EXPERIENCES OF PATIENTS ATTENDING AND PARTICIPATING IN CLINICAL NURSE SPECIALIST-MANAGED HEART FAILURE CLINICS.

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Abstract

It is very clear from discussions with patients attending outpatient clinics, that nurse-led clinics fulfilled an important function in the holistic care of patients with heart failure. Previously the biomedical model of health care dominated the health system and was considered all that was required. Knowledge about health care has improved greatly and this is in keeping with patients' expectations in today's world of easy access to Internet information. Ongoing health care therefore, needs to meet the needs of these patients in the interests of improved quality of life in a population with a significant chronic illness.

This research sits in the mixed method paradigm, however the focus is predominantly qualitative using exploratory narrative inquiry informed by Polkinghorne (1988) to gain a perception of the meaningfulness of patients' experience of nursing clinics. The aim of this research is to explore what is important to the patients; to explore what the patient's perceive as their needs when they attend or participate in Heart Failure Clinical Nurse Specialist (HFCNS) clinics; to describe the experiences of patients attending the HFCNS services with the aim of gathering information to develop and improve the health care of these patients.

All patients attending the nurse-managed heart failure secondary care clinic over an eight-week period were invited to fill in a questionnaire. Fifty-five patients completed the form. The aim of the questionnaire was to describe the clinic population demographics. Three short answer questions were also included to give direction for the interviews that were to follow. The six participants for interview were chosen purposely to give a range of age, gender and ethnicity that would be representative of the clinic population.

Key themes for the patients were identified and included: gaining knowledge; making changes; partnership/mentorship; ethnicity/cultural perceptions; and collegial collaboration/ professional care.

The research gave a clear picture of the patients' perceptions of the reality of the experience of nurse-managed secondary care clinics. Issues to do with cultural safety as well as general care presented a multi- faceted and complex canvas. Furthermore knowledge of ethnicity and cultural mores shows a need for ongoing efforts to be innovative in reducing disparities that persist in Maori and Pacific peoples' health and wellness. Overall the evidence indicates that nurse-managed heart failure clinics show positive outcomes for patients' perceived needs and, fill what was a gap in care.

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Chapter One

Introduction:

This research is aimed at gaining knowledge on how patients experience nurse-managed secondary care clinics, and what we as health professionals can do to make the patient's health experience a process that enhances their ability to cope with what is a significant chronic illness. Nurse-managed/led clinics are seen as integral to the holistic care of a population that has a longer life expectancy and concomitant of coping with chronic age related illnesses. With that comes an increase in the need for services for coping with concomitant age related chronic illnesses.

Nurse-managed/led clinics are now an accepted part of patient care. They elaborate and expand the medical clinic that was once the sole focus for patients. The addition of the nursing focus is leading to a holistic approach where patients' psychosocial needs are taken into account. For the individual, knowledge that he/she has a chronic illness can be a frightening experience. For such an individual to achieve the optimum quality of life, he/she may well need to adopt extensive lifestyle changes. At the very least each person needs to understand the illness and the measures – both pharmaceutical and life style - that are necessary to obtain and retain wellness Martensson, Karlsson and Fridlund (1998), posit "nurses should study patients from a holistic point of view, focusing on the relationship between body, mind and spirit, where the whole person is cared for, not just the disease, injury or functional impairment" (p.1217). Martensson et al (1998) description is the essence of holistic nurse-managed care.

The literature suggests that nurse-managed/led clinics can be distinguished by certain characteristics. For the purpose of this study, the terms nurse-led and nurse-managed clinics are used interchangeably. These are clinics providing a service for patients, in this context, patients' diagnosed with heart failure, which are managed and staffed solely by nurses, who assess and manage patients in collaboration with cardiology colleagues and refer the patient to other multidisciplinary health professionals as necessary (Page, Lockwood, & Conroy-Hiller, 2005).

This chapter reviews the history of nurse-led cardiology clinics at a District Health Board (DHB). Ethical issues and possible bias were considered to inform which nurse-led cardiology clinic would be invited to participate in this research. Finally, the process and development of heart failure nurse-managed clinics are described from their inception and from referral of the patient through to attending and participating in HFCNS clinics.

History of clinics:

Nurse-managed/led clinics are not a new concept. As early as the late 1980's nurses-led clinics were being developed in the United States of America (Dracup et al, 1994). DHB clinical nurse specialist-led clinics became part of the cardiac rehabilitation process from 1990 in response to outpatient clinic demand. Various evidence-based studies identified the need for ongoing support and follow-up of patients with coronary artery disease to prevent further cardiac events and also to reduce morbidity and mortality.

With the ever-increasing expenditure on health and the longer lifespan of individuals, it was calculated that promoting nurse-led clinics would have a positive impact on the access and availability of cardiology services for a DHB population. A senior cardiologist had the foresight to recognize the potential value and benefit of promoting nurse-led clinics at his resident hospital to reduce the gaps in service. This is confirmed by Harris and Redshaw (1998) who comment on gaps in services pointing out that it, "has encouraged nurses to take up the challenge of expanding the boundaries of their practice" (p.1381).

Cardiac Rehabilitation is a process of education, providing support and advice for patients following a cardiac event. It is time consuming, and to be successful reinforcement of an individual's goals for managing risk factors is essential to maintain wellness in his/her future life. Nurse-managed clinics were seen as a way to reduce the gap in after care for this group of high-risk people, to maintain the reinforcement and support for lifestyle adjustments and adherence to medication regimes. This expansion of services from traditional nursing was also seen as a way to respond to political and social changes in health care strategies as stated in the Ministry of Health's 'Health Strategy' (2003).

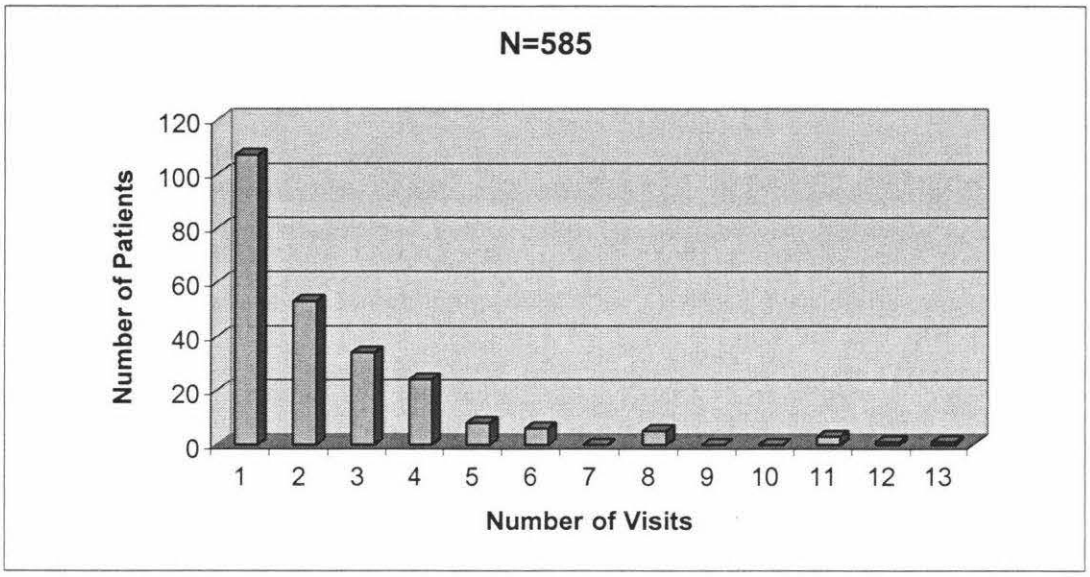
Following on from the cardiac rehabilitation (CR) process it was acknowledged that heart failure patients had specific needs that were not being met. The heart failure service was initiated after discussions with appropriate service team personnel and the development of a business plan. Developing a service means knowing your population, developing a program then getting support to get the program underway. To this end it means being ready, having done all the preparatory work and being able to follow through to create a sustainable, efficient and effective service.

HFCNS managed clinics became an entity in the mid 1990's as it became apparent from national and international statistics that heart failure patients were being underserved and were having frequent re-admissions to hospital, sometimes with lengthy stays and also with increasing health care costs (Anderson et al, 2006; Michalsen, Konig & Thimme, 1998; Phillips, Singa, Rubin & Jaarsma, 2005; Stewart & Horowitz, 2003). The aim of the HFCNS clinic was to reduce re-admissions from exacerbations of heart failure (Gheorghiade, Filippatos, DeLuca & Burnett, 2006), by educating, supporting the patient and family and using best practice evidence in the provision of appropriate medication regimes as well as an action plan for the management for symptoms such as acute shortness of breath.

Henrick (2001) elaborates, commenting, "we are in an era where quality, cost-effective outcome-based care is a mandate" (p. 10). Henrick (2001) also considers nurse-managed clinics are positioned to achieve these goals. An audit of the HFCNS clinic was undertaken by Hawkins (1999), which showed a significant reduction in readmissions, however symptomatic patients were seen more frequently in clinic to reduce the need for admission. An example of the individual patient visits to HFCNS clinic over the year 1st July 2006 – 30th June 2006 ranged from one visit to thirteen visits with a median of two visits, with forty eight patients attending clinic four or more times as represented in Table1.

Table 1:

Number of Patient Visits to Clinic July 06 - June 07



Although a number of patients were seen frequently in clinic, the cost of these visits overall compared favourably with the cost of days in hospital if the patient had been admitted shown in Table 2a and 2b.

Table 2a:

Cost per Patient for stay at DHB hospital 2007		
Patient Location	**Day Stay Costs**	**Seven Day Stay Costs**
Medical Ward	$446.07	$3122.52
Cardiac Care Unit	$740.06	$5180.43

Source: Revenue Department, DHB

Table 2b:

Cost per Patient for Clinic Visits 2007	
HFCNS Clinic	**Costs are approximate**
First Visit	$76.46
Follow Up Visits	$52.94
Seven clinic visits including first visit cost	$394.10

Source: Revenue Department, DHB

The Question: which clinic?

The interest in undertaking this research was generated from an audit of a specific group of cardiology clinic patients (Dewar & Cuthbert, 2004). The first step was to obtain the necessary approval after considering ethical issues and possible bias regarding which was the most appropriate nurse-led clinic to research. After due consideration and with the approval of the HFCNS's, patients attending the HFCNS clinics were invited to participate in the research to discuss their experiences while attending and participating in nurse-managed clinics.

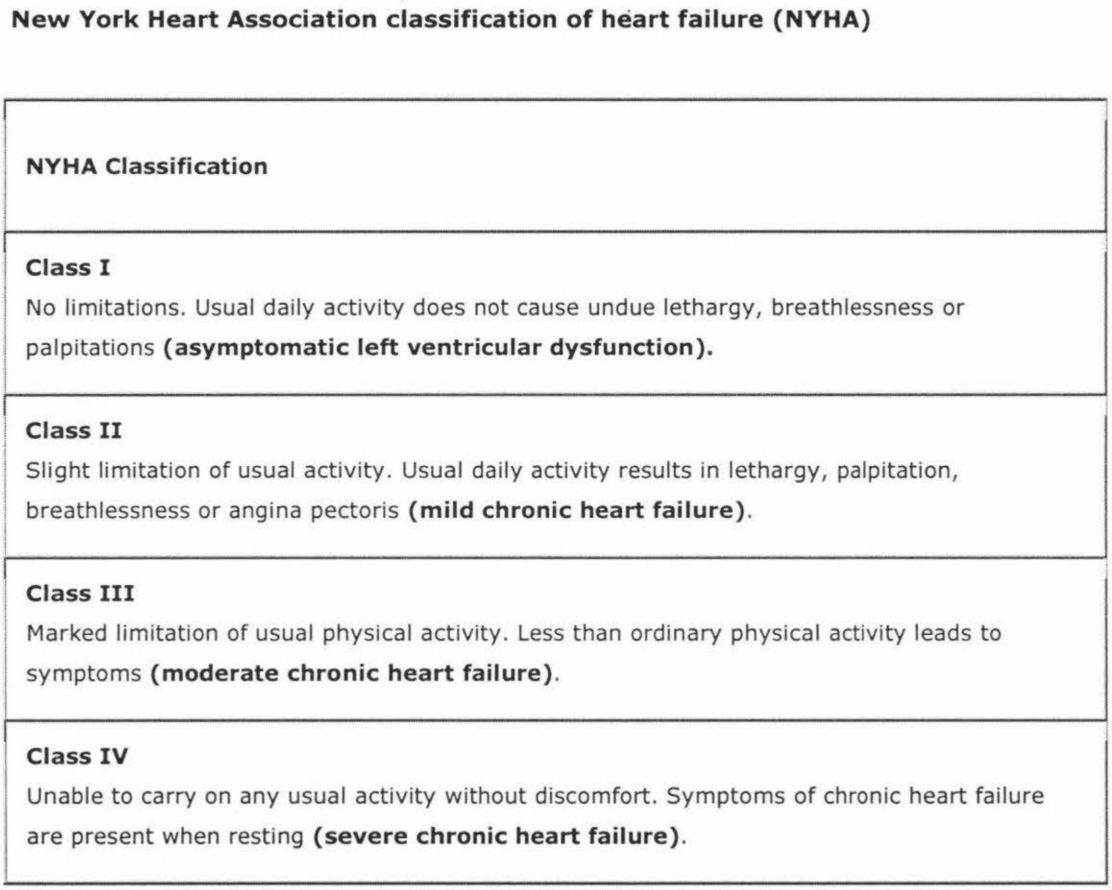
Heart failure clinics have been operating at this local hospital since the mid 1990's with an audit being undertaken in 2001 that showed excellent outcomes from reduced readmissions and length of stay, however mortality in this community stayed at approximately 10% which is similar to international experiences (O'Meeghan, Hawkins & Cuthbert, 2002). The audit showed promising statistical outcomes for nurse - led management but only looked at outcomes from a data collection point-of-view. An overall view would include finding out what the people accessing the service needed. Nurses are acknowledged leaders in the management of complex chronic illnesses, and this notion will be discussed further in describing the complexity of care of heart failure patients and the interaction between primary and secondary services needed to achieve support for patients' with this complex illness (Stewart & Blue, 2004).

Clinical Nurse Specialist Heart Failure Clinic:

A pilot program funded for two years with the support of the cardiology team and hospital management was initiated in the early 1990's. The aim of the program was to optimize individual therapeutic treatment, reduce readmissions, reduce length of stay when admitted, and overall, reduce costs relative to heart failure management (Hawkins, 1999). The heart failure program was developed alongside an already well-established cardiac rehabilitation service.

The new heart failure program was initially home-based care with a HFCNS assessing, educating and supervising medication use. The HFCNS also assisted in the management of this group of patients by coordinating the care between primary and secondary health sectors. Referral to the HFCNS program was through hospital physicians. After a period of time and again following on from cardiac rehabilitation experience, HFCNS clinics were commenced. The criteria for referral included, patients classified as New York Heart Association (NYHA) Grade II, III or IV heart failure illustrated in Table 3.

Table 3:



New York Heart Association classification of heart failure (NYHA)

NYHA Classification
Class I No limitations. Usual daily activity does not cause undue lethargy, breathlessness or palpitations **(asymptomatic left ventricular dysfunction).**
Class II Slight limitation of usual activity. Usual daily activity results in lethargy, palpitation, breathlessness or angina pectoris **(mild chronic heart failure)**.
Class III Marked limitation of usual physical activity. Less than ordinary physical activity leads to symptoms **(moderate chronic heart failure)**.
Class IV Unable to carry on any usual activity without discomfort. Symptoms of chronic heart failure are present when resting **(severe chronic heart failure)**.

Adapted from: American College of Cardiology/American Heart Association (2005)

The process commenced with referral to the HFCNS program from the cardiologists, physicians, medical unit and coronary care unit nursing staff. Once the referral was processed a home visit was arranged and then follow-up by a HFCNS clinic review in collaboration with a cardiologist colleague. Patients stayed in the program until their condition was stable and they were able to manage independently in their home or in a supported environment. Patients were then discharged to their regular health care provider. In the intervening years the HFCHS team has developed collegial relationships with most General Practitioners (GP's) so that GP's now refer patients to the service for management and education.

The HFCNS service is a comprehensive service that includes referrals from the primary and secondary sectors. Patients admitted to hospital with a diagnosis of heart failure are seen by the HFCNS before discharge and home visit arranged within 1-2 weeks of discharge. The patient is seen in the HFCNS clinic as required for follow-up with cardiologist input when necessary. The patients know that telephone contact to the cardiac care team after discharge is available 24 hours a day via the coronary care unit direct telephone line. The nature of heart failure denotes that it is a progressive disease and for this reason patients are able to refer themselves back into the program if they need further advice or support or if their condition deteriorates.

