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CONTINUITY OF CARE FOR COMPLEX HEALTH POPULATIONS EFFECTIVENESS AND EFFICIENCY OF TWO MODELS OF HOSPITAL TO HOME TRANSFER

By

MARGARET B. HARRISON

A Thesis

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ABSTRACT

CONTINUITY OF CARE FOR COMPLEX HEALTH POPULATIONS
EFFECTIVENESS AND EFFICIENCY OF TWO MODELS OF HOSPITAL TO HOME TRANSFER

OBJECTIVES: To evaluate the effectiveness and efficiency of a model of transition from hospital to home compared to optimal usual care for individuals with congestive heart failure (CHF), selected as an exemplar of a complex health population.

INTERVENTION: Strategic alliance or partnership between hospital and community health care sectors focused on the transition phase to 2 weeks post hospital discharge. Implementation of an evidence-based protocol for supportive care activities and enhanced linkages with the providers and patients.

STUDY QUESTIONS:

1: Does Transitional Care, as an example of an inter-agency service alliance, improve the health related quality of life outcomes (MLHFQ & SF-36) for individuals with CHF more than optimal usual care?

2: What were the comparative expenditures for health services utilization at 6 weeks post hospital discharge with Transitional Care versus optimal usual care for the CHF population from a societal point of view (Browne et al., Health Services Utilization Inventory)?

3: Was there a subgroup of individuals with CHF recently discharged from hospital for whom one of the approaches to care was more effective and less expensive?

DESIGN: Randomized control trial with baseline (pre hospital discharge), 2 and 6 week post discharge follow-up and outcome assessment.

SAMPLE & SETTING: 123 individuals with heart failure admitted to two nursing units at a tertiary university affiliated teaching hospital. (60 experimental, 63 control)

RESULTS: Clinically and statistically significant improvements in emotional well-being

was associated with Transitional Care with no greater expense from a societal point of view. However, there was an important difference in the types of resources used by each approach with greater use of institutionally based resources in the usual care group and more community based resources accessed by Transitional Care participants. No statistical interactions or characteristics of subgroups of participants could be identified who were better served by one approach or the other.

IMPLICATIONS: All types of heart failure patients can benefit in measurable emotional gains in health with Transitional Care. Transitional Care is effective and the gains in outcome were achieved at no additional expense to society as a whole.

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Grimes, retired director of the Loeb Research Institute, whose concept of 'bench to bedside' enquiry frames our teaching hospital's approach to research activities.

This large-scale trial conducted across the hospital and community health sectors involved the support of several agencies and many individuals. My gratitude is extended to the Ottawa Carleton Victorian Order of Nurses, the Ottawa Civic Hospital Clinical Teaching Units (A5 & B5), and the Community Care Access Centre. To each of the organizations, the directors and clinical managers, and the many nurses who formed the alliances, I owe a great deal. Thank you. Special thanks to Becky Hollingsworth RN, MA, Assistant Executive Director VON and Kathleen Nunn RN, MScN, Clinical Director, OCH Medical Portfolio, who have believed in and actively supported this work since its inception and feasibility phase.

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TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

PREAMBLE

Introduction

This thesis is about continuity of care and the transition of care from one health sector, agency and care provider to another. The research design was a randomized control trial working within and across health care sectors. This study was guided by a continuity of care framework developed by the investigator. A partnership was formed between hospital and community agencies and their available, well established programs and services. The focus of the study was the transition period and the linkage of care activities promoting continuity of care between health sectors. The study put 'on trial' two competing structures and philosophies of care: a systematic, integrated, inter-sectoral, proactive transition process compared to 'best' usual hospital discharge care and planning. A unique aspect of the study was that no new services or additional providers, such as dedicated case managers or extra visiting nurses, were added to either approach to care. Outcomes of the study consisted of individual health related quality of life (HRQL) and functional status, and the expense for health services resource use. It was hypothesized that greater continuity of care, improved individual outcomes and savings from decreased use of institutional health care services would result from an alliance between hospital and community sectors creating a smoother transition between hospital and home settings of care.

The motivation for undertaking this research stemmed from a growing concern with a lack of integration and the interruptions in the linkage between, and continuity within, health care services for complex health populations. Extraordinary effort is required by front-line nursing personnel to appropriately attend to patient and family continuing care needs. Nurses must function to provide the 'glue' between components of care through indirect activities such as communication and coordination. Separate organization, funding and administration of health care sectors reinforce fragmentation of services, which interrupts continuity of care for the same episode of illness. As a consequence, nursing's contribution to health care has been shaped and made invisible by the context of the fragmented bureaucracy. This 'glue' component of nursing care is even more difficult to deliver and less rewarded during these times of fiscal restraint and organizational change. Research regarding nursing practice needs to be directed not only at the clinical, individual client level, but also at the organization of health services. Empirically-based, prescriptive changes at the organizational level have great potential to remove barriers to more effective and efficient provision of nursing care at the individual patient level.

This study was directed at 'illness care' in a population of persons with a chronic, long term, cardiac condition with a need for secondary prevention. Typically, complex health populations are characterized by a host of personal, technical, preventative and management care needs. These individuals often have more than one medical diagnosis, are faced with idiosyncratic routines of daily living and usually have an ongoing requirement for care from more than one health care sector. These factors make these

individuals vulnerable and at risk for discontinuity - individuals commonly referred to as the ones who 'fall through the cracks'. Effective management of complex health populations necessitates comprehensive, individualized, supportive assistance in addition to the medical regimes. Supportive interventions help the client achieve comfort, improve or maintain function, and live within their health constraints, all of which ultimately affects the course of disease. Supportive assistance helps the individual shape the illness course or trajectory, while also maintaining quality of life.

In the next two decades the problems of discontinuity and lack of integrated care will only increase for complex health populations. Greater longevity, medical, pharmaceutical and technological advances, combined with the demography of an aging population, will increase the actual and relative numbers of persons with complex health problems requiring care and accessing the health care system. As the millennium approaches, the effectiveness and efficiency of health services, and in particular continuity of care, for such populations is a high priority. This is a pressing concern especially in view of the debt crisis facing all levels of government (Health and Welfare, 1990; Ministry of Health Ontario, 1993; Scott & Rantz, 1997).

This study evaluates the effectiveness and efficiency of a model of transition from hospital to home compared to 'best' usual care. The transition of persons between health care sectors was facilitated by the use of an evidence-based protocol, enhanced linkages at the provider and consumer level, and a strategic alliance or partnership between hospital and community health care sectors. Congestive heart failure (CHF), as a prime example of a complex health population, was selected as the medical condition of

interest. Heart failure is an increasingly prevalent, complicated, costly, chronic condition.

Outline of the Thesis

In Chapter 1, the nature of complex health populations is examined with heart failure as a primary example. The morbidity, mortality and current management of the CHF condition is described. The recent innovation of clinical practice guidelines for heart failure is then evaluated. The findings from research related to complex health populations and continuity of care are summarized. Using recognized frameworks, research related to continuity of care specific to the heart failure population, is critically appraised for the strength of the methodology and presence of bias which may weaken conclusions.

Focusing on continuity of care as a concept, the second chapter of the thesis provides an analysis of the conceptual advancement and review of research related to the topic. Limitations of the work to date, particularly the focus on discharge planning, are explicated. Integrating and building on the meaning that important stakeholders place on the concept, the investigator develops a study definition of continuity of care and offers a framework for intersectoral research.

In Chapter 3, the Intersectoral Continuity of Care framework is specifically operationalized for the hospital to home transfer of individuals with congestive heart failure. The framework elements are discussed along with the outcomes of interest.

The study's research methods are described in Chapter 4, including the design, study sample, detailed procedures, sample size justification, quality control, analysis plan,

and rationale for selection of primary and secondary outcome measures. The ethical implications and study limitations are explained.

In Chapter 5, the results of the randomized control trial are presented. In studying 123 participants, from hospital admission through to 6 weeks post discharge, the transition between health care episodes is evaluated and explored. In Chapter 6, the discussion and conclusions are summarized and recommendations are offered for nursing practice, health care service delivery organization and policy as well as areas for continued research.

CHAPTER 1: THE PROBLEM OF COMPLEX HEALTH POPULATIONS

Complex Health Populations

Management of Chronic Illness and Health Care Services

Complex health populations are characterized by a host of personal, technical, preventative, and management care needs and are at risk of discontinuity of care. These individuals often have more than one medical diagnosis and are faced with idiosyncratic routines of daily living. Usually they have an ongoing requirement for care from more than one health care sector. Many chronically ill populations fit these criteria and present enormous challenges. Increasing longevity and medical, pharmacological and technical advances can bring related difficulties, as well as benefit, to individuals and families dealing with chronic, complex health conditions. Without well coordinated, prudent, continuous management and support with such conditions, a longer life span may have profound detrimental consequences for not only the individuals, but also the family and community caring for them (Health and Welfare, 1990). A recent report from the World Health Organization refers to this phenomenon as a "crisis of suffering" with enormous economic costs (World Health Organization, 1997).

The incidence of many complex health conditions rises with age. As well, the actual number of health problems an individual has generally increases with age. In the Ontario Health Survey (1990), 90% of those 65 or older had one or more health problems compared to 75% of those 46-64 years old, and 32% of those 20-44 years old.

Improvement in the effectiveness and efficiency of health care of older adults must address these issues of co-morbidity.

Actual numbers of elderly are growing and at the same time the average age of seniors is increasing. The fastest growing age cohort in the population is the group 85 years or older (Health and Welfare, 1990, p. 7). The aged are aging with their increasing co-morbidity. Recent Ontario figures indicate that 40% of health care budgets are spent on seniors who comprise 10% of the province's population (Ministry of Health Ontario, 1993). The Canadian Study of Health and Aging (1994) found that many of those caring for their family members are old as well. Attention to the supportive care for older adults and their care-givers dealing with complex health conditions is undoubtedly becoming even more of a priority (Health and Welfare, 1990, 1994).

New directions and changes in health care delivery further compound the challenges of caring for older persons with complex health conditions. Greater use of home based care and early discharge from hospital are resulting in a higher level of acuity of patient illness and an increase in the use of technology in the home (Donlevy & Pietruch, 1996; Health and Welfare, 1990; Ministry of Health Ontario, 1993, p. 8-11; Peters, 1989). In Ontario's recent health care plan for the 1990's, the reform strategies outlined for hospital, rehabilitation, long term care and support services, emphasize alternatives to institutional care; expansion of community and outpatient care; improvement in linkages; and consumer participation and partnership (Ministry of Health Ontario, 1993, 1997). However, the present structure and financing of segregated health services perpetuates gaps, fragmentation and discontinuity of service, leading to reactive, on-demand isolated services rather than a pro-active integrated system of care for such

populations. Planning and reform of health services at the local level offer great opportunity to avoid duplication, enhance co-ordination and pro-actively respond to needs. (Browne, et al. 1994).

Heart Failure: Common, Complex & Costly

Samuel Johnson, writing to his physician in 1784 described his heart failure - *"The water encreases (sic) almost visibly and the squills which I get here are utterly inefficacious. My spirits are extremely low."* (Peitzman, 1992)

One of the fastest growing and challenging complex health populations is the congestive heart failure (CHF) community. The incidence of CHF increases dramatically with age, and there is a 50% mortality after 5 years (Dunbar & Dracup, 1996; Funk & Krumholz, 1996). Described as the final common pathway of cardiovascular and numerous other diseases, heart failure poses a significant health problem in North American adults. CHF is reported to be the only cardiovascular condition that is increasing in incidence, prevalence, morbidity, and mortality (Funk & Krumholz, 1996; Rideout, 1992; US Dept. of Health & Human Services, 1994; Wolinsky, Smith, Stump, Overhage, & Lubitz, 1997).

Reported to be the most frequent discharge diagnosis seen in patients with Medicare (USA), heart failure has profound implications for the health care system (Croft et al., 1997; Dunbar & Dracup, 1996; Retchin & Brown, 1991). The situation is undoubtedly similar in Canada, although the statistics on diagnostic groupings and case costing are not readily available. In 1993, the most recent compilation of national

statistics, cardiovascular conditions topped the list of hospital care and drug expenditures (18.6% and 21.9% respectively) in Canada (Health Canada, 1997, p. 18, 22). In 1996, a one-month study of the home care client profile in Ottawa-Carleton Home Care, revealed that CHF comprised 3% of the primary diagnoses in the total caseload (Alcock, 1997). On closer examination, 81% of these home care cases had a secondary diagnosis. When primary and secondary diagnostic groups were combined 54% had a diagnosis related to heart, vessel or blood disorder. In 1993, the Ottawa Civic Hospital (OCH) admitted 704 patients with CHF accounting for 836 admissions. During this 12 month period 12.4% of those admitted had two or more admissions. More than 74% were 65 years or older and the mean length of stay (LOS) was 21 days. Although the LOS generally increased with age, the 65-74 years group had the longest LOS at 26 days. During the same period, a home nursing agency (Victorian Order of Nurses Ottawa-Carleton Branch), carried a caseload of 438 patients with CHF. Nearly 60% were reported to be in the living 'alone' categories as single, divorced, separated or widowed. Death (15.3%) or admission to hospital (17.4%) accounted for one third of the discharges from home nursing. As the prevalence of CHF increases with age, and the Ontario population is aging overall, it can be expected that the impact of CHF will rise proportionately.

Clinical Manifestation

"Dropsy from heart-disease appears first as a slight swelling about the ankles or insteps, which comes on towards evening; if the parts are firmly pressed by the finger for a few seconds a dent is left." *(Humphry, 1890, p. 74)*

Heart failure is a complex clinical syndrome manifested by signs and symptoms of

intravascular and interstitial volume overload, which may include shortness of breath, rales, and pulmonary or peripheral edema, and/or characteristics of inadequate tissue perfusion e.g. fatigue or poor exercise tolerance, cognitive changes. *Congestive* heart failure involves pulmonary or systemic congestion (US Dept. of Health & Human Services, 1994). Moran (1991) identifies treatment goals for congestive heart failure which include: relief of symptoms of dyspnea, orthopnea, peripheral edema and ascites; an increase in exercise capacity and decrease in fatigue; and an improvement in a sense of well-being. Despite new medical therapies there is a lack of significant change in CHF outcomes in the past 20 years (Funk & Krumholz, 1996; Goldberg & Meyer, 1997). Patient and family education, counseling and support are considered critical to effective treatment and care (US Dept. of Health & Human Services, 1994) yet reductions in hospital beds, subsequently shorter hospital stays, and increasing pressures on the community sector, present special challenges for provision of these services.

A classification system for heart failure has been established and widely used - the New York Heart Association Functional Classification. In Class I there is no limitation on physical activity and the individual has no undue fatigue, palpitation, dyspnea or anginal pain with usual activity. In Class II there is slight limitation of activity, comfort at rest but normal activity causes fatigue, palpitation, dyspnea or anginal pain. With Class III there is marked limitation on activity with less than normal activity producing fatigue, palpitation, dyspnea or anginal pain; however, there is comfort at rest. The most severe group are Class IV in which any physical activity, or even at rest, there is discomfort and symptoms of cardiac insufficiency (Patterson & Adams, 1996; Stanley, 1997).

Many aspects of CHF supportive care are within the scope of nursing practice. Specifically, this includes supporting medication regimes, diet, rest and activity, symptom monitoring, and ongoing individual and family support (US Dept. of Health & Human Services, 1994). Ghali, Cooper, & Ford (1990) suggest that in addition to long term strategies aimed at the prevention and treatment of CHF, attention should be paid to interventions that eliminate or minimize factors precipitating hospitalization. Improved outpatient care is an important strategy to prevent hospitalizations (Dunbar & Dracup, 1996). Exacerbations of CHF are due in part to its natural history but may be precipitated by changes in modifiable lifestyle factors such as activity, medication adherence, diet, or by other complicating conditions such as anaemia, arrhythmia, infection, pulmonary embolism and thyroid disease (Braunwald, 1991). Experts strongly advise that patients should not be discharged from hospital until symptoms of heart failure are adequately controlled and adequate home support and follow-up care have been arranged (Dunbar & Dracup, 1996; Johnstone et al., 1994; US Dept. of Health & Human Services, 1994). This will contribute to maximizing function and health related quality of life (HRQL) which is the primary aim in a population that does not realistically expect any probability of cure.

There is often a fragile balance between coping with this long-term illness at home and dealing with the life-threatening exacerbations which require hospitalization. Considering this balance, continuity of care becomes critical. The movement between hospital and home is highly dependent on supportive care activities and linkages for a successful transition (Rich et al., 1995; US Dept. of Health & Human Services, 1994).

Funk & Krumholz (1996, p. 8) summarized the broaad extent of concern at all levels regarding the heart failure situation,

> "... With the continuing increase in the proportion of older adults in the population, and as mortality from coronary artery disease decreases and more people are saved from premature death, the prevalence of CHF is expected to rise. CHF currently has an extraordinarily poor prognosis and is likely to remain a major clinical, economic and public health problem.... patients with CHF have impaired quality of life, restrictions in functional capacity and a plethora of symptoms."

Clinical Practice Guidelines

Clinical practice guidelines are a recent innovation developed to provide guidance in the management of specific conditions (heart failure), diseases (AIDS), or particular clinical problems (e.g. incontinence, pain). Recommendations are formulated through systematic and extensive review of available research. The level of evidence is graded using acknowledged standards, and the consensus of expert opinion is sought when evidence is lacking. Such guidelines offer a standard of practice for evidence-based care and management (Brunt, 1993; Dracup & Dracup, 1996). The Canadian Cardiovascular Consensus Conference (Johnstone et al., 1994) and the Agency for Health Care Policy and Research (AHCPR) are two bodies that have recently formulated guidelines in the area of heart failure. The Canadian group, with medical representation from across the country, developed guidelines for physicians to use when diagnosing and managing

patients with heart failure (Johnstone et al., 1994). The AHCPR guideline involved a multidisciplinary panel who developed a comprehensive set of recommendations including prevention, diagnosis, hospital admission and discharge criteria, patient counseling and education, and exercise and rehabilitation.

With regard to hospital discharge, transition and follow-up of individuals with CHF, the AHCPR clinical practice guideline has eight recommendations which are based on non-experimental research, weak evidence or expert opinion (Level B or C evidence).

1. Patients with heart failure should be discharged from the hospital only when (Strength of Evidence = C):

- Symptoms of heart failure have been adequately controlled.
- All reversible causes of morbidity have been treated or stabilized.
- Patients and caregivers have been educated about medications, diet, activity and exercise recommendations, and symptoms of worsening heart failure.
- Adequate outpatient support and followup care have been arranged.

2. After a diagnosis of heart failure is established, patients and their families or caregivers should be counseled regarding the nature of heart failure, drug regimens, dietary restrictions, symptoms of worsening heart failure, what to do if these symptoms occur, and prognosis. The impact of heart failure on a patient's life may be related as much to psychological adaptation to the disease as to impairment in physical functioning. Nursing interventions, family involvement, and support groups may all help patients cope with heart failure. All patients should be encouraged to complete advance directives regarding their health care preferences. Practitioners should emphasize the importance of

not smoking or chewing tobacco. Practitioners should recommend that patients receive vaccination against influenza and pneumococcal disease. (Strength of Evidence = C.)

3. Regular exercise such as walking or cycling should be encouraged for all patients with stable NYHA Class I - III heart failure. (Strength of Evidence = B.)

4. There is insufficient evidence at this time to recommend the routine use of supervised rehabilitation programs for patients with heart failure, although such programs may be of benefit to patients who are anxious; are dyspneic at a low work level; or have angina, a recent myocardial infarction (MI), or a recent coronary artery bipass graft (CABG). (Strength of Evidence = C.)

5. Dietary sodium should be restricted to as close to 2 grams per day as possible. In no case should sodium intake exceed 3 grams daily. (Strength of Evidence = C.)

6. Alcohol use should be discouraged. Patients who drink alcohol should be advised to consume no more than one drink per day. (Strength of Evidence = C.)

7. Patients with heart failure should be advised to avoid excessive fluid intake. However, fluid restriction is not advisable unless patients develop hyponatremia. (Strength of Evidence = C.)

8. Patients should be encouraged to keep a record of their daily weights and to bring the record with them when visiting their practitioner. Patients should be instructed to call if they experience an unexplained weight gain greater than 3-5 pounds since their last clinical evaluation. (Strength of Evidence = C.)

Clinical practice guidelines are a valuable tool in setting a standard of practice within and across settings. However, it has been recognized that such guidelines may

require modification for implementation in local settings (Grimshaw et al., 1995; Logan & Graham, 1996). It is also important to evaluate clinical practice guidelines in areas where the evidence is not strong, particularly if they contribute to the decision-making regarding allocation of scarce resources such as nursing time, expensive equipment or procedures (Dunbar & Dracup, 1996; Harrison, Wells, Fisher, & Prince, 1996).

Given the prevalence of the condition, the aging population, the high costs of treatment particularly in hospital settings, and the guidance from clinical practice guidelines (Johnstone et al., 1994; US Dept. of Health & Human Services, 1994), a number of groups have focused on, and evaluated CHF innovations for improved management across the sectors of care (Donlevy & Pietruch, 1996; Rich et al., 1995; Welsh & McCafferty, 1996). Problems of continuity of care have been a central theme. Empirical studies will be reviewed in the following section.

CHAPTER 2: CONTINUITY OF CARE LITERATURE REVIEW

The Concept of Continuity of Care

"One of the most significant trends in medicine and in nursing is the shift of emphasis from the disease to the patient and to his family and community, and consequently the projection of his treatment from hospital to home without any break in its continuity." (Harriet Frost, 1947, p. 761)

Continuity of care is a commonly used term in nursing and in health care circles. It is held up as an aim and a philosophy of care at the clinical and the policy level. Many facilities incorporate it in mission statements, e.g. "...providing leadership in collaboration with all care providers, community agencies and other institutions to achieve an efficient and integrated continuum of health care delivery" (Ottawa Civic Hospital, 1997). Euphemisms such as 'seamless care' and 'continuing care' in an 'integrated health system' are often referred to in policy documents and the popular press. Continuity of care has even been referred to as a principle and an ideal (American Nurses Association, 1975; Bedder & Aikin, 1994; Hartigan & Brown, 1985). Most clinicians consider it a standard of care (Bedder & Aiken, 1994). The concept of continuity of care encompasses discharge planning, transitional care, coordinated care, continuing care, and community care. These terms are inextricably intermeshed in the literature, used interchangeably, and usually not well defined (Anderson & Helms, 1993; Feather & Nichols, 1985; Haddock, 1991; Jackson, 1994; McClelland, Kelly, & Buckwalter, 1985; McKeehan & Coulton, 1985; McWilliam, 1992). In the following section the history of the concept of continuity of care will be summarized and the meaning which has evolved

over time from different perspectives will be integrated. Using this definitional foundation, the investigator's Intersectoral Continuity of Care framework is then presented and operationalized to guide the study.

Background

Emergence of the Concept

The evolution of the concept of continuity of care in North America mirrors the characteristics and development of the health care system itself. Institutional and community health services have developed as largely distinct sectors in terms of their policy formation, financing, organization and providers. The continuity of care movement started with continuing care from hospitals. The primary focus was with hospital to home transfer. Initially, the institutional sector of hospitals began the movement of discharge planning as one component of continuity of care to expedite hospital discharge (Bedder & Aiken, 1994). This led to discharge planning as the 'means to the end' of continuity of care. Early work was mainly within the discipline of nursing and later appeared in the emerging field of social work.

The notions of continuity of care have been evident since the early part of this century (Shamansky, Boase & Horn, 1984). A nurse, Mary Strong Burns (1921) probably conducted the first formal study of discharged hospital patients (n=200) requiring ongoing care. Burns had a vision of the patient as an 'active field agent' in promoting good health practices. Key elements for continuity found in Burns' final recommendations included the development of a plan with the patient for their aftercare,

adequate patient instruction about their condition and treatments, as well as general hygiene. By the 1930's, with the Great Depression and difficult economic times, concern continued with regard to hospitals discharging patients without a plan for their continued care in the community. It was not until after the Second World War however, that hospitals and public health nursing agencies began to collaborate with referrals to community agencies (Frost, 1947). Comprehensive community planning started in the 1950's and it was evident by the 1960's that discharge planning had become the focus of transitional care (Shamansky et al., 1984). In the 1960's the term 'discharge planning' first appeared as the vehicle in attaining a philosophy of continuity of care. Discharge planning programs were still exclusively located in hospitals and the activity of discharge planning seemed to take on a life of its own. One author describes it as "almost a movement" (Fenwick, 1979). With the emphasis on structure, procedures, and policies, few substantive evaluations or research studies of discharge planning were published during the 1960's.

By the 1970's, escalating health care costs and the era of consumerism and patient satisfaction in health care brought about efforts dedicated to utilization review and quality improvement (Shamansky et al., 1984). In this decade, "continuity" becomes formally and widely acknowledged by professional and accreditation bodies and well integrated in health service delivery (American Hospital Association, 1972, 1974; American Nurses Association, 1975; Canadian Council for Hospital Accreditation, 1967; Fenwick, 1979; Hartigan & Brown, 1985). By the early to mid-1980's there was a profound change in health care delivery in North America generally, and Canada specifically. It was

characterized by a sharp departure in policy and/or reimbursement shifting from institutional care to home based alternatives (Premier's Council on Health Strategy, 1990, 1991; Rachlis & Kushner, 1989; Shamansky et al., 1984).

