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INFORMATION GAPS: A GROUP PERSPECTIVE ON THE MANAGEMENT OF HEART FAILURE

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ABSTRACT

Heart failure is a complex condition that incurs considerable socio-economic burden, and poor prognosis. Careful management of the syndrome is required if a patient is to have a reasonable quality of life. Health professionals generally acknowledge that there is a need to improve care of patients with heart failure and that there are treatment gaps between the recommended therapies, and the care patients are actually receiving.

This pilot study used the grounded theory approach to discover the main concerns, and how they are continually resolved, of a group that manage heart failure. It is argued that **information gaps** are present in the management of heart failure. It was demonstrated that when there is an *absence of a cohesive group,* occurring under conditions of *changing funding structures* within the context of *boundaries merging,* it is often necessary to *alert others.* The alerting of others is how the group continually resolve the **information gaps**. However, when people are not alerted, are *left out of the loop*, poor symptom management is more likely to occur, and **information gaps** are perpetuated. The loop in this study is comprised of information relating to heart failure and the members who both send and receive it. Indeed, if the loop is able to be activated so that people are *in the loop* information is shared and the chances for better heart failure management are more likely. The impact of effective heart failure management for the patients means that although heart failure as a chronic disease is limiting, it is still possible in many cases, to improve quality of life and longevity. The findings of this study also suggest that there is a need for nurses as health professionals to move towards ways to reduce information gaps and improve access to information, and it is suggested that case management and information systems are the ways to do so.

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CHAPTER ONE

Introduction

Heart failure is a condition that is both acute and chronic. The nature of the condition is such that it requires careful management if a patient is to have a reasonable quality of life. Treatments for heart failure have advanced significantly in recent years so that people with heart failure are living longer, and thus the way in which patients who have this condition are managed, has become increasingly significant.

Health professionals both worldwide and within New Zealand, generally acknowledge that heart failure is not managed well and agree that there is a need to improve the care of patients with this condition. According to Pearson and Peters (1997) advances in treatment for heart failure are not reaching many of those who need them, and this means that there are treatment gaps between the recommended therapies and the care patients are actually receiving. While reasons for the treatment gaps are currently unclear, Pearson and Peters suggest that gaps could occur anywhere in the chain of care from inpatient/hospital programmes and specialist/generalist communication to ambulatory care, and patient compliance. Clearly, it is possible that any one of these factors, or a combination of them, could be responsible for the apparent lack of effectiveness in management. Further investigation is required.

It is important to understand how patient care is managed because heart failure has a high morbidity rate and poor prognosis, and it is also a syndrome that incurs a considerable socio-economic burden. Dargie, McMurray and Poole-Wilson (1996) connect the devastating impact of heart failure on a person's quality of life to the frequent use of health care services in Europe and the USA. Few figures are available to reflect the New Zealand situation. Hence, in this country, international studies tend to be used as a yardstick, as it is assumed that they must bear some relation to the New Zealand figures (Doughty, Yee, Sharpe & MacMahon, 1995). For example, international research recognises that the three year mortality for severe heart failure is approximately 50 percent; that developing trends include a rising incidence of heart failure and increasing mortality; and that the cost of heart failure treatments and hospitalisations is rising, as is the frequent number of repeat admissions.

In New Zealand the hospitalisation costs for heart failure are estimated to be $50 million annually. This figure represents one percent of the total health care budget (Scott & Scott, as cited in The National Heart Foundation of New Zealand, the Cardiac Society of Australia and New Zealand, and the Royal New Zealand College of General Practitioners Working Party, 1997, p. 100). In this country, hospital admission data shows that readmission rates for heart failure patients remain very high (Sharpe & Doughty, 1998). Added to this is the fact that the total health expenditure on heart failure is increasing with hospital admissions amounting to only a part of the cost for heart failure (Doughty et al., 1995). Other costs include general practice and hospital outpatient consultations, medical investigations and drugs. These changes make it timely for the introduction of new models of healthcare.

As health care services are restructured increasing financial constraints are also emerging. The recent health reforms and health policy changes have led to a new environment for healthcare. Heart failure management in particular is affected because disease management is also facilitated or constrained by certain structural conditions that pervade society. Indeed, Blank (1997) argues that "By capping hospital budgets, the government was responding to the increasing gap between the rising demands and expectations to health services, and the nation's ability to pay" (p. 270). Although the mortality rate for ischaemic heart disease fell for 1996 and 1997 (New Zealand Health Information Service, 1999) it was still the second most common cause of death. It is suggested that the response and surging interest into the management of heart failure that is commonly caused through ischaemic heart disease has been due to an underlying political agenda to decrease costs arising from those surviving ischaemic heart disease.

The economic pressures on health service delivery mean that new, more cost effective ways of service delivery are being examined worldwide, with the end result being the introduction of some of the services into New Zealand. At the same time changes in the role of patients, and health care personnel alike are also beginning to occur as a result of cost constraints. The complexity of disease management is such that patients with heart failure require access to a range of health workers in both the hospital and community. These new services include case management models of health, managed care schemes, and nurse practitioners managing specialised clinics. These new models of service delivery support the view that hospitals are for acute, short term care only. Community care for the heart failure patient is therefore becoming increasingly important. For example, Sullivan and Hawthorne (1996) note that heart failure represents a significant challenge to caregivers because of the complexity of care, the fragile nature of the patients, and the dramatic increase in patient numbers. Heart failure is a very complicated disease and it is perhaps not surprising that it is not managed well.

This chapter begins with an overview of definitions of the term heart failure. This is followed by an outline of some of the background factors that have shaped the study. In this research project the extensive literature on the topic will be presented in Chapter Two. Literature is organised using Radley's (1994) disease, illness, sickness model. These ideas which are introduced briefly later in the chapter, will be discussed in more depth in Chapter Two. Included next is a brief synopsis of the method and aims of the research. Finally, an account of the overall structure of the thesis is presented.

Overview

Heart failure: Dropsy, or the heart in a plastic bag that fills up?

Although it is difficult to find a concise definition of what heart failure is in the current literature, it is helpful if some understanding is provided at the beginning of this thesis. The problematic nature of the condition emphasises the difficulties finding a standard definition. Heart failure is not a diagnosis but a clinical syndrome that can encompass many pathophysiological states (Dargie, et al. 1996). The symptoms commonly include breathlessness both on exertion or at rest, fatigue, and signs of fluid retention. In recent times progress in understanding the pathophysiology of the condition has improved treatment for patients with this disease.

What was once known as 'dropsy', defined by Dorlands Pocket Medical Dictionary as "an accumulation of fluid in cellular tissues or body cavities" (Freil, 1977, p. 218), has progressed through advances in medicine to the molecular level of understanding. However, although there is little in the literature on how patients themselves describe the syndrome, the patient's understanding of the disease may be quite different to the illness experience. For example, a patient known to the researcher has referred to heart failure as 'the heart in a plastic bag that fills up' (personal correspondence anonymous patient, May 21, 1999). This definition illustrates well the differences between scientific and personal understandings of heart failure. Clearly, the personal experience of illness and the implications this has in relation to sickness, alters perspective and definitions. Whatever the view, it is necessary to generally acknowledge that heart failure is defined as a disease, indeed as a clinical syndrome with a wide variation of pathophysiological states (Dargie et al., 1996).

Some of these states are reflected in terms such as congestive cardiac failure, left heart failure, left ventricular failure, and low output failure, that have been replaced by the term chronic heart failure. According to Dargie et al. (1996) this is because chronic heart failure is the most common manifestation of heart failure and it most accurately describes the persistent nature of the condition. For this thesis, the term heart failure is used to mean a condition that is enduring, and where acute exacerbations occur, often requiring hospitalisation. Consulting the New Collins Dictionary (1991) in order to validate or confirm the definition of failure as it is associated with heart failure suggests that failure is a cessation of normal operation, a power failure, or a decline or loss as in health. Evidence from these sources clearly delineates heart failure to mean a general decline in the ability of the heart to meet normal physiological function.

Background

Background clinic knowledge of events discovered by the researcher stimulated an interest in this study on heart failure management. In the outpatient clinic situation, patients are seen as part of a supplementary and ongoing follow up to clinical trials. The researcher noticed that, despite extra education and follow-up as part of a previous randomised clinical trial on heart failure management (Doughty, Whalley, Postow, Gordon, Sharpe & Pearl, 1996) the clinic patients presented with differing levels of understanding, and many people demonstrated definite gaps in knowledge. These gaps and differences appeared detrimental to both the quality and length of the patient's life, and explanation was incomplete as to why these gaps occurred with some patients and not others. While some patients managed their heart failure in a manner that could be considered as being proactive, with full understanding of the affects of weight gain, shortness of breath, what it meant to their regime, and when to contact staff for expert advice, others did not.

These contrasts in understanding, or differences in the standard of management could not be explained easily, and this led the researcher to choose a method of research that would allow the main concern to emerge, and explain how a group continually manage their concerns about heart failure. This approach, the grounded theory approach, supported research that sought further understanding of the behavioural patterns of a group. In this study, the group was diverse. For the most part, the heart failure patient is managed by various health professionals including pharmacists, dieticians, general practitioners (GPs), general cardiologists, specialist heart failure cardiologists, nurses, specialist nurses, and practice nurses. There is also some lay input for many patients who are very often supported by a close family member.

Although the group of health professionals managing heart failure patients tends to be diverse, it is also interesting to note that the nurse seems to be the central pivot in the management of heart failure within the group (Erhardt & Cline, 1998). This may be because nurses are considered to be more available than other health professionals and because they have key roles in education, assessment, and providing support, and understanding. However, little is known as to why their role is so vital. Little is understood about the group perspective, or about what happens within the group interactions. Overall, the literature relating to the topic of heart failure management, reveals a variation in the input between health professionals. Nevertheless, nurse practitioners are reported to be the common thread throughout a variety of heart failure management studies (R. Doughty, personal communication, August 12, 1999). Since nurses have been shown to be such an integral part in the management of heart failure patients, then nursing input must be considered an important part of the overall process of management.

It is vital that the process of group interaction is understood at a time when a shift to integrated care is demanded. Marquis and Huston (1994) suggest that group interaction challenges members to contribute individually and collectively to the work being done, and also build roles for the care and maintenance of the group. Marquis and Huston argue that particular group roles facilitate group integration. These roles include those of encourager, harmonizer, gatekeeper, standard setter, compromiser, group commentator, and follower. For example, the commentator is defined as the member who has the role of providing feedback to the group. When this model is considered in relation to the group managing heart failure, the researcher questions how the group is managed, and wonders if, when group process is not managed well, the care of the patient is compromised. Clearly, the role of commentator is critical to assist the flow of information between members of the group, but whether this occurs or not, is debatable. Although health professionals perform individual specialist roles and tasks, it is possible that the general care and maintenance of the group is overlooked. Because no one member is responsible for providing feedback to the group, it is also probable that the flow of information is impaired, creating a gap, which possibly hinders the effective management of heart failure. If this is so, it is likely that integrated care would be compromised.

Ovretveit (1993) suggests that in an integrated model of healthcare, people from different professions and agencies work together to meet the health and social needs of people in a community. Belcher and Alexy (1999) define integrated care as a strategy that is designed to promote community based care and decrease hospitalisation costs. Integrated care can do this through design and implementation that takes into account patient profiles and the resources used for a particular group. In this respect, integrated care is about making the most of different skills to meet people's needs and creating satisfying and supportive working groups. If this concept is related to the heart failure population, benefit from the skills and knowledge of different specialists involved in patient management can be of benefit only as long as their contribution is well coordinated. Furthermore, if the group can be brought together to provide a range of integrated client-focused services, rather than a set of separate disciplinary services, better care should eventuate.

In New Zealand an integrated model of health is emerging. For example, one conference for health professionals entitled "Integrated care the way forward" (Cardiac Rehabilitation Association of New Zealand, 1999, p. 1) suggested that the focus in cardiac rehabilitation is shifting towards integrated care. This model of care is quite different to the bio-medical model of health that has previously dominated health service delivery. The associated disease focus has meant that specialist knowledge emphasised diagnosis, treatment, and management plans that have dominated heart failure management to date. This has occurred without much knowledge on how the patient experiences illness, or the reality of what they do in managing their care at home. Therefore, it is little wonder that gaps are appearing in the management of heart failure, because information that is biomedically focused is likely to be incomplete and neither is it transferred to all concerned, in a coordinated fashion.

In this thesis it is argued that the traditional use of the bio-medical model of health care in heart failure management has meant that there has been a strong focus on detailed knowledge of the cellular and molecular mechanisms involved in the diseases leading to heart failure, which have led to extensive development of drug therapies. In fact, Parker (1991) states that "through concentration on smaller and smaller fragments of the body, modern medicine loses sight of not only the patient as human being but also of the broader environmental and sociopolitical context in which disease occurs" (p. 301). It is not feasible in a research project of 75 points to investigate the whole socio-political context of health care and its specific impact on heart failure management. However, it is important to note that the influence of the bio-medical model of health and the influence of technology has meant that the link between the medical model and technology has lead to technology as a dominant driving force in disease management. This single emphasis is now questionable as heart failure as an acute episodic complication is being replaced by heart failure as a long term condition. When disease can no longer be cured a focus on managing long term conditions that merge into chronic illness becomes necessary. With more information on heart failure becoming available along with a move to integrated care, the dominance of the disease factors in heart failure management is no longer valid.

At the beginning of this study the researcher was drawn to consider Radley's (1994) question "do doctors and patients concentrate to different degrees upon symptoms and the disruption to the patients everyday life" (p. 1). Radley highlights how the bio-medical model of disease has dominated the other factors relating to health, which are sickness and illness. While it is likely that there has been an emphasis on the disease, and its diagnosis and treatment, by health professionals, group integration and management is now taking place. It is anticipated that in having a group focus, there will be more emphasis on the illness experience, how this influences sickness, and how this disrupts the patient's everyday life. In this respect it is hoped that better management practice might occur through greater understanding of how patients describe their illness, and the effects it has on their lives. It is possible that disease, illness, and sickness can be integrated and thus extend knowledge about more effective heart failure management.

The Research Focus

Studies of heart failure management that cover areas such as diagnosis and treatment, education, counselling, clinical pathways, heart failure clinics, and the back up support available, are often statistically based and analysed. Many of these will be discussed in the next chapter. To date though, an in-depth qualitative perspective on heart failure management, is notable for its absence in the literature. Creswell (1998) defines qualitative research as:

> an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analyses words, reports detailed views of informants, and conducts the study in a natural setting. (p.15)

The available literature on heart failure places an emphasis on what health professionals, and in particular medical professionals regard as being important. Current literature, and the researcher's professional experience as a research nurse, indicate that what happens in the group management of heart failure is poorly understood because the social and human perspectives of the syndrome are ignored.

In researching this area the researcher believed that a research method that would illuminate the group processes and interactions within the management of heart failure, was needed. The grounded theory method of research was deemed the most appropriate because it allows previously unknown data to emerge from the participants' perspectives (Glaser, 1998). Attempting to gain an understanding based upon participants' subjective experience meant that a quantitative method with the use of surveys, and questionnaires would not adequately measure the social and human problems of participants, or allow for their main concern to emerge. Therefore, the researcher chose grounded theory because the method would allow participants to provide rich data with context bound information, that could systematically be analysed through the rigorous use of constant comparative analysis, theoretical sampling and theoretical coding. As a result, according to Glaser (1998), the resulting integrated set of hypotheses should account for much of the behaviour seen in a substantive area. Furthermore, the main concerns of the participants in the management of heart failure, could be identified in a way that would account for many of the behavioural patterns emerging in this study.

Through this study it was expected to gain a new point of view in a familiar setting. Grounded theory as a research method, is a useful method for gaining a new point of view in a familiar setting (Glaser, 1995). Working as a research nurse in the heart failure clinic had stimulated an interest in the management of heart failure. Such an interest is supported by Glaser (1998) who states that "It is hard to resist studying a life-cycle interest or a committee demanded professional interest that one has read a lot about and/or experienced" (p. 120). Although the researcher had a clear understanding of clinical practice in the outpatient clinic, she had little idea of the problems that would be identified in the research or, how the participants resolve their concerns in the day to day management of heart failure. However, with the focus of health tending toward a collaborative, integrative approach, and away from the bio-medical model, the research seemed timely.

Aim of the Study:

The aim of the study was to explain the main concerns of a group, comprised of the patients, their partners, and the health professionals, who manage heart failure and how they continually resolve that concern. It was hoped that the indepth data gained from the study might enable increased awareness, and understanding of effective management strategies of heart failure from a multi disciplinary perspective.

Structure of the study:

This thesis is presented in five chapters.

The first chapter has provided an overview on definitions of heart failure, and the background, aim and structure of the thesis.

Chapter Two reviews the literature related to the management of heart failure and appropriateness of a literature review in a grounded theory study is discussed. Radley's (1994) disease-illness-sickness model is included as a way of organising the review. Although there is a predominance of disease-focused medical literature, this material is an essential slice of data that shapes understanding. It is important that certain factors relating to the disease are understood, for effective management practice to occur. Progress has been made in the understanding of the pathophysiology of heart failure that impacts on the management and treatment of the disease. Contextual issues such as the difficulty diagnosing heart failure, the increasing prevalence of those in society with the syndrome, recent developments in treatment and management from a medical as well as a nursing perspective are included. A section on the various strategies that are being used internationally to manage heart failure and overcome the gaps that are apparent between inpatient services and the community care, are discussed next. The chapter concludes with a section on issues relating to the elderly who are most likely to experience heart failure.

Chapter Three presents the research approach and method used in this study. The chapter outlines the appropriateness of not taking a small study to a theoretical level, which is the usual aim of a grounded theory study. The grounded theory principles that shape the research are explained. This is followed by a description of data collection that follows Glaser's (1998) research method. Rationale as to why Strauss and Corbin's (1990) paradigm model for data analysis is used, is also presented. Discussion about participants and ethical issues follows.

Chapter Four presents the results from the data analysis including the main phenomenon, **information gaps**. The data is systematically analysed and linked in complex ways using variables related to cause, context, conditions, action or interaction, and consequences. The five subcategories that emerged in this study, *absence of a cohesive group, changing funding structures, boundaries merging, alerting others,* and *being out of the loop,* are linked.

The final chapter, Chapter Five, discusses implications of **information gaps** for clinical practice. In particular information management and case management is discussed as ways to overcome the information gap and improve access to information. The limitations of the study and areas for further research complete the work.

CHAPTER TWO

Literature Review

In this chapter, literature related to heart failure in New Zealand, the United States, and the United Kingdom is reviewed. The chapter is divided into five sections. The first three sections are arranged using Radley's (1994) health and illness model; a model based on defining what she sees as the distinctions between disease, illness, and sickness. This model has been used to structure the review because of the dominant focus on disease in the literature. Included in the section on sickness is a discussion of the literature on changing roles and service delivery within society. Finally, issues of heart failure management of the elderly, the group in society most affected by heart failure, are presented.

Although an initial literature review is not usually associated with emerging grounded theory (Glaser, 1998), some study of current material is inevitable in a programme of study. This means that this study on heart failure management began with some knowledge about current issues and developments related to the condition. This position is not unusual and is clearly supported by Baker, Wuerst, and Stern (1992) who argue that the researcher's prior knowledge on the topic is valuable and previous experiences are essential.

Radley's (1994) model has been helpful to organise this literature review. Radley defines disease as something that physicians diagnose and treat. It involves changes in the body, and emphasises cause and effect relationships. In contrast, Radley believes that illness is how the patient experiences disease. It includes changes in usual capabilities and the ensuing effects and feelings related to changes in body state. The third category, sickness, is according to Radley, a social condition where the sick are deemed by others to be ill, so that a particular role or status in society is attributed to them.

This model is useful to a researcher seeking a well-rounded understanding of changes in a person's bio-psycho-social state. It is a useful way of appreciating the participants' perspectives. Although literature on heart failure management may appear to be predominantly medical, nursing knowledge is also valuable and fundamental to optimum client management in an environment that supports integrated care. While the inclusion of medical literature in a nursing thesis is less common, it is especially important in a topic area such as this that is inclusive of medical and nursing input. That inclusion is consistent with Glaser's (1998) advice to include various slices of data in grounded theory studies because this adds different perspectives and meaning to the emerging theory.

In fact, the literature review highlighted the lack of nursing research on the management of the heart failure patient. What was apparent though, was the abundance of medical literature, that predominantly focused on the disease aspects of heart failure. Although there has been a lot of literature on nursing management and debate as to who is the best person to manage heart failure, and where, this is gained from overseas journal publications. There are few nursing articles on heart failure management and trends in New Zealand. Any advances in the treatment and disease management of heart failure tend to be mainly medically focused. In an environment that supports integrated care, the bio-medical perspective alone is limiting.

Therefore, the reasons behind the dominance of medical literature are examined, as they contribute to the ways in which health professionals make sense of illness. An emphasis on one perspective, disease, influences society values. This influence in turn influences decisions that lead to funding issues, health reform and the global perspective of health and illness as described by Radley (1994). Those who are ill are often constrained by the financial factors of illness and societal funding decisions. For this reason, discovering what currently happens, from the group perspective, is important for future successful management practice to occur.

Heart failure as a disease

Disease can be defined as a physiological and biological malfunction (Turner, 1987). Physicians are trained to cure the physical manifestations of disease and diagnosis is fundamental to disease management. Diagnosis is fundamental to disease management. However, most clinicians concur that there is no clear definition of heart failure (Ikram, 1997; Sharpe & Doughty, 1998). As already stated in Chapter One, it is described as a clinical syndrome, or condition, rather than a disease (English & Mastrean, 1995; Frattini et al., 1998). According to Dargie et al. (1996) the syndrome of heart failure encompasses a constellation of symptoms and signs, attributable ultimately to cardiac dysfunction. Therefore, it encompasses a wide variation of any number of clinical states, which are the cause of the heart failure.

It is suggested that what is described as a syndrome is in fact consistent with Radley's (1994) description of a disease. This is because the symptoms and signs are often defined from the medical perspective, that is from a practical clinical point of view that emphasises physiological and biological imbalances. This perspective is valuable when diagnosis is required, but it is not necessarily consistent with the patient's experience of the disease. There is a vast difference between the subjective meaning of 'gasping for breath, and feeling like dying' (personal correspondence anonymous patient, March, 1999) to the objective identification of dyspnoea, as this symptom is commonly referred to in the literature (Didsbury, 1997; English & Mastrean, 1995; Rich, 1999). When objective-subjective differences are dichotomised the cultural divisions between mind and body are emphasised in ways that are "philosophically and sociologically very problematic" (Turner, 1987, p. 2).

Because of the prevalence of heart failure it is important to have as full an understanding of the disease as is possible, in as much as recent developments allow. However, even looking through the disease lens alone, heart failure is well recognised as a complex disease. As the clinicians Dargie, McMurray and Poole-Wilson (1996) elaborate:

> The precise medical and socio-economic consequences of heart failure are difficult to quantify, largely because of the lack of a universally accepted definition and its protean clinical manifestations. Urgent efforts are therefore required to improve our understanding of its causes and pathophysiological mechanisms in order to develop more effective treatment modalities and, perhaps more importantly, preventative strategies. (p. 23)

Following on from this idea of complexity, more recent developments in the medical world recognise that other pathophysiological processes, apart from the initial one of salt and water retention, are behind heart failure. Cleland (1998) believes that heart failure is a medical 'hydra' that may be compared to the Hydra of Argos. Each time Hercules severed the head of Hydra, a mythical many-headed beast, two more grew in its place. Similarly, each time a new pathophysiological process hypothesis is discovered for heart failure, it seems to multiply as it is dissected. This means that while more is understood about the heart failure process, and better treatment is being instigated, the problem is becoming increasingly complex.