Heart failure is a complex, chronic, debilitating disease that requires patience and holistic care to enable patients' achieve the best possible quality of life. It is a chronic illness that requires continuency of health professional care to enable vulnerable patients cope with having a chronic progressive illness as well as the complexity of polypharmacy that most patients with heart failure are prescribed. Fagermoen (1997) alludes to the notion that these needs are a reality stating,

> A core characteristic of nursing as a practice discipline is that its practitioners work in close and continuous relationships with patients who are both vulnerable and partially or totally dependent on the nurse for the maintenance of their basic needs in coping with health deficiencies (p.434).

This research has been located in a secondary hospital, however having nurse-led clinics such as the HFCNS located in the primary sector may well enhance accessibility for some patients but issues such as cost to the patient for a visit to a health practice would need to be considered and the qualifications of the staff. Access to specialist colleague's advice is readily available in the secondary workplace and this may be a further issue that would need consideration as the primary health care develops the skills to successfully care for people with complex chronic illnesses such as heart failure. Further innovations to improve access to specialist care in the primary sector needs to be addressed such as the secondary service being more readily available to support and provide specialist advice to the primary healthcare givers, which could be a possible area of research to follow on from this study.

Summary:

HFCNS clinics are part of a strategy that has the propensity to improve and make available easy health care access, in order to achieve the best possible health outcomes for those people with chronic health illness such as heart failure. HFCNS clinics are an opportunity to integrate evidence-based best practice care with close collegial interaction with hospital based medical colleagues as well as GP's and practice nurses in managing and supporting this growing population of people with a condition that has potential outcomes that are worse than some malignancies (Martensson, Karlsson & Fridlund, 1998; Murray et al, 2002; Nainggolan, 2007; Toman, Harrison, & Logan, 2000).

Chronic illnesses are a health issue that require innovative ways to reduce the impact on the health dollar by enabling patients to understand their condition and learn to be proactive in managing their symptoms so that the need for admissions to hospital for exacerbations can be reduced further and when admitted be discharged home earlier. The HFCNS nurse is ideally situated to act as intermediary between the primary and secondary sectors to improve access to health care. This is particularly so with reference to Maori and also the elderly where evidence shows that these two groups appear to be most affected by chronic illnesses (Ministry of Health, 2003). In this research the terms chronic heart failure and chronic illness will be used interchangeably.

Aims of the study:

The aims of this study are:

- To explore what is important to the patients living with chronic heart failure;
- To explore what patients perceive as their needs when they attend or participate in HFCNS clinics;
- To describe the experiences of patients attending the HFCNS services from referral through to attending and participating in HFCNS clinics with the aim of gathering information to develop and improve the health care of these patients.
- To support and encourage patients with chronic heart failure develop self-management strategies.

Heart failure is a significant health issue that is at epidemic proportions and, increases exponentially with age. It is a chronic illness that is progressive with outcomes that are worse than some malignancies and is in contrast to other cardiovascular disease where mortality has reduced significantly over the last decades according to (Horowitz, Rein & Leventhal, 2004).

Chapter Two

Exploration of the Literature

Introduction:

This literature review aims to examine literature relating to patients' with chronic heart failure and nurse-managed clinics; to gain an understanding of the patients' experience of nurse-managed clinics and to understand what it is about nurse-managed clinics' that has made a difference to patient outcomes. Issues such as adherence to treatment, cultural norms, knowledge and education of heart failure, participation, empowerment and collaboration will be reviewed as they are all part of the continuum of care in nurse – managed clinics and reflect a holistic approach of expert nursing care.

As New Zealand literature on the topic is sparse, studies on nurse managed clinics in the primary and secondary health care sectors nationally and internationally have been reviewed. To increase the evidence on best practice management of patients with heart failure, international studies that have studied nurse-managed clinics in association within the broader concept of coronary heart disease and heart failure as a chronic illness have been reviewed.

A large number of articles relating to nurse-managed/led clinics/care and heart failure were found using CINAHL, Pubmed, Medscape, Omnus, MEDLINE, a DHB hospital library and Massey University Library system. The keywords used included heart failure, nurse–managed clinics, nurse-led clinics, patients' experiences, partnership, chronic illness and patient empowerment.

New Zealand Literature:

There were few articles that could be located from New Zealand relating to nurse-managed clinics. The principle ones are Clendon, (2003); Clendon and Krothe, (2004); Krothe and Clendon, (2006) on nurse-led community health clinics, and two audits of a nurse-managed cardiology clinic and nurse-managed heart failure clinic. Two studies relating to various aspects of heart failure management utilizing, the same cohort were described by the Auckland Heart Failure management group. A study exploring heart failure patient self-medication in nurse-managed clinic settings has been included as it is deemed appropriate for this research. No studies of specifically nurse-managed heart failure clinics were identified.

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Clendon and Krothe (2004) describe a dual study from the United States of America (USA) and New Zealand (NZ) using fourth generation evaluation to understand the factors that contribute to the success of nurse-managed clinics in the primary care setting. The Brown County Health Support Clinic (USA) and Mana Health Clinic (NZ) are two such clinics. Mana Health Clinic was the first nurse-managed clinic in a low decile school for primary aged children, which is also accessed by family members, caregivers and other people in the community in New Zealand. The clinic was opened in 2001 and provided treatment for minor injuries and illness, health education and promotion, and assessment with referral to other appropriate health services.

Although this is the first school clinic of this type in New Zealand similar clinics have been run in the USA since the 1970's but little evaluation had been done in that country. With the setting up of the first New Zealand clinic this was seen as an opportunity to combine two similar settings in two different countries and review outcomes using fourth generation evaluation methodology. The outcomes of the study suggested that using fourth generation evaluation was appropriate for analyzing the performance of nurse-managed clinics as it allowed the participants voices to be heard and it is 'especially appropriate with disenfranchised and indigenous populations who are traditionally disempowered through the use of traditional research tools' (p.248).

A study by Clendon (2003) evaluated nurse-managed clinics suggesting that understanding the effectiveness of the clinics would be greatest by utilizing a combination of quantitative and qualitative data. These clinics, although in the primary care setting, have relevance to this study particularly from the increasing need for secondary and primary care to promote more cohesiveness in the care and treatment of people with chronic health issues.

Hawkins and Cuthbert (2001) and Dewar and Cuthbert (2004) presented two papers at Australian and New Zealand Cardiac Society Scientific meetings. These studies were considered appropriate as both studies are related to the operation of nurse-managed clinics. Hawkins and Cuthbert (2001) audited a nurse-managed heart failure clinic aiming to understand what affect a nurse–managed clinic had on readmission rates. Admissions to hospital the year prior to attending the clinic and the year following attending a nurse-managed heart failure clinic were analysed and showed a significant reduction in re-admission rates in patients participating in nurse-managed heart failure clinics of 54%, however mortality rate remained similar to international standards of 10% per annum. As this study was quantitative, a qualitative study examining what patients valued from clinic attendances would add substance to the effectiveness of nurse-managed care.

Dewar and Cuthbert (2004) audited outcomes of a clinical nurse consultant clinic in a hospital setting for cardiac patients utilising the recommendations of the New Zealand Guidelines Group to show effectiveness. The data gathered, such as, cholesterol levels, blood pressure recordings and medications usage, suggested that the clinic had successfully achieved the goals for risk factor management. In the conclusion to this study the writers suggested that a qualitative study looking at patients experiences of nurse-managed clinics would add a further dimension to the value and benefit of these clinics.

Two studies relating to heart failure issues in New Zealand were identified. These studies were all part of the Auckland Heart Failure Management Study (AHFMS) analyzing different aspects of the study. Pearl et al (2003) hypothesized that there would be potential gains for patients with collaborative strategies linking secondary and primary care in their management of heart failure in the AHFMS study. One hundred and ninety seven patients were selected and randomly assigned to either usual care or a management group. The study was over a twelve-month time frame with the management group patients receiving education, clinical review alternating between their GP and the hospital clinic. Each patient had a diary to record medication and daily weight. The usual care group follow-up was with the GP. While there was no significant statistical difference between the two groups in their medication and weights, the GP's and patient's management group expressed a high level of satisfaction with the strategy of patient education and clinical reviews.

In the same study described above, further analysis was described by (Wright et al, 2003). Wright et al (2003) compared outcomes for patients who were randomized to either usual care or management care. The usual care group was followed up by their GP's, whereas the management care group completed daily dairies recording their weight and had three education sessions while attending the heart failure clinic program. The study concluded that the management group who completed daily weight diaries, attended the heart failure clinic and education sessions, self managed significantly higher that those in the usual care group. Those in the management group who did not or who were unable to do weighs or attend clinic had poorer outcomes overall. Although this study utilized the multidisciplinary team to manage the patients, follow-up did not include home visits from the clinic nurses. For those patients who might have had difficulty accessing the heart failure clinic or were perhaps socially isolated there may have been benefits from home visits.

Self-management is a concept that has been developed as a method of helping patients be proactive and manage symptoms when they occur and with the notion that this should reduce the need for hospitalization for exacerbations of heart failure. However not all patients are necessarily able to learn this skill with confidence due to a variety of reasons for instance cognitive functioning, language barriers and motivation. One aspect of self-management was described by Lindsay (2005) in the following section.

Lindsay (2005) explores medication self-management in a research report on heart failure patients' decision-making processes and perceptions when self-medicating diuretics in response to symptoms of heart failure. Lindsay used a mixed method approach to explore the topic with twelve participants who were recruited from a DHB that had three HFCNS clinics. The outcome of the study highlighted patient satisfaction with self-management and education from the HFCNS clinics, but also identified areas where inappropriate self-dosing and duration of medication changes were apparent with the recommendation that improvements to diuretic titration protocols should be considered.

Summary:

All the studies discussed above have described various aspects of care for HF patients', however none have reflected the more intimate aspect of the actual experience of attending and participating in nurse-managed care. This research is unique in New Zealand as no other studies of HFCNS clinics were identified in the literature. HFCNS clinics are becoming accepted, are enhancing access and providing holistic care. Local research into the efficiency and effectiveness of this role is essential to promote the role and also to provide evidence of quality of care and best practice guideline management. The role complements and does not usurp that of the doctors, providing a further channel for access focusing particularly on holistic care. A comprehensive program offering home visits and heart failure clinic reviews has had a positive impact on reducing readmissions and the cost of heart failure at a DHB (O'Meeghan, Hawkins & Cuthbert, 2002). Although this study is only reviewing one aspect of clinical nurse specialist–managed care, another very important aspect is the home visits that the HFCNS do as part of the program. These visits are an integral part of the program of nurse-managed care. Further studies incorporating both nurse-managed HF clinics and home visits would add to the information on the value and benefit of a comprehensive care package.

International Literature:

There is extensive international literature on nurse-managed/led clinics, heart failure and chronic illness. For instance, mortality, readmission rates, length of stay, quality of life and cost are all issues that impact on the value and benefit of nurse-managed clinics. Phillips, Singa, Rubin and Jaarsma (2005) performed a meta-regression analysis of specialist nurse-led heart failure clinics to determine whether a hierarchy of effectiveness was apparent in nurse-led clinics.
Of 3741 studies reviewed, the authors identified seven reports of six randomised controlled trials that were judged appropriate for the purposes of the analysis represented in Table 4. Qualitative methods were used to deconstruct and analyse the study protocols for recurrent themes. The six studies were categorised for complexity and the number of components to the study and patient outcomes such as mortality, re-admission, length of stay and cost were extracted as well as quality of life information gathered from the short form 36 (SF36) quality of life measurement, a validated tool used frequently to measure health and wellness. Outcomes

from these studies were positive, with complex programs showing a trend towards 70% relative risk reduction for readmission, reduced length of stay and a 70% reduction in risk of heart failure readmission relative to usual care. Less complex programs also showed a benefit, but somewhat less than the latter.

Table 4:

Characteristics of HF disease management in specialist heart failure nurse-led clinics.

Source	Sample number	Country	Components of the studied nurse-led clinics	Length of follow-up
Cline; Israelsson; Willenheimer; Broms & Erhardt, 1998	190	Sweden	CHF education and medication review. Home visit, telephone follow-up, nurse-led clinic, discharge planning.	12 months
Ekman, 1998	158	Sweden	CHF education, diary for daily weights, medication review, telephone follow-up, nurse-led clinic review.	6 months
McDonald et al, 2003 Ledwidge et al, 2002	98	Ireland	CHF education, medication optimization, telephone follow-up, nurse-led clinic review.	3 months
Doughty et al, 2002	197	New Zealand	CHF education, diary for weights, medication optimization, telephone follow-up, GP- nurse-led follow-up.	12 months
Kasper et al, 2002	200	USA	CHF education, medication optimisation, telephone follow-up, nurse-led clinic follow-up.	6months
Stromberg et al, 2003	106	Sweden	CHF education, medication review, counseling, telephone follow-up, nurse-led clinic follow-up.	12 months

Programs such as the above provide outcomes that are necessary for ongoing management support as savings can be shown from reduced length of stay and reduced readmissions. It is much harder to show the cost benefit from issues such as patient satisfaction, however it is important to understand patients' perceptions of outpatient clinics as issues such as access, availability, waiting times and usefulness of the clinic can all have an impact on whether or not the patient will attend their appointment. A recent DHB innovation to reduce patients classified as - did not attend (DNA), is to give patients the opportunity to select a day and time that suits their needs when being offered an appointment to a clinic. At this stage there have been no outcomes reported on this latest initiative that is being trialed as a measure to reduce waiting list time for appointments by reducing the number of DNA's.

Randomised controlled trials are one method of quantifying scientific evidence of the usefulness of specialist nurse-led interventions such as home visits and telephone follow-up. Blue et al (2001) performed a randomized controlled trial of specialist nurse intervention in heart failure. One hundred and sixty five participants were either randomized to usual care or specialist nurse intervention. Usual care consisted of management by the admitting physician and GP follow-up, with the intervention group having home visits and telephone follow-up by the specialist nurses with the aim of the specialist nurses educating the patient about heart failure, its treatment as well as teaching the optimum management of drugs, diet, self management and exercise. Outcomes monitored between the two groups included mortality, readmissions and cause specific readmission on a time to first event basis as well as length of stay. Although this study had relatively small numbers, the authors suggested that specialist nurse intervention could reduce readmission significantly with nurses being ideally placed to monitor titration of medications in the community for instance.

DHB management, with the aim of reducing health care expenditure, regularly reviews readmissions and healthcare costs. This is evident in a study by Cline, Israelsson, Willenheimer, Broms and Erhardt (1998), refer to Table 4, who studied the effects of a management program looking at outcomes of readmission and healthcare costs one year after discharge from hospital for heart failure. This was a prospective randomized trial with the control group managed according to routine clinical practice versus the intervention group who received education on heart failure self-management and ready access to nurse directed heart failure clinic. After one year the intervention group had fewer readmissions and the health care costs were less, possibly from fewer in hospital bed days. An assumption could be made that with patient education in self management and ready access to advice from heart failure nurses, the patients in the intervention group may have managed their symptoms better or have come to hospital earlier, therefore have been treated more effectively. The resulting outcome would be early discharge due to symptomatic relief and improvement of their condition.

Client satisfaction in nurse-managed care is an important concept that has been studied by Bear and Bowers (1998) who describe a nursing framework to measure client satisfaction at a nurse-managed senior health clinic. The framework chosen reflected the role of the nurse practitioners in the clinic utilizing therapeutic listening, education, the physical and psychosocial issues of individuals, setting goals and usual clinic processes. A tool was developed based on Cox's

Interactional Model of Client Health Behaviour to measure client satisfaction with the quality of the services received according to the nursing framework. Outcomes from the study highlighted client's satisfaction with the clinic and a step-wise regression model confirmed this satisfaction. It further explained that both technical competence and education on management strategies for self-care were particular aspects the clients found useful. Other aspects of the nurse-managed clinic such as collaborative holistic care will be discussed in the following chapters.