In the 1990's, the conceptual advancement has not progressed much beyond that of defining the term. Even today, no comprehensive model or framework has managed to describe what the concept of 'continuity of care' involves, how it is implemented, or how it is measured. There remains a paucity of research on the effectiveness of widely acknowledged components of transition in care, such as discharge planning or case management approaches. This has further contributed to the lack of understanding of continuity of care. Maturation of the continuity of care paradigm has been stunted by the emphasis and testing of individual phenomena. The whole is undoubtedly greater than the sum of the parts. Fragmenting and testing of continuity of care sections may result in erroneous conclusions of no effect. There is a need to acknowledge and study the complexity of continuity of care. The next level of enquiry needs to be deductive from the known elements such as discharge planning, case management strategies and supportive family care, while at the same time being inductive from what may be the result of a dynamic interplay of elements. This more comprehensive approach will form the basis of this and future studies of continuity of care.

In summary, several observations about discharge planning are pertinent for advancing the understanding of the concept of continuity of care. Historically, continuity of care has typically been viewed, defined and measured from the perspective of one sector or setting, usually the hospital. This has led to a focus on discharge planning and

case management as a means to accomplish this. The focus on discharge planning may be a pragmatic issue because of the difficulty in determining a model or framework for continuity of care. As well, discharge planning has been an accreditation requirement in institutional care for several decades and has become a discrete, identifiable component of health services delivery. Although discharge planning has been highly focused as the sine qua non of continuity of care, there is little research supporting the effectiveness of discharge planning in and of itself (Anderson & Helms, 1993; Jackson, 1994; Shamansky et al., 1984).

In terms of chronically ill populations in particular, this single perspective and directionality have limited the evaluation of the concept of continuity of care. This is likely explained by the fact that those with chronic or long term conditions have different needs and requirements in contrast to individuals experiencing single acute illness episodes. The emphasis shifts from a *cure* to *care*. This involves the alleviation of symptoms, maintenance or improvement in functional capacity, and aiding in the day-to-day management as key aspects. Related to continuity, the inpatient hospital to home transfer is not the only transition individuals with chronic conditions encounter. Other significant elements of the continuum of care include the use of the emergency rooms, ambulatory services, rehabilitation and long term care settings (Bedder & Aikin, 1994; Phillips-Harris & Fanale, 1995). An important practical and philosophical orientation is that home, not the hospital, is usually the pinnacle and centre of care with the management of chronic or long term conditions. Relatives, rather than professionals, are the main providers of care to the chronically ill (Morris, Sherwood & Morris, 1996). The

hospital and other health care facilities, and professional providers should be considered the backup to be called upon to supplement and facilitate the center of care (Corbin & Strauss, 1991). Table 1 contrasts these different assumptions regarding acute and chronic care.

Table 1

Comparisons of acute and chronic care

	Acute Care	Chronic Care
Health Services Utilization Pattern	family practice, tertiary institutions, emergency room	family and specialist practice, ambulatory clinics, emergency room, tertiary hospital, respite care, home care
Transitions	hospital to home	multiple settings
Care Providers	professionals	self, relatives, unregulated workers (attendants, aides) professionals
Health Care Access	infrequent, limited	variable, often frequent, unlimited

Continuity of Care: Conceptual Advancement

Despite its longevity as a concept and its common usage, actual definitions of continuity of care were relatively difficult to locate. Computer searches of the literature produced some published definitions (e.g. Anderson & Helms, 1993; McKeehan & Coulton, 1985). Many other important definitions had to be retrieved from the original

sources, for example the Canadian Council for Health Services Accreditation (CCHSA) and the Canadian and American Nurses' Associations (CNA, ANA respectively). A hand search of CNA provincial and territorial jurisdiction policy statements revealed that only one association, the Alberta Association of Registered Nurses, had published statements related to continuity of care. Sources at the American Nurses Association reported that there have been no further updates on the 1975 ANA policy statement (personal communication ANA librarian, June, 1997). Table 2 contains a representative grouping of these definitions, chronologically ordered, from professional and accreditation bodies as well as individual authors. In scrutinizing the definitions several themes appear in common. Key sustaining elements of the concept of continuity of care are *linkages* and *care/activities, over time,* with the *client* and *family,* and *providers.*

Following the search for definitions of continuity of care, enquiry then progressed to how these ideas were brought together in either a descriptive or explanatory blueprint. Although no comprehensive model or framework was found in the published literature of what the concept 'continuity of care' involves, how it is implemented, or how it could be measured, several writers have advanced the understanding of the concept. Shortell's (1976) initial work on continuity, further developed by Rogers and Curtis (1980), identified seven dimensions developed for medical practice which have applicability to the health care team in general (Beddar & Aiken, 1994).

Table 2

Representative Continuity of Care Definitions in Chronological Order

Definitional Statement	Source
The uninterrupted succession of care and services offered in the continuum to individuals in the community.	Canadian Council on Hospital Accreditation in Du Mouchel (1967, p. 1)
Continuity of care is an ideal. It is a process designed to meet the needs of the patient or client during every phase of care and involves admission planning, discharge planning, referral, and follow-up.	American Nurses Association (1975, p. 2)
Extent to which medical services are received as part of a coordinated and uninterrupted succession of events consistent with the medical care needs of patients.	Shortell (1976, p. 377)
A means by which separate episodes of illness are joined and structured.	Rogers & Curtis (1980)
The integration over time of staff and patient information and actions directed toward furthering the physical and social-psychological rehabilitation of the patient beginning in the hospital and continuing after discharge.	Davis (1980)
A coordinated process of activities that involves the client and health providers working together to facilitate the transition of health care from one institution, agency, or individual to another.	McKeehan & Coulton (1985, p. 79); see also Haddock (1991, p. 10)
A series of organized, connected patient-care events or activities that occur on a continuum even though the patient's need or desire for care varies, and even when the health care is given by numerous providers. An ideal requiring linkages; multiple contributing providers; planning, coordinating, communicating, referral, and follow-up to achieve mutually agreed upon goals.	National League of Nursing in Hartigan & Brown (1985, p. 10)

Representative Continuity of Care Definitions in Chronological Order (continued)

The coordinated delivery of health services which recognizes the client's requirement for ongoing health care. It is based on communication between health team members within a facility and/or community.	Gikow, Anderson, Bigelow, Hanford & Kisielius (1985, p. 195); see also Alberta Association of Registered Nurses (1989)
Continued supportive assistance through the illness trajectory (course) where past and future are considered when planning care in the present.	Corbin & Strauss (1991, p. 166)
A series of linkages across time, settings, providers and consumers of health care.	Anderson & Helms (1993, p. 41)
A process which provides for seamless transitions through reciprocal linkages between agencies, formal caregivers, and informal caregivers within a dynamic health system. Comprehensive, co-ordinated, and integrated provision of appropriate health services. It centers on the needs of the client/ family, acknowledges clients and informal care-givers as partners in care, and requires an interdisciplinary approach by formal caregivers.	Alberta Association of Registered Nurses (1996, p. 3)
The extent to which care and service are coordinated in relation to clients, families, and the community; providers; organizations, sites/locations, departments/services; and time.	Canadian Council on Health Services Accreditation (1997, p. 47)

The dimensions include a 'chronological dimension' of services provided over time; a 'geographic dimension' of sites at which care is given; the 'interdisciplinary dimension' of integrating a focus on disease, psychosocial, behavioural, and family issues; a 'relationship dimension' between caregiver and patient; an 'informational dimension of communication' via medical records, telephone, and other sources of data; an

'accessibility dimension' of the ease with which services are accessed; and a 'stability dimension' of the community involving the patient and family. The dimensions offer direction for a more comprehensive measurement of continuity of care going beyond the limited approach of hospital readmissions and resource use. This work recognizes the complexity and explicates important aspects for study.

Rogers and Curtis (1980) and others (Bedder & Aiken, 1994; Starfield, 1980) clarify the distinction between a regular source of care, which is referred to as longitudinality, and an overall concept of continuity. Provider approaches to improving continuity, such as case management or primary nursing, are aimed at longitudinality. The broader definition of continuity of care encompasses not only longitudinality, but the notions of integration and comprehensiveness. This distinction becomes important when considering care across time and various episodes of care.

This distinction was furthered in a Canadian nursing masters thesis (Glenn, 1995). Using a concept analysis approach, Glenn (1995) studied the continuity of care concept from a nursing, social work, medical and administrative perspective. She describes three overlapping themes: provider continuity, intra-agency continuity and inter-agency continuity. Glenn, like others, discovered a number of surrogate terms for continuity of care. However, it is not evident that she searched the literature using all these terms; therefore, she may have left out important papers from the concept analysis. Another major limitation of the Glenn study is that research publications were not differentiated from opinion or editorial papers. The absence of a data matrix makes it difficult to validate Glenn's conclusions. In the end, Glenn does not articulate either a definition nor

model of continuity of care. This work contributes to the understanding of continuity of care as a concept and its complexity by explicating the difficulties with the concept based on the various perspectives.

Study Definition and Approach to Continuity of Care

Given the lack of a comprehensive framework or model of continuity of care, the investigator returned to the level of definition. It was critical to integrate and build on the meaning that various key stakeholders such as professional associations, accreditation bodies and researchers have used with this concept. These perspectives are essential because over time the meaning of continuity of care has been shaped by regulation as well as the ideals or vision of care.

Conducting a simple content analysis of the already established definitions (Table 2), revealed that the central axis of the concept is coordination of care. Accepting and building on the recurring themes or elements of *linkages, care/activities, over time,* with the *client* and *family,* and *providers,* continuity of care for this study is defined as:

> A coordinated and integrated process of care, creating linkages across settings, between providers, with recipients of health care that facilitates the transition of health care from one sector, institution, agency, or individual to another over time.

The goal is to optimize health care delivery through a prudent use of resources. This definition recognizes that continuity of care operates at a number of levels within

health care sectors, as well as with agencies and institutions within a sector; between individual providers; and with patients and families. Implicitly, this requires partnership at, and within, multiple levels of the organization involved in the transition points of services. Continuity of care is considered a process rather than an outcome in this definition. The outcomes of continuity of care are affected by: who is involved, where it is taking place, what is being done, when it is happening, and the desired result(s).

From the definition, the investigator formulated a study framework which was then operationalized for continuity of care. The Intersectoral Continuity of Care (ICC) framework in Figure 1, provides a schema of the basic elements of continuity of care during the transition from one health care sector or setting to another. Each of the key elements comprises a fundamental part of the process of continuity of care and provides an important construct for evaluation. Table 3 contains the definition of these elements.

Figure 1. Intersectoral Continuity of Care (ICC) Framework

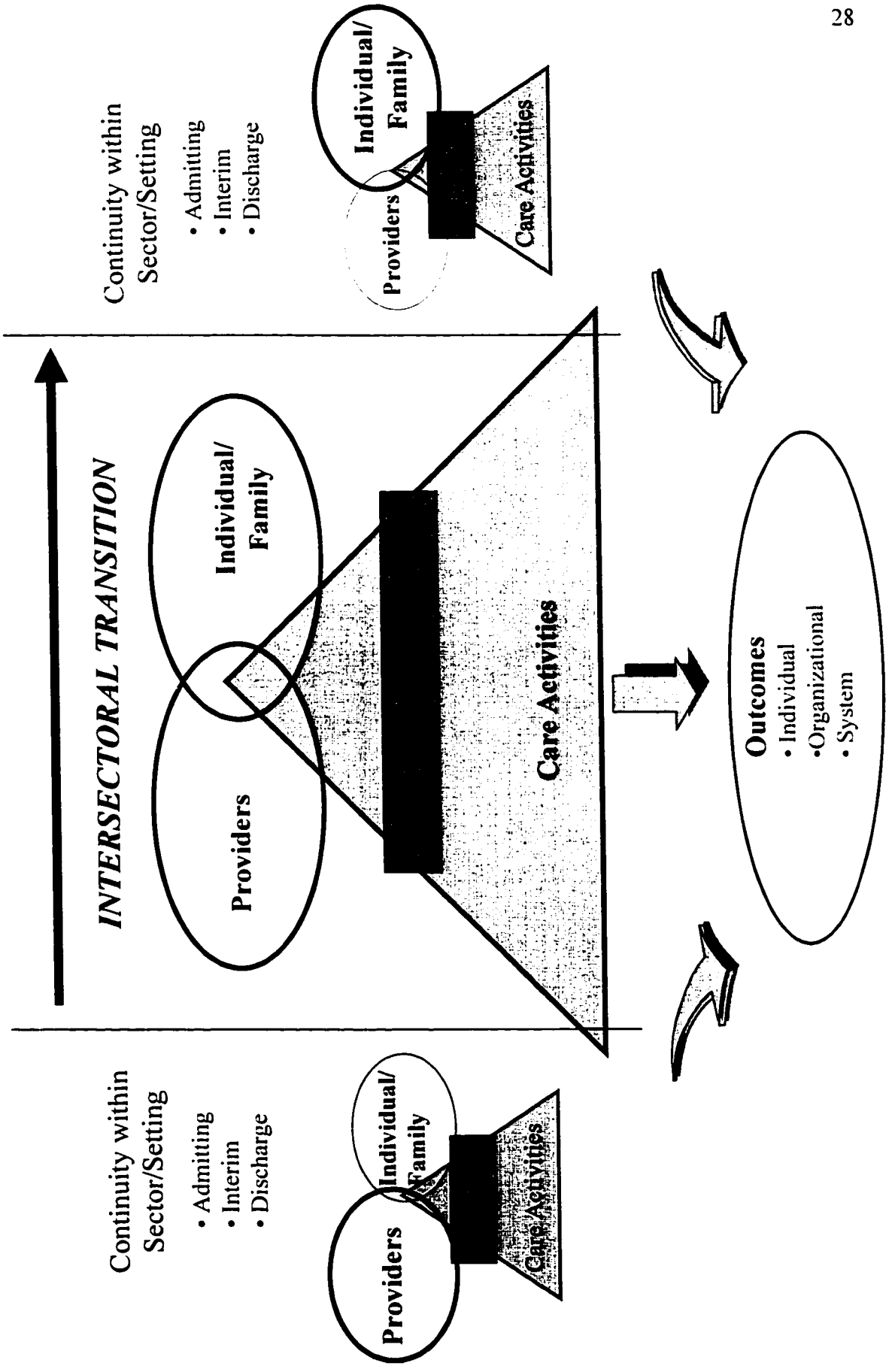

Table 3

Definition of Intersectoral Continuity of Care Framework Elements

Care Activities	Activities & interventions, direct & indirect services rendered by members of the health professions and/or family for the benefit of the patient/client (O'Toole, 1997).
Family	Meant in the broad sense of significant others, particularly those involved as informal care providers.
Individual	Recipient or consumer of care. Used interchangeably with client a community sector term and patient, the more common term in the institutional sector (McGee, 1996; O'Toole, 1997).
Linkages	The formal and informal communication and connection between agencies and institutions, sectors, providers, clients and families for the purpose of facilitating care provision.
Outcomes	Individual, organizational and system level accounting for before, during and after the transition.
Over Time	Denotes the particular continuum of care required by an individual as they progress from diagnosis to death.
Providers	Professional caregivers including physicians, nurses, social workers, allied health personnel.
Sector	Division of public services separate by distinct structure, organization & funding usually determined by government. Health care sectors include institutional, community based, cancer care, mental health services.
Setting	Agency (e.g. hospital, rehabilitation centre, ambulatory clinic) or venue (home) of care provision
Transition	Transfer of care from one sector or setting to another.

Linkages - Beyond Communication

Efficient and effective communication processes are clearly necessary linkages. The organization of care delivery is important, as is the method by which case management is being conducted e.g. understanding the delivery system contribution to provider longitudinality within the setting and across settings such as primary nursing, or physician specialist to generalist arrangements. The connection between setting and providers can be made or further enhanced in many ways through practice patterns such as the provision of consistent, evidence-based care, through accepted professional standards of care, or using the recent innovation of clinical practice guidelines.

Measurement of Continuity of Care

Most of the knowledge in continuity of care to date has been the result of provider and system estimates of outcome (Bull, 1994; Evans & Hendricks, 1993; Hansen, Spedtsberg, & Schroll, 1992; Kennedy, Neidlinger & Scroggins, 1987, Naylor et al., 1994; Rich et al., 1995; Weinberger, Smith, Katz, & Moore, 1988). At present, outcome assessments are almost entirely based on the perspective of the provider, agency or health care sector and have not included the subjective assessment of the recipient of care or the family. A more comprehensive approach to the measurement of continuity of care is needed. The individual and/or family subjective estimates of their health state, emotional and social function have been shown to impact help-seeking behaviour and use of health and social services (Arpin, Fitch, Browne & Corey, 1990; Bennett, Pressler, Hays, Firestine, & Huster, 1997; Browne, Arpin, Corey, Fitch, & Gafni, 1990; Browne et al.,

1993; Crook, Tunks, Rideout & Browne, 1986; Judd, Browne & Craig, 1985; Weir, Browne, Tunks, Gafni & Roberts, 1992). A focus on subjective, self-assessed outcomes would add an important dimension if adopted (Bedder & Aiken, 1994; Glenn, 1996; McKeehan & Coulton, 1985). With complex health populations, the individual's and family's own estimate of their quality of life, function and burden should be included with the objective measures of morbidity, mortality, hospital readmission rates, and the utilization of health services. As well, greater emphasis should be placed on evaluating the continuity of care process. This will further the understanding of grouping interventions such as communication and care linkages, the extent to which they were received, and the factors that contribute to continuity of care.

Continuity Over Time and During Discrete Episodes of Care

The continuum of care for complex health populations involves many health sector interfaces where numerous scenarios are possible, such as hospital to long term care setting, emergency room to home and so forth (see Figure 2). During the transition from one sector or care setting to another, the care and linkage elements require special attention. For example, the settings and providers each need to in-reach and outreach from their well established structures and processes to ensure a successful transfer and maintenance of continuity of care. The transition points in an individual's health care continuum are where all the elements require reassessment. In the ICC framework, the transition period is recognized as a distinct phase of activity or focus for improving continuity. The care activities and linkages require proactive, systematic, intersectoral effort at the transition points.

Figure 2. Continuum of Care for Complex Medical Populations

With a hospital to home transfer, transition has been defined as the time between hospital discharge and the first home care visit (Rhoades, Dean, Cason, & Blaylock, 1992). These authors recognize this period as a gap where providers engage in a "shared venture" for increased collaboration and interaction. In the Rhoades descriptive model of discharge planning, the provider role is not integrated with the client and family, nor are the care activities and linkages during transition evident. Herein lies the crux of the matter - it is during this period that usual discharge planning activities carried out by providers are likely to be mainly administrative and highly invisible to clients and families. Yet this is often a most stressful time for families as they feel disconnected from the hospital and not yet linked into the community services. The first two weeks after hospital discharge have been shown in recent studies to be critical in terms of the individual and family's connection with providers and health services for a successful transfer home (Bull, 1992; Dansky, Dellasega, Shellenbarger, & Russo, 1996; Lough, 1996; Mamon et al., 1992; Runciman, Currie, Nicol, Green, & McKay, 1996)

The Intersectoral Continuity of Care framework emphasizes the inter-sectoral transition as the main focus and identifies the components requiring attention. In order to move beyond and build upon the well established structure and processes of the individual sectors the intersectoral period requires an in-reach and outreach from each sector for a successful transfer during a period for which neither sector is totally responsible or financed.

Continuity of Care Studies and Complex Health Populations

By far the largest body of literature related to continuity of care is published in the area of discharge planning. The predominant approach has been to explicitly (e.g. Haddock, 1991) or implicitly (e.g. Naylor et al., 1994) equate discharge planning with continuity of care.

Discharge planning has been a formal requirement of hospitals for some time and is considered the means for ensuring that an individual's needs are met post discharge from hospital (American Hospital Association, 1974; Canadian Council of Hospital Accreditation, DuMouchel, 1967; Joint Commission on Accreditation of Health Care Organizations, 1996). Although all patients should be receiving discharge planning, it is not known in practice what the outcomes are or which strategies work to benefit which type of patients. A recent large American study (n= 919) found that 97% of those 60 years of age or older leave the hospital with needs for aftercare (Mamon et al., 1992). Many other reports document the lack of provision for these needs particularly with the elderly (Hansen et al., 1992; Jewell, 1993; Kromminga & Ostwald, 1987; Tierney, Closs, Hunter, & MacMillan, 1993; Victor, Young, Hudson & Wallace, 1993). The publications on discharge planning mainly represent the perspective of the institutional sector, with a few reports being found from the community. Although the literature is largely descriptive of programs or approaches, there are few research studies which provide empirical information on continuity of care.

In a recent critique of the discharge planning literature, Jackson (1994) noted three major assumptions underlying these programmes: cost-effectiveness for the health care

system, the provision of continuity of care, and quality of life enhancement for patients and families. In looking at these assumptions, Jackson concluded that the results were equivocal with regard to cost-effectiveness based on the usual measures of length of stay and readmission outcomes. As well, economic evaluations did not consider the community and family costs. Jackson found that there was no evidence that one approach or model to discharge planning is superior nor were generalizations possible about continuity of care and quality of life from the existing research. Jackson argues for increased information sharing between sectors and establishment of common databases for improved continuity of care (Jackson, 1994, p. 498).

Discharge Planning Studies

A multi-hospital descriptive study of various approaches to discharge planning, reported findings that 'highly structured discharge' planning was linked to greater patient satisfaction and greater provision of post-discharge services (Haddock, 1991). A British study team suggested specific organizational changes to improve continuity of care (Jowett & Armitage, 1988). They recommended that the liaison role be a dedicated, full time commitment to a clearly defined group of patients. Additionally, organizational changes should be undertaken which improve communication and linkage with the hospital and community nurses (Jowett & Armitage, 1988, p. 586). Positive outcomes in terms of communication were shown in another hospital and visiting nurse partnership study (Leimnetzer, Ryan, & Niemann, 1993). In a retrospective descriptive study of 300 records, Anderson and Helms (1993) demonstrated that discharge models outlined in theory vary

markedly from what is implemented in practice. This was further supported in a prospective descriptive study of discharge plans for elderly patients (n = 205) hospitalized with CHF (Proctor, Morrow-Howell & Kaplan, 1996). Proctor and colleagues found that 40% of the patients with CHF had one or more components of their discharge plan not implemented. These studies point out that the theoretical models for discharge planning simply describe allocation of responsibility and should receive less attention. The complex process of communication was the key issue and future research should concentrate on the barriers to, and dynamics of communication in practice. Also of importance were clear lines of responsibility and incentive structures for nurses (Anderson & Helms, 1993). An Ontario study involving patients, caregivers, and health professionals, identified a need to better facilitate communication and coordinate the hospital discharge of elderly persons (McWilliam, 1992). Again the underlying issue tthat was tackled was the linkages across sectors. Danish researchers reported that early follow-up with the elderly after hospital discharge, and adequate authority by the visiting nurse to adjust services were important factors for optimal continuity of care (Hansen et al., 1992). These studies further support the conclusions about communication, and structural and organizational factors reported in Jackson's (1994) critique.

Studies using more stringent research methods made pertinent discoveries about effective discharge planning. A recent three year study (n = 214) followed individuals after their hospitalization and acceptance for heart transplant (Fonarow et al., 1997). It was found that a comprehensive heart failure management programme led to improved functional status and an 85% decrease in hospital admissions after referral to the

programme. Three randomized control trials (RCT) evaluated the use of clinical nurse specialists (CNS) as case managers during the discharge process and transition from hospital to home. In a trial of older, surgical and medical cardiac patients, a CNS delivered an individually tailored discharge protocol (Naylor et al., 1994; Naylor, 1990). Patients were followed for a 2 week transition phase after hospital discharge with fewer hospital readmissions. Fewer total days of rehospitalization were documented for the cardiac medical group but no differences were found for the cardiac surgical group[1] . Patient reported outcomes were not assessed in this trial. Brooten and colleagues (1986), demonstrated that early discharge for a pediatric complex health population (low birth weight infants), with an outreach for 18 months by a hospital based clinical nurse specialist (CNS), was safe and cost effective. In another RCT, discharge planning by a CNS in gerontology resulted in shorter lengths of stay (2 days) and increased time (11 days) between readmissions (Kennedy et al., 1987). A significant factor in all these trials was a concentration on the transition from hospital to home, a CNS functioning as a case manager, and resulting decreases in the use of health services resources post-discharge (Brooten et al., 1988). This was an additional provider and expense to the system.