Nonetheless, the symptoms of heart failure are recognised as being shortness of breath, both on exertion and at rest, and congestion related to the inadequate perfusion of tissue during exertion, often related to the retention of fluid (Cohn, 1996; Dracup et al., 1994; Hixon, 1994; Jarsma et al., 1999). "Patients with heart failure are chronically ill, and, over time will have increased symptoms" (Erhardt & Cline, 1998, p. 15). Progressive signs of worsening heart failure are intensifying of symptoms. These may include accelerating dyspnoea on exertion, sudden changes in orthopnea or paroxysmal nocturnal dyspnoea, and increased fatigue and weight (Dracup et al., 1994).

However, it is also recognised that many symptoms are not necessarily disease specific, as some symptoms such as breathlessness can be attributed to many other conditions (Guyatt, 1999). Because it is difficult to diagnose heart failure on the basis of symptoms alone, a collaborative approach to integrate primary and secondary care is fundamental to the effective management of the syndrome. The experience of the person with heart failure is typically one of a cycle of acute exacerbation of symptoms, acute admission to hospital, stabilisation, return to community care, then gradual increase of symptoms until acute exacerbation precipitates another unplanned admission for hospital care.

The literature reviewed highlights heart failure as a growing concern among the cardiovascular diseases. "Cardiovascular disease remains one of the most important causes of morbidity and mortality in Western society" (Cowie et al., 1997, p. 208). These authors state that this is because heart failure often develops as a consequence of cardiac disease. It is also a major and escalating health care problem (Dargie et al., 1996). Coates (1998) and Sharpe and Doughty (1998) attribute the growing incidence of heart failure to the ageing population and greater survival of those with coronary heart disease, which would include those surviving after myocardial infarction. There is a transition from more acute cardiac disease to that of a chronic form such as heart failure (Mosterd, 1999).

What becomes clear from the medical literature is that the effective management of heart failure depends on clearly identifying its cause (Ahrens, 1995; Doughty & Sharpe, 1997). General causes of heart failure include hypertension, coronary artery disease, congenital heart disease, idiopathic dilated heart disease, alcohol, and rheumatic fever (English & Mainstrean, 1995; Ho, Pinsky, Kannel, & Levy, 1993; The National Heart Foundation of New Zealand, the Cardiac Society of Australia and New Zealand, and the Royal New Zealand College of General Practitioners Working Party, 1997). Many researchers and clinicians agree that the main cause of heart failure is coronary heart disease (Cowie et al., 1997; Cowie, Wood, et al., 1999; Sharpe & Doughty, 1998).

As there is no certain cure for the disease, the aim of the treatment at the moment is to help the patient to lead as normal a life as possible, and to alleviate symptoms, delay disease progression, and reduce mortality (Dargie et al., 1996). Ideally, the underlying cause should be identified and treatment commenced. Ikram (1997) emphasises that therapeutic intervention is critical, if acute myocardial infarction is to be prevented from developing into chronic severe heart failure.

Reliable diagnosis, therefore, is the first and most important step in management (Mair, Crowley & Bundred, 1996). However, it is quite clear that the diagnosis of heart failure is not straightforward. The difficulty in diagnosis is illustrated by Mair et al. (1996) who noted that some patients with severely reduced ejection fractions [how much blood volume the ventricle ejects with each systole] may have few symptoms. In a study by Cowie et al. (1999), designed to determine the incidence and aetiology of heart failure in the general population, 220 patients met the case definition of new heart failure over a 20 month period. Seventy-five percent of the patients in the study who were thought to have heart failure by their general practitioner were found not to on further investigation, and only 40 out of the 220 cases, which met the heart failure criteria, were identified by the general practitioner. The strict definition of heart failure in this study may have led to the inaccurate diagnosis of those with mild heart failure. None of the patients identified as incorrectly diagnosed with heart failure by their general practitioners were further investigated to determine whether they had other diseases, or might develop heart failure in the future. Also, the study did not necessarily produce an accurate picture of whether general practitioners are over-referring patients for specialist opinion, because of the strict criteria for diagnosis in the study, which may not reflect general practitioner practice in usual circumstances. However, Mair et al. (1996) state that despite the difficulty in managing and diagnosing the disease, there is a high level of neglect on the topic of heart failure in the general practice literature compared to coverage of other chronic diseases such as diabetes and asthma.

The problems with diagnosis mean that any bio-medical identification of heart failure is increasingly dependent upon scientific and technological advances. This point is supported by findings from one population based study into the incidence and aetiology of heart failure which revealed that, in one third of 220 cases, the aetiology could not be determined by non-invasive investigation alone (Cowie et al., 1999). To aid in the diagnosis of heart failure Mosterd (1999) suggests that a formal evaluation is needed of newer techniques in diagnosis which include natriuretic peptides [cardiac enzymes released by those with heart failure] and rapid access clinics providing echocardiography services.

It is hardly surprising that quality of life is affected to a varying extent for those people who have heart failure. When disease is the focus, most clinicians agree that heart failure patients eventually have a reduced quality of life (Erhardt & Cline, 1998; Rich et al., 1995), to the degree that some clinicians state that, "Heart failure is a morbid condition with a survival rate akin to many cancers" (Didsbury, 1997, p. 29). Some studies have used a quality of life tool known as the SF-36 (short form 36) to investigate patient's quality of life. It measures health-related quality of life, classified by eight dimensions (Lyons et al., 1999). Shively, Fox and Brass-Mynderse (1996), American nurses, reviewed eight health related quality of life (HRQOL) studies that measured HRQOL as outcomes for patients. The authors report that studies using the HRQOL were the first large-scale effort to describe functioning and well being of patients with a variety of chronic conditions. Information to modify treatment and guide patient and family teaching to facilitate adaptation to heart failure has been developed through the use of such assessments. Shively et al. (1996) suggested that limitations in applying such assessments to practice include a lack of standardised questionnaires for measuring HRQOL, and the development of optimal timing of HRQOL measurements to evaluate interventions. While these tools ask participants to answer questions on their quality of life, the questions are pre-set and do not evolve from participant input. Personal patient input via open ended questions is missing. However, the tool certainly is an attempt to involve the patient in expressing some part of how they feel about how disease shapes the illness experience.

Symptom control seems to be the main patient issue in the above quality of life studies. Therefore, the inclusion of the short form 36 emphasises disease rather than the patient illness perspective described by Radley (1994). As such, it is suggested that quality of life is dominated by a prominence on disease focus.

Treatment and education with a disease focus mean that heart failure is very often confirmed as something that physicians can diagnose and treat (Radley, 1994). From this perspective a major focus becomes patient compliance with the treatment regime. Compliance is especially important where drugs must be prescribed. While a drug regime of ace inhibitors has been shown to be mandatory in most cases of heart failure (The National Heart Foundation of New Zealand, the Cardiac Society of Australia and New Zealand, and the Royal New Zealand College of General Practitioners Working Party, 1997), Pearson and Peters (1997) advocate that patient management may not be optimal if factors such as, using an inappropriate drug, or, too low a dose of recommended drug is prescribed, or, drugs with low potency are used, or, if the patient does not adhere to therapy, or has a large number of risk factors that are not addressed. From the bio-medical perspective medications play an important part in providing relief from symptoms and thereby help to provide an improved quality of life for a patient with heart failure.

While drug treatment is the treatment mainstay, a small group of patients undergo transplantation as part of a cure, but the majority are managed through symptom control and have no hope for a cure (Karmilovich, 1994). Clearly, understanding the mechanism and treatment of heart failure is critical and affects access to the best therapy (Cohn, 1996).

In this chronic illness, when disease is central, the issue of compliance is significant. Telephone links and just one home visit have been investigated as ways of improving compliance (Stewart, Pearson, & Horowitz, 1998). These researchers also looked at prolonged benefits, related to cost effectiveness, which was found to be favourable. However, this study did not state guidelines on what was involved in the input given at the home visit, nor on patient readiness to learn, all of which could realistically be quite variable in nature. The variation in what occurred during the home visit could easily have affected the outcome, and was not identified as a limitation. An emphasis on compliance seems to link to the disease model as discussed by Radley (1994). It involves "changing the behaviour of individuals in ways defined as desirable to alleviate pain and suffering" (p. 11).

An emphasis on medication compliance features in many studies (Haynes, McKibbon, Kanani, Brouwers, & Oliver, 1998; Kegel, 1995; Rich, Gray, Beckham, Wittenberg, & Luther, 1996). A study by Shah, Der, Ruggerio, Heidenreich and Massie (1998) investigated automated reminders to overcome the problem of patients forgetting to take medications while at home. They found that medication compliance was improved by the use of daily bleeper reminders and facilitated telephone communication with a nurse monitor. However, a small proportion of patients reported that these reminders were intrusive. This study was a pilot only, not randomised, and involved a small sample of 27 male patients. Therefore, conclusions on the sorts of patients who would benefit from this type of programme, or the specific intervention responsible for compliance, can not be drawn. Radley (1994) believes that the limitations in trying to sample the personal and social context are present because some variables simply do not connect in a meaningful way. Qualitative differences need to be acknowledged between distinct phenomena such as anatomy and physiology and psychological factors, for meaningful data to be revealed.

Another issue that is evident in the literature is revealed by studies showing that patients do not fill their scripts frequently enough to be taking drugs as prescribed (Rich, Gray, Beckham, Wittenberg & Luther, 1996; Stewart, Pearson, & Horowitz, 1998). Rich et al. (1996), in a randomised clinical trial of 156 patients, statistically analysed results using multiple regression rates to compare compliance rates between two groups, and to evaluate the effect of a multidisciplinary treatment approach on medication adherence. Results show that Caucasian race and not living alone were independent predictors of compliance. However, a limitation of this study is that patient compliance or non-compliance with prescribed drug regimes is not made meaningful because the reasons why patients who lived alone, or were non-Caucasian, did not adhere to prescribed or suggested self care regimes still needs to be examined. The effect, therefore, of the multi-disciplinary team is not made clear. Turning all phenomenon into variables and continuing to cross-relate them hoping that statistical associations will by themselves explain the relationship between the variables, is not adequate in Radley's (1994) opinion.

According to Karmilovich (1994) some hospital admissions are preventable. Reasons for possible unnecessary readmission are related to being non-compliant with medications or diet, inadequate discharge planning or follow up, a failed social support system, and failure to seek medical attention promptly when symptoms recurred. Jaarsma et al. (1999) argue that increased education and support from a nurse in hospital and at home, significantly increases patient self care ability, but they also believe there needs to be a change in the organisation of patient care and intensity of follow-up to prevent unnecessary readmission. This means that in New Zealand, work must be done on the group aspects of heart failure management, in order to improve care in the New Zealand context.

Pearson and Peters (1997) acknowledge problems associated with a treatment gap, where little is known on why recommended therapies for patients and the care they actually receive, and patient motivations in complying to treatment, vary. Components of this gap are identified and include barriers such as medical staff time constraints, and lack of knowledge and access to specialist care when required. Because medical time is often constrained in every day life due to varying factors (Pearson & Peters, 1997) instigating health professionals such as nurses to co-ordinate services may improve care. Because the course of heart failure involves the use of widespread health services, integrated care is vital.

Nonetheless, certain bio-medical knowledge is necessary as a prerequisite to understanding the disease. This knowledge enables a practitioner to offer the best available treatment to the patient with the illness. A thorough understanding of the disease focus therefore underlies effective management. Although patients experience heart failure as an illness, most still invariably go to see a health practitioner who they believe has knowledge about the disease and will offer the best treatment. However, some practitioners may be better at understanding the illness experience than others.

Heart failure as an illness experience

As noted earlier, Radley (1994) believes that people decide they are ill on the basis of their own bodily feelings. It is of note that there is much less literature about the illness experience from the patient perspective. The researcher assumes that this gap in information is because of the importance that society has placed upon knowledge about disease. When patients talk about their illness experience they often refer to the dominant language of the disease and even when allowed, mention only a small part of the outcomes reflecting their illness experience in their own words. Symptoms are reported in terms of their relation to the medical world. The terms dyspnoea and fatigue are seldom personalised.

Heart failure patients are rarely given the opportunity to describe their needs or their experience of illness. The needs of the heart failure community are often defined by medical people (Doughty et al., 1995), who talk of managing needs, such as early assessment, education and counselling, appropriate treatment and long term follow-up. However, according to Jewes and Murcott (1995) those assessing the needs of a community may find that the needs differ if they are actively engaged in that community. Yet, spokespersons do not exist for heart failure patients in New Zealand, so it is therefore difficult to have a consensus on the illness experience or even to have an individual account of the experience.

Although patient education is considered to be a vital part of patient management, there is little literature focusing on education. Research studies that assess the effectiveness of patient education are scarce (Jaarsma, Halfens, & Saad, 1996). Frattini, Lindsay, Kerr and Park (1998) note that there is minimal research on the education needs as defined by patients. These Canadian nurses surveyed a small sample of cardiac nurses and a group of patients diagnosed with heart failure, using a needs inventory, an instrument that asks participants to score answers on a Likert scale, which is then statistically analysed. The sample size consisted of 50 patients and 47 nurses. Frattini et al state that the limitations in their study consisted of only the sample size, the fact that the study involved a specialist cardiac centre, and that convenience sampling was used. Although the patients learning needs were revealed, the survey was done in the hospital environment where the patients could easily focus on risk factors due to non-familiar surroundings as opposed to the nurses who would be more familiar and comfortable in the hospital environment. No allowances for this were made in the study. Frattini et al found that nurses and patients understood diet and psychological aspects to heart failure rather differently. The researchers state that the differences should be the launching point to create new educational programmes.

Another aspect of the illness experience is fatigue. This aspect was investigated in a nursing study by Schaefer and Shober (1993). In this descriptive study, the researchers extended and refined an original study by Schaefer (1990) (cited in Schaefer and Shober), when they sought understanding about the fatigue experience of heart failure patients. The aim of the study was to describe the patient's experience of heart failure. The researchers wanted to determine the relationship between selected objective parameters and the severity of heart failure. The sample consisted of 38 participants. The researchers emphasised that "of particular importance to this study was the importance that the patients perceive themselves as whole" (p. 261). The perception of illness in this instance fits with Radley's (1994) illness experience because it relates to the feelings involved with changing bodily states and the consequences of having to bear an ailment. These nurse researchers found that patients described fatigue as feeling tired and exhausted, and consisting of both physical and emotional components. Although fatigue is a subjective experience, efforts to determine relationships with physiological parameters were made. Physiological data, such as blood results and vital signs were examined, and compared. Results showed that the presence of fatigue did not correlate with the physiological data. However, overall results contribute to the ongoing development of theory through description leading to an increased understanding of the phenomenon.

Another descriptive study used the case study method to describe the care received by a patient with heart failure. Interestingly titled as 'Clinical Crossroads' this work in some ways reflects the diversity inherent within the illness experience when a relative of the patient talks of "arranging the medications" (Guyett, 1999, p. 2322). As the patient cannot speak English his daughter gives the case scenario. The anecdotal approach describes how, as a close relative, the daughter has come to "understand that, although the person can drop 'dead any second', they can also live with it" (Guyett, 1999, p. 2322). From the relative's viewpoint, the experience of living with some one who has heart failure is scary. Also, because the care takes place in the United States, another factor that emerges in how illness is experienced, is financial. The emphasis on finances and insurance seems to affect the quality of care. "Because the money is not there looking at my Dad, I think they are too quick to stop his care" (Guyett, 1999, p. 2322). This non-direct patient input extends understanding of the complex factors that effect the management of heart failure.

When the illness experience is addressed, quality of life emerges as a significant issue. A nursing study by Rideout (1992) focuses on the improvement in the quality of life of patients, rather than on symptom control. Rideout describes heart failure as a long term illness, and looks at providing a framework for nursing action designed to maximise quality of life for heart failure patients. By adhering to principles of self care and by introducing strategies that emphasise the decision making role of the patient in relation to assessment and treatment, she concludes that nurses can play a major role in assisting patients. Participation in an approach that requires patients to self observe and act upon changes means that an enhanced quality of life may be a goal developed between the patient and the nurse involved in management.

Although self-care may well be significant much of the care of the heart failure patient takes place within the family, who influence the illness experience as well. Stress and burden feature as important factors when spouses talk about caregiving for a family member who has heart failure. Karmilovich (1994) states that the role of caregiver or spouse is vital in sustaining the patient's quality of life. This is especially true when home care is becoming more complex, but also more common as hospitals shift to an acute short stay focus. It is hardly unexpected to find that, when adequate back up and support is not readily available, the caregiver can face an exhausting and stressful time. Karmolovich used a caregiving demands scale to assess stress and burden in a group of 41 spouses in this descriptive study. It was noted that future research should include a qualitative component to assess the burden and strain in more depth, because it was hypothesised that no instrument can adequately describe the experience. Although the study concerned personal capabilities, it also examined the consequences of caregiving, and as such, was considered to be part of the individual experience of illness and health for the caregiver or spouse. Even so, even the most conscientious, meticulous and reliable patient may still get sicker (McCann, 1996), which must be stressful in itself, but this aspect was not investigated.

The social view of heart failure as a sickness

The social view focuses on social roles and how society views those who are ill or diseased. This approach supports Radley's (1994) view of sickness as it is analysed from the perspective of society. When society is introduced as a variable affecting the management of heart failure, the predominance of the biomedical model and the accompanying technological emphasis means that it is difficult to avoid discussing the cost of health when disease, illness and sickness are under review. The focus on economics within society means that often sickness is thought of as a financial burden to society, because it is so resource intensive. "The constantly escalating cost of health care has led to societal mandates to constrain costs ..." (Sullivan, 1998, p. 4). Welfare benefits provided are part of this societal cost.

The increased prevalence of heart failure supports data indicating it has significant socio-economic implications (Frattini et al., 1998). "In New Zealand, the full medical and socioeconomic impact of this condition has not been fully appreciated, hence no comprehensive plan for tackling the problem exists" (The National Heart Foundation of New Zealand, the Cardiac Society of Australia and New Zealand, and the Royal New Zealand College of General Practitioners Working Party, 1997, p. 99). Similarly, "the high utilisation of health care resources by patients with heart failure places a considerable economic burden on health care systems" (Dargie et al., 1996, p. 23). Equally, morbidity statistics show that patients with heart failure have a poor quality of life when compared to those with angina, or chronic kidney or lung disease. The incidence of rising heart failure amongst the population means that the condition is a serious public health concern and that funding the condition is an important economic issue facing society today.

New Zealand is currently moving toward the collaborative, integrated model of health care, but so far nursing research into heart failure as a sickness is scarce. While funding affects disease management it is also an important factor in stimulating research, so when absent, there is a lack of research produced. This researcher believes that nursing input into current heart failure research is vital for good management practice in the area of heart failure to occur as the health services are being restructured. Yet, because the social view of sickness within society values medicine highly, funding tends to favour medicine more than other allied disciplines which could provide different approaches to knowledge development.

Funding is only one issue. Very often, the social view of health is viewed through the lens of the medical perspective. Radley (1994) points to this dominance when she talks of doctors placing patients in the sick role and using their knowledge to position themselves in a position of dominance over their clients. Although this may be done with the best of intentions, it means dominance of the medical perspective filters through and affects health planning and policies. At the policy and planning level there is a lack of consultation with those who manage heart failure as a group. Instead, consultation is with those who are dominant within this area of society, that is the medical profession so that their interests are served, rather than those of the clients (Freidson, 1986). When a social view of heart failure is sought the bio-medical emphasis is limited if it "individualises problems rather than laying bare the social causes of ill-health" (Mackay, Soothill, & Melia, 1998, p. 8).

Since the management of heart failure is resource intensive, effective patient management, so that health care funding is used effectively and efficiently, is essential. Keeping up to date with new developments for best patient care is challenging. The way society has been led to view sickness, ie, through a dominant biomedical lens, means that very often certain sectors and groups in the health sector hold more power than others. For example, medicine has traditionally dominated health service delivery to the extent that consumers have felt that their voices have not been heard (Freidson, 1986). In order to manage this increasingly complex situation effectively, this researcher believes that team input is essential. Indeed, Sullivan (1998) argues that collaboration is a healthcare imperative. However, the way the members of a group managing heart failure are viewed by society has an influence on the role that they are able to develop. Role development impacts on approaches to sickness and, thus, affects client management.

While there is much medical literature about heart failure, and nurses' roles in general, this is not necessarily helpful to nurses. From a nursing perspective it is of grave concern. Medical health professionals' research tends to regard nursing input into disease management as a small contribution. Hanumanthu, Butler, Chomsky, Davis and Wilson (1997) described nurses as being dedicated cardiovascular nurse specialists, who assisted with the management of patients. Within areas of healthcare nurses potential is often underdeveloped This point is well illustrated in a Waikato study (Lightfoot et al., 1999) into practice nurses' occupational profile, where research into nursing practice was carried out. This study found that nurses were involved in assessment and monitoring proceedures. However, a third of the 189 nurses carried out tasks associated with practice administration and reception duties. The Lightfoot et al study concluded that practice nurses' potential was underdeveloped. Possible societal reasons for this outcome were not examined or discussed, and no attempts were made to develop suggestions for developing the practice nurse role. If society is implying that medical research is of more value than that of nursing, interpretations of sickness are likely to be limited and this has implications for heart failure management. If a medical condition cannot be cured it must be managed.

Mackay et al. (1998) argue that managing illness requires different skills and strategies on the part of both the patient and the staff. Planning is the basis of good management. Therefore the impact of the health sector changes, affects heart failure management especially if limits are placed upon interventions, available support, and the roles and responsibilities of health management professionals. The inclusion of the word 'management' in the researcher's topic and its link to heart failure implies that decisions about the condition are made when necessary. But, Ikram (1997) asserts that heart failure progresses through a series of stages, and management needs to be organised and integrated to match each particular stage. Decisions need to be coordinated. According to Marquis and Huston (1994) the successful decision-maker needs to take into account the significance each individual's values, life experience, preferences, and way of thinking has upon the selected alternatives.

Competent decision making is vital because today, people who have heart failure are likely to live longer. This means that there is an underlying expectation in society that patients will be more active in the management of their disease. Radley (1994) describes this idea as self-monitoring. There is an increased emphasis placed upon individuals who are expected to take greater personal responsibility for illness prevention and health care. As a result, the patient with heart failure, as well as primary health professionals, need to reconsider their roles so that everyone is better able to decide when to seek specialist advice on their condition, and where that specialist advice should be available.

As New Zealand moves away from the bio-medical model of healthcare, and health services are restructured, the effects also carry over into the roles and expectations of those health professionals working within healthcare systems. Grant, Forrest, and Starfield (1997) examined primary healthcare and health reform in New Zealand. According to these authors "dramatic changes in the financing and organisation of health care have unknown effects on the delivery of primary healthcare" (p. 36). This is important because a great deal of health care for heart failure is done in the primary setting as noted by The National Heart Foundation of New Zealand, Cardiac Society of Australia, and New Zealand, Royal New Zealand College of General Practitioners Working Party (1997). Currently, within New Zealand, the general practitioner has a central role in detection and ongoing treatment of heart failure and it is more common for patients to see this type of health practitioner than any other.