The phenomena of participation and non-participation of patients attending nurse-led clinics was studied by Eldh, Enfors and Ekman (2004). Narrative interviews were conducted with ten patients using a preformulated guide to elicit the notion of participation and non-participation in the patients' health care. In the analysis, participation was revealed as being confident, comprehending and having a sense of control whereas non-participation was not understanding the notion of participation, lack of control and not being accountable for one's actions. The study had issues with trustworthiness and validity, and the complexity of the qualitative method the writers chose. One of the concluding comments suggests that interaction between the nurse and client should include a discussion on the patient's views and experience of participation in healthcare, an area that is an integral aspect of expert holistic nursing care in CNSHF clinics. Collaboration between the patient and nurse is an essential component of successful nursing care. It enables the giving of knowledge both from the nurse to the patient and also the reverse, from the patient to the nurse knowledge that may be the key understanding how the patient perceives healthcare.

Partnership between the patient and nurse is a key theme in a study by Henrick (2001). It is a concept that has gained momentum in the last decade. Henrick studied the outcomes of a HF clinic managed by a clinical nurse specialist in consultation with the chief of cardiology. The clinic is located in the outpatient department with criteria for referral of patients such as, NYHA classification 11-1V HF, an ejection fraction of equal to or less than 40% and one or more admissions to hospital for HF in the last year.

The philosophy of the clinic is partnership with the nurse and patient working together to overcome barriers likely to deter adherence to behavioural changes. The study highlights strategies through case studies of patients who have been successful in making and maintaining changes and as a result improving their health outcomes. Three validated tools are used in the clinic to measure health outcomes. They are; The Chronic Heart Failure Questionnaire, The Minnesota Living with Heart Failure Questionnaire, and The Yale Dyspnea-Fatigue Index for CHF. The tools are useful to gage patient centered outcomes. Other data was also gathered to show admission rates before and after referral to the clinic and savings from reduced readmissions and reduced length of stay when admitted.

Henricks (2001) study represents the patients who are referred to a DHB HFCNS clinic, however the tools that have been used in the study provide valuable and useful evidence as to the effectiveness and efficacy of the CNSHF clinic, tools that will be investigated for utilization in a DHB clinic as a validated measure of effectiveness.

Having expert knowledge of heart failure and ability to communicate are necessary skills for the nurse that can make the difference for the patient coping with and managing the symptoms of heart failure. Communication between the patient and nurse enables the giving of knowledge and both knowledge and communication are aspects that are aptly discussed in an article by Rogers et al (2000), who studied twenty seven patients using in-depth interviews to investigate the patients knowledge and information needs starting with an opening question 'can you tell me how your heart failure started.' A constant comparative method was used to analyse the data as this method allows expected and new themes to be explored and be used to guide subsequent interviews. In conclusion the writers comment 'good communication requires the ability both to listen and impart relevant information' which are essential attributes of CNS's who care for patients with chronic illnesses. Although this study discussed communication issues between patients and doctors it can be applied to HFCNS clinic as the working of the DHB clinic is collaborative with both nurses and doctors participating equally in the care of the patients.

The importance of knowledge and having tools to enable self-care are issues that Riegel, Dickson, Goldberg and Deatrick (2007) measured in a mixed method study of twenty-nine participants with chronic heart failure. Qualitative and quantitative data were combined to gauge whether patients had poor, good or expert knowledge of heart failure self-care. In this study just over 10% of the participants mastered self-care according to the criteria of the study. This low number suggests that new ways need to be found to help patients develop expertise in self-care, as self-care is an essential component of managing and coping with chronic illness.

Discourse on adherence/compliance has been the subject of numerous studies to try and elicit the primary causes of non-adherence in people with health problems. Scotto (2005) used phenomenological approach in her research on the lived experience of adherence to a prescribed regimen of care with fourteen patients attending an outpatient heart failure clinic. Scotto (2005) identified themes that have an impact on adherence that include personal values and beliefs, support from family and friends, support from health care professionals and strength to persist in lifestyle changes. From this study one could assume that issues such as social isolation can impact on adherence. It also gives credence to the need for consistency in care from health professionals, a role that sits well with nurse-led clinics and a partnership model to aiding adherence.

Ayers (2005) evaluated a nurse-led heart failure clinic. There were six main objectives of the service that included providing a holistic service; provide education for patients and health professionals; optimize medications; follow patients up; develop links with palliative care and develop links between secondary and primary care. The HF team included a consultant nurse, two CNS of whom one was employed in secondary care and the other in the primary sector providing a seamless integration of care. Evaluation of outcomes included; readmission rates, optimal medications, GP consults and mortality data. The project has been ongoing for three years at the time of reporting with acknowledged improvement in outcomes for patients, with the conclusion that " nurse-led initiatives can make dramatic improvements in patients' lives as well as to families, health care resources and the National Health Service (p. 36).

Summary:

This international literature review has identified concepts that have the potential to impact on the value and benefit of nurse-managed clinics. HFCNS clinics are acknowledged as an innovative method of reducing health care costs by reducing readmissions and length of stay in a population that has a progressive chronic illness.

Concepts such as participation and partnership have shown increased patient satisfaction and adherence to management strategies that in turn increases the likelihood of patients learning self care strategies. Furthermore the notion of nurse-managed heart failure clinics has gained impetus from scientific evidence of their success as another avenue for access to expert holistic health care.

Heart failure: a chronic illness

Chronic illness includes, but is not limited to, diabetes, heart failure, chronic obstructive airways disease and cardiovascular disease, hence heart failure is recognized as one of the continuum of chronic illnesses according to (Rea et al, 2007).

Heart failure is recognized as a common clinical syndrome representing the end-stage of several different cardiac diseases. It may be related to structural or functional cardiac problems that have impaired the ability of the ventricles to fill with, or eject blood from or into, the circulatory system. Left heart failure – systolic dysfunction and right failure – diastolic dysfunction, are the two mechanisms by which reduced cardiac output and HF occur, (Colucci, 2006).

There are a number of factors that may cause HF that include: coronary artery disease, Hypertension, Valvular Heart Disease, Viral Infections, Alcoholic and Idiopathic Cardiomyopathies, Endocrine disorders - Thyroid particularly, Congenital heart disease and chronic arrythmias (Heart Foundation, 2001). Damage to the left ventricle from ST elevated myocardial infarction is the commonest cause of heart failure in people under 75 years of age, whereas in the elderly diagnosis is often more difficult due to co-morbidities such as hypertension, hypertrophy and fibrosis obscuring the findings.

Living with Heart Failure means living with a complex clinical syndrome that is characterized by episodes of acute decompensation along with periods of relative stability (Feenstra, Grobbee, Jonkman, Hoes, & Stricker, 1998; Leventhal, Reigal, Carlson, & De Geest, 2005). The major problems associated with heart failure are dyspnoea and fatigue as a result of reduced oxygen delivery to the working skeletal muscle mediated through impaired left ventricular function and, as a result, a significantly reduced quality of life with frequent exacerbations and frequent hospitalization (Kaan & Dunne, 2001; Yu, Lee, Woo, & Thompson, 2004). In New Zealand heart failure represents one of the commonest discharge diagnoses in elderly patients (Doughty, 1999).

When heart failure is diagnosed it may mean a drastic change in lifestyle for the patient and family. Health professional support is key in educating and counseling the patient and family on how to manage and adhere to treatment plans so that physical function and the best quality of life is maintained for as long as possible (Dracup et al, 1994). Riegel, Dickson, Goldberg and Deatrick (2007) state, "as the syndrome advances, persons with HF begin a cycle of fluid retention, acute symptom exacerbation, and hospitalization that is best prevented with vigilant self-care" (p.235).

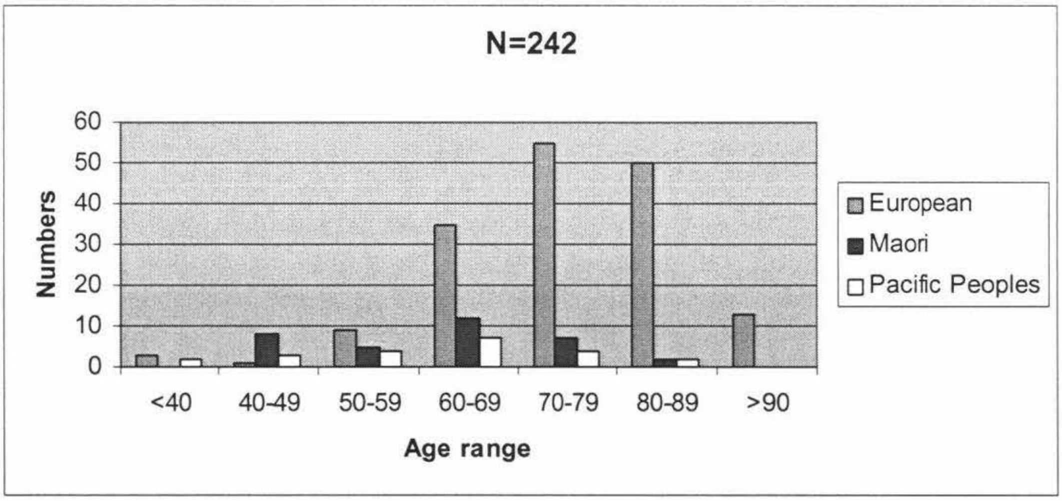
Heart failure outcomes have not changed significantly in the last 20 years with the prognosis being comparable or worse than many malignancies (Martensson, Karlsson & Fridlund, 1998; Murray et al, 2002; Nainggolan, 2007; Toman, Harrison, & Logan, 2000), with mortality in mild to moderate heart failure at 5 years of 50% and in severe heart failure at 50% - 60% at one year (Friedrich & Bohm, 2007). Levy, Kenchaiah, and Larson, (2002) comment on gender differences in heart failure apparent at five years with mortality at 45% for females and 59% for males. Ancheta (2006) expands on HF mortality further suggesting that men and women have an approximately 21% risk of developing heart failure overall, with only 20% of women living longer than 8 to 12 years.

The incidence of heart failure has been described as epidemic and likely to increase, even after adjustment for an aging population (Caboral, 2006; Deaton & Grady, 2004; Profant, & Dinsdale, 2000; Zambroski, 2003), a phenomena that is recognized throughout the Western world. It is recognized as one of the leading causes of hospital admissions and its prevalence increases exponentially from the age of sixty years (Almeida & Flicker, 2001; Artinian, Magnan, Sloan & Lange, 2002; Cline, Israelsson, Willenheimer, Broms & Erhardt, 1998).

In the United States of America approximately one in twelve elders suffers from heart failure according to Riegal et al (2002), and this incidence is similar in New Zealand. However, Maori bear the brunt of heart failure in New Zealand particularly in the younger 45-64 year group in comparison with non-Maori (Riddell, 2005). This is comparable with figures from a local hospital clinic population for the year July1st 2006 – June 31st 2007, with Maori average age of 62.5 years of age being 12 years less than the average for non-Maori of 74.5 years of age as represented in Table 5. Sisk et al, (2006) contends that in the USA the elderly and blacks have a higher incidence of heart failure similar to that described by Riddell (2005).

Table 5:

Heart Failure Clinic Age range and ethnicity July 1st 2006 - June 31st 2007



Heart failure is a chronic condition that can impose a significant financial, physical and emotional burden on patients, their families and society as a whole according to Baas, Fontana, and Bhat, (1997), with health care costs estimated at 1-2% of total health care budgets (Cline et al, 1998). Heart failure is reaching epidemic proportions and it is listed as one of the most frequent and costliest conditions (Blyth et al, 1997). Strategies need to be developed to reduce the incidence of HF, reduce hospitalization and, length of stay when a patient is admitted.

Sharpe (2000) notes that hospitalization for heart failure is not only common but also prolonged giving figures for length of stay for the UK of 11.4 days on acute medical wards and 28.5 days on acute geriatric wards. Hay (2004) quotes figures for length of stay in hospital for heart failure in New Zealand with a mean of 9.9 days for men and 26.2 days for women. The difference between men and women in length of stay is suggested by Hay (2004) to be due to a prolonged length of stay for women with heart failure. Nicholls and Richard (2007), report that at least 54% of admissions to hospital for acute exacerbation of heart failure are most likely preventable. Nicholls and Richard (2007) consider that comprehensive programs emphasizing heart failure education are necessary to help the patient understand the need for adherence to medication regimes and compliance with treatments, such as a low salt diet and regular exercise.

Chronic heart failure is a debilitating disease that requires a holistic approach adapted to each individual's unique set of medical, psychosocial, behavioural, educational and environmental circumstances (Cheng & Ng, 2004; Grange, 2005). Chronic heart failure can be an emotional as well as physically disruptive experience, which impacts on family and friends. The term heart failure in itself has negative connotations that can confer a sense of hopelessness. This is addressed by working with the patient in a partnership, providing empathy, advice, knowledge and support to maintain the best quality of life for as long as possible. HFCNS clinics are an ideal setting for developing connectedness with patients enhancing the potential of meaningful comprehensive collaborative care.

Summary:

Heart failure is a significant health issue that is at epidemic proportions, increasing exponentially with age. This is reflected by an aging population and lives saved and people living longer from improved management of people with coronary heart disease, valvular cardiac disease and diseases that impact on the heart such as diabetes, hypertension and cardiomyopathies, attributed to medical and surgical therapies. According to Gheorghiade, Filippatos, De Luca & Burnett, (2006) secondary prevention medications or rehabilitation contribute the greatest proportion in saved lives. It is a chronic illness that is progressive and in contrast to other cardiovascular diseases where mortality has reduced significantly, HF deaths have increased 145% from 1979-1999 in the USA alone (Horowitz, Rein & Leventhal, 2004). Innovative measures need to be taken to improve quality of life and outcomes for this growing group of people who have a preponderance of older people and Maori with a greater risk of developing this chronic condition. It is vitally important that preventative strategies are focused on, to enable heart failure patients to be motivated to take responsibility for understanding how best to manage their illness and with care slow down the progress of the disease, and achieve the best possible quality of life for as long as possible.

Conceptually, nurse-managed/led clinics for patients with chronic illness such as heart failure have the propensity to provide an avenue of expert holistic care for a population that has a worse outcome than most malignancies. With the continuing evidence of disparities in health and health care and the aging of the population innovative measures need to be encouraged, and this is in keeping with ‘health for all’ strategies outlined by the (Ministry of Health, 2003). This literature review has shown that nurse-managed clinics are integral to evidence-based best practice holistic care of patients with chronic illnesses.

Chapter Three

Research design and method

Introduction:

In this chapter the tenets supporting this inquiry will clarify the paradigm within which this research sits. The reasons for mixed method as the design and the choice of narrative as the form of methodological inquiry; the relevance contextually with both the underlying paradigm and the research setting will be discussed.

Paradigm

A paradigm is defined by Andrew and Halcomb (2008) as, "philosophical underpinnings from which specific research approaches stem" (P.180). These philosophical underpinnings will be considered under ontological and epistemological accords. Schneider, Elliot, LoBiondo-Wood and Haber (2003) expand paradigm further in the setting of qualitative studies suggesting, "Qualitative research requires consideration of three philosophical concepts – ontology, epistemology and methodology.

The three concepts; ontology, epistemology and methodology are articulated by Schneider et al (2003) in this way;

- Ontology provides the world view that guides a study

- Epistemology provides focus for a study
- Methodology provides a design for conduction of a study (p.141).

Ontology is defined as knowledge around the context of the nature of what kind of being is a human being and what is the nature of reality. Reality is defined in Blackwells Dictionary of Nursing (1998), as "the aggregate of all things that have an objective existence; not imaginary, fictitious or pretended" (p. 569). In this study objective existence is gaining an understanding of living with chronic heart failure and the reality of the experience of attending and participating in HFCNS-managed clinics.

Interrelated to ontology is the concept of epistemology, or ways of knowing between the inquirer and the known, providing the focus for this study. Another definition of paradigm is alluded to by Roberts and Taylor (1999) as, "a broad view or perspective on something" (p.12). That is to say a "world view" or in other words "a comprehensive approach to a particular area of interest" (p.12).

Design

The design for this study was selected after discussions with research supervisors and research students with the conclusion that the work was exploratory. The purpose of exploratory research is to study an issue or problem that has not been studied before and this is in context with the research being undertaken in this study according to Oman, Krugman and Fink (2003).

This study has narrative inquiry as a main qualitative strategy that underpins the mixed method design. This was seen as a feasible way of understanding the workings of a nurse-managed clinic from the patients' perspective using both questionnaires and unstructured interviews to obtain the necessary data.

Mixed Method

Although this research is mixed method utilizing quantitative and qualitative paradigms, the principle methodology is qualitative. The aim of this study is to identify the clinic population for the purpose of context and then focus specifically on the patients' perceived needs when they attend or participate in HFCNS clinics.