Other experimental studies have evaluated various structure and process factors in discharge planning. In a large scale clinical trial (n = 835) patients were screened for risk of readmission and then randomly assigned to either early discharge planning from day 3 of hospitalization, or to the control group which would only receive discharge planning if

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[1] Note: there is an in-depth appraisal of this study in the review of CHF studies later in this chapter.

there was a physician order (Evans & Hendricks, 1993). The early, proactive, systematic discharge resulted in an increased likelihood of successful return to home and decreased chance of unscheduled readmission during the 9 months of study. In a Danish study, intensive home follow-up of persons 75 years and older was evaluated and compared at one year to usual discharge procedures (Hansen et al., 1992). The intervention involved a visit by a district nurse on the first day home and two weeks later an evaluation at home by their general practitioner. The experimental group ($n = 163$) had significantly fewer numbers of admissions to nursing homes (24/10, $p < 0.05$) and a lower proportion of days in institutions (2700/1950) compared to the control patients ($n = 181$). A British RCT, evaluated a follow-up screening in the home by a health visitor with 222 elderly people discharged from an emergency department and compared to 192 control patients for whom no special arrangements were made. The experimental group received more services and were significantly more independent at four weeks. These studies and the three CNS RCTs demonstrated the value of an enhanced discharge and follow-up for identified 'at risk', complex health populations. The caveat is that in each example, except the Danish study (Hansen et al., 1992), a new provider was added and increased resource use and/or health service utilization was experienced.

Nursing Practice and Discharge Planning

While discharge planning activity is multidisciplinary, nurses are considered the lynch pin of effective discharge and transition from hospital to home (Jackson, 1994; Rhoades et al., 1992; Shamansky et al., 1984; Tierney et al., 1993). The nurse, whether

formerly in the role of a case manager or working from a philosophy of case management, is the one who interacts with the provider team, has sustained contact with patients and family during an illness episode, functions from a holistic approach and is positioned to improve the effectiveness and efficiency of care (Bower, 1992; Ethridge & Lamb, 1989; Gibbs, Lonowski, Meyer, & Newlin, 1995; Zander, 1988). One author describes admission to hospital as "a referral to nursing" (Packard-Helie & Lancaster, 1989 p.32).

Three recent qualitative studies suggest that clinical nurses have the knowledge of what is needed for effective discharge planning but nurses encounter frustration and failure to overcome system barriers at the clinical level. Jewell (1993) studied the process of discharge to "move away from the snapshot study of discharge outcomes" (p. 1288). Jewell taped interviews with a range of individuals (professional providers, liaison officers, family caregivers) at 10-14 days after hospital discharge for each of 32 case situations. This author identified two key factors for continuity of care: information-giving structures and the quality of communication between and among hospital, patient/family and community. In an Ontario study of nurses' work in discharging patients from hospital to home, McWilliam and Wong (1994) have shed light on the complexities of hospital nursing practice and difficulties in dealing with the organization's discharge process. Their methodology included observation of the discharge planning process, review of patient's charts and kardexes, conducting in-depth interviews with patients (n=9), all key participants in their care (n=65), and expert informants (n=14). Three aspects of nursing practice and the discharge process related to the work context were identified: working with the characteristics of bureaucracy (e.g.

facilitating centralized control and mending fragmented work); compensating for the bureaucracy on behalf of the health care team (e.g. coordinating the work of others, troubleshooting, acting as physician's handmaiden); and providing leadership which ensured effective care from others (e.g. serving as primary source of information, acting as the patient's advocate). Another Ontario researcher looked at the decision-making around the hospital discharge of elderly patients (n = 31) and further supported the findings of McWilliam and Wong (1994) . Using 'Critical Theory', Wells (1995) concluded that the decision-making process was one sided in that it was functional or instrumental to the hospital in its orientation and biased toward administrative concerns such as bed turnover, economic viability of the hospital. These three qualitative enquiries describe how the structure and process of the exisiting sectoralized health care system impedes a smooth transition from hospital to home.

State of Knowledge from the Discharge Planning Literature

In summary, over the past three decades the majority of studies have been on hospital discharge planning. These studies have been largely driven by the hospital sector in order to successfully transfer patients out to the community or to another level of institutional care. But discharge planning only reflects the episodic passage from institution, usually hospital to community and home. Although discharge planning is a central and important process for achieving continuity of care it is a contributing process rather than a complete remedy (Mamon et al., 1992; Rhoades et al., 1992; Shamansky et al., 1984). Discharge planning remains primarily episodic in its organization and

occurrence. Research to date has been highly focused on methods of discharge planning and not on outcomes of continuity of care in the broader sense. From this literature and research, several conclusions can be drawn with regard to continuity and complex health populations:

(i) the majority of older individuals leave hospital with ongoing care requirements

(ii) a case management perspective is critical, but no single model of discharge planning has been demonstrated to be superior using strong research methodologies

(iii) the communication processes are key issues in achieving continuity of care

(iv) the structural and organizational factors within the involved agencies offer significant influence over the degree of continuity achieved.

The focus on discharge planning has brought about a limited notion of the health continuum which is episodic and circumscribed by the venue of the planner e.g. the hospital. It does not recognize the compartmentalization of the health system into institutional, community and other sectors. This is an important issue, administratively and financially, when dealing with the notion of linkages and coordination. The process of discharge planning does not necessarily bridge or cross over these separately funded and organized sectors of health care.

The work to date on discharge planning does however provide optimism that improvements in continuity of care are possible with some redesign of the existing system. Case management, communication processes, and structure and organizational

factors are coupled with nursing delivery systems and the divisions of health services. Thus, opportunities for practice innovation and development should be investigated in order to move beyond discharge planning and the simple addition of new resources or providers. One population that exemplifies this challenge to provide continuous care are those individuals with heart failure. In the next section, this group will be examined as a complex health population appropriate to a study on continuity of care.

Congestive Heart Failure and Continuity of Care Research Literature

Systematic Review

A systematic review was undertaken in order to appraise the research to date with regard to continuity of care and the congestive heart failure population. The approach involved a defined retrieval, searching and critical appraisal methodology. Research published in the past ten years was sought as studies prior to this period would have limited relevance given the substantive changes in health services delivery over this time. Summaries in the form of structured abstracts of each study were completed by the investigator and alphabetically organized (Tables 4a-4g).

Databases Utilized

Medline	January 1987- September 1997
Cinhal	January 1987- September 1997
Health	January 1987- September 1997

Search Strategy

1. Main Mesh headings of continuity of care, patient discharge and case management were combined using an 'or' statement.

2. The resulting set was then limited to: human subject , English.

3. In order to retrieve the research based papers a two pronged approach was used:

i) the set was first limited by publication type: controlled trials, controlled clinical trials, randomized controlled trials, meta analysis or reviews.

ii) using the text word search option, the words 'research', 'study', and 'trial' were searched individually, the 3 sets combined using 'or' to exclude duplicate papers.

4. Using the text word search option the words 'heart failure', 'elderly' and 'aged' were searched individually and combined using the 'or' to exclude duplicate articles.

5. The results of #3 and #4 were combined constructing 2 new sets. Using 'and' to construct a set which had 'research', 'study', and 'trial' with 'heart failure', 'elderly' and 'aged'. Using 'and' to construct another set with publication types of controlled trials, controlled clinical trials, randomized controlled trials, meta analysis or reviews of the literature. The resultant 2 sets were combined using 'or' to delete the duplications.

6. A total of 735 papers were identified from the above strategy and the abstracts of these were then individually scanned for inclusion using the following criteria: heart failure as the study population or part of a study group, experimental or quasi-experimental study design, intervention related to continuity of care, discharge planning or transitional care. The abstract scan revealed five large scale trials and two randomized pilot studies which fit the criteria and abstract summaries were completed using a format adapted from Tugwell & Bennett (1983) (see tables 4a-4g).

Critical Appraisal

The critical appraisal of the research papers related to the congestive heart failure population was guided by published standards for methodological review of the literature

(Guyatt, Sackett, & Cook, 1993; Guyatt, Sackett, Sinclair, Hayward, Cook & Cook, 1995; Roberts & Bennett, 1997; Sackett, 1989). The scientific merit of the methods, significance of results, and clinical applicability were assessed using a worksheet (Roberts & Bennett, 1997; Sackett, Haynes Guyatt, & Tugwell, 1991). Four studies were assessed at Level I or II evidence. A prospective cohort study was also included (Level IV) because of its large scale, 12 month follow-up, and emphasis on functional measures and subjective outcomes as well as health service utilization.

Table 4a

Summary Appraisals of 6 Research Studies and 2 Pilot Studies Related to Continuity of Care and Individuals with Congestive Heart Failure

TITLE & AUTHORS	Outcomes for older men and women with congestive heart failure. Burns, McCarthy, Moskowitz, Ash, Kane, & Finch. (1997).
DESIGN	Large Scale Prospective Cohort Study (1988-1989) Research nurse interviewed each patient 2 days before discharge, and at 6 weeks, 6 & 12 months post discharge.
SETTING	Minneapolis (19 hospitals), Pittsburgh (18 hospitals) Houston (15 hospitals)
ELIGIBLE POPULATION	Patients from Post-Acute Care Study, 65 years or older, discharged from hospital with CHF
SAMPLE SIZE	n = 519
MEASUREMENTS i) Constructs ii) Instruments	 1. ADLs, Shortness of breath on walking, 2. Perceived Health 3. Living situation 3. Rehospitalization 4. Mortality 1. ADL Score. New method, weighted sum 6 functions. Shortness of breath on 1 block walking: dichotomous variable. Self report. 2. Self report single question (excellent/good vs air/poor) 3. Home with no formal care vs formal care at home or institutional care. Self report 4. Self report at interview time points, no verification noted. 5. Research staff follow-up with identified caregiver, verified from Health Care Financing administrative files
FINDINGS	1. 1/3 population substantial impairment (SOB < 1 block), difficulty with ADLs 2. 25% readmit by 6 weeks, 33% by 6 months & 50% by 1 year 3. 1/3 received formal care 1 year after discharge 4. 48% men and 35% women deceased at 1 year
METHODOLOGICAL CONSIDERATIONS	1. 10 year lag in study completion and reporting 2. Sample size: 519 patients identified from PAC dataset, report 48% participation by Houston hospitals, did this exclude the non-participating centers? What proportion? 3. Loss to follow-up not reported, all tables indicate n=519, issue important with 1 year study & large number hospitals in 3 large cities.
IMPLICATIONS FOR CURRENT STUDY	6 week, 6 & 12 month follow-up period, 6 weeks seems key, track carefully because drop-out & loss statistics leave a lot questions

Table 4b

TITLE & AUTHORS	Comprehensive discharge planning for hospitalized elderly: A RCT. Naylor, Brooten, Jones, Lavizzo-Mourey, Mezey, & Pauly. (1994).
DESIGN	RCT, 2, 6, 12 weeks post hospital discharge testing (1989-92)
SETTING	Hospital of University of Pennsylvania
ELIGIBLE POPULATION	Patients: 70 years or older admitted with selected medical diagnoses (CHF, angina/myocardial infarction) or surgical diagnoses (CABG or valve replacement). English speaking & alert & oriented Caregivers: identified by patients as those assuming primary responsibility for their care after discharge.
SAMPLE SIZE	n = 364 & 125 caregivers (total medical & surgical groups) final study sample=276 (minus 36 deaths & 52 withdrawals) medical group (control=70, intervention=72) surgical group (control=66, intervention =68)
INTERVENTION i) Description ii) Personnel	Control: Routine hospital discharge plan Intervention: Comprehensive, individualized discharge plan specifically developed for elderly & implemented by CNS. Protocol from hospital admission -2 weeks after D/C included: i) comprehensive & ongoing assessment patient & caregiver ii) planning in collaboration with elderly person, caregiver, physician, primary nurse & other members health team iii) validation patient & caregiver education iv) extra coordination through to 2 weeks after discharge v) interdisciplinary communication, ongoing evaluation of plan Research staff (CNS) delivered intervention Usual providers for control participants
OUTCOMES i) Constructs ii) Instruments	 1. LOS, time between D/C & readmit, rehospitalization rates 2. Charges for care (hospital, medical, nursing) 1. 12 week follow-up by study team 2. Based on index hospital DRG groups, 'charge' data used for other reported health service utilization
FINDINGS	Medical group had fewer readmissions & total days in hospital, & lower charges at 6 weeks. No differences found in surgical group.
METHODOLOGICAL CONSIDERATIONS FOR CURRENT STUDY	1. No subjective outcome measure included. 2. Effectiveness requires evaluation of intervention delivered by existing providers (feasibility of masters prepared nurses dedicated to this activity in Canadian setting is questionable) 3. No consumer costs included in analysis
IMPLICATIONS FOR CURRENT STUDY	Readmits reduced with intensive D/C process, supportive care and linkages, added provider(s) were highly prepared RNs. Caregivers enrolled.

Table 4c

TITLE & AUTHORS	Comprehensive discharge planning for hospitalized elderly: A pilot study. Naylor, M. D. (1990a).
DESIGN	Randomized Pilot Study
SETTING	Hospital of University of Pennsylvania
ELIGIBLE POPULATION	Patients: 70 years or older admitted to medical or surgical units Caregivers: identified by patients as those assuming primary responsibility for their care after discharge. No specifics of diagnoses.
SAMPLE SIZE	n = 40 (control=20, intervention =20)
INTERVENTION i) Description ii) Personnel	Control: Routine hospital discharge plan Intervention: Comprehensive, individualized discharge plan implemented by gerontological CNS. Which included: i) assessment within 24 hrs admission, communicated to primary RN ii) validation patient & caregiver education iii) extra visits during hospitalization & for 2 weeks after discharge iv) ongoing evaluation of plan Research staff (CNS) delivered intervention Usual providers for control participants
OUTCOMES i) Constructs ii) Instruments	 1. LOS, time between D/C & readmit, re-hospitalization rates 2. Discharge morbidity 3. Charges for care (hospital, medical & nursing) 1. 8 week follow-up by study team 2. Short Portable Mental Status Questionnaire, Enforced Social Dependency Scale 3. Based on index hospital DRG groups, 'charge' data from patients' bills used for other reported health service utilization
FINDINGS	No difference in groups in LOS or rates of post hospital infection. Statistically significant number re-hospitalizations during study period.
METHODOLOGICAL CONSIDERATIONS FOR CURRENT STUDY	1. Small sample size. Need for larger study. 2. No subjective outcome measure included. 3. Use of charges may not be reflective of actual costs. Also, no consumer expenditures included in analysis.
IMPLICATIONS FOR CURRENT STUDY	2, 4 & 12 week data collection points for health service utilization - reasonable time-frame for recall

Table 4d

TITLE & AUTHORS	A multidisciplinary intervention to prevent the readmission of elderly patients with congestive heart failure. Rich, Beckham, Wittenberg, Leven, Freedland, & Carney. (1995).
DESIGN	RCT, baseline on enrolment and 3 months testing
SETTING	Jewish Hospital at Washington University Medical Center
ELIGIBLE POPULATION	patients 70 years or older admitted to medical wards with CHF and at least one of following criteria: prior history CHF, >3 hospitalizations in past 5 years, CHF precipitated by acute M.I. or uncontrolled hypertension
SAMPLE SIZE	n = 282 (control=142, experimental=142)
INTERVENTION i) Description ii) Personnel	 Control: Standard Rx & services ordered by primary physician Intervention: Nurse directed multidisciplinary intervention Intensive CHF education, individualized dietary protocol, medication review by geriatric cardiologist, supplemented home visiting & telephone contact with study team Study team for intervention group Usual providers for control participants
OUTCOMES i) Constructs ii) Instruments	 1. Event-free Survival (primary outcome) 2. Medical costs, caregiver costs (subgroup, n = 57) 3. Quality of life (subgroup, n = 126) 1. 90 day follow-up by study team, # re-admissions, days of hospitalization 2. Cost logs, self report by participants & providers 3. Chronic Heart Failure Questionnaire
FINDINGS	Survival without readmission for 90 days greater in the intervention group (P=0.09). Number of multiple readmissions higher in the control group (risk ratio, 0.39; P=0.01). Quality of life improved in intervention group from baseline (P=0.001)
METHODOLOGICAL CONSIDERATIONS FOR CURRENT STUDY	1. 175 participants excluded for discretionary reasons, another 116 for patient or M.D. refusals to the trial, no data presented on this group to compare with trial participants 2. Costing & quality of life done on non-randomly selected small subgroups 3. Generalizability is questionable: 1306 fulfilled the criteria for CHF diagnosis but only 282 (21.6%) were randomized 4. Compliance data not available regarding 'dose' of components of intervention & difference with usual care
IMPLICATIONS FOR CURRENT STUDY	Readmits can be reduced with intensive D/C process with supportive care activities & linkages, addition of new providers, collect QOL data on whole sample, significant outcome

Table 4e

TITLE & AUTHORS	Prevention of readmission in elderly patients with congestive heart failure. Rich, Vinson, Sperry, Shah, Spinner, Chung, & Davila-Roman. (1993).
DESIGN	Randomized Pilot Study
SETTING	Jewish Hospital at Washington University Medical Center. Secondary & tertiary care university teaching hospital
ELIGIBLE POPULATION	Patients 70 years or older admitted with documented CHF
SAMPLE SIZE	n = 98 control=35, experimental=63
INTERVENTION i) Description ii) Personnel	 Control: standard care ordered by attending physician Experimental: Non-pharmacological; 4 components, Intensive CHF education, medication review geriatric cardiologist, early discharge planning, enhanced home care & telephone contact Study team for experimental group Usual providers for control participants
OUTCOME MEASURES i) Constructs ii) Instruments	 1. Unplanned Re-hospitalizations 1. 90 day follow-up by study team, # readmissions, days of hospitalization
FINDINGS	Reduced rate of readmission on experimental group Full scale trial, with larger sample is justified (n = 300)
METHODOLOGICAL CONSIDERATIONS FOR CURRENT STUDY	1. Small sample size, insufficient statistical power 2. No subjective outcome measure included 3. Cost effectiveness not assessed
IMPLICATIONS FOR CURRENT STUDY	Older patient population. Emphasis on supportive care activities & communication linkages

Table 4f

TITLE & AUTHORS	The cost-effectiveness of intensive post discharge care: A RCT. Weinberger, Smith, Katz, & Moore. (1988).
DESIGN	RCT, pre-discharge & 150 days post hospital discharge testing (1985)
SETTING	Wishard Memorial Hospital, University affiliated in Indiana
ELIGIBLE POPULATION	Patients admitted to the medical wards who would be discharged the General Medical Clinic (GMC) for follow-up, 42% were enroled.
SAMPLE SIZE	n =1,001 (control=502, intervention=499) stratified low (422), medium (398) or high risk (181) for admission
INTERVENTION i) Description ii) Personnel	Control: Routine hospital discharge & follow-up procedures Intervention: Telephone intervention within 1 week of discharge & enhanced monitoring to review needs, medications and regimens, scheduled appointments & barriers. CHF, COPD, diabetes patients received cards in mail describing symptoms warranting immediate M.D. or R.N. contact. Mailed reminders for GMC appointment., missed appointments rescheduled. GMC team nurses delivered both intervention & provided usual care to control participants
OUTCOMES i) Constructs ii) Instruments	 Inpatient & total health care costs Charge & cost data from WMH (inpatient and outpatient) collected by a blinded research assistant.
FINDINGS	Lower inpatient costs with high risk group. This study was increased intensity of previous trial intervention using outpatient nurses, telephone intervention & enhanced monitoring (previous used mail-out notices, follow-up of missed visits).
METHODOLOGICAL CONSIDERATIONS FOR CURRENT STUDY	1. No objective or subjective individual outcome measure included. 2. Validation of the low, medium, high risk groups 3. No consumer costs included in analysis 4. Representativeness of sample (mean age 53 yr, 60% Black)
IMPLICATIONS FOR CURRENT STUDY	Active linking inpatient & outpatient care seen as key aspect.

Table 4g

TITLE & AUTHORS	Does increased access to primary care reduce hospital readmission? Weinberger, Oddone, & Henderson, et al. (1996).
DESIGN	RCT, baseline, 30 & 180 day testing
SETTING	multi-center, 9 Veteran's Affairs Medical Centers in various states
ELIGIBLE POPULATION	patients 70 years or older admitted to VA centers with one of following diagnosis: COPD, CHF, or diabetes
SAMPLE SIZE	n = 1396 (control=701, experimental=695)
INTERVENTION i) Description ii) Personnel	 Control: Standard Rx & services ordered by community MDs or VA clinics, no access to primary care RN, no supplemental education, assessment Intervention: Team of experienced RN and primary care physician delivered inpatient (assessment, CHF education, card to access RN or MD beepers, RN visit 2 days prior to D/C, appt. With clinic one week after D/C) and outpatient intervention (RN telephone follow-up & assessment 2 days post D/C, reminder re: appt., follow-up clinic appt. or missed visit protocol) Study nurses & physicians for intervention group Usual providers for control participants
OUTCOMES i) Constructs ii) Instruments	 1. Health service utilization (primary outcome) Days of rehospitalization, rates of readmission, emergency & outpatient clinic visits 2. Quality of life 3. Patient satisfaction 1. 180 day follow-up by study team, using national administrative database, non VA data estimated from pt. reports 2. SF-36 3. 11 scales from Patient Satisfaction Questionnaire (Ware et al., 1983)
FINDINGS	Increased access to primary care resulted in an increased rate of readmission (0.19 vs 0.14 per month, $p = 0.005$), more days re-hospitalization (10.2 vs 8.8, $p = 0.041$) but increased satisfaction ($p.< 0.001$) for intervention group during the 180 days follow-up. No difference in quality of life scores which remained low in both groups.
METHODOLOGICAL CONSIDERATIONS FOR CURRENT STUDY	1. Interviews at 1 & 6 mos, no earlier assessment 2.Not disease specific protocol, intensified general follow-up 3. Generalizability limited; 99% male sample, disadvantaged group men, 43.5% of eligible patients randomized, 971 refused to participate 4. Compliance data reported regarding 'dose' of intervention components, no data re: components of usual care 5. No costs for community resources e.g. home nursing or respiratory care
IMPLICATIONS FOR CURRENT STUDY	Addition of new providers, supportive care & linkage interventions Satisfaction a significant outcome, importance tracking data on eligible pt.

Summary of Congestive Heart Failure Continuity of Care Studies

The systematic review resulted in the discovery of a small number of studies with rigorous methods. There were four with experimental designs (RCTs) and one cohort study which was included because of its specific focus on CHF, large size (n=519), and extensive follow through for one year. Generally, the research is characterized by assuming a provider, hospital perspective in terms of outcomes (readmits, utilization) and presentation of administratively important findings. The home care expenditures and the family costs however were not considered. Individual and clinically important issues were also not addressed. Subjective outcomes, such as quality of life, function, burden or satisfaction were not used as primary outcome measures and only one RCT included quality of life and patient satisfaction as a secondary outcome. Generalizations could not be made from the multi-center Veterans Affairs RCT because the population was not representative with 99% being male and described as "disadvantaged men" (Weinberger et al., 1996). Only one of the RCTs (Rich et al., 1995) and the cohort study were focused specifically on the CHF population. The others included other medical and/or surgical populations. Three of the RCTs (Naylor et al., 1994; Rich et al., 1995; Weinberger et al., 1988) report that with added resources (e.g. case manager or CNS), an enhanced discharge process, and a more intensive follow-up, hospital readmission and health service utilization could be reduced. The focus of the interventions in the three RCTs was on indirect care activities (coordination, case managing and communication) and supportive care (telephone outreach, patient education and information). It is of note that research staff, not the usual clinical RNs and MDs delivered these interventions.

CHAPTER 3: CONCEPTUAL FRAMEWORK FOR STUDY

Application of the Intersectoral Continuity of Care Framework for the Study

In this project the congestive heart failure population serves as an exemplar of a complex health population. In order to operationalize the Intersectoral Continuity of Care (ICC) framework, necessary preliminary work was completed which included: an environmental scan of the current community and hospital organization and delivery of services for this group; appraisal of completed research on continuity for patients with CHF; and examination of the practice patterns of providers and care standards with CHF management. Once this preliminary work was completed the ICC framework could then be applied with regard to a hospital to home transfer for individuals with congestive heart failure incorporating evidence-based practice, with usual providers, within already existing services and programs. With a hospital to home transfer, the coordination of care involves two health care sectors (institutional and home care) and three organizations and their providers; a university teaching hospital (Ottawa Civic Hospital), the regional home care department (Ottawa-Carleton Community Care Access Centre) and a home nursing agency (Victorian Order of Nurses Ottawa Carleton Branch). The application of the ICC framework was drawn from the following summations.

Direction from Research to Date

"'The real service to the patient is but half done on the date of discharge" (Mary Strong Burns, 1921, p. 525).

