects of high stress; (3) and the interaction between it and stressors is important. They also found that social support has a mediating effect that stimulates the development of coping strategies and promotes mastery, and the lack of social support exacerbates the impact of stressful life events.

Dimond and Jones (1983, p. 245) concluded that:

Until we pay more attention to the processes through which support operates, the conditions under which it is or is not present, and the circumstances under which it has either positive or negative effects, we will not begin to understand the powerful influence of this phenomena on the direction and course of adaptation to stressful or challenging conditions.

Many nurse scholars have contributed to the literature which has found that social support protects individuals from the harmful effects of stress and improves well-being and levels of adjustment to chronic illness (Dimond, 1979; Funch & Mettlin, 1982; Bloom & Spiegel, 1984; Dunkel-Schetter, 1984; Pearlin & Aneshensel, 1986; Corbin & Strauss, 1988; Primomo, Yates & Woods, 1990); Stewart, 1993; Stewart et al., 1997a & b). Most of these studies advocated the provision of social support as an intervention for promoting well-being and adaptation across a variety of life circumstances (Corbin & Strauss, 1988; Primomo et al., 1990; Stewart, 1993; Stewart et al., 1997a & b). The prevalence of chronic illness poses problems of

social isolation and increased dependence on family members. Conversely, social support can alleviate the feelings of loneliness associated with disease and disability. Furthermore, unmet needs for support increase human vulnerability to physical and psychological illness and prolong recovery from illness (Gottlieb, 1985; Wortman & Conway, 1985; Bloom, 1990; Stewart, 1993; Stewart et al., 1997a & b).

Stewart (1993) noted that the nursing profession found social support to be a valuable adjunct to psycho-social and physiological knowledge of acute and chronic illness, as well as healthy states. It was also stated that social support may not always result in a positive outcome for the recipient. Critical aspects of social support are: timing, amount of support, provider mode of behaviour, and the relationship between the provider and the recipient (Vaux, 1988; Stewart, 1993). One of the most important determinants of satisfaction with support is the person's perception of support (Fondacaro & Moos, 1987; Hobfoll, Nadler & Lieberman, 1987; Schulz et al., 1987; Vinokur, Schul & Caplan, 1987; Baillie, Norbeck & Barnes, 1988; Stewart, 1993; Yates et al., 1994; Stewart et al., 1997a & b).

Perceived support, which is defined as "the cognitive appraisal of being reliably connected to others" (Stewart, 1993, p. 11), has been shown to be related to a wide variety of outcomes, including physical health, mental well-being, and successful social functioning. Perceived social support is composed of multiple relational functions, including: attachment/intimacy, social integration, nurturance, reassurance of worth, and providing informational or material aid (Weinert, 1988).

Many studies suggest that perceived/functional social support (i.e., instrumental and emotional) is more powerful in predicting psycho-social adjustment to a chronic illness (i.e., heart disease) than the structure and composition of the social network (Stewart, 1997b). For

example, social support, in particular encouragement (emotional support) and practical support, was linked with self-esteem and mastery post-myocardial infarction (Ben-Sira & Eliezer, 1990). These authors also noted that the presence of a loving and supportive spouse seemed to enhance emotional and cognitive readjustment, coping with physical restrictions, and adherence to risk-reduction behaviours. A study of 111 first-time myocardial infarction patients revealed that perceived social support predicted interpersonal dependency and healthy outlook at one month (Riegel & Dracup, 1992). In another study, adaptation to a myocardial infarction was facilitated by high-quality family relations and high self-esteem (Derenowski, 1988).

In order to provide support to individuals and families with chronic illness, it is vital to understand the nature of supportive interpersonal relationships, as well as the complexities of the illness experience (Primomo et al., 1990; White et al., 1992; Stewart et al., 1997a & b). The effects of social support variables in the chronically ill population and its resultant outcome on psycho-social well-being and adaptation continue to be studied.

2.1.4 Relationship between perceptions of illness and psycho-social adjustment to illness

Attempts to find meaning in the experience of chronic illness are highly relevant to the process of adjustment (Arpin, Fitch, Browne & Corey, 1990). When positive meaning can be construed, a better psychological adjustment often results (Rideout, 1992).

Haan (1977) cited that adjustment to an undesirable event is more difficult when: (1) it is not anticipated; (2) it has a hopeless outcome; (3) the onset and outcome are out of one's control; (4) conditions are ambiguous or uncertain, and efforts to secure pertinent information are defeated; (5) the event is viewed as negative, stressful or serious; (6) it historically resembles other difficult situations; (7) there are already other stressful circumstances occurring in the

individual's life; and/or (8) there is a lack of social support. Cornwell and Schmitt (1990) stated that self-esteem, locus of control, perceived support, and severity of impairment influence individuals' perception of their illness. Those with positive self-esteem and internal locus of control do not have negative attitudes toward their illnesses.

Often, chronically ill adults have experienced a healthy life prior to the onset of a debilitating disease such as heart failure. These adults may have a negative self-perception of their illness because it requires modification or elimination of various lifestyle behaviours (Wichowski & Kubsch, 1997). In the heart failure population, this negative self-perception has often led to non-adherence to a prescribed regimen with resulting exacerbations in the condition, requiring rehospitalisation. It has been noted that adults may counteract a negative self-perception by living as if they were not ill. By ignoring medication regimens and dietary restrictions, neglecting to engage in therapeutic exercise programs, and failing to keep medical appointments, these people attempt to demonstrate to themselves and others that they are not ill or limited in any profound way (Wichowski & Kubsch, 1997).

According to Weir et al. (1994), cognitive appraisal processes or the meaning a person gives a stressful event such as illness are believed to mediate an individual's reaction to an event and, as such, have been demonstrated to explain adjustment to illness. In a study of 222 patients with chronic pain, cognitive and other social and illness variables were tested to determine adjustment to illness. In this sample of pain patients, psychological adjustment was most explained by social support variables which, in turn, were strongly correlated with the cognitive variables of meaning. Presumably, it was this combined influence of social and cognitive variables that most explained psychological adjustment to illness. The importance of social

support and cognitive appraisal in explaining psycho-social adjustment to chronic pain has been strengthened by these findings.

A number of studies point to the importance of perception of illness or the cognitive meaning given to illness in determining psycho-social adjustment to a cardiac event (Byrne, Whyte & Butler, 1981; Byrne, 1982; Burgess & Hartman, 1986; Derenowski, 1988; Markle-Reid, 1989; Ekman, Lundman & Norberg., 1999).

Markle-Reid (1989) tested the relationship of the patients' perceived social support and perceived meaning of illness post-myocardial infarction. She reported a strong positive correlation between perceived social support from family and friends, and the patients' perceived meaning of the illness event, which enhanced the clients' coping mechanisms in adapting to a myocardial infarction.

Ekman et al. (1999) studied elderly patients and their perceptions of illness as they related to being in the hospital for treatment of congestive heart failure. Findings indicated that these individuals remained at home too long with grave symptoms of deterioration before they sought hospital care. Rehospitalisation became a period of transition which posed a threat to their day-to-day routines and forced them to adapt yet once again to a new regimen. The loss of comforting, stabilising caregivers during the period in the hospital signified a period of unpredictability and incomprehensibility to these individuals. In order to alleviate negative perceptions of the illness and outcomes which were not within the patient's control, it was stated that an ideal system needed:

... to create safe, calm, and intelligible hospital care for elderly patients with CHF, the organisation of the care would optimally offer hospitalisation with known caregivers to the patient. To give comprehensible and safe care during hospitalisation, it may also be important to plan caring actions from the patient's narrative of his or her illness. This narrative would help the caregiver to see the

patient's ordinary human identity. Caring is a shared experience and should be characterised by "presence with" and not "doing for". The nature of such a relationship creates community and mutual understanding (Ekman et al., 1999, p. 208).

2.1.5 Relationship between perceived social support and perception of illness

A number of studies that include participants with coronary heart disease indicate that there is a relationship between perceived social support and perception or meaning given to illness (Cohen & McKay, 1984; Burgess & Hartman, 1986; Markle-Reid, 1989; Primomo et al., 1990; White et al., 1992; Weir et al., 1994). Burgess and Hartman (1986) found clinical improvements in myocardial infarction patients' quality of life (psychological distress, social independence, re-employment barriers) were attributable to supportive, psychological nursing interventions operating to change restrictive patterns of belief surrounding their illness. These supportive nursing interventions had the greatest impact during the first three months after discharge.

Markle-Reid (1989) showed that perceived social support enhanced the client's coping mechanism in adapting to a myocardial infarction. This study explored the relationship between perceived social support and meaning of illness in the early discharge phase for patients who had experienced their first acute myocardial infarction. Findings revealed that subjects perceived their social support to be high and that meaning of illness was generally positive, which indicated that subjects seemed to be managing well. Perceived social support was found to account for 22% and 14% of the variance in the meaning of illness variables which involved beliefs about personal control, such as feelings of mastery, competence, and positive self-esteem.

However, no literature could be found that measured perceptions of social support and perceptions of illness in chronic congestive heart failure patients.

2.2 Theoretical Framework

2.2.1 *Introduction*

When health care professionals wish to assess available support for individuals who have experienced a cardiac event, there is very little theoretic and empiric data available to empower family members about how to be supportive or about how to choose the most appropriate support in the acute and recovery phases of the illness (Yates et al., 1994). Many studies that examine social support in cardiovascular patients do not explicitly use a theoretical framework.

Nurse scientists have contributed to the theoretical development of social support through concept refinement, creation of measures, and intervention research. Nevertheless, deficiencies persist pertaining to the conceptualisation of the construct and the design of intervention studies. Cultural, technological and political contexts have an effect on social support (Stewart & Tilden, 1995, p. 535).

The significance of social support, nurses' scholarly contributions, and continuing conceptual and methodological challenges continue to be studied.

Miriam Stewart's (1993) conceptual approach to social support was one of two theoretical frameworks chosen for this study because it encompasses a social focus, emphasises the consumer, explicates the environmental domain, acknowledges client-environment interaction and, as well, identifies a role for nursing in the provision and assessment of supportive interventions. Stewart (1993) defines social support as:

Interactions with family members, friends, peers, and health care providers that communicate information, esteem, aid, and reliable alliance. These communications improve coping, moderate the impact of stressors, and promote health. Social support occurs as a by-product of people's on-going interactions. However, we cannot assume that it is accessible or beneficial. Instead, it is important to understand how supportive interactions are elicited with different associates, forms of expression of social support, and how social support can be miscarried or dissipate over time (Stewart, 1993, p. 7).

Lazarus and Folkman's (1984) mid-range theory of stress, appraisal and coping also provides an additional framework to conceptualise what it is like to live with a chronic illness such as heart failure.

For the purposes of this study, social support will be highlighted as a coping resource which can ultimately be used by the individual to buffer the effects of stress from a chronic illness which may, in turn, enhance adaptational outcomes.

The following sections will describe the theoretical underpinnings for the framework of this study.

2.2.2 Stewart's conceptual framework for social support

The four components of Stewart's (1993) framework for social support are: environment, health, nursing, and focal person/client. Each of these concepts is defined as follows:

Environment: Social support concepts under environment can be operationally classified as social embeddedness, enacted support, and perceived social support (Stewart, 1993). "*Social embeddedness* refers to connections that individuals have to significant others in their social environment" (Stewart, 1993, p. 11). "*Enacted support* can be conceptualised as actions that others perform when they render assistance to individuals" (Stewart, 1993, p. 11).

Perceived social support "is the cognitive appraisal of being reliably connected to others" (Stewart, 1993, p. 11). Perceived social support is a coping resource, derived from a social network: "a specific set of linkages among a defined set of persons" (Lazarus & Folkman, 1984, p. 247), which the individual must cultivate and use (p. 250). Perceived social support refers to evaluation or appraisal of whether, and to what extent, an interaction is supportive in general or specific contexts (p. 249). The individual's primary appraisal of the event (living with

heart failure) will determine what amount, source, and type of support, as a coping resource, is significant to well-being (p. 251).

Different types of support need to be distinguished, because each may have independent effects on well-being (Schaefer, Coyne & Lazarus, 1981). Three types of support are identified: a) *emotional support*: intimacy and attachment, reassurance, and ability to confide in and rely on another, and feeling that one is loved or cared about; b) *tangible support*: direct aid or services; and c) *informational support*: access to information and/or advice which could help a person solve a problem (Schaefer et al., 1981).

Health: There are two competing views concerning the relationship between social support and health outcomes. In the stress buffering model, it is thought that social support acts as a protective factor in times of stress. The beneficial effects of support on health become increasingly evident as the stress levels rise (Yates et al., 1994). The main/direct effect model has a primary preventive function, where lack of social support has been shown experimentally to influence susceptibility to some infections and disease processes (Cohen & Wills, 1985). Therefore, social support has a direct, beneficial influence on health regardless of the degree of stress. At this time, there appears to be more evidence in support of the buffering hypothesis; as yet, the precise nature of the relationship has not been described (Stewart, 1989 & 1993).

Focal person/client: Coping, loneliness, self-esteem, and self-care/self-help concepts are pertinent to social support from the focal person perspective (Stewart, 1993). Studies have shown that people who are enmeshed in supportive networks have higher levels of self-esteem and take better care of themselves by engaging in more positive health practices. Loneliness can negatively impact on health outcomes. For instance, widows and widowers living alone may be more isolated and less likely to have a support system to reinforce efforts to adhere to lifestyle

changes and medical regimens. They may also lack the financial resources to insure a healthy diet and proper medication (Hubbard, Muhlenkamp & Brown, 1984; Berkman et al., 1991).

Nursing: The main concepts in this category involve collaboration, helping, partnership formation, as well as primary health roles which are assumed to be congruent with social support premises and with nursing. The knowledge of the professional nurse is also included, and is vital to the recipient of the support (Stewart, 1993).

The nurse's interaction with both the focal person and the social network increases collaboration and, in turn, enhances helping and coping effectiveness. The nurse can also, through consultation, promote reciprocal exchange of support between focal persons and their natural social network, which may in turn enhance self-esteem and the effectiveness of helping. Another role for the nurse is to facilitate resocialisation of focal persons and their support networks from traditional, passive patient role expectations (by society and health care professionals) to new partner roles (Stewart, 1993).

Although the type of social support that is associated with cardiovascular morbidity is not clear, most of the evidence for a relationship exists between perceived social support and the development and severity of coronary heart disease (Medalie & Godbout, 1976; Haynes & Feinleib, 1980; Cohen, 1988b; Yates et al., 1994).

2.2.3 Lazarus and Folkman's conceptual framework for stress, appraisal, and coping

Lazarus and Folkman's (1984) mid-range theory of stress, appraisal, and coping also provides an additional framework to conceptualise what it is like to live with a chronic illness such as heart failure. The physical, psychological, social, and spiritual aspects of the individual are considered; and the focus is on the relationship between the person and environment, which is compatible with nursing's view of the patient as a holistic being.