In the health sector today, health professionals work consistently with cost constraints as they seek the best quality service for their patients. Resources are limited, but there is still opportunity to provide quality cost effective care within these constraints. Cline, Israelsson, Willenheimer, Broms and Erhardt (1998) support the argument that there is a need for alternative strategies to optimise management and curtail costs. However, in the quest to contain costs throughout society, it is also important to ensure that the ill patient is cared for in a way that recognises their illness, as their individual experience. Understanding must be all-inclusive and not just disease or sickness driven. Role changes, if they do occur among health care professionals, need to focus on all three components. While there are differences between the New Zealand and United States health systems, it is also helpful to recognise the similarities. If health statistics of other Western countries are known to accurately parallel the situation in New Zealand (Doughty et al., 1995) then some aspects of their management styles should be relevant. However, the focus on costs in the United States (Guyett, 1999) seems extreme from a New Zealand perspective. Guyett's suggestion that participants be entered into randomised clinical trials investigating rehabilitation only if they are covered by an insurance plan, is at odds with the New Zealand culture of health.

Inpatient, outpatient, or home care - a gap, within the changing service delivery in society

As has been indicated, heart failure management takes place in various contexts throughout society. Abraham and Bristow (1997) attribute successful management to management by specialists in specialist clinics. Clinics are seen to provide better clinical and economic outcomes through decreased hospitalisations, and increased patient satisfaction. Although the clinic staff consist of cardiovascular nurse specialists, and physicians who work exclusively with heart failure patients, the role of the nurse specialist is less well defined in this context. Some nursing guidelines for heart failure management were published by nurses in the United States (Ahrens, 1995). Ahrens developed the guidelines to include the initial period as well as long term management.

Inpatient clinic management of the heart failure patient seems to be complex. Erhardt and Cline (1998) describe nursing roles in heart failure clinics that incorporate delegation of the right to adjust treatment with specific drugs, as well as the opportunity to examine, and educate patients, with a focus on the individual patient. Nurses also have responsibility for implementation of non-pharmacological treatment. Paul (1997) discusses the multi disciplinary outpatient clinic and the concomitant clinical development of the nurse practitioner role. Venner and Seelbinder (1996) describe co-ordination of inpatient, outpatient, and home care models of health delivery:

> In a 1993 survey of more than 50 U.S. hospitals by the Cardiology Board Company, Washington DC, seven different coordinated approaches with variable levels of efficacy were identified. These are: heart failure clinics, home health cardiac specialists, community based case managers, patient telemanagement, hospital-sponsored cardiac rehabilitation, emergency department observation units, and CHF subacute care. (p. 72)

Heart failure clinics have been instituted in many centres in the United States. For example, at the heart failure institute, Christ Hospital and Medical Centre, Illinois (Silver, 1999), target doses of recommended drug therapies are offered alongside many other services such as education, rehabilitation and exercise training. Silver states that core professionals are critical to the success of such clinics, and nurses must be included as part of the clinic structure.

There are no similar heart failure clinics in New Zealand. Once patients are discharged from hospital they are considered to be community based, and as such require management within a community network. New Zealand is currently without a major plan for the management of heart failure in the community, so that nurses make sure that they develop their potential in this changing environment. The question of who is better prepared to manage chronic heart failure patients in the community needs examination and further research. Castledine (1996) shares some of the British problems of practising is such an environment. Issues he discusses include:

> ...confusion over traditional nursing activities: the need to respond dynamically, and flexibly to economic and national health targets: the pressure to reduce doctors' hours and to provide substitutes for the shortage of doctors ... .(p. 1338)

Castledine also believes that nurses should accept those amongst them who have developed their role through knowledge and skill development. The central issue is that patient care warrants improvement. However, the nursing input will vary according to role development and not all nurses will be specialists. In fact, Castledine advocates four distinct roles for nurses: the generalist, the specialist, the advanced nurse practitioner and the paramedic. Each role has something different to offer and is dependent on the setting.

Part of role development is the inclusion of case management. According to McCann (1996) "Case management can play a significant role in co-ordinating appropriate care. Its emphasis on cost containment is a relatively new element in nursing, but it is a natural outgrowth of the historical nursing role of patient advocate" (p. 386). Case managers are seen as being highly skilled, creative practitioners who are able to keep the patient on track with self-management within the home environment. Coordination of care and information is more likely to occur when the patient can be managed and assisted to maintain quality of care, within his or her own community setting.

The search for strategies to decrease readmission soon after discharge is significant. Repeated hospital admissions for worsening heart failure are not cost effective. Indeed, Brass-Mynderse (1996) argues that "rehospitalisation is common in this population partially because of lack of treatment adherence and patient knowledge deficits" (p. 54). It is hardly surprising that patient quality of life is decreased by frequent hospitalisations, which remove people from their familiar home environment. Venner and Seelbinder (1996) describe how the coordination of inpatient, outpatient, and home care can lead to positive outcomes "in terms of functional capacity changes, length of stay, readmission rates, patient self care knowledge, and patient satisfaction" (p. 72). Perhaps the personalised approach to care that nurse case managers offer, is part of its benefit. Lasater (1996) observes that the patient is an active participant in a continuous process of care when nurses manage clinics and follow up all patients after discharge.

Equally, when a nurse case manager follows the patient through hospitalisation, monitoring key indicators and responding promptly according to pre-decided strategies, certain benefits are apparent. In this situation the use of clinical paths is important when quality care, clinical and cost outcomes are considered (Huggins & Phillips, 1998; Morrison & Beckworth, 1998; Topp, Tucker, & Weber, 1998). Clinical pathways are mostly used in inpatient settings that emphasise the cost effectiveness of decreasing hospital stays through the following of care maps. It is suggested that nurse case managers coordinate information so that it is more available to other members of the health group. Effective information coordination supports more efficient care.

When health services are restructured monitoring outside the hospital setting is more difficult. Different management strategies for different contexts need to be investigated. Hagland (1998), a journalist, describes one such innovative strategy using software to monitor 80 patients' progress at home. The team involved consisted of physicians, advanced practice nurses, data management staff, and clerical workers. Hagland asserts that the use of an information technology system leads to consistent monitoring, care management, and health data tracking and analysis, which helps to keep heart failure patients out of the emergency room. Although it is clear that managing heart failure patients out of hospital saves money, again and again quality of life comes up as an issue that must also be taken into consideration. It seems likely that some hospitalisations, or heart failure clinic admissions, will always be necessary for improved quality of life.

McCann (1996) discusses the elements that increase the likelihood of rehospitalisation of heart failure patients as being related to non-adherence with medications or diet, inadequate patient education, discharge planning or follow-up, and an insufficient social support service. Stewart, Pearson, and Horowitz (1998) examined the effect of one, home-based intervention visit on a cohort of 'high risk' (p. 1067) patients discharged home from acute hospital care. The nurse research led, statistically analysed, study involved 97 patients randomised into either a control or an intervention group. Results after six months showed reduced hospitalisation and out of hospital death rates. The period of the study was extended to eighteen months (Stewart, Vandenbock, Pearson, & Horowitz, 1999) with similar results. The researchers noted that the precise mechanism of the beneficial effect of the home based intervention was unable to be elucidated. Although factors that enabled patients to be labelled as high risk for readmission were described well, a focus on the actual home intervention programme content was not given.

Topp, Tucker, and Weber (1998) evaluated the effect of case management by a Clinical Case Manager/Clinical Nurse Specialist in acute areas and focused on length of stay. Results from the study led to a discussion over whether the Clinical Case Manager/Clinical Nurse Specialist brings a holistic focus to patient care that enhances the clinical expertise of the cardiologist. However, social factors such as the level of spousal support were not examined, which limit the findings. Good family support in the home may bias results because a patient with such support may be discharged sooner.

Clearly, nurses with specialist skills are well positioned to manage heart failure in different contexts. Wensley (1998) talks of the current significant contribution that nurses make towards the care of patients with heart failure in New Zealand. She recommends that consultation with nurses needs to occur to ensure that all options are explored in the search for an integrated management approach. The nursing role seems to be significant. The positive impact of nursing on the quality of, and cost of, health care is supported by Jones and Peach (1994) who state that, "For the patient and their family, there is no doubt that the nurse is very important in the planning, implementation and coordination of care delivery, in providing information, support, guidance, advocacy, and encouragement" (p. 4).

Hospitals in the United States now regard home care as an alternative to institutional care as the long term arrangement for heart failure management (Barella & Monica, 1998). It is apparent that nurses have an impact on both the cost and quality of care of heart failure patients in society. Kegel (1995) asserts that advanced practice nurses (APN's) with excellent knowledge of cardiovascular disease, have the ability to intervene across settings and provide quality care while optimising use of health resources through decreasing hospital admissions. Nurses can maintain an assessment promotion followed by close follow-up and involve patients with their plan of care through coordination and provision of care in the hospital and outpatient settings.

However, it is increasingly evident that improvements in home interventions and the non-acute area are still needed. It has been well established that health funding in society has focused on acute care to the detriment of chronic community care. Barella and Monica (1998) discuss the pivotal role that the cardiac home care nurse assumes in the management of these complex patients. These American nurse clinicians discuss the programme their hospital's home care department developed in response to the changing health care environment. With input from the hospital's cardiologist, the cardiac nurse specialist developed a programme in which 92 patients have enrolled since it started in 1996. Nurses are reported as pivotal to the successful management of the heart failure patient at home. Home patients are made aware of how their actions affect their symptoms and outcomes are tracked monthly, based on patient satisfaction and readmission rates.

Brass-Mynderse (1996) and Brass-Mynderse and Kaliagana (1997) discuss the place of a nurse management team that included nurse practitioners, and clinical nurse specialists. The clinic managed chronic disease generally heart failure patients in particular. "The Nurse Practitioner provides the necessary experience with ambulatory care, whereas the Clinical Nurse Specialist provides experience with the more acutely ill heart failure patient" (p. 56). Research to investigate various aspects of the disease management of the programme is being developed.

Currently in New Zealand there are few heart failure clinics where significant nursing input into heart failure management takes place. One hospital however, has rehabilitation nurses who have established a programme for patients admitted with heart failure. The service has an emphasis on effective patient and family education, discharge planning, self-management and ongoing nurse follow-up in liaison with the general practitioner and cardiologist (Monigatti, 1998). The heart failure management group at another large hospital conducted a trial involving two groups of patients. One group, the intervention group, received intervention and progress checks by a group of health professionals, involving the cardiologist, a nurse and a dietician, and the other, the control group, was followed up one year later. Results of the study, which was medically led, and involved about 200 patients (Doughty et al., 1996), are yet to be published.

Heart failure management and the elderly

Heart failure is the most common cause of hospitalisation for the older population (Shah et al., 1998). As such, it warrants its own special mention because of the huge challenge it presents for health professionals. It is suggested that heart failure has become a prominent disease because, as Radley (1994) describes, the patterning of diseases, where surveys bring disease to media attention, occurs in order for action to be instigated due to raising social consciousness, in society. Further, compounding the problem is the high hospital readmission rate for heart failure. Equally, if not more importantly, when examining health from the societal viewpoint, is that society is faced with extra costs because the condition is not managed well. For example, American statistics show that almost half of the patients 70 years or older hospitalised with heart failure are readmitted one or more times within 90 days of discharge, and it is projected that 50 percent of these readmissions are potentially preventable (McCann, 1996).

There are many factors associated with the readmission of the older heart failure patient. Jarsma, et al. (1996) found that important factors related to rehospitalisation included socio-demographic and medical factors, premature discharge, failing support system, medication related problems, and non-compliance. Although strategies, treatment and prevention are important in the older heart failure patient, different aspects of non-pharmacological interventions need to be studied, including content, and organisational aspects such as group intervention, to improve care.

Happ et al. (1997), all American nurse researchers, used qualitative data from advanced practice nurses' logs, and medical record summaries, in a small descriptive study. Investigated in this study were factors contributing both to rehospitalisations and the prevention of rehospitalisations of elderly heart failure patients who received transitional care. Results are limited because inclusion criteria as to why 16 participants from the intervention group were purposely selected for review, from an initial intervention group of 25 from a previous clinical trial studying the effects of comprehensive discharge planning, are absent. Results from interactions with the 16 patients over a six month period revealed that social risk factors and problems with treatment adherence were factors relating to rehospitalisation but in circumstances where social support was good, and treatment plans followed, there was reduced likelihood of readmission.

Limitations of the above study were acknowledged related to the sparse scope and depth of the written documentation for each patient. Because the study was retrospective in nature, the researchers stated that the validation of results with individual patients was not possible. However, there were no deaths from the group, and further investigation on a more personal basis if ethically allowed, might have been useful to further validate results. The study therefore is a guide to further research only, and verification would need to be more consistent with defined criteria.

It is hardly surprising that studies have demonstrated that successful management of older people with heart failure often requires the patient and spouse to make lifestyle adjustments. These adjustments may include dietary adherence, good general health behaviours, and the following of medication schedules. Rich et al. (1995) look at a multi disciplinary intervention to prevent the readmission of elderly patients with heart failure. Results showed that a nurse-directed, multidisciplinary intervention improved quality of life and reduced costs. However, there were limitations concerning the generalisability of the results, as only 282 out of 1306 patients were randomised.

There is a lack of literature on the elderly relating specifically to their illness or experience of heart failure. It is estimated by Dargie et al. (1996) that as many as 10 percent of individuals over the age of 80 are affected by heart failure. Most researchers who investigate the elderly, such as Hixon (1994), and Jaarsma et al. (1996) focus on disease, as opposed to illness, in their research. The researcher can only hypothesise that the reasons behind this are that the researchers are following the natural science path in choosing their methods of research. In doing so, therefore, they are following a perspective that focuses on a cure for the disease and treatment to relieve suffering (Radley, 1994). This is less than helpful as, very often, long-term and chronic illness constrains the everyday activities of patients who need complex, continuous management that is quite different to acute care management (Mackay et al., 1998).

Summary

This review reveals that heart failure is a complex condition that affects a high proportion of the elderly in Western countries. From a disease focus, abundant literature reveals that important features of diagnosis, and treatment have improved. Management of symptoms can be enhanced and thereby, the patients' quality and length of life increased. However, it is recognised that treatment gaps occur, in the management of heart failure especially in community care. In New Zealand it is hardly surprising that professional groups such as the Cardiac Society for New Zealand the National Heart Foundation and the Royal New Zealand College of General Practitioners produce the key ideas for treatment and management of heart failure. However, the guidelines these groups produce may not be the answer for best practice to occur. Being the dominant group in society, it is argued that they have focused on the disease aspect of health, from a bio-medical perspective, with little understanding of the reality of the patient experience of illness. When there is dominance of one perspective of the health illness spectrum, that of disease, it is little wonder that improvements in technological advances in the understanding of the pathophysiology and treatment options have not filtered through to improved patient management. Added to this, the environment of health care delivery today demands that cost constraints be met. Heart failure is a huge cost to the health budget and improvements in care are required to meet the challenge of improved quality and length of life, at a cost. The literature reveals that, because of the dominance of a disease focus in heart failure treatment, there is little research that examines the group interaction and processes that affect heart failure management, although some research discusses which health professional should coordinate and provide care.

This literature review therefore supports a need for research studies that explore the illness experience of patients with heart failure. Further, not enough is known about group interaction in the management of heart failure to propose mechanisms for beneficial effective interventions, whether they be pharmacological or non-pharmacological. Improved technological advances in management of the condition need to follow through to the patients. It would therefore appear that benefits may ensue from understanding heart failure from a broader perspective. It is possible that better information flow and improved knowledge management may result in an integrated approach to heart failure management. The realisation that the spouse or coordinating person is vital in the effective management of heart failure is an important clue as to how health professionals could improve co-ordination, and integration. Further investigation is essential.

The following chapter presents the research approach. An introduction and development of grounded theory is outlined, followed by discussion on grounded theory, nursing and this study. Finally issues related to the study setting, sample, data collection and analysis are presented.

CHAPTER THREE

Method

The intent of this research into heart failure management was for the researcher to examine how heart failure is managed by everyone involved in the care. The literature review showed that heart failure is not managed well and that what happens when a group of people manage this condition is largely an unexplored area. The aim then, was to explain the main concerns of a group, comprised of the patient, their partner, and the health professionals who manage heart failure and how they continually resolve those concerns. Taking into account these factors, the researcher chose the method of grounded theory. The particular style of grounded theory used in this study follows that of Glaser (1998), although some minor modifications were made. These will be explained later in the chapter.

Grounded theory is an inductive research method that is well suited to a qualitative approach to research. According to Glaser (1998) "it is a general method to use on any kind of data and is particularly useful with qualitative data" (p. 40). McCallin (1999) explains that "the aim in grounded theory research is to explain and predict behaviour, and discover the underlying social processes shaping interaction and human behaviour" (p. 28). This method was congruent with the research question and it allowed the 'how' and 'what' focus of the group management of heart failure to emerge. As little was known on why heart failure was not managed well from the participants' perspectives, and the focus driving the research would be on the participants' main concern, grounded theory was chosen. As such, grounded theory can be used to examine group interactions, and it is ideally suited to qualitative research.

Grounded theory is often used to generate theory from data. In this small study, however, while theory development is not the goal, the grounded theory principles are certainly followed throughout the research process. The decision to follow grounded theory principles only was made because this pilot study pilot study was designed to meet the requirements a 75-

point, 25000 word masters thesis. On this basis what is discovered cannot be generated into a theory. This position is supported by Glaser (1998) who suggests that "partial doing is a start and better than no doing at all" (p. 4). At the same time, studies that do not develop a theory can still be of benefit to the nursing profession. Conceptual development can be advanced and existing nursing practice may certainly be challenged. Important clinical issues may be raised and can be explored in greater depth in later studies, so that nurses can be more aware of what works for the patient with heart failure and what does not. Although the researcher does not see herself as expert in the area, it is hoped that nursing practice will be improved once the findings are presented to colleagues.

In order to understand the process and method used in this research study, the roots and development of the grounded theory method are presented. This is followed by definitions of the key components in order to assist understanding of the research method. Grounded theory and its relevance as a research method in nursing is then outlined, followed by discussion on how the method was applied in this research study. Finally, access to the field, the study setting, sample, participants, data collection and analysis, ethical considerations, rigour, and constraints related to this study are discussed.

Introduction to Grounded Theory- Roots and Development

In order to understand grounded theory some understanding of the background factors that shaped the method is helpful.

The theoretical orientation for the grounded theory method evolved from symbolic interactionism. McCallin (1999) states that "grounded theory is a general research method that has been shaped by pragmatism and informed by symbolic interactionism" (p. 28). Chenitz and Swanson (1986) state that symbolic interaction is a theory about human behaviour, and an approach to the study of human conduct and human life. As such, it focuses on the meaning of events to people in natural or everyday settings. According to these authors, grounded theory was shaped by George Herbert Mead, a pragmatic philosopher and social psychologist, who believed that "a biological organism develops a mind and a self and becomes, through social interaction and society, a rational being. It is in social interaction that the individual achieves a sense of the self" (p. 4). Social interaction underpins the group interaction that is essential for social life, in which meanings must be shared.

According to McCallin (1999) although there were different schools of thought on symbolic interactionism, common to all were Herbert Blumer's basic premises. These are that "people act towards things according to the meaning those things have for them; meaning evolves from social interaction with others; and meaning changes as interpretation alters once people are actively engaged within the world" (p. 19). This definition is further clarified by Glaser (1998) who describes the social construction of realities as "symbolic interaction making meanings through self indications to self and others" (p. 32). Applied to the management of heart failure a grounded theory perspective involves the exploration of human behaviour and interaction.

In a grounded theory study, during data analysis a basic social process becomes evident. Glaser (1978) describes basic social processes as theoretical reflections and summaries of the patterned and systematic uniformity flows of social life, which can be conceptually captured and further understood. Further, Glaser (1978) states that evidence of a basic social process is defined when, "the analytic focus involved seeks theoretical coverage and not descriptive completeness which is seen as impossible" (p. 114). It can explain the conditions of the phenomenon from an integrated perspective, that is, how the variables connect. As such, the process is explained rather than the conceptual unit involved.

The grounded theory approach to research was discovered in the 1960's by two sociologists. Anselm Strauss from Chicago University, and Barney Glaser, a researcher from Colombia University. Together they wrote the grounded theory approach (Glaser & Strauss, 1967). According to Strauss and Corbin (1990) and Glaser (1998), their techniques for analysing data reflected both backgrounds. Glaser (1998) states that the combination of the two approaches allowed for the analysis of qualitative data through the application of quantitative ideas. The discovery of tying theory to data through constant comparison occurred. This meant that ongoing, systematically obtained and analysed data were collected and analysed simultaneously, with the outcome being the generation of theory from data (Glaser & Strauss, 1967).

At the time of discovery, 30 years ago, few studies were done using grounded theory. However, more recently, especially over the last two decades, this research method has become more popular. Although grounded theory was originally used in the field of sociology, its use has since expanded and it has been used as a research method in many other disciplines. Glaser (1998) suggests that this is because people working in education and health are dealing with vital relevant problems that reflect areas of concern. Professional people want answers that fit, work, are relevant, and easily modifiable to constantly changing situations. This makes the method particularly relevant in the health field where the relationship between business and medicine is changing and altering the nature of professional work. In this context, grounded theory is a method of research that, when followed rigorously, allows the main concerns of participants to emerge, from the data. According to Glaser (1998) "in grounded theory there is no need to force meaning on a participant, but rather a need to listen to his genuine meanings, to grasp his perspectives, to study his concerns, and to study motivational drivers" (p. 32).

In more recent years, Glaser and Strauss have differed over methods involved with grounded theory. This has led to work by Strauss and Corbin (1990), and Glaser, most recently (1998). It is important to note that although their approaches to grounded theory differed, the original authors continued with grounded theory research. Glaser (1998) states that although he has a more open ended discovery approach, and does not force emerging data, Strauss is more self sufficient and structured in approach. This researcher, while certainly aware of the debate on the differing approaches to grounded theory, followed the principles of both authors, who despite their differences, continue to share many similarities. Work from Glaser's latest book (1998) and aspects of Strauss and Corbin's (1990) paradigm model were used in conjunction with the method of grounded theory as advocated by Glaser (1998).

Key Components

The grounded theory method involves systematic steps of data collection, coding, and analysing. A systematic, rigorous, grounded theory study using the constant comparative method proceeds through: memoing, theoretical sampling, and sorting to writing. Therefore, the main components in a grounded theory study are: the use of constant comparative analysis, theoretical coding, and theoretical sampling.

Glaser and Strauss (1967) define constant comparative analysis as a process including comparison, integration, delimiting theory, and writing theory. It is a strategy that aims to identify the main concerns defined by study participants and in the process generates and suggests categories and concepts about the problem being studied. Polit and Hungler (1991) outline the procedure of constant comparison whereby the categories from the data are constantly compared with data obtained earlier in the data collection, so that commonalties and variations can be determined. Although this process when taken to the level of producing a grounded theory, requires data saturation, this researcher did not anticipate that in her small study data saturation would occur. Data saturation is described by Chenitz and Swanson (1986) as occurring when "no new data and no additions are added to the category and one overriding core category can explain the relationship between all others" (p. 8). Constant comparison of data in the researchers study produced a core category that explained the relationship between all other categories.