Research on the continuity of care with heart failure patients has shown that adding a provider (CNS or case manager) and/or more intensive, comprehensive discharge processes in the transfer from hospital to home has an impact on reducing readmission rates and health service utilization (Naylor et al., 1994; Rich et al., 1995). In these trials the care activities, particularly education and information, and the linkages through structured follow-up were found to be effective with regard to the health services utilization and system expenses. What remains to be determined from these important findings is the technical[2] and allocative efficiency[3] (Birch & Gafni, 1996). Are these enhancements possible to accomplish within existing services and providers i.e. with redeployment rather than the addition of a case manager or CNS? Could the same gains (or better) in hospital savings (readmissions, LOS) be achieved? A large proportion of individuals with CHF are managed in general medical ambulatory clinics and inpatient units by providers not specialized in cardiac care. Can practical, feasible methods to support and deliver evidence-based practice beyond the specialized providers be implemented? Lastly, since the research to date has focused on the provider and system

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[2] Technical efficiency relates to fewer resources consumed by a proposed programme when the benefits produced are the same as the current programme. Or if the resources consumed are the same in both programmes, the one with greater benefits is the technically efficient choice.

[3] Allocative efficiency relates to the value placed on alternative programmes, in this case institutionally delivered care versus more community care.

perspective, a determination of the effect from the patient's perspective is needed to further assist in effective and prudent use of scarce resources.

Planning & Preliminary Work

Intersectoral Continuity of Care Conceptual Framework

To undertake a continuity of care study with the congestive heart failure population a systematic, intersectoral, proactive approach was developed using the Intersectoral Continuity of Care Framework (ICC). The process required extensive research and preliminary groundwork prior to the implementation of the randomized control trial. In order to negotiate a strategic alliance and design a comprehensive approach to continuity of care, a purposeful planning methodology was undertaken by the investigator. The purpose was to understand the study patient and provider populations: who the involved agencies were and their CHF care practice patterns; the organization within the involved settings; the usual interface of the involved settings; provider needs; and the research evidence to support new or innovative approaches to CHF care. Not having clinical agency ties, the investigator was based from a neutral point within a Clinical Epidemiology Unit. This was a good position to assist in the formation of the alliance and to be considered unbiased (Browne, Arpin, Fitch & Corey, 1988). Thus, it was easier to act in the role of facilitator for the collaboration between and among settings using the potential for a large scale, integrated project as the motivating factor. Briefly the steps involved:

1. Population Profile

- literature review of CHF morbidity and mortality statistics

- description and profile of the local population from available data sources from the community and hospital sectors

2. Population Needs Assessment

- client and family assessment of unmet need (Advisory Group from hospital and home nursing agency)
- provider assessment related to their episode of care (key stakeholder interviews)
- perception of gaps during transition (community/hospital provider joint workshop)
- development of a list of perceived needs

3. Environmental Scan

- identification of settings and review of their policy and procedures
- identification of decision-makers at clinical, managerial and organizational level
- joint workshop with providers - determination of practice patterns
- description of the interface during transition (joint workshop, clinical collaborative group)
- identification of organizational and clinical practice barriers to 'best practice' (as perceived by providers, joint workshop)
- discovery of factors intervening the willingness to 'buy-in' to the strategic alliance in each of the settings

4. Determining Evidence-Based Practice

- systematic review and critique to identify 'best-practice' related to continuity for individuals with CHF

- review of professional practice standards and clinical practice guidelines
- evaluation of current provision of care in relation to acknowledged 'best practice'

5. Development Intervention/Care Activities

- negotiation of a feasible 'best practice' intervention strategy (joint workshop, clinical collaborative group) integrating the evidence from research, standards and practice guidelines into locally usable protocol
- development of the necessary client and provider supports to implement the evidence-based intervention
- operationalization and testing of the intervention (clinical collaborative group, pilot study)

6. Linkages

- addressed the list of barriers to best practice in designing the intervention (e.g. responsibility or authority issues in ordering home care, in this study the primary nurse in the hospital had to be given authority to order home care, as previously this was a physician function)
- documentation (written, verbal, electronic) negotiate what can be shared across the transition period and routing between and within settings

The following section describes the development of the care activities and linkage elements of the ICC model. Clinical practice guidelines and the published studies provide concrete, externally validated direction in developing a protocol to be used by the usual agencies and providers with no additional operational resources. Although specific to Ottawa-Carleton, the linkages between community nursing agency, regional home care

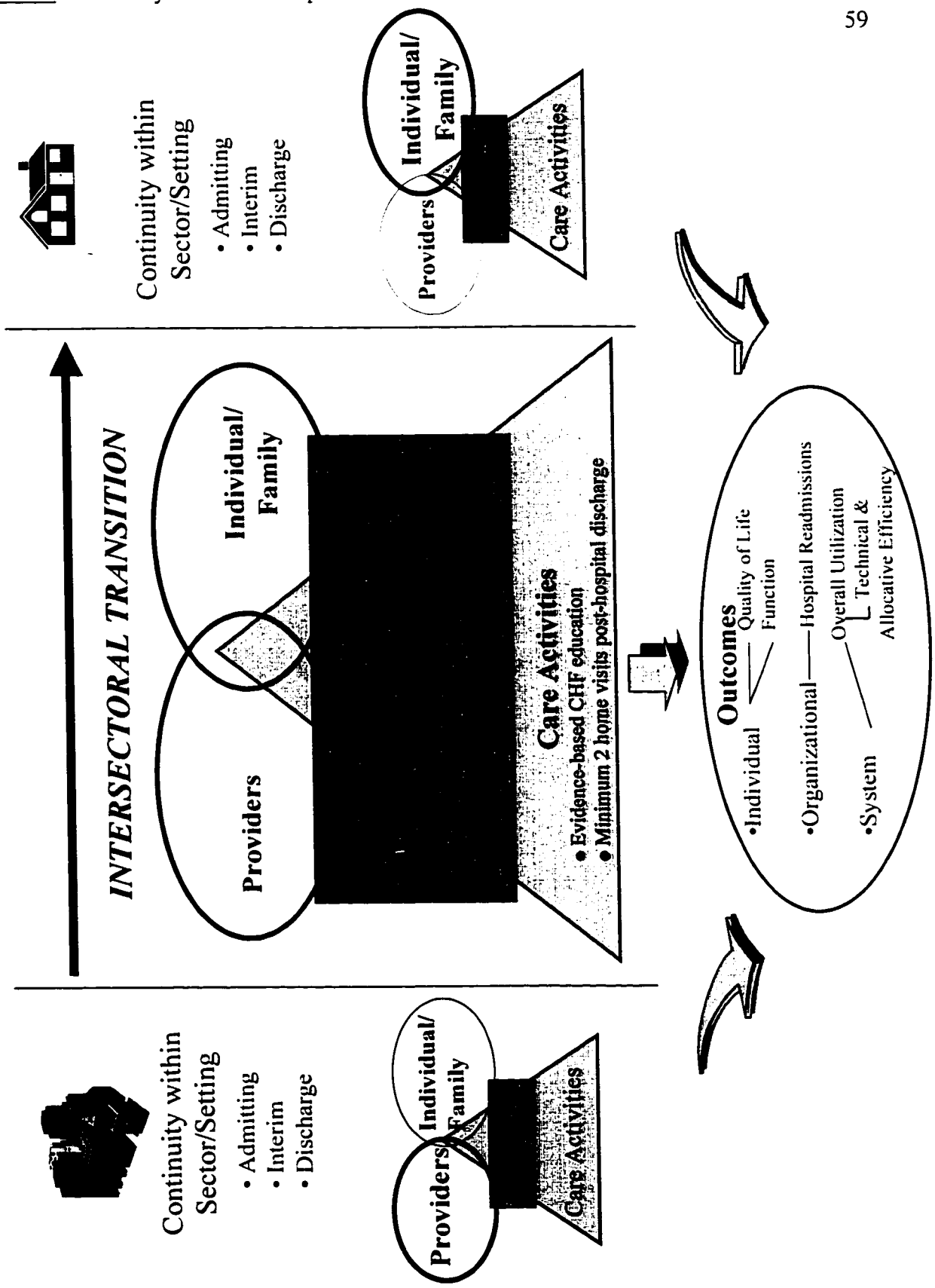
authority, and hospital likely represent similar barriers to those found in other Ontario jurisdictions. Figure 3 has this information integrated in the ICC framework for this continuity of care study of congestive heart failure patients.

Evidence Based Care Activities

"In determining the relative efficiency of a number of different methods, the decision would be based on the results of actual scientific investigations so far as these could be applied."
(Isabel Stewart, 1919, p. 451)

The heart failure population has specific requirements for the management of their condition and symptoms. These are broadly articulated in the 1994 AHCPR Clinical Practice Guideline and the Canadian Consensus Document (Johnstone et al., 1994). The major supportive care issues for nurses to address are identified as patient and family education, and information for symptom management. Care activities for this study were designed to meet the standard of care outlined in the practice guidelines as it represents the most current, research and knowledge. However, no comprehensive teaching materials addressing the components identified in the clinical practice guideline were available. This was particularly significant when considering implementation within general practice areas such as hospital mixed medical nursing units and district nursing caseloads in the community. If usual, non-specialized, providers (hospital and home nurses) were going to deliver the intervention additional provider support would be necessary. Thus, in planning for this study, the development of an evidence based teaching program was imperative (Harrison, Toman, & Logan, 1998). Entitled, 'Partners in Care for Congestive Heart Failure', the program consists of an Education Map, the clinical guide and nurses' documentation form, an Education Booklet for individuals and families, and the practitioner's Resource Manual which summarizes the evidence (Harrison, Toman, & Logan, 1996).

Figure 3. Continuity of Care conceptual framework



The Education Map (Appendix A) is set up as a grid with learning modules horizontally across the top and nursing process elements vertically down the left side. The nursing process elements serve as the nurses' guide to the assessment, planning, implementation, and evaluation of the learning process for individual clients. It is a one page, double-sided form with space for the patient profile and individual learning challenges and strategies to be identified. The format is similar in style to clinical pathways, which are currently under development to manage care in a variety of patient populations. However, the progress through the map is based on the learners' and nurses' mutual assessment of the learning process, rather than events or points in time such as day 1, day 2 post-operatively. This one form can be easily faxed between nurses and settings to provide continuity, as well as consistency in teaching.

Each module on the Education Map corresponds to a module in the patient Education Booklet. The Booklet, which serves as a guide, is based on CHF knowledge and treatment aspects related to self-management and self-care components, as recommended in the AHCPR practice guidelines. It realistically recognizes that learners may be at different levels of motivation and capability, and may need to be directed to supplemental materials (US Dept. of Health & Human Services, 1994).

The CHF content is organized into seven modules, each of which includes specific material. These modules incorporate the themes of management (rather than cure), personal responsibility of the learner for self-management, and the development of self-care skills required for monitoring and self-management. The focus is on maximizing heart function and quality of life. The information progresses from general to specific within each section. The format is designed to allow for individualization of

the content to the learner's experience of CHF. At the end of each module, there is a corresponding activity sheet for the learner to actively participate in the process.

The third component of the education program is the Resource Manual for clinicians. It was created to provide the evidence underpinning the program in a user friendly format. The supporting evidence is provided in several forms to meet the needs of different users. A "Shadow Document" summarizes the state of knowledge behind the guiding principles and content in the form of an overview or synopsis. The literature has been organized into structured abstracts for a more critical appraisal. A hard copy of the primary source documents is contained in the manual for users wishing to access the original source material. The Resource Manual and a workshop were prepared for the clinicians to support the providers and learners for such an approach (Hagenhoff, Feutz, Conn, Sagehorn & Moranville-Hunziker, 1994; Welsh & McCafferty, 1996). Most clinical settings are not yet equipped with access to on-line professional literature. Therefore, a binder format was deemed to be the most appropriate, cost-effective, and portable adaptation at this time. The manual facilitates the application of research to practice for nurses and supports nurses with potential strategies to use when teaching challenges develop with learner (Cronenwett, 1995; Funk, Tournquist & Champagne, 1995).

Linkages

"...nurses themselves must assume their share of responsibility for the continued nursing care of their patient after his discharge from the hospital."(Frost, 1947, p. 763)

The identified communication and efficacious linkages as reported in previous

research in caring for those with heart failure relate to phone and home visit follow-up for assessment and provision of supportive care, ability of patient or family to directly contact a professional provider (usually a nurse), and strategies for direct contact of involved providers with one another to bridge the agencies. Within our setting the usual route for written and verbal communication around discharge is from the hospital to the home care central office to the involved nursing agency. The first nursing visit often occurs without detailed history or clinical information. The hospital nurse would not usually be aware of either the home nursing agency or the nurses' identification. A number of nonprofit and for-profit home nursing agencies provide services. As one hospital nurse indicated, "Patients may well have been dropped in from the moon and be returning to Mars for all we know." Hospital nurses did not usually phone out or follow-up with discharged patients prior to the first home nursing visit. An additional challenge was the documentation requirements of individual agencies. As the transition period ensues, documentation which can move across the continuum was needed to track and assist progression with care. This is particularly important with patient education which is extremely individualized.

Finding a Practical Solution

"But after the last day (of hospitalization) comes unexpectedly, his bed being needed for a more urgent case, and he finds himself at home, several miles from the hospital, wondering why he managed to find out so little of what the hospital knew so well." (Burns, 1921, p. 527)

This research was designed to work within the well-established and available programs and services of the hospital and community sectors using a university research unit as a third party with incentive for collaboration and connection. Maximizing function and health related quality of life (HRQL) is a primary aim with a population that does not realistically expect any probability of cure. Key aspects of care are symptom monitoring and management, adequate knowledge and abilities, and supports for self care. This requires enhanced consultation, activities and linkage between primary nurses in the hospital and the community, involvement of individuals and their families, a consolidated approach to patient/family teaching and an outreach from the hospital to the community and vice versa. The intervention put 'on trial', two competing structures and philosophies of care. A systematic, inter-sectoral and pro-active transition process versus the usual hospital discharge planning was compared in order to evaluate the effect on self-assessed individual outcomes and health care utilization and expenditures. Through a hospital community-care alliance, focussed on case management for a smooth transition between the hospital and home episodes, the goal was better outcomes of continuity of care as evidenced by improved self-reported individual health related quality of life and function at less or no more expense to the health care system as a whole. This alliance and program are called Transitional Care.

CHAPTER 4: RESEARCH METHODS

Design

A randomized control trial was used to test the effects of a Transitional Care program in comparison to usual practice with discharge and post-discharge care (usual care control group) for individuals with heart failure. The research questions were:

1. Does the Transition Care Program, as an example of an inter-agency service alliance, improve the outcomes for individuals with CHF with respect to health related quality of life and function?

2. What are the comparative expenditures for health service utilization at 6 weeks post hospital discharge with Transition Care and optimal usual care for the CHF population from a societal point of view?

3. Was there a subgroup of individuals with CHF recently discharged from hospital for whom one of the two approaches to care was more effective and less expensive?

Within 24 hours of hospital admission to two nursing units, participants were randomly allocated to usual care or the transition program. The two study nursing units each had a computer generated block, randomization assignment to ensure a balanced number of participants in each arm from each unit.

Setting

This research has been a collaborative project between the institutional sector (a university affiliated tertiary hospital, Ottawa Civic Hospital), the community (nonprofit home nursing agency, Victorian Order of Nurses, and the regional home care department) and two university research centres (System Linked Research Unit, McMaster University and University of Ottawa, Clinical Epidemiology Unit). During the period of hospitalization two general medical units at the teaching hospital delivered both control (usual care) and the experimental intervention. The two nursing units were similar with respect to patient population, workload measurement, implementation of primary nursing, staff mix, management style, size, occupancy rates and turnover of staff. The home nursing following hospital discharge was provided by members of the Victorian Order of Nurses (VON). The VON nurses are organized by district with the basis for nursing assignment and caseload normally being location of clients as opposed to medical surgical or diagnostic groupings. Because study patients were dispersed across all districts in Ottawa-Carleton, a randomly selected group of VON nurses was organized in a 'float' intervention team to provide care for patients in the experimental Transitional Care group. The float team was trained to provide the experimental Transitional Care intervention and this team delivered care across all districts. The usual care group remained on the caseload of the normally assigned district nurse.

Sample

Patients who were admitted from their homes to the hospital with a diagnosis of congestive heart failure or an exacerbation were the target population. Assignment to the nursing units was independent of the study. The admitting department assigned patients

to either of these units based solely on bed availability. Admitting department staff had no knowledge of study procedures, therefore, there was unbiased allocation to the units. Once admitted to the nursing unit, individuals who met the study inclusion criteria were met by research staff to provide information about the study and request written informed consent (see Appendix B for information sheet and consent form). Consenting patients were then randomized to receive usual care or Transitional Care. Criteria for study inclusion were:

1. admitting diagnosis of CHF or a CHF exacerbation
2. resident of Ottawa-Carleton
3. expected to go home with home nursing care
4. consenting
5. English or French speaking
6. admitted for more than 24 hours to the study nursing units
7. not severely cognitively impaired (score <8 on MMSE)

Family caregivers identified by eligible and consenting participants as the individual with primary responsibility for their care following discharge, and who verbally consented were also enrolled in the study to assist in the assessment of health care resource use. It was not necessary for a subject to have a family caregiver to participate in the study.

Study Groups

Control Group (Usual Care)

Patients in the control group received the optimal usual care afforded to patients with CHF with respect to discharge planning and post-discharge care. Within 24 hours of hospital admission, the patient history and nursing assessment form, including a multi-disciplinary discharge planning component, was completed by the registered nurse (see Appendix C). At a discharge planning meeting held once a week, members of the hospital care team identified patient needs and a physician completed a referral to home-care. The regional Community Care Access Centre hospital based home-care coordinator consulted with the hospital team as required, may or may not have met directly with the patient/family, and immediately prior to discharge, arranged for necessary services and supplies. Patient requirements for home-care services were communicated by the home-care co-coordinator to the home nursing agency. Usual home nursing care, provided by the Victorian Order of Nurses (VON) included assessment, health teaching, provision of direct care such as administering medications orally or intravenously; monitoring vital signs, managing needed equipment and treatments, and supportive care. Usual care was tracked and documented to compare with the baseline usual care routines in both the hospital and community setting. This was done to evaluate a possible contamination effect occurring.

Intervention Group (Transitional Care)

Eligible patients and family caregivers in the intervention group received the usual discharge planning protocol plus a comprehensive program of Transitional Care designed specifically for patients with CHF. On admission to hospital, the patient's chart was

flagged and the Transition Program process followed closely with a protocol checklist. The protocol extended from admission to two weeks after discharge with regular prompts provided to the nurses delivering care to the patients in the experimental group. A key component of this program was the focus on inter-sectoral case management of supportive care using evidenced-based interventions[4], by usual providers (hospital and community primary nurses and the home care coordinator) already involved in care. In addition to the usual practice, described in the control arm, direct linkage was made between the primary hospital and community nurses in order to improve communication and continuity of care. Contact or correspondence was previously done through the regional home care department which results in delay. Compared with the usual care, the Transitional Care program included the following features:

Intensified care activities and linkages were designed to fortify *inter-sectoral case management*. This included:

(a) home care ordered by the hospital primary nurse within 24 hours of admission with physician consultation prior to discharge if necessary for designated medical acts;

(b) provision of an evidence-based educational program, 'Partners in Care with Congestive Heart Failure' (Harrison, Toman, & Logan, 1996, 1998) that was developed collaboratively with hospital and community nurses;

(c) use of an education map (Harrison, Toman, & Logan, 1996) to track the education intervention across the institutional and community episodes of care;

(d) home visit by community nurse (VON) within 48 hours of discharge from hospital;

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[4] Evidence-based intervention is defined as care based on current research or, in the absence of strong empirical findings, on expert opinion. This involves use of professional standards of practice and clinical practice guidelines when available.

(e) at least 2 visits from the community nurse within the 2 week period following hospital discharge;

Enhancement of *linkage and communication* between all care providers and the patient and family. This included:

(a) discharge planning that directly involved the hospital primary nurse, patient, family caregiver, home care coordinator and community nurse;

(b) the hospital primary nurse reviewing with the patient and family their discharge needs to prepare them for discharge;

(c) the completion of a Discharge Summary Sheet and consultation letter, both of which were forwarded directly to the community nurse (VON) by the hospital primary nurse;

(d) the hospital primary nurse was able to actively and directly consult with the community nurse (VON) and home-care coordinator in determining community care requirements;

(e) the implementation and documentation of a telephone outreach from the hospital primary nurse to the patient and family was implemented and documented within 24 hours of discharge to assess how they were managing, answer questions and reaffirm the previously arranged discharge plans.

Following the two week transitional period, patients were transferred to the usual care by the VON transitional nurse. They may or may not have remained on home care after this period. Patients who were readmitted within two weeks of discharge (intervention endpoint) were followed. Usual care participants were not crossed over. Experimental and usual care participants were interviewed on the planned two and six week schedule based on the date of the original hospital discharge.

Study Procedures

Assessment of Setting

To understand the background in which the intervention was being delivered and if changes had occurred over the duration of the study an environmental analysis was conducted of the one month period prior to study initiation and upon study completion. Patient population characteristics, implementation of primary nursing, staff mix, management style, size, occupancy rates and turnover of staff were examined. The usual discharge procedures and unit characteristics were examined .

Study Nurses: Training

Scheduled in-services were held with all health professionals and clerical staff on both study units, and in the community to provide a general overview of the study prior to its commencement. Nursing staff involved in the research underwent a period of training to ensure that they were knowledgeable with respect to the intervention protocol, their responsibilities with patients and families, and their role to facilitate recruitment and data collection. Upon completion of this phase, patients and families were entered into the study and data collection commenced.

Consent

Computerized ward reports and admission log books on the two study units were reviewed by research staff on a daily basis to identify newly admitted heart failure patients. An eligibility screening form was used by the research coordinator, and in collaboration with the hospital primary nurse, potential participants were identified (see

Appendix B). Informed consent to participate from patients and caregivers was obtained by research staff (see Appendix B).

Randomization

Once consent was received the participants were randomized using the computer generated schedule of randomization for that particular unit. Neither the patient nor members of the study team were aware of treatment assignment until after randomization which was controlled centrally from the principal investigator's office. Prepackaged, opaque, consecutively numbered, sealed envelopes containing the group allocation were prepared for each unit in the event a subject was recruited on a weekend or holiday. This eliminated any nursing unit bias with randomizing to usual care or the experimental intervention. The principal investigator or the coordinator were on call over holidays and weekends for the duration of the study in order to recruit all eligible inpatients.

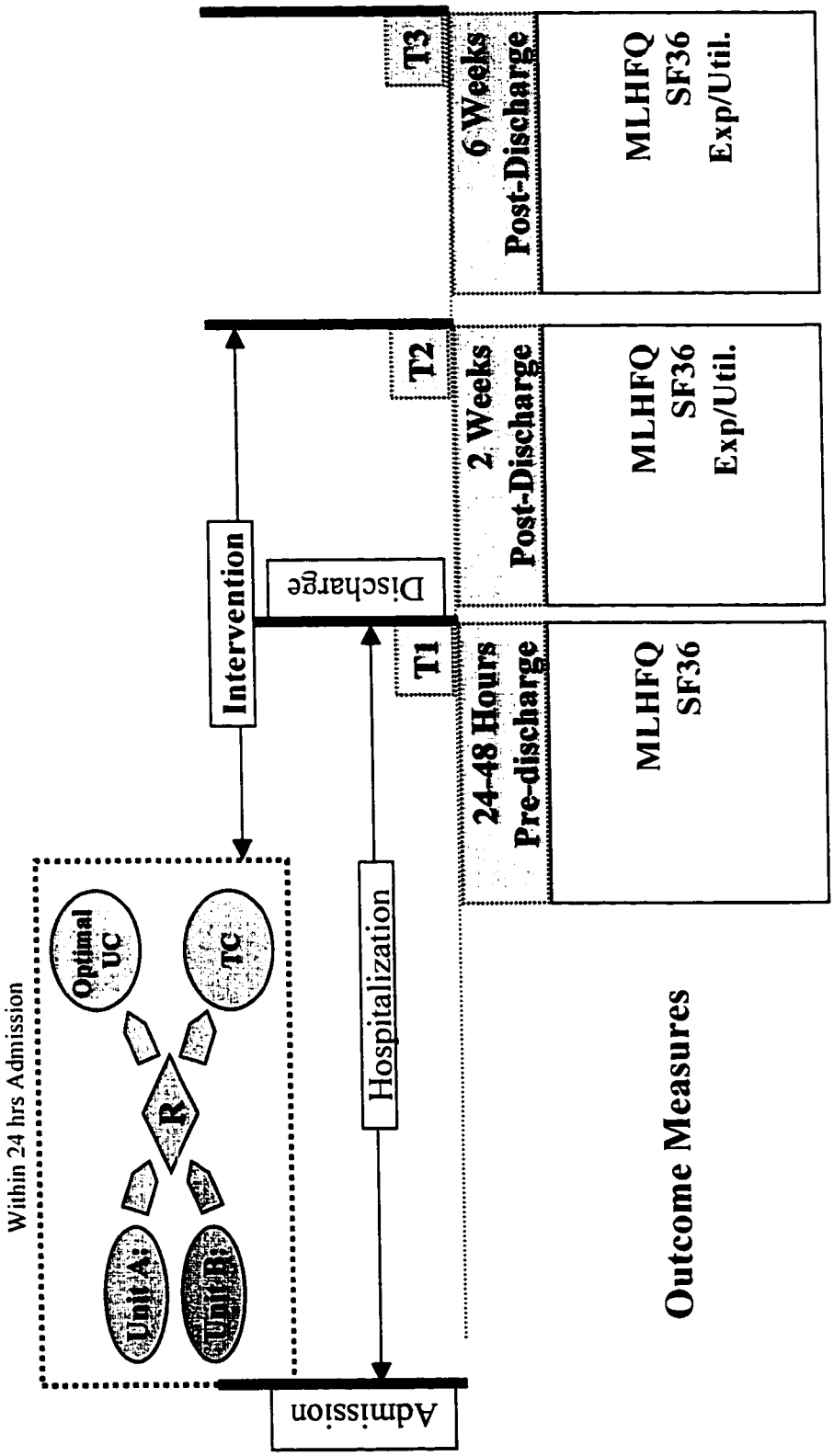
Data Collection

Data were collected from patients at four points in time; upon admission, within 24 hours of discharge (T1), and at two (T2), and six weeks (T3) following the date of hospital discharge (see Figure 4).