According to Lazarus and Folkman (1984), stress is a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his resources and endangering his well-being. This relationship is called a transaction and is initiated by a potentially stressful event (i.e., living with heart failure). Transaction is time- and process-oriented, and involves mutually-reciprocal, bi-directional relationships between the person and the environment (Lazarus & Folkman, 1984). Both cognitive appraisal and coping mediate the person-environment transaction and determine the degree of stress and state of well-being (Lazarus & Folkman, 1984). The focus of this study will be on cognitive appraisal.

Cognitive appraisal is the process of evaluating the potential outcome of a person-environment transaction with respect to its significance or meaning to well-being (Lazarus & Folkman, 1984). There are three appraisal processes that interact to determine the meaning of the stressor (living with heart failure) to well-being, namely: primary appraisal, secondary appraisal, and reappraisal.

Primary appraisal evaluates the impact of an event on one's sense of well-being and focuses on answering the question: "Am I okay or in trouble?" The answer to this question lies in the meaning of the event to an individual in relation to past experiences, resources, values, beliefs, goals and commitments (Folkman, Schaefer & Lazarus, 1979; Lazarus & Folkman, 1984). Information provided by others directly influences an individual's primary appraisal of a situation (Folkman, et al., 1979; Lazarus & Folkman, 1984; Stewart, 1989).

Through primary appraisal, the encounter is perceived and evaluated as: a) irrelevant, when the encounter is not considered to have any implications for personal well-being; b) benign-positive, where the outcome is foreseen as having a positive effect to preserve or enhance the individual's well-being and is associated with emotions of joy and happiness; or c) stressful,

when appraisal reveals that demands, either internal or environmental, have taxed or exceeded the individual's adaptive resources (Lazarus & Folkman, 1984).

Stress appraisals include three forms: harm/loss, threat and/or challenge. In harm/loss, some damage to the person has already occurred and appraisal focuses on the nature and extent of the damage sustained. Threats are anticipated harms or losses which are characterised by negative emotions such as anger, fear and anxiety. Challenge, as opposed to threat, harm or loss, is considered positive in that the person perceives the encounter as potential for gain, growth or mastery. A person is more likely to consider the stress challenging if he or she has a sense of control over the situation (Lazarus & Folkman, 1984). Threat and challenge can occur simultaneously in a given encounter.

Secondary appraisal is a complex evaluative process that focuses on answering the question: "What can I do about the trouble?" (Folkman et al., 1979; Lazarus & Folkman, 1984). The individual determines what coping options are available, whether the coping option will meet the individual's needs, and whether or not one can apply a coping strategy or set of strategies effectively (Lazarus & Folkman, 1984). At this point, the person draws on coping resources to manage the situation.

Reappraisal refers to a changed appraisal on the basis of new information from the environment, which may resist or nourish pressures on the person, and/or information from the person's own reactions. A reappraisal is simply an appraisal that follows an earlier appraisal in the same encounter and modifies it (Lazarus & Folkman, 1984).

The interactions between primary appraisal of the meaning of the event (illness), secondary appraisal of coping options, and reappraisal of coping options in light of the stressor, influence coping which determines subjective well-being (Lazarus & Folkman, 1984).

Subjective well-being consists of a dynamic balance of positive and negative emotions that determines how an individual feels about himself and his conditions of life in a particular stressful encounter (Lazarus & Folkman, 1984).

Adaptational outcomes refers to the way in which a person appraises and copes with stress and can be evaluated in terms of both long- and short-term outcomes. The immediate or short-term outcomes refer to the individual's judgement of the successful resolution of the encounter. Long-term outcomes are evaluated in terms of health, ability to carry out social roles, and morale (Lazarus & Folkman, 1984).

2.2.4 Summary

The literature has indicated that perceived social support has an impact on an individual's appraisal of a situation, and is also available as a resource in the environment that may influence the coping process.

The following diagram (Figure 1), which guides the objectives of this study, is the author's schematic representation of Lazarus and Folkman's (1984) theory of stress, appraisal and coping, and Miriam Stewart's (1993) model of social support.

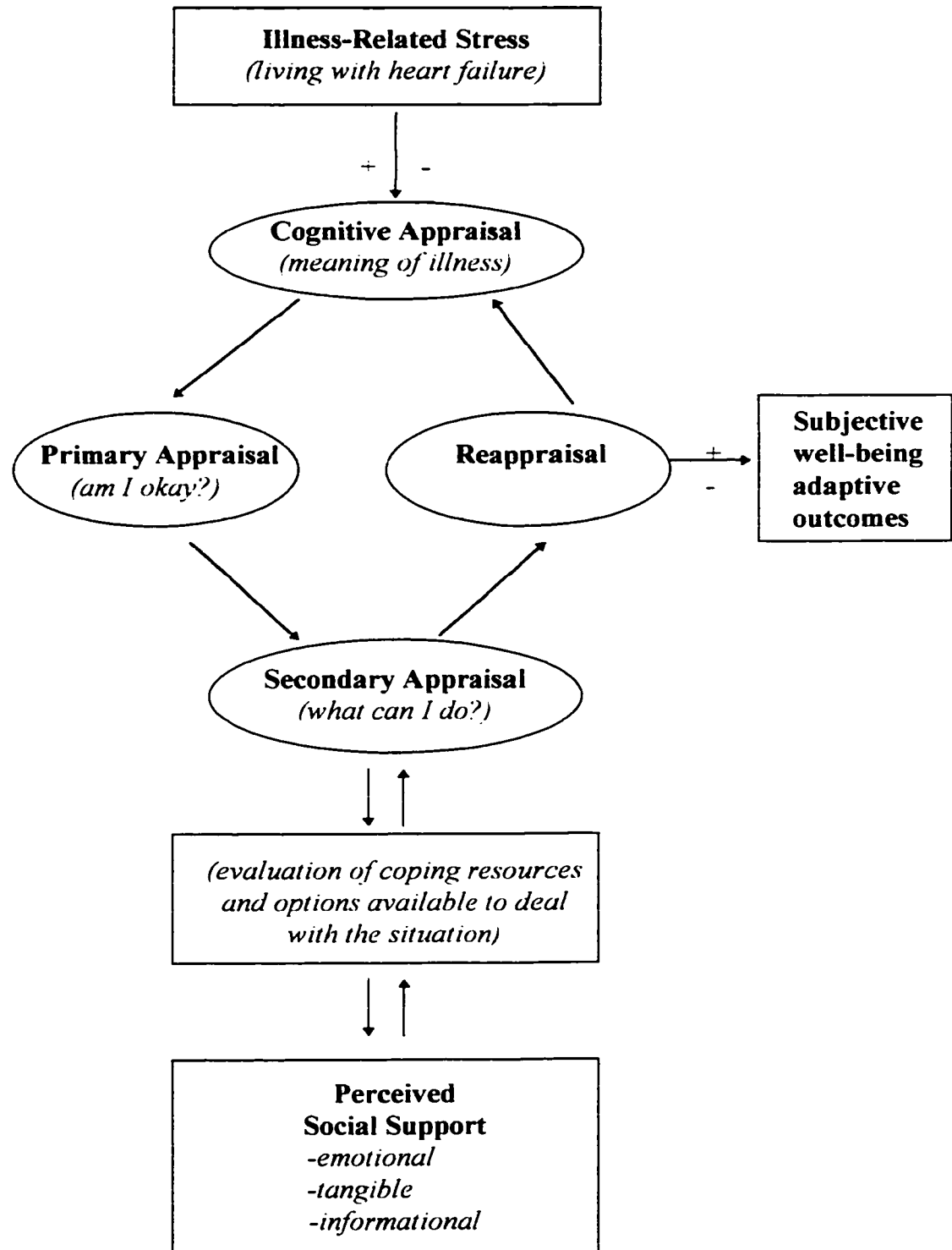
Following an encounter with an illness-related stress (living with heart failure), an individual experiences a dynamic process of cognitive appraisal (meaning of illness). Several factors can influence how an individual appraises this encounter (am I okay or am I in trouble?). If appraised as stressful (what can I do about it?), coping strategies (social support) are mobilised to assist the individual in managing the stress. Social support (perception of what is available, i.e., emotional, tangible, informational) can be called upon by the individual to buffer the effects of stress, which may, in turn, enhance adaptational outcomes and subjective well-being.

Perceived social support and perception of illness have been conceptualised as complex interactive processes which require further exploration. Although the type of social support that is associated with cardiovascular morbidity is not clear, most of the evidence for a relationship exists between perceived social support and the development and severity of coronary heart disease (Medalie & Godbout, 1976; Haynes & Feinleib, 1980; Cohen, 1988b; Yates et al., 1994).

It is the immediate intention of this study to describe the direction and strength of the relationship between these variables so that interventions can be developed to facilitate how an individual adjusts to living with an illness such as heart failure.

Figure 1

CONCEPTUAL FRAMEWORK



2.3 Study Assumptions

This study is based on the following assumptions:

- (1) Congestive heart failure is a chronic and progressive illness and is viewed as a stressful event for the patient and his/her family;
- (2) Chronic illness can exert positive and negative influences on the family unit;
- (3) Cognitive appraisal or perception of one's illness can influence adaptational outcomes to illness;
- (4) Individuals are unique in defining and shaping stressful transactions through cognitive appraisal and coping;
- (5) Social support is one of the factors that can influence both perception and adjustment to illness;
- (6) Perceived social support is more important to well-being than the actual composition and structure of the social network.

Chapter Three

METHODOLOGY

This chapter discusses the methods employed in this study. In particular, the research design, setting, sample size, method of measurement, data collection procedure, data analysis plan, and the protection of human rights are described.

3.1 Research Design

For this study, a descriptive correlational design was used to determine if there is a relationship between the variables: perceived social support (independent variable) and cognitive appraisal/perceptions of illness (dependent variable) in patients living with chronic congestive heart failure.

3.2 Setting

The setting for the data collection was the University of Ottawa Heart Institute, Ambulatory Heart Failure Clinic. This clinic is staffed by three cardiologists, an advanced practice nurse, cardiac nurses, and a multidisciplinary group of professionals. The clinic operates each Friday morning. Approximately twenty patients are evaluated and reassessed at each of these clinics. The patients are initially referred by their own general practitioners and have experienced at least one previous hospital admission for congestive heart failure.

3.3 Sample

A non-random convenience sample of 34 patients was obtained over a four-month period. Criteria for inclusion in the study were as follows:

1. Eighteen years of age or over.
2. At least one previous hospital admission for treatment of congestive heart failure.
3. Able to read and comprehend English.
4. Diagnosed and classified in either the NYHA Class Two or Class Three definition of heart failure.

3.4 Sample Size

A review of the literature for estimates of effect size for correlation of perceived social support and cognitive appraisal of illness was unavailable. When prior estimates of effect size are not available, one must select a conventional value (Polit & Hungler, 1995). A large effect was needed because descriptive literature has established that perceived social support is an important factor in predicting perceptions of illness in the chronic population (Cohen & McKay, 1984; Burgess & Hartman, 1986; Markle-Reid, 1989; Primomo et al., 1990; White et al., 1992; Weir et al., 1994).

A conventional value for a large effect size in a bivariate correlation situation is .50 (Polit & Hungler, 1995, p. 456). Therefore, an *a priori* effect size of .50 was established for this study. Given an effect size of .50, at a .05 level of significance (two-tailed), and a desired power of .80, a sample size was calculated and verified using several references. The calculation used was from Howell (1997, p. 219) where:

d = effect size

δ = power as a function of d at a significance level of .05 for a two-tailed test for a desired power of .80 = 2.80 (Howell, 1997, p. 679). Therefore, the sample size was calculated as follows:

$$N = \left(\frac{\delta}{d} \right)^2 = (2.80/.50)^2 = 31.36 \text{ or } 32 \text{ participants}$$

This finding was supported in the literature (Cohen, 1977 & 1988a; Polit and Hungler, 1978 & 1995; Streiner & Norman, 1995) and verified with Dr. Penny Guerney (Department of Education, University of Ottawa).

The N size was increased to 34 to allow, if necessary, for participant withdrawal from the study.

3.5 Measurement Instruments

Data was obtained by means of three instruments. The following variables were investigated: (a) perceived social support (Personal Resource Questionnaire-85/Part Two), (b) cognitive appraisal/perception of illness (Meaning of Illness Questionnaire), and (c) a personal and demographic profile, which included the following data: age, gender, marital status and length of time married, place of residence, occupational status, number of children, education, date of last discharge from hospital, other cardiovascular-related illnesses, treatments, and ethnic background. All information was recorded on the personal and demographic profile sheet (Appendix A) by the subjects, with help from the researcher if necessary.

3.5.1 Personal Resource Questionnaire

Perceived social support was measured by the Personal Resource Questionnaire (PRQ-85/Part Two) (Weinert & Brandt, 1987) (Appendix B). The Personal Resource Questionnaire (PRQ-85) was developed by Brandt and Weinert in 1981 and was modified in 1985 and 1987. The PRQ-85/Part Two was chosen because it is designed to measure perceived social support, and because it is based upon the conceptualisation of social support that is consistent with the literature and conceptual framework for this study.

The PRQ-85/Part Two is based on social relationship dimensions and consists of five dimensions of perceived social support, including: (a) provision for attachment/intimacy, (b) social integration, (c) opportunity for nurturant behaviour, (d) reassurance of worth as an individual and in role accomplishments, and (e) the availability of informational, emotional and material help.

These dimensions are congruent with the emotional (a, b and d, above), informational, and tangible support dimensions (e, above) described by Schaefer, Coyne and Lazarus (1981), and used in the conceptual framework for this study.

The concept of nurturance (c, above) is consistent with the transactional and reciprocal nature of Lazarus and Folkman's (1984) stress/coping paradigm. That is, nurturance and subjective well-being are both dependent upon the mutually reciprocal bi-directional interaction between the individual and the environment. Thus, the concept of nurturance in the PRQ-85/Part Two ensures a more complete measurement of perceived social support as depicted by Lazarus and Folkman (1984).

There are five items for each of the social relationship dimensions. The respondents were asked to rate each of the twenty-five items on a seven-point Likert scale ranging from "strongly disagree" (1) to "strongly agree" (7). Theoretically, the score would then range from 25 to 175, with a high score representing a perception of being highly supported.

3.5.1.1 Reliability and validity

Reliability and validity of the instrument has been established in a variety of acute and chronic care populations (Brandt & Weinert, 1981; Weinert, 1983; Catanzaro, 1986; Weinert, 1987; Yarcheski, Mahon & Yarcheski, 1992).

Internal consistency for PRQ-85/Part Two has been established in a number of studies with samples representing a broad age range from adolescents to the elderly population. The authors report a high internal consistency reliability coefficient ($\alpha = .89$) for Part Two (Weinert & Brandt, 1987). Two studies in samples of mothers with young children utilised the PRQ-85/Part Two to assess social support. The alpha coefficients were .91 and .90 (Catanzaro, 1986 & Gibson, 1992).

Further evidence of the psychometric properties has been reported by Weinert and Brandt (1987). Using a sample of 100 adults, aged 30 to 37, a test/retest reliability coefficient of $= .72$ was obtained for the PRQ-85/Part Two, within a four to six week interval.

Weinert (1987) and Gibson (1992) examined convergence across support measures by comparing scores on the PRQ-85/Part Two to scores on five other measures of social support. Inter-correlations between the PRQ-85/Part Two and the other social support measures ranged from .25 to .74, thus establishing construct validity of the PRQ-85/Part Two questionnaire as a measure of social support.