For this reason mixed method approach was used as it is acknowledged that this study sits well within the mixed method design described by Morse (2003),

> Mixed method design is the incorporation of various qualitative or quantitative strategies within a single project that may have either a qualitative or a quantitative theoretical drive. The 'imported' strategies are supplemental to the major or core method and serve to enlighten or provide clues that are followed up within the core method (p.191).

Morse (2003) explains using a strategy incorporating both qualitative and quantitative thus "in qualitative inquiry, supplemental data may be quantitative - the results of psychometric testing, for instance - and these results are then incorporated into the emerging model, providing a richer explanation" (p.193). Morse's (2003) explanation sits well with the intent of this research of using qualitative narrative with supplemental data looking at the demographics of the HFCNS clinic population and three short answer questions to give direction to the planned interviews. The notion of using two forms of data collection are discussed by Renwick, Brown and Nagler (1996) who articulate that for researching individuals and their environment, quantitative methodology has definite value in the validity of the evidence it provides, it's ease of use, and the ability to generalize to similar groups or populations from the evidence. Whereas for qualitative research the uniqueness of the individuals life experiences are valued with semi-structured or open-ended interviewing utilized to gain information.

This study is about understanding the notion of healthcare from the patients' perspective, and this is confirmed by Brookes (2007) who states, "qualitative research is able to capture and communicate the client perspective of healthcare" (p. 32).

Narrative sits in the qualitative domain and as such "qualitative researchers operate under a set of beliefs and assumptions that differ to those held by quantitative researchers. These relate to ontology and epistemology, truth and objectivity, and researcher/participant relationships (Roberts & Taylor, 1999, p. 141). Denzin and Lincoln (1994) suggest a different approach to qualitative research stating

> Qualitative research is multi-method in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret phenomena in terms of the meanings people give to them (p. 2).

A methodological framework informed by Polkinghorne's (1988) narrative work was decided on because it is inclusive of narrative referring "to any spoken or written presentation" (p.13). And whilst this study is mainly of an oral narrative context with 6 in-depth interviews, it also contains references to written responses from questions in the study questionnaires. Polkinghorne (1988) articulates, "...when in a questionnaire the 'narrative' designates that answers are to be given in sentences or paragraphs instead of single words or short phrases" (p. 13). This fits well with the questionnaire data source of this research. As the replies to the questionnaire were unsolicited many of the answers contained insightful meanings of attending and participating in CNSHF clinics and have been used to emphasize certain aspects of this study. This sits well within the overarching mixed method design where imported material from the questionnaires is supplemental to the interview data.

Narrative as story

Schwandt (2001) defines story this way,

> Several senses of this term figure prominently in many versions of qualitative inquiry. Generally the term refers to any spoken or written presentation, but it is primarily used in a more narrow sense to mean a form of genre of presentation organized in story form (p. 168).

The description is congruent with Polkinghornes (1988) description of stories, "the oral stories produced by respondents in an interview are dynamically different from the written texts of history or fictional narratives, which have been the focus of attention in previous studies of narrative' (p. 164).

Polkinghorne (1988) describes the use of discourse theory to understand how narrative is effected in the situation of an interview, stating in discourse theory, "the story is the result of the total situation – the teller of the story, the codes of the story, the interviewer and the hearer. In this context the story selected to be told can function to present a particular image of the teller; and the kind of interview the hearer undertakes can affect the kind of story told" (p. 164).

The concept of stories is expanded by Koch (1998) who comments,

> People live stories, and in their telling of them, reaffirm them, modify them, and create new ones. Constructions of experience are always on the move. Stories, when well crafted, are spurs to the imagination, and through our imaginative participation in the created worlds, empathic forms of understanding are advanced (p.1183).

Narrative as inquiry for nursing

Using narratives for understanding personal and social issues has been the domain of psychology for well over a decade, prior to which scholars such as philosophers, sociologists and anthropologists utilized narratives in their studies (Hurwitz, Greenhalgh & Skulans, 2004; McCance, McKenna & Boore, 2001).

Nursing has of more recent times begun to see the value in narrative as a way of explaining experiences according to Frid, Ohlen, and Bergbom (2000) and a pathway to improving knowledge about nursing care. Hurwitz, Greenhalgh & Skultans (2004) state, "narratives in healthcare have found maturity as field of interdisciplinary study" (p.2).

Aranda & Street (2000) suggest narrative is a useful tool for making sense of experiences as it provides a methodology that encourages the gathering of rich, multidimensional data in the clinical setting such as a nurse-led clinic. Furthermore Edwards (2001) suggests that understanding how the narrative of a person can affect nursing practice is an issue that must be put into context.

The lived experience of patients in this study and their creativity in their stories are the essence of Koch's (1998) viewpoint on stories and how "stories can make nursing practice visible" (p.1183).

Narrative as inquiry for participants

Mattingly (2004) discusses narrative and how patients narratives can be healing for them stating, " I look at narrative in an expanded sense, not only as something told but also as something that can be acted in the form of healing dramas" (p. 73). Furthermore Mattingly (2004) suggests "these performed narratives can play a powerful role in clinical care" (p. 74). The concept of performed narrative can be seen in one of the participants' response in this study in an attempt at negotiating with the doctors for further options for the management of his illness (Max; Lines 188-189).

Narratives present the voice of the patient and can be therapeutic, or they may show us where changes could be made to improve practice (Koch, 1998). Hence the use of narrative as the principle methodology for this study. Narrative research is one of many qualitative research designs that can be used to answer questions about personal experiences in health, illness, death and health care delivery, by using narratives to look back at the experiences of patients either individually or as groups (Minichiello, Sullivan, Greenwood & Axford, 1999).

Narrative as meaningfulness

Polkinghorne (1988) considers narrative in its relation to meaning making stating,

> It is a complex form, which expresses itself by drawing together descriptions of states of affairs contained in individual sentences into a particular type of discourse. This drawing together creates a higher order of meaning that discloses relationships among the states of affair. Narrative recognizes the meaningfulness of individual experiences by noting how they function as parts in the whole (p. 36).

Narrative is a rich source of knowledge according to Clinchy (2003). Clinchy suggests that the procedures for constructing and interpreting narratives add to a more meaningful essence of what is being studied.

O'Reilly (2002) discusses the concept of meaningfulness in relation to illness experience and suggests that "narrative is seen as natural to the way that nurses work with people, and intrinsic to the way that people create meaning" (p. 22). Polkinghorne (1988) proceeds to define the meaning of narrative as "the fundamental scheme for linking individual human actions and events into interrelated aspects of an understandable composite" (p. 13). Bailey and Tilley (2002) address narrative further by commenting on nursing using a paradigm where meaning rather than truth are a legitimate expression of qualitative inquiry.

Researching the experiences of patients attending and participating in clinics will generate useful insights into the workings of the clinics, the natural way nurses work with people and also provide meaningful information on the needs as seen by patients with illnesses such as chronic heart failure. Polkinghorne (1988) confirms this commenting, "Experience is meaningful and human behaviour is generated and informed by this meaningfulness" (p.1).

Narrative as experience

Using narrative design allows the researcher to make sense of experience, in this case the experiences of patients attending and participating in nurse-managed clinics.

Narrative is a methodology in which researcher and the research participants walk a journey together, in a two–way process of listening and learning (Maher, 2003), and effective listening can elicit meaningful messages that help the health professional gain insight into the patient's experiences. Reflecting on the narratives/stories in nurse-patient discussions, and analyzing them may give insight into what effect they might have, how they might be used and how they can change individuals. Specifically Edwards (2001) states, " that in order to understand a person, to understand what they say and do, it will be necessary to place what they say and do within the context of their narrative" (p. 93).

Personal Narratives Group (1989) wrote about personal narratives of people this way:

> When talking about their lives, people lie sometimes, forget a lot, exaggerate, become confused, and get things wrong. Yet they are revealing truths. These truths don't reveal the past "as it actually was," aspiring to a standard of objectivity. They give us instead truths of our experiences…. Unlike the truth of the scientific ideal, the truths of personal narratives are neither open to proof or self-evident. We come to understand them only through interpretation, paying careful attention to the contexts that shape their creation and to the worldviews that inform them. Sometimes the truths we see in personal narratives jar us from our complacent security as interpreters "outside" the story and make us aware that our own place in the world plays a part in our interpretation and shapes the meanings we derive from them (p.261).

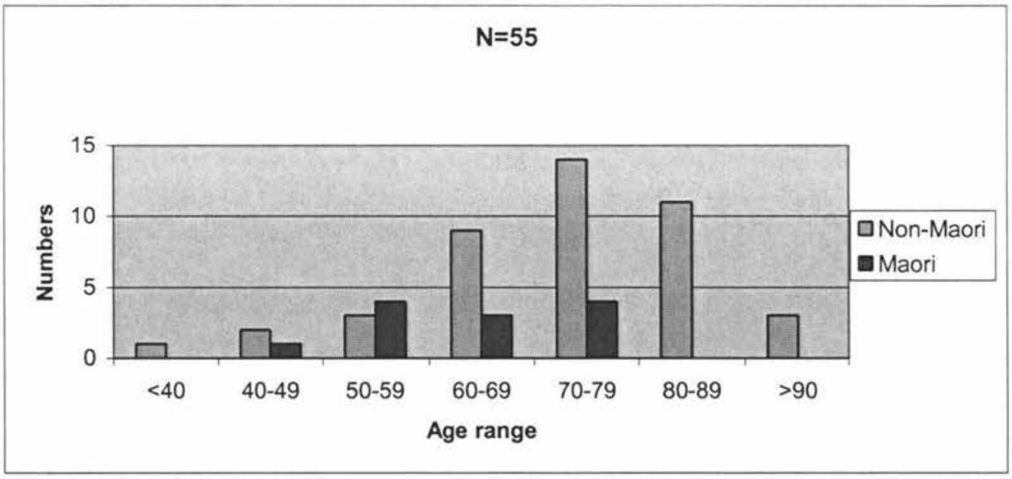
Personal Narratives Group (1989) comments can be seen in responses from participants in this research. For instance one participant gave a very colourful rendition of his life with what one could assume were gross exaggerations as to his drinking habits but in reflection his story was possibly his way of trying to understand why he had developed heart failure and the chronicity of this illness. Another participant described how her perceptions of her culture had influenced her negativity regarding health care and medications. After several HFCNS clinic sessions the meaningfulness of the advice and education she received from the CNS's helped her cope with a regime of medications recommended for the management of chronic heart failure. In both stories described above the participants are interpreting their lifestyles and cultures as a way of understanding living with chronic heart failure.

Research setting and recruitment

After gaining the support of the HFCNS nurses for the study and ethical approval, all patients attending the heart failure clinics over approximately eight weeks were invited to complete a questionnaire while they were waiting for their appointment or alternatively they could take the questionnaire home and complete it and then return it to the clinic. Over the study time period, 55 patients classified as either non-Maori or Maori ethnicity with an age range similar to patients in Table 5 completed the questionnaires represented in Table 6. The similarity in age range and ethnicity suggests that the HFCNS clinic population over the study time was appropriate and gave a realistic view of patients' perceptions and needs that will be described in further chapters.

Table 6:

HFCNS clinic population age and ethnicity over eight-week timeframe of study



Participants were asked as part of the questionnaire if they would be available for an in-depth interview. From the positive responses, three males and three females were purposely selected for interview. Of the six participants two were Maori, and this was to ensure a range of ages, sex and ethnicity. All interviews with the exception of one were undertaken in the participant's own home with interviews lasting between 34 and 55 minutes. As Morse (1994) suggests, a good informant is "one who has the knowledge and experience the researcher requires, has the ability to reflect, is articulate, has the time to be interviewed and is willing to participate in the study" (p.228). All interviews were audio recorded on a laptop computer and transcribed by a medical typist. Prior to the interview the reasons for the interview were restated, and the participants were reminded of the objectives of the research. It was important that the participants understood the need to sign the consent form prior to the interview commencing. The interview commenced with an opening question 'what were your first thoughts when you realized you were coming to a specialist nurse clinic?' The style of the interviews was unstructured and as Mischler (1986) suggests, using relatively unstructured interviews allows the respondents to speak in their own voices, and therefore be freer with their responses.

Issues such as consideration of the clinician/researcher dyad was important, as the researcher participates in the clinic environment with the heart failure team, and although the participants and respondents in this study are cared for by the HFCNs there is the potential for an unequal relationship to occur. Minichiello, Sullivan, Greenwood and Axford (2004) comment on the potential for unequal power when the researcher is strongly motivated and encourages participants to be part of the study, which may put a vulnerable participant in a position of feeling that they should participate. Careful consideration of the potential of unequal power was deliberated on with the ensuing method of inviting the administration staff to handout and collect in the questionnaires so that the researcher was not seen to be influential on recruitment outcomes. Yanos and Zeidonis (2006) also comment on the need to be aware of vulnerable patients where there is a risk of exploitation or harm, stating that vulnerable patients should not be considered for research projects.

Ethics committee approval

Since this study constitutes part of a Master of Philosophy (Nursing) program at Massey University and databases at a DHB were accessed, ethical approval and permission was sought from the Central Regional Ethics Committee, (Appendix 1) Massey University Human Ethics Committee, and the DHB Human Ethics committee. The DHB process could not be commenced until Central Regional Ethics Approval had been gained. The DHB process involved getting approval from 7 disciplines:

- The Maori Health Unit
- Pacific Health Unit
- Medical Director
- Nursing Director
- DHB Lawyer
- Quality Unit
- Medical Services Manager

This process can take up to a month for sign-off but is necessary to protect the participants, the researcher and the DHB.

The Central Regional Ethics approval process was somewhat longer with two requests for more information and some changes to wording required. Understandably, time constraints are issues that need to be thoroughly considered when working to deadlines.

Patient Questionnaire

All patients attending HFCNS clinics were invited to take part in the research. The clinic nurse handed out an information sheet (Appendix 2) on the research project to each patient along with the questionnaire (Appendix3). The questionnaires were anonymous. Questionnaires that were not completed while waiting for clinic could be taken home and filled in and returned to the clinic in an addressed, prepaid envelope. Out of eighty-six patients who attended the HFCNS clinics, fifty-five or 64% questionnaires were completed and returned to the clinic nurse. Reasons for not completing the questionnaires were noted by clinic administrators as: difficulty in reading English, not interested, and taken home and not returned (Anderson. D, personal communication, May 27th, 2007). The questionnaire consisted of several yes/no questions on demographics such as, age, gender, ethnicity, and marital or otherwise status and would they attend a similar clinic in the community and if so where should it be located. Three short answer questions were asked to gain early an impression of the HFCNS clinic and as guides for the interviews. The questions are,

- What did you find most useful about the specialist nurse clinic?
- In your own words what is wrong with your heart?
- What are the most important health issues for you today?

Interviews

There are 2 basic types of interviews, structured and unstructured. For this study unstructured interviews has been chosen as more likely to elicit in-depth information from the participants. Unstructured interviews are similar to a normal conversation with the responses of the participant used to enlarge on the topic. The interviewer guides the conversation through a general framework of open ended questions with the minimum of interruptions, tying the interviewers questions and comments to those of the participants and repeating their words wherever possible to encourage the participant to expand on their thoughts – you mentioned…could you tell me a bit more about that (Roberts and Taylor, 1999). Morse (1994) discusses unstructured interviews, commenting that participants are encouraged to tell whole stories rather that bits and pieces that you might for instance get in a questionnaire. Polkinghorne (1988) elaborates further suggesting, "if we wish to hear respondents stories, then we must invite them into our work as collaborators, sharing control with them, so that together we try to understand what their stories are about" (p.164).

Of the fifty five questionnaires that were completed and returned, fourteen participants answered yes to the question 'if you would like to participate in a further interview to discuss your experiences of attending and participating in HFCNS clinics more fully, please advise the clinic nurse.' Of the 14 participants who indicated yes to the question, four identified as Maori, ten as non-Maori or other. The clinic nurse collated names, ethnicity and telephone contact details of patients who voluntarily agreed to be interviewed. For this study six respondents were purposely selected to give a range of age, gender and ethnicity that reflected the HFCNS clinic population.

Patients attending the HFCNS clinics were predominantly European, followed by Maori or Pacific represented in Table 5, and it is therefore important to hear different cultures experiences of attending and participating in HFCNS clinics. Maori experiences are particularly important as studies continue to show that there is disparity in health care for Maori compared to non-Maori according to (Penney, 2005; Riddell, 2005; Wilson, 2007). Gaining an understanding of participants' perceptions of health care may give an understanding of what health care issues are foremost in being the causative factors in the recognized issue of unequal treatment for different cultural populations. Phibbs (2007) comments on positioning stating "social relationships and cultural practices are embedded in the stories (narratives) through which people constitute their identities" (p.3), and furthermore Phibbs (2007) contends that when conversing with others, people draw on their own cultural and personal experiences to actively build a picture of the current event.