Glaser (1998) recommends that the six C coding paradigm be used for analysis. This paradigm incorporates causes, contexts, contingencies, consequences, covariances and conditions. He states that most studies fit into a causal model, a consequential model, or a conditional model. They each have sub families of models. For example, "the causal model has a sub family model named: sources, reasons, explanations, accountings, or anticipated consequences" (p. 74). However, according to McCallin (1999), the theoretical sorting for integration that this model of data analysis would involve drove her towards Strauss and Corbin's (1990) coding paradigm. As she states " the axial coding system was seen as another way of linking data together according to causal conditions, action/interactional strategies, and consequences" (p. 119). In addition Glaser (1978) also states in relation to theoretical coding families, that "we hope to have touched on the most useful, but they continually emerge and arrive..." (p. 82). Glaser also suggests that researchers can develop their own coding families. Strauss and Corbin (1990) discuss axial coding as "not talking about the relating of several main categories to form an overall theoretical formulations, but the development of what will eventually become one of several main categories" (p. 97). As such, the researcher decided that Strauss and Corbin's (1990) model for data analysis was clearer and more suited to analysis within her study. She was not developing theory, and was taking the study to the emergence of a main core category that would explain the participants main concern and how they continually resolve that. Therefore, the decision was taken to use the Strauss and Corbin (1990) axial coding paradigm for data analysis.

The paradigm approach involves causal conditions, context, intervening conditions, action/ interaction, and consequences. This was used to put data back together in new ways after open coding. The making of connections between categories, and subcategories is classified as axial coding. Strauss and Corbin's (1990) axial coding model consists of integrated causal conditions. In this study, unlike McCallin (1999) and Strauss and Corbin (1990), causes and conditions are presented as two separate sets of data. This separation occurs because it was consistent with the participants explanations and had definite separations in meaning. Whereas the causes were related to the events, incidents, and happenings that lead to the occurrence of the phenomenon, the conditions were more to do with what facilitated or constrained the strategies chosen. A definition of the concept, the context in the paradigm model, refers to the particular set of conditions within which the actions or interactions are taken (Strauss & Corbin, 1990). Interactions include what is directed at managing or responding to a phenomenon as it occurs in context. The last component of the paradigm model, the consequences, are the outcomes or results of action and interaction taken in relation to the main phenomenon understudy.

According to Strauss and Corbin (1990) theoretical coding conceptualises relationships between data through the process of relating concepts, categories, and integration of data into a main category. Coding can be classified as being axial, general or selective. All coding begins with open coding that is the initial step in the coding procedure, whereby all data is gathered. "It fractures the data and allows one to identify some categories, their properties, and dimensional locations" (Strauss & Corbin, 1990, p. 97). Coding does not necessarily take place in stages and the researcher can operate between one type of coding and another in order to build categories from data. Selective coding occurs when the researcher selects the core category and relates it to other categories validating those categories and expanding on areas where more data is needed to give better meaning and understanding. When the initial stages in the Strauss and Corbin (1990) paradigm model for data analysis had revealed gaps in some categories, the researcher selectively coded for more data.

Theoretical sampling focuses and limits the collection and analysis of data by responding to the need for more data that is relevant to the emergence of new categories and properties. Although grounded theory is an inductive method of research, the use of theoretical sampling requires deductive thinking on the part of the researcher. As such, according to (Glaser, 1998) "deductive reasoning comes into play through the sampling procedures as sources of more data are looked for and the researcher is able to deduce where they may need to go to get more" (p.43). Theoretical sampling is used to compare already gathered data, to test whether the researcher is on the right track. Therefore, theoretical sampling is a tool whereby data is either conceptualised, and therefore verified, or corrected.

Grounded Theory and Nursing

Nursing studies have used grounded theory for many years (Charmaz, 1990; Christensen, 1995; Estabrookes & Morse, 1992; Irurita, 1994; Wilson, 1977). As a research method it is well suited to nursing because in many respects nursing practice is about dealing with patients' concerns, and endeavouring to resolve them. Nurses are well experienced at identifying the concerns of others and managing problems to optimise patient care outcomes.

Writers argue that grounded theory is useful in developing understanding when little is known about a phenomenon, and in complex situations such as the health system, because it assists in conceptualising behaviour (Chenitz & Swanson, 1986; Charmaz, 1990). The health system in New Zealand has undergone great change in its philosophical outlook over the last ten years (Blank, 1997). The strong bio-medical emphasis is challenged to recognise lay conceptions of health and illness (McKay et al., 1998). The researcher used grounded theory principles because little is known about how heart failure is managed from the group perspective in a system that is undergoing restructuring.

Grounded theory provides a set of useful strategies for studying heart failure as a chronic illness. According to Charmaz (1990) "the experiences of people with chronic illnesses do not entirely unfold before the researcher's eyes. Rather, researchers create their analyses" (p.1170). Strategies for focusing and controlling large amounts of data underpin the grounded theory method, and it is thus useful in developing a deeper understanding of a chronic illness such as heart failure. Glaser (1998) states that "grounded theory is a package that is a revolving step method that starts the researcher from a 'know nothing' to becoming an expert in the substantive area" (p. 13).

Grounded theory and this research study

As a beginner in the methodology of grounded theory, following Glaser's (1998) method allowed for research to be taken to the level of a core category. Even though the researcher began the research with the knowledge that a small study would not allow theory generation, it was certainly necessary that this study be consistent with grounded theory principles. The researcher did not want to confuse conceptual description with theory generation. The emergence of a core category from rigorous data analysis would be the end point for this research. A core conceptual category is important as it should explain the main concern of the group, and how they continually resolve that concern. This core category would come from the 'doing' (Glaser, 1998, p. 1), of grounded theory, and be useful for examining the integrated picture.

Using a grounded theory approach to a certain level has been described as a beneficial start to research. According to Glaser (1998) any level of doing is better than none. Chenitz and Swanson (1986) also report that the researcher may stop at any level of analysis and report findings. Grounded theory may be done at either the descriptive, theoretical, or process levels. "The researcher is empowered to discover and generate new categories and their properties, instead of being forced to use received concepts" (Glaser, 1998, p. 133). However, in this study, in order to understand what happens when a group of people manage heart failure, it was important to take the study beyond the descriptive level. The researcher wanted to gain insight into the reasons behind the descriptions.

In earlier years, researchers were advised to carry out a literature review related to their research question in order to develop a theory on which to base their research would be done. In grounded theory a literature review is not recommended, so that the data that emerges is not forced to fit pre-existing theory. For this study on heart failure management, the researcher had reviewed some literature prior to carrying out the research. This was done to place the topic of heart failure management in context, and had already been partially completed prior to commencement of the study. The literature surveyed did not indicate what the problem is with the way the heart failure patient is managed, or look at group interaction in the management of heart failure. The researcher could therefore "start out on a need to know basis in order to stay open to the emergent problem and beginning set of categories and their properties" (Glaser, 1998, p. 100).

Admitting to knowledge about the literature on the topic of heart failure at the outset of the study, means that the researcher is aware of the potential for findings to be based on existing theoretical knowledge. The researcher also has an interest in the area under investigation through her work as a research nurse in the heart failure clinic. Glaser (1998) notes that when the researcher has an interest in the area under investigation, it is hard to resist doing a study in that area. However, just like a judge telling a jury to disregard something they may have heard, the researcher can suspend their knowledge in reaching a verdict. Although many researchers may argue that the suspension of knowledge is impossible, certain measures are followed to ensure checks as emerging data occur. These will be discussed in the section on rigour later in the chapter.

By following grounded theory principles, the researcher was hoping to gain a broader understanding about the group management of heart failure, as experienced by the twelve participants in this study. It is argued that two foci are necessary if any understanding of the whole is to be realised. The first of these are on the clinical details, the second, the various interactive factors that influence the process, which may, or may not be the social phenomena taking place. This is supported by Glaser (1995) when he states that "A process analysis tends to have much explanatory power because it integrates the multiple parts of the problem under study into a logical and understandable whole" (p. 174).

The Study Setting

The study setting consisted of a Specialist Heart Failure Clinic within a hospital setting. The clinic is the base for specialist heart failure health care for a small number of outpatients who have been involved in clinical research trials. Patients are seen on an as needed basis depending upon their health requirements. Some patients are seen at three monthly intervals, others are seen weekly. The three patients who were selected for the study are seen on a three monthly basis, and have not been part of a randomised trial for at least six months. At the time of data collection the setting was also the work setting for the researcher, and although there was the potential for bias, this is recognised and dealt with. The researcher was a research nurse in the heart failure clinic so therefore, she had a knowledge of the participants in the study, who were also patients in the clinic. As the researcher, she had deliberately chosen patients that she did not know well in a professional capacity. Another nurse in the clinic had been more involved with the health care of these patients. The researcher also had a collegial relationship with health professionals from other disciplines, who were working in the area. The practice nurses who looked after the patients in the community were approached, but declined to be interviewed, saying they were unable to commit to the time such an interview would require. However, the pharmacist, and the general practitioner who managed care of the patients in the community between clinic visits, were willing to join the study. These participants were interviewed at their place of choice, in their respective work areas.

Because the clinic is also involved with drug trials of various sorts, which are sponsored by pharmaceutical companies and the clinical trial research unit, it is recognised that these patients are representative of a select group of patients. As such they are not the norm for outpatient clinics that currently operate in New Zealand. Not all heart failure patients are entered into drug trials. Those that are have usually met respective select screening criteria, and have undergone more intensive follow-up and clinic support. As a result, they probably have a better knowledge of the clinic team than the usual outpatient setting would allow. The health professionals involved in the clinic are a cardiologist, a cardiology registrar, and a nurse. Available on an as needed basis are other members of the multi-disciplinary health team, such as the dietician, and the pharmacist. The pharmacist consulted most often was the community pharmacist. Initial approaches to the heart failure patients asking them to participate in the study took place at the clinic. The interviews then took place in the clinic setting. After an initial phone call from the researcher to enquire about possible participation, the health professional interviews involving non-clinic staff took place at their work, in a room of their choice, or at their home.

Access to the field

Access began with ethical approval from the Massey University Human Ethics Committee, and the Northern Regional Health Ethics Committee. Once this was acquired the researcher was able to access the patient participants from the hospital as management approval for hospital patients, health professional time, and use of premises had been gained as part of the Northern Regional Health Committee approval. The researcher's role in this study was both as interviewer, and observer. Observation was useful as it helped the researcher check perceptions, recollections, and provided further information on the data. Access to the GP clinics was gained by phone, and included in the ethical applications of the study. The interviews took place in a room of the participant's choice.

The participants

The participants were identified from two groups. The first group were members of the multi-disciplinary team involved with the health management of the patient. The second group were patients from the heart failure clinic. In grounded theory research the participants are chosen because they can clarify the phenomenon being studied. While the nurse researcher may have some knowledge about the patients and colleagues, that knowledge is always limited and does not encompass a full understanding of the social processes and behavioural patterns acquired when a group works together to manage heart failure.

The total number of participants included in the study was anticipated as being ten. Twelve participants were asked for at the ethics committee hearings because of the nature of the disease being studied. Four patients were identified at the start of the study. It was not anticipated that four patients would be included at any one time. The intention in this pilot study was to talk to two patients with heart failure. Four patients were identified because those people had severe heart disease, and if they had become unwell, or hospitalised, then the interviews could not have continued. There was therefore the potential that a participant could die. In order for the research to remain feasible, if one or more participants had died, others would have been available. However, it eventuated that three patients were included because when theoretically sampling, the researcher wanted to verify conceptual categories identified with another patient participant.

The management team was anticipated as including the practice nurse, general practitioner, pharmacist, cardiologist or cardiology registrar, and the partner or support person of the patient participants. That group of people seemed to offer the best potential for theoretical sampling that is essential in grounded theory. As discussed earlier, Strauss and Corbin

(1990) state that "the aim of theoretical sampling is to sample events, incidents, and so forth, that are indicative of categories, their properties, and dimensions, so that you can develop and conceptually relate them" (p.177). It is perhaps interesting to note that the Strauss and Corbin (1990) approach to theoretical sampling is the same as Glaser and Strauss (1967), Glaser (1978), and Glaser (1998). Guiding the theoretical sampling are questions and comparisons that evolve during analysis that help a researcher to discover and relate relevant categories, their properties, and dimensions. "The more sensitive you are to the theoretical relevance of certain concepts, the more likely you are to recognise indicators of them in the field and in the data" (Strauss & Corbin, 1990, p.180).

In grounded theory the participants are not selected from the population based on certain variables prior to the study. "The initial sample is determined to examine the phenomena where it is found to exist" (Chenitz & Swanson, 1986, p. 9). The researcher chose the participants who she thought would be willing to discuss their main concern and how they continually resolved that concern. The site and group to study was an initial sampling decision taken simply because the heart failure clinic, and the participants involved, were available for research. Interviews were used as the main source of data gathering. The professional literature on heart failure management was seen as another significant slice of data. After talking with experts in the heart failure field to get leads on how to track down a rich supply of data, the researcher decided that the best way to choose a patient participant was to use purposeful sampling. Theoretical sampling does involve purposeful sampling in the initial stages and therefore creates a beginning foothold for the research (Glaser & Strauss, 1967).

Three patients joined the study. Criteria required for selection was that participants have moderately severe heart failure, and be between 70 and 90 years old, had had heart failure for at least one year, and had been hospitalised at least once with worsening heart failure. All participants were on a range of heart failure medications, and were able to communicate freely in English.

Initially, these potential participants were invited to join the study by an intermediary, who was a senior nurse at the hospital. An informal approach was used so that the research could be briefly introduced. If a patient was interested they were asked if they would like an information sheet (Appendix 1) on the study. The ethical issues affecting the study were explained to the proposed participants and phone numbers for further contact were gained with the patients' consent. It was then left to the participant to approach the researcher by phone within one week. If there had been no contact from the participant within this time, then the senior nurse would phone the participant. The participant was asked if they would like their partner or support person present with them during the interviews.

The health professionals were recruited on the basis of their being the group of health professionals managing the patient's heart failure. It was assumed that they would be interested in joining a research study and discussing how heart failure is managed. They were approached informally by phone or in person, and the research was briefly introduced. If the participant was interested, they were given an information sheet (Appendix 2) about the study. With their permission, it was clarified that the researcher would then approach them again, either by phone or in person, in one week to ascertain their formal interest in participating in the study.

Data collection and analysis

The researcher's role was to gather data about the management of the heart failure patient. This involved gathering information about what persons do or do not do in terms of action and interaction, variations in action and interaction, and what range of conditions cause the variations, as well as how conditions stay the same or do not stay the same in relation to the context of management of heart failure.

The three participants with heart failure were interviewed once. The interviews were approximately one hour in length. Interviews were conducted over a three month period. The health professionals were interviewed once. The interview technique as described by Glaser and

Strauss (1967) was used. This technique involves the use of the researcher using open-ended questions and then listening to the respondent's stories. Interviews began with the question asked of the patient:

> *I understand that you have had heart failure for some time now, and I am interested in finding out what it is like being managed by a group of people. What are some of the experiences that you have had...?*

The questioning techniques were designed to uncover more than superficial descriptions of what it was like having the heart failure managed by a group.

Patients gave the researcher permission to talk to others managing their care with the understanding that their names would have to be known. An initial question that was asked of all health professionals was:

> *I understand that you have been involved in the management of the heart failure of (Patient X) and I am interested in your experience...*

After the initial question the researcher aimed to clarify her understanding of emerging concerns. Asking general questions in relation to the overall phenomena being discussed provides further clarification. Strauss and Corbin's (1990) paradigm model for data analysis has been defined earlier in this chapter. Specific questions were asked about the causal conditions, contextual determinants, interactive strategies used, and the consequences of actions, as they related to the main concern revealed by participants. The interviews were audio-taped and field notes taken.

Memoing helped clarify ideas for further sampling, and aided in clarification of data. Glaser (1978) suggests that, because grounded theory produces a proliferation of ideas, memoing is a way to store ideas during coding. The researcher certainly found that memoing was a way to keep track of ideas when going through the data, and assisted in integrating categories and their properties. Categories of the data such as *belonging to a cohesive group* were filled out through memoing. In some cases memos included the researcher's thoughts about the non-verbal cues that were picked up during interview. Non-verbal cues complement verbal expression and help the researcher build a picture of the whole. According to Sandelowski (1993) the researcher arranges features of the interview event, such as facial expression and body movement, and sounds, such as sighing, and laughing, so that they are preserved to give extra meaning to text. These non-verbal cues appear in the text and are critical because they directly influence the analytical process.

Data analysis

In analysing data, Glaser (1998) states that there never is the most important point, but that there is the constant shifting of variables as theoretical codes change. Similarly, the researcher found that what she considered significant categories at the beginning of the study changed throughout the analysis process as further data and verification emerged.

As already discussed, the grounded theory method uses a constant comparative method of analysis. Data collection is less structured as coding and analysis begin concurrently after the first set of data have been collected (Glaser & Strauss, 1967). The researcher analysed the data as close to the interview time as possible, in order to retain what was said. It was important to note who initiated a line of talk or used a certain phrase first, so that errors were not made in attributing information or salience of information to the wrong person (Sandelowski, 1993). Once data is collected, and interviews are transcribed, analysis begins. The researcher's time constraints did not allow for a leisurely transcription of interviews. Glaser (1998) states that it is better to encourage more immediate coding and analysis of data than to waste time transcribing. Therefore, transcripts were either typed up the day of the interview by the researcher, or the transcriber. Data can be lost while waiting for tapes to be transcribed. Time restrictions would have meant that the researcher could not transcribe all the tapes herself. Audiotaping of interviews occurred so that selective note taking and possible bias could be avoided. The tapes were replayed so that careful and accurate constant comparative analysis could occur. This process took the researcher a few attempts to master because she was new to grounded theory principles.

The data was examined, concepts discovered, and grouped, and then categorised. This process pulls together groups of categories or concepts (Strauss & Corbin, 1990). Categories were then named, according to their properties and dimensions. The researcher followed the process of comparison of incidents to one another as advocated by Strauss and Corbin (1990) "We compare incident with incident as we go along so that similar phenomena can be given the same name" (p. 63). "To understand the nature of properties and dimensions and their relationships is a requisite task for understanding, in turn, all of the analytic procedures for developing a grounded theory" (Strauss & Corbin, 1990, p. 70). Questions that were asked when reading through the data were aimed at bringing out the major idea in the sentence. "Insight and understanding about a phenomena increase as you interact with your data" (Strauss & Corbin, 1990, p.43). These authors state further that "Causal conditions, context, intervening conditions and showing how they facilitate or constrain action/ interaction and when appropriate how action/interaction is managed are part of axial coding which link and develop categories" (p. 104)

Comparisons were made during analysis as the analyst sought similarities and differences. Glaser (1998) defines theoretical sensitivity as the constant comparing and conceptualisation of data. It is the ability to generate theory and keep its conceptual level. Concepts need to relate to each other "The more theoretical codes the researcher learns the more he or she has the variability of seeing them emerge and then fitting them to the theory" (p. 165). Strauss and Corbin (1990) clarify this further when they suggest that theoretical sensitivity is the ability to recognise what is important in data and to give it meaning. This sensitivity is acquired through continual interactions with the data, and through collection and analysis keeping a balance between the researcher and the real. It is done by: "asking what is going on here, maintaining an attitude of scepticism toward any categories or hypotheses brought to or arising early in the research, and validating them repeatedly with the data themselves" (p. 46). In this study phone calls and further checks with participants that the analysis was representative of their data supported this process.

Theoretical sampling and the deductive approach that this involves led the researcher to approach health professionals other than those who worked in the clinic. A wider sample group was required to verify data. These people were also selected because the researcher had collected and analysed data but found that there were gaps in some areas, and she thought that they would be able to provide further explanation of what was happening.

Ethical Issues

Ethical approval covered such aspects of the study as informed consent, confidentiality of participant and information, and the potential harm to participants. and possible researcher / nurse bias.

Informed written consent was gained from all participants The participants could choose to use their own name or remain anonymous by choosing a special name, or pseudonym. The participants were given information sheets about the study and the study was explained to them, by the researcher. Participants were informed that the findings would be used in the researcher's thesis.

Participants were given one week to decide whether they were interested in taking part or not. After one week, if there had been no response, an intermediary was to phone potential participants to check on whether the participants were interested in the study. An opportunity was given to all participants for any questions or to discuss the research with others. Participants had the right to feel free from any coercion and from answering interview questions that they did not feel comfortable answering. Participants were also made aware that they had the right to ask for audio-taping to stop.

Although there may have been no perceived danger of physical risk to the participants, since interviewing was the main method of data collection, the researcher was aware of the possibility that emotional issues which may have been raised through disclosure of sensitive experiences could be ones which the participant may still have needed to work through. If this situation had arisen, the researcher would have terminated the interview, and, as a nurse with over ten years experience, would have offered support or information as required. Participants were informed that they were able to withdraw from the study at any time.

Participants were given the opportunity to review their own audio-tapes, field notes and transcripts. During the study all audio-tapes and written material were securely stored and accessible only to the researcher and her supervisor. A typist was used for the transcribing of some transcripts. She had consented to non-disclosure of information. At the end of the study participants were offered the taped material or it was destroyed. At the request of the Ethics Committees the transcripts and the participants' data files are to be stored in a confidential file for 16 years, after which time all data will be destroyed.

Rigour

Rigour concerns the way in which a research method is grounded and structured within the study. This means that it is necessary for the method to be documented, and an audit trail followed, in order that the research outcome can be assessed for trustworthiness (Krefting, 1990). Krefting states that a model that is "appropriate to qualitative designs needs to ensure rigour without sacrificing the relevance of the qualitative research" (p. 215). Therefore, the researcher elected to follow Glaser's (1998) criteria for checking rigour. Glaser suggests that fit, workability, relevance, and modifiability are criteria for judging the rigour of a grounded theory study.

Glaser's (1998) four criteria for judging the study are now outlined. Firstly, the fit, or the validity, of the study checks that the concept adequately expresses the pattern in the data that it claims to conceptualise. Workability occurs when the concepts and the way they are developed into hypotheses, account for how the main concern of the participants in the substantive area are continually resolved. Relevance deals with the main concerns of the participants involved. To study something that interests no-one is to focus on non-relevance for the participants. Modifiability deals with the process of data generation, where theory is modified by comparisons with new data. As such, new data provides an analytic challenge.

Glaser (1998) argues that in grounded theory the researcher who forces data through preconceived ideas of the problem under study will not let emergent data take precedence or will be blocked to it. In this sense, rigour could be compromised. Consequently, the researcher in this study was conscious of the fact that she had done an initial literature review prior to the study, and that work in the heart failure clinic may have influenced her in the substantive area under investigation. She was anxious to let the participants elaborate and define without constraint, their experiences of heart failure. In order to stay open to the problem of the participants, even though most of the literature had been on contextual issues, she constantly worked to suspend knowledge on problems of heart failure management. Glaser (1998) states that the method when applied rigorously overcomes bias. To attain this level of rigour the researcher made certain through constant comparison of data, that she stayed open to the problem of the participants. At the same time, she memoed assumptions and biases and reflected on these during analysis. Forcing the self to critically analyse assumptions extended understanding and broadened the analytical perspective.

The researcher believes that this study meets the criteria of fit, because the concept of **information gaps**, the core category to emerge from data collection and analysis is relevant and workable, and is based on naming a pattern that emerges in incident after incident. As Krefting (1990) notes, "the credibility of any argument is enhanced by the establishment of structural coherence, and ensuring that there are no inconsistencies between the data and their interpretations" (p. 220). Comparing incident after incident involved continuous fitting by constantly going back to the data and checking and verifying the pattern that emerged. These processes sharpened the fit. For example, early on in the study, it seemed that role confusion would be the pattern that emerged to explain the cause of the main concern. However, when further coding of data took place the researcher realised that participant data did not fit the pattern of role confusion and open coding therefore, continued. Open coding continued until the researcher was certain that *absence of a cohesive group* was the corrected pattern that emerged. This follows Glaser's (1998) advice to keep coding, analysing and generating new properties to be sure that the researcher has identified the real problem.