3.5.2 Meaning of Illness Questionnaire

The Meaning of Illness Questionnaire (MOIQ) was chosen to measure cognitive appraisal/perceptions of illness (Appendix C). The MOIQ was developed by McAdams, Byrne, Browne, Roberts and Streiner in 1985 (Browne et al., 1988). The MOIQ was chosen for investigation of this problem because it was the only instrument found that measures meaning of illness to well-being, and is based on a conceptualisation of meaning of illness that is consistent with the conceptual framework for this study.

After clinical testing, a more recent update was done by Roberts, Byrne, Browne and McAdams (1992). The authors define meaning of illness to well-being in terms of 30 items in the questionnaire, as outlined in Appendix C.

According to Browne et al. (1988), the MOIQ is derived from the literature (McCrae, 1971; Dohrenwend & Dohrenwend, 1974; Haan, 1977; Fontana et al., 1979; McFarlane et al., 1980; Lazarus & Folkman, 1984) and is designed to quantify the degree to which people apply a mix of appraisals to life circumstances: the impact of illness on day-to-day living and on their relationships with family and friends; seriousness; context (enduring or episodic); as well as a perception of what is at stake (harm, threat, challenge). The desirability, controllability, uncertainty, or ambiguity of the circumstances and the degree to which it interferes with previous commitments also influence meaning. In addition to this primary appraisal, one's secondary appraisal of coping resources, or efforts to manage the life circumstances in a manner congruent with beliefs about preferred behaviour, also shapes the meaning.

Each MOIQ item is rated on a seven-point scale ranging from "Not at all" (0) to "Definitely yes" (6). These items are grouped into five sub-scales: (a) impact of illness on daily living; (b) type of stress (negative attitude of harm, loss, threat); (c) degree of stress, change in commitments, secondary appraisal of coping resources; (d) positive attitude of illness as challenge, hope, motivation and control; and (e) expectancy and reoccurrence (Browne et al., 1992).

The user has two options when scoring the MOIQ. It can be scored using each item, or by using several items making up one of the five factors described previously. Each of the sub-scales is scored separately; therefore, there is no total score for the Meaning of Illness Questionnaire (Roberts et al., 1992). This present study used the five factor method.

3.5.2.1 Reliability and validity

Reliability and validity of the MOIQ instrument has been established in a variety of chronic patient populations (Arpin, Fitch, Browne & Corey, 1987, 1988, 1989; Browne et al., 1988; Weir et al., 1994). In a study using seventy chronically ill patients, test-retest reliability was substantial and ranged between kappa = .49-.99 on 33 items (Arpin et al., 1987, 1988, 1989).

In another study, test-retest reliability was computed for 76 of the 320 respondents from three ambulatory care clinics and three Canadian teaching hospitals. Kappas ranged between .45 and 1.00, with the majority falling between .60 to .77 (Browne et al., 1988).

Further testing for reliability and validity of the MOIQ was done by Weir et al. (1994), where 222 patients, randomly selected from an original sample of referrals to a chronic pain speciality clinic, completed a questionnaire by telephone interview or mail. The questionnaire consisted of psycho-social scales (Psycho-Social Adjustment to Illness Scale-Self-Report (PAIS-SR), Social Support) and cognitions including the MOIQ. Fifty-six percent of the sample had poor psycho-social adjustment to their pain problem. Seventy percent of the variance in adjustment was explained by social and cognitive variables, which corroborates their importance. The Meaning of Illness Questionnaire (MOIQ) five-factor structure was supported and provides credible evidence of the role of cognitions in differentiating between the poor and well-adjusted. The factor structure is consistent with the theoretical constructs. The inter-correlations among the various factors, which are shown in Appendix E, indicate the independence of the types of meaning, but relate to each other in the expected direction. The MOIQ has a strong relationship to health outcomes and greater utility than coping behaviours in

explaining variance in adjustment to chronic illness among those attending specialty outpatient clinics (Weir et al., 1994).

3.5.3 Open-ended questions

Two open-ended questions were posed to the participants by the researcher upon completion of the questionnaires. These questions were included to obtain additional data from the patients' perceptions of their illness. The questions were reviewed for clarity by a qualitative research expert, as well as three expert nurses in cardiac care. These questions were: (1) "*Is there anything else that you would like to share on how it has been like living with heart failure?*"; and (2) "*Who or what has helped you the most?*".

3.6 Data Collection Procedures

Patients who met the inclusion criteria were approached by a member of the clinic team in the family waiting room, and their willingness to discuss the study was determined. The researcher then approached the patient and informed the individual of the purpose of the study and the procedure involved in collecting the data. A private area within the clinic was used for the interviews. The subjects were given the questionnaires (demographic, PRQ-85/Part Two and the MOIQ), with a standard verbal and written explanation for their use. The investigator remained with subjects while they completed the questionnaires.

In addition, two open-ended questions were posed to the participants by the researcher upon completion of the questionnaires. These questions were: (1) "*Is there anything else that you would like to share on how it has been like living with heart failure?*"; and (2) "*Who or what has helped you the most?*". The questions were reviewed by the Research and Ethics Committee, a qualitative research expert, as well as three expert nurses in cardiac care prior to

being utilised in this study. The average length of time for each participant was between 30-45 minutes to complete the questionnaires and to answer the two open-ended questions.

3.7 Data Analysis

3.7.1 Statistical analysis of questionnaires

Data was analysed using the Statistical Packages for the Social Sciences software (SPSS-6.1).

Descriptive statistics were used to describe the mean, standard deviation, and range of scores, as well as minimum and maximum scores achieved and total scale scores for the five sub-scales/dimensions of the PRQ-85/Part Two, as well as the MOIQ questionnaire factors/sub-scales.

To measure the relationship between perceived social support and perceptions of illness, the statistical test, Pearson's Correlation Coefficient, was used. For this study, a powerful effect size was established at .50, with a level of significance at $p < .05$.

3.7.2 Analysis of open-ended questions

Content analysis was used to explore the participants' feelings and views on what it has been like living with heart failure, as well as resources that have been most helpful to them.

All interviews were tape-recorded and ranged from ten to fifteen minutes in length. Field notes were dictated into a recorder after each interview, and then the interviews were transcribed verbatim. Data was analysed using thematic content analysis (Burnard, 1991). This method involved several in-depth readings of the transcripts for underlying meanings, category derivation, and labelling of categories. Coloured highlighting pens were used to distinguish between the categories, and then each of these coloured sections was extracted and grouped together to form themes. A qualitative expert reviewed the analysis.

3.8 Protection of Human Rights

This protocol was approved by the Human Research Ethics Committee of the University of Ottawa, as well as the Human Research Ethics Committee of the University of Ottawa Heart Institute. Risks and benefits, as well as the rights of the individual, were explained, and participants were informed that they could withdraw from the study at any time. Participants were told that there were no risks in participating in this study. The inconveniences of participating would only be the time that it took to complete the questionnaires, and answer the two open-ended questions. An informed consent was obtained from each of the eligible participants (Appendix D).

All data from this interview was kept in the strictest confidence, and a code number was assigned to assure confidentiality. Only the researcher and thesis advisor had access to the data from the interviews. The responses were not shared with physicians or any other health professionals involved in their care. All tape recordings obtained in the interviews were destroyed once the data was transcribed.

Chapter Four

STUDY RESULTS

The results are presented as they relate to the study's objectives. Demographic data presentation is followed by the statistical findings and the results from the content analysis.

4.1 Demographics

A total of 34 participants were interviewed. The majority of participants (n=33) or 97% were Caucasian. The participants' ages ranged between 32 and 84 years, with a mean of 65 years. Sixty-five percent (n=22) were males, and 35% (n=12) were females.

Seventy-seven percent (n=26) were married. Of interest, 91% of the male group (n=20) were married and living with their spouses, compared to only 50% (n=6) of the female group. The mean number of years married for the males was 38.5, compared with 29 years for the females. Seventy-one percent (n=24) of the participants lived in a single-dwelling home, 21% (n=7) lived in an apartment, 6% (n=2) in a senior citizens home, and one of the participants (2%) lived with her daughter. All of the subjects who lived in their own home were married. All but two of the participants had children, and four of these had one child still living at home.

Seventy-nine percent of the population were retired (n=27), 6% were still employed (n=2), and 15% (n=5) were living on long-term disability.

The subjects were asked to identify in the demographic questionnaire whether or not they had been previously treated for heart disease prior to being referred to the heart failure clinic and whether or not they had been taking medications related to their heart condition. They were also asked when they had been last hospitalised for their heart failure. Only nine out of the 34

participants (26%) were able to say with certainty that they had been treated for another cardiovascular-related illness prior to being diagnosed with heart failure and subsequent referral to the heart failure clinic. As well, only these same subjects were able to say with certainty what the diagnosis was (i.e., angina, pacemaker, myocardial infarction). Fifty percent (n=17) were uncertain about the exact nature of their problem (i.e., angina versus MI), but admitted taking medications for a “heart problem” before being referred to the heart failure clinic. The remaining eight subjects (24%) made no comments regarding their previous cardiovascular history. Fifty-nine percent (n=20) of respondents had been hospitalised and treated for heart failure within the last year. The remaining 41% (n=14) reported being hospitalised for a heart failure-related event in the previous two years.

TABLE 1

**Demographic Data
(n=34)**

Gender	Marital Status	n	Percentage
Male	Married	20	91
	Divorced	2	9
	Widowed	0	0
	Total	22	100
Female	Married	6	50
	Divorced	0	0
	Widowed	6	50
	Total	12	100

4.2 Research Objective One: To Determine the Perception of Social Support for Patients with NYHA Class Two or Class Three Congestive Heart Failure

The multidimensional construct of perceived social support was measured by the PRQ-85/Part 2 questionnaire. The PRQ-Part 2 has a seven-point Likert format, composed of 25 items, and is rated from “Strongly agree” (7) to “Strongly disagree” (1). This part of the questionnaire consisted of five dimensions of perceived social support: a) provision for attachment/intimacy; b) social integration; c) opportunity for nurturing behaviour; d) reassurance of worth as an individual and in role accomplishments; and e) the availability of informational, emotional and material help.

The possible range of scores for this instrument is 25-175, with higher scores representing higher levels of perceived social support.

The mean, standard deviation, and the range of scores for the total PRQ-Part 2 and each of its five dimension are shown in Table 2.

TABLE 2

To Determine the Perception of Social Support for Patients with NYHA Class Two or Class Three Congestive Heart Failure (Using the PRQ-85/Part 2 Questionnaire) (n=34)

Sub-Scales	Mean	SD	Min-Max Scores of Participants
1. Intimacy (max. = 35)	27.87	6.69	12-35
2. Social Integration (max. = 35)	25.47	5.64	7-33
3. Nurturance (max. = 35)	27.65	5.41	14-35
4. Worth (max. = 35)	31.29	3.42	20-35
5. Assistance/Guidance (max. = 35)	28.91	4.82	16-35
Total PRQ (max. = 175)	141.2	20.8	90-167

In general, participants in the study reported a high level of perceived social support with a mean score of 141.20 (SD 20.88, range 90-167). Also, the mean scores for each of the five dimensions were in the high range of perceived social support.

In order to highlight which items were perceived to be most important for social support, an analysis of each of the five dimensions of PRQ-Part 2 was undertaken. The mean and standard deviation, as well as the minimum and maximum scores for the participants, are illustrated in Tables 3-A to 3-E.

Sub-scale 1, which measured provision for attachment/intimacy, revealed high scores in each of the five items, particularly in question 1 (mean = 6.29), where the high score indicated that many of the subjects had a close and significant relationship in their lives (Table 3-A).

TABLE 3-A

**PRQ-Part 2 Questionnaire (Sub-Scale 1—Intimacy)
(n=34)**

Sub-Scale Variables	Mean	SD	Min-Max Scores of Participants
PRQ-Part 2 S1: Intimacy (max. = 35)	27.87	6.69	12-35
1. There is someone I feel close to who makes me feel secure	6.29	1.19	2-7
2. I have enough contact with the person who makes me feel special	5.82	2.07	1-7
3. People let me know that I do well at my work (job, homemaking)	5.33	1.63	1-7
4. I belong to a group in which I feel important	5.21	2.27	1-7
5. I cannot count on my relatives and friends to help me with problems*	5.21	2.23	1-7

*This item was reverse scored.

Sub-scale 2 (social integration) revealed both moderate and high mean scores. The higher scores are seen in questions 1 and 2. The participants indicated that there was a significant other available to them to share their feelings, and provide help if needed over an extended period of time. These scores are listed in Table 3-B.

TABLE 3-B
PRQ-Part 2 Questionnaire (Sub-Scale 2—Social Integration)
(n=34)

Sub-Scale Variables	Mean	SD	Min-Max Scores of Participants
PRQ-Part 2 S2: Social Integration (max. = 35)	25.47	5.64	7-33
1. There are people who are available if I needed help over an extended period of time	5.79	1.61	1-7
2. There is no one to talk to about how I am feeling*	5.79	1.81	1-7
3. There is little opportunity in my life to be giving and caring to another person*	4.76	1.94	1-7
4. Others let me know that they enjoy working with me (job, committees, projects)	4.76	1.86	1-7
5. I spend time with others who have the same interests that I do	4.35	1.67	1-7

*These items were reverse scored.

The results from sub-scale 3 revealed high mean scores in all of the items that measured opportunity for nurturant behaviour. The scores revealed that the individuals felt that there was ample opportunity to participate in a reciprocal relationship that involved both giving and receiving support and encouragement from their family and friends. It could also be seen (question 1) that the subjects still perceived themselves to be important members within the family unit. These scores are listed in Table 3-C.

TABLE 3-C

**PRQ-Part 2 Questionnaire (Sub-Scale 3—Nurturance)
(n=34)**

Sub-Scale Variables	Mean	SD	Min-Max Scores of Participants
PRQ-Part 2 S3: Nurturance (max. = 35)	27.65	5.41	14-35
1. My family lets me know that I am important for keeping the family running	5.92	1.54	2-7
2. I have relatives or friends who will help me out even if I can't pay them back	5.76	1.58	2-7
3. When I am upset, there is someone I can be with who lets me be myself	5.62	1.48	2-7
4. Among my group of friends, we do favours for each other	5.26	1.64	1-7
5. I have the opportunity to encourage others to develop their interests and skills	5.09	1.75	2-7

Sub-scale 4, which was a dimension that explored reassurance of worth as an individual and in role accomplishments, was notably high at 31.29 out of a possible 35. It can also be seen in Table 3-D that the five sub-scale variables scored in the high range as well.

TABLE 3-D

**PRQ-Part 2 Questionnaire (Sub-Scale 4)—Worth and Self-Esteem
(n=34)**

Sub-Scale Variables	Mean	SD	Min-Max Scores of Participants
PRQ-Part 2 S4: Worth (max. = 35)	31.29	3.42	20-35
1. I feel no one has the same problems as I*	6.71	0.58	5-7
2. There is someone who loves and cares about me	6.59	0.92	2-7
3. I enjoy doing little extra things that make another person's life more pleasant	6.15	0.93	4-7
4. I know that others appreciate me as a person	6.12	1.04	3-7
5. I have people to share social events and plan activities with	5.74	1.48	2-7

*This item was reverse scored.

