

Copyright is owned by the Author of the thesis. Permission is given for a copy to be downloaded by an individual for the purpose of research and private study only. The thesis may not be reproduced elsewhere without the permission of the Author.

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

SUZANNE JUDITH DEWAR

**A thesis submitted to Massey University of Wellington in partial fulfillment of the
requirements for the degree of Master of Philosophy (Nursing)**

2007

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.

Acknowledgments

This thesis is the culmination of 7 years of part time study. A journey that, has at times stretched my will power to keep working on achieving a Masters degree. I have to thank my husband and family for their encouragement and support, and constantly saying 'you can do it.'

My very grateful thanks to the participants and respondents in this study for their time, thoughtful answers, and for opening up their homes to me for the interviews.

My very grateful thanks to Anne Cuthbert and Ria Kleintjes, my colleagues and friends, who have given me tremendous help with their knowledge of computer skills and encouragement to get this thesis completed. Thank you also to Pauline Robertson for putting the transcripts together and Dianne Yarrall for digging out data for this research.

To Kim vanWissen, thesis supervisor, thank you for your time, patience and always-constructive advice in what has been a long journey for both of us.

Lastly to June Gordon-Crosby, my mentor, advisor and friend thank you for your inspirational guidance.

Table of Contents:

Abstract	1
Acknowledgements	3
Table of Contents	4
Chapter One	
Introduction	9
History of clinics	10
The Question: which clinic?	14
Clinical Nurse Specialist Heart Failure Clinic	15
Aims of the study	20
Chapter Two	
Exploration of the Literature	
Introduction	21
New Zealand literature	22
International literature	27
Heart failure: a chronic illness	35
Summary	40
Chapter Three	
Research design and method	
Introduction	42
Paradigm	42

Design	43
Mixed Method	44
Narrative as story	46
Narrative as inquiry for nursing	47
Narrative as inquiry for participant	48
Narrative as meaningfulness	49
Narrative as experience	50
Research setting and recruitment	52
Ethical committee approval	54
Patient Questionnaire	55
Interviews	56
Chapter Four	
Participants stories	
Introduction	59
Andie's story.....	61
Andrew's story	63
Max's story	66
Mada's story	68
Celia's story.....	70
Lona's story	72
Conclusion.....	73

Chapter Five

Analysis of interviews and questionnaires 74

Themes..... 75

Gaining knowledge

Sub themes

Gaining knowledge/understanding heart failure..... 76

Educating 77

Taking time/pacing education 78

Explaining treatment..... 79

Learning self-care/developing expertise..... 81

Making changes

Sub Themes

Gaining confidence 82

Hopelessness/hopefulness 83

Rationalizing..... 84

Family/relationships 85

Physical incapacity 86

Partnership/partnering

Sub themes

Trusting environment 88

Partnership/partnering 89

Ethnicity/cultural safety

Sub themes

Communication/talking the talk	90
Accessibility/availability	92
Values, beliefs, cultural safety.....	93

Collegial collaboration/professional care

Sub themes

Collaboration	95
Expert care.....	96

Chapter Six

Discussion	98
Gaining knowledge	102
Making changes	104
Partnership	105
Ethnicity/cultural safety	106
Collaboration/ professional care	107
Limitations	108
Future research	109
Conclusion	109
References	111

Appendices

Tables

Table 1	13
Table 2a	13
Table 2b	14
Table 3	16
Table 4	28
Table 5	38
Table 6	52

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).

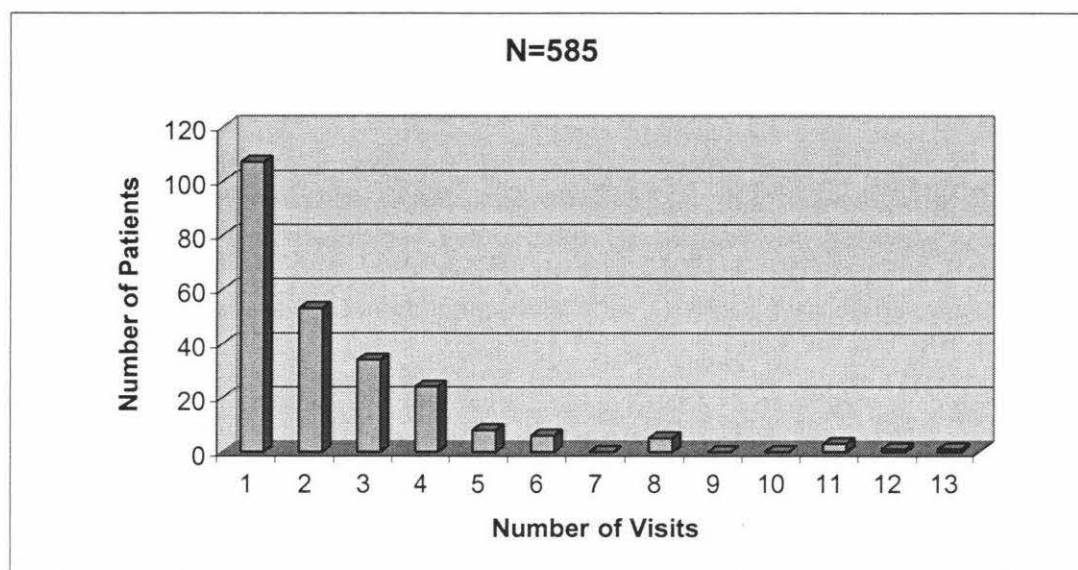
Cardiac Rehabilitation is a process of education, providing support and advice for patients following a cardiac event. It is time consuming, and to be successful reinforcement of an individual’s goals for managing risk factors is essential to maintain wellness in his/her future life. Nurse-managed clinics 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 (Gheorghide, 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 Table 1.

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

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 continuity 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).