Categories were carefully generated from patterns of meaning that came from the constant comparisons of incidents. For example, the category of *alerting others* emerged after indicating data such as checking, reassuring and adjusting were taken to the level of conceptual analysis (See Table 1, p. 63). The concept of *alerting others* was compared to the next incident, socialising, and the category was saturated by the interchangeability of indicators. The researcher believed that it was important that conceptual analysis rather than pure description took place. She did not want to have pure conceptual description as analysis where deciding what is happening occurs with no need to generate an explanation for it. Glaser (1998) states that there are three levels in a grounded theory study. The first level is descriptive data. The second level consists of conceptualisation of data into categories and properties. The third, integration through sorting into a theory did not occur. Instead, integration of the data into a core category using Strauss and Corbin's (1990) paradigm model was the goal.

Strauss and Corbin's (1990) paradigm model was useful to link data together. The decision to use Glaser's (1998) approach to grounded theory overall, even though the coding method was not his, was taken. It was recognised that similarities between Glaser's (1978) coding family of causes, contexts, contingencies, consequences covariances, and conditions is very similar to the paradigm model but there were also some constraints in the later stages of coding that affected the establishment of a core category (McCallin, 1999). The way that the data is analysed is an important part of the rigour of the research. Krefting (1990) supports this position when she says that "the structural coherence is influenced by the way that the researcher integrates the masses of loosely connected data into a logical holistic picture" (p. 220).

Memos made by the researcher were another way of validating her hypotheses against the data, and assisted in the fit, relevance, and integration of categories. As Glaser (1998) explains, memos capture, track and preserve conceptual ideas that the researcher may have. For this researcher memos allowed her to move away from the data to abstract thoughts, and thus, on return to the data, to check these analytic thoughts with the emerging data. Statements regarding the categories and relationships under varying contextual conditions were developed and finally validated against the data.

The researcher believes that Glaser's (1998) criteria of workability was met. Krefting (1990) also notes that the study must allow another researcher to arrive at comparable conclusions given the same data and research context. Although theoretical saturation (Glaser & Strauss, 1967) was not met in this study it was not anticipated that it would be, because a theory was not going to be developed. Rather, categories, and their conceptual properties among the 12 participants in the study, were arrived at. Category saturation and property saturation was not possible in such a small pilot study. However, when the researcher used the coding process of selective coding for a core category, she found repeated evidence for the conceptual categories. Charmaz (1990) describes theoretical saturation as filling, supporting, and providing repeated evidence for the relevant conceptual categories. Integration of all properties was further met because the researcher deductively ascertained where to sample next. Workability of the data, and the way it developed into hypotheses, sufficiently accounted for how the main concern of participants was continually resolved. The core category of **information gaps** related to all other categories explaining how the main concern of the participants was continually resolved. Deductive, theoretical sampling led the researcher to sample outside the clinic area using others involved in the rehabilitation of heart failure patients. Therefore the main concern of **information gaps** became based on categories, and establishing their relation to other categories and their properties.

In this study the researcher did not allow enough time for participants to be interviewed twice, so participants were phoned to check data. Findings were shared and confirmed by them. Relevance occurred when findings were shared with an experienced cardiac rehabilitation nurse from another centre. She recognised the relevance of the study results because they had similarities to her practice experience with other nurses and with heart failure patients from her region. The researcher believes this meets the test for grounded theory to be rigorous and relevant that Glaser (1998) expects when he writes that "when applied to categories with similar settings and to other types of problems over time, they evoke instant grab" (p.18).

Modifiability, the last criteria for rigour of the study was more difficult to meet because the theory, or in this case the core category, was not been modified by new data to compare it to. Although there are only twelve participants in a fairly confined area of heart failure management, it is not really possible that the core category, **information gaps**, could be taken to another field and be modified by new data to compare it to. Krefting (1990) states that the criteria of transferability of data means that it is critical that researchers provide dense background information about the informants and the research context to allow others to assess how transferable the findings are. This researcher believes that the contents of the interviews are typical of the lives of the participants, because time sampling and member checking were used to identify that data was typical for the group understudy.

The researcher deems that rigour of the study has been accomplished. This is because in a grounded theory study, as Glaser (1998) states, " In the final analysis the criteria that grounded theory fits, works, and has relevance, resolves its legitimisation" (p. 17).

Constraints that shaped the study

The main constraint is the small size of the sample. This means that results are context specific. The study is unable, therefore, to generate theory from data, as a grounded theory study would ordinarily do. The researcher was however, able to take the data to the level of producing the core category; the participants main concern and their continual resolving of this (Glaser, 1998). There is also limited constant comparative data and theoretical sampling because of the small sample size as well as time constraints. Despite these restrictions, Glaser believes that doing a grounded theory study to a certain level is of use as long as limitations are openly identified. Of utmost importance is that the grounded theory method of Glaser (1998) was followed rigorously.

Summary

This chapter has introduced the research method of grounded theory. Exploration of the history of the method has revealed that there are two main pioneers of the method, Glaser and Strauss (1967). The aim of the research was to explain the main concerns of a group, comprised of the heart failure patient, their partner, and the health professionals who managed their care. Selecting a grounded theory approach to the study presented an opportunity to reveal what the participants' main concern in the management of heart failure was. The research process of grounded theory Glaser (1998) used in the study was outlined, and reasons for using Strauss and Corbin's (1990) paradigm model for data analysis were given. The study setting, participants, data collection and analysis were discussed. Finally, issues related to maintaining ethical principles and rigour were identified.

The next chapter presents the findings of the study.

Table 1

Alerting others – *conceptual category*

Substantive Codes	Interview Text	Indicators
Proactive responsibility	*I think there was one afternoon when he got a bit breathless....I rang [the GP's] surgery and they couldn't get him in, but I said that I wanted him checked as he got over his breathlessness fairly quickly...*	Ringing for help, Checking, Requesting help
Reassuring	*He examines me and checks my blood pressure and so on and I feel I achieve something by going to him.*	Checking, examining, Achieving
Adjusting	*Well you see when I first had this problem, I was booked to go on a trip]away], and I was told no you can't go...[and I had to] cancel it. And then some time [later] when I came in again, [a doctor] said, "Well I think you are fir enough now..."*	Getting the message across, problems, telling
Instructions	*...and the guidelines are still not being used by general Practitioners which is a problem not so much for the GP's its probably the whole area around the implementation of guidelines.*	Producing guidelines and booklets to foster standardisation of practice, implementation
Admission	*So [I'm] not quite sure how he got into hospital on that occasion and I think it might have been through a locum. In this day and age you would not have thought that was required[all he needed was] a minor adjustment in his treatment.*	Quality of life affected in hospitalisations, adjusting, treatment

CHAPTER FOUR

Information Gaps

Information gaps emerged as the main concern, or phenomena in this small study on the management of heart failure. In this chapter the findings of the study are presented. An overview of **information gaps** is followed by the subcategories that relate to this phenomenon. While the subcategories are explained as separate entities, use of a paradigm model allows the researcher to make links between the subcategories and the main phenomenon. The nature of the paradigm model is such that the data can be systematically analysed and related in complex ways that include variables related to cause, context, conditions, action or interaction, and consequences (Strauss & Corbin, 1990). In this study, these slices of data are an integral part of the main phenomenon, **information gaps.**

Information gaps refers to a gap in knowledge, and often relates to the level of understanding between members of the group managing heart failure. **Information gaps** are not merely present at the beginning or during diagnosis of heart failure, but, because the condition is managed by various members of the group, can occur at any time. When cracks in the exchange or access of information between members of the group occur, gaps are created leading to the likelihood that the patient may receive less than optimum care. Because heart failure is generally a chronic condition, service delivery often occurs in the dual settings of primary and tertiary care. This means that the process of managing heart failure well, necessitates ready access to information systems in order to obtain updated information and specialist involvement, both in the hospital and in the community. It is of vital importance that the patient and /or their caregiver understand what heart failure is. Information is critical in order to facilitate good symptom management. Therefore, any interference to the smooth flow of information has the potential to impact on patient management.

In this chapter it is argued that when a group manage heart failure, there is the high possibility of an *absence of a cohesive group* occurring under conditions in which *changing funding structures*, impact on care in a context where *boundaries are merging* as acute care and community care are integrated. Everyone concerned in the heart failure management responds by *alerting others* as they try to rectify the **information gaps,** but when gaps in information persist, people are left *out of the loop,* and poor symptom management is more likely to occur, and **information gaps** are perpetuated. The loop in this study is comprised of information relating to heart failure and the members who both send and receive it. Indeed, if the loop is able to be activated so that people are *in the loop* information is shared and the chances for better heart failure management are more likely. The impact of effective heart failure management for the patient means that although heart failure as a chronic disease is limiting, it is still possible in many cases, to improve quality of life and longevity. This is possible as long as health professionals appreciate the importance of information sharing when acute care episodes are replaced by chronic illness that necessitates different forms of clinical management.

Table 2

The categories and indicators of information gaps

Information Gaps

Axial Coding	Category	Indicators
Cause	Absence of a cohesive group	Differing understandings, and interests, lack of close contact, last resort, breadth of access, time, no reinforcement, not talking things through with patients, having a different focus, not sharing care, not meeting regularly.
Conditions	Changing funding structures	Attitude of expense, socio-economic issues, being unable to afford, reimbursement, health planning
Context	Boundaries merging	Fields, barrier, flexibility, self-management, expectations, local contextual determinants, persons need for services
Actions and Interactions	Alerting others	Ringing for help, being concerned, proactive responsibility getting the message across, producing guidelines and booklets to foster standardisation of practice, bridging the gap in treatment management, discussion, checking
Consequences	Being in or out of the loop	Being unaware, losing to follow-up, a gap, not being included because of skills, not having a tag, working the system

Absence of a cohesive group

Absence of a cohesive group is a term that explains the cause contributing to the main category, **information gaps**. According to Strauss and Corbin (1990) causes are the events, incidents, and happenings that lead to the occurrence of the phenomenon. When heart failure management was explored with the participants, many discussed how varying degrees of interest in heart failure among members of the group contributed to what sort of information was exchanged within the group. The degree of information exchanged influenced the cohesiveness of the group. As indicated by the data, it is probable that differing expectations regarding information exchange influence what input the patient receives from health professionals managing heart failure. Information shared was variable. Whether the patient understands the information, and acts upon it, was also variable. The indicators of *absence of a cohesive group* were differing understandings, and interests, lack of close contact, last resort, breadth of access, time, no reinforcement, not talking things through with patients, not sharing care, having a differing focus, and not meeting regularly (See Table 2, p. 66). Clearly the *absence of* a *cohesive group* affected **information gaps**.

> *...the interest in the participation from the GP section of the group, was not as great as our expectations of them in the sense that they accepted our letters, but they didn't interact with us if the patient had any particular problems. Whereas, some GP's, in certain circumstances, if they had any concerns about the medications [or] the patients condition, they didn't hesitate to ring up our clinic. (Stephanie, p. 30)*

Such variable behavioural patterns are not particularly unusual. Whitworth (1995) discusses groups, cohesiveness and decision making in the field of computing, and notes that the group cohesive effect is dependent upon individual identification within the group. Producing the right answer may be ineffective if members lack the confidence to implement it, or if there is opposition from colleagues. Although the heart failure setting within the health care arena is not the same as that of computing, the above holds true as both patients and health professionals alike seem to have trouble accepting what are considered by some to be foregone decisions, especially regarding medications. Certainly, Pearson and Peters (1997) note that although ace inhibitors have been proven to extend both quality and length of life general practitioners are not prescribing them according to the recommended levels. It would seem that it is very difficult for a general practitioner to do so it there is an *absence of a cohesive group* as the possibilities for discussion with colleagues and information sharing are minimal. In the hospital setting however, medications are adjusted much more easily.

> *...in the hospital they increase their ace [inhibitor] if their creatinine is moderately abnormal, whereas the GP is not comfortable to do that. (Jane, p.34)*

When backup and co-ordination among the group is not apparent, treatment is affected. Time influences opportunities to share information.

> *...we probably should sit down and have a meeting with the cardiologist ideally every week or two, where we actually manage to have twenty minutes with them instead of a question on the stairs. ...I suppose it's a matter of making the time. (Jane, p.37)*

Time shortages impacted on hospital and community co-ordination, and, the *absence of a cohesive group* meant that the patient was not managed by a team once the initial post-hospitalisation check was completed. This influenced the information exchange, the overall patient management and prescription management, in particular. Although reasons for the low prescribing rates by general practitioners are uncertain, there is little doubt that the lack of close regular contact to check on how the patient is tolerating the dose in the community influences patient management.

> *Patients are predominately cared for by their GPs, and don't have close personal contact [within the hospital clinic] after the initial post hospitalisation check up. (Stephanie, p.28)*

Despite the declining contact, in fact there is an attitude of reliance upon hospitals by some health professionals. It is possible that the hospital emphasis on specialist knowledge means that general practitioners have **information gaps** that influence heart failure management.

> *Definitely [the general practitioners] rely on the hospital [for specialist advice] once the patient has been in hospital. (Marion, p.34)*

However, because there is not a *cohesive group* managing the patient with heart failure, it takes a lot of perseverance on the part of some member of the group when it is necessary, or advisable, to get the patient referred back to those who do prescribe specialised treatment.

> *I asked our cardiologist the other day about a patient getting back on an ace [inhibitor ...the patient had] stopped it ... I asked [the patient] to go to his GP, [who] said "Oh I don't do that without the hospital." So the hospital said, "No I wouldn't do that without [the specialist Hospital saying]." So I asked our cardiologist and he said, "Yes, tell him to go back on 2.5mgs, the lowest possible dose." So [the patient] went back to the GP and still the GP said "No I'll send you to the hospital clinic." So we brought him in to say the same thing... .(Jane, p.36)*

Follow up arrangements also tend to perpetuate a *non-cohesive group* that is not exchanging information frequently. As a result, when **information gaps** become evident, patients will turn for advice to those they have come to know well over the course of time. Although the person from whom advice is sought does not always have expert knowledge, any offer of help, even though it maybe unhelpful in the long term, is appreciated. When bio-medical support from an informed health professional is absent, informal lay support is often sought, as the need for information, any information at all intensifies.

> *I went to see an old friend of mine who was a nurse and she said to me "No wonder you are having heart problems with all these pills," and she was basically my last resort. (Ernest, p. 41)*

In some situations, there was not a great deal of interaction or follow through on what each member had said. The **information gap** tended to deepen when explanations were given by many individuals but not reinforced collectively across the team. Participants spoke of differing understandings amongst the group about the disease process and the outcome of heart failure. Several participants noted that while some patients had had heart failure for years, much time had passed before they had finally understood this disease. Sometimes, because the patient has had no opportunity to interact within the whole group, to explain that they do not really understand, patient understanding is mistakenly assumed.

> *When someone has had heart failure for years [we need] to finally [make time for them]. Some one has actually sat down, and they say "You know no-one has ever actually told me much about it," when they have had it for years. (Marion, p.33)*

While information processing is undoubtedly affected by the patient's readiness to cope with new information, **information gaps** are more than likely in the *absence of a cohesive group* when information is not shared.

> *I mean if the practice nurse [could do] that, exactly what we are doing, just reinforcing every time they see their patient [and asking], "Are you aware when you need to come back to the GP?" Tell me why you would need to come back to the GP. (Jane, p.36)*

Understanding needs to be checked out if **information gaps** are to be avoided. For example, the pharmacist discussed how understanding affected symptom management. However, members of the group appeared uncertain whose responsibility it was to explain each important part relating to heart failure, and therefore understanding may be compromised.

> *They don't understand that they are taking [that drug] as a preventative, to prevent the lungs filling with fluid. They don't understand that it is a preventative keeping them alive....I don't know that they understand that, so I don't know where that needs to come from. (Amanda, p.8)*

Advances in understanding the pathophysiology of heart failure have largely occurred as the result of the findings developed from clinical trials. However, the bio-medical emphasis on understanding the disease process, means that very often health professionals fail to understand how the patient experiences illness and sickness. Even though knowledge is increasing, if knowledge management is poor, it may not be passed on to the patient.

> *...if you look at trials, people don't survive long. Like for instance [there is] a 5 year survival.... We don't really talk that through with patients very well....We didn't really know that it was such a poor prognostic condition until we started doing all the ace inhibitor trials. (Sue, p. 17)*

In contrast, when patients had access to good group interaction, where people could talk through their ideas and experiences, a cohesive functioning group developed and information was shared readily.

> *They thought through their ideas; they were encouraged to talk and say what they had experienced and how others managed their drugs and how others did things... .(Joyce, p.4)*

Such meetings were arranged as part of a specialised heart failure programme, but are not typical of heart failure service delivery within New Zealand. The patient, who initially had experienced a complete absence of group support, appreciated the benefits of regular liaison when it eventuated.

> *I feel that I have had benefit from these meetings with people and so on and the fact that my health seems to have improved, seems to have been put down to these people. (Lance, p.5)*

Clearly, group members have differing foci, and different roles, even though their combined aim is to improve patient management. There is a challenge here because diagnosis is often difficult, and co-ordinating care for the patient is fraught with problems and requires many health professionals to be involved in ongoing management. Although there is an implicit expectation that the team will work together for the best patient outcome, pooled knowledge on a complex disease often does not occur. The absence of both a cohesive clinical structure and a co-ordinator of care perpetuate **information gaps,** and means delays and neglect in some circumstances.

> *In the community, people may go to their GPs with shortness of breath, and it's much harder for GPs to diagnose. Its hard to get the examination, the examination is not very accurate particularly if the patient has got lung disease....we also know that GPs are missing a considerable number of people who have left ventricular dysfunction and would benefit from ace inhibition and they aren't diagnosed. Either they don't have symptoms or they do have symptoms but they are labelled as having something else....Cardiologists are much more treatment focused...[they] concentrate a lot on the pharmaceutical management and neglect the social side of it. GPs probably spend more time on the social side of it, and the trouble is they may neglect some treatments. (Sue, p. 20,21)*

Integrating the complex dimension of patient management is challenging. The long term relationships that people once shared with their general practitioner or other health professionals are often a thing of the past, as society in general becomes more transient in nature. It is probable that this influences how much knowledge is shared between the patient and the health professional, especially as the busyness of life limits time. When patients are not known well, an *absence of a cohesive team* means that follow-up is problematic.

> *Well, in a really busy pharmacy it's really difficult to look up on the computer and go, oh Mr [a patient] hasn't been in for his scripts lately, because a lot of your patients are transient and so they don't have that and go somewhere else. (Amanda, p.8)*

However, when long term relationships exist and where personality traits, family and lifestyle are known, it is more likely that there will be a cohesive functioning group, because of the knowledge shared over the years. Shared knowledge has the potential to extend understanding and thus improve patient management. A general practitioner discusses his patient:

> *In fact it would be thirty years since I have known them....He is an ex bank employee...he trusts the person...[he is a person who is] caught up in the system of discipline. (Graham, p.10)*

Absence of a cohesive group emerged as a distinct subcategory of **information gaps**. Heart failure is a disease that is difficult to diagnose, and requires both community and hospital specialist service involvement in care. Clearly, heart failure is being managed in a fashion despite infrequent meetings, and differing interests and skills. However, co-ordinated care seems to be occurring more by good luck than by good management.

Changing funding structures

In the paradigm model, Strauss and Corbin (1990) argue that the conditions are those that facilitate or constrain the strategies taken. *Changing funding structures* is a term that refers to the conditions, the structural variables such as funding issues and technological change, which impacted on **information gaps**. The indicators of *changing funding* *structures* were attitude of expense, socio-economic issues, being unable to afford, reimbursement, and health planning (See Table 2, p. 64).

Frattini et al. (1998) argue that costs, that is financial aspects, and implications, are closely related to the management of heart failure. However, some participants in this study did not emphasise funding to the same extent. While reasons for this are uncertain in such a small study, financial indicators were certainly present in the data.

Even though some patients have access to specialised heart failure services, others do not. In one case a specialist clinic was funded through participation in clinical trials, while, in others, funding occurred through a funding authority. The *changing funding structures* of the health system within New Zealand affects the types of services that are available for people with chronic medical conditions such as heart failure.

> *...if they had an acute exacerbation of heart failure within office hours they had the understanding they could ring us anytime... Financial reasons often meant that people rang us instead of their GP, and we were funded for those calls. (Stephanie, p.32)*

Access to services and access to information are inter-related. *Changing funding structures* influence service delivery and are aimed at improving current services in terms of cost effectiveness and outcome. Cost constraints affect the care that is sought and provided for patients. Both contribute to **information gaps**. In particular, some patients who need to see a doctor think twice, regardless of whether they are subsidised or not.

> *I think it's just the attitude we have got. Of course now days there is an attitude of we don't go to the doctor because they're too expensive. (Ernest, p. 43)*

The nature of heart failure means that if people do not access or are unable to pay for general practitioner visits, early help may not be sought, leading to the frequent admission scenario.

> *This leads to a large social component to the reasons people get admitted over and over again....They may not pay for GP visits, so it might be difficult for them to get help early. They miss their scripts, if*

> *they are not complying. Plus [there are] socio-economic issues too if you can't afford prescriptions, so [we must] make sure people are on the right benefits, if they are entitled to them. (Sue, p.21)*

Although *funding structures* have changed, the delivery of services has altered little. The backstop in the New Zealand community dealing with heart failure is the general practitioner, who is funded per patient visit. Because the funding structure benefits the general practitioner it is less likely that the practice nurse will see the patient. Sharing care has not yet emerged as a viable option.

> *...in this country, whilst you still have got fee for service, unless the general practitioner sees that patient the general practitioner doesn't get reimbursed for the patient coming out. So the incentive for the practice nurses to build up their skills to see and assess these patients isn't there... .(Flo, p.46- 47)*

Economics affects the time that health professionals are able to spend educating patients and rectifying **information gaps**. If *changes in funding structures* were to better support nurse practitioners, patient time with doctors may be reduced and the outcome of information sharing may change.

> *...talked about doctors getting involved in education and they would spend half an hour educating the patient, whereas the practice nurse would spend three hours, and the nurse practitioner would spend three hours, but the outcomes for the nurse practitioner were always much better than what came out of their half hour sessions [with the doctor]. And then you start getting down to the whole economics of it....And maybe that [hourly rate] changes if you have a nurse practitioner who is paid [highly]...maybe they will start halving their sessions and start having the same outcome, as the cardiologists. (Flo, p.51)*

Outcomes are unpredictable because heart failure is a disease that is insidious. Accurate diagnosis is critical and very often reliant on expensive technology. *Changing funding structures* seem not to have fostered or kept pace with changing technology.

> *I think a lot of people say that it is very difficult to diagnose heart failure correctly ....Echoes [are more effective but] are more expensive than [physical] examination. (Sue, p. 20)*

Constraints on diagnosing occur because general practitioners need a hospital referral for an echo. These constraints maintain **information gaps**. Technological changes in diagnosis mean that funding is important in the diagnostic stages to instigate the right treatment early on and also to educate and rehabilitate those with heart failure.

> *...and GPs often can't get an echo without a referral from a hospital or a specialist which often with the breadth of access there is a delay. (Sue, p. 20)*

Funding structures have the potential to block a coordinated approach to health service delivery because providers are funded per patient. McCann (1996) suggests that, in terms of cost, case management may prove to be the perfect framework for the future, as it averts duplication and fragmentation, and encourages the integration of patient demands and the health system. Coordinated care through case management introduces the possibility of a service that would be useful for high risk chronic disease conditions, however, this approach can be be expensive.