In sub-scale 5, the availability of informational, emotional, and material help was explored. The participants reported high mean scores in all of the questions, and most notably in items 1 and 2. The results from sub-scale 5 are listed in Table 3-E.

TABLE 3-E

**PRQ-Part 2 Questionnaire (Sub-Scale 5)—Assistance/Guidance
(n=34)**

Sub-Scale Variables	Mean	SD	Min-Max Scores of Participants
PRQ-Part 2 S5: Assistance/Guidance (max. = 35)	28.91	4.82	16-35
1. If I got sick, there is someone to give me advice about caring for myself	6.35	0.77	4-7
2. I have a sense of being needed by another person	6.21	1.43	1-7
3. People think that I am not as good a friend as I should be*	5.65	1.52	2-7
4. If I need advice, there is someone who would assist me to work out a plan for dealing with the situation	5.47	1.76	1-7
5. I am responsible for helping provide for another person's needs	5.24	2.06	1-7

*This item was reverse scored.

Because of the distribution of males and females in the sample and marital status of each group, it was decided to compare males and females on the components of the PRQ-85/Part Two.

T-tests for independent samples of gender revealed no significant differences between males and females for their perceptions of social support in any of the five sub-scales (Table 4). It can be seen, however, that the females scored higher than the males in the dimensions of intimacy, nurturance, worth, and assistance and guidance; while the males scored higher means in the dimension of social integration. Despite the fact that most males (91%) had a wife at home, compared to females (50%) living with a spouse, the perceptions of support between the males and females were similar. This interpretation, however, is limited due to the small sample size.

TABLE 4

**T-Tests for Independent Samples of Gender as Measured in Each of the
Five Sub-Scales of Perceived Social Support
(n=34)**

Variable	# of Cases	Mean	SD	T-Value	2-Tail Sig. (.05)
PRQ-S1 Intimacy				-.47	.646
Male	22	27.46	6.71		
Female	12	28.60	6.86		
PRQ-S2 Social Integration				.91	.376
Male	22	26.22	4.3		
Female	12	24.08	7.4		
PRQ-S3 Nurturance				-1.96	.059
Male	22	26.51	5.9		
Female	12	29.75	3.72		
PRQ-S4 Worth				-1.11	.278
Male	22	30.86	3.78		
Female	12	32.08	2.61		
PRQ-S5 Assistance and Guidance				-.44	.663
Male	22	28.68	5.61		
Female	12	29.33	3.02		
PRQ Total				-.56	.584
Male	22	139.75	21.66		
Female	12	143.85	19.99		

Multiple regression analysis was done to determine whether or not there was a significant relationship between the predictors age and gender, and the dependent variable total PRQ. Neither age nor gender were significant predictors of perceived social support in this study.

TABLE 5

Results of Multiple Regression Analysis to Determine if Age and Gender are Statistically Important Predictors of Perceived Social Support (Total PRQ) (n=34)

Predictor Variables	Multiple R	R ²	T	P (.05)
Dependent Variable = Total PRQ ($\bar{x} = 141.2$)				
Age	.23499	.055	1.230	.2278
Gender	.23499	.055	.575	.5692

4.3 Research Objective Two: To Determine the Perception of Illness for Patients Experiencing NYHA Class Two or Class Three Congestive Heart Failure

The meaning of illness questionnaire (MOIQ) was used to measure subjects' primary appraisal of their illness and the secondary appraisal of coping resources to deal with it (Roberts et al., 1992; Browne et al., 1992). The 30 MOIQ items rated on a seven-point scale ranged from "Not at all" (0) to "Definitely yes" (6). This questionnaire explored whether the participants had a positive or negative view of various aspects of their illness. The questions were grouped together to make up five factors, which look at the (1) impact of illness on daily living; (2) type of stress (negative attitude of harm, loss, threat); functional context (disabling, disfiguring, deteriorating); (3) degree of stress, change in commitments, secondary appraisal of coping resources; (4) positive attitude of illness as challenge, hope, motivation, and control; and (5) expectancy and reoccurrence (Roberts et al., 1992). Since there is no total score for the MOIQ, only the mean scores for each of the five factors were used for analysis. The questionnaire was designed to reflect that the higher the score, the more positive the meaning given to illness, and therefore the more positive psycho-social adjustment to the event. To reiterate, the authors of the MOIQ have interchanged the words "meaning of illness", "perceptions of illness", and "cognitive appraisal of illness".

The mean standard deviation and range of scores for each of the five factors are illustrated in Table 6.

TABLE 6

To Determine the Perception of Illness for Patients with NYHA Class Two or Class Three Congestive Heart Failure (Using the MOIQ Questionnaire) (n=34)

Factors	Mean	SD	Min-Max Scores of Participants
Factor 1: Impact of illness on daily living (max. score = 24)	9.21	6.78	0-24
Factor 2: Type of stress (negative attitude of harm, loss or threat), functional context (disabling, disfiguring, deteriorating) (max. score = 36)	12.63	6.25	1-27
Factor 3: Degree of stress, change in commitments, secondary appraisal of coping resources (max. score = 30)	18.76	6.53	1-30
Factor 4: Positive attitude of illness as challenge, hope, motivation, and control (max. score = 30)	22.12	4.68	7-30
Factor 5: Expectancy and reoccurrence/non-anticipated vulnerability (max. score = 18)	10.53	2.94	1-15

The scores for each of the five factors are analysed and listed in Tables 7-A to 7-E.

Factor 1 measured the impact of the illness on day-to-day living and its effect on relationships with family and significant others. An overall low mean score was reported by the participants. Further analysis revealed moderate mean scores (on items 1 and 2) with respect to the negative impact on family and friends. Lower mean scores (on items 3 and 4) revealed the negative impact of the illness on activities of daily living.

TABLE 7-A
Meaning of Illness Questionnaire (Factor 1—Impact of Illness)
(n=34)

Factors	Mean	SD	Min-Max Scores of Participants
Factor 1: Impact of illness on daily living (max. score = 24)	9.21	6.78	0-24
<i>Has this illness negatively affected:</i>			
1. How you get along with your family (max. score = 6)*	3.35	2.51	0-6
2. How you get along with your friends (max. score = 6)*	3.21	2.33	0-6
3. Your job, school or daily work activities (max. score = 6)*	1.47	1.99	0-6
4. How you live day-to-day (max. score = 6)*	1.18	1.82	0-6

*These items were reverse scored.

In each of the four items for Factor 1, the higher the score, the more positive the meaning given the illness for the elements of daily living.

The wide range of scores (0-24) reflect the presence of outliers.

Factor 2 reported a low mean score overall. Analysis of these items showed a moderate mean score in terms of the illness causing an appearance change for the worse. Lower mean scores reported by the participants revealed that they perceived their illness to be harmful, threatening, disabling, and as well, they saw this illness as a loss in their lives.

TABLE 7-B
Meaning of Illness Questionnaire (Factor 2—Type of Stress)
(n=34)

Factors	Mean	SD	Min-Max Scores of Participants
Factor 2: Type of stress (negative attitude of harm, loss or threat), functional context (disabling, disfiguring, deteriorating) (max. score = 36)	12.63	6.25	1-27
<i>Would you describe this illness as:</i>			
1. Disfiguring/causing an appearance change for the worse (max. score = 6)*	4.71	1.85	0-6
2. Deteriorating or getting worse (max. score = 6)*	2.65	1.94	0-6
3. Harmful (max. score = 6)*	1.62	1.78	0-6
4. A loss (max. score = 6)*	1.42	1.51	0-6
5. Threatening (max. score = 6)*	1.32	1.66	0-6
6. Disabling/causing a loss of physical activity or strength (max. score = 6)*	0.91	1.94	0-6

*These items were reverse scored.

In each of the six items for Factor 2, the higher the score, the more positive the meaning given illness.

The wide range of results reported (1-27) reflect the presence of outliers.

Factor 3 reported an overall moderate mean score of 18.76 out of a possible 30. The items in this category measured degrees of stress, change in commitments, and secondary appraisal of coping resources.

Upon further analysis, it could be seen that patients reported higher mean scores (on items 1, 2 and 3) which reflected a positive attitude toward the way they were handling things, their outlook, and their ability to change for the better what they cared about. A moderate mean score (item 4) reflected the participants' feelings of limited energy and stamina to get through the ordeal. A low score (1.59) for item 5 revealed that the subjects found this illness to be stressful and worrying.

TABLE 7-C
Meaning of Illness Questionnaire (Factor 3—Degree of Stress)
(n=34)

Factors	Mean	SD	Min-Max Scores of Participants
Factor 3: Degree of stress, change in commitments, secondary appraisal of coping resources (max. score = 30)	18.76	6.53	1-30
1. Are you pleased with the way you are handling things (max. score = 6)*	4.53	1.66	0-6
2. Are you pleased with your outlook on things (max. score = 6)	4.47	1.73	0-6
3. Do you feel you have changed for the better what you care about since this illness (max. score = 6)	4.26	1.54	0-6
4. Do you feel you have energy and stamina to get through this (max. score = 6)	3.91	1.93	0-6
5. Would you rate the experience of this illness as stressful or worrying (max. score = 6)	1.59	1.96	0-6

*This item was reverse scored.

In each of the items for Factor 3, the higher the score, the more positive the meaning given to the illness.

The wide range of results reported (1-30) reflects the presence of outliers

Factor 4 focused on challenge, motivation, and a positive attitude towards the illness, and reports the highest mean score overall (22.12 out of a possible 30). Further analysis revealed higher mean scores with items 1 and 2 for functioning independently and making a contribution. More moderate mean scores were seen for items 3, 4 and 5 with respect to seeing the illness as challenging and somewhat within their control, as well as having a positive outlook regarding the outcome. These results are illustrated in Table 7-D.

TABLE 7-D
Meaning of Illness Questionnaire (Factor 4—Positive Attitude)
(n=34)

Factors	Mean	SD	Min-Max Scores of Participants
Factor 4: Positive attitude of illness as challenge, hope, motivation, and control things (max. score = 30)	22.12	4.68	7-30
1. Are you determined to try to function independently in spite of this illness (max. score = 6)	5.47	0.79	3-6
2. Do you have a lot of say regarding the things you care about (max. score = 6)	4.85	1.69	0-6
3. Would you describe this illness as a challenge (max. score = 6)	4.35	1.94	0-6
4. Do you think things will turn out well (max. score = 6)	4.00	1.37	0-6
5. In terms of this illness, to what extent do you feel you could change or do something about it (max. score = 6)	3.44	1.64	0-6

In each of the items for Factor 4, the higher the score, the more positive the meaning given to the illness.

Factor 5 measured items which looked at expectancy and reoccurrence of the illness and the non-anticipated vulnerability in their lives. Subjects reported a moderate mean score of 10.53 out of a possible 18, reflecting some element of expectancy and reoccurrence. The breakdown of the scores for each of the three items measured is illustrated in Table 7-E.

TABLE 7-E

**Meaning of Illness Questionnaire (Factor 5—Expectancy and Reoccurrence)
(n=34)**

Factors	Mean	SD	Min-Max Scores of Participants
Factor 5: Expectancy and reoccurrence/non-anticipated vulnerability (max. score = 18)	10.53	2.94	1-15
1. Was this illness expected before the doctor told you (max. score = 6)*	5.06	1.87	0-6
2. Do you believe it is likely that this illness will reoccur (max. score = 6)*	3.09	1.66	0-6
3. Do you think you played a part in the occurrence of this illness? (max. score = 6)*	2.38	1.97	0-6

*These items were reverse scored.

In each of the three items for Factor 5, the higher the score, the more positive the meaning given to the illness.

The wide range of results reported (1-15) reflects the presence of outliers.

T-tests for independent samples of gender revealed no significant difference between males and females for meaning of illness in any of the five factors of the MOIQ (Table 8). This interpretation is limited, however, due to the small sample size.

TABLE 8

**T-Tests for Independent Samples of Gender as Measured from
Each of the MOIQ Factors
(n=34)**

Variable	# of Cases	Mean	SD	T-Value	2-Tail Sig. (.05)
MOIQ-F1 Impact of Illness					
Male	22	8.63	7.53		
Female	12	10.25	5.25		
				-73	.471
MOIQ-F2 Harmful, Threatening, Disabling					
Male	22	12.65	6.9		
Female	12	12.58	4.9		
				.03	.973
MOIQ-F3 Degree of Stress, Change in Commitments					
Male	22	18.77	7.40		
Female	12	18.72	4.83		
				.02	.984
MOIQ-F4 Challenge, Positive Attitude					
Male	22	22.13	5.30		
Female	12	22.08	3.47		
				.04	.972
MOIQ-F5 Non-anticipated vulnerability					
Male	22	11.04	2.38		
Female	12	9.58	3.67		
				1.24	.232

Multiple regression analysis was done to determine whether or not there was a significant relationship between the predictors age and gender, and the dependent variables MOIQ-1 to MOIQ-5. The following results indicated that neither age nor gender proved to be significant predictors for perceptions of illness.

TABLE 9

Results of Multiple Regression Analysis to Determine if Age and Gender are Statistically Important Predictors of Meaning of Illness as Measured by the MOIQ (n=34)

Predictor Variables	Multiple R	R ²	T	P (.05)
Dependent Variable MOIQ-F1: Impact of Illness				
Age	.33938	.11518	1.88	.068
Gender	.33938	.11518	.728	.472
Dependent Variable MOIQ-F2: Illness as Threatening, Harmful, or Disabling				
Age	.18512	.034	1.04	.302
Gender	.18512	.034	-.006	.995
Dependent Variable MOIQ-F3: Degree of Stress				
Age	.06852	.00470	.382	.705
Gender	.06852	.00470	-.009	.992
Dependent Variable MOIQ-F4: Positive Attitude of Illness				
Age	.14425	.02081	-.811	.423
Gender	.14425	.02081	-.050	.960
Dependent Variable MOIQ-F5: Expectancy and Reoccurrence				
Age	.34359	.11805	1.449	.157
Gender	.34359	.11805	-1.397	.172

4.4 Research Objective Three: To Determine the Strength of the Relationship Between Perceptions of Social Support and Meaning of Illness for Patients Experiencing NYHA Class Two or Class Three Congestive Heart Failure

Pearson's Correlation Coefficients were calculated between the total support score (PRQ-Part 2) and the mean scores of each of the MOIQ factors. One significant but moderately positive correlation was found between perceived social support and MOIQ Factor 3 (degree of stress, change in commitments, secondary appraisal of coping resources). No relationship was found between perceived social support and MOIQ Factor 1 (impact of illness on daily living), Factor 2 (illness seen as harmful, threatening, disabling, loss), Factor 4 (positive attitude of illness as challenge), and Factor 5 (expectancy/vulnerability and reoccurrence).

Linear regression analysis showed that perceived social support accounted for 24% ($p=.004$) of the variance in MOIQ Factor 3, and 11% ($p=.059$) of the variance in MOIQ Factor 2.