Research staff collected patient profile information (demographic data, previous use of resources and severity of medical problems) by chart audit and personal interview on a standardized form for all consenting participants within the first 24 hours of admission (see Appendix B). Within 24 hours (T1) prior to discharge from hospital, the participant completed the outcome measures that appraised their health related quality of

life, function and symptom distress (Minnesota Living with Heart Failure Questionnaire, MLHFQ; Medical Outcome Study Short Form, SF-36). Participants either completed the forms themselves or with the coordinator or investigator conducting a structured interview. With a mainly elderly population, this choice of administration helped to avoid loss of data due to visual deficits, literacy problems or difficulties related to feeling too fatigued or ill. In this study population, the majority (>90%) preferred the structured interview. Two weeks (T2) and six weeks (T3) post-discharge, the research coordinator or investigator made a home visit and participants again completed the forms or were interviewed using the same HRQL instruments. In addition, data was also collected by questionnaire on the utilization and expenditure questionnaire at these time points.

Figure 4. CHF Transitional Care Study Schema



Outcome Measures

General Considerations

The outcomes emphasize and capture the patients' self reported experience. The main purpose of the primary outcome was to evaluate, the impact of the hospitalization and transition episode back to the home environment for individuals with CHF. Therefore, in evaluating a supportive care intervention, such as the Transition Program, a subjective assessment of how individuals with heart failure felt in this regard was most appropriate. In this study the measurement of quality of life is limited to *health* related qualify of life (HRQL). Conceptually this represents a separation of what quality of life *is* from what *contributes* to quality of life (Stewart, 1992). It recognizes that health care and health professionals are limited in what they can change or affect. Incorporating subjective evaluation of one's life against natural capacity with meeting personal goals by narrowing the gap between expectations and one's achievements[5], the definition of HRQL for this study is: "An individual's perception of their health state and aspects of their life considered important in relation to their expectations of normal living" (Harrison, Juniper, & Mitchell-Dicenso, 1996, p. 56).

Quality of life and functional status are considered valuable endpoints in assessing heart failure patients' response (Dunbar & Dracup, 1996; Shively, Fox, & Brass-Mynderse, 1996). The nature of the illness is a downward trajectory that is mediated with medical management and one's ability to monitor symptoms and self-care (Braunwald, 1991; Moran, 1991). Due to the age and medical condition of these individuals, it was essential that the HRQL measures be easy to administer, adaptable to either self-

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[5] Known as Calman's gap (Calman, 1984)

administration or interview method, and aimed at measuring variables of practical importance. The outcome measures and study variables are summarized in Table 5.

Primary Outcome Measure: Health Related Quality of Life (HRQL) and Function

Health related quality of life and function as the primary outcome was measured with the Minnesota Living with Heart Failure Questionnaire, MLHFQ (Rector & Cohn, 1992; Rector, Kubo, & Cohn, 1987; Rector, Kubo, & Cohn, 1993). This instrument is a condition specific measure comprised of a self administered test of 21 questions on a likert type scale ranging from 0 - 5 where the higher score indicates greater deficits and lower scores indicate better quality of life. The MLHFQ specifically assessed the limitations commonly associated with heart failure and has been found to be reliable measure with weighted kappa of 0.84, moderate to strong (0.50 to 0.86) relationships between most items and the overall score, and high correlations (r = .88) with test retest at baseline (Rector & Cohn, 1992; Rector, Kubo, & Cohn, 1987). The MLHFQ has been used as a primary or secondary efficacy measure with pharmaceutical placebo control and prevention trials with the CHF population and has shown to be a valid indicator of therapeutic benefit of the medications (Gorkin et al., 1993; Kubo et al., 1992; Massie et al., 1993; Rector et al., 1993; Rector & Cohn, 1992; Rector, Kubo, & Cohn, 1993).

Table 5

Variables and Measures for Study

CONTINUITY MODEL ELEMENT	VARIABLE	MEASURE
Care Activities (direct and indirect)	Dose of intervention, process intervention delivery -early assessment & order for home care after hospital admission -initiation of evidence-based CHF Education Program in hospital and continuation in the home -within 24 - 48 hr. Hospital discharge visit by home nurse -minimum of 2 visits within 2 week post-hospital intervention period	Protocol checklist Harrison et al. (1998)
	Type of individualized support requested or required	Unit telephone log Home care checklist
Linkages	-liaison between home care coordinator & hospital nurse to determine eligibility -discharge summary directly to home nurse -hospital phone outreach by hospital nurse within 24 hr. of hospital discharge -RN transfer letter sent home with patient -transfer of all teaching materials (booklet and map) home with patient -ability of hospital nurse to link directly to home nurse and vice versa	

Providers	Evidence-based approach based on the AHCPR Clinical Practice Guideline (US Dept. Of Health & Human Services, 1994) -use of education map -case management focus	
Patient & Family	Demographic characteristics	Intake screen
	Patient clinical characteristics	MLHFQ, recent previous hospital admissions, number of medications/daily NYHA Functional Class
	Living arrangements	Intake screen
	Diary, unstructured reporting	Field Notes
Outcome: Primary	Disease-specific Health related quality of life Symptom Distress & Function	Rector et al. (1993) MLHFQ
Outcomes: Secondary	Generic Health related quality of life	Ware et al. (1992) SF-36
	Expenditures & Utilization	Browne et al. (1990) Health & Social Services Utilization Questionnaire

The MLHFQ also offers two dimension scores: physical (8 items) and emotional (5 items). These have been predefined by factor analysis. The dimension scores can be used to further characterize changes that may occur. A clinically important change in total MLHFQ score (range 0-105) is considered to be 5 points. Clinically this would mean the difference in walking about or climbing stairs with little difficulty to having great difficulty with these activities. A 5% change in the physical (range 0-40) or emotional dimension (range 0-25) is determined to be a clinically significant change (personal communication with T. Rector, June 1996, November 1997).

Secondary Outcome Measures

Generic Measure of Health related quality of life

Health related quality of life was also measured generically using the SF-36 instrument which has been widely tested (Katz, Larson, & Phillips, 1992; McHorney, Ware, & Raczek, 1993; McHorney, Ware, Rogers, Raczek & Rachel, 1992; Ware, & Sherbourne, 1992). The SF-36 has been used in studies of a variety of medical conditions including CHF (Lansky, Butler, & Waller, 1992; Ware, Kosinski, & Keller, 1994; Weinberger, Samsa, & Hanlon, 1991). The SF-36 includes eight multi-item scales with 2 - 10 items. The sub-scales measure the following aspects of health: physical functioning, role functioning-physical, bodily pain, general health, vitality, social functioning, role functioning-emotional, mental health. These eight scales contribute to two summary scores, the Physical Component Summary (PCS), and the Mental Component Summary (MCS) which were used in this study (Ware et al., 1995). The Physical and Mental

Component Summary measures are linear composites aggregated using norm-based scoring methods. The scoring algorithms (on disk) and the developer's validation methods were followed (Ware, Kosinski & Keller, 1994). As secondary outcomes, the component measures, are relevant to the MLHFQ and previously have been used in trials with CHF populations (Tandon, Stander, & Schwarz, 1989; Weinberger et al., 1996) . The sensitivity and usefulness of these subscales and the physical and mental summary measures have been evaluated. Reliability on internal and consistency and test-retest methods ranged from 0.89 to 0.94 for the PCS and from 0.84 to 0.91 with the MCS. (McHorney et al., 1992; McHorney et al., 1993; Ware et al., 1995; Ware et al., 1994; Ware & Sherbourne, 1992). Importantly, the SF-36 has been tested and validated as suitable for use with an elderly population when used in an interview format. The completion rates were high at 98.8% and a high degree of internal consistency with Cronbach alpha > 0.8 for each parameter (Lyons, Perry & Littlepage, 1994).

The SF-36 can be administered in 10-15 minutes which is a distinct advantage over many other generic health measures. It is important to have a general measure of well-being because symptom distress and physical activity impact many other aspects of health related quality of life . By using both a specific (MLHFQ), and a generic (SF-36) health related quality of life measure, the assessment of the symptom specific and general impact of this supportive care intervention were possible (Guyatt, VanZanten, Feeney & Patrick, 1989; Harrison et al., 1996; Jalowiec, 1990; Jambon & Johnson, 1997; Vickrey, Hays, Genovese, Myers, & Ellison, 1997). Another advantage of using a generic

instrument is that it will allow future comparison of the CHF degree of impairment to other different complex health conditions in other studies.

Expenditures for the Use of Health Services

The economic evaluation consisted of an assessment of the use and expenditures for hospital and community based health services during the 6 weeks following discharge. Expenditures include direct and indirect costs. Direct expenditures include the utilization of the different types of health services (measured as resources used) and unit costs to calculate total expenditure. Direct expenditures were determined through length of stay, re-hospitalization rates, by primary nurses, number of VON visits, and other related contacts such as emergency room visits, clinic and family physician visits. The Browne inventory (Browne, Arpin, Corey, Fitch, & Gafni, 1990; Browne, Gafni, Roberts, Goldsmith, & Jamieson, 1995; Browne, Roberts, & Gafni, 1992) was used to capture the expenditure and utilization information from participants and/or caregivers (Appendix D). The time points for reporting are based on a Canadian study that evaluated recall. The reliable recall is restricted to two weeks for doctor, nurse, or therapist visits and laboratory work, and six months for hospitalizations and emergency room visits (Spitzer, Roberts & Delmore, 1976).

Study Quality Control

Protocol and Data Collection

Systematic quality assurance procedures were implemented to ensure the integrity

of the protocol and the data (Kirchhoff & Dille, 1994; Rabeneck, Viscoli & Horwitz, 1992; Gilliss & Kulkin, 1991). The procedures for eligibility screen, recruitment and consent, intervention delivery and monitoring, data tracking, interviewing procedures, data entry and management were delineated in a detailed protocol manual used by the investigator and study staff. All potential participants on the two study units were recorded and explanations were noted if they did not enter the trial. These included reasons for refusal or the specific eligibility criteria that were not met. The research coordinator or investigator were present on the nursing units six days per week and on call by pager after hours and on Saturdays for recruitment and protocol issues. Nurses involved in the study were monitored and prompted regarding the intervention procedures to maintain quality control and consistency with adherence to the protocol. Once recruited, participants were assigned a code number to be used on all subsequent study documentation to ensure confidentiality. Upon completion of the trial, participants were sent a letter from the investigator thanking them, informing them that their participation was complete and that a summary report of the study's findings would be available to them when the study was complete (Appendix E).

Study outcome data was collected from participants and their caregivers by the investigator or the research coordinator. For consistency with the participants, effort was made to have the same individual who gathered baseline data do the follow-up with the repeated measures. At each repeated measures time point, the research assistant responsible for data entry, scrutinized the chart for any missing or questionable responses. In this way, problems could be rectified immediately with the data collector and subject if

necessary. A log record was maintained to track the study status of participants throughout the project (see Appendix F). Hospital nurses and community nurses (VON) were also assigned code numbers to be recorded on the log record. Case records were entered in batches of 10-15 on completion of the outcome measures.

Database

Data was entered onto SPSS/PC (version 6.0) software on a Pentium 100 computer. Where possible, upper and lower limits on response categories were set for each individual variable. Logical errors and range errors were detected immediately by the programme and highlighted to the data entry clerk who was then obliged to address the problem before being allowed to proceed with further data entry as a verification procedure. Twenty percent of the case records were double entered. An error rate of less than 0.002 was detected, which was below the preset standard (0.005) for acceptance.

Statistical Analysis

Descriptive statistics were employed to develop a profile of the study population. A comparison of characteristics was also made between those completing the trial and the drop-outs. The profiles of the usual care participants and the Transitional Care participants were compared for any differences in demographic and clinical variables at baseline.

Hypotheses were tested using the mean difference in the health related quality of

life and symptom distress (MLHFQ, SF-36) outcomes at pre-discharge, and at 2 and 6 weeks post-discharge in the two cohorts. Mean differences were compared by using the independent t-test using either the pooled or separate variance estimate as appropriate. It was planned that in the event that the usual distribution properties of the parametric approach using t-tests were not met, the corresponding nonparametric procedures such as the Mann-Whitney for independent samples were to be used to make the comparisons. A two-way analysis of variance (ANOVA) compared each outcome across two factors: the cohort (usual or Transitional Care) and time (baseline at pre-discharge, and post discharge repeated measures) assessed trends over time in the outcome measures. In order to explain and distinguish the characteristics of the individuals for whom the intervention was most effective, sub-group analysis was conducted. Using a three-way analysis of variance design, the cohort, time and following discrete baseline factors were analyzed; (i) age, (ii) gender, (iii) heart failure functional class, (iv) number of medications and, (v) circumstance of origin/living arrangement. Rates were compared using chi-square procedures.

Sample Size Justification

The sample size was based on detecting a clinically important difference in the Minnesota Living with Heart Failure Questionnaire. It was determined by the originating developers of the scale that a 5 point difference between groups in score was considered clinically significant (Rector, 1996; Rector & Cohn, 1992, Rector, Kubo & Cohn, 1993, Rector et al., 1993). For a probability of a type I error to be .05 and power of 80%, 50

patients per group were required to detect a 5 point difference in the MLHFQ score. This difference uses a standard deviation of 9 for the change scores (personal communication Thomas Rector, May 1996). Allowing for 20% withdrawal due to study drop-out or death, 60 participants per group were required with 60 individuals in Transitional Care and 63 in the usual care arm enrolled.

Ethical Implications

Study patients were assured that their decision to participate in the study would in no way affect the care they would receive in hospital or at home. They were informed that they could withdraw from the study at any time for any reason, that information collected during the study would be kept confidential, and used only for the purposes of study analysis. Using a coding procedure, all participants and nurses were identified by a study number. The identifying code numbers with participants' and nurses' names were kept by the principal investigator in a locked file. Data were analyzed by group without the ability to identify specific patients. Participants received a letter notifying them that their participation was complete and indicating a summary of results would be available to them. A summary report was made available (Appendix E).

Ethical approval for the study was received from the Ottawa Civic Hospital, Loeb Research Institute, Ethics Review Board and renewed yearly as required (Appendix G). Prior to study commencement, administrative approval was received from each of the participating agencies (Ottawa Civic Hospital, University of Ottawa Clinical Teaching

Unit, Ottawa Carleton Victorian Order of Nurses, Regional Community Care Access Center).

Limitations

The major limitations of this study design relate to conducting the trial in a naturalistic manner in the usual setting of care with the usual providers. In the community, experimental nurses were organized in a float team and crossed districts to provide the experimental intervention. Regularly assigned nurses provided usual care to the control group clients. Hospital nurses provided both experimental and control interventions. This was unavoidable as this was the only feasible means to conduct such a trial in the clinical setting and not unduly disrupt service organization. The possibility of contamination and Hawthorne effect with the hospital nurses providing best usual care (control group) was anticipated. If usual care nurses were doing more than usual care because they believed their practice was closely scrutinized, it was expected that with their busy workloads, routine usual care would return in a short period of time. To assess the possible impact of this limitation, verification that the intervention happened and that the number of events in control group differed from usual care was undertaken.

Another point is that usual care was made better by the study. The process of notification and assessment early on admission was rigorously adhered to in both groups. Awareness was heightened due to the study protocol with the hospital, home care and home nursing staff. Also, in 15% of the cases home care was ordered and reimbursed by the study because at the time of discharge the cases were not considered eligible as per

home care criteria or the medical staff did not consider it needed. Two home visits within the first two weeks after hospital discharge were ordered and provided in both groups to accInter-sectoralntion effect. However, this meant that usual care clients received extra care than may have been normally provided. NevInter-sectorale effect from these acknowledged limitations would tend to minimize the difference in groups, thus any difference would be a true and underestimated difference attributable to the experimental manoeuver.

The time frame of six weeks may have been too short to adequately assess the full impact of the Transitional Care intervention on health related health related quality of life and health service utilization. Three months, and possibly six months would likely provide the longitudinal information necessary to fully assess the continuing effects of the Transitional Care following acute hospital episode.

CHAPTER 5: Results

Descriptive Statistics

Study Environment

The two nursing units where the study was conducted were medical wards at the Ottawa Civic Hospital, a teaching facility affiliated with the University of Ottawa. They were examined just prior to and upon completion of the trial. The statistics were for a one month period just before and after study recruitment. The units were similar on all characteristics at baseline. During the course of the study not a great deal changed in terms of total numbers of staff, or patient populations served (Table 6). However, during the study period the units had changes in their monthly statistics in occupancy and workload. Unit A's occupancy rate increased by 3% with workload measure up by 20%, while Unit B had a 4% decline in occupancy and a commensurate 25% decline in workload measure. This probably reflects recent internal changes in the Clinical Teaching Unit when more responsibility for a particular inpatient group, neuroscience patients, was shifted to Unit A. Since experimental and control groups were admitted to both nursing units this would not bias the study results.

Table 6

Study Nursing Units Characteristics Pre and Post Study

	Unit A		Unit B	
	Pre-Study	Post-Study	Pre-Study	Post-Study
Unit Size	35	37	B5-32, AMA-6	B5-32, AMA-6
Occupancy Rate	95%	98%	94%	90%
Total RNs:	57	58	59	56
full time staff	28	30	29	22
part time staff	19	17	19	14
casual staff	10	11	11	20
Staff Turnover	2			
RN's leaving		16	6	23
RN's arriving		11	11 (7 on mat leave)	18
Patient Population	haematology, CHF, COPD,MI, pneumonia, GI bleeds, CVA, cancer, overdose, geriatric	CHF, COPD pneumonia, MI, GI bleeds, CVA, cancer, overdose, geriatric	haematology, CHF,COPD, MI, pneumonia, CVA, GI bleeds, cancer, overdose, geriatric	haematology, CHF, COPD, MI pneumonia, CVA, GI bleeds, cancer, overdose, geriatric
Workload Measurement	4225 hours/ 4 weeks	5167 hours/ 4 weeks	4820 hrs/ 4 weeks	3850 hours/ 4 week

Eligible Population

Applicability

All individuals admitted to the two hospital study units with CHF or a CHF exacerbation were screened for eligibility. Between June 1996 and May 1997, 264 patients with heart failure were admitted to the two units. Once screened, 126 of these admissions (48%) were eligible for the study and 123 individuals subsequently consented and entered the study (2% refusal rate). Figure 5 documents the flow of the population through the study, detailing all reasons for ineligibility and loss once enroled. The most common reason for ineligibility (43%) for this study was that patients either came from, or were being discharged to, a long term care setting, and thus these were inappropriate for home care. The next most frequent reason for exclusion (22%) was living outside the Ottawa-Carleton region's home care catchment area, i.e. beyond the approximate 60 kilometer radius (cities of Ottawa, Nepean, Kanata, Gloucester and the rural townships of West Carleton, Goulbourn, Rideau, Osgoode and Cumberland).

Representativeness

The study population of 123 consenting inpatients presented with a mean age of 76 years and a slightly higher proportion of males (54%) than females (46%). In screening the CHF population admitted to the medical units during the study period it was calculated that the mean age was 78 years for those who were not eligible or refused participation. Gender statistics were incomplete with 4% missing. Of the known cases, 40% were men and 56% women. Thus, age was similar between the non-eligible patients

and eligible patients admitted to the study units. Gender statistics were different between those who entered the study and those who did not, with more males as study participants.

Comparisons were made between those completing the study (n=104) and those who dropped out or died (n=19). There were no statistically significant differences found in the social, demographic or clinical characteristics (Table 7). The profile of the completer and drop-out groups is similar with both groups characterized by a higher proportion of men than women, an average age over 75 years, the majority being single, divorced or widowed, and approximately half living on their own. Clinically, as a group both completers and non-completers are fairly ill. There was an average of more than three co-morbidities and over 80% of the participants had a New York Heart Association Functional Class III or IV heart failure at the time of hospital discharge. This classification system indicates: ordinary physical activity does not cause undue fatigue, palpitations, dyspnea or angina (Class I), ordinary physical activity results in fatigue, palpitations, dyspnea or angina (Class II), less than ordinary physical activity results in fatigue, palpitations, dyspnea or angina (Class III), and symptoms of cardiac insufficiency ir of angina may be present even at rest (Class IV). Additionally they report, on average, taking seven medications daily and the length of hospital admission at the time of study was more than one week. This is a relatively long stay given the restraints on hospital days with the Ontario health care restructuring which has resulted in shortened stays and bed reductions during the time of study in 1996-1997.

Table 7

Comparison of Descriptive Variables Between the Study Completers and Non-Completers at Baseline

	Completers (n=104)		Drop-outs (n =19)		Statistic	
Characteristic	n	(%)	n	(%)	χ^2	p
Gender						
females	48	(46)	8	(42)	0.11	0.74
males	56	(54)	11	(58)		
Marital Status						
married	41	(39)	11	(58)	2.25	0.14
other	63	(61)	8	(42)		
Living Arrangements						
alone	55	(53)	7	(37)	1.65	0.20
with others	49	(47)	12	(63)		
Education	(n=103)					
grade school	24	(23)	5	(26)	2.35	0.50
high school	55	(55)	11	(58)		
college	5	(5)	2	(11)		
university	17	(17)	1	(5)		
Employment Status						
employed	4	(4)			1.61	0.90
unemployed	6	(6)	1	(5)		
retired/disability	94	(90)	18	(95)		
NYHA Functional Class						
Class I (less severe)	2	(2)			1.47	0.69
Class II	16	(15)	3	(16)		
Class III	72	(69)	15	(79)		
Class IV (most severe)	14	(14)	1	(5)		
	Mean	(SD)	Mean	(SD)	t	p
Age (years)	75.9	(9.9)	76.7	(6.9)	-0.31	0.76
Number Admissions in Last 6 Months	0.7	(1)	0.53	(0.77)	0.68	0.50
Length of Stay (days)	7.5	(8.2)	9.2	(11.5)	-0.78	0.44
Severity of Illness Factors						
Number Co-morbidities	3.6	(1.9)	3.4	(1.8)	0.45	0.65
Number Medications/ Daily (n=102)	6.6	(3.8)	7.1	(2.7)	-0.48	0.63

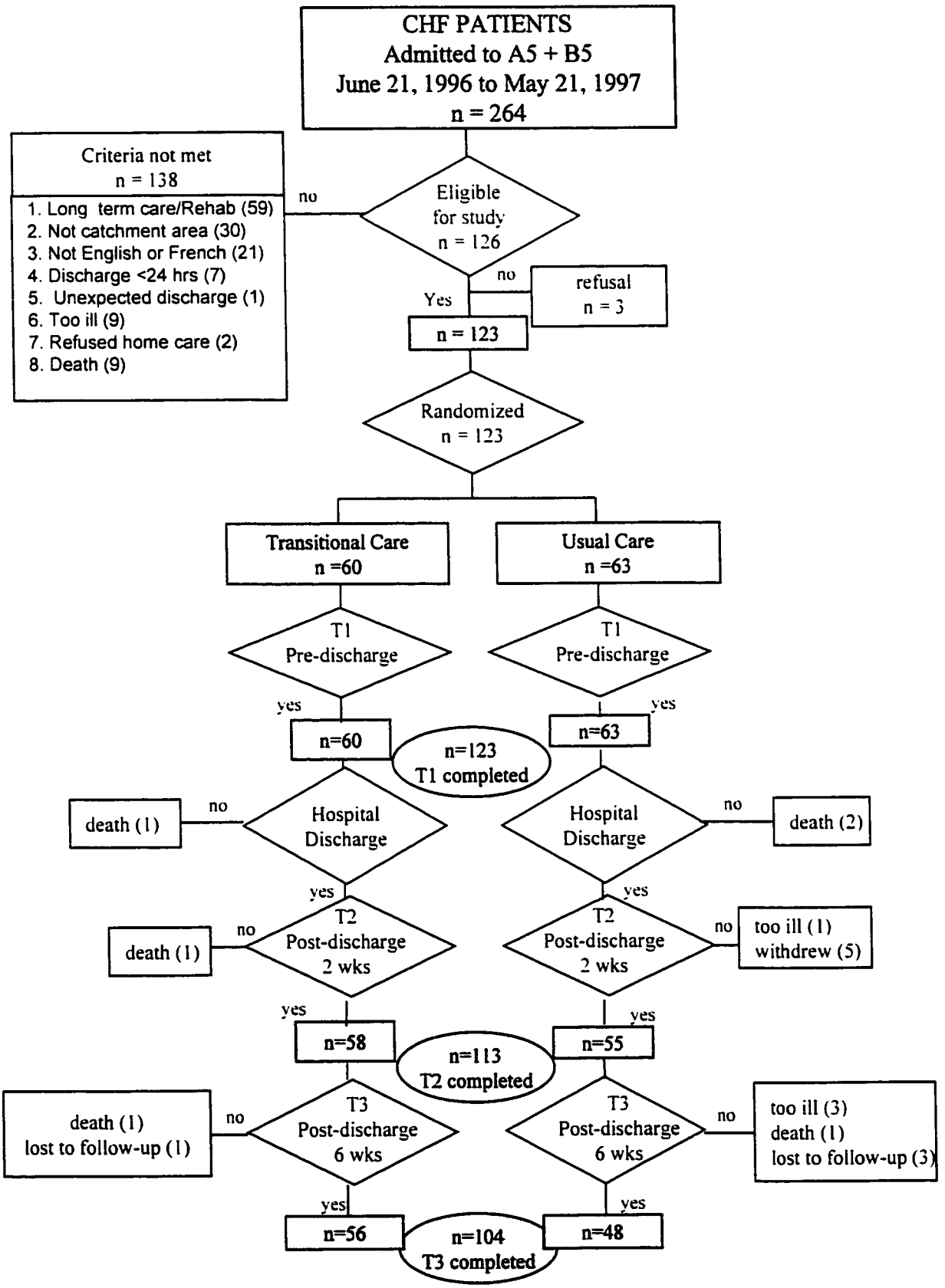
Note. The 'other' category under Marital Status includes single, divorced & widowed.