Interviewing takes practice and even then it can be quite challenging to keep the focus on what the interview is about. Participants purposely selected for interviews were sent a further information sheet outlining the interview process (Appendix 4). A consent form for the interview was sent at the same time so that the participant could have time to consider the implications of consenting to a personal interview (Appendix5). A timeframe of three weeks was suggested giving the potential participant time to read and discuss the research with family or significant others and decide whether he/she still wished to participate.

All except one interview were undertaken in the participant's own homes, at a time that was suitable to participants. One participant chose to come to the hospital for his interview as he found it convenient to come in after work. Five of the participants had attended the HFCNS clinics several times. For one participant it was her first visit to the HFCNS clinic.
The following chapter will present the stories of the participants individually in the context of their perception of chronic heart failure and HFCNS care.

Chapter Four

Interviewed participants' stories:

Introduction:

The notion of narrative means that one needs to have a concept of the background to the person writing or telling the story, for this reason an overview of each of the six participant's stories is written to illuminate commonalities and also individual aspects that highlighted their impressions of nurse-managed clinics. This is in keeping with Polkinghorne's (1988) discourse on narrative, where he states,

> narrative is a form of 'meaning making.' It is a complex form that expresses itself by drawing together descriptions of states of affairs contained in individual sentences into a particular type of discourse. The drawing together creates a higher order of meaning that discloses relationships among the states of affair. Narrative recognizes the meaningfulness of individual experience by noting how they function as parts in a whole (p.36).

The impact of having a chronic illness is discussed and how this impacts on the participant and their personal and cultural environment. Each story is followed by the researchers' reflection, as interpreting the stories and developing a more in-depth understanding of the participant's experiences is, the essence of this research. Each story is unique in its own way and is presented on a separate page as an indication of uniqueness, and 'meaningfulness', and of the privilege the researcher has had in being invited to listen to participants stories.

For privacy and confidentiality the participant's names have been changed as agreed in discussion with the participants. The researcher has mainly used adaptations of the letters in the names to make new names for the participants. The respondents to the questionnaires are identified in order of attendance at the HFCNS clinics as Pt.1 to Pt.55.

Andie's story

Andie retired from work as a librarian some years ago. She was in her home, a place that is also home to lots of plants, books and cats that give Andie companionship as she copes with several illnesses. She has recently been diagnosed with heart failure as a complication of diabetes, hypertension and obesity. Andie was referred to the nurse-managed clinic for education and medication titration. Andie had some useful insights into healthcare as a regular user that she willingly shared,

> *"I am a firm believer that if it's anything to do with me, I should know about it – I need to know who I am dealing with. People need to introduce themselves and I need to understand what follow-up is arranged and what for"* (Lines 88-90).

Andie had attended a doctors' clinic where the first question from the doctor was,

" Well what are you here for? and I said, well I don't know – I just received the appointment in the mail, so he did change some of my medication, improved things there which was useful – just so you won't have a wasted journey he said – but I don't know – you just get a thing to say you are to see so and so at a certain time and there is nothing there to say why you are coming and certainly on my previous visit here(doctors clinic) I was not told I would get further appointments" (Line 96-100).

Andie found the comments not helpful, as the impression Andie had was that she was wasting the doctors' time.

Andie knows her way around the health system and this is clearly described by Andie,

> "*Last time I had to come in for a procedure they wanted me here at 7.30 in the morning of all the ridiculous times, so I got myself admitted to hospital a couple of days beforehand. And they said 'seeing you are here we don't need to go down so early,' that was when they were going to shock the heart to try and get it going evenly again*" (Lines 45-49).

Andie has services such as home help for personal cares and house cleaning which enables her to remain mainly independent, however, Andie commented that sometime in the future she would probably need the care of a rest home. Andie has insight into her healthcare needs but finds it difficult to make and maintain lifestyle changes that would possibly decrease her healthcare needs.

Reflection

Andie was the first interview I carried out. Andie appeared comfortable and seemed quite relaxed about being interviewed. Andie was interested in the concept of a laptop computer being used for interviews and watched, as it was set-up and a trial run done. The interview lasted for 36 minutes and I had to remind myself to listen and not interrupt or give reasons as to why events had occurred. This was Andie's story and it was important that she felt free to express herself.

Andie is a confident person who appeared to be happy with the opportunity to have her say about health care. Andie knows how to access health care and also understands that sometimes it is necessary to pre-empt health care plans to suit individual needs.

Andrew's story

I interviewed Andrew in his home with his partner quietly working in the background. Andrew was referred to the nurse-managed clinic after he had 'messed up' his pills that had resulted in an admission to hospital with grossly swollen legs and breathlessness. Andrew identified as Maori and has lived a colourful life. He had developed cardiomyopathy as a result of his earlier lifestyle and was now learning to live with heart failure. Andrew is not comfortable with the restrictions of a hospital system but he will access hospital care when he feels he needs that level of care. Andrew listens to people who respond in a vernacular that he understands, and is reactive if too many demands are made. This was apparent when the HFCNS suggested to Andrew that she would admit him to the ward. Andrews tells the story thus

> *"She (CNS) tried to make me stay in here. I said I am not going to stay here. She said why not and I said I don't have to stay here if I don't want to. I said to her, all I came for was a check up and see what happened to me"* (Lines. 62-64).

Andrew took some time to feel comfortable with talking about his experiences of nurse-managed care, he needs to get to know people to develop the sense of trust to feel free to relate the colourful stories of his life. Andrew describes his first visit to clinic

> *"I didn't know who the nurse was, I just told her to go take a hike until I got used to her after a while and then she started to get me going in there quite a lot and standing on the scales…"* (Lines.156-157).

Andrew's partner is important in ensuring Andrew takes his medications regularly, does daily weighs and keeps in contact with his GP. Andrew has realized he has a health problem that is going to impinge on his life if he does not take steps to manage it.

Reflection

It took several phone calls to finally make contact with Andrew. Andrew appeared to lead a busy life. He agreed to be interviewed after I had answered questions regarding the format of the interview. After arriving at Andrews home and introducing ourselves, Andrews first question was

> "*What is this all about anyhow?*" (Line.1).

It took some time to encourage Andrew into talking about his clinic experience. Andrew was somewhat reluctant to discuss this and would go off on a tangent about his rather colourful life as a younger person. Andrew said to me after I had guided him back to the study concepts for the third time.

> "*You are persistent, you really do want to know about the clinic*" (Line. 197).

Andrew had initially found coming to the HFCNS clinic threatening stating,

> "*She was the one I got angry with*" (Line. 4).

One might assume that Andrew having thought the nurse was of Maori ethnicity was annoyed that the nurse had not followed Maori cultural processes by introducing herself correctly identifying her iwi, hapu and whanau, so that Andrew could then follow the same process and thereby set the scene for the clinic appointment to proceed. Verbal reports from the HFCNS suggest that not infrequently the issue of the HFCNS ethic origins is discussed and is not infrequently incorrect. One could assume that cultural safety needs have not been met in that the cultural values and norms for the participant were not recognized. Cultural safety involves recognizing that we all have our own cultures and that we need to be aware of the concept of unequal power when we impose our views on other cultures distinct from our own.

Max's story

Max was sitting on the front step of his home smoking a cigarette when I called around to interview him. Max's first words to me were apologetic about his smoking but, as he said,

> *"The doctor's have told me there is nothing else they can do for me so I might as well enjoy my cigarettes, but I don't smoke as many now".*

Max invited us into the dining room for the interview and immediately started discussing the hopelessness he felt. During the interview Max reiterated several times the hopelessness of his situation and how he was struggling to make the changes to his lifestyle that the doctors had recommended, stating

> *"So I gave up drinking but I still have maybe 5, 6 or 7 smokes a day because what else is there left in life? Because as the doctor said to me at Christmas, there is nothing more we can do for you. So I have just got to put up with it"* (Lines. 27-30*).*

Max's story was about loss and frustration, loss of hope, loss of a lifestyle he had enjoyed, frustration that he was not suitable for heart surgery, frustration that he had a chronic disease that impaired his quality of life, stating,

> *"Having chronic heart failure has ruined my life, I was working and walking everywhere, now it takes me all my time to walk to the local shops"* (Lines. 40-47).

Max participates in nurse-managed care and with support has gradually made changes to his lifestyle and has a goal of making it to his 70th birthday. Max is comfortable with coming to the HFCNS clinic, he 'knows' the nurse he sees. Max's perception of nurse-managed care is that it

> *"It takes the strain off the doctors to start with and as I said, if a person doing the clinic wasn't capable or didn't have the qualifications then they just wouldn't have the job"* (Lines. 215- 217).

Max commented on issues with hospital information, in particular discharge letters stating, that they need to be written in a laypersons language and not abbreviations that he did not understand.

Reflection

When I rang Max to confirm the interview, Max's comment over the telephone 'well I might as well do something useful'. This was the feeling throughout the interview. Max felt hopeless as most of the activities he had enjoyed were now outside his capabilities, and Max was struggling to cope with the knowledge that there was nothing more the Doctors could do to help him. Max comments

> *"I ask myself why I lived like I did, but then that's what we all did as merchant seamen"* (Lines. 179-180).

Max continues to adjust to his changed life. After a recent admission with exacerbation of heart failure Max is determined to continue with the changes, he has goals he wants to achieve and appears more positive about his future. Max has developed trust in the heart failure team and is starting to see that there is a future for him as he learns to cope with the vagrancies of chronic heart failure.

Mada's story

Mada chose to come to the hospital for his interview as he worked nearby. Mada is comfortable with the environment of the hospital as he sees it as where he receives specialist care that has kept him alive. Mada's story developed around his recognition of chronic illness and the impact on his family and the need for as much normality as possible. Mada feels he needs regular specialist care as he had experienced gaps in his care previously. Mada's sees nurse-managed clinics as an ideal way of accessing specialist care for security and for regular follow-up. Mada also feels that Doctor's are to busy for more than a brief to the point clinic review whereas at the HFCNS clinics he has time to think and ask questions, saying,

> *"You have the perception that the cardiologists are very busy–you tell them as much as they want to know, but you don't tell them anymore because you perceive their time is very - , they need every bit of every minute. Nurse clinic is more relaxed and you can think of things to ask"* (Lines. 226-231).

Mada pointed out that although he had a very good relationship with his GP, he considered that the GP looked after routine health care and the hospital provided specialist care and was the most appropriate environment for that level of care. Mada and his family had lived with Mada's chronic illness for over seven years through several life threatening acute episodes. At Mada's last acute admission he had an internal cardio defibrillator implanted due to his unstable heart rhythm. Mada and his family discussed life and death issues and all were aware that sudden death was a possibility, and they were told he would not be able to work again. When Mada returned home he decided with his families support to totally rest himself, take the stress off himself and let his heart heal itself. He gradually increased his activity levels over the next 4 years and when he felt he was mentally ready, returned to full-time work, which he continues to do today.

Reflection

Mada understands the health system and is proactive in arranging the health care he perceives as his right. Mada kept his family informed but also liked to be in control of any decisions regarding his health. Mada is an example of patient empowerment. He has learnt how to manage his chronic illness and he knows whether GP or specialist review is the best option for his symptoms. Mada keeps his GP informed of his specialist appointments as Mada sees the services complementing each other in his health care.

Celia's story

I visited Celia in her sunny home for the interview. Celia has had heart failure for a number of years and was initially reluctant to make changes, as she was quite suspicious of Pakeha treatments, a hangover from before her university years.

Celia identified as Maori and had led a very active life prior to her illness being diagnosed. Celia talked about being Maori and perceived research involving Maori as,

> *" Maori being the most highly qualified research people Maori for everything and anything researched and it would be good to see some outcomes fed back from the research"* (Lines. 115-116).

Celia has participated in several research projects and has also studied at tertiary institutes. Celia has adapted her life to living with chronic illness and with support and advice from the nurse-managed clinic has learnt to recognize changes in her health and adjust her medications appropriately. Celia talked about her experiences of HFCNS clinic saying,

> "*They (HFCNS) have done a good job on me because I am pretty stubborn. HFCNS clinic advises on what all the meds are about so you understand that –I began to get suspicious that now I have got all these pills one must counteract the other pill and you get all these suspicions in your head and you think, oh I'm not going to take it then. But I used to go in there (HFCNS clinic) and I would get another one and I would think, what the hell have I got that one for. If this one does the same thing but they did assist each other doing the same thing but I thought why the hell were they giving me two when I already had one. But then I realized one was not enough if I was to look after myself. So*

what HFCNS clinic did for me was to help me gain some confidence in that perhaps the medication offered was helping. I found them really good (HFCNS) I enjoyed going to see them actually" (Lines. 50-58).

Reflection

Celia is a woman who has confidence in her culture and is not afraid to talk about how her cultural perception to health initially made it difficult for her to accept Pakeha advice. Patients' cultures can affect the way they understand health and illness, as is evident form Celia's response to Pakeha medications. Celia has developed knowledge and skills in managing her health with the advice and support of the HFCNS's. Celia enjoys an active life and has also learnt to listen to her body and say no if she feels her health could be affected by to many demands on her time. A persons' culture can also affect how they access to health care services and respond to treatments. This is evident from Celia's apparent frustration with accessing primary health care. Celia has no difficulty now a days in accessing secondary care for herself but finds the primary system is harder to negotiate and at times out of sheer frustration at delays or not knowing the health professional she is seeing, has left the surgery before being seen. Anecdotally, cardiology clinic patients have vented their frustrations on the lack of 'family doctors.' The perception that you have a named GP for your primary health care giver is no longer the norm and patients' report that having to retell their medical history each time a different doctor is seen can have a negative impact in accessing timely and appropriate health care.

Lona's story

Lona invited me into her home that is surrounded by hills and trees. Lona is an older woman who lives with her husband, who like Lona has had heart surgery. Lona had been quite well and really hadn't had much to do with the hospital until a heart valve became incompetent. Being on the public waiting list meant a long wait for surgery to replace the valve with Lona getting more debilitated over that time. It also meant that Lona's heart valve became more compromised with the outcome of the valve surgery not being as beneficial as projected because of the long wait. . Lona had quite a rough recovery following her mitral valve surgery, and became chronically ill with heart failure. Lona was referred to the nurse-managed clinic to educate and support her cope with the illness. This is evident from Lona's comment

> *"the nurses taught me how to use my pills properly – I found them very, very beneficial"* (Lines.18-20).

Lona now feels confident in managing her symptoms and has no hesitation in seeking advice from appropriate services when needed. Lona explained her feelings stating

> *"It is horrible when you are first told there is something wrong with your heart as it is the main organ in your body"* (Line. 26.)

Lona has regained her confidence and is now happy to go and stay at an isolated beach with her husband in their caravan, something they had not done for some years owing to Lona's illness.

Reflection

My first impression of Lona when I spoke to her on the telephone was her anxiety and dependence on health services for any issue concerning herself. Lona had lost confidence in managing her symptoms because she had expected the heart valve surgery to make her feel better. Unfortunately with the long wait for surgery and a gradual deterioration in her health over this time, Lona had become more reliant on health professionals to manage her symptoms. When visited at home Lona was very thankful for all the advice and help that she had been given by the heart failure team. Lona had regained her confidence and was back to living well and enjoying activities with her husband.

Conclusion

The six stories from the participants have commonalities but they are also all uniquely individual with each participants' story of living with chronic heart failure. The participants' perceptions of attending and participating in HFCNS care are compelling listening. The researcher is deeply indebted to the participants for being so free with their personal experiences of health care. The different perspectives of health care and levels of connectedness with health professionals will be highlighted further in the thematic analysis of the participants' stories, which follows in the next chapter.

Chapter Five

Analysis of the interviews and questionnaires data:

In this chapter, analysis of the narrative data will utilize an inductive method of thematic analysis to determine major concepts and themes that were common to all the interview participants and respondents to the questionnaires. Mischler (1986) suggests that in analysing narratives, the researcher works to actively find the voice of the participant in a particular time, place or setting. In this study the analysis will be working with both oral and written narratives to understand personal experiences of nurse-managed care.

The questionnaire respondents wrote their narratives, while the interviewed participants verbalized their narratives, but both groups, respondents and participants, had common themes that are presented in the thematic analysis. It is important to point out that the answers to the questions in the questionnaires were collated to see what themes were emerging before proceeding with the interviews.