TABLE 10

Strength of Association (Pearson's Correlation Coefficient) Between Total Support Scores and Meaning of Illness Factors (PRQ-Part 2/Meaning of Illness Questionnaires) (n=34)

Meaning of Illness Factors	Correlation Between Total Support Score (mean=141.2) and MOIQ Factors	
Factor 1: Impact of illness on daily living	0.2845	$p=.103$ $r^2=.08$
Factor 2: Type of stress (negative attitude of harm, loss or threat), functional context (disabling, disfiguring, deteriorating)	0.3266	$p=.059$ $r^2=.11$
Factor 3: Degree of stress, change in commitments, secondary appraisal of coping resources	0.4850 *	$p=.004$ * $r^2=.24$
Factor 4: Positive attitude of illness as challenge, hope, motivation, and control	0.2231	$p=.205$ $r^2=.05$
Factor 5: Expectancy and reoccurrence/non-anticipated vulnerability	0.0212	$p=.905$ $r^2=.0004$

Pearson correlations were also calculated between the means of the social support sub-scales and the mean scores of each of the MOIQ factors (see Table 11). A significant but moderately positive correlation was found between the PRQ-S1 (provision for attachment/intimacy) and the MOIQ Factor 1 (impact of illness on daily living), MOIQ Factor 2 (illness perceived as harmful, threatening, disabling, etc.), MOIQ Factor 3 (change in commitments and secondary appraisal of coping resources), and MOIQ Factor 4 (positive attitude of illness as challenge, hope, motivation, and control). This proved to be an interesting finding and one that has not been noted before in the literature.

TABLE 11

Strength of Association (Pearson's Correlation Coefficient) Between Social Support (PRQ-Part 2) Sub-Scales and Meaning of Illness Factors (n=34)

	MOIQ 1 Impact of Illness	MOIQ 2 Type of Stress	MOIQ 3 Degree of Stress	MOIQ 4 Positive Attitude of Illness	MOIQ 5 Expectancy and Reoccurrence
PRQ S1 Intimacy	r=.3433 * p=.047	r=.3787 * p=.027	r=.4526 * p=.007	r=.3463 * p=.045	r=.0712 p=.689
PRQ S2 Social Integration	r=.1567 p=.376	r=.2299 p=.191	r=.3555 * p=.039	r=.0461 p=.796	r=.2152 p=.222
PRQ S3 Nurturance	r=.1397 p=.431	r=.2183 p=.215	r=.2228 p=.205	r=.0785 p=.659	r=.1488 p=.401
PRQ S4 Worth	r=.3196 p=.065	r=.1050 p=.555	r=.4779 * p=.004	r=.2812 p=.107	r=.0732 p=.681
PRQ S5 Assistance/ Guidance	r=.1888 p=.285	r=.3006 p=.084	r=.4676 * p=.005	r=.1441 p=.416	r=.0394 p=.825

4.5 Results of Open-Ended Questions

Two open-ended questions were posed to the participants by the researcher upon completion of the questionnaires. Content analysis was used to explore the participants' feelings and views on what it has been like living with heart failure, as well as resources that have been most helpful to them.

4.5.1 Open-ended question #1: "Is there anything else that you would like to share on how it's been like living with heart failure?"

Despite the variety of events and situations cited by the participants, it became evident at an early stage of the interviews that themes were emerging which illustrated the impact of the illness on subjects' day-to-day living patterns. Some of the participants openly cried or had tears in their eyes. Many had stated that no one had ever inquired of them what it had been like to live with heart failure.

Six major themes developed which described the patients' perception of how their life had been affected by heart failure: a) physical limitations, b) surprise and disbelief, c) need for knowledge, d) adjustment, e) support from significant others, and f) getting in touch with one's spirituality.

4.5.1.1 Physical limitations

This theme highlighted the patients' view about the limitations in their lives and the impact of the illness on their daily living patterns. They related feelings of social isolation because of difficulties in continuing to work and the ability to pursue leisure activities. As well, patients reported increased dependence on family and friends because of the restrictions related to physical impairment. The stress of being chronically ill was illustrated in their comments

describing loss of control, and decreased energy related to frequent episodes of fatigue and shortness of breath

I feel that you are restricted in your work and in your activities. You get tired faster and sometimes you really feel down.

I am more and more careful, and I realise that I can't act the way I was before... it makes a difference, because you know your heart... well, you know there's something wrong there."

I feel more tired too!

Well, it's not nice living... trying to live a normal life with heart failure because you can't. You haven't got the stamina nor the breath to do it.

It's a hell of a life.

The adjustments required are more difficult than I would have imagined.

I was told to restrict doing many things, and this is the part that really bugs you because you have to depend on somebody else to do the things that you once did yourself.

The constant shortness of breath, the rude awakenings during the night that affects your breathing, your sleeping, your normal daily activity and your appetite is affected.

4.5.1.2 Surprise and Disbelief

Many of the participants expressed disbelief at being told by their doctors that they had heart failure. In fact, all of the subjects, even those who had reported having a previous history of heart disease, stated that they were surprised by this diagnosis and the chronic nature of the illness.

It was a surprise to... realise that I had heart failure.

It struck when I was 62 [heart failure], I didn't know I had a heart problem. But back in 1992, I was diagnosed with diabetes, and I was also told I had two heart attacks that I didn't know about.

Well, for four years it was a terrible experience after the heart attack. I thought I had pneumonia, and it turned out to be heart failure.

Before I didn't have heart failure, I had the operation [bypass surgery] and everything was fine.

4.5.1.3 Need for knowledge

Many of the participants expressed a need for more information from the physicians and the nurses. They also felt a need for closer monitoring after going home from the hospital. Living with the unknown and a lack of knowledge/information about the illness were perceived as being very stressful.

I think it is important to be monitored closely, especially after they release you. I would have liked more sessions in the exercise program, it is getting cold and it is more difficult to walk outside in the wintertime.

Many times you don't get enough information from the doctors to really know what it is or what you are looking at, and that scares you too because you don't know if you are really bad or what the situation is.

The rehab time is much greater than I expected, the doctors told me it would be awhile before I started feeling better, but I don't feel that I am making the progress that I should.

I have not received counselling on my heart problems. My own doctor unfortunately is not a specialist in the field of hearts. So I feel this is crazy, I have had this for eight months and I have got too many questions that could have been answered sooner.

I would really like to know if there is anything else that can be done, or if there is any possibility that any of this can be cured.

4.5.1.4 Adjustment

All of the patients in this study have been living with heart failure for several months to years. In this theme, it can be seen that many patients and their families have attempted to adjust to their new life situation.

Without the medicine, I don't think I'd be here today. I can't believe I'll be 65, because in 1995, I wasn't given too much hope that I would be around a year, much less five years later.

I do believe that the hospital and the doctors, all of them have been very helpful to me.

Nothing can be done as far as a heart transplant goes, so I have been taking loads of medications. In the last two visits, the doctors and nurses have been pleased with my conduct and the check-up and so forth, and this has helped me a great deal.

I'm not depressed or anything. I haven't got time to be depressed. I read a great deal, and you know I've had to adjust.

The only thing I regret is not being able to travel. But you have to face it you know, sometimes I chance it and I go across the border and stay a couple of days and come back and thank God that... [tears].

The thing about having heart failure is you have to accept what you have, and you have to turn around and understand the situation that is. You are going to have your down days and you are going to have your up days.

It has made me have more of a short-term outlook on life, I enjoy myself now no matter what.

It wasn't good at the start, but you have got to learn to live with it and go by what the doctor says.

The salt-free diet is difficult, but my wife has coped very well.

I have it, I live with it, and I accept it. I can't change it.

It is just a matter of getting used to it and changing your lifestyle, for instance the way you cook things.

4.5.1.5 Support from significant others

This category describes the nature of the support, interest, and encouragement from significant others in their current life situation.

My wife has made a practice of coming to see the cardiologist with me so we could compare notes and make sure that we weren't missing anything.

My wife has been most helpful. She cares for me, looks after everything for me. My children are very good. They support me. Whenever she's at work, I get calls about four times a day from Houston, Texas, Chicago, and Ottawa. They're making sure that I'm there and they support me.

My wife has been most helpful, she's a nurse and she is very loving and supportive.

My daughter, she's more like a guardian angel for me. She helps me out a lot, and she really cares [voice breaks a little] If I keep going, I'll cry [small laugh].

It's mainly been my wife that's been most helpful and carried the load. She has been positive and encouraging and so on and so on.

I've had good days and bad days, but when I have a bad day my wife is there to console me.

My family's been supportive. They come in and stay and cook for me, and my daughter looks after me.

4.5.1.6 Getting in touch with one's spirituality (religion)

Some of the participants noted that they were more in touch with their own spirituality, and there was a stronger belief in God and prayers.

You are going to have your down days and your up days, but I have a great family and believing in the Lord has helped me a lot.

Most helpful to me has been my pastor and my church friends who prayed for me when I needed it most. They prayed for me almost constantly when I was at my worst.

It's been a great thing because I have discovered my spirituality.

What has helped me the most has been God and my prayers.

4.5.2 Open-ended question #2: "Who or what has helped you the most?"

"Who or what has helped you the most?" The response to this second open-ended question elicited five major categories. It must be noted that each participant was asked to give only one response to this question. Table 12 illustrates the breakdown of responses.

TABLE 12
Who or What Has Helped You the Most?
(n=34)

Source of Support	N	Percentage
1. Wife	14	41.0
2. Medical care (physician/nurse/dietician)	9	26.5
3. Son/daughter	6	17.6
4. Lord/spirituality	4	11.7
5. Husband	1	2.9

Fourteen out of the 20 (70%) married males identified their wives as being the most helpful and supportive. Only one of the six married female patients named their spouse as being instrumental in helping the most. Fifty percent of the female participants (n=6) named a son or daughter, while 26% of all the participants (n=9) named their physicians, nurses, and dieticians. Four patients spoke of the Lord, prayer, spirituality and the church as being the most important factor in their ability to cope with living with CHF.

4.6 Summary of Findings

This descriptive correlational study explored the relationship between perceived social support and perceptions of illness for patients with functional class two or class three congestive heart failure.

Findings from this study indicated that subjects reported a high mean score for perceived social support, as measured by the PRQ-85/Part 2 questionnaire. Each of the five dimensions of support—intimacy, social integration, nurturance, worth, and assistance/guidance—also revealed high mean scores. In general, the participants felt cared for and valued, that significant others were available to them in times of need, and that they were satisfied with the relationships they had.

Social support networks were described as primary (i.e., spouse, family, friends), and secondary (i.e., work, school, community associates) (Stewart, 1993). Although the PRQ-Part 2 did not discriminate between primary and secondary sources of support, the content analysis of the open-ended questions revealed that most participants reported receiving more support from their primary rather than their secondary networks. Seventy percent of the male participants identified their wives as being most helpful and supportive, while the female participants mostly relied on a son or a daughter.

Perceptions or cognitive appraisal of illness was measured using the Meaning of Illness Questionnaire (Browne et al., 1992). This measurement tool examined the subjects' perceptions of illness and was divided into five separate factors for analysis and interpretation.

A generally positive outlook regarding illness was reported in Factor 4 (positive attitude toward illness as challenge, hope, motivation, and control), with a high mean score of 22.12. Results for Factor 3 revealed moderate mean scores, which reflected a change in commitments

and a secondary appraisal of coping resources. The negative impact of the illness on everyday living patterns was evident by the low mean scores in the other factors, as well as concern for the unpredictability, controllability, and vulnerability of the disease. This was also verified in the interview data.

Perceived social support was seen to account for 24% of the variance in Factor 3 (degree of stress, change in commitments, and secondary coping resources to deal with it), and 11% of the variance in Factor 2 (type of stress, negative attitude of harm, loss or threat, and viewing the illness as disabling, disfiguring and deteriorating).

The results of this study did not support gender differences in perceptions of social support or perceptions of illness as measured by the PRQ-Part 2 and Meaning of Illness questionnaires. Multiple regression analysis revealed that neither age nor gender were good predictors of either social support or perceptions of illness.

Content analysis revealed six major themes which described the subjects' feelings about how heart failure had affected their lives. The themes that were elicited were: physical limitations, surprise and disbelief, a need for knowledge, adjustment, support from significant others, and getting in touch with one's spirituality (religion).

4.7 Study Limitations

The use of a descriptive correlational design has limitations in that the investigator has no control over the independent variables. That is, there is no experimental manipulation or random assignment to groups; however, unlike other types of *ex-post facto* studies, the aim of descriptive correlational research is to describe the relationship among variables rather than to infer cause and effect relationships (Polit & Hungler, 1995).

The non-random convenience sample, for purposes of efficiency and expediency, limited the generalisability of the results. The use of a convenience sample also introduced the risk of bias associated with non-probability sampling (Polit & Hungler, 1995). While there was some variation in the demographics of the sample, it was a relatively homogenous group in terms of ethnocultural background. The majority of participants were white, English-speaking, middle class and had a high school education; also, most had lived in the Ottawa area for many years. Thus, applying these results to people from other cultural backgrounds may not be appropriate.

In addition, the sample was obtained from a major and specialised cardiac centre with a credible and well-established heart failure clinic. This sample may not be representative of heart failure patients from other centres with respect to the educational and support services that are received.

Chapter Five

DISCUSSION

This chapter will begin with a brief discussion of the participants. The discussion of the findings will be related to each of the research objectives. Recommendations and implications for nursing practice and education, as well as directions for future research will be highlighted.

5.1 The Study Participants

The majority of the participants were male (65%), and the average age for all the participants was 65 years. The literature reports that 80% of people with chronic heart failure are 65 years and older (Levine & Hall, 1998).

The presence of heart disease, plus advancing age, are the principal determinants of heart failure.

However, in this current study, 74% of the subjects did not expect to be told that they had heart failure, and expressed surprise with this information. This finding has not been reported in other studies, and needs to be explored more fully.

Seventy-five percent of the participants in this study were married and living with their spouses. This percentage is higher than what was observed in Harrison, Toman and Logan's (1998) study of 438 patients with congestive heart failure living in the Ottawa-Carleton region where nearly 60% of participants were reported to be in the living-alone category as single, divorced, separated, or widowed. The literature indicates that adaptation to a cardiac event is facilitated by high-quality family relations and high self-esteem (Terry, 1992). It has also been established that marriage and closeness are major predictors of well-being, lower mortality, as

well as fewer repeat coronary events (Yates et al., 1994). In this current study, the subjects perceived their support to be high. Further research in a larger population of heart failure patients is needed to examine the long-term effects of high social support.

Although the eligibility criteria for this study mandated that the subjects must have been hospitalised at least once for their CHF after a diagnosis had been made, the results indicated that 59% had been rehospitalised at least once during the previous year. The high rate of readmissions is consistent with the current statistics for readmission for all stages of heart failure. According to Canadian statistics, approximately 40% of patients were hospitalised at least once within a year of the diagnosis of CHF being made (Johnstone et al., 1994). The American statistics report close to 50% readmission rates in the first six months after the initial admission (Krumholz et al., 1997). Indeed, heart failure is the leading cause of rehospitalisation in people greater than 65 years of age in the United States (Packer & Cohn, 1999).