> *Case management in certain areas is very very good because we do need to move towards a more multidisciplinary approach, because people with an overview [are needed] so they can see all the professionals who are involved or need to be involved. The problems are that it is expensive....[It is really] a sort of health planning question. (Sue, p. 23)*

It is quite clear that the rehabilitation strategies and focus in heart failure management are changing as funding is altering. In order to be in a position to distribute information that promotes rehabilitation in heart failure, the funding structures need to be managed to the best advantage. Rehabilitation services that focus on effective mainstream treatment, are important. Community support is expensive, however, when it is missing, as a result of *changing funding structures*, **information gaps** are more likely to occur.

> *...and as you know that funding dried up with the change in [a pharmaceutical funding regulatory body]. So we were left fighting the [funding authority] to continue, and they funded us last year and we just got funding this year. We provide education, so patients can understand about their condition. (Jane, p.33)*

Changing funding structures means alternate options are being explored.

> *A drug company approached us...and said they were prepared to fund rehab for heart failure, and of course they would want something in return... .(Marion, p.33)*

In summary, where there are *changing funding structures* occurring in health service provision, socio-economic issues also play an important part in the quality of access to services. Competition for services requires careful health planning in order to provide the best service so that patients can understand their disease, and how to manage it well in order to prevent the frequently unnecessary readmission scenario.

Boundaries merging.

According to Strauss and Corbin (1990) the context refers to the particular set of conditions within which the actions or interactions take place. In this study *boundaries merging* refers to the context that the group acts in when managing heart failure. Health service delivery depends on various health professionals performing different roles in different contexts. Guyett (1999) argues that organising care for a patient with heart failure is both challenging and crucial. Efficient, effective patient management becomes even more complicated when role changes occur as *boundaries merge.* While some aspects of the role redefinition may be well understood, and working well, other aspects of each other's roles may be forgotten, or not considered. **Information gaps** can occur when breaks in information flow occur when roles change. Consequently, patients may not be benefiting from the advanced knowledge that is available if it is unable to be tapped and understood by all. The indicators of *boundaries merging* were fields, barrier, flexibility, self-management, expectations, local contextual determinants, and the need for services.

Support was considered both a necessity and an integral part of good quality care. This was particularly so when roles were of a specialist nature and relatively new. In some areas, boundaries between primary and secondary care are beginning to merge. When *boundaries merge* care can be improved, but an integral part of that merge is the role of the specialist heart failure nurse. For example, the nature of the merge means that more time can be spent with patients at a time when their readiness to learn can be fostered.

> *From what I experienced in [another hospital], the heart failure nurses, were very well supported by the cardiologists...and they had taken their care of the patient to the level where they would actually communicate by letter to the GPs and so they were seen as an integral part of that care. So [perhaps] that's because they were really well supported to do that. And [they have] I suppose, a history of running these clinics at the hospital, for the heart failure patients in the community with a totally different set-up...the barriers and the boundaries weren't there between the tertiary and the secondary and the primary [sectors]. (Flo, p. 48)*

As *boundaries merged* patients had to adapt in the course of surviving their heart failure.

> *As I've aged I've had to make adjustments, learn new skills and reassess how and when to do things, learn about strategies and boundaries in order to survive ....You learn about boundaries. (Ernest, p.44)*

Expectations appear to be changing across the whole health care system. Contextual change certainly affected the nature of group interactions. When health professionals have specialist roles, if role expectations are uncertain, gaps in treatment can appear. Equally well, improvements are possible when boundaries between roles merge, such as improved co-ordination of tests and drugs. Specialist service delivery supported changing roles when *boundaries merged.*

> *I think that as we are merging more, we are looking at blood tests and looking at their drugs, and those sorts of things...so you [nurses] are merging more with the doctors. (Marion, p.36)*

Understanding of specialist/generalist knowledge was also affected in this context.

> *GPs probably spend more time on the social side of it and the trouble is they neglect some treatments. Also they have less concentrated knowledge about some fields particularly the general view about lots and lots of different sorts of general medical problems. (Sue, p.21)*

Teamwork is increasingly accepted as an essential component in the practice of modern medicine. In certain circumstances there is a lot more flexibility among team members when suggesting treatment options. In former times the patient did not often suggest drug treatments to health professionals. Increased access to information, today means that lay people, and the patient, can overcome the **information gap** by suggesting changes to the existing regime if s/he believes s/he is not on recommended therapy.

> *At the same time this man* knew *about ace inhibitors and he had read the magazine...he kept thinking and discussing...and he wanted to give it another try. (Jane, p.36)*

In some cases the *boundary merge* between patient and health professional means that the patient may prompt reinitiating the drug treatment that is vital for managing their heart failure effectively.

> *...there is a lot more flexibility with suggesting something or other. (Marion, p.36)*

At the same time patients are expected to be able to adjust their medications to a certain degree and, in most cases the team managing their care presume such an understanding. For example, patients weigh themselves in order to judge whether they need to adjust a diuretic such as frusemide. When *boundaries merge* there is often no longer a clearly defined patient or health professional role. To a certain extent, an implicit emphasis on self-management exists, although some patients are reluctant to merge their patient role with a more involved role in medical management.

> *One of the most difficult things is doing the weights and doing it well. For a number of years as I've got used to my patients, over twenty years, one of the most difficult things is making people [weigh themselves] and making them call. (Graham, p.12)*

When *boundaries merge* and expectations health professionals and patient have of each other change, the partner may sometimes become involved as well and assume a stronger informal caring role. In some instances, participants recognised that those who have strong back up with a supportive partner, were more focused on their care. Caregiver support thus appears critical, as social services are lacking in the community to provide important social backup. As *boundaries merge,* those with heart failure who live alone progress less favourably compared to those who have close support. In addition, Rideout (1992) suggests that for patients without supportive partner back up other confidants are less effective substitutes.

> *I think it's because [the family] keep people focused because they are wanting to stay well... There aren't the social services out there for those patients [who live alone] and ...[those that live alone] have not been particularly interested in getting to them. (Helen, p.30)*

Health professionals spoke of not realising the contribution made by the patient's partner in the home situation. Understanding each other's role is not always complete, which means that when *boundaries merge*, very often, some aspects of the merge are not fully understood.

> *She obviously does much more for him than we ever appreciate. (Sue, p.19)*

However, the general practitioner still remains the backstop for all patients, because, when *boundaries merge,* knowledge of advances in treatment must be balanced by experience. In effect, the general practitioner is working within the difficult situation of balancing specialised knowledge with the fundamental reality of life in the community.

> *Treatment today is far better than what it was ten years ago. In fact there has been a very fine improvement in the presentation of the disease...but you are lucky if you can get five percent [of patients] ... following on [with daily weighs]. (Graham, p. 12)*

At the same time, cultural contextual determinants within New Zealand are particularly relevant to heart failure management. The high incidence of heart failure in Maori and Pacific Island groups means that ethnicity and socio-economic status determine people's needs for service delivery. Cultural issues cannot be ignored, but must be examined as a contextual aspect when roles merge and standardised care programmes are implemented.

> *What may work for some people may not work for others. So it's got contextual determinants that are local. For instance, here we have in New Zealand lots of Maori and Polynesian groups, and they are quite*

> *different to white European New Zealanders. It's much more difficult than it appears, and maybe we ought to concentrate on that sort of thing like ethnicity, socio-economic level and how that determines peoples needs for services. (Sue, p.22)*

Thus, it is evident that multiple contextual realities exist and must be recognised if heart failure is to be managed effectively and efficiently.

Alerting others.

Interactions are described as being those factors directed at managing, or responding to a phenomenon as it exists in context (Strauss & Corbin, 1990). In this study, a*lerting others* refers to the strategies the group used as they responded to the **information gaps** that emerge in managing heart failure. They managed this successfully by becoming actively involved and *alerting others. Alerting others* takes the form of various actions. Although the actions are not referred to often as actually *alerting others*, the intent is implicit in the data. The indicators are ringing for help, being concerned, proactive responsibility, getting the message across, producing guidelines and booklets to foster standardisation of practice, bridging the gap in treatment management, discussion, and checking.

One significant aspect of *alerting others* included being checked out by the doctor. In most cases the doctor was alerted to a problem by phone contact. Wanting to be checked out was viewed as an alerting action that occurred because there was concern or worry about the patient's condition. In particular, being alert meant watching for signs of worsening heart failure such as an attack of breathlessness or sudden weight gain. By being alert to these symptoms some patients and/or their partners recognised that attention was needed. They also knew who to contact.

> *Quite often with him, his wife will ring up to say if he has any problems like increasing shortness of breath....She is also the type of person who alerts the doctors in the clinic if he is getting symptoms that she is worried about. He may put up with them, but [his wife] will ring up and say "he's not so well and she is worried. (Sue, p.16)*

Partners were very often sensitive to the subtle changes in health status and were ready to take action as required.

> *I think there was one afternoon when he got a bit breathless....I made an appointment to see [the GP] on the Friday...I couldn't make an appointment on Thursday so I made one for the Friday and that was before he came to hospital. I rang [the GP's] surgery and they couldn't get him in, but I said that I wanted him checked as he got over his breathlessness fairly quickly, so I just said I'd like to have him checked. (Joyce, p.1, 6)*

Participants spoke of appreciating being able to gain immediate access by telephone to the specialised centre at the hospital if they needed to. Benefit and improvement were noted as the result of meetings at the hospital heart failure clinic. A key factor influencing good heart failure outcomes therefore appears to be a supportive partner, who will ring for help if concerned.

> *The only thing I got a little worried about once was that he seemed to be losing a lot of weight, and I thought well now is it fluid or is it something else. But of course if we are concerned we can always go and see the doctor....I can always ring [the GP], or I can ring here, but not everybody has that privilege of ringing [the specialist clinic]. (Joyce, p.2,6,)*

Some patients could differentiate between symptoms that required immediate attention and those that could wait until later for people to be alerted.

> *Its just that shakiness at walking that I might apply to heart failure....I don't know at all....it just happens....I just carry on regardless and hope for the best. (Lance, p.4)*

Regular check ups provided a certain sense of security in chronic illness. Some patients relied on their general practitioner alerting them to changes in their health status.

> *He examines me and checks my blood pressure and so on and I feel I achieve something by going to him. (Lance, p.1)*

Furthermore, the maintenance of good health was associated with wide-ranging health measures.

> *He has kept good quite good health ....I think that regular checks have got things sorted out fairly quickly and kept the best of diets and otherwise looked after themselves with long holidays and the trips [away]. (Graham, p.10)*

Very often the check ups happened on a regular basis, although in some instances the doctor would alert the patient that it was time to be seen again.

> *Well my doctor, will contact me through the nurse on the phone.[He will say] "Its time you saw me again," and we'll have a chat and that's the way it goes. (Ken, p. 53)*

It is suggested that an important aspect for heart failure patients is ongoing support and encouragement because of the chronicity of the illness. In particular, key support, such as someone to listen and advise and not just treat physical symptoms, was discussed. The nature of heart failure means that there are often complex medical conditions present. Therefore, the group managing heart failure are required to be confident in their ability to recognise when to refer on to others for expertise. 'Referring on' is also an aspect of *alerting others* to the fact that more knowledge, help, or advice is needed.

> *...our cardiologists are quite good in referring on to other specialities. (Stephanie, p.29)*

Being able to *alert others* has an element of self-empowerment and control which requires forward planning ability. It was suggested that the perception that the patient has to stay well, to keep up with their spouse, or to have a family focus, is a motivating factor in staying well, and therefore a motivating factor in *alerting others.*

> *Perhaps you need family to stay focused. As you get older the patients who have lived alone haven't really done as well as those who have family who are more concerned with their progress. (Helen, p.30)*

As circumstances of daily living change, checking and forward planning are required. Health professionals who know their patients and their partners well are better able to respond to individual needs, when they are alerted to changes in circumstances such as when a trip away is imminent.

> *As you get to know a patient better, you are able to tailor the needs ....psychologically, him not being able to travel, him not being able to*

> *do that, will enter into the perception that keeps him really well, he has to be well enough to keep up with her really. (Sue, p.16,18)*

When needs are individualised, specific warnings can be given and heeded.

> *Well you see when I first had this problem, I was booked to go on a trip [away], and I was told no you can't go...[and I had to] cancel it. And then some time [later] when I came in again, [a doctor] said, "Well I think you are fit enough now to take that trip to [away]."....But I had that checked before I went. (Ken, p.53)*

Individualising heart failure management is somewhat at odds with the political drive to standardise patient care. If health professionals do not know their patients, any move to standardising practice in the community will not necessarily solve the information problem. The literature shows that physician compliance with consensus guidelines for heart failure management are sub-optimal (Rich, 1999). In this study, data highlights an absence of an overall standard of care. This means that when someone who is unfamiliar with patients takes over care, they need to be temporarily alerted to the standard of care because unfamiliarity with patients and the system affects **information gaps** and subsequent decision making.

> *So [I'm] not quite sure how he got into hospital on that particular occasion and I think it might have been through a locum. In this day and age you would not have thought that was required...[All he needed was] a minor adjustment in his therapy. (Graham, p.11)*

Even when guidelines for standardised management exist, if the health professional does not have that information, they may be ignored. This may occur because New Zealand guidelines on the management of chronic heart failure provide recommendations for average patients (The National Heart Foundation of New Zealand, the Cardiac Society of Australia and New Zealand, and the Royal New Zealand College of General Practitioners Working Party, 1997).

> *...and the guidelines are still not being used by General Practitioners which is a problem not so much for the GP's its probably the whole area around implementation of guidelines. (Flo, p.47)*

Despite the fact that general practitioners may have been slow to integrate guidelines into their practice, families gathered as much information as they could and took their responsibilities for *alerting others* very seriously. Actions in staying well that had been taught to the patients, and often their partners, were based on knowing when to *alert others*. Every day actions at home, which became part of a routine, included: watching weight, supervising the situation, and adjusting drugs.

> *What we do is, as we have the washing machine and drier in the bathroom, the books [heart failure diary] stay on top of the machine with a pen, and every morning when [my husband] goes out to have his shower he weighs himself and writes it in and I do the ticks and I check it like that....Having something to do and think about each day I think is good, and I do think that weight is the only way you can tell. (Joyce, p.2)*

Very often a partner takes on an active role in decision making, *alerting others* when necessary. In this respect, a partner helps to manage the patient.

> *[His wife] is there and she is managing him making the right decisions. (Graham, p.12)*

When a patient has confidence in the doctor, and a good doctor patient relationship has been established, it is easier for the patient to redress the **information gap**. A health professional who is familiar with a patient and takes an interest in their condition, and knows what to do, will be more likely to be alerted, enabling appropriate action to be taken.

> *[The doctor] said "Right! That's it. Now if you have any problems don't hesitate to ring me." And that's good to know, if you have any doubts you can ring...because she wants to know all about what is happening, and they know what is supposed to be done. (Ken, p.54)*

In summary, clearly, *alerting others* was one way to overcome **information gaps**, to share information, a critical factor for the effective management of heart failure.

Being in or out of the loop.

Strauss and Corbin (1990) refer to the last component of the paradigm model, the consequences, as the outcomes or the results of actions and interaction taken in relation to the main phenomenon understudy. The outcome of *alerting others* is either *being in or out of the loop.* In this study, the term *the loop* refers to the group of participants managing heart failure, and the information that is both sent and received by them. When interactions between group members such as *alerting others* fail, or do not occur, information may bypass some participants. This leaves those participants *out of the loop.* As a consequence, either some or all members do not receive the information, and therefore, the management of heart failure is not as good as it would be if everyone was included *in the loop.* In this respect, symptoms of heart failure are either managed well, or managed poorly, depending on whether participants are *in or out of the loop. Being in or out of the loop* can affect any member of the group managing heart failure. The indicators of this category were, being unaware, losing to follow-up, a gap, not being included because of skills, not having a tag, and working the system (See Table 2, p. 66).

Being out of the loop may result in situations when there are **information gaps,** and information is not communicated to all team members. If specialist knowledge is absent it tends to exclude those health professionals from the information loop.

> *...the practice nurses were unaware that these patients were rebounding back to the practice or back to hospital because they were out of the loop, and out of the loop because they actually didn't have the skills to assess the patient ....they did not have the skills to assess the patient so they just withdrew. (Flo, p.46)*

Losing to follow-up is also an aspect of being *out of the loop* in the long term continuity of patient care, and reflects the lack of communication and information channels in patient care.

> *A lot of patients with heart failure die sudden cardiac deaths in their own homes, from say ventricular arrhythmias, so the cardiologists or doctors looking after them [don't know]. They are not following them closely ... obviously we know when our patients die, but in the hospital you might not know, and so you just sort of forget about them. And you don't realise that all your heart failure patients you're not seeing is because they are dying at home if they have got bad heart failure. So [the patients are] losing to follow-up basically. (Sue, p.18)*

Although heart failure usually has a poor prognosis, this can change for reasons that are not fully understood. This means that when death is presumed imminent, the patient is left *out of the loop*. But, if perchance the patient rallies and survives, that information is lost to the team as there is no follow-up.

> *We have not got a tag on CHF...he was sent out of hospital with a poor prognosis really to come back [to the resthome] to die ....he has fully recovered. He really was given a death sentence when he was discharged from hospital. You just wonder what happens with some of these characters. I don't think we have got a tag on CHF. (Graham, p.14, 15)*

At times, some of the health professionals involved in the care were not known well by the patient participants. From the client's viewpoint incidents occurred where they felt that their treatment was based on clinical knowledge, and that their individualised view of their illness was somewhat neglected, creating a significant **information gap**.

> *There is a big gap, this is one of the things that immediately came to mind ...using heart specialists, people training to be doctors but they are not given the advice that they need and are not getting education....because you are going on the clinical side of everything and not allowing them to expand their knowledge with patients. (Ernest, p.42)*

Although hospitalisation for an exacerbation of heart failure is sometimes necessary, in some cases the exacerbation could easily have been prevented if information was shared. In many cases exacerbation of heart failure is attributable to non-medical factors such as poor compliance with diet, or medications, rather than a decline in cardiac function (Rich, 1999). In these circumstances, episodes of exacerbation are most likely caused by a break down in case co-ordination. It has not been realised that some member has either not imparted, or understood, information relating to effective management practice in the community. It is suggested that informing, teaching, and encouraging ways of managing health is especially difficult when chronic illness must be managed.

> *Trying to get people to understand that it is a chronic illness that is not reversible seems to be a major problem, and trying to inform them, encourage them, teach them about ways of managing their*

> *health, and I suppose its the same with any chronic illness, is difficult... . (Stephanie, p.28)*

If patients do not have access to specialist heart failure clinics, the options are restricted. The practice nurse may be effectively blocked from *being in the loop* and may even be excluded altogether.

> *...the only options are the general practitioners and the practice nurse ...the general practitioners were loathe to include the practice nurse in the integrated task force on heart failure. They were loathe to see that the practice nurse had any potential for treating these patients or sharing their care. (Flo, p.48)*

Yet, when care is shared, this has significant ramifications for the patient. If someone familiar in the health care team is away, such as the general practitioner, there are professional replacements, but the care is unlikely to be the same. Although the patient visits the general practitioner to have physical symptoms alleviated there is much more to the relationship. Patients background personal information is not easily or readily available to temporary locums. This means that the replacement is therefore *out of the loop*, and the focus on tasks limits what can be done.

> *He thought I'd become a hypochondriac and that's when he gave me the prozac....Well they carried out their duties. There was basically nothing they could do physically for me when I came in....my General Practitioner was still away. (Ernest, p.41)*

Being in the loop is vital for effective symptom management. It improves access to information and readiness to learn about new treatments. Successful symptom management now means that people with heart failure are usually out of hospital and keeping quite good health at home. Many, are able to live longer, better quality lives. For those who have information about how to work the system to best advantage, the benefits of better quality of life are extensive.

> *He has got so much better it is almost unbelievable. Mind you, I would say that's the treatment. Whatever drug treatment he is having is obviously agreeing with him....they are keeping [him] stable. It's a chronic thing really and it's really just keeping [him] stable and treating the symptoms and signs as they come. But nevertheless, what they have done has improved [him]. We can do what we virtually like. (Joyce, p.2,3)*

It is suggested that in order for the patient with heart failure to have an improved quality of life, it is important to have someone with an overview of heart failure. It takes time to care and assimilate specialist information if **information gaps** are to be avoided. These factors support entry *into the loop.*

> *It's a horrible disease to have. It's very disabling, and I don't know that it is talked about in terms of how can we help you manage your symptoms in order that you can lead a better lifestyle. [It seems unlikely that] you're going to get that in a ten minute appointment with the doctor. You're not going to go to a doctor and say I want to talk to you about my quality of life. [However] a nurse who has got good education, and a good rapport with the patient will actually just keep that patient boarded up, or at least the spouse. (Flo, p.49, 50)*

Also having knowledge on health service delivery enables the patient and family to stay *in the loop.*

> *...and perhaps now she has a good understanding and a better way of not so much using the system but knowing how the system works to assist him. (Stephanie, p.26)*

All recent innovative planning defines measures such as guidelines, pathways and clinics in an effort to address the **information gap**. It is possible that the role of those running the clinics is more important than the clinic itself. What health professionals do specifically, in terms of care, and the time that is spent with the patients, rather than the structure of the clinic, makes a difference. If health professionals want to be *included in the loop,* it is necessary for them to spend time and develop a keen interest in heart failure.

> *I really think it depends on the individual and some doctors see their role as strictly medical management and the nurse's role as more of a holistic kind of role in that they look at stuff around the periphery as well....Some GPs [take] blood pressure, pulse [and say] "You're fine see you later"....Well you have got the time to develop the personal relationships with the patients and they (in the clinic) have put a lot of effort into that and whether or not that translates into a real world kind of situation [I don't know]. In a busy practice, unless there is someone that has got a keen interest in heart failure that's only a part of what they do. And so whether or not [it] would attract as much attention as we give it here. (Helen, p.27, 29)*

However, in a poorly managed system, using existing channels may be easier but not necessarily up to the requirements of today's demands. Sometimes there is no attempt to reactivate *being in the loop* by instigating new specialists.

> *Spending time with these patients is important, but also what you do with the time...it seems that all the focus tends to be on the stuff that is tangible like the medications, but even that isn't actually managed properly. It's so tangible....My question always has been why do we keep looking at GP's, to solve the problem, when they have had years and years of it[supporting these patients]. It's about time that we actually looked beyond the GP and brought in other specialists. (Flo, p.50)*

Without the heart failure nurse, or the time to put into heart failure management to build rapport, heart failure management is destined to fail, no matter what guidelines are put in place. In reality, when difficulties occur at home, the patient or their partner has to make a decision to see a health professional. This requires ready access to health services and the ability to know when help is required to avert unfavourable consequences.