Trial Participants

The study population of 123 consenting inpatients presented as a fairly elderly group. Less than 10% were under 65 years of age and the mean age was 76 years. There was a higher proportion of men (55%) than women (45%) in the study. Considering the age distribution, they had a higher than expected education attainment with more than three quarters (76%) having at least some high school or higher education. The majority (91%) were retired or on disability pension and half lived alone.

Completion of outcomes measures at each time point was followed according to group allocation (Figure 5). Of the 123 consenting patients entered into the trial, a total of six people (5%) died. Three participants died after baseline assessment but prior to hospital discharge and three more participants died during the 12 week study duration. After accounting for deaths, 89% of the remaining 117 participants completed the trial. Broken down by group, that represented 80% of the participants in the usual care arm and 98% in the Transitional Care arm that completed, thus more completed in the experimental group. The main reason for non-completion after randomization (n= 13) was subject withdrawal which only occurred in the usual care arm. A few participants (3%) were lost to follow-up; one subject in the transitional arm and three participants in the usual care arm. The 'too ill' category participants were not able to complete outcome measures. Reasons included being on life support, in palliative care or in intensive care. All were in the usual care thus making it likely that this group appears better off in the health related quality of life and health service utilization analysis and again making it more difficult to detect a difference between groups.

Figure 5. CHF Transitional Care Study flowchart



The severity of illness and complexity for self-management of the 123 trial participants is typified in the following statistics gathered before their hospital discharge at baseline:

- 71% report taking 4-9 prescription medications daily, 15% take 10 or more
- 83% were quite functionally limited with Stage III or IV NYHA Functional classification.
- 73% reported that moderate activity is greatly limited now
- 43% had one or more other admissions in the past 6 months
- 66% reported that their health was somewhat or much worse that one year ago

Comparability Between Experimental and Control Participants

At baseline the comparison of clinical, social and demographic characteristics between those randomized to usual care and those in the Transitional Care group are displayed in Table 8. A further comparison was made with these characteristics and the 104 participants who actually completed the study (Table 9). Both comparisons revealed no statistically significant differences in the baseline characteristics between the experimental and control participants. Therefore, any post test differences between groups can not be attributable to differences in baseline characteristics.

Table 8

Comparison of Characteristics of Those Allocated to Usual Care and Transitional Care Groups at Baseline

	Total (N=123)		Usual Care (n=63)		Transitional Care (n = 60)		Statistic	
Characteristic	N	(%)	n	(%)	n	(%)	χ^2	p
Gender								
females	56	(46)	26	(41)	30	(50)	0.94	0.33
males	67	(54)	37	(59)	30	(50)		
Marital Status								
married	49	(40)	29	(46)	20	(33)	2.07	0.15
other	74	(60)	34	(54)	40	(67)		
Living Arrangements								
alone	62	(50)	28	(44)	34	(57)	1.84	0.17
with others	61	(50)	35	(56)	26	(43)		
Education (n =122)								
grade school	29	(24)	14	(22)	15	(26)	1.64	0.65
high school	68	(55)	36	(57)	32	(54)		
college	7	(6)	5	(8)	2	(3)		
university	18	(15)	8	(13)	10	(17)		
Employment Status								
employed	4	(3)	1	(2)	3	(5)	5.61	0.35
unemployed	7	(6)	3	(5)	4	(7)		
retired/disability	112	(91)	59	(93)	53	(88)		
NYHA Functional Class								
Class I (less severe)	2	(2)	2	(3)		(0)	2.15	0.54
Class II	19	(15)	9	(14)	10	(17)		
Class III	87	(71)	45	(72)	42	(70)		
Class IV (most severe)	15	(12)	7	(11)	8	(13)		
	Mean	(SD)	Mean	(SD)	Mean	(SD)	t	p
Age (years)	76.1	(9.5)	76.4	(8.1)	75.7	(10.9)	0.46	0.65
Admissions last 6 mos	0.67	(0.98)	0.63	(0.81)	0.70	(1.1)	-0.36	0.72
Length of Hospital Stay (days)	7.7	(8.7)	7.2	(8.1)	8.1	(9.4)	-0.58	0.57
Severity of Illness								
Number of Co-morbidities	3.6	(1.9)	3.5	(1.8)	3.7	(2.0)	-0.66	0.51
Number of Medications/ Daily (n =121)	6.7	(3.7)	6.8	(4.0)	6.6	(3.3)	0.25	0.81

Table 9

Comparison of Baseline Characteristics of Usual Care and Transitional Care Participants Who Completed the Trial (n = 104)

	Usual Care (n=48)		Transitional Care (n =56)		Statistic	
Characteristic	n	(%)	n	(%)	χ^2	p
Gender					0.21	0.65
females	21	(44)	27	(48)		
males	27	(56)	29	(52)		
Marital Status						
married	27	(56)	36	(64)	0.7	0.40
other	21	(44)	20	(36)		
Living Arrangements						
alone	23	(48)	32	(57)	0.88	0.35
with others	25	(52)	24	(43)		
Education			(n = 55)			
grade school	11	(23)	13	(24)	2.47	0.48
high school	26	(54)	31	(56)		
college	4	(8)	1	(2)		
university	7	(15)	10	(18)		
Employment Status						
employed	1	(2)	3	(5)	5.14	0.40
unemployed	2	(4)	4	(7)		
retired/disability	45	(94)	49	(88)		
Functional Class						
NYHA Class I (less severe)	2	(4)	0	(0)		
NYHA Class II	6	(13)	10	(18)	2.91	0.41
NYHA Class III	34	(70)	38	(68)		
NYHA Class IV (most severe)	6	(13)	8	(14)		
	Mean	(SD)	Mean	(SD)	t	p
Age (years)	76.6	(8.5)	75.4	(11.1)	0.61	0.55
Length of Stay (days)	7.4	(8.8)	7.5	(7.7)	0.47	0.97
Severity of Illness Factors						
Number Co-morbidities	3.6	(1.8)	3.6	(2.0)	-0.05	0.96
Number Medications/Daily (n=118)	6.7	(4.5)	6.5	(3.2)	0.27	0.78
Number admissions past 6 mos.	0.63	(0.8)	0.75	(1.2)	-0.64	0.52
MLHFQ Baseline (T1)	45.7	(20)	44.6	(19.3)	0.29	0.77

Description and Dose of Intervention

Those participants randomized to the transition care group were informed of the specific aspects of the intervention and the intervention was initiated prior to hospital discharge. Elements of the intervention were tracked in the hospital and in the home setting for compliance with implementation. Aspects of expected usual care were also tracked.

Table 10

Dose of Intervention by Group as Tracked by Protocol Checklist

	Usual Care	Transitional Care
Hospital Primary Nurse Assigned on Admission	96%	98%
Home Care Notified of Study Participation	98%	98%
Evidence-based Education Program Initiated (Harrison, Toman, and Logan, 1996)	0%	100%
Written Referral to Home Care on Discharge	52%	73%
Nursing Transfer Letter Received by Home RN	0%	95%
Phone Outreach Within 24 hours of Discharge	0%	77%
Phone Advice From Hospital Nurse	0%	21%
Education Booklet Used at Home	0%	100%
Education Map	0%	100%
Community RN Consult with Hospital RN	0%	11%
Community Nurse Visits minimum 2 visits in first 2 weeks Post-Discharge	94%	100%

The intervention as planned (home care organized early in the admission, enhanced verbal and written linkage between sectors, inter-sectoral evidence-based education program) was received by the majority of Transitional Care participants. Both approaches are focused on the hospital to home transfer but Transitional Care is more intense and focused on the supportive care with regard to education and information. It should be noted that usual care was made more timely and consistent by the study due to the screening, randomization and notification process early in the hospital admission.

Primary Research Questions: General Effectiveness of Intervention

1. Does the Transition Care Program, as an example of an inter-agency service alliance, improve the outcomes for individuals with CHF with respect to health related quality of life and function more than usual care?

Health related quality of life and function outcomes as measured by the MLHFQ and SF-36 were compared over time from baseline (pre-hospital discharge), 2 weeks (T2) and 6 weeks post. hospital discharge (T3) with the 104 valid, completed cases. The hospital admission for CHF (at the time of recruitment) indicates an important and pressing need for medical intervention, thus the effect of hospitalization and the intervention are intertwined at T2. Mediation of this exacerbation as the result of hospital care, would be expected to improve the health-related quality of life in both groups to a certain degree. Therefore, the T2 measure provides a second baseline check on the similarity of the groups. By 6 weeks post hospital discharge (T3) the effect of hospitalization itself should be worn off providing a point at which the effect of the Transitional Care intervention may be assessed.

Comparison of Usual Care and Transitional Care Groups at Pre and Post Hospital Discharge: MLHFQ

On the primary outcome measure, the MLHFQ, a lower score indicates less disability from symptoms (total scores range from 0-105). Participants in both the usual care and Transitional Care showed a comparable improvement at the 2 week point (Table 11, Figure 6). The Transitional Care group continued to show improvement at 6 weeks while the usual care participants scores showed slight deterioration. The pattern was similar with the MLHFQ physical and emotional dimensions (see Figures 6-8). Although clinically important improvements continued to occur in the transitional group, differences in group mean scores were not statistically significant in either the total or physical and emotional dimension scores, when baseline scores were not controlled for.

FIGURE 6. Mean Total MLHFQ scores at baseline, 2 weeks and 6 weeks post hospital discharge.

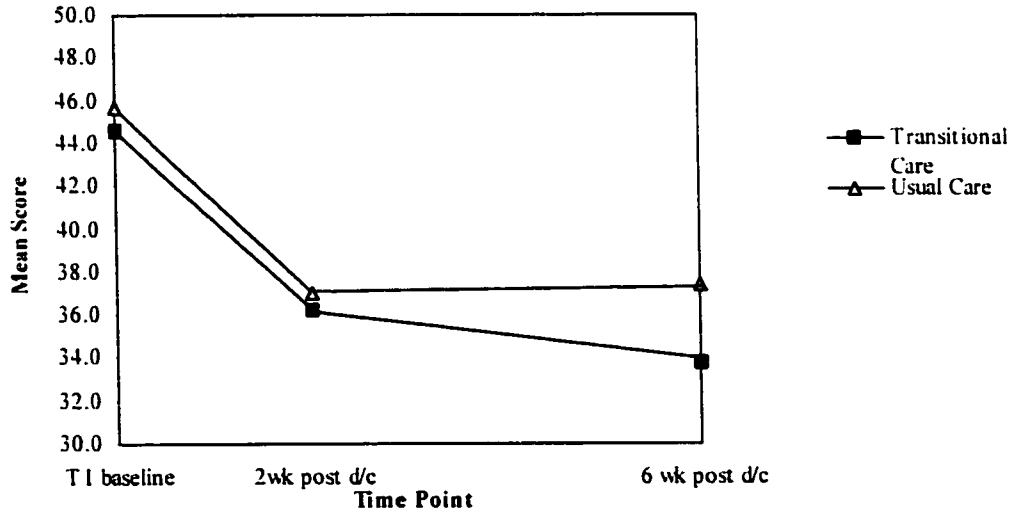


Table 11

Comparison of Mean Total MLHFQ Score and Physical and Emotional Dimension Scores at Baseline, 2 Weeks and 6 Weeks Post Hospital Discharge

		Usual Care (n=48) Mean	(SD)	Transitional Care (n=56) Mean	(SD)	Statistic t	p
MLHFQ Total Score (Physical + Emotional Dimensions + 8 items)	T1	45.7	(20.0)	44.6	(19.3)	0.29	0.77
	T2	37	(20.6)	36.2	(22.0)	0.2	0.84
	T3	37.4	(22.1)	33.7	(20.1)	0.9	0.37
Physical Dimension (8 items)	T1	25.6	(10.4)	24.3	(10.0)	0.61	0.55
	T2	21.2	(10.7)	20.6	(12.1)	0.25	0.80
	T3	21.2	(11.5)	20	(11.4)	0.53	0.60
Emotional Dimension (5 items)	T1	7.3	(6.1)	8.2	(6.7)	-0.67	0.51
	T2	6.3	(5.5)	6.8	(6.8)	-0.42	0.68
	T3	7	(6.5)	5.1	(5.5)	1.6	0.11

FIGURE 7. Mean MLHFQ Physical Dimension scores at baseline, 2 weeks and 6 weeks post hospital discharge.

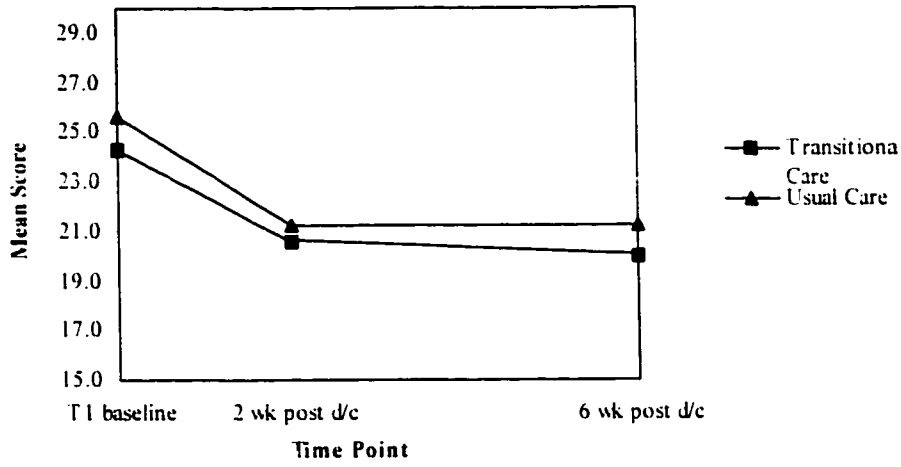
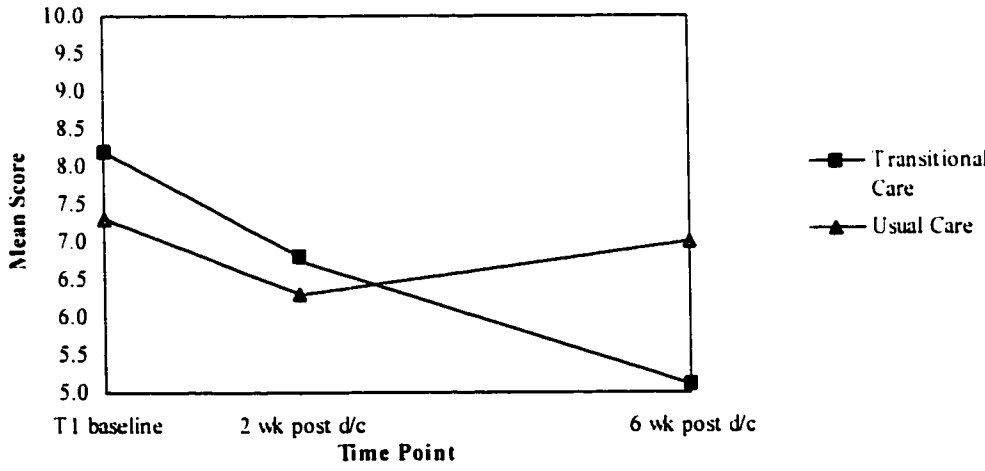


FIGURE 8. Mean MLHFQ Emotional dimension scores at baseline, 2 weeks and 6 weeks post hospital discharge.



MLHFQ Change Scores at Baseline and 6 Weeks Post-Hospital Discharge

The change scores (delta for individual participants) from baseline to 6 weeks (T1-T3) for the MLHFQ total score and physical and emotional dimension scores were examined to understand individual improvement over time (Table 12, Figure 9). At 6 weeks, both groups had improvement in individual change scores on the total and both dimension scores. However, the transitional group demonstrated a 38% greater improvement in the overall score of the MLHFQ. While statistical significance was not achieved with the difference in total score, there were clinically important changes in total score (5 points) in both groups. From T1 to T3, the mean usual care change score was 8 points for those in usual care compared to 11 points with the Transitional Care participants. The experimental group improved by 3 points more (a 38% greater change) than the usual care group.

The Transitional Care group emotional dimension change scores showed both statistically and clinically significant improvement ($t = -2.0$, $p = .045$) over the usual care group by 6 weeks. The physical dimension indicated comparable status between groups by 6 weeks.

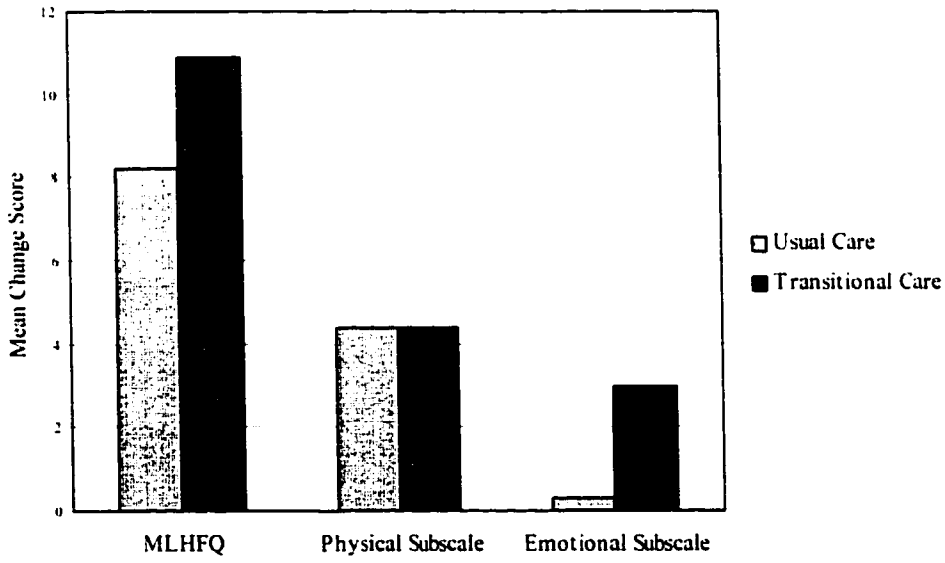
The total MLHFQ and physical dimension were not statistically significant while the emotional dimension score was statistically different with the Transitional Care improving more than the usual care group.

Table 12

Comparison of Mean Change Scores of MLHFQ and Subscale Baseline and 6 Weeks Post Hospital Discharge

	Usual Care (n=48) Mean	(SD)	Transitional Care (n=56) Mean	(SD)	Statistic t	p
MLHFQ T1-T3	8.2	(23.6)	10.9	(16.0)	-0.65	0.52
Physical Subscale T1-T3	4.4	(12.0)	4.4	(9.8)	0.01	0.99
Emotional Subscale T1-T3	0.3	(7.9)	3	(5.7)	-2	0.045

Figure 9. Mean change scores of MLHFQ Total Scores and Physical and Emotional Dimension Scores between baseline and 6 weeks post hospital discharge.



Ceiling & Floor Effect on MLHFQ Change Scores

Examining if ceiling or floor effects would have affected the change scores, an analysis of covariance was also done (Polit, 1996). With T3 scores as the dependent variable and baseline scores (T1) entered as a covariate, the MLHFQ total score and physical and emotional dimension change scores indicated the same results as those using student - t test. In controlling for scores at baseline, the score at 6 weeks for the MLHFQ was not statistically significant for total score change ($F = 0.77$, $_{df\ 1,\ 103}$, $p = .38$) or in physical dimension score ($F = 0.67$, $_{df\ 1,\ 103}$, $p = .80$). The emotional dimension again showed a statistically significant difference ($F = 4.07$, $_{df\ 1,\ 103}$, $p = .046$).

Clinical Importance of MLHFQ Change Scores

When looking when looking at the improvements in MLHFQ scores and accounting for baseline scores (T1 - T3, divided by T1) one can assess the clinical importance of the changes. For instance, in the total MLHFQ scores the improvement from baseline was 24% with Transitional Care participants compared to 18% for usual care participants With the physical dimension, the improvement from baseline was 18% with Transitional Care participants compared to 17% for usual care participants. In the emotional dimension, the changes were greater with 4% improvement for usual care and 37% for individuals in Transitional Care.

To further understand the importance of the change scores clinically, the proportion of individuals with minimally clinically important difference (MCID) scores at 2 weeks and 6 weeks were tabulated by group (Table 13). A MCID change is 5 points in the total MLHFQ score and 5% change in the dimension scores (personal communication

T. Rector, November 1997). This is 2 points on the physical dimension scale (range 0-40) and 1.25 on the emotional dimension score (range 0-25). As the scores are calculated in whole numbers on a 5 point scale, the MCID for the emotional dimension was rounded upward to 2 points. Thus -2 to 2 meant staying the same. This had the conservative effect of requiring a 12% deterioration to be in the 'worse' category. At 6 weeks the proportion of usual care patients that deteriorated (total MLHFQ) was three times that of the Transitional Care group. Status was maintained or improved in 93% of the Transitional Care group compared to 77% of the usual care group. In the emotional dimension scores the proportion of usual care participants who deteriorated was six times that of Transitional Care participants. Very little change was noted in either group in the physical dimension at 2 or 6 weeks compared to baseline.

Table 13

Proportion of Usual Care and Transitional Care Participants With Clinically Important Changes on MLHFQ from Baseline to 2 and 6 Weeks Post Hospital Discharge

	2 weeks				6 weeks			
MLHFQ Total Score MCID=5 points	Usual Care (n = 48)	Transitional Care (n=56)	Statistic χ^2	p	Usual Care (n = 48)	Transitional Care (n=56)	Statistic χ^2	p
Worse	20.8%	17.9%	0.47	0 .79	22.9%	7.1%	5.53	0.06
Same	22.9%	28.6%			20.8%	30.4%		
Better	56.3%	53.6%			56.3%	62.5%		
Physical Dimension MCID=2 points								
Worse	22.9%	25.0%	0.13	0.93	29.2%	26.8%	0.29	0.87
Same	14.6%	16.1%			12.5%	16.1%		
Better	62.5%	58.9%			58.3%	57.1%		
Emotional Dimension MCID=2 points								
Worse	29.2%	14.3%	6.5	0.04	29.2%	5.4%	11.5	0.003
Same	33.3%	57.1%			29.2%	48.2%		
Better	37.5%	28.6%			41.7%	46.4%		

Comparison of Usual Care and Transitional Care Groups at Pre and Post Hospital Discharge: SF-36

The SF-36 was examined in two ways; compilation of the physical and mental component scales, and the general health subscale (five items). A higher score indicates a better status with the SF-36 items and scales. The scores at baseline and two and six

weeks post-discharge are displayed for the physical and mental component scales and the general health subscale in Table 14 (also Figures 10 - 12) and what is seen is a pattern in both groups of poor scores with little change across time. The pattern in both component scales is similar in the usual care and Transitional Care participants with essentially no improvement seen in the physical scale and slight improvement over time in the mental scale. The change scores were also analyzed between baseline and six weeks post discharge. The general health subscale on the SF-36 indicates a broad assessment of one's health and the change scores between baseline and 6 weeks post discharge indicated a seven point deterioration in usual care and a slight improvement (< one point) in Transitional Care participants (Table 15). This difference of 7.05 in change scores between the groups is thought to be clinically important. However due to the large standard deviation, the power to detect the difference of 7.05 was only 44%. The SF-36 generally did not discriminate differences in the non-physical dimensions with these two groups which were identified by the condition specific measure (MLHFQ).