Techniques used to promote credibility of the findings included audio taping the interviews on a laptop computer and verbatim transcription of each interview to ensure accuracy of the data. The transcriptions were returned to the participants for their opinion on whether the preliminary interpretation of the findings made sense of their experience, and that the authenticity of the data was guaranteed. Two participants made minor changes to wording in their interview transcriptions.

Themes:

The over arching theme in this study is the giving of meaningful knowledge in HFCNS clinics, and by doing so, helping patients to understand how to live with and self manage strategies to enable coping with chronic heart failure.

Principle themes and sub themes that emerged from the data included:

- **Gaining knowledge**
    - Gaining knowledge/understanding heart failure
    - Education
    - Taking time/pacing education
    - Explaining treatment
    - Learning self-care/developing expertise
- **Making changes**
    - Gaining confidence
    - Hopelessness/hopefulness
    - Rationalizing
    - Family/relationships
    - Physical incapacities
- **Partnership**
    - Trusting environment

    - Partnership
    - Learning adherence
- **Ethnicity/cultural perceptions**
    - Communication/talking the talk
    - Accessibility/availability
    - Values, beliefs and cultural safety
- **Collegial collaboration/professional care**
    - Collaboration
    - Expert care/ professionalism

Gaining knowledge

Sub themes:

Gaining knowledge/understanding heart failure;

The sharing of knowledge and helping patients understand heart failure is an essential component of nursing care in a HFCNS clinic. As stated previously, heart failure is a complex illness that is difficult to manage with polypharmacy which can be confusing, with dietary requirements and lifestyle changes needed to help improve outcomes in a disease that is progressive with the possibility of frequent readmissions for exacerbation of heart failure.

Gaining knowledge is recognized as an important facet by patients and is commented on by 18 out of 38 respondents to the question –'what did you find most useful about the HFCNS clinic?' Comments that alluded to the usefulness of the clinic care as perceived by patients included,

> *"The nurse had practical ideas – down to earth- very useful"* (Pt.4);
>
> *"understanding my condition and the effect of the drugs used to manage my condition"* (Pt.13);
>
> *"It's very good for me that one of the nurses is Samoan and can explain things to me in my own language"(*Pt.16);
>
> *"The nurses' explanation excellent, understands condition better"* (Pt.39),

Knowledge is power and is constituted through discourse. This can be applied to patients with HF who through discourse with HFCNS are empowered to take control, to feel confident and be proactive about the management of symptoms such as adjusting a diuretic dose (a medication the helps remove excess fluid from the body) according to sudden weight gain and or increased breathlessness. From the writer's experience, comments from patients attending nurse-led clinics frequently include thanks for taking the time to listen and answer questions in a way that the patient could understand.

Educating:

Education is an essential component of expert nursing care in a nurse-led clinic. The nurse educates the patient to self manage his/her lifestyle and medications to prevent symptoms and to be proactive when his/her condition changes. Celia who commented articulates this,

> *"I have found them (HFCNS) exceptionally good for me. It (HFCNS clinic) encourages me to look at what I can do for myself to well, really live longer"* (Lines. 37-38).

Mada elaborated on education stating,

> *" I have learnt to self titrate medications as worked out by HFCNS with an action plan for sudden weight gain and/or increased breathlessness"* (Lines.68-70).

Educating patients can be a long and sometimes frustrating process for the nurse and this is reflected by Andrew who has struggled with the notion of having a chronic condition that needed him to take some responsibility for regular healthcare and medications. It was taking the time to listen and, acceptance of the stage where Andrew was at by the HFCNS nurse that eventually helped Andrew understand his chronic condition and the part he had to play in maintaining his wellness. It aided Andrew having a partner. She made sure he had regular health checks and had his prescription filled before he ran out of his medications. These were all activities that previously Andrew had been reluctant to do and probably did not understand the implications of not doing so

Taking time/pacing education;

Timing and pacing of education follows on from the previous sub-section and reflects the health professional taking time to listen and pace the education to the patients needs. Several participants commented on having time in the clinic to think and be listened to, and this is alluded to by Mada as he reflected on differences between health professional clinics, stating

> *"If they (doctors) ask any questions you tell them as much as they want to know but you don't tell them any more because you perceive that their time is very – they need every bit of every minute whereas in a nurse clinic yes, it is more relaxed and you can think of things to ask..."* (Lines. 29-231).

Taking time and listening is confirmed by the respondents to the question 'what did you find most useful about the HFCNS clinic?'

> *"Nurse excellent – very patient, keeps me informed of changes"* (Pt. 5),
>
> and, *"very informative, not at all rushed"* (Pt.22).

This leads on to the notion of listening, which several participants acknowledged in the HFCNS clinic. Taking the time to listen as well as answer questions is time consuming, however it is very clear from the interviews and the questionnaires that taking time and not being rushed is an essential component of a well-managed nurse clinic.

Explaining treatment;

Listening and explaining the reasons for treatment, medications and what heart failure is may need to be repeated at each clinic visit. Lona who stated reflects this,

> *"The HF nurses explain everything and it has gradually sunk in"* (L.69).

Celia who talks about having heart failure explained to her in the HFCNS clinic highlights this further,

> *"It is a lot easier now you actually know what the Doctor's are talking about"* (Line.79).

Furthermore Mada makes the comment that again reflects educating and explaining when commenting

> *"She (nurse) explained what different drugs do, making sure the Warfarin is right, the water retention pills and that sort of thing…"*(Lines. 51-52).

One area that patients were particularly interested in was medication side effects and what to do if they perceived intolerance to a medication, which is similar to Mada's need to know the reasons for, and class effect of medications. Andie reflecting on the nurse clinic commented,

> *" It is good to have things explained in your own language as to what is wrong with you and why things are being done and I think nurses are better at that"* (Lines. 203-204).

Andie commented that the nurses took the time to listen and answer any questions she had. For Andie, having good clear explanations was necessary as she liked to know what was happening to her body and why. Acceptance of health issues can be daunting but with having a rationale for treatment and risk versus benefit explained, often the patient can then 'get to grips' with the issue and cope better. Celia makes this point stating

> *" I know now how to manage most of it – irregular heart beats - and so for me it is retaining the ability to look after one's self"* (Lines. 99-100).

Conversely Mada commented on health professionals not listening with particular reference to a side effect of a medication. Mada verbalized his frustration saying

> *"I find that nobody says anything about that and when I mentioned it to the nurses and doctors the whole three of them said, really I didn't know that"* (Lines.111-112).

In Mada's case, simply listening and empathizing with him over the side-effect as he sees it would probably dissipate the frustration and make the medication more tolerable to him. Health professionals have a professional body to report medication side effects to, 'The Centre for Adverse Reactions Monitoring' MIMS 2007, (p.g.13). The researcher believes health professionals should be reporting possible side effects of medications to appropriate monitoring agencies so that more information can be gathered and further action taken if necessary.

Learning self-care/ developing expertise;

Learning self-care is an essential skill for patients with chronic illness to enable them to have some control over exacerbations of their illness. Recognising changes in their health and initiating measures such as an action plan for acute shortness of breath (appendix 3) may make the difference to the need for a visit to the emergency department or GP. Mada acknowledges this in a comment about care in the HFCNS clinic when he talked about coming to clinic at his request,

> *"I have asked to see her (HFCNS) on a yearly basis… it just keeps me on track and gives me just a bit of back-up"* (Lines. 80-81).

That the patient is the expert in their own care was described several times in a DHB clinical services document, and this is the focus of HFCNS clinics. The patient is the expert in his/her own care and nurse-led clinics are providing support, advice and encouragement to empower the patient to manage what is a significant chronic illness.

Making changes

Sub themes:

Gaining confidence;

Lona describes gaining confidence when she was asked about heart failure symptoms. She stated,

> "*I don't panic now*" (Line.125),

Lona had gradually learnt to take control when she had symptoms such as palpitations or breathlessness and knew what activities were likely to bring on symptoms so had adjusted her activities to cope. Lona also knew she could get advice/ support anytime by ringing the coronary care unit if it was after-hours, or talking to one of the heart failure team during normal work hours. Lona pointed out clearly the value and benefit of having ready access to advice stating

> *"There was always someone there if I rang up who would help which I rang quite a lot and there was always someone to advise me what to do and things like that"* (Lines.36-37).

Over time Lona has gained confidence and now rarely needs to call in for advice (D.Carter, personal communication, August 21, 2007).

Hopelessness / hopefulness;

In this section I am reminded of Max and his sadness at being told by the Doctor's,

> "*There is nothing more that we can do for you*" (Lines. 28-29).

Max repeated this three times during the interview as he talked about what chronic illness meant to him and how difficult it was to accept he would not be offered surgery to repair his heart valves. He wondered what point there was in making any changes to his lifestyle such as reducing alcohol and cigarette smoking, if there was nothing more that could be done for him. Tinged with the sadness of not being able to manage as much effort, Max had gradually made some changes and had started to feel some hopefulness by having some goals in mind such as reaching his seventieth birthday.

Conversely, Andie reflected on the impact of chronic illness and talked about hopefulness from even simple messages such as

> *"getting good news even if it was just to say the ECG was good and how this buoys you up a bit"* (Lines.108-109).

Both Max and Andie initially had a sense of hopelessness with the knowledge they had to cope with heart failure, but with time and the support of the HFCNS clinic have both made changes albeit gradually and both now have future goals in mind.

A perspective on living with chronic illness is posited by Le Maistre (1999) "chronic illness is being able-hearted when you can no longer be able-bodied" (p.1). This would suggest that hopelessness has changed with the chronic illness being lived with rather than being seen as a failure, a change of attitude, which both Andie and Max appeared to be accepting of.

Rationalizing;

Blackwell's Dictionary of Nursing (1998) defines rationalizing as " a mental process whereby a person explains an emotionally activated occurrence by substituting one that is more acceptable than the truth, both to himself and to others" (p.568).

Mada rationalized his near death experience by telling his family he needed to rest his whole body to allow his heart to heal. Furthermore a viewpoint on rationalizing came from Max as he explained a vision that occurred whilst he was critically unwell. In the vision he was in a tunnel that was red, hot and smoky and he could hear voices telling him not to give in, to keep fighting. When I discussed this with Max later he stated

> *"He thought the devil didn't want him and that his time hadn't come yet and when it did it would be to the 'other side', which he said would be much better and did not worry him at all."*

Several heart failure patients in an answer to a question in the questionnaire 'In your own words, what is wrong with your heart' stated there was nothing wrong with their heart even though they had all been admitted to hospital for heart failure. One could suggest they rationalized that they did not have anything wrong with their heart because they perceive heart failure as an acute condition rather than a chronic illness and therefore believe they are cured when their symptoms have been relieved as suggested by Horowitz, Rein and Leventhal, (2004). This is where reinforcement that heart failure is a chronic illness which is progressive, is essential as symptom onset can be gradual with subtle changes that may not be recognized until the patient requires admission to hospital for acute exacerbation of heart failure.

Family/Relationships;

Mada's story of resting his body for 4 years with his family supporting his need to try and regain his wellness by complete rest and making do financially as best they could is not an uncommon scenario for families struggling with chronic illness (Asbring, 2000).

Mada also struggles with the loss of sexuality but in saying this accepts that in the meantime reducing or changing medications that can be implicated with impotence is not an option as he has been told by his health professionals, that he might not survive without the medications.

Sexuality is an issue that is often forgotten in the illness continuum but is an issue that can have a seriously negative impact on family well being if not discussed with careful and empathetic advice given. The issue of sexuality is reflected on by Mada, who commented on the need to know possible side effects of medications. He had not realized sexual difficulties were possibly due to medications. He had been told just to accept this as medications are more important, and as Mada commented

> *"Well you know, if it is going to prolong your life then you have to accept it (impotence), but it isn't easy to accept"* (Lines.128-129).

At the time of the interview Mada gave the impression that he was disappointed and frustrated with his sexual status but had also realized that if it was the difference between living and possibly dying then he really had no choice.

Max at the end of the interview also reflected on sexuality after the microphone was turned off when he discussed his

" lack of sexual activity and wished he understood why it (penis) wasn't working as he missed this part of his life."

Sexuality is an issue that health professionals may well find difficult or embarrassing to discuss with their patients. However if not attended to, one misses the opportunity to provide care for the whole patient rather than just a part.

Physical incapacity;

Most of the participants in this study had to restrict their activities due to their heart failure symptoms. Max comments

" Actually it has stuffed up my whole life hasn't it" (Line. 55)?

Conversely Mada has accepted he has limitations, stating,

" I can still do a lot of things" (Line.139).

Rather than focus on what activities the participant cannot do, in clinic the nurses concentrate on the activities the participant can do even if adjustments need to be made to achieve the activity. It is often a matter of suggesting 'chunking' activities into ten – fifteen minutes of activity and then taking a rest. This way activities like gardening or housework can be managed albeit slowly (M. Hawkins, personal communication, September 20th, 2007).

The majority of participants had to give up work because of their chronic illness. The older participants particularly had given up fulltime work as this was to taxing. They either retired or were involved in part-time or voluntary work mainly for the social activity.

Celia had made changes with advice and support from the HFCNS clinic. Celia commented on the HFCNS clinic

> *"... helping to keep my basic functions going, because I was really sporty and then all of a sudden I just did not want to do it because it was to much of a hassle, ran out of puff and all that sort of thing and here I was thinking I was unfit, but it was the sickness...It (HFCNS) encourages me to look at what I can do"* (Lines.28-33).

Several respondents to the question 'what are the most important health issues for you today?' commented on their desire to be physically well enough to return to work or either in the community or in the home. Comments such as

> *"Returning to work full-time, I want to be independent"* (Pt. 12).
>
> *"I want to return to work and live normally"* (Pt.14).
>
> *" Surviving so I can look after my wife and continue to live at home"* (Pt. 11).

Clearly defined goals are an important part of coping with a chronic disabling illness. When physical incapacity leads to unemployment it can also cause financial stress for the participants and this came through from Mada in his comment

> *"It was financially tough for his family"* (Line. 161).

For issues such as financial or psychosocial, drawing on the expertise of other interdisciplinary team members such as social workers is recommended for holistic care of patients (Rankins, Stallings & London, 2005).

Partnership

Sub themes:

Trusting environment;

An environment that enables the development of trust is essential for patients to feel secure and respected. This in turn encourages patients to feel their concerns are taken seriously so that they feel free to confide in you. The notion of trust is evident in the answers from several respondents to the question 'what did you find most useful about the specialist nurse clinic?'

> *"A sense of being a human being and not a disease. My husband has someone who knows him who we can contact for advice-good feeling"* (Pt. 15).
>
> *"It is nice to go somewhere where people care about you"* (Pt.2).

Several participants also reflected the notion of trust with comments such as Mada's comment

> *"I actually knew the nurses capabilities before I actually went to the clinic so it did not worry me at all coming to a nurse-led clinic"* (Lines. 3-4).

Lona describes trusting the advice of a HFCNS commenting

> *"I rung down there and HFCNS was on and I managed to get him and he eased my mind and I think it is very very beneficial to have the heart failure part and the nurses and everything to go with it. I think it is very very good"* (Lines. 41-44).

The notion of trust is a necessary component of effective health care relationships in treating chronic illness. Celia describes this when she said

> *"I felt I was a number attending lots of things earlier than that (HFCNS clinic) and that they (HFCNS) were actually interested in my condition. More interested in the beginning than I was, I just thought I would have to attend so would come. So I have found then (HFCNS) exceptionally good for me. It encourages me to look at what I can do for myself to really, well live longer, to be able to do things I would normally have done in the sporting and all those sort of things that I probably would not be able to do had I just kept going and doing things my way instead of how they have provided"* (Line.34-39).

Partnership/partnering;

Partnership approaches have the potential to empower patients and enhance their ability to be independent by involving them in learning to manage their own health issues.

In this research the process of partnership is related to power sharing and negotiation aimed at empowering the patient become independent in self-care strategies such as knowing when to access health professional advice if breathlessness increases associated with sudden weight gain or being able to appropriately adjust diuretics, thereby avoiding hospitalisation.

In the HFCNS clinic situation, utilizing a partnership model of caring creates an environment for enabling the patient to develop autonomy in self-care although; the process of learning self-care may take several visits and in some patients, mixed success.

Lona reflects this stating,

> "S*ince I have been going to the HF clinic I haven't had to go to hospital again - I could ring up anytime, there was always someone there who could give me advice and ease my mind"* (Line. 36-37).