> *If you had a monitoring system set up where you have got the stability period....so as soon as this patient starts to put on two kilos of weight or is going on a flight and wants some information on how they can adjust their medication to tide them over....there are a whole lot of basic things that practitioners seem to pick up ....through having a good rapport with the patient....but you are actually catching it before you sort of have this advanced exacerbation of symptoms. (Flo, p.49)*

There are some people within the group of heart failure patients who will cope, no matter what the system is comprised of or what changes are implemented. This seems to be because they are financially secure and have a good social support system as well as being in a partnership where they are motivated, so they know when and who to contact for treatment as required. For some, the realisation of what heart failure means comes later, at home, in familiar surroundings, or when the patient has had time to consider what has happened, possibly due to *being in the loop.*

> *Didn't mean a great deal initially....I accepted and dwelt on it. At that stage it didn't mean a great deal ...Heart failure meant that my heart*

> *failed to function. It didn't mean a great deal to me at that stage ....Well yes I knew just what was happening to me. (Lance, p. 1)*

Findings suggest that home care was not the most frequent topic of advice. Similarly, a spouse spoke of her interest in the events that might happen at home with her husband who had heart failure. She also spoke of her interest in knowing and sharing knowledge, and her willingness to impart to others in a group setting, knowledge that she felt was important, but had not been discussed in the normal course of events with any member of the health care team. Sharing concerns in a group situation helped some people enter *the loop,* and by doing so, they could overcome **information gaps**.

> *When we were around the table with the people with congestive heart failure, they were telling us all about the drugs and that was really great, but I asked what happens if a person has a heart attack and what to do in the house....you know it is such a help trying to explain what might happen or could happen and what to expect and what to do ...but for me this is what I wanted to go over and I thought well you know I can't be the only one....I thought it was a great idea for people to be together, especially from the patient's point of view, because you know it makes them realise that they are not the only one....they were a super crowd. (Joyce, p. 3, 4)*

The complex nature and chronicity of heart failure makes it difficult for all concerned to keep abreast of the latest treatment. Information overload for the general practitioner means there is the possibility of being overwhelmed by the amount of information received on a daily basis, so that sifting of information is a necessity in order to work within the time constraints of the workforce. Although some have access to information, they may have too much, and when they are overloaded, they too are *out of the loop.*

> *GP's get so many general articles, and guidelines, and literature from the drug companies they just can't look through it all. (Sue, p.21)*

When the information keeps coming it is all too easy to move *out of the loop* as it is impossible to keep up with it all.

> *GP's are bombarded with new [drug] regulations, different drugs and the new levels to treat, the whole rigmarole, faxing to get authority forms. (Jane, p.34)*

In fact, it appears when some one is able to filter information there is less of an **information gap**.

> *...he probably sees her as expert and she can sort out all the stuff that he is exposed to...perhaps he relies on her to filter what he needs to know and what he doesn't need to know and look after his best interests. (Helen, p.26)*

However, not everybody knows all the answers, and when they are not *in the loop* and not receiving answers, patients sometimes seek other means.

> *Trial and error not getting put off and not getting disappointed because you can't find the answers....I persevere and try to find out by asking friends where and how to obtain information that is relevant and important to me. (Ernest, p.44)*

Overall for this subcategory, findings suggest that, within the heart failure management group, including the partner, neighbour, or health professional, may be the pivot for co-ordinating successful care for patients. If information can be accessed and dealt with effectively, there is more of a chance of being *in the loop*, and obtaining successful or better heart failure management.

Conclusion

From the data in this study, **information gaps** clearly emerged as the main phenomenon that affected the management of heart failure. Expectations of members often differ and, in situations where there is a lack of reinforcement of information between the group, and things are not talked through with patients, there is likely to be an *absence of a cohesive team*. Subcategories making clear links to the phenomenon of **information gaps** indicate that the reality of *changing funding structures* and financial constraints means time spent with patients is often limited. Uncoordinated care by any health professional within the group can lead to family involvement to overcome the gap, which may either help or hinder the good health of the patient. The context of *boundaries merging* affects roles, and creates an opportunity for new roles to develop. When the system works with a group member co-ordinating care and *alerting others* the **information gap** is not so apparent. When all the information is available it may not get conveyed from the health professional to the patient in time to prevent exacerbation of symptoms because some or all group members are *out of the loop*. In situations where relationships can be transient in nature, especially those between patient and health professional, **information gaps** become apparent. Although in some cases, the dominance of the bio-medical model of care is declining there is still considerable room for improvement if patient focused care is to occur.

The emerging phenomenon of **information gaps** clearly has some major implications for practice if health professionals are to implement measures to overcome the gaps. Data would suggest that a member of the group must effectively co-ordinate patient care across health services if improved patient outcomes is the goal. Access to information within the group is vital, and in some instances, reinforcement needs to occur between members so that understandings can be improved. Information technology clearly has an impact upon access to information and this also needs to be addressed.

The last chapter presents the conclusion of this study. The discussion of the significant findings will emphasise the two categories, *absence of a cohesive group,* and *in or out of the loop,* that emerged from the study. The researcher thought these were the most important categories to follow up in the management of heart failure when **information gaps** are present. Information management implications for nursing practice, and case management will also be discussed. This will be followed by an outline of the limitations the study and thoughts on areas for future research.

CHAPTER FIVE

Discussion

The aim of this study was to explain the main concerns of a group, comprising the patient, their partner and the group of health professionals, that managed heart failure, and how they continually resolved those concerns. This study demonstrated that **information gaps** are present in the management of heart failure. **Information gaps** was the main phenomenon, the main concern to emerge from the data and, as such, has major implications for the clinical practice of all health professionals who manage their concern in heart failure management by *alerting others*. The observation of **information gaps** is significant, as it has the potential to influence symptom management, and thus, impact on the patient's quality of life which is being balanced with the prevailing cost constraints influencing healthcare today. In this chapter, information systems and case management with a nurse specialist will be discussed as ways to reduce **information gaps,** and improve access to information. Significant findings, contextual issues related to information management, the implications for nursing practice, limitations of the study, and areas for future research will also be discussed.

Significant findings

In this study two subcategories of **information gaps** are of particular significance. The implications of the two sub-categories, *absence of a cohesive group*, and *in or out of the loop* will be discussed further.

Clearly, participants indicated that very often those with heart failure do not really understand their condition or what it means, for some time. This lack of understanding may occur despite the belief by health professionals that education on the disease has been given either during hospitalisation or post discharge. From the health professional's viewpoint, participants in the study indicated that often understanding of what happened when the patient was at home, such as the input that the partner had, or why people did not take medication as prescribed, was not really understood either. *The* *absence of a cohesive group* managing heart failure meant that information gaps were present. To overcome this **information gap**, some patients obtained information in the guise of advice and support from lay people who were familiar to them such as neighbours or friends, rather than from those with expert knowledge. Sometimes information given from non-expert sources was incorrect, and the consequences were that those with formally recognised expert knowledge were *out of the loop* with regard to being able to intervene because they were not alerted to the problem.

Results also indicated that when information overload occurs as the result of the availability of increasing data and guidelines for treatments, people do not access all the information, or even sift through it, and, thus do not always pass important details on to others. Sharing important patient details in a confidential manner among health professionals, and with the patients themselves is a necessary function of a *cohesive group.* When no one in particular coordinates care, a *cohesive group* is less likely. There is therefore, the likelihood that important information and potential may be lost. Reasons for information overload vary, but may occur due to a variety of factors including: limited interest, or time and financial constraints. Patient records and knowledge in regard to particular patients varied between health professionals, however, where there was a *cohesive group* working together, patient care was improved.

These findings support the argument that when a group does not work together in a cohesive fashion, people are left *out of the loop,* and patient care is compromised because incorrect advice is often the only information available. In these instances incomplete information is better than none at all even though the **information gap** persists. Often who and when to contact for full information is not fully understood by patients. Clearly, the flow of information is often impaired between health professional and patient. A discussion on the sending and receiving of information is warranted.

Factors related to receiving and sending information, which affect the cohesiveness of a group, are firstly, that of task and process, and secondly, that of communication. Communication is described by DeBack (1999) as being the "key to effective dialogue, exchange of information and knowledge transfer" (p. 212). It would appear that when there is an *absence of a cohesive group,* group functioning focuses more on a task than on the process structure. Communication and group cohesion are less likely to occur because the part, the task, rather than the whole, the process, is the group focus. Similarly, according to Hammer (1996) the difference between task and process is the difference between the part and whole. In a business sense a task is the unit of work, usually performed by one person, whereas process is the related group of tasks that together produce value in the form of delivered goods for customers. If this is transferred into the competitive environment of the health arena, the members of the group are often focusing on their particular task or speciality, and the whole, which is the groups' coordinated efforts, is often overlooked in the process of performing the task.

Some participants indicated that if members of the group were left *out of the loop* information was not accessed, available, or able to be communicated to all team members. In this study the term *the loop* is used to refer to the group of participants managing heart failure and the information that was both sent and received by them. Findings suggest that often there was so much information sent that it was not accessed or even sifted through to find the vital parts. On the other hand, group members often noted, that in relation to aspects of patient care, there was a lack of information received. Also, when interactions such as *alerting others* failed, or did not occur, information could bypass some participants.

As the literature outlines (Dracup et al., 1994), patients often do not adhere to their plan of treatment once discharged from hospital. Dracup discussed the reasons for this and suggests they include factors such as patients not being convinced that the treatment is beneficial, or not understanding what they are supposed to do or the rationale behind instructions they are given. The management of heart failure requires input from a large group of people because of the complex nature of the condition. Each member of the group has a specialist focus, whether it is drug management, diet, exercise, or counselling, however, as there is often no specific group coordination process the whole plan of care may not be followed well, or consistently, by each member of the group. It is suggested that each member of the group has their own particular outlook on health whether this is a disease, illness, or sickness focus (Radley, 1994). Differing understandings of how health, illness and sickness are viewed without any group process for coordination of views can result in impaired communication between members of the group involved in managing heart failure. Therefore, the management of heart failure into the new millennium needs to take a collaborative approach in which lay people, patients, family and health professionals work together as they focus on effective service delivery and best practice (MacKay et al., 1998).

Contextual issues

Without doubt, the contextual issues of limited resources, unlimited demand, an ageing population, government desire for increased equity in healthcare provision, and technological advances are a major influence on the way health care is delivered in New Zealand (Dixon, 1998). It can be argued that effective and efficient health service delivery depends on the information context. Rowley (1998) defines information contexts as including the forces of "sociological, technological and political forces as well as those of the information marketplace which are matters of pricing, intellectual property, social inclusion and exclusion, security and data protection" (p.365). The bio-medical model of health care has been a major influence on what information is regarded as important. With its focus on disease, this model tends to exclude patients from the information loop because of their desire to talk about the experience of the illness and their concerns with how sickness is experienced (Radley, 1994).

Even though, in the past, a focus on disease has worked it is argued that it is time to change to a more integrated model of health service delivery, especially when taking into account the contextual issues mentioned above which highlight the need for change. Today, it is increasingly acknowledged that ill health arises from more factors than a biological imbalance and, more often than not, it is socially determined (MacKay et al. 1998). Currently we are faced with a health service that is changing focus towards short term acute inpatient care complemented by a longer term community focus on chronic care. In these circumstances, services are more open to being disparate, and communication of information is more vital than ever before. Escalating readmission rates and burgeoning hospital budgets for heart failure are part of the reason that heart failure is being examined so closely.

It is evident that in health care service provision, a paradigm shift is underway. Rantz and Scott (1999) describe the old paradigm where "persons with chronic illnesses assumed passive dependent roles and accepted being cared for and treated by health professionals who managed their chronic illnesses" (p. 217). Furthermore, these authors propose that a new paradigm is now taking shape, where active roles are encouraged for patients, who are expected to assume responsibility for managing their illnesses through their own actions. But, health professionals need to change their behavioural patterns too. Patients need health providers who are prepared to focus on the task and process issues of service delivery and who are willing to regard new challenges as opportunities to integrate the lay perspective within the biomedical approach. Education is fundamental here.

Educative information is in fact essential and it is preferable that it be developed collaboratively with patients, families, and the health professionals who look after them. It may well be timely to identify the main concerns of lay professional interactions in heart failure education. Most literature on heart failure patient education focuses on one to one sessions, such as those between the general practitioner and the patient (Didsbury, 1997) and clinics (Erhardt & Cline, 1998). Literature also shows that studies that assess the effectiveness of education are scarce (Jaarsma et al., 1996). Therefore, it is difficult to be certain that a patient understands education given and if they do not, there is the risk that they will be *out of the loop*, and not managing their heart failure well, especially in the home environment. The best time to organise education sessions with patients appears to be variable. However, the findings from this study are similar to the nursing literature (Barella & Monica, 1998), in that follow-up and co-ordination of care at home, helps to create a better level of understanding for patients.

While education is an important aspect in heart failure management, effective co-ordination of all care requires collaboration by members involved in the care. Collaborative practice in a *cohesive group,* where members work together cooperatively, means sharing responsibility for solving problems and making decisions to formulate and carry out care, which allows for better patient outcomes in the providing of high quality health care (King, Parinello, & Baggs, 1996). King et al report that integrated patient records and a climate of trust and respect between physicians and nurses, in an inpatient setting, resulted in increased patient satisfaction and decreased hospital stay. It is more likely that when collaborative practice occurs important information will be shared and that this will add to the cohesiveness of the group managing heart failure, rather than information and potential being lost.

A major challenge for nursing is that when the client need is the central focus, professional practice needs to become collaborative and incorporate service accessing and co-ordination if cost containment is to be realised (Litchfield, 1998). This study on heart failure management demonstrated that in many cases **information gaps** between the group managing heart failure are the result of a lack of collaboration between members of the group. In particular, although all the information is there, it does not get to the patient in time to prevent an exacerbation of symptoms, so optimal therapy is compromised. As a result a cycle of events takes place, leaving people either *in or out of the loop* with regard to information access.

The concept of a loop is not mentioned in the medical or nursing literature on heart failure. However, loops are discussed in business information with reference to recognising that every action taken within a loop has a tendency to produce a movement in the opposite direction (Morgan, 1997). If loops are accepted as an integral part of information flow, Melody (1994) believes that internal institutions generate information that is also critical for individual decision making in an external environment. If the external environment is taken, in this instance, as being the community environment that the patient is discharged home to, often there is a gap in the loop of information flow between the two areas. Those managing heart failure patients in the hospital setting, the internal institution, need to recognise that co-ordination of this two-way flow of information is vital especially when the patient is managed across inpatient and outpatient service settings.

Although a treatment gap is seen as part of the problem in heart failure management, this pilot study has extended the gap to that of **information gaps**. It is highly probable that **information gaps** contribute to treatment gaps. Pearson and Peters (1997) argue that the treatment gap exists between recommended therapies for patients and the care that they are actually receiving. They have noted that it is not clear why this gap exists. What is clear is that rehospitalisation is common because of a lack of treatment adherence and patient knowledge deficits (Brass-Mynderse, 1996). For the most part, participants in this study indicated that while information is often there it is frequently not communicated in a meaningful way, or is not able to be accessed for some reason. If information then, is impaired, or not communicated well, the outcomes for heart failure patients are not as good, because their management is inextricably linked to the management of information itself.

In summary, in the bio-medical model of health care where disease is dominant, knowledge appears to be regarded as consisting of discrete parts. When knowledge management is reduced to the management of a series of isolated parts the potential for **information gaps** is high, as a synthesis of knowledge is necessary when managing patients with chronic illness in an uncertain, ambiguous context.

Information management and the implications for nursing practice

Drucker (1992) suggests that "very few people have information, what they have is data, and such quantities of it that it may cause information overload or blackout" (p. 347). This position is supported by participants in this study who indicated that they were sometimes overloaded with information, in the sense that they did not have time to access it. While the participants constantly referred to the sifting of information, this idea is not mentioned in the literature at all. Nonetheless, the sifting of information by various members of the team appears, from this study, to be essential to heart failure management. While the health professionals in the study had a good understanding of heart failure generally, they had to individualise information in order to manage the patient well. Some patients would take longer than others to understand their condition, and needed more time and input to become confident in managing their condition at home. Clearly, any member of the group managing heart failure has to be able to skilfully sift through information available so that access to important pertinent information is made easier and more individualised.

The need to sift information in the information age is not unusual. Rowley (1998) discusses the fact that information is now not as structured as in the non-electronic age, where paper documents allowed for presentation and production processes. Over the last twenty years, with the introduction of the electronic age, organisations and society have experienced more information from a wider range of sources, and a wider range of channels, which have faster response and turn around times. Rowley (1998) states that what we need is:

> to consider the competitiveness and effectiveness of individuals, increasingly dependent on their information processing and knowledge capacity, which means that there is greater focus on individual organisational and societal competencies in relation to communication, information processing and knowledge creation. (p. 362)

This has significant implications for nurses as health professionals because information technology and the increased flow of information do not appear to have bridged the information gap as effectively as they might have. This would indicate the need to have a member of the heart failure management team responsible for coordinating the transmission of information. Consideration of the team coordination role is important as it also raises questions of the responsibility for management of information. For example, MacKay et al. (1998) question how realistic it is to expect patients to be the centre of professional activity, accepting responsibility for some quite sophisticated management of their condition. Even though it is preferable that patients and their families be actively involved in the management of their heart failure, any over-emphasis on lay responsibilities should be considered carefully. It may be inappropriate for patients to assume such heavy responsibilities for a highly complex condition that the medical profession struggles to understand.

Rowley's (1998) point is critical to this discussion because her framework recognises the need to consider the individual, the organisation and the systems in information management. The framework consists of different levels on which information processing and, therefore, information management takes place. These levels are those of retrieval, systems, and context. While retrieval often occurs individually, in order to meet information requirements selection of sources is necessary alongside interaction of sources, either by phone or conversation. The systems are the tools that support the information processing of individuals or organisations, which, in the health arena, includes case management and information technology. Finally, as discussed earlier in the chapter, the context or environment is where information processing and management take place. The process that involves certain information to be communicated to all participants is explored through this framework, and examined in relation to communication.

The message transmission theory in communication is described by Leiss (1994) and consists of source, transmitter, signal, received signal, receiver and destination. This theory is also vital to this discussion because all of these factors reflect on how problems associated with a part or many parts of the message can develop. The transfer of information is definitely problematic.

This problem means that it is important that nurses, and all health workers, recognise that not all information shared or provided to others represents communication. Providing information or education on heart failure should be an aspect of most health professionals' roles, whether they are in the cardiology or the gerontology field. However, the data in this study was similar to the literature in that some health professionals are more suited to concentrating on imparting education to patients than others because of factors such as time constraints and economics. While all health professionals communicate with each other, and with patients and their partners the quality of communication affects how information is understood and used to improve the quality of life.

The link between information and effective communication is explained by Drucker (1992). He states "Information becomes communication only if the recipient understands and accepts it" (p. 331). It is vital that health professionals access information on heart failure so that evidence from randomised clinical trials can be integrated into practice (Cleland, 1998). However, the emphasis on task should not mean that process issues are given less attention. For example, some participants in this study indicated that a way in which health professionals could assist the transfer of information as knowledge, rather than as mere transfer of data, was to reinforce information previously given. This means that health professionals should recognise the importance of information processes. Another process issue is that patients should be offered the opportunity to regularly communicate their illness experience when given information by disease-focused health professionals.

The recognition of task and process issues in information management is even more critical when change constantly underpins patient management. The aspect of change incorporates all three factors (retrieval, systems and context) of Rowley's (1998) framework of information management. Change is, paradoxically, a constant factor in heart failure management, as improved understanding of the nature of the problem and ways to improve symptom management and longevity unfold. Therefore, access and acceptance of ongoing changing information on best practice, by all participants involved in heart failure management, is critical. Morgan (1997) proposes that a dialectical imagination allows us to embrace contradiction and flux, as opposed to the resistance to change that is likely to develop when thinking in lines. Because of the presence of treatment gaps and information gaps, new ways of dealing with information on heart failure by all members involved in its management is necessary. As interview data shows, when patients state that they do not understand heart failure, nor realise that they have been diagnosed with it after having had it for many years, clearly something has gone wrong in that particular information loop.

Another issue worthy of mention concerns knowledge workers and the nature of specialist knowledge (Druker, 1992). Druker proposes that, in business, the flow of information is both sideways and across department lines. However, despite this, sectors and departments are more used to reporting separately 'upstairs', and reported what 'upstairs' [management] had asked for. Today, however, sectors and departments have to think through information management and decide who they owe, and who they need information from. Consequently, all managers in an organisation have to know and understand the entire process, not just their particular task, thus, they need to think and act as team members mindful of the performance of the team as a whole. While health professionals involved in heart failure management may have specialist knowledge, they often have little realisation of what patients are faced with once they are dealing with everyday issues in their particular home environment. This can make process knowledge scant, because only part of the process, often the task, is understood, and there is little information retrieved to piece together the whole picture for the particular patient.

Retrieval of information

Within the health system and its sources, the retrieval of information can be time consuming and costly. Therefore, any information retrieved should benefit both patients and health professionals. An understanding and an interest in sharing meaningful information has to be present as well. If information is not understood, regardless of how vital, it is of little benefit. If the health professional is not considering the patient illness experience, and only concentrating on the disease dimensions of the condition, information sharing is less likely to occur. It is argued that, in order for effective co-ordination of care to occur, the team co-ordinator must have an understanding of the wider dimensions of disease, sickness, and illness and how they affect health. Information sharing then becomes fundamental so that multiple viewpoints can be integrated to improve service delivery and practice. Radley (1994) supports this stance when she states "How people think about health and illness and what they do about these are joint concerns" (p.16). In response to this, the interview data revealed that heart failure represents a condition that is open to huge **information gaps**. Data from this study highlights the importance of taking the patient experience into account when planning future initiatives for healthcare. Heart failure is much more than a condition and it must be examined as a disease, an illness, and a sickness (Radley, 1994). Such an examination requires that health professionals and lay people work together. Indeed, MacKay et al. (1998) argue "at the centre - which draws all groups together must be the appropriate delivery of services and a focus on 'good practice', rather than the priorities of any particular group" (p. 12).

Future initiatives for health care are discussed by Smith and Brooks (1999) who propose that, in the not too distant future, "health care consumers will determine a major role in determining what information they need from providers as partners in care" (p. 199). As societies value change, and appreciate better how the patient and their partner manage heart failure in the home environment, it is possible that information relayed and accessed may improve. If **information gaps** are overcome through stronger lay-professional interactions improved management of chronic conditions such as heart failure may result. This idea is supported by Smith and Brooks (1999) who state that "the creation and nurturing of a strong consumer-provider relationship will be the major driver to define quality and service options based on consumer needs in the future" (p. 200). Communication is a vital factor in sharing knowledge between patient and health professional to benefit the management of chronic diseases such as heart failure.

It is apparent that the specialised aspect of much knowledge affects how knowledge is shared. Druker (1992) asserts that specialists remain specialists, becoming ever more skilful. However, getting participants in group management to work as a team requires knowing how to manage knowledge. In terms of extraction of information, the predominant organised players today are researchers and research institutions. The knowledge these players acquire is generally recorded and transmitted, albeit not universally received. Wilcox (1997) states that "in addition there is a vast if not poorly tapped body of knowledge being generated outside the research laboratories by experience, by trial and error and [this] is impossible to measure indirectly" (p. 3). Pearson and Peters (1997) believe that the lack of implementation of appropriate treatments and accurate diagnosis of heart failure is widespread. They suggest that this is happening because there is a gap in the uptake of recommended best-evidence based practices due to a lack of extraction of specialist knowledge by the generalist players, ie, the general practitioners.

While specialist knowledge undoubtedly exists and information is available, once again the key to transmission seems to be communication and how that takes place. According to Melody (1994), the functioning of any society depends upon information, and the efficient and effective communication of that information among society's members. An examination of the information processes of any society must focus on its communication characteristics. New communication networks are often the driving force behind the generation of vast quantities of information. Melody states that "when the institutional structure changes for whatever reason, the communication processes and information flows are changed" (p. 256). When society's values change it is probable that there is a lag effect in the flow of information between members. Therefore, when heart failure management requires patients to take a more active role in the management of their complex condition at home, communication and access to sources of information are vital. This is especially so because heart failure patients are managing an unstable condition, where adjustment of a complex drug regime is very often necessary in order to prevent an exacerbation of the condition and consequent hospital readmission. When the means of communication have changed due to the possibility of instant electronic communication, it should be possible to provide more effective and efficient means of communication between patient and health professional.