Table 14

Comparison of Mean Total Scores for the SF-36 Physical and Mental Component Scales and General Health Subscale at Baseline, 2 Weeks and 6 Weeks Post Hospital Discharge

		Usual Care (n=48)		Transitional Care (n=56)		Statistic	
		Mean	(SD)	Mean	(SD)	t	p
Physical Component	T1	29.2	(9.1)	29.6 (n=55)	(9.8)	-0.20	0.84
	T2	30.2	(10.6)	29.9 (n=55)	(9.9)	0.16	0.88
	T3	28.9	(10.2)	29.0 (n=54)	(10.7)	-0.04	0.97
Mental Component	T1	48.0	(12.4)	50.1 (n=55)	(12.6)	-0.85	0.40
	T2	49.6	(12.4)	51.7 (n=55)	(13.9)	-0.82	0.42
	T3	51.3	(11.5)	52.6 (n=54)	(11.8)	-0.57	0.57
General Health	T1	56.3	(24.5)	52.7	(24.5)	0.75	0.46
	T2	52.2	(26.0)	50.1	(23.0)	0.45	0.66
	T3	49.3	(23.3)	52.9 (n=55)	(23.2)	-0.79	0.43

FIGURE 10. Mean total scores for SF-36 physical component scales at baseline, 2 weeks and 6 weeks post hospital discharge.

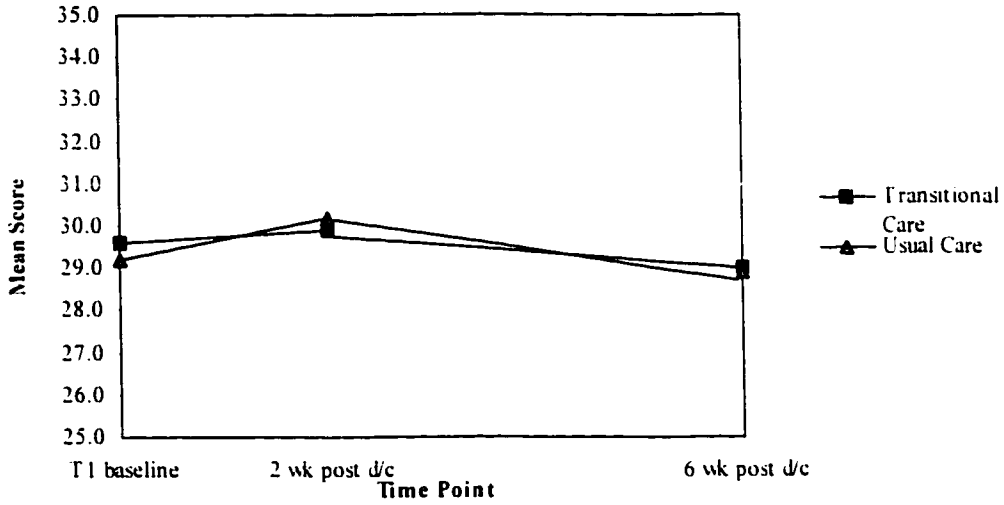


FIGURE 11. Mean total scores for SF-36 mental component scales at baseline, 2 weeks and 6 weeks post hospital discharge.

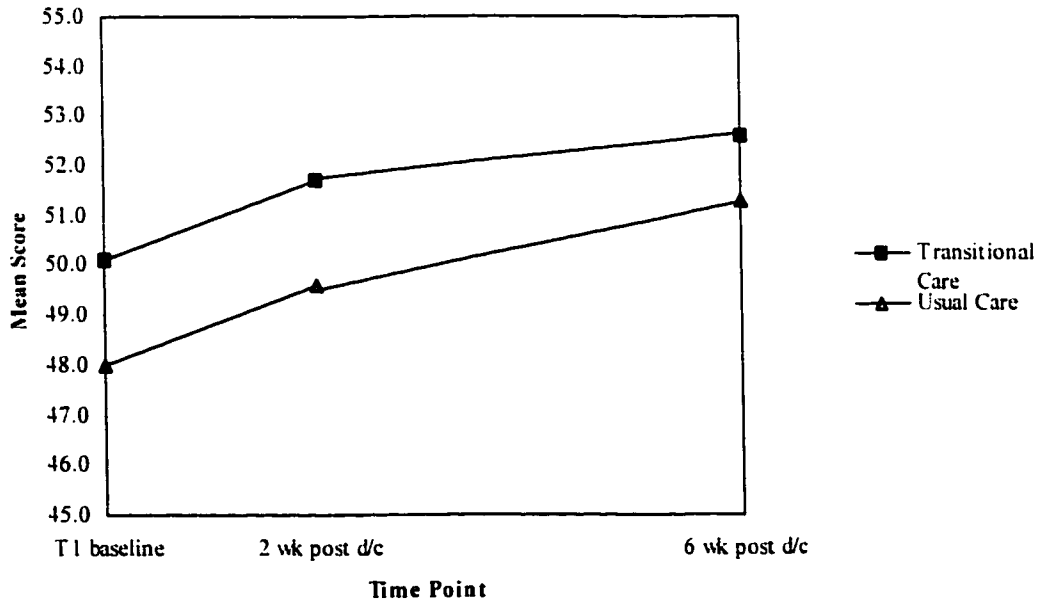


FIGURE 12. Mean total scores for SF-36 general health scales at baseline, 2 weeks and 6 weeks post hospital discharge.

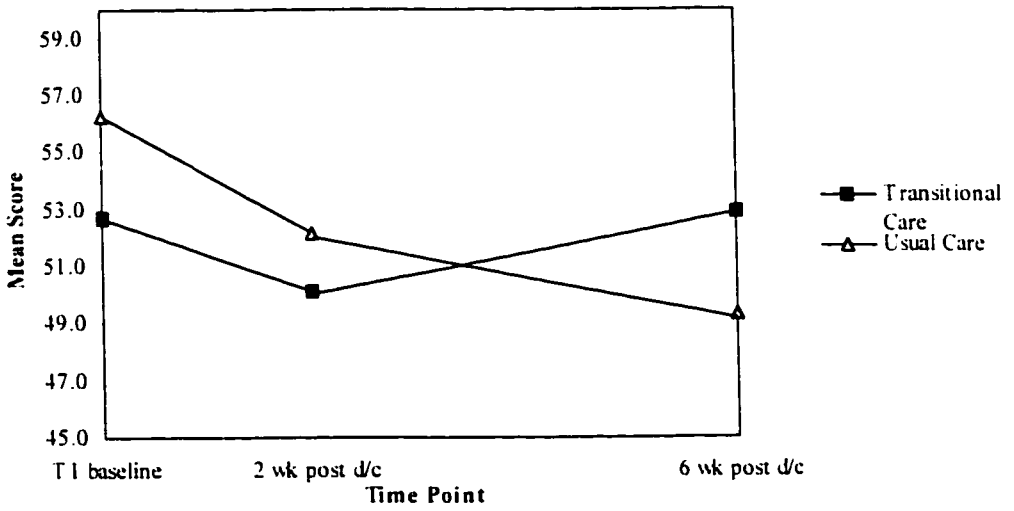


Table 15

Comparison of Mean Change Scores for the SF-36 Physical and Mental Component Scales and General Health Subscale at Baseline and 6 Weeks Post Hospital Discharge

	Usual Care (n=48)		Transitional Care (n= 56)		Statistic	
	Mean	(SD)	Mean	(SD)	t	p
Physical Component T3 -T1	0.0	(9.8)	-0.60	(9.0)	0.32	.75
Mental Component T3 - T1	2.8	(13.0)	2.3	(12.6)	0.18	.86
			(n=55)			
General Health T3 - T1	-7.0	(18.9)	0.05	(20.4)	-1.83	.07

Note: Difference calculated from T3 to T1 as the SF-36 runs opposite to the MLHFQ i.e. higher scores are better thus negative number indicates deterioration.

Secondary Research Question: Health Services Expenditure and Utilization Analysis

2. What are the comparative expenditures for utilization of health service at 6 weeks post hospital discharge with Transition Care and optimal usual care for the CHF population from a societal point of view?

The direct expenditures for use of all health services are displayed in Table 16 by persons allocated to usual care and Transitional Care groups. There was a great deal of variance in all the services accessed. As can be seen, the utilization data capture a dichotomy in resource use by the two groups. Usual care accessed more physician, hospital, laboratory, and emergency room resources and the Transitional Care participants used more community based services particularly community nursing. There were no statistical differences in expenditures for any particular resources used; however, laboratory resources were much higher in the usual care group ($39 versus $60 per person). The total direct costs not including hospitalization per person were $724 for usual care and $791 for Transitional Care. Hospital costs are slightly higher with usual care ($1,603) than Transitional Care ($1,586) with neither difference being statistically significant. The delivery of the more intense Transitional Care does not add additional expense overall to society but it does shift the cost for this more effective service from the institutional sector to the community.

Table 16

Comparison of Actual Per Person Direct Expenditures at 6 weeks Post-Hospital Discharge by Group

Health Service Expenditure	Total		Usual Care		Transitional Care		Statistic	
	Mean ($)	(SD)	Mean ($)	(SD)	Mean ($)	(SD)	t	p
Family Physician	$34.58	(23.89)	$ 38.63	(26.40)	$ 31.12	(21.20)	1.6	0.11
Specialist	$106.41	(171.59)	$122.97	(193.66)	$ 92.23	(150.49)	0.91	0.37
Hospital Emergency Room	$ 92.33	(157.86)	$100.02	(147.83)	$ 85.73	(167.02)	0.46	0.65
Physiotherapist	$ 27.71	(70.34)	$ 19.24	(43.77)	$ 34.96	(86.68)	-1.1	0.24
Occupational Therapist	$ 6.15	(26.60)	$ 5.00	(25.60)	$7.14	(27.62)	-0.4	0.68
Social Worker	$ 4.01	(18.95)	$4.34	(22.24)	$3.72	(15.79)	0.17	0.87
Nutritionist	$ 0.65	(2.90)	$ 0.28	(1.95)	$0.96	(3.51)	-1.3	0.22
Community Nurse	$223.26	(235.69)	$187.13	(154.43)	$254.23	(285.53)	-1.5	0.13
Home Care Worker	$176.09	(249.60)	$170.39	(232.93)	$180.98	(265.06)	-0.2	0.83
Meals on Wheels	$ 4.67	(17.32)	$3.43	(16.64)	$5.74	(17.96)	-0.7	0.50
Other Health Practitioner	$ 23.51	(158.09)	$ 2.09	(10.72)	$41.88	(214.39)	-1.4	0.17
Ambulance Service	$11.54	(51.59)	$ 10.00	(48.47)	$12.86	(54.53)	-0.3	0.78
Laboratory Costs	$ 49.00	(60.29)	$ 60.33	(66.93)	$39.29	(52.64)	1.79	0.08
Total Health Services Expenditure Without Hospital	$759.92	(527.67)	$723.85	(440.73)	$790.83	(594.43)	-0.6	0.52
Hospitalization	$1593.63	(4718.69)	$1602.52	(5043.28)	$1586.00	(4468.01)	0	0.97
Total Health Services Expenditure With Hospital	$2353.50	(4703.50)	$2326.37	(5005.78)	$2376.83	(4473.91)	0	0.96

Hospital re-admission has been a primary outcome in many previous studies of discharge planning and Transitional Care. In this study the readmit rate during the 6 weeks of the trial was 31.6% in the usual care participants compared to 20.7% in the Transitional Care group (χ^2= 1.77, $_{df\,1}$, p = .18). Emergency room visits (range 1 - 5) were also higher in the usual care group (40.4%) compared to Transitional Care (32.7%) (Pearson Correlation 3.98, $_{df\,5}$, p = .55). Of those accessing the emergency room, 50% of the usual care participants had more than one visit, compared to 32% in the Transitional Care group. While not statistically significant, this is an administratively and economically important reduction in hospital readmission and in emergency room use associated with Transitional Care.

Secondary Research Question: Who Benefits Most from a Transition Program?

3. Was there a subgroup of individuals with CHF recently discharged from hospital for whom one of the two approaches to care was more effective and less expensive?

Analysis of co-variance was conducted to understand for whom the intervention was most effective using MLHFQ as the dependent variable. The three-way analysis of variance design with the cohort, time and following discrete baseline factors were analyzed; age, gender, heart failure classification, number of daily medications, and circumstance of living. Using chi-square procedures rates were compared. This analysis did not reveal any statistically significant factors. In addition, analysis of variance using these variables for interaction terms indicated no subgroups of participants for whom one intervention was more favourable than the other.

CHAPTER 6: DISCUSSION

Summary

Transitional Care Intervention

This randomized controlled trial evaluated the use of a systematic, inter-sectoral, proactive transition process for heart failure patients compared to best usual hospital discharge care and planning. Usual home care or the experimental Transitional Care was applicable to half of the individuals admitted with CHF or CHF exacerbation to nursing units in one large teaching hospital. Many of the individuals with heart failure admitted to these nursing units were discharged to a long term care facility (43% those ineligible) or lived outside of the regional home care catchment area (22% those ineligible). The Transitional Care was acceptable to 98% of those to whom the program applied. In total, 104 of 123 participants completed the trial and these individuals were statistically and clinically similar to those who dropped out with respect to gender, age, living arrangements, and baseline outcome measures. In particular the completion rate was highest for the Transitional Care participants (98%) compared to the usual care participants (80%). Although not statistically significantly different than participants, drop-outs, of which there were more in the control group, were sicker at the time of drop-out since reasons given were "in intensive care", "too ill". Clinically, the trial participants presented as elderly (mean = 76.2 years), fairly ill with an average of 4 co-morbidities,

83% having a NYHA Functional class of III or IV, most (86%) taking from 4-25 medications daily, and 50% living alone. The experimental and control participants were equivalent in terms of severity of disease, social demographic characteristics and baseline outcome measures.

The study was conducted in the hospital and home settings in which these individuals would usually receive medical and supportive care. Usual care was probably made better by this trial in comparison to standard practice in that it was provided in a more timely and more regular fashion. In 15% of the cases it was provided at study cost when it would not normally have been offered. To minimize the possible effect of attention the usual care and Transitional care participants received the same number of visits (two in first two weeks after discharge). However, this likely had the effect of minimizing differences which would have been observed in the real life situation.

Both approaches to discharge resulted in clinically important improvements in the MLHFQ at two weeks post hospital discharge. This was expected as a hospital admission indicates a pressing need for medical intervention with the heart failure. At 2 weeks post discharge both groups had improved scores in the MLHFQ assessment of health related quality of life. Alleviation of the exacerbation during the hospitalization would be expected regardless of the group assignment. However, at 6 weeks post discharge, Transitional Care participants continued to improve health related quality of life while usual care participants showed no further improvement. By this time, compared to baseline, Transitional Care participants were 3 points more improved in HRQL than usual care participants (8% versus 11%). Given the severity of illness of the participants, this

might be considered to be a clinically important gain for those receiving Transitional Care. In addition, statistical significance was achieved in the emotional scale of the MLHFQ which indicates that in spite of only modest improvement in physical status and function the Transitional Care participants felt better emotionally. While both approaches resulted in similar improvements in subjectively assessed physical function, it is noteworthy that Transitional Care resulted in a 37% improvement in emotional function compared with a 4% improvement with usual care. After exposure, it is noteworthy that there were no statistical interactions or characteristics of subgroups of participants who were better served by one approach to community care or the other. It is concluded that for all types of heart failure patients Transitional Care results in measurable emotional gains in health.

Expenditures for Use of Health Services

Not only was Transitional Care more effective but these gains were achieved at no additional expense to society as a whole. The utilization data captured the increased use of community resources that were expected as part of Transitional Care. Even when these additional community costs of Transitional Care were incorporated into the analysis, the six week follow-up per person total direct expenditures indicated that for individuals in the Transitional Care it was no more expensive than it was for those receiving usual care. This was because of greater use of physician, hospital emergency room, and inpatient resources by usual care participants. In other words, it was possible to provide more intense service for no more expense to society compared to usual care.

The dichotomy (i.e. community versus institutional) in the types of services used by participants in the usual care and Transitional Care approaches is important. During the six weeks follow-up period, the hospital readmission rate was 10% higher in the usual care group. At a time when the number of hospital beds and access to emergency rooms are declining, services and ceilings on the number of generalist and specialist physicians being trained, Transitional Care clearly supports the redirection to community health services. This is particularly true if, with support of an evidence-based protocol, generalist hospital and community nurses can provide the education/information and assessments that might otherwise only be available through specialist practice such as Clinical Nurse Specialist delivered working from a dedicated CHF ambulatory clinic. In economic terms, this indicates an improvement in technical and allocative efficiency.

Complex Health Populations: The Case of Heart Failure

Congestive heart failure participants in this trial provided a revealing profile of complex health populations. The study population was elderly, with less than 10% being under 65 years of age, 86% were taking from four to twenty-five daily medications, and 50% were living alone. Complex health populations characteristically have numerous diagnoses from which one is singled out as the primary diagnosis and the others may or may not be identified as secondary or contributing to the hospital admission. Although the current admission may have been for heart failure, the status of their other medical concerns, such as diabetes or Parkinson's disease, undoubtedly required assessment and management. Working and studying with such populations strictly from the primary

diagnosis perspective is limiting when considering interventions to improve continuity of care. Capturing this complexity seems critical to understanding the continuity of care needs as these individuals transfer from one care setting to another or to home. This study empirically contributes to describing the hallmarks of a categorical grouping the investigator refers to as 'complex health populations'. The variables include the number and type of diagnoses, severity and course of illness considerations, as well as personal and living circumstance factors. Using such a composite in relation to health care resources planning will aid in understanding self-management support required for during discharge, transfers and transition in care.

Health Related Quality of Life Outcome Measurement

The experience in this study indicates that with individual outcomes there is a need for both a generic and condition specific self-assessed health related quality of life measure. In order to compare this CHF study group to future studies of complex health populations it is necessary to include a generic HRQL instrument. Theoretically, due to the nature of complex health populations, the measurement of generic HRQL should be helpful. During clinical assessments it is often difficult for individuals to separate the contribution of a particular comorbidity, such as CHF, to perceived deficits. For example is lack of mobility and/or ability to socialize due to the CHF or their Parkinson's disease? The condition specific instrument used to measure health related quality of life for heart failure (MLHFQ) was sensitive to differences in the control and Transitional Care groups relative to heart failure symptoms. Practically speaking, it was similar to a short clinical

history interview and easy to administer. The generic instrument, the SF-36, was less sensitive to detecting the changes in emotional quality of life aspects noted by the MLHFQ. The heterogeneity in both the usual care and Transitional care groups on the SF-36 indicates the need for a larger sample size. The general health component of the generic instrument (SF-36) was however sensitive to changes in the participants' overall assessment of their health over the past year. More work in the application to complex health populations, of both condition specific and generic health related quality of life instruments is required. Using both instruments did not present an undue burden of administration with this fairly ill study population. However, some participants did find the redundancy in question focus tiresome.

Another observation worthy of further investigation relates to coping and resilience. Given the complexity of illness, it was revealing that on interview, these individuals often assessed their own health quite positively. Often noted comments were; "there are lots worse off", "I can still get around" or "I am enjoying what I can". This optimism and rather positive assessment of their status indicates the resilience and capacity to cope and self-manage the conditions that can so severely interfere with one's daily life. The challenge for health providers is finding ways to support and sustain this in a population facing inevitable declining health status.

Study Implications

Nursing Practice Implications

This study demonstrated that using, an intersectoral strategic alliance as a framework for the organization of nursing practice across autonomous, sectoralized agencies is effective and no more expensive to society as a whole. Through such an alliance, service issues related to the intersectoral transfer can be resolved through modest reorganization of usual organizational structure and process, and provision of evidence-based supportive care can be accomplished efficiently. Working in this way, agencies and providers maintain their autonomy yet collaborate, link, plan and implement care based on the specific patient/client problems. The relationship is complimentary and prudent in that scarce resources - e.g. clinical, education and research expertise - these scarce resources are not only shared during the reorganization of service delivery but will endure thereafter because barriers have been overcome through personal relationships and efficiencies that previously hindered linkage .

The Intersectoral Continuity of Care framework used in this study provides a theoretical basis for a comprehensive intervention. The framework identifies the particular aspects of focus for improved continuity when transferring individuals across sectors of care. The framework assumes the individual organization and funding of separate sectors and agencies. Engaging a proactive, intersectoral, alliance the approach works within the existing programmes, services and providers. In other examples of application, it might only be the linkages that require adjustment or as in this study,

linkages and care activities may require redeployment and reorganization. The importance of understanding the focus of adjustment in reorganization of existing services cannot be overstated. This not only provides clarity with direction but the points for evaluation of change.

Policy Implications for the Organization of Health Services

In the case of complex health populations, decision-makers must incorporate the population's characteristics as a compounding factor in the needs assessment phase for service planning. Many regions grappling with restructuring, analyze needs based on diagnostic categories and particular medical task requirements, such as home intravenous administration or leg dressings. This oversimplifies the situation a hospital nurse has in discharging a patient and complicates the situation that a home nurse encounters on entering. The effect is that it compromises the ability of the agency, and the nurse to assess and assist with ongoing management and self-care of the conditions that face such clients. Accurately capturing the complex health profile requires the consideration of a non-diagnostic grouping that encompasses the co-morbidities, activity of daily living deficits, circumstance of living in addition to primary, secondary and contributing diagnosis classification of hospital and home care cases.

Given the types of services used by Transitional Care participants in this study and the improved outcomes at no additional expense, re-investment in community based services must become a priority. Savings from closure of acute care beds need to be directed toward a renewed and revitalized community health service sector. For the

management of complex health populations the indications are particularly significant in the area of home nursing services.

Feeling better emotionally as assessed by a specific HRQL measure (MLHFQ) was associated with an economically important shift in expenditures for use of health services. In summary the study's findings point to recognition and compensation for the transition period and the complete care that may save the system money immediately as well as in the longer term.

Implications for Future Research

Given the expected increase in long term care, there are indications for study of transition of patients with CHF to these settings. Over 40% of those not eligible for this study were going to or coming from such settings. Additional support in symptom management and continuity will be required between the hospital and long term care setting. Linkage and evidence-based practice support to assist the long term care setting where the typical caregiver is an unregulated health workers supervised by a Registered Practical Nurse (formerly Registered Nursing Assistant).

The time frame in following subjects should be extended to a minimum of 3 or 6 months to better understand the impact of such interventions. In this study the gains in HRQL that were being made at 6 weeks with TC and the determinant seen in usual care may have continued. This would have had important implications on health services expenditures in a longer term.

Methodological studies should be directed at the use of specific and/or generic HRQL measures with complex health populations to assist health service researchers in the following areas: criteria in selection of primary HRQL as primary outcome measure for experimental studies; the value of using one or both approaches in groups with multiple diagnosis; decreasing the burden of administration with similar scale items without compromising individual instrument reliability and validity; selection of the most appropriate and feasible generic assessment for comparative studies.

Sample size calculation for studies of complex health populations is going to be challenging. Much of the data on outcome measures has been derived from clinically defined homogenous groups e.g. specific classification of heart failure for a drug intervention. An increased sample size will be required for health services research directed at complex health populations as they are not homogenous diagnostic groups but rather populations characterized by their complexity of diagnostic, severity of disease, as well as circumstantial and personal factors. Pilot studies to estimate variance in a complex health population with outcome measures is critical even with well tested instruments.

A classification system which not only captures diagnostic categories and co-morbidities (e.g. Deyo, 1992) but also encompasses important personal factors such as living arrangement factors, advanced age, and self assessment of circumstance, would be an important tool for health service researchers and planners, and policy decision-makers. Research and development of such a methodology requires immediate attention as Canadian provinces grapple with allocation of scarce resources in the health system and

reorganization of health services. In this way the planning for complex health populations will incorporate the factor which influence health service use.

Conclusion

Outcomes can be improved for patients with CHF going from hospital to home. Through a systematic, inter-sectoral, proactive transition process to enhance the continuity of care, emotional well-being was improved and this resulted in a decreased use of institutionally based resources compared to optimal usual hospital discharge care. The study sample of patients with CHF (n=123) was representative in age to those ineligible for the study. The experimental and control group participants were similar in demographic and clinical characteristics. It was found that Transitional Care was acceptable to the heart failure population as 98% completed the protocol. Transitional Care was more effective and no more expensive than optimal usual care.

This trial has advantages over prior studies in that it has avoided many methodological pitfalls found in other studies. All non-completers were accounted for and outcome data was prospectively captured. Outcomes included both objective and self-assessed, subjective reliable and valid measures. In contrast to other studies, the subjective, self-assessed appraisal was the primary outcome while hospital readmissions and health service utilization were secondary measures, as subjective appraisal of one's situation leads to help seeking behaviours and resource use. Expense outcomes are more appropriately interpreted within the context of the self appraisal of one's well-being. Most reported studies have used chart audit for economic data. In this trial, expense and

utilization information was collected prospectively on all subjects, in both the usual care and Transitional Care arms, by interview at two and six weeks after hospital discharge using a standardized methodology and validated recall period.