The more the nurse truly involves him/herself in what the patient experiences, and the more he/she listens to and supports the patient, the more effective the education and strategies are likely to be (Diers, 2004). Andie expands further on partnership stating,

> *" You do feel part of a team rather than just poked out on my own"* (Line. 186), and
>
> *"I have always sort of been on my own all my life and it is nice to have someone there"* (Line. 189).

Ethnicity/cultural perceptions

Sub themes:

Communication/talking the talk;

Communication is defined in Mosby's Medical, Nursing &Allied Health Dictionary (2002) as "any process in which a message containing information is transferred, especially from one person to another, via any number of media. Communication is basic too all nursing and contributes to the development of all therapeutic relationships" (p.368). This is reflected in the answers to a question – what did you find most useful about the specialist nurse clinic?

> *" It's very good for me that one of the nurses is Samoan and can explain things to me in my own language*" (Pt.16).

A number of patients who attend the HFCNS clinic are from the Pacific Islands and particularly in the older group may have minimal English skills. Having a Samoan speaking HFCNS has been beneficial in the management and care of this group of patients. Furthermore Andrew and Max commented on the difference in communication styles by staff and how they responded to those different styles. For instance Max commented on a staff member saying

> *"You could speak to her because I think she swore at me as much as I swore at her"* (Line. 46).

Andrew also responded to staff who spoke in a similar vernacular to his own rather colourful, humourous and sometimes pointed responses.

Benner (1984) talks about humour suggesting that expert nurses use humour as part of a communication strategy. It is knowing how and when to use humour and knowing your patient to be able to do this. It may be as simple as picking up on a humourous moment and responding similarly that helps you connect with a patient.

Wilson (2008) makes some interesting points regarding practicing in 'an uniformed manner'. What Wilson (2008) is suggesting is that nurses need to have a good understanding of Maori values when providing health care such as, manaaki ki te tangata and titiro, whakarongo, korero. Manaaki ki te tangata is about looking after people, working together in collaboration and reciprocity and titiro, whakarongo, korero suggests that the nurse should look, listen and then speak, so that so that you work together for an outcome that both parties are comfortable with, rather than impose a 'one shoe fits all' approach to health care. Being listened to, was identified by several of the respondents and participants as one of the benefits of attending and participating in nurse-led clinics and this is why nurse-led clinics have time slots of one hour for each appointment. This allows time for listening and talking through issues that might well impact on how the person copes with a serious illness.

Accessibility/availability;

Accessibility and availability were issues that were mentioned by several of the participants and respondents. The issue with access was related to transport and car parking and the distance needed to walk from car parks to the clinic especially if breathlessness was an issue. One participant also remarked on the difficulty in getting appointments at his health practice and therefore would come to the emergency department if he perceived he required help.
In the questionnaire, 28 out of 55 respondents to the question 'Where would you like a clinic such as the heart failure clinic …replied they would like a clinic in their local area, for instance on a marae or on a bus route or somewhere local where there were car parks available. The remaining 27 were happy accessing the hospital with comments such as

> *"I like coming here"* (Pt. 42) and
>
> *"I like seeing the same nurse"* (Pt. 44).

Conversely Celia commented on waiting in the waiting room for clinic and how good this was as it allowed for discussion with other patients with similar conditions and was reassuring for Celia. From personal experience with adult cardiology patients the same message has been given, that waiting is not viewed negatively but rather, seen as an opportunity to read information and talk with patients in the waiting room and to have time to think about what they want to ask during the clinic visit.

Values and beliefs, cultural safety;

At a recent clinical reference group meeting discussing heart disease, it was apparent that Maori remain underserved in most areas of cardiovascular care (Penney, 2005; Riddell, 2005). A topic that was discussed was that of cultural values and beliefs and the impact of these on accessing care. Celia described values, beliefs and cultural acceptance when she talked about being suspicious of 'Pakeha' medicine. Celia commented on the time it took for her to trust and become confident in the CNSHF clinic management stating

> *" It (clinic) is there to assist and yet sometimes it might take a while , but it is adding more to the lives of our people and led me to ensure that the options that are given to you are taken"* (Lines. 44-46).

Cultural values and beliefs could also be perceived as the reason for Andrew's response on his first visit to the HFCNS clinic. Andrew responded

> *"I did not know who the nurse was, I just told her to go take a hike ..."* (Line.155).

As I re-read the interview, the perception of Andrew's need to know who the HFCNS was became apparent as he stated later in the interview,

> *"I thought at first I thought she was a Maori and that is when she said to me, no I am Samoan, and I said really'* (Line.158-159).

Maori culture could expect a Maori nurse to introduce herself, her iwi, hapu and whanau, and if this protocol is not followed it could be seen as disrespectful. Personal experience in the setting of a cardiology clinic was similar when a middle age Maori patient burst into clinic demanding to know why he had to be seen. He proceeded to say who he was, his family and his tribal connections, his work history and areas where he had lived. After listening quietly, quite fascinated by his story it was possible to talk about family and family connections. Only then was it possible to talk about why he was at the clinic. Appropriate introduction is not just specific to Maori as the issue of introducing one's self was also mention by Andie, a non-Maori woman who commented

"I find that quite a few people are not to good at introducing themselves and that is something I got confused with, with the nurse-led clinic but the doctors have done it too – not introduced themselves" (Lines. 88-90).

Wilson (2003) comments on a dominant biomedical world view on health held by many health professionals which Wilson states does not recognise the issues impacting on indigenous health and therefore health care can be unresponsive to cultural diversity. Wilson (2003) notes that nurses are ideally situated in all health sectors from primary through to tertiary services to make an impact on indigenous health. With the advent of nurse-led clinics there is an opportunity to be at the forefront of providing a service that reflects an understanding of cultural diversity with the skill and knowledge to enable care that will enhance the health of all people.

Collegial collaboration/professional care

Sub themes:

Collaboration;

Collaborative practice exists in a number of forms including traditional hierarchical relationships however as the HFCNS clinics have developed the hierarchical relationship has changed to a more collegial relationship. Mada reflected this when he commented

> *" You know when you come to clinic, backup is there, is not just one person, the whole team is there"* (Lines. 279-280).

Mada went on to discuss GP care commenting that he sees his GP every three months and HFCNS annually and that they regularly collaborate over his management. Collaborative care can also be seen in the interaction between the HFCNS and colleagues when any advice or support is needed for example in the titration of medications or interventions. Protocols have been developed so that the HFCNS can titrate medications in clinic such as frusemide (a diuretic which helps remove excess fluid from the body) and carvedilol (a new generation beta-blocker that reduces the workload of the heart) and collaborate over further investigations for example.

Expert care/ Professional care;

The concept of expert care is based on clinical expertise, knowledge of the clinical population and advanced observational skills. Mada, acknowledged this, commenting,

> *"I actually knew the CNS's capabilities before I actually went to her clinic, so in that case I clearly understood I had congestive heart failure and I was past just check-us by the cardiologist, so it did not worry me at all coming to nurse-led clinic because I knew they specialized in congestive heart failure (CHF)….*" (Lines. 3-6) and
>
> *" Well to me I have got it (CHF) and it is of great benefit to be able to keep coming to those clinics just to have someone monitoring it rather than going cardiologist who is only interested in repair of heart but I think the CHF, you know, if you go and see them in the nurse-led clinic you know that person is specialized in that area and you are going to get the same sort of benefit"* (Lines. 20-24).

Furthermore Max supports the concept of expert stating,

> *"If you are really sick they send you to a specialist who spends his time dealing with that complaint all the time. He must be an expert at it because that is all he is doing. Nurse-led clinics to me are just the same"* (Lines. 222-224).

Celia also commented in a similar fashion stating,

> *" A nurse-led clinic, I did not consider it any different to receiving medical attention from someone"* (Line. 20).

On professionalism, several respondents described their perception of professional care with comments such as

"The professional way they presented themselves and completed the tasks of care" (Pt.10).

"They were most helpful, answered all my questions, gave me information I wanted and lastly made me feel I was wanted – not just an old person" (Pt. 30).

"They are contactable, (I) can ask questions, (they)are approachable, they feel like a safety net" (Pt.35).

Being professional can be perceived in a variety of different ways such as, how the health professional presents him/herself, the ability to communicate with people of all walks of life, the knowledge and ability to share that knowledge, and most importantly, having a holistic approach too care, the essence of a professional nurse.

Chapter Six

Discussion

Prior to the early 1990's the biomedical model of care was dominant in outpatient clinics. This attended mainly to physical issues such as diagnosis, interventions and medication. Quality of life for patients implied more than this. To understand and attend to patients' cultural needs, social mores, lifestyle changes, individual hopes and concerns, led to the development of nurse-led clinics which have in the nursing tradition, a holistic approach, with care of the individual aimed at enabling the best possible quality of life for him/her.

The nurse-led clinic in the area of chronic illness is, as has been discussed, a relatively new adjunct to patient care in New Zealand. It is apparent that such clinics have an important part to play in an increasingly high demand, expensive area of health care. It is only since the late 1970's that a diagnosis of heart failure did not mean 'nothing could be done.' With vastly improved understanding and availability of effective medications and treatments, healthcare has more to offer patients with heart failure in managing their condition. So while we have expanding measures for preserving quality of life for this group of people with chronic illness, we also have a diminishing resource in terms of health care. It is evident that the nurse-led clinic is an important part of the system of health care. It is also understanding how best to integrate such clinics in a way that is meaningful to the patients. Who better to help in understanding these dynamics than the users of the system – the patients!

This research project is a small one that sits well with a mixed method approach as described by Morse (2003), 'it is the incorporation of various qualitative or quantitative strategies within a single project that may have either a qualitative or quantitative theoretical drive. The "imported" strategies are supplemental to the major or core method and serve to enlighten or provide clues that are followed up within the core method.(p.190).

Questionnaires were completed by 55 respondents, which provided demographics of the HFCNS population with three short answer questions giving a sense of direction for the subsequent interviews. Mixed method utilizing exploratory narrative is the mainstay of the project and the focus is predominantly of qualitative methodology and is informed by Polkinghorne (1988) who suggests that "experience is meaningful and human behaviour is generated from and informed by this meaningfulness" (p. 1). Smythe and Giddings (2007) discuss qualitative research suggesting "qualitative research always seeks to find the issue of concern in its everyday context, and by means of interviews and/or observations and or accessing text, hear the voices of those closely involved" (p.37). Smythe and Giddings (2007) sentiments are the crux of this study, listening to, hearing and reading of the experiences of the respondents and participants in this study.
From the questionnaires and interviews, common themes that were meaningful to the respondents and participants included:

1. The uniqueness of the individual and the effect of that uniqueness on the interpretation of chronic illness such as the fears of, and living with heart failure.
2. The patients need to know and understand their condition and treatment rationale, and the need for simple understandable terms.

3. The need for repetition taken from Andrew “What’s this all about?” Sometimes patients hear but don’t always listen.
4. Cultural issues, with particular reference to Maori, for instance, Celia having misgivings about ‘Pakeha’ medications, and Andrew needing to ‘know’ the nurse in the cultural sense.
5. Hopelessness as described by Max.
6. Taking time to listen and explore issues – particularly those issues where there was reluctance to raise them with the ‘busy’ doctor.
7. Continuity of care with the same health professional. Not needing to retell their story to a different doctor each time they came to clinic.

For the nurse, the participants’ interpretation had a different meaningfulness such as;

1. Understanding and being reminded of the uniqueness of the individual.
2. Having expert knowledge of the illness trajectory and of the individuality of people in their coping mechanisms.
3. The need for expert communication skills that importantly include good knowledge of interview techniques.
4. The need to be sure patient has been heard and understood the information.
5. Common cultural issues.
6. Patience and persistence required to change a sense of hopelessness to one of hopefulness; of helpfulness to one of being helpful in attending to their care; a sense of loneliness to one of care and support.

7. For time with the patients to be well used while being aware of the patients need to feel free to question.

The aim of this research was to;

- Explore what is important to the patient with chronic heart failure;
- Explore what the patient's perceive as their needs; and
- Describe the experiences of attending and participating in secondary care HFCNS clinics with the aim of gathering information to develop and improve the health care of these patients.

This research is unique in the field of chronic heart failure. Although there is a great deal of research related to heart failure, actually hearing what the patients perceive as their needs and how they experience nurse-managed clinic care has not previously been explored.

From the themes identified in the chapter five one could conclude that nurse-managed care in this context is that of the expert nurse as described by Benner (1984) who posits "clinical expertise is exhibited by experts when they show an in-depth knowledge of a clinical population; advanced skills in observation; and increased use of reference to similar past events for understanding the clinical situation" (p.32). Berra, Miller and Fair (2006), suggest nurses by their education and philosophy and with scientific knowledge and skills in pharmacotherapy, counseling, education, motivation, emotional support, are well positioned to manage patients, all aspects of meaningful care essential in managing patients with complex medical conditions, such as seen in people with heart failure.

In the following section the themes and sub-themes will be discussed supported by the literature from published studies to emphasize aspects of care from the participants and respondents point of view as described previously.

Gaining Knowledge

In this study, the need for knowledge and education is alluded to by a number of participants. Participants expressed that there is an expectation that knowledge of heart failure and education on how best to manage symptoms would be part of a clinic visit. The importance of knowledge and beliefs, in association with compliance issues was explored by van der Wal et al (2006). Van der Wal et al suggested the greatest contributor to health care costs for HF patients was non-compliance with taking medications and understanding dietary changes leading to repeat hospitalisation and that knowledge and beliefs about medication and diet was essential for patients with HF to reduce incidents of exacerbations of HF. Stromberg (2006) also follows this line of thought stating "the responsibility of health care professionals is to prescribe treatment according to guidelines and to set aside time and effort to help patients adhere" (p. 380). The issues discussed by van de Wal et al (2006); Stromberg (2006) studies are reflected in the responses from participants in this study. Regular HF clinic reviews, that should build on a partnership approach and allow time for education is seen as an effective model of caring and will be discussed further in this chapter.

Patient education was studied by Hagenhoff, Feutz, Conn, Sagehorn and Moranville-Hunziker (1994). They found that although there were some differences in the patients' and nurses' perceptions of the patients learning needs, there were also commonalities such as medications being ranked highest in the need to know by both groups. In this study patients generally rated education higher than nursing staff and this discrepancy may be because nursing staff do not want to overload patients with information when they are in hospital. If this is the reason, this makes it even more important to have nurse-managed clinics to provide ongoing education and support for patients with chronic illness.

Self-management is discussed by Rankin, Stallings and London (2005) who suggest that "patient education is a dimension of caring when it considers the best interests of the patient and recognizes that the best case-manager is the patient him or herself " (p.4).
Martensson, Karlsson and Fridlund (1998) reflecting on heart failure comment "in order to understand the implications of this syndrome, patients with heart failure must be provided with accurate information and knowledge to enable them to be able to make decisions and to be able to plan for the future" (p.1217). Carlson, Riegel and Moser (2001) comment that self-care is difficult for patients with heart failure because of the polypharmacy, the sodium restriction and self-monitoring regimes that are difficult to manage. Carlson et al (2001) suggest that educational activities need to impress on the patient the importance of self-monitoring with, specific strategies taught for particular symptoms such as sudden weight gain, breathlessness and decreasing activity level. MacLaury (2000) discusses self-care further stating, "empowering patients to take control of their health and to make decisions about their health are regarded as

fundamental aspects of health education" (P.157). Empowerment is often discussed in nursing articles, one such is by Paterson (2001) who comments on empowerment in chronic illness, as encouraging participants to be equal partners with their health professional in any decisions relating to their health issues, and this is important if the patient is going to take control of his/her chronic illness and be proactive in managing symptoms.

Making changes

Heart failure is a progressive illness and has a chronicity that sees a loss of autonomy and self esteem. Murray et al (2002) describe the illness trajectory of heart failure as "episodes of exacerbation of heart failure requiring acute hospital care punctuating an overall progressive decline with an unpredictable terminal phase" (p.930). This picture is true for many HF patients and this is where having access to consistency of HFCNS care can reduce readmission rates and improve quality of life. With guidance and support, making changes and taking control can change the sense of hopelessness into hopefulness as described by Max and Andie in the participants' stories in Chapter Four. Putting a new perspective on aspects of chronic illness and rationalizing the experience are all part of coping mechanisms that patients use to make living with illness manageable, as described by Mada in Chapter Four.