Overall, information gathering, processing, storage, and transmission, are important issues related to information management. Melody (1994) suggests that perhaps the most significant change between a technologically advanced society and the oral tradition of the Greek city-state is not the volume of information but the structure, the institutions, and the dependence. The sheer volume of information available today exceeds that which can be individually assessed. Therefore, if integrated care is the goal, "information from inpatient settings must be integrated with information from other care settings, such as physician offices, home care agencies, and long-term care facilities." (Simpson, 1999, p. 233).

Information is generated to be consumed by others, the only additional costs being those associated with bringing the same information and additional consumers of it together under conditions where it can be consumed. Therefore, the focus on integrated care with health professionals, such as a case manager who is aware of how patients experience illness and other professionals see heart failure as a disease, should be to consider the information structure, and the improvement of processing, storage, and transmission of information.

Information Systems

It is argued that, in order to foster improved patient control of heart failure in the community, care co-ordination and integration are required and there has been an increasing call for co-ordination of care (Brass-Mynderse & Kaliangara, 1997). Indeed, Sharpe and Doughty (1998), question 'Who best to manage heart failure?". Perhaps "an integrated, participatory approach involving primary and secondary care, patient and family or support persons, may be the most effective and efficient" (p. 26, 27). While this would indicate that group involvement is necessary in managing a chronic complex disease, co-ordination is absent to date. Despite the introduction of information technology and the call for integrated primary and secondary care, in many cases, this is not happening. It is probable that the lack of integration is caused by poorly developed information systems in both the hospital and the community.

Information systems enable a person to organise and integrate his or her own work (Drucker, 1992, p. 348). They are also something a person can takes control of and responsibility for and feedback can intensify the strength of a system by helping to identify any weaknesses. Information systems and the dissemination of information are important in the team based organisation of healthcare. "Many organisation implementing teams have had to modify and supplement their information processing through a combination of quick fixes to the existing systems and additional manual processes to plug the holes" (Manion, Lorimer & Leander, 1996, p. 346). Health services in New Zealand are making efforts to become part of the information technological age. Computerised patient records are not yet part of practice, so this makes access to information more difficult for health professionals. Confidentiality of information is an issue that will need to be considered alongside ready access to records.

According to Szajina and Scamell (1993) new information systems are either failing to improve organisational processes or they are being underutilised. More integration needs to occur between new knowledge and technical expertise (p. 493). The impact for heart failure is that information systems are a part of organisations. Because knowledge among the group managing heart failure is specialised, in order for the group to be working collectively on the process of managing heart failure, rather than focussing on the task, the coordinating and monitoring roles needs to be examined in detail.

Because many inpatient admissions can be prevented by better monitoring practices (Karmalovich, 1994) it is important to have in place a system that will work at home to prevent readmission, but also maintain a best quality of life for the patient. Such a system is suggested as being that of case management involving a clinical nurse specialist.

Case management

New more effective ways of managing chronic diseases in different contexts require systems that are capable of the challenge. It has already been noted that, within healthcare today, a paradigm shift is underway. Case management as a care delivery system is inherently well positioned for the paradigm shift. With the changing emphasis on empowering patients to live in the community rather than long inpatient stays, existing channels have to cope with heart failure in community care. In the main, these are the general practitioner, with small contributions from other health professionals such as practice nurses. Although some health professionals have changed practice to integrate better with changing funding structures, others maintain restrictions on accessing services so that integration is hindered. Dixon (1998) believes that "GPs have positioned themselves carefully for managed care aided by the fact that they have no real competition since they are paid a medical benefit and act as gatekeepers to all other health services" (p. 5).

The position of the general practitioner is significant when case management is considered. Any undue focus on disease impacts on social funding. Changing funding structures were a significant factor in this study because, in some cases, cost appeared to prevent the seeking of advice about symptoms from the general practitioner. The concept of nurses as case managers co-ordinating care, or the role of the partner in managing the heart failure patient at home, may well challenge existing funding structures and the role of the general practitioner. While some participants in this study found that they could easily access health professionals for advice, usually in a specialist hospital clinic, thereby alerting others that something was wrong, this did not always happen. Therefore, new more effective ways of managing care will need to be negotiated.

Data from this small study on heart failure management supports the existing literature in reinforcing that there has, so far, not been a strong focus on support networks for health care in the community. The development of an integrated service for primary and secondary care is thus compromised (Jaarsma et al., 1999). It is suggested, that in order to improve medical care and reduce costs, the use of national guidelines and care maps, or critical pathways, to encourage standardisation are necessary. Also important is the use of tools such as case management, which is a useful model of care to solve problems on a systems basis. However, monitoring is required in the developmental and implementation phases so that the outcomes of care can be evaluated carefully (Mark, 1997).

The nursing literature increasingly supports the concept of case management of heart failure (Huggins & Phillips, 1998; McCann, 1996). Case management is defined by Litchfield (1998) as "the form of health service delivery concerned with service co-ordination at the interface between funds management and professional practice" (p. 27). In this respect, nurses are well-positioned because they are used to teamwork. As Christensen (1999) notes, nurses need to be competent in collaborative interdisciplinary teamwork, because they can rarely be autonomous and work in isolation from all other disciplines. It is argued that, integral to the implementation of case management are the roles of both the clinical nurse specialist and the nurse manager, as educator, resource manager and advanced clinician (Gibbs, Lonowski, Meyer & Newlin, 1995).

It is suggested in the literature that the role of specialist nurses with specialist knowledge, assessment, experience and understanding of therapy is vital, as the focus of the non-acute healthcare environment expands into the community (Kegel, 1995). It is assumed that clinical nurse specialists are advanced nurse practitioners. However, Christensen (1999) states that advanced nursing practice in New Zealand "has not developed much further that the toddler stage of taking its first faltering steps" (p. 10). She suggests that attributes necessary for advanced practice include amongst other things,

> ...increased knowledge and skills within the particular scope of practice acquired through a masters level programme as well as ongoing informal and formal learning experiences, that fosters interdisciplinary collaboration, and critical analysis of complex human health circumstances. (p. 10)

In New Zealand there are few centres that use specialist nurses, or advanced nurse practitioners, to follow up heart failure patients. In the community there has so far, been little uptake of the nurse specialist roles in heart failure rehabilitation. The focus remains with cardiac rehabilitation. A lack of direction and focus for heart failure in the community fosters poor symptom management for heart failure patients. Case management by heart failure specialist nurses may bridge the gap in rehabilitation. Gibbs, Lonowski, Meyer and Newlin (1995) state that case management can play a significant role in co-ordinating patient care by:

> an approach that focuses on co-ordination and integration of in the delivery of patient service, places controls on the resources used for care, increases involvement of nurses and other healthcare providers in decisions regarding practice, and promotes continuity and consistence of care. (p. 28)

Case management can, therefore, be viewed as a useful strategy that would help people to be kept in the information loop and bridge some of the apparent **information gaps** reflected in patient care.

Rantz and Scott (1999) state that "Nurse case management as a strategy supports the ability of chronically ill persons to maintain self-management skills while increasing the co-ordination of care, decreasing fragmentation of care, and decreasing consumption of health care dollars" (p. 217). Given the changing health care service environment, a care delivery model that allows for self-management and care co-ordination skills would benefit the management of heart failure as a chronic illness. An effective case manager can contribute by assessing treatment options, assessing and coordinating risk, planning and developing treatment, controlling cost, and evaluating care and long term accountability (Goodwin, 1994). Nurses who have specialist knowledge and the time and ability to manage care across both the primary and secondary sectors, should make excellent case managers. McCann (1996) believes that "case management eliminates fragmentation of care, and the talented nurse case manager can integrate services while addressing the competing demands of the patient and the system" (p. 399).

Limitations of the study

Limitations of the study relate to the small sample. While the use of only one interview provided useful information, more would deepen understanding. More data needs to be collected from a range of participants including people from different cultural groups. As such, results need to be viewed with caution. However, this was acknowledged early on in the study and emphasis given to the fact that this is a pilot study only. The study is also limited as data collection and analysis is insufficient to allow theoretical development. Nonetheless, the results are still of some use to clinicians and can be used as a beginning point to stimulate further research in the area.

Recommendations

More work needs to be done on investigating lay-professional interactions. Research into the effectiveness of education for heart failure patients is also important, while more research to study the significance of sifting of information is also recommended. Heart failure has been neglected as a research topic in general practice and further work is required here.

Conclusion

This grounded theory study has examined the main concerns of a group managing heart failure. In doing this it has clearly demonstrated that **information gaps** were present and the group continually resolved this by *alerting others*. The significant findings included the *absence of a cohesive group* and *being in or out of the loop*, which both contributed significantly to incomplete information being shared between members of the group. When information management focused on specialist knowledge, management was reduced to handling a series of isolated pieces of information, and, thus, the potential for **information gaps** increased.

Within the health care setting, the disease emphasis in the health illness equation works to reduce the legitimacy of the patient experience of illness and sickness, so that this experience tends to be ignored. Also, when funding for heart failure favours new treatments there is the tendency for existing treatments to lag behind in implementing up-to-date recommendations. **Information gaps** are perpetuated when care is not coordinated and patient care is compromised. This study has implications for clinical practice, particularly that of nurses in regard to issues surrounding knowledge management and collaborative practice in an interdisciplinary team. Case management is identified as a strategy to overcome the **information gap**. Case managers who have the potential to support patients seeking self-management skills may decrease fragmentation and enhance quality of life. Nurses with advanced specialist practice knowledge are ideally situated to case manage heart failure and its complexities.

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APPENDIX 1
MASSEY UNIVERSITY
DEPARTMENT OF NURSING AND MIDWIFERY
PARTICIPANT INFORMATION SHEET

MANAGEMENT OF HEART FAILURE

1. Who is the researcher and who is the supervisor?

My name is Susan Reed. I am a research nurse working at Auckland Hospital with the Department of Medicine. I am a student enrolled in the masters programme at Massey University. This research is the fieldwork associated with a masters thesis which should be completed by December 1999. My supervisor is Antoinette McCallin who is a Senior Lecturer in the School of Health Sciences at Massey University. She can be contacted on (09)4439700 Ext 9819.

2. What is the study about?

This is a study about patient experiences with heart failure. I am interested in exploring your care, and any problems you may have faced. With your consent I would also like to talk to some of the people who have looked after you, such as your GP, cardiologist, pharmacist, dietician, and your support person. These people will need to know who you are.

3. What would this research involve?

I am inviting you to join my research by volunteering to be interviewed. If you agree you will be asked to take part in two interviews with me. These interviews would be at a place and time that is agreeable to each of us. In the interview I would like us to begin by discussing your experiences of what it is like to be diagnosed with heart failure and the management you have received. I would begin by asking you the following question:

> *" I understand that you have had heart failure for some time now, and I am interested in finding out what it has been like being managed by a group of people.... "*

The interviews would be like conversations. I would like your agreement to tape our conversation. You will always be able to ask for the tape- recorder to be turned off at any time. The interviews would last for about an hour. As I collect more information from different people I would want to ask you particular questions related to ideas shared by other people in this research. (Any ideas would always be confidential – see paragraph 4).

The number of times I would talk to you would be twice. If you agree to talk to me you would also be asked to read the typed information that comes from the interviews. Some people read this while others do not. The choice is yours. The main thing is that you are happy with what you have said. At this time you will always be able to take out any details that you want to.

4. Will anyone know who I am?

To make sure you would not be recognised by anyone, your name will not be used in the research. I will ask you to choose a 'special' name, or pseudonym to be known by. The information shared between us will be strictly confidential. The only people who will have access to it will be the supervisor, a transcriber who will confidentially transcribe the tapes, and myself. When interviewing your care team, with your permission, they will have to know who you are. All the interviews and the typed information will be kept safely in my home during the research. Once the research is complete I will offer to return your interview tape to you. If you do not want to receive the audiotaped interview, then the audiotape will be destroyed. All data will be kept safely for 16 years. Then typed material will be shredded and computer discs wiped clear of all information.

5. How will this study affect me?

Taking part in this research is not going to change the way you are looked after by the group of people. However, when some people discuss the experiences they have had, they can find themselves wondering about things that have happened more than they would have done if the discussion had not taken place at all. This may be uncomfortable. Experiences may be pleasant or unpleasant for different people. If any distressing situations were to occur for you, I can listen and support you at the time. We would then discuss how best to proceed if you needed ongoing support. I would like to talk to your group of health professionals, as well as your partner/ support person, with both your and their consent.

6. Can I leave the study at any time?

Yes. You should only talk to me if that is OK for you. You are free to ask for more information about the research at any time. *You are also free not to join the study, or, to change your mind, and leave at any time.*

7. Will there be any compensation?

In the unlikely event of a physical injury as a result of your participation in this study, you will be covered by the accident compensation legislation with its limitations. If you have any questions about ACC please feel free to ask the researcher for more information before you agree to take part in this trial.

8. Can I contact you at any time?

Yes. If you would like to ask any questions about the research, and/or have decided you would like to be a participant in this research you are welcome to contact me:

Susan Reed
Department of Medicine
4th Floor
Auckland Hospital **Telephone (09) 3074949 ext 6416**

If you have any questions about the research that you would rather not ask me, please feel free to contact my supervisor whose telephone number is at the beginning of this information sheet. If you would prefer to talk to a consumer advocate about any queries or concerns regarding your rights as a participant in this research you are welcome to contact the Health Advocates Trust, phone 0800 205 555.

It is important that you realise that you have the right to decline to participate in this research.

Summary

If you agree to be in this research you should be clear about the following points:

- You have had the details of the study explained clearly to you. Your questions have been answered to your satisfaction. You can ask further questions at any time.
- You can leave the study at any time. You can refuse to answer any questions.

- Your name will not be used. You will choose a 'special name' for your interview. The information will be used only for this research and publications and presentations coming from this research project.
- You understand that you will be entitled to a summary of the research results when the project is completed.
- You will decide if the interview/s will be taped.
- You understand that the audio-tapes can either be destroyed, or returned to you, at the end of the study.
- You can ask for the tape to be turned off at any stage during the interview.
- You agree to the researcher talking to the others involved in the management of your heart failure. These people would need to know who you are. Their consent will also be required.

This study has received ethical approval from the Auckland Ethics Committee, and the Massey University, Albany Campus, Human Ethics Committee.

Thank you for taking the time to read this.

Susan Reed

APPENDIX 2

MASSEY UNIVERSITY
PARTICIPANT INFORMATION SHEET

MANAGEMENT OF HEART FAILURE

1. **Who is the researcher and who will be the supervisor?**

My name is Susan Reed and I am a research nurse working at Auckland Hospital in the Department of Medicine. I am enrolled in the masters programme at Massey University. This research is the fieldwork associated with a masters thesis which should be completed in 1999. My supervisor is Antoinette McCallin who is a senior lecturer in the Department health Sciences at Massey University. She can be contacted on 4439700 Ext 9818.

2. **What is the aim of this study?**

I am seeking voluntary participation in this study. The aim this research is to explore the management of the heart failure patient from the group perspective. The health professionals I would like to include are the pharmacist, GP, cardiologist, and dietician. The patient and their partner/support person will also be interviewed. My intention is to create a better understanding of the needs of the heart failure patient, so that, a more effective, efficient, and quality service can be provided.

3. **What will be your involvement in this study?**

I invite you to be involved in my research by volunteering to be interviewed. In this study the management team as well as the patient will be included in the participant group. If you decide to join this study you will be asked to take part in two interviews with me. These interviews could take place either at your work place or at a location that is convenient to each of us. In the interview I would like us to begin by discussing your thoughts and experiences related to working with the chosen heart failure patient. For example:

> *"I am interested in how patient 'x', who has been diagnosed with severe heart failure is managed from your experiences..., and what your experiences on managing patient 'x' have been like"*

The interviews, which I would like your permission to tape, will be conducted as focused conversations. You will have the right to ask for the tape recorder to be turned of at any time. The interviews would last for about half an hour to one hour. In the second interview as more information is collected, I would expect to ask more specific questions related to ideas that have been shared by the participants. (*Any information shared will always be confidential – see over to 4*). I may want to clarify things you have said and may ask you to describe particular situations you have referred to.

If you agree to join this research project, you would also be asked to read over the transcript that comes from your interview. Some participants read their transcripts, others do not. The choice is yours. The main point is to ensure you agree with what has been said. At this time you will have the right to withdraw any detail which you prefer not to be included in the data. Tapes will be confidentially transcribed.

4. **Will I be able to be identified in the study?**

You are given the option of choosing a pseudonym or using your own name. The choice is yours.

The information shared between us will be strictly confidential. The only people who will have access to the data will be my thesis supervisor, the confidential typist, and myself. All taped interviews and transcripts will be kept safely in my home during the research. Once the research is complete I will offer to return your interview tape to you. Otherwise after 16 years, the transcripts will be shredded and the computer discs wiped clear of all material.

5. **How will this study affect you?**
The aim of this research is to explore the management of heart failure patients. Taking part in this study will not change your working relationships and situations. When some people discuss their situations they can find themselves considering concerns more than they would have done if the discussion had not taken place at all. There is always the potential that this may be uncomfortable. Experiences may be pleasant or unpleasant for different people. If any distressing situations were to occur for you, I can listen and support you at the time. We would then discuss how best to proceed if you needed ongoing support.

6. **Can I withdraw from the study at any time?**
Yes. Your involvement in this research is based on your willingness to participate. This means that you are free to ask for further information or explanation about the research at any time. You are also free to decline participation or to withdraw at any time.

7. **Am I able to contact you as the researcher?**
Yes. If you would like to ask any questions about the research and/or have decided you would like to be a participant you are welcome to contact me

Susan Reed
Department of Medicine
4th Floor Auckland Hospital
Park Rd
Auckland **Telephone 3074949 Ext. 6416**

Should you have any concerns about the research that you do not wish to address to me, please contact my supervisor Antoinette McCallin on 4439700 Ext 9818. If you would prefer to talk to a consumer advocate about any of queries or concerns regarding your rights as a participant in this research you may also contact the **Health Advocates Trust**, phone **0800 205 555**
It is important that you realise that you have the right to decline to participate in this research.

Summary
If you decide to take part in the study you need to be clear about the following points:

- You have had the details of the study explained to you. Your questions will have been answered to your satisfaction. You can ask further questions at any time.
- You have the right to withdraw from the study at any time and to decline to answer any questions.
- Your name will not be used unless you want it to be used. The choice is yours. You have the option of choosing a pseudonym if you want to. The information will be used only for this research and publications and presentations coming from this research project.
- You will be given access to any tape recordings, and transcripts, with a summary of the research findings being made available to you should you want it.
- You have the right to decide if the interview/s will be audio-taped.
- You have the right to ask for the audio-tape to be turned oft at any stage during the interview.

This study has received ethical approval from the Auckland Ethics Committee.

Thank you for taking the time to read this.

Susan Reed

APPENDIX 3
CONSENT FORM

Title of Project: **Management of heart failure**
Principal Investigator: **Susan Reed**

English:	I wish to have an interpreter.	Yes	No
Maori:	E Hiahia ana ahau ki tetahi tangata hei, Korero Maori ki ahau	Ae	Kao
Samoan:	Oute mana'o e iai se fa'amatala upu	Ioe	Leai
Tongan:	'Oku fiema'u ha fakatonulea	Io	Ikai
Cook Island:	Ka inangaro au I tetai tangata uri reo	Ae	Kare
Niuean:	Fia manako au ke fakaaoga e tagata Fakahokohoko vagahau	E	Nakai

Name of Participant:

I have read the information sheet and had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at anytime.

I understand that taking part in this study is voluntary. I have the right to withdraw from the study at any time, until after the first interview, without jeopardising any care. I also have the right to decline to answer particular questions.

I have had time to consider whether to take part in this study. I know whom to contact if I have any questions about the study.

I agree/ do not agree to the interview being audio-taped. I also understand that I have the right to ask for the audio-tape to be turned off at any stage during the interview.

I understand that I can choose to have a confidential identity by using a pseudonym, or special name. Information that could identify me will not be used in any reports on this study. If I participate in this study I agree to the health professional being interviewed knowing my identity.

I agree to the researcher talking to my GP, dietician, pharmacist, and cardiologist about the management of my heart failure. ……………………………………………YES/ NO

I agree to my GP, dietician, pharmacist, and cardiologist knowing my name and who I am……………………………………………………………………YES/ NO

I wish to receive a summary of the final report…………………………………YES/ NO

I wish to either receive my audio-tapes from the interviews………………………..YES/NO
Or by answering No I agree to have the audiotapes destroyed.

I ……………………………………………..hereby consent to take part as a participant in this research.

I wish to use a pseudonym, or special name ……………………………..YES/ NO
Date……………………………………..

Participant Signature………………………………..

Full name of researcher…Susan Reed ……………………………………**Contact phone number for researcher (09) 3074949 Ext 6416**

Project explained by……………………………………..

Project Role……………………………………**Signature**……………………………………….

Date……………………………………..

I am clinically responsible for this patient's care at Auckland Hospital and I have no objection to his/her participation in this project.

Attending Physician Signature………………………………… **Date**…………………

APPENDIX 4
CONSENT FORM

Title of project: **Management of heart failure**
Principal investigator: **Susan Reed**

English:	I wish to have an interpreter.	Yes No
Maori:	E Hiiahia ana ahau ki tetahi tangata hei korero Maori ki ahau.	Ae Kao
Samoan:	Oute mana'o ia iai se fa'amatala upu.	Ioe Leai
Tongan:	Oku ou fiema'u ha fakatonulea.	Io Ikai
Cook Island:	Ka inangaro au I tetai tangata uri reo	Ae Kare
Niuean:	Fia manaka au ke fakaaoga e tagata Fakahokohoko vagahau	E Nakai

Name of participant:

I have read the information sheet and had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I understand that my participation in this study is voluntary. I have the right to withdraw from the study at any time, until after the first interview, and to decline to answer particular questions.

I agree to the interview being audio-taped.

I also understand that I have the right to ask for the audio-tape to be turned off or parts of it deleted at any time during the interview.

I agree to provide information to the researcher on the understanding that my name or identity details will not be used without my permission, and the information I give will only be used for this research and associated publications and presentations.

I wish to use a pseudonym……………………………………YES/ NO

I wish to receive a summary of the final report…………………YES/ NO

I wish to receive my audio-tapes from the interviews………YES/ NO
OR by answering No I must agree to the researcher destroying the audio-tapes.
I wish to have my audio-tapes from the interviews destroyed ... YES/ NO

I agree to participate in this study under the conditions set out in the Information Sheet.

Signed ………………………………………………

Name………………………………………………………………

Date…………………………………………………………

APPENDIX 5

Transcriber non-disclosure of information

NON-DISCLOSURE OF INFORMATION

TRANSCRIBER

I, ______________________________agree not to disclose the name of, or any other information that would lead to the identification of the participant in the research study being undertaken by Susan Reed. The audiotapes, transcriptions and computer discs will not be made available to any other person but the researcher or her supervisor, and will be kept securely while in my possession. I will not retain any copies of the audiotapes, computer discs, or transcriptions.

Signed: ____________________________

Name: ____________________________

Date: ____________________________