The findings of this study support the continued need for research to examine these increasing rates of readmission. This may provide insight, and enable practitioners to make decisions regarding allocation of resources for increased outpatient services and interventions that will provide more cost-effective outcomes.

5.2 Research Objective 1: To Determine the Perceptions of Social Support for Patients with NYHA Class 2 or Class 3 Congestive Heart Failure

Perceived support refers to a generalised appraisal that individuals are cared for and valued, that significant others are available to them in times of need, and that they are satisfied with the relationships they have (Stewart, 1993).

The results of this study reported a high overall mean score of ($\bar{x}=141.2$) for perceptions of support as measured by the PRQ-Part 2 questionnaire, suggesting that subjects felt they had high levels of support.

The literature shows that various dimensions of social support have been positively linked with decreased mortality and morbidity in cardiovascular illness. A variety of factors appear to be related to the degree to which support is perceived as helpful, including the timing of the support, the type of stressful event and recovery outcome, the personality characteristics of the recipient, and the match between the type of support needed and the support provided (Yates et al., 1994).

In the present study, spouses and family members were the predominant sources of support for these subjects. In other investigations (Conn, Taylor & Abele, 1991; Coyne, 1991; Stewart et al., 1997b), spouses were also the key supporters of persons who had experienced a cardiac event. It is not surprising that most support for these cardiac survivors came from family and spouses, as the ties of kinship and marriage create commitment to the support recipient, and lead to the perception that support will be available when required. Intimates, like a spouse/partner, are also valued for emotional and appraisal support that is less present in interactions with health care professionals. The results in this study indicated that health professionals were valued for informational support. Individuals, such as those in this present study, must contend with major life transitions and may seek informational support concerning lifestyle changes to cope with a new regimen (Stewart et al., 1997b).

5.2.1 Attachment/intimacy

In the sub-scale 1 dimension, which measured provision for attachment/intimacy, there was evidence of a strong relationship with an informal social support network, consisting of the

spouse, family, relatives and friends, and accounted for the major sources of support as perceived by the subjects. Although the PRQ-Part 2 (1985) did not delineate which dimension of perceived support was being provided for by a specific source, an open-ended question posed to the participants at the end of the interview—“*Who or what has helped you the most?*”—was able to identify a spouse or a child as being most instrumental for 59% of the subjects. These responses were consistent with findings in other studies (Meagher-Stewart, 1994, Paulsen & Altmaier, 1995, Yates, 1994). However, what was interesting in this study was that the majority of married males (n=14/20 or 70%) identified their wives as being most helpful, but only one of the six married females (17%) identified a husband. It is possible that the results reflect that these males were simply more comfortable in seeking and receiving support from their wives on a day-to-day basis, and would only solicit support from a secondary source such as the health care system when adapting to a new care regimen.

Friedman (1997) examined support for women with heart failure. She found that older women with children often identified their children as their most frequent source of both emotional and tangible support, and that older women with heart failure were also more likely to add the assistance of paid helpers to supplement the care that the family routinely provided in order to stay in their homes and to avoid moving into a residential facility.

Coyne and Smith (1991) found that women patients following discharge were more likely to fall back into their traditional caregiver role and look after their well spouse. Therefore, Coyne and Smith (1991) postulated that females might not be encouraging attention and support from their spouses because experience had taught them that males did not change their offering of support sufficiently to meet their wives' needs.

Health care professionals must remember that family members, particularly spouses, need help to accomplish the task of providing support for the patient. Spouses need detailed information about exercise, diet and strategies for coping, as well as emotional support. Several subjects in this study spoke of the importance of having someone pay attention to their experiences of what it has been like living with heart failure. This can also be true for the spouses/caregivers.

Therefore, providing opportunities to link heart failure patients and their families to peer support groups, heart failure clinics, and follow-up telephone support are but some of the interventions that need to be further explored by health care professionals.

5.2.2 Assistance/guidance

Perceived support from more formal or secondary sources, such as the health care system (i.e., physicians/nurses/dieticians), is a finding that is reflected from sub-scale 5 (assistance/guidance) and from the open-ended question, "*Who or what has been most helpful to you?*". Only 27% of the subjects (n=9) perceived that their main sources of support were from the health care team. A mean of 6.35 out of a possible 7.0 in question 1 of this sub-scale ("*If I got sick, there is someone to give me advice about caring for myself*") was also not surprising in light of the fact that these participants were regularly followed by the health care team at the heart failure clinic.

The increased incidence of hospitalisation, as well as the fact that all of these patients were classified as NYHA Class 2 or Class 3 CHF, made them excellent candidates for referral to the heart failure clinic, because the goals for treatment during this stage of the illness are to improve the quality of life by optimising their medical regimen and by slowing down the progression of the disease. The heart failure clinic, which consists of a multidisciplinary team,

strives to empower the patients with heart failure and their families with the knowledge to manage their illness, and to adjust to the necessary lifestyle changes. Previous studies have shown that 50 to 60% of CHF readmissions can be avoided with a multidisciplinary approach to care (Rich et al., 1993; Rich et al., 1995; Happ et al., 1997).

This study verified the continued need for informational support throughout the illness. The need for more formal (informational, professional, and structured) support may be a result of timing in terms of the last acute event or exacerbation that was experienced by the individual. Patients with CHF are often in transition from hospital to home. This becomes a period of physical, psychological, and relational change that involves a shift in the individual's existing world (Yates et al., 1994). Jacobsen (1986) theorised that the best type of help during transitions would be informational support because it helps the individual grasp the meaning of the changes experienced. Woods, Yates and Primomo (1989) found that families experience different demands of illness in different phases of the disease. Demands such as dealing with uncertainty about the consequences of the illness may remain fairly constant. As a result, emotional support may be needed throughout the illness, and informational support may be more important in transition. Therefore, in each phase of the illness, from disease onset through phases of recovery and adaptation, there appear to be specific types of support from a variety of sources that best predict outcomes (Yates et al., 1994).

This has important implications for nursing care and the provision of social support to patients and their families. Support that is provided out of sequence to the identified needs will be ineffective and may not be perceived as supportive by the patient or family.

5.2.3 Social integration

Social integration as measured in sub-scale 2 is defined as the existence of social ties and typically includes such indicators as: marital status, close family and friends, and degree of participation in group and religious affiliations (Yates et al., 1994). The results of this study revealed that subjects perceived close ties with the significant others around them. They felt that they had the opportunity to both give and receive support from a significant other, but to a lesser extent felt involved in outside social activities. Experiential data indicates that there is a tendency for older spouses to rely on one another for help with the things they can no longer do by themselves.

Studies looking at social integration and cardiovascular disease have concluded that individuals with a greater degree of social integration are at lower risk for cardiovascular-related mortality, and individuals with greater perceived availability of support are at a lower risk for the development of coronary heart disease (Yates et al., 1994).

Twelve percent of the participants (n=4) noted that the church and prayer became major sources of support during their illness. Spirituality and church-going can be seen as a tie to the community and as a form of built-in support for elderly clients and should be further explored.

5.2.4 Nurturance

The opportunity for nurturing behaviour was measured in sub-scale 3. In general, the subjects felt that they had sufficient opportunity for nurturing behaviour towards their family and friends. Even in the context of early retirement/disability as a result of their illness, the subjects still saw themselves as important for keeping the family running, and as a central figure in their lives.

On the other hand, Weir et al.'s (1994) study of a group of chronic pain patients found that those individuals who were poorly adjusted lacked the resources to engage in and nurture relationships with others. Largely, this was due to the absence of a confidant and the inability to give and receive in relationships.

Therefore, more research is needed on the presence of a significant other as to their impact on and individual's adjustment to illness.

5.2.5 *Worth*

Sub-scale 4, which explores reassurance of worth as an individual and in role accomplishments, revealed that subjects perceived themselves to be secure in their roles and relationships with family and friends. High scores also showed that the participants were comfortable giving and receiving affection, and as individuals, their degree of self-worth was high.

The literature that explores the relationship between self-esteem and social support shows that common to all definitions of social support is the recognition of the positive impact of social support on feelings of self-esteem. King et al. (1993) found that esteem support (feedback that one is valued and respected) was the single most important type of support related to emotional well-being. King's study attributed the relationship between esteem support and emotional well-being to its ability to make the person feel valued, loved, and accepted through confiding and intimate relationships. Fontana et al. (1989) also found that esteem support and significant others were important in relieving strong psychological distress, angina, and dyspnea after a cardiac event.

The above findings are also supported by the results of this study, whereby an overall positive attitude and outlook towards the illness, as well as enhanced coping abilities, could be attributed to the presence of a significant other, such as a spouse or a child.

The qualitative analysis particularly highlighted this finding, with the following comments:

It's mainly been my wife that's been most helpful and carried the load. She has been positive and encouraging and so on.

My family's been supportive. They come in and stay and cook for me, and my daughter looks after me.

5.3 Research Objective 2: To Determine Perceptions/Cognitive Appraisal of Illness for Patients with NYHA Class Two or Class Three Congestive Heart Failure

Cognitive appraisal, or the meaning a person gives a stressful event, is believed to mediate an individual's reaction to an event(s) and has been found to aid in explaining adjustment to illness (Weir et al., 1994).

The Meaning of Illness Questionnaire seemed to cause some confusion with respect to the subjects' understanding of the questions and how they related these statements to their heart failure. It was often necessary for the researcher to reiterate and/or to rephrase the questions in a manner that was more comprehensible. This problem has not been noted by any other researcher. Although face-to-face interviews can introduce bias into a study, under these circumstances, the benefits of having the researcher present far outweighed the limitations that it might have imposed.

5.3.1 Impact of illness

Factor 1, which measured the impact of illness on daily living, revealed the lowest mean score overall ($\bar{x}=9.21$ out of a possible 24). This illustrated the negative impact that heart failure

had on the subjects' lives and how poorly adjusted they felt with respect to this aspect of their illness. These findings are also supported in the open-ended question, "*Is there anything else that you would like to share on how it's been like living with heart failure?*". Examples of comments were:

The constant shortness of breath, the rude awakenings during the night that affect your sleeping, your normal daily activity and your appetite is affected.

Well it's not nice living...trying to live a normal life with heart failure because you can't. You haven't got the stamina nor the breath to do it.

The overall low mean score, as well as the comments from the interviews, showed that the physical symptoms were quite problematic for these individuals with heart failure.

CHF has often been characterised in the literature as being associated with physiological and psychological consequences. Many of the troublesome symptoms described by the subjects in this study, such as dyspnea and fatigue, were consistent with findings from previous studies (Bennett et al., 1997, Freedland et al., 1991, Grady et al., 1992, Grady et al., 1995). Physical limitations were also emphasised by Rideout (1992), where symptoms such as breathlessness, fatigue, and weakness restrict functional capacity. The participants in this present study indicated the extent to which both physical limitations and social restrictions impacted on their day-to-day living with comments such as:

I am more and more careful, and I realise that I can't act the way I was before.

The only thing I regret is not being able to travel.

5.3.2 Type of stress

Factor 2 revealed a low mean score as well, but contained a mix of moderate to low scores for the individual variables. The items that were measured addressed the type of stress (negative attitude of harm, loss, or threat), and the functional context (did they see the disease as

disabling, disfiguring, or deteriorating). The questions in this section appeared to be ambiguous to the participants, and it was often necessary to explain the terms in the context of their illness.

The subjects in this study had the most difficulty with understanding the terms harmful, loss, threatening, and disfigurement, as well as seeing the disease as causing an appearance change for the worse. This particular section did not seem to be sensitive to the stresses often seen in heart failure patients, such as dyspnea, fatigue, and cognitive impairment including forgetfulness, decreased attention span, and diminished concentration. The literature is replete with terms that are used to explain changes in people's lives, as well as the increased stress of being ill. These changes include: loss of social and vocational roles, permanent changes in lifestyle, threats to self-image and self-esteem, disruption of normal life transitions, uncertain and unpredictable futures, and decreasing resources (White et al., 1992). The need for clarification by the researcher to many of the individuals seemed to suggest a certain difficulty in relating those more negative terms to themselves. With a chronic illness such as heart failure, physical changes are not always visible. The individual may not "look sick", but almost always will state that they are unable to function as they once did. The adaptive demands resulting from these stresses can be overwhelming, and patients suffering from a chronic illness such as heart failure often feel that they are asked to adapt at a time in their lives that is most difficult for them to do so.

5.3.3 Secondary appraisal of coping resources/positive attitude of illness

Subjects in this study had moderate and higher mean scores on factors 3 and 4. The subjects reported a positive attitude toward the way they handled things, their outlook, and their ability to change, for the better, what they cared about. In spite of a chronic illness, they were determined to function independently. They felt challenged, believed that they still had control

over the things that they cared about and, in general, seemed to feel that things would turn out well. The more positive scores may have been related to coping resources such as the support from both primary (family, friends) and secondary (health care teams) sources.

Patients who are more optimistic tend to execute their daily activities to a greater extent, irrespective of the physical restrictions which arise on account of CHF. For instance, changing the level of physical activity is a common management strategy for a variety of symptoms. In response to shortness of breath, tiredness, chest pain, and difficulty bending over, health care professionals can instruct patients to wait for a few minutes to perform an activity, complete activities at a slower pace, rest between activities, and move more slowly and carefully.

The link between an individual's perception and how they use their coping mechanisms to adapt is illustrated both by the higher scores in Factors 3 and 4, and the comments derived from the content analysis with respect to adjustment to illness. There was also a realisation that they did not have a great deal of control to change or do something about the progression of their illness, as evidenced by the following statements.

The thing about having heart failure is you have to accept what you have, and you have to turn around and understand the situation that is. You're going to have your down days, and you're going to have your up days.

I have it, I live with it, and I accept it. I can't change it.

It is just a matter of getting used to it and changing your lifestyle, for instance the way you cook things.

Additional coping strategies, such as following a sodium-restricted diet and managing medications to alleviate symptoms, are a form of support that can be provided to patients by health care professionals. This additional support can serve as a motivator to encourage individuals to strive towards their own emotional and physical goals. The literature has shown

that supporting individuals to call upon new and alternate strategies in adapting to illness has empowered them to cope with stressful problems; as well, they can enable individuals to direct energies to overcome obstacles (Johnson, Dahlen & Roberts, 1997).

5.3.4 Expectancy and reoccurrence

Results from the analysis of Factor 5 suggested that the participants were surprised to be diagnosed with heart failure. Seventy-four percent (n=25) of the participants scored 0 (“Not at all”) on this question, “*Did you expect this illness before the doctor told you?*”. The subjects had not expected to be dealing with an illness that could not be “fixed”, and their perceptions of health and health care for themselves at that time held a more positive meaning. For example:

“It was a surprise to...realise that I had heart failure.”

Also, the participants did not believe they played a strong role in the occurrence of the illness (“*Do you think you played a part in the occurrence of this illness?*”). This was an interesting finding in the present study, considering that many of the subjects had previously experienced heart disease in the form of myocardial infarction, dysrhythmias, and/or pacemaker insertions. Clearly, the links between risk factors, heart disease, and heart failure had not been made.

The literature shows that patients tend to adapt better when they are able to conclude that the reasons for developing their health problems were somewhat under their control or at least identifiable (Bennett, Corses, Westmoreland, Castro & Donnelly, 2000).