Haworth and Dluhy (2001) suggest that symptoms are more than the underlying illness stating "within a nursing perspective, managing symptoms requires an understanding of the person's experience and the meaning associated with each symptom and for this reason a holistic nursing approach to symptom management is particularly well suited to the increasing number of people with chronic illness (p.302). Having family for support was another aspect that was described by all of the participants during the interviews, ranging from help around the home to 'being with' the participant during acute episodes of illness and 'doing' for the participant. Relationship also concerned sexual issues and the impact on well being, when, this aspect of care was not discussed as part of holistic care by health professionals. Sexuality issues were clearly described by Mada and Max in Chapter Four. Haworth and Dluhy (2001) allude to the term symptom management as including "altered social interactions, diminished functional status, and/or decreased economic capabilities" (p. 303), all aspects of living with chronic heart failure that have been described by the participants in Chapter Four.

Partnership

The notion of partnership between the patient and the nurse as discussed by Eldh, Ehnfors and Ekman (2004) is fundamental to addressing the concept of adherence to treatment regimes. This can often be difficult for the individual patient as it includes elements of self-management, and lifestyle change as well as a commitment to a regular medication regime. The notion of partnership is elaborated by Brown, McWilliam and Ward-Griffin (2006) who suggest that partnership implies a relationship based on respect and trust between the nurse and patient enabling the patient to become independent in self management. Furthermore Brown, McWilliam and Ward-Griffin (2006) discuss the notion of patient autonomy as, "partnership approaches have the potential to empower clients and enhance their independence by involving them in managing their own life and health" (p.161).

Ayers (2005), suggests partnership also involves consistency of care with the patient visiting the same health professional in the clinic setting, a point that was made by several respondents and participants in this study. Brown et al (2006) also allude to partnering stating "we can be with people…it's different…as opposed to treating the patient, we are being with them" (p. 5). Being with the patient and forming a relationship based on respect and trust is the essence of partnership in nurse-managed care. It is what makes a difference in care models between the biomedical diagnosis and treatment model and the holistic partnering nursing model. Crowe, O'Malley and Gordon (2001) allude to a partnership model being flexible to the needs of the patient. Flexibility is a concept that is particularly apparent when caring for patients coping with the day-to-day chronicity of heart failure. From personal experience, patients will describe good days and bad days as part of their health continuum, which may mean rescheduling appointments to their needs or changing a clinic appointment to a home visit if they are unable to come to clinic for instance.

Ethnicity/ cultural perceptions

Another concept that was evident in this study was the need for knowledge on cultural safety. Mindfulness of the notion of cultural safety was present with all participants. The patients attending the HFCNS clinics are of different ethnicities with the majority being European followed by Maori, Pacific and others. As was evident in this research, issues on cultural safety were reflected in the stories from Andrew and Celia discussed in Chapter 5. The issue of cultural safety, was articulated by Ramsden (2000) as "protecting people from nurses, from our culture as health professionals, our attitudes, our power and how we manage these things whether intentionally or otherwise" (p.4). Wilson (2003) discusses indigenous health commenting that Maori are less likely to go to their GP for health care and are over represented in secondary care. Wilson (2003) suggests that nurses are ideally situated to improve health of individuals and local indigenous groups as disparities in health care continue to exist in New Zealand. Therefore there is a need as health professionals to be proactive in finding innovative ways to help reduce inequality by developing clinics that focus on the needs of a diverse range of patients from different cultural groups.

Collegial collaboration/professional care

Collaboration according to Henneman, Lee and Cohen (1995) is "a complex, sophisticated process. It requires competence, confidence and commitment on the part of all parties involved. Respect and trust, both for oneself and for others, is key to collaboration" (P.108)
Collaborative practice is the essence of HFCNS clinics as teamwork is the central focus in achieving evidence-based best practice care for the patients. The development of these clinics was from the initial concept of the multidisciplinary team. This team included a cardiology consultant, physiotherapist, dietitian, social worker, occupational therapist, chaplain and last but by no means least, the nursing group. Initially, medical treatment was the main focus in discussions regarding patient care. To all, it became clear that effective care included a far more

holistic approach. The patients understanding and involvement was clearly critical to successful care outcomes

A skilled nursing group was available and it was an obvious evolution of the nurse-managed clinic. This has developed over time and now is an accepted part of the scope of patient care. Both patients and health care professionals, now accept the nursing group, as an integral part of the continuum of care of patients with chronic heart failure. A body of knowledge is emerging from this early beginning and the future should see a further development to an even more sophisticated model. It continues to depend on its development on the involvement of all disciplines and on strong collegial relationships of respect and trust, and the aim at all times being the best quality of life for each and every patient with chronic heart failure.

Limitations of the study

This study has limitations that should be considered. The research project was mixed method with small numbers for both the questionnaire respondents and the interviewed participants. However the data from both the respondents and the participants has been rich with the respondent's answers providing confirmation of many issues in the participants' stories.

The research was undertaken in a secondary level general hospital and studied patients who were domiciled to that hospitals district. Other district hospitals either tertiary or secondary may have different referral systems or locate services such as those of the study population in the community. Consequently, caution should be taken in generalising these findings of the experiences of nurse-managed care to all patients or district health boards.

Future research

Findings from this study clarify directions for future research. There is an opportunity for research into expanding the service and making it more accessible to those in the population where disparity in health care services remains apparent, such as taking the service to the community and/or working with the community to develop similar services. While home visits and telephone follow-up are part of the existing care, further research including these in the nurse managed care groups would be of value in increasing knowledge of the effectiveness and efficiency of the CNS managed care. Developing the role from clinical nurse specialist to nurse practitioner would be in keeping with the Nursing Council nurse practitioner guidelines and certainly would provide another expert avenue of care to support general practitioners and cardiologists cope with patient population that is expected to grow exponentially as the baby boomers move into the older/elderly age group over the next two decades.

Conclusion:

The analysis indicates that narrative or story telling by patients in the context of nurse-patient interactions inform understanding of the value and benefit of attending and participating in nurse-managed heart failure clinics.

This study has shown the concept of nurse-managed clinics have a significant role to play in the overall management of people with chronic heart failure. It has shown that innovative measures that provide evidence-based best practice care can reduce readmissions, length of stay when admitted and improved quality of life for patients with an illness that is progressive and often comparable to cancer in its outcome. This study has shown the value and benefit of NFCNS clinics and it has also shown areas where further work would enhance the workings of the clinics with particular emphasis on cultural safety issues.

To improve patient outcomes, roles such as HFCNS should be developed in all disciplines of nursing to improve access to care; to provide management of patients that is holistic in concept; to enable patients to learn the concept of self-care; and to improve outcomes for patients, particularly those patients with chronic illnesses or those patients who would benefit most from consistency in care. Furthermore, for improved patient outcomes, one could anticipate the usefulness of the role of nurse practitioner being instrumental in the care and management of people with chronic disabling illnesses over the lifespan and furthermore developing this role would enhance health care practice in New Zealand.

This study did not follow through on the home visit aspect of the CNS heart failure program. Further studies that include home visits in combination with outpatient nurse-led clinics by clinical nurse specialists would add to the knowledge of initiatives that can only enhance the holistic care of people with chronic heart failure.

Consistency in health care is paramount to enabling successful health care partnership, promoting empowerment of the patient. Developing and promoting the concept of specialist nurse-led services can achieve this.

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Appendix 1

Health
and
Disability
Ethics
Committees

Central Regional Ethics Committee
Ministry of Health
Level 2, 1–3 The Terrace
PO Box 5013
Wellington
Phone (04) 496 2405
Fax (04) 496 2191

19 October 2006

Ms Judy Dewar
Cardiology Department
Hutt Valley District Health Board
Private Bag 31 907
Lower Hutt

Att: Ms Judy Dewar

Dear Judy

CEN/06/08/078 - Experiences of patients participating in specialist nurse-managed heart failure clinics: an exploratory study

The above study has been given ethical approval by the **Central Regional** Ethics Committee.

Accreditation
The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

Progress Reports
The study is approved until **April 2008**. The Committee will review the approved application annually and notify the Principal Investigator if it withdraws approval. It is the Principal Investigator's responsibility to forward a progress report covering all sites prior to ethical review of the project in **October 2007**. The report form is available on http://www.newhealth.govt.nz/ethicscommittees. Please note that failure to provide a progress report may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.

Amendments
It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study is altered in any way, including all documentation eg advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Yours sincerely

Claire Yendoll

Claire Yendoll
Central Ethics Committee Administrator

Email: claire_yendoll@moh.govt.nz

Appendix 2

Massey University
COLLEGE OF HUMANITIES AND SOCIAL SCIENCES

SCHOOL OF HEALTH SCIENCES
Wellington Campus
Private Box 756
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Questionnaire Information Sheet.

Experiences of Patients Participating in Specialist Nurse - Managed Heart Failure Clinics.

My name is Judy Dewar, and I am a Postgraduate student at Massey University. I would like to invite you to participate in my research. This research is part of my Master's degree and will be supervised by staff from Massey University.

Your participation in this research is entirely voluntary (your choice). **Whether or not you choose to accept or decline participation in this study will not in any way influence your right to or access to future health care.**

Specialist nurse-managed patient care is important for optimising health care for patients with chronic heart failure. This research is hoping to understand more about the experiences of heart failure patients who have received nurse-managed heart failure care.

This research will consist of a questionnaire to all patients attending outpatient heart failure clinics over an 8-week period, and then a follow-up interview with up to 8 patients. You will be invited to fill in the questionnaire while waiting for your clinic appointment or alternatively you can take it home, complete it and then post it back in the envelope provided within 2 weeks. If you are willing to participate in an interview you will be asked to identify yourself to the cardiology receptionist. Participation in an interview is optional and whether you choose to participate or not will in no way affect your future healthcare. You may withdraw at anytime without giving a reason.

The interview is expected to take between 60 and 90 minutes and will be audiotape. The interview will take place at a time and place that you choose. The interview will be one on one, and I will be the only interviewer. The goal is to describe your experience of attending and participating in specialist nurse-managed clinics as fully as possible.

If you would like to participate in an interview, further written information will be given to you so that you are fully informed about the interview process.

The Central Region Ethics Committee and Massey University Human Ethics Committee have approved this research. If you have any concerns about ethical conduct involved with the research project please contact either of the following agencies:

The Chairman
Human Ethics Committee
Massey University
Wellington Campus
Private Box 756
Wellington

Health and Disability Commissioner
PO Box 12299
Wellington
Telephone 0800 11 22 33

Please feel free to ask any questions you might have about this research before, during and after the questionnaire and interview processes. Taking part in this research is entirely voluntary. You may withdraw from this research at any time without influencing future health care.

The supervisor for this research is:

Ms Kim van Wissen
Senior Lecturer
Massey University
Telephone 04 801 5799 Ext 6755

Yours faithfully

Judy Dewar
Clinical Nurse Consultant
Department of Cardiology
Hutt Hospital
Telephone 04 570 9377

Appendix 3

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Research Questionnaire

Research topic: "Experiences of Patients Participating in Specialist Nurse-managed Heart Failure Clinics".

Thank you for taking the time to complete this questionnaire. Please return the completed questionnaire to the cardiology receptionist on your way out or return it in the prepaid envelope provided. Completion and return of this survey indicates consent to take part.
Please tick appropriate boxes or write in your answer to each question.

1. Please indicate your age range 18-24 ☐ 25-34 ☐ 35-44 ☐
45-54 ☐ 55-64 ☐ 65-74 ☐
75-84 ☐ 85 + ☐

2. Please indicate your gender F ☐ M ☐

3.Please indicate your ethnicity Non Maori ☐ Maori ☐ Other ☐

4. Please indicate what language you usually speak? English ☐ Maori ☐ Other ☐
5. Please indicate whether you live with your wife ☐ husband ☐ partner ☐ family member?☐ Alone ☐

6 Please indicate whether you are retired ☐ beneficiary ☐ work part-time ☐ work full-time?☐

7. Have you participated in specialist nurse heart failure clinics before? Y ☐ N ☐

8. If yes, what did you find most useful about the specialist nurse clinic?

....

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9. In your own words, what is wrong with your heart?

....

....

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....

....

10. What are the most important health issues for you today?

....

....

....

....

....

11. Would you attend a specialist nurse clinic like this in the community?
Y ☐ N ☐

12. If yes, where would you like the clinic to be located? ....

If you would like to participate in a further interview to discuss your experiences of attending and participating in specialist nurse clinics more fully, please advise the cardiology receptionist at the reception desk.

Appendix 4

Massey University
COLLEGE OF HUMANITIES AND SOCIAL SCIENCES

SCHOOL OF HEALTH SCIENCES
Wellington Campus
Private Box 756
Wellington
New Zealand
T 64 4 801 5799
F 64 4 801 2884
www.massey.ac.nz

Interview Information Sheet.

Experiences of Patients Participating in Specialist Nurse- Managed Heart Failure Clinics.

My name is Judy Dewar, and I am a postgraduate student at Massey University. Thank you for completing the questionnaire, I would now like to invite you to participate in an in-depth interview. This research is part of my Master's degree and will be supervised by staff from Massey University.

Specialist nurse-managed patient care is important for optimizing health care of patients with chronic heart failure. This research is hoping to understand more about the experiences of heart failure patients who have received nurse-managed heart failure care.

Your participation in this research is entirely voluntary (your choice). **Whether or not you choose to accept or decline participation in this study will not in any way influence your right or access to future health care.**

The interview is expected to take between 60 and 90 minutes and will be audiotape. The interview will take place at a time and place that you choose. The interview will be one on one, and I will be the only interviewer. The goal is to describe your experience of attending and participating in specialist nurse-managed clinics as fully as possible.

You might wonder if there is any risk for you being involved in this research. It is not anticipated that there will be any risks, although talking through experiences can sometimes be difficult.

At the beginning of the interview you will be invited to select a name other than your true name, by which you will be known while you take part in this research.

A trained typist will transcribe the audiotapes provided from the interviews, and sign a confidentiality agreement stating that she will not discuss the transcription with anyone other than the researcher. The audiotapes will be kept in locked storage in the researchers office area, in a different location to the consent form signed by you. All audiotapes will be destroyed at the end of the research unless you want your personal audiotape returned to you.

All transcripts will be identified by a numbered code or by the false name you have selected. The only other people who will have access to these items will be the research supervisors. No research participant's names will appear on any material produced as a result of this research without the permission of the individual involved. Every step will be taken to ensure your identity is not disclosed.

The transcript of the interview will be returned to you so that you can confirm that the transcripts are a true copy of our discussion together. You can after reading the transcript change or withdraw any of the information. After you have approved the transcript, analysis of the transcripts will start and your experience will become part of several experiences of attending and participating in specialist nurse-managed care.

The Central Regional Ethics Committee and Massey University Human Ethics Committee have approved this research. If you have any concerns about the ethical conduct involved with the research project please contact either of the following agencies:

The Chairman
Human Ethics Committee
Massey University
Private Bag 756
Wellington

Health and Disability Commissioner
P O Box 12299
Wellington
Telephone 0800 11 22 33

Feel free to ask any questions you might have about the research before, during and after the interview process. Taking part in this research is entirely voluntary, and you may withdraw from this research at any time without influencing any future health care.

The supervisor for this research is:

Ms Kim van Wissen
Senior Lecturer
School of Health Sciences
Massey University
Telephone 04 801 5799 Ext 6755

Yours faithfully

Judy Dewar
Clinical Nurse Consultant
Department of Cardiology
Hutt Hospital
Telephone 04 570 9377

Appendix 5

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Consent Form

Research Topic: "Experiences of Patients Participating in Specialist Nurse-Managed Heart Failure Clinics; an exploratory study"

Name of participant ....

I have read and I understand the information sheet for volunteers taking part in the research designed to understand how patients perceive specialist nurse-managed heart failure clinics. I have had the opportunity to discuss this research. I am satisfied with the answers I have been given. I have had the opportunity to use whanau support or a friend to help me ask questions and understand the research. I understand taking part in this research is voluntary (my choice), and that I may withdraw from the study at any time without giving a reason, and this in no way will affect my future health/continuing health care.

I understand my participation in this study is confidential and that no material, which could identify me, will be used in any reports on this study.

I have had time to consider whether or not I wish to take part.

I consent to my interview being audio taped. Y ☐ N ☐

I consent to my GP being informed of my participation in this research. Y ☐ N ☐

I .... hereby consent to take part in this research.

Signature .... Date ....

Person obtaining Informed Consent
I have explained the research project; the patient appears to clearly understand and has consented to participate in the research.

Signature .... Name.......................................

Date ....