Research has shown that the presence of a heart failure clinic in the lives of this population provides a means of educational and emotional support while reinforcing self-care strategies for better management of their symptoms. Ultimately, this leads to a more positive

adjustment to illness with better physical and emotional adaptational outcomes (Bennett et al., 2000).

This was also true for many of the patients in this study, as evidenced by the following statements from the content analysis.

In the last two visits, the doctors and nurses had been pleased with my conduct and the check-up and so forth, and this has helped me a great deal.

It's just a matter of getting used to it and changing your lifestyle.

I do believe that this hospital and the doctors have been very helpful to me.

5.4 Research Objective 3: To Determine the Strength of the Relationship Between Perceptions of Social Support and Perceptions/Cognitive Appraisal of Illness for Patients Experiencing NYHA Class Two or Class Three Congestive Heart Failure

It was stated in the theoretical framework that “perceived social support is the cognitive appraisal of being reliably connected to others” (Stewart, 1993), and that perceived social support is a process that changes with shifts in the person/environment relationship. Therefore, the amount, type, and source of support as a coping resource that is called upon, is dependent upon the individual’s cognitive appraisal of the event (Lazarus & Folkman, 1984).

Cognitive appraisal processes, or the meaning a person gives to stressful events, is believed to mediate an individual’s reaction to an event and, as such, has been demonstrated to explain adjustment to illness (Weir et al., 1994). The kind of support that individuals seek changes as a function of the stage of the stressful person/environment encounter (Lazarus & Folkman, 1984, p. 286). Therefore, an individual’s appraisal of the meaning of the stressor (heart failure) may determine what amount, type, and source of support, as a coping resource, is significant to well-being.

The MOIQ was designed to use five factors or sub-scores of meaning that a person may give to a stressful event such as illness. Therefore, correlations (Pearson Product Moment) were calculated between the total support score (PRQ-85/Part Two) and the mean score of the meaning of illness factors (MOIQ) in an attempt to more clearly understand the relationship between these variables in a heart failure population.

Only one significant and moderately positive relationship was found between perceived social support and MOIQ Factor 3 (degree of stress, change in commitments, secondary appraisal of coping resources). Linear regression analysis revealed that perceived social support was found to account for 24% of the variance in this relationship. This significant and positive correlation between perceived social support and the MOIQ Factor 3 is further supported by the comments made to the researcher during the interviews. For example:

The thing about having heart failure is you have to accept what you have, and you have to turn around and understand the situation there is. You are going to have your down days and you are going to have your up days. Personally with the great family I have and believing in the Lord, has really helped me a lot.

This finding was similar to the findings from Markle-Reid's post-MI study (1989). Although her study found two positive and significant relationships, this probably reflected the different nature of the populations and their differing perceptions of needs and adjustment to illness. Markle-Reid (1989) studied a group of male patients between the ages of 30 and 40 who had suffered a first-time myocardial infarction. Most of these males had wives and small children, and were able to return to work six weeks after their discharge home. Clearly, their support needs, both physically and emotionally, were different as a result of age and the ability to return to work, where additional support could have been present from colleagues. As well, there was a tendency toward a more optimistic outlook for the future, because these patients felt

challenged to modify their lifestyle behaviours in order to enjoy and support their young families.

No significant relationship was found between perceived social support and MOIQ Factor 1 (impact of illness on daily living), Factor 2 (type of stress), Factor 4 (positive attitude toward illness as challenge), and Factor 5 (expectancy and reoccurrence). Social support was found to account for 11% of the variance in Factor 2 (type of stress), 8% of the variance in Factor 1 (impact of illness), and 5% of the variance in Factor 4 (positive attitude of illness as challenge).

These results did not suggest a strong relationship between the study variables, despite the high scores indicated on the PRQ-85 Part 2 questionnaire, which was a measure of perceived social support. Therefore, in order to further delineate which dimension of perceived social support most strongly impacted on perceptions of illness, correlations were done between each of the sub-scales of perceived social support and the MOIQ factors (Table 11). Although these correlations had not been previously reported in the literature, the findings were interesting. There were significant but moderately positive correlations between PRQ sub-scale 1 (provision for attachment/intimacy) and four out of the five MOIQ factors. The presence of a significant relationship in an individual's life seemed to suggest that it might be the most important link to one's cognitive appraisal of illness and, therefore, how well or how poorly one adjusts to a chronic illness. Therefore, during discharge planning, nurses need to explore with patients and their families how these significant individuals may be of assistance to the patient.

The findings of this present study also seem to support Weir's (1994) results which indicated that it was the ability to engage in and nurture relationships with others that made the most difference on how well-adjusted one was to illness.

Further analysis in this study showed that the presence of a spouse or a close family member impacted significantly in four out of the five MOIQ factors that measured meaning of illness to the subjects (Table 11). As well, this finding was further strengthened by the results of the interview data from the open-ended question, “*Who or what has been most helpful to you?*”, with comments like:

My wife has been most helpful, she's a nurse and she's very loving and supportive.

My daughter, she's more like a guardian angel for me. She helps me out a lot, and she really cares.

My wife has made a practice of coming to see the cardiologist with me so we could compare notes and make sure we weren't missing anything.

In summary, the quantitative and qualitative results from this study indicated that subjects perceived their social support to be high. Spouses and family members were the predominant sources of support. Health professionals were valued for their informational support concerning lifestyle changes to cope with a new regimen.

Meaning of illness was generally positive with respect to the subjects reporting a positive attitude toward the way they were handling things, their outlook and their ability to change, for the better, what they cared about. However, uncertainty, related to the unpredictability of the disease, its physical limitations, and the impact that the illness had on their day-to-day living activities, was evident from the statistical findings, as well as from the interview data.

5.5 Implications for Practice, Education, and Research

The following section will discuss implications of the study findings for nursing practice, education, and future research in the heart failure population.

5.5.1 Implications for practice

Results of this study suggest that the participants reported their perceptions of illness as positive with respect to challenge, hope, and motivation, but more negatively with respect to day-to-day living practices and the uncertainty, and controllability of the illness. Nurses should assess the meaning given illness, and the perception of social support from the patient's perspective. Similarly, participants perceived their support to be quite high, but it was the presence of a significant other, such as a spouse or a child, who made the most difference in how they adjusted to living with heart failure. Therefore, it is important that nurses identify with patients who it is that actually provides this support. In these situations, nurses may reinforce and encourage positive behaviours and attitudes of the patient and the family. Specifically, it may be necessary to work with, teach, and support the primary caregiver. Conversely, those patients who perceive their social support to be low may need additional support from the health care team, requiring more complex interventions, such as therapy, counselling, and additional tangible support.

It is also important to assess whether or not there is available support in order to identify those individuals more at risk. A failed social support system is one factor that contributes to readmissions (Rich et al., 1995). In a study done by Friedman (1993), the author described several rehospitalised patients who had relatives living with them but were "essentially alone" with inadequate social or tangible support. As nurses, before we assume that support is available, it would be important to identify the patient's perception of the available support in the context of their ongoing needs. Berkman et al. (1991) concluded that unmarried cardiac patients were at greater risk for rehospitalisation, because of the isolation of living alone and a decrease in available support systems. Happ et al. (1997) found that for higher risk individuals like those

living with heart failure, the quality of support from family and friends was more critical in preventing rehospitalisation. Therefore, nurses need to have a repertoire of specific questions that can help to delineate the presence or absence of support for patients.

As well, when planning care for an elderly and chronically-ill population, it is imperative that health care professionals are aware of the issues related to age and chronic illness. Increased age has been associated with less social support, higher depression, lower quality of life, poor health status, and less participation in rehabilitation, particularly in males with cardiac disease (Conn et al., 1991). Of 194 seniors hospitalised for myocardial infarction, lack of emotional support was significantly associated with six-month mortality after controlling for severity of myocardial infarction, co-morbidity, risk factors, and socio-demographic factors (Berkman et al., 1992).

The provision of informational support includes delivering details regarding anticipated changes in lifestyle modifications such as diet and medication, and self-care management such as learning a new diuretic protocol. Informational support should also include a discussion of the emotional and physical responses encountered when trying to adapt to a new regimen. This information allows cognitive reappraisal of stressful conditions such that they may be placed in a more optimistic light (Moser, 1994). Emotional support that enhances recovery and that nurses can provide includes the promotion of self-esteem and positive patient perceptions regarding recovery. These supportive interventions may be included with discharge planning while still in the hospital and reinforced during follow-up care in an out-patient setting.

The literature indicates that health care is expensive for patients with chronic illnesses such as heart failure. Congestive heart failure is the most frequent diagnosis for admission to the hospital among older adults in North America (Rich et al., 1995). Hospitals in turn have

decreased lengths of stay in an attempt to reduce costs (Kegel, 1995). Therefore, shorter hospital stays must be supplemented by preparing patients and their families for increased self-care at home.

Clearly, patients with heart failure and their families face changing health care demands associated with consequences of the disease and treatment. Often, patients can manage their self-care for some time, but new demands will emerge that require more complex actions (Jaarsma et al., 1998). It is important that nurses review and balance self-care demands with self-care agencies in order to determine the existence or potential for self-care deficits. This process can be started during discharge planning from the hospital and continued to the community or clinic where these individuals are being followed. The provision of care within a speciality clinic is one approach that has been shown to improve outcomes for heart failure patients (Rich et al., 1990; Rich et al., 1995). Speciality clinics, guided by advanced practice nurses and specialist physicians, are better able to incorporate the benefits of greater knowledge, more experience, and enhanced care for this specific population (Levine & Hall, 1998). The goals of a heart failure clinic are to improve physiologic function; to reduce crises in heart failure through education, monitoring and optimal pharmacological management; to minimise use of health resources (i.e., emergency room use) while improving functional status; to empower people with heart failure to manage their illness and to support patients and families who are adjusting to heart failure.

Heart failure clinics with advanced practice nurses provide increased accessibility to health care and have been shown to reduce morbidity and costs associated with shorter hospital stays (Kegel, 1995). Patients are followed closely and are able to inquire about medications, proper diet, weight counselling, and self-directed diuretic protocols. Clearly, this system

promotes better management and support for these individuals and, more importantly, it limits the need for unnecessary emergency room visits.

5.5.2 Implications for education

Heart failure requires close follow-up and assessment of the patient for early signs and symptoms of relapse, and this requires that patients be actively involved with their plan of care. Several studies show that more frequent contact with the health care system has a major influence on successful management (Cargill, 1992, Fineman & DeFelice, 1992). Health care professionals and services can be an ongoing source of support. For example, patients need access to ongoing education, assessment, and counselling; and nurses need to elicit information about what patients believe they should learn in order to design effective educational interventions.

The educational needs of heart failure patients have traditionally been outlined to include topics such as anatomy and physiology, medications, sodium restrictions, dietary changes, activity levels, and psychological responses (Dunbar, Jacobson & Deaton., 1998). The health care policy and research guidelines (Agency for Health Care Policy and Research, 1994) for the management of heart failure suggest that education become a standard part of management plans, and that both content and counselling be included. For example, medication therapy and dietary recommendations are essential components of patient management, and thus become a priority in educational needs. For patients who have been hospitalised, it is important to discuss medications and diet before discharge from the hospital, and to repeat this information in the out-patient setting. This will allow patients time to assimilate the information and to formulate more questions. The provision of support from the traditional health care professionals' "expert role" differs greatly from the collegial "consultant role" called for in health system reform.

Moving from expert provider to equal partner will require role modification and preparation (Stewart et al., 2000).

The typical symptoms of worsening heart failure (orthopnea, paroxysmal dyspnea, leg edema, or exercise intolerance) should be explained, and patients should be advised to contact their doctor or nurse if such symptoms develop. Patients should also be told to obtain a bathroom scale and to weigh themselves each morning before eating. They should contact their provider if their weight has changed by more than three to five pounds since their last clinical evaluation. If patients know the symptoms and signs of worsening heart failure, they may be able to seek care early and avoid hospitalisation. In addition, a diuretic regimen that the patient adjusts on the basis of weights taken at home can be a useful method for preventing decompensation and hospitalisation.

An explanation of what patients can expect to experience will help avoid uncertainty over symptoms and prevent patients from becoming afraid to perform daily activities that might provoke shortness of breath. Patients should be advised to stay as active as possible, and should understand that they may feel tired the following day if they over-exert themselves.

It is vital that patients understand their condition and be involved in developing a plan for their care. Patients and their families should be encouraged to ask questions about any aspect of the management of heart failure. Patient and family education should be designed to help patients arrive at realistic expectations about the outcome of an intervention. Patients with heart failure and their families must understand the serious implications of the diagnosis. These individuals should be provided with accurate information in order to make decisions and plan for their future. It is also important to maintain hope and morale. Psychological factors can be more important to patients' quality of life and social functioning than the degree of physiologic

impairment. Nurses, physicians, family members, qualified local support groups, and other caregivers can all play an important role in optimising patients' functioning and quality of life.

Heart failure clinics are meant to bridge the gap between hospital and home for CHF patients and their families. In this study, all of the participants received support from a heart failure clinic which provides a multidisciplinary approach to meeting the clinical, educational, and psychological needs of the patients. These subjects are already in a venue where standards of care as outlined previously are being implemented. However, as nurses we must be particularly mindful of the fact that heart failure has implications for the patient's family and support system, because often the home management regimen for this population is complex. The literature indicates that family members are ideal sources of social support for older people with heart failure (Friedman, 1993). The majority of participants in this study were married and living with their spouses and reported their spouses as being the most helpful and supportive in their day-to-day lives. The study indicated a moderately high correlation between support and day-to-day coping resources, so perhaps it is not just the presence of a significant other but the ability of that individual to support the patient to meet their self-care needs at home. Therefore, nurses in any practice setting for heart failure must make that critical connection to the caregivers as well as to the patients via education and counselling in order to optimise outcomes.

This present study revealed that 50% (n=17) were uncertain about the exact nature of their cardiac problems prior to being told by their physician that they had heart failure. Many admitted being aware of the fact that they were taking medications for their heart but were uncertain as to the exact reason. This was an interesting finding, and it sends a powerful message to all health care professionals in that we must be mindful of the fact that the "educational information" we provide may not always be interpreted or understood as was intended, and

therefore may impact on outcomes. For instance, lack of financial resources, cultural beliefs, and personal values are some of the obstacles which may create difficulties with adherence. Nurses must also be sensitive to differences in language, and other physical impairments such as diminished hearing and sight which may impede patients' understanding and compliance.

Nurses are proficient in psycho-social assessment, and studies have found that patients are more likely to recall health education information and follow suggestions for prevention when they perceive psycho-social concern (Campbell, Neikirk & Hosokawa, 1990). As well, better collaboration and communication between multiple health care providers must exist so that management for overall care can be effective. Collaboration between all health care professionals will be necessary to create a system that will achieve appropriate outcomes. Nurses at all staffing levels across the continuum of care will need to take increasing responsibility and accountability for the outcomes of educational programs. Therefore, we need more continuing education programs to inform nurses about how to teach patients.

5.5.3 Implications for research

Further investigation of perceptions of social support and perceptions of illness should be conducted with heart failure patients and with a larger randomised group in order to make the results more generalisable. A longitudinal study could be carried out at various phases post-discharge to determine if the relationship with perceived social support and perceptions of illness varies with the illness trajectory. As well, gender differences could be determined with the above variables in order to better differentiate caregiver needs. A correlational study to include a psycho-social adjustment to illness scale could also be conducted to determine the degree to which perceived social support and cognitive appraisals of illness explain psycho-social adjustment to illness at various stages in the illness trajectory.

Despite nursing's practice orientation, there have been few nursing studies using social support as an intervention. Since outcomes are an international research priority, nurse investigators need to focus efforts on social support interventions at individual and group levels, both in clinical and community settings. Research evidence is needed to show that social support interventions enhance role functioning, lead to the development of new skills and behaviours, enable coping, or alleviate social isolation (Stewart et al., 1995).

More research is needed to develop supportive nursing interventions that can help change patients' beliefs about their illness. For example, more studies, such as the transitional care study (Harrison et al., 1998), can be done to guide nursing care towards better evaluation of discharge planning needs and follow-up. Also, studies can be done to look at the impact of telephone support on educational interventions such as the self-directed diuretic protocol, in order to determine compliance and better outcomes related to understanding and reinforcement of the protocol between clinic visits.

The management of heart failure is complex, with research and education playing an increasingly important role (Dunbar et al., 1998). Because future projections predict an increasing prevalence of heart failure, the importance of addressing educational issues through research will become even more paramount.

Further research is also needed which provides the opportunity for the individual to enter the world of the patient. The result of this would lead to the development of more constructive interventions that would be helpful from a patient's point of view.

5.6 Role of the Advanced Practice Nurse

Hamric, Spross and Hanson (2000) describe the advanced practice nurse (APN) in terms of five major practice domains which include: expert clinical practitioner, consultant, educator,

researcher, and leader. The APN is responsible for managing a group of clinically-complex or resource-intensive patients in order to optimise clinical and cost outcomes (Hamric et al., 2000). These outcomes are achieved through partnering with patients, families, and the health care teams with skills such as communication, collaboration, and co-ordination

Advanced practice nurses can provide a strong source of secondary support to patients and families. For example, they can play an important role in optimising patient functioning and quality of life. Interventions to address difficulties with patient self-care management at home and in outpatient settings such as heart failure clinics could be an APN focus.

Clark et al. (1991) described four self-management tasks for older adults living with chronic illness: (1) Engage in activities that promote health and build physiologic reserve: exercise, proper nutrition, social activities, and sleep; (2) Interact with health care providers and systems, and adhere to recommended treatment protocols; (3) Monitor physical and emotional status, and make appropriate management decisions on the basis of symptoms and signs; (4) Manage the impact of the illness on ability to function in important roles, on emotions and self-esteem, and on relations with others.

In general, patient self-management includes monitoring the level and intensity of symptoms (i.e., shortness of breath) and objective data (blood pressure, daily weights) and adjusting the treatment plan accordingly (Dunbar et al., 1998). For patients with heart failure, the self-management plan includes monitoring changes in such symptoms as fatigue, shortness of breath, daily body weights, and, knowing when to report the changes to the health care providers. The advanced practice nurse must be able to assess and intervene at various stages of the illness' trajectory and use different strategies to facilitate patient self-management and family assistance to the patient.

Advanced practice nurses can tailor educational strategies for individual patients. Since most heart failure patients are elderly, they often have significant co-morbidity which make interventions for this population even more challenging. Identification of patients at risk for non-adherence to a specific regimen is important. For instance, forgetting to take medications and running out of medications are often observed by practitioners as reasons for not adhering to medication regimens. The advanced practice nurse's expertise can be used to develop teaching strategies that address these specific problems. Strategies must include assessment of the needs of the particular patient which are based on perceptions of illness and treatment plans. Patients and families can then be aided to fit the treatment regimens to their daily behaviours by making treatment activities part of the daily routine. For example, teaching patients and families self-directed and flexible diuretics regimens for changes in fluid balance can reduce the need for clinic visits and hospitalisations. By following electrolyte and drug levels, the APN can manage outpatient care and intercede early in decompensation of CHF.

Another role for the advanced practice nurse would be in program development and implementation. Programs could be developed such as care-mapping, educational interventions, computer-assisted instruction, audio and video tapes, telephone surveillance and follow-up. These programs could be designed and tested as part of the research mission in the centre.

Technological advances are increasingly playing a role in the provision of social support. A challenge for nurse scientists is to keep abreast of technological developments that link humans and that can be avenues of support (Stewart et al., 1995). For example, computers have been helpful for informational support and have been able to reach large numbers of people at home and at work. Telephones as another vehicle of support have been used for follow-up, education and emotional support when patients have been discharged home. Telephones with

visual display monitors allow the opportunity for both verbal and non-verbal communication. In addition, smaller communities can also be linked to heart failure clinics through telehealth technology so that these same services may be accessed by individuals in the outlying regions.

Advanced practice nurses must take part in formal research studies and must manage data within their own practice settings for evaluation of practice and outcomes. The success of a program or strategy should be determined by its effect on patients' knowledge, adherence to treatment regimens, behavioural change, psychological measures such as anxiety and depression, quality of life, functional status, emergency department visits, and hospital admissions (Dunbar et al., 1998). Ultimately, the advanced practice nurse must be aware of the available resources and the best utilisation of these resources to guide both optimal clinical and cost outcomes in the heart failure population.

5.7 Conclusion

This present study provides additional insight for nursing about the relationship between perceived social support and perceptions of illness for patients living with heart failure. Clinically, the findings may contribute to the social support literature with respect to the heart failure population. As health care professionals, the more knowledge we have about the patient's view of the illness and their perceptions of their support systems, the more effective we can be in bolstering support in the context of living with this chronic illness.

The conceptual framework for this study was based on Lazarus and Folkman's (1984) mid-range theory of stress, appraisal and coping, and Miriam Stewart's (1993) conceptual approach to social support.

The results indicated that subjects perceived their social support to be high. This was mainly attributed to the presence of a significant other, such as a spouse or a child. Perceptions

or cognitive appraisal of illness were generally positive with respect to MOIQ Factor 4 (positive attitude toward illness as challenge, hope, motivation, and control). Results for MOIQ Factor 3 revealed moderate mean scores, which reflected a change in commitments and a secondary appraisal of coping resources. The negative impact of the illness on everyday living patterns was evident by the low mean scores seen in the other factors that reflected a concern for the unpredictability, controllability and vulnerability of the disease.

A key finding was that perceived social support accounted for 24% of the variance in MOIQ factor 3 (satisfaction with coping resources). Another interesting finding in this study was that the presence of a significant individual in the lives of heart failure patients had a statistically significant but moderately positive correlation with four of the five MOIQ factors that dealt with the impact and stresses of the illness on: daily living, satisfaction with coping resources, and a positive outlook with respect to seeing the illness as a challenge.

In conclusion, the experience of managing a chronic illness such as heart failure does not occur in isolation, but requires a complex interaction of supportive resources if successful adjustment is to occur and be maintained.

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APPENDIX A:
DEMOGRAPHIC QUESTIONNAIRE

Appendix A

DEMOGRAPHIC QUESTIONNAIRE

1. Age: _____
2. Gender: _____ Male Female _____
3. Marital Status: _____ Married _____ Single _____ Divorced
 _____ Widow/Widower _____ Common Law
4. Living with Spouse/Significant Other: _____ Yes _____ No
5. Length of Time Married: _____ Number of Years
6. Place of Residence: _____ House _____ Apartment _____ Seniors Dwelling
 _____ Other
7. Number of Children: _____
8. Number of Children Living at Home: _____
9. Employment Status: _____ Presently Employed _____ Retired _____ Other
10. Education: _____ High School _____ Technical School/College
 _____ University _____ Post-Graduate Studies _____ Other

(Please indicate your highest degree or number of years)

11. Date of Discharge from the Hospital: _____
(for treatment of heart failure)
12. Other Cardiovascular-Related Diseases/Medications:

_____ Angina	_____ Myocardial Infarction
_____ Pacemaker	_____ Coronary Artery Bypass Surgery
_____ Cardiac Arrhythmias	_____ Peripheral Vascular Disease/Surgery
_____ Cardiovascular medications (please specify) _____	
13. What is your ethnic origin? _____

APPENDIX B:

**PERSONAL RESOURCE
QUESTIONNAIRE (PRQ-85)
PART II**

Appendix B

PERSONAL RESOURCE QUESTIONNAIRE (PRQ-85)

PART II

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Below are some statements with which some people agree and others disagree. Please read each statement and CIRCLE the response most appropriate for you. There is no *right* or *wrong* answer.

1 = Strongly Disagree
2 = Disagree
3 = Somewhat Disagree
4 = Neutral

5 = Somewhat Agree
6 = Agree
7 = Strongly Agree

STATEMENTS:

- | | | | | | | | |
|--|---|---|---|---|---|---|---|
| a. There is someone I feel close to who makes me feel secure | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| b. I belong to a group in which I feel important | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| c. People let me know that I do well at my work (job, homemaking) | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| d. I can't count on my relatives and friends to help me with problems | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| e. I have enough contact with the person who makes me feel special | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| f. I spend time with others who have the same interests that I do | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| g. There is little opportunity in my life to be giving and caring to another person | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| h. Others let me know that they enjoy working with me (job, committees, projects) | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| i. There are people who are available if I needed help over an extended period of time | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| j. There is no one to talk to about how I am feeling | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| k. Among my group of friends, we do favours for each other | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

1 = Strongly Disagree
 2 = Disagree
 3 = Somewhat Disagree
 4 = Neutral

5 = Somewhat Agree
 6 = Agree
 7 = Strongly Agree

l.	I have the opportunity to encourage others to develop their interests and skills	1	2	3	4	5	6	7
m.	My family lets me know that I am important for keeping the family running	1	2	3	4	5	6	7
n.	I have relatives or friends who will help me out even if I can't pay them back	1	2	3	4	5	6	7
o.	When I am upset, there is someone I can be with who lets me be myself	1	2	3	4	5	6	7
p.	I feel no one has the same problems as I	1	2	3	4	5	6	7
q.	I enjoy doing little "extra" things that make another person's life more pleasant	1	2	3	4	5	6	7
r.	I know that others appreciate me as a person	1	2	3	4	5	6	7
s.	There is someone who loves and cares about me	1	2	3	4	5	6	7
t.	I have people to share social events and fun activities with	1	2	3	4	5	6	7
u.	I am responsible for helping provide for another person's needs	1	2	3	4	5	6	7
v.	If I need advice, there is someone who would assist me to work out a plan for dealing with the situation	1	2	3	4	5	6	7
w.	I have a sense of being needed by another person	1	2	3	4	5	6	7
x.	People think that I'm not as good a friend as I should be	1	2	3	4	5	6	7
y.	If I got sick, there is someone to give me advice about caring for myself	1	2	3	4	5	6	7

APPENDIX C:
MOIQ-SR (1992)

Appendix C

MOIQ-SR (1992)

Please circle the number that best describes your response.

	Not at All		Somewhat		Definitely Yes		
Has this illness negatively affected							
1.	0	1	2	3	4	5	6
2.	0	1	2	3	4	5	6
3.	0	1	2	3	4	5	6
4.	0	1	2	3	4	5	6
Would you describe this illness as:							
5.	0	1	2	3	4	5	6
6.	0	1	2	3	4	5	6
7.	0	1	2	3	4	5	6
8.	0	1	2	3	4	5	6
Do you see this illness as something that:							
9.	0	1	2	3	4	5	6
10.	0	1	2	3	4	5	6
11.	0	1	2	3	4	5	6
Do you see this illness as:							
12.	0	1	2	3	4	5	6
13.	0	1	2	3	4	5	6
14.	0	1	2	3	4	5	6
15.	0	1	2	3	4	5	6
16.	0	1	2	3	4	5	6
17.	0	1	2	3	4	5	6
18.	0	1	2	3	4	5	6

19. Do you believe it is likely that this illness will reoccur, or a second illness like it will occur? 0 1 2 3 4 5 6
20. Do you think things will turn out well? 0 1 2 3 4 5 6
21. Are you determined to try to function independently, in spite of this illness 0 1 2 3 4 5 6
- In terms of this illness, to what extent do you feel:**
22. You could change or do something about it? 0 1 2 3 4 5 6
23. You have to accept it? 0 1 2 3 4 5 6
24. You need to know more before you act? 0 1 2 3 4 5 6
25. You have to hold back from what you want? 0 1 2 3 4 5 6
26. You have changed, for the better, what you care about? 0 1 2 3 4 5 6
27. Do you believe you have a lot of say regarding the things you care about? 0 1 2 3 4 5 6
28. Do you feel you have the energy and stamina to get through this? 0 1 2 3 4 5 6
29. Are you pleased with your outlook on things? 0 1 2 3 4 5 6
30. Are you pleased with the way you are handling things? 0 1 2 3 4 5 6

APPENDIX D:
PATIENT CONSENT FORM

Appendix D

PATIENT CONSENT FORM

Research Project Title: The Impact of Social Support on Living with Heart Failure

Principal Investigator: Elaine Doucette, R.N., BSc.N.
Tel: (514) 693-0714

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

I am a Masters of Science in Nursing student at the University of Ottawa, and I am undertaking a research project to learn more about patients' experiences in living with heart failure. The sharing of your own experiences and your perceptions of the illness may help other patients as they progress through their illness.

Participation in this study would involve answering questions on three questionnaires with your interviewer, Elaine Doucette, who will take note of your responses. A tape recorder will be present during the last two questions of your interview only. The tape will be erased and destroyed as soon as the information is transcribed.

The interview will take place in your home or at a scheduled follow-up appointment in the cardiology clinic within three months of your discharge from the hospital. The choice of location for the interview will be yours. The interview will take a maximum of 60 minutes.

You have the right to refuse to participate in this study or to withdraw at any time without concern for the care you are receiving. All data from this interview will be kept in the strictest confidence, and a code number will ensure your confidentiality. Only the researcher, Elaine Doucette, and the thesis advisor, Dr. Frances Fothergill-Bourbonnais, will have access to the data from this interview. Your responses will not be shared with your physician or be used to determine any future care needs.

It is understood that there will be no direct benefit to you for participating in this study. It is also understood that there are no risks involved in your participation.

You may ask now or in the future any questions about the study. Any reporting of the results of this study will be done in such a manner that no individual will be identified.

Informed Consent:

The purposes and procedures involved in this study on patients' experiences with living with heart failure have been explained to me by the researcher, Elaine Doucette. I understand the purpose and procedures of this study. I am willing to participate in this study.

Participant's Name

Participant's Signature

Date

Investigator's Name

Investigator's Signature

Date

APPENDIX E:

Correlations Among Factors in the Meaning of Illness Questionnaire Scale

Appendix E**CORRELATIONS AMONG FACTORS IN THE MEANING OF ILLNESS SCALE**

	Factor 2	Factor 3	Factor 4	Factor 5
Factor 1	0.46*	0.14*	-0.19*	0.19*
Factor 2		0.04	-0.14*	0.25*
Factor 3			0.39*	0.08
Factor 4				0.09

*P < .05 df = 244