This trial was an evaluation of effectiveness in that usual providers and setting were used. Results were computed for all participants regardless of whether the intervention was perfectly delivered or whether the patients were compliant to the protocol. The home care and hospital arrangements are similar in other regions of Ontario, thus this approach could be used elsewhere in the province without conducting all the preliminary work necessary for this project. Application in other provincial jurisdictions would likely require the preliminary work and feasibility study. Importantly, Transitional Care has applications to other settings and various transitions. In particular with the CHF population this protocol should be modified to delivery in the long term care setting.

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APPENDIX A: Education Map

LOBB RESEARCH INSTITUTE

Partners In Care Education Map: Congestive Heart Failure©

PROFILE:

Patient's name: _____

Address: _____

_____

Phone number: _____

Instructions:

At the top of the column for each module: sign your name, status, and the date of teaching.
If material needs to be re-taught, continue to add name(s) and date(s) appropriately.
For each session, initial in the column as each component is completed.
General content is in the patient education booklet, organized by modules.

NURSING:	MODULE #1	MODULE #2	MODULE #3
	Nurse's signature and date: _____ _____	Nurse's signature and date: _____ _____	Nurse's signature and date: _____ _____
Assessment	__level of prior learning __patient perception / readiness __learning challenges	__review of activity sheet #1 __respond to questions arising __level of understanding achieved	__review of activity sheet #2 __respond to questions arising __level of understanding achieved
Planning	__decision on readiness to learn __strategies to meet learning challenges (identify these at top of page 2)	__decision to re-teach previous session __decision to progress __learning strategies in place	__decision to re-teach previous session __decision to progress __learning strategies in place
Interventions	**Teaching content:** __overview of the teaching program __the heart as a living pump (basic anatomy, physiology) __personal responsibility __controllable aspects of CHF __present Activity sheet #1	**Teaching content:** __principle components of CHF management __specific signs / symptoms from patient's experience __self-monitoring skills __present Activity sheet #2	**Teaching content:** __patient's medications for CHF management __patient's related cardiac medications __non-prescription medications used by the patient __signs / symptoms of high and low potassium (if required) __use of the medication record __present Activity sheet #3
Evaluation (patient outcomes)	__verbalizes readiness to learn __acknowledges personal involvement in managing CHF __verbalizes controllable aspects of CHF	__identifies self-monitoring skills __relates individualized signs and symptoms of CHF to basic heart function __participates with learning activity sheet	__identifies personal medication management components: name, dose, frequency, description, and side effects __identifies self-monitoring aspects of own medications

Current Medications:

_____

_____

_____

_____

_____

_____

_____

_____

Previous CHF status: _____

Present CHF status: _____

Learning challenges: _____

_____

Strategies for meeting challenges: _____

_____

Designated learner(s):
(Client, family member, other caregiver) _____

_____

_____

MODULE #4

Nurse's signature and date:

_____

_____

_review of activity sheet #3
_respond to questions arising
_level of understanding achieved

decision to re-teach previous session
_decision to progress
_learning strategies in place

Teaching content:

_diet in the management of CHF: components of weight control, salt and sodium, fat and cholesterol, fluids, use of alcohol
_food preparation
_planning for special occasions
_changes in appetite
_present Activity sheet #4

_identifies main CHF dietary components
_recognizes relation of diet to own signs / symptoms
_recognizes importance of changed appetite
_evaluates current dietary practices

MODULE #5

Nurse's signature and date:

_____

_____

_review of activity sheet #4
_respond to questions arising
_level of understanding achieved

_decision to re-teach previous session
_decision to progress
_learning strategies in place

Teaching content:

_role of exercise, rest and energy conservation in CHF
_reflection on present levels
_benefits
_techniques for use
_related self-monitoring skills
_present Activity sheet #5

_identifies self-monitoring aspects
_identifies preferred techniques
_participates in self-monitoring skills

MODULE #6

Nurse's signature and date:

_____

_____

_review of activity sheet #5
_respond to questions arising
_level of understanding achieved

_decision to re-teach previous session
_decision to progress
_learning strategies in place

Teaching content:

_Stress management, relaxation and environmental influences
_related self-monitoring skills
_techniques for use
_present Activity sheet #6

_identifies personal situations of stress
_identifies own preferred coping techniques

MODULE #7

Nurse's signature and date:

_____

_____

_review of activity sheet #6
_respond to questions arising
_level of understanding achieved

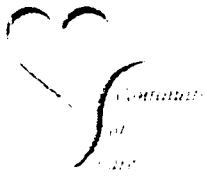
_decision to re-teach previous session
_decision to progress
_learning strategies in place

Teaching content:

_resources and support systems for CHF
_patient role
_professional's role
_community resources
_present wall chart guide for daily self-care activities

_identifies personal sources of support
_identifies community resources for continued learning about CHF
_review of draft forms for patient education related to CHF

APPENDIX B: Subject Recruitment Eligibility Screen, Information Letter, Consent Form and Patient Profile



ELIGIBILITY SCREEN

Patient's Name:_____

Nursing Unit:_____ **Room #:**_____

Primary Nurse code #:_____ **Associate code #:**_____ **VON code #:**_____

Discharge Date : _____

For inclusion to the PIC study:

___ Admitting diagnosis (Most Responsible Diagnosis or Primary Diagnosis) of Congestive Heart Failure (CHF) or Congestive Heart Failure Exacerbation (CHF exacerbation)

___ Resident of Ottawa-Carleton

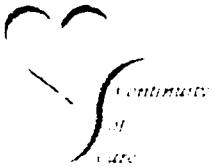
___ English speaking

___ Admission to study nursing units of A5 and B5

___ Not previously enrolled

___ Consent to participate in the study. Date consent signed:_____

Study Coordinator:_____ Date:_____



CONTINUITY OF CARE STUDY FOR CHF PATIENTS
INFORMATION SHEET

What is this study about?

This study looks at the care of persons with heart failure and their families during the time of change from care given in a hospital to care given at home. It will examine the information necessary for the person and the family to have in order to take better care of themselves at home. It will examine the links necessary for nurses in the hospital and in the community to have with each other.

Why are you being asked to take part in this study?

Health care is changing. Patients are in the hospital for a shorter time which may mean less time for them to learn how to care for themselves at home. Much more of your recovery and learning will need to happen after you go home. Nurses need to find ways to improve this teaching and be more effective in providing you with needed resources. You are the best person to help us decide which materials are more effective and which ways of teaching are more helpful to you.

How does your participation in the study affect your nursing care?

If you decide to participate in the study, you will continue to receive all of the usual nursing care and the usual teaching given both in the hospital and at home. You will be assigned at random, to one of two educational programs. One of the educational programs will use newly-developed materials in addition to the usual teaching. You will not be told which program is being used for you. No other changes will be made.

You will be interviewed before going home, as well as three and six weeks later in your home. These interviews will take approximately 40 minutes to complete. A VON nurse will make at least two visits to your home in the first two weeks, to continue your teaching program.

Your participation is voluntary and you have the right to refuse to participate, or to withdraw from the study at any time. If you decide not to participate, now or later, neither your present nor future care will be affected in any way. Your name and all of your answers will be kept confidential. No identifying information will be used in any discussion of the study results. Only the researchers will have access to your answers. You will receive the final grouped results of the study.

If you have any questions or concerns regarding this study, please contact:

Margaret B. Harrison, RN	Cynthia Toman, RN	Spencer Ross, RN
Principal Investigator	Study Coordinator	Study Coordinator
(613)798-5555, ext.3028	(613) 798-5555, ext. 3028	(613) 798-5555, ext. 3028

CONTINUITY OF CARE STUDY FOR CHF PATIENTS

CONSENT FORM

Patient's Name:_____

Caregiver's Name (if applicable):_____

Study: Transition from Hospital to Home for Congestive Heart Failure Patients: Promoting Continuity of Care

Investigators:

Ottawa Civic Hospital:	Margaret Harrison, R.N. (Principal Investigator)
	J. Logan, R.N., K. Nunn, R.N.
Victorian Order of Nurses:	B. Hollingsworth, R.N.
University of Ottawa:	M. Ross, R.N.
Regional Home Care:	J. Davidson, R.N.

Purpose:

The purpose of this study is to determine the effects of a transitional care program aimed at improving continuity of care for patients with congestive heart failure. The knowledge gained from this study will assist nurses and other health professionals in planning and providing care to congestive heart failure patients and their families.

What Happens If I come Into The Study :

With the study, you would be admitted to whatever unit you normally would have gone to - usually determined by where a bed is available. What is different is that you will have an interview and some follow-up with a nurse. Medical units at the Ottawa Civic have been designated as those with usual discharge planning and post-discharge care **OR** usual care <u>with</u> a specific transitional care program for patients with congestive heart failure. In either case, the study patients will be asked by a nurse to answer questions about how you are coping with your condition at five points in time : upon admission, just before discharge, at two weeks, and 6 weeks following discharge. These questions will take approximately 30 minutes in total to answer.

Risks and Benefits:

There are no known risks or benefits to the participants. Interviews will be scheduled at a time and location convenient to you. Some people may find it helpful to talk about how they cope with their disease and others may find it upsetting. The research nurse will respect any wish to stop the interviews.

Rights of Participants:

You have the right to refuse to participate in the study and the right to withdraw from the study at any time without any change in your care. The information collected during this study will be strictly confidential. A code number will be used to identify the information so your name will not appear on any documents. If the results of the study are published in a journal, there will be no way to identify you.

Consent:

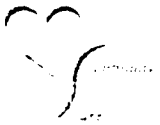
I have read and understand this consent form and I agree to participate in this study.

Name of Patient:_____

Signature:_____ Date Signed :_____

Witness' Signature:_____ Date Signed:_____

If you have any questions about this study, you can telephone the Principal Investigator, Margaret B. Harrison, RN, Nursing Research, Ottawa Civic Hospital at (613) 798-5555, ext. 3028.



PATIENT PROFILE

Patient Code Number:_____

Date of Admission:_____

Age:_____ years

Sex: __female __male

Marital Status: __single __married __separated/divorced __widowed __unknown

Living Arrangements: __lives alone __lives with others __unknown

Utilization of Community Resources: __home care __meals on wheels __homemaking

Employment Status: __retired __unemployed __part-time __full-time __homemaker __unknown

Education Level: __grade school __some high school __high school diploma __some college __college __some university __university

Health Status: 1. Comorbid Conditions (specify) _____

_____

_____

_____

_____

2. New York Heart Association Functional Classification of Severity of Cardiac Illness_____

3. Please circle appropriate class: I II III IV

TO BE CAPTURED AT DISCHARGE

Number of Prescribed Daily Medications_____

Number of Admissions During the previous 6 Months

Study Coordinator:_____ Date:_____

T2 Appt._____ T3 Appt._____ T4 Appt._____

Date & Time Date & Time Date & Time

APPENDIX C: Ottawa-Carleton Community Care Access Centre Medical Referral Form

OTTAWA-CARLETON
COMMUNITY CARE ACCESS CENTRE
1223 Michael Street
Gloucester, Ontario
K1J 7T2
(613) 745-5525

NOTE: USE BLACK INK PEN ONLY

C.M. Code _____

MEDICAL REFERRAL FORM

Name _____

Address _____

Date Of Birth _____ Phone: _____

OHN _____

C.A.F. # _____

CCAC OFFICE USE | Referral Source: _____ | Date Rec'd | Adm. Date

DIAGNOSES AND HISTORY: Including Goals of Treatment

A COPY OF THIS REFERRAL MAY BE KEPT IN THE CLIENTS HOME

Projected Discharge Date from Hospital:

Level of Care: Acute ☐ Convalescent ☐ Chronic ☐ Palliative ☐

Prognosis: Immediate: Good ☐ Fair ☐ Poor ☐ Patient Informed ☐ Family Informed ☐

Long Term: Good ☐ Fair ☐ Poor ☐ Patient Informed ☐ Family Informed ☐

SERVICE REQUESTED — TREATMENT WILL BE TAUGHT AND FREQUENCY REDUCED AS APPROPRIATE

NURSING ☐

General Nursing Care ☐

Additional Nursing Orders:

Laxative and/or Enema _____

THERAPY ☐

PHYSIO ☐ O.T. ☐ SPEECH ☐

THERAPY ORDERS:

Gait Training: Walker ☐ Crutches ☐ Canes ☐

Non Weight bearing ☐ Duration _____

Partial Weight bearing ☐ Duration _____

Full Weight bearing ☐ Contraindication: _____

Nutritional Counselling ☐ Diet: _____ Social Worker ☐ _____

MEDICATIONS Specify drug name, dosage, frequency and method of administration: (Include Oxygen if applicable)	
1	9
2	10
3	11
4	12
5	13
6	14
7	15
8	16

REFERRING PHYSICIAN | ATTENDING PHYSICIAN / CCAC

Name: _____

Staff Physician's Name (if applicable) _____ Telephone # _____

SIGNATURE _____ DATE _____

If other than Referring

Name _____ Telephone # _____

Attending Physician Notified: Yes ☐ No ☐

Return Appointments: _____

YELLOW - PATIENT FILE PINK - CCAC COPY

SEE REVERSE FOR EXPLANATION

2.26(96/03)

OTTAWA-CARLETON COMMUNITY CARE ACCESS CENTRE

INSTRUCTIONS FOR THE COMPLETION OF THE MEDICAL REFERRAL FORM

Diagnosis and History:	Indicate the primary medical diagnosis which necessitates this referral to the CCAC. Include the secondary diagnosis contributing to the need for referral to the CCAC. Indicate pertinent information which will assist the CCAC staff and service providers to treat the patient safely and effectively at home.
Projected Discharge Date from Hospital:	Indicate the expected date of discharge from hospital.
Level of Care:	Indicate with a tick the appropriate level of care required by the patient.
Diagnosis:	Indicate immediate and long term prognosis. Indicate with a tick if the patient and/or the family are aware of the prognosis.
Service Requested:	Indicate with a tick the appropriate service(s) required by the patient. Specify orders in the adjacent space. Note: Contraindications for treatment are to accompany the specific orders for a service provider. Treatments will be taught to patient and/or reliable persons in the home and the frequency reduced unless otherwise indicated.
General Nursing Care (GNC):	GNC allows the nurse to provide the following: 1. sponge or tub bath as assessed 2. shampoo 3. skin care 4. manicure and pedicure
Diet:	Indicate the prescribed diet.
Social Worker:	Indicate with a tick if service is required and specify the reason for the intervention.
Medication:	Indicate the complete medication regime as prescribed including the name of the drug, dosage, frequency and route of administration. Include oxygen if applicable.
Laboratory:	Indicate the required laboratory tests which need to be done in the home setting. Indicate with a tick if arrangements need to be made or if they have already been made.
Medical Supervision While on the CCAC	Indicate the name of the physician providing general medical management of the patient while receiving services through the CCAC. Specify if the physician assuming the above medical arrangement of the patient in the community has been contacted and agrees to the plan. If the contact is not made, the referring physician will be considered as the attending physician until other arrangements are made.
General:	The Medical Referral Form (similar to a hospital order sheet) is the legal document which authorizes services for a specific patient to be treated at home. A CCAC Case Manager will assess the patient for the legislated criteria found in the Health Insurance Act. Once eligibility is confirmed, the Case Manager will order the required professional and support services. If the patient is not eligible for the CCAC, the physician or his designate will be informed and alternate suggestions and/or arrangements will be make by the Case Manager.

NOTE: 48 hours is required from the time of the referral before the assessment is completed.

APPENDIX D: Data Collection and Measurement Tools

Date :_____ Interview ID____ Patient Code_____

LIVING WITH HEART FAILURE QUESTIONNAIRE

These questions concern how your heart failure (heart condition) has prevented you from living as you wanted during the last month. The items listed below describe different ways some people are affected. If you are sure an item does not apply to you or is not related to your heart failure then circle 0 (NO) and go on to the next item. If an item does apply to you, then circle the number rating how much it prevented you from living as you wanted.

Did your heart failure prevent you from living as you wanted during the last month by :

	N/A	NO	Very Little				Very Much
1. Causing swelling your ankles, legs, etc.?		0	1	2	3	4	5
2. Making you sit or lie down to rest during the day?		0	1	2	3	4	5
3. Making your walking about or climbing stairs difficult?		0	1	2	3	4	5
4. Making your working around the house or yard difficult?		0	1	2	3	4	5
5. Making your going places away from home difficult?		0	1	2	3	4	5
6. Making your sleeping well at night difficult?		0	1	2	3	4	5
7. Making your relating to or doing things with your friends or family difficult?		0	1	2	3	4	5
8. Making your working to earn a living difficult?		0	1	2	3	4	5
9. Making your recreational pastimes, sports or hobbies difficult?		0	1	2	3	4	5
10. Making your sexual activities difficult?		0	1	2	3	4	5
11. Making you eat less of the foods you like?		0	1	2	3	4	5
12. Making you short of breath?		0	1	2	3	4	5
13. Making you tired, fatigued, or low on energy?		0	1	2	3	4	5
14. Making you stay in a hospital?		0	1	2	3	4	5
15. Costing you money for medical care?		0	1	2	3	4	5
16. Giving you side effects from medications?		0	1	2	3	4	5
17. Making you feel you are a burden to your family or friends?		0	1	2	3	4	5
18. Making you feel a loss of self-control in your life?		0	1	2	3	4	5
19. Making you worry?		0	1	2	3	4	5
20. Making it difficult for you to concentrate or remember things?		0	1	2	3	4	5
21. Making you feel depressed?		0	1	2	3	4	5

TRANSITION FROM HOSPITAL TO HOME FOR CHF PATIENTS : IMPROVING CONTINUITY OF CARE RESOURCE UTILIZATION AND PATIENT EXPENDITURE QUESTIONNAIRE

Please circle the appropriate answer for each section. Identify times and amounts where indicated. Ask for help if you need it.

1. **During the period since your discharge from the Ottawa Civic Hospital on (*insert date*), have you had any:**

				If yes, How many?
a)	visits to or from a family physician?	No	Yes	_____
b)	visits to a physician specialist?	No	Yes	_____
c)	Emergency Room visits?	No	Yes	_____

2. **During the period since your discharge from the Ottawa Civic Hospital on (*insert date*), have you had a:**
   a) Hospital admission? (Includes day surgery) No Yes
   b) Total number of days in hospital. _____ Days

3. **During the period since your discharge from the Ottawa Civic Hospital on (*insert date*), have you had any visits with:**

				If yes, how many?	Did you pay for this service yourself?			Cost to You
a)	Physiotherapists?	No	Yes	____	No	Part	Yes	$_____
b)	Occupational Therapists?	No	Yes	____	No	Part	Yes	$_____
c)	Social Workers?	No	Yes	____	No	Part	Yes	$_____
d)	Nutritionists?	No	Yes	____	No	Part	Yes	$_____
e)	Community Nurses?	No	Yes	____	No	Part	Yes	$_____
f)	Chiropractors?	No	Yes	____	No	Part	Yes	$_____
g)	Homemakers?	No	Yes	____	No	Part	Yes	$_____
h)	Meals on Wheels?	No	Yes	____	No	Part	Yes	$_____
I)	Psychologists?	No	Yes	____	No	Part	Yes	$_____
j)	Other health care providers or services	No	Yes	____	No	Part	Yes	$_____

Please specify: _____

4. **During the period since your discharge from the Ottawa Civic Hospital on (*insert date*), have you had any Out-Patient tests done :**
   a) at the hospital lab or clinic? No Yes
   b) at a lab outside of the hospital? No Yes

List each test with number of times done. Please provide specifics if known.

TEST	**# OF TIMES**	**TYPE**
Blood	_____	_____
Specimens (i.e. urine, throat swab)	_____	_____
Scopes (i.e. endoscopy, bronchoscopy, sigmoidoscopy)	_____	_____
X-Rays	_____	_____
Scans (i.e. ultrasound, CT scan)	_____	_____
Breathing Test (i.e. spirometry)	_____	_____
ECG (heart monitoring)	_____	_____
Other (please specify)_____	_____	_____

5. List any medications you have taken in the last 2 days:

	Drug Name and Dosage	Number of Pills or Doses in the last 2 days
a.	_____	_____
b.	_____	_____
c.	_____	_____
d.	_____	_____
e.	_____	_____
f.	_____	_____
g.	_____	_____

6. List any supplies, aides or devices bought by you or received from a helping service (eg Red Cross) during the period since your discharge from the Ottawa Civic Hospital on (*insert date*). I.e. wheel chairs, syringes, walkers, crutches, dressings, etc.

Item	**Did you pay for this service yourself?**			**Cost to you**
_____	No	Part	Yes	$_____
_____	No	Part	Yes	$_____
_____	No	Part	Yes	$_____

7. Due to your health, during the period since your discharge from the Ottawa Civic Hospital on (*insert date*), did you:

				If yes, how many times?	
a)	receive free household help other than a Home Care homemaker?	No	Yes	_____	
b)	pay for household help other than a Home Care homemaker?	No	Yes	_____	Cost $_____

8. During the period since your discharge from the Ottawa Civic Hospital on (*insert date*), did you:

a) travel to receive any health care services? No Yes

If yes, please use this chart to show how you travelled:

Type of transportation	Number of ***one way*** trips? (a trip from your home to your doctor's office counts as 2 ***one way*** trips)	Cost or distance per ***one way*** trip?
Bus		cost: $
Taxi		cost: $
Car		distance: km

b) pay for any parking? Yes No Total Cost _____

9. During the period since your discharge from the Ottawa Civic Hospital on (*insert date*), was any time lost from work due to your health?

				If yes how many days?	Amount of lost wages (if any)
a)	by you	No	Yes	_____	_____
b)	by others, i.e. family	No	Yes	_____	_____

10. What is your current employment status? (Circle as many as apply to you)

1) working full-time
2) working part-time
3) self-employed (full-time)
4) student
5) homemaker
6) on sick leave
7) on Worker's Compensation
8) on Unemployment Insurance
9) on Disability Plan
10) retired from work
11) receiving a pension
12) unemployed
13) other - please specify_____

11. As a rule, how much time do you have to miss from work when you go for health care visits?

1) none
2) ½ to 1 hour
3) >1 to 2 hours
4) >2 to 3 hours
5) > 3 hours

How much money do you lose as a result of this time lost? _____

Thank you for taking the time in responding to this questionnaire, we greatly appreciate it.

DATE :_____INTERVIEW ID _ _PATIENT CODE _____

THE MOS 36-ITEM SHORT-FORM HEALTH SURVEY(SF-36)

INSTRUCTIONS : This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. **In general, would you say your health is :**

	(Circle one)
Excellent	1
Very good	2
Good	3
Fair	4
Poor	5

2. **Compared to one year ago, how would you rate your health in general now?**

	(Circle one)
Much better now than one year ago	1
Somewhat better now than one year ago	2
About the same as one year ago	3
Somewhat worse now than one year ago	4
Much worse now than one year ago	5

3. **The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?**
(Circle one number on each line)

Activities	Yes, Limited A lot	Yes, Limited A Little	No, Not Limited At All
a. **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports.	1	2	3
b. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.	1	2	3
c. Lifting or carrying groceries.	1	2	3
d. Climbing **several** flights of stairs.	1	2	3
e. Climbing **one** flight of stairs.	1	2	3
f. Bending, kneeling or stooping.	1	2	3
g. Walking **more than a mile.**	1	2	3
h. Walking **several blocks.**	1	2	3
I. Walking **one block.**	1	2	3
j. Bathing or dressing yourself.	1	2	3

4. **During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?**
(Circle one number on each line)

	YES	NO
a. Cut down on the **amount of time** you spent on work or other activities.	1	2
b. **Accomplished less** than you would like.	1	2
c. Were limited in the **kind** of work or other activities.	1	2
d. Had **difficulty** performing the work or other activities (for example, it took extra effort).	1	2

5. **During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?**
(Circle one number on each line)

	YES	NO
a. Cut down the amount of time you spent on work or other activities.	1	2
b. Accomplished less than you would like.	1	2
c. Didn't do work or other activities as carefully as usual.	1	2

6. **During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?**
(Circle one)

Not at all..... 1
Slightly..... 2
Moderately..... 3
Quite a bit..... 4
Extremely..... 5

7. **How much bodily pain have you had during the past 4 weeks?**
(Circle one)

None..... 1
Very mild..... 2
Mild..... 3
Moderate..... 4
Severe..... 5
Very severe..... 6

8. **During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?**
(Circle one)

Not at all..... 1
A little bit..... 2
Moderately..... 3
Quite a bit..... 4
Extremely..... 5

9. **These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the <u>past 4 weeks</u>**
(Circle one number on each line)

	All of the time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
a. Did you feel full of pep?	1	2	3	4	5	6
b. Have you been a very nervous person?	1	2	3	4	5	6
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d. Have you felt calm and peaceful?	1	2	3	4	5	6
e. Did you have a lot of energy?	1	2	3	4	5	6
f. Have you felt downhearted and blue?	1	2	3	4	5	6
g. Did you feel worn out?	1	2	3	4	5	6
h. Have you been a happy person?	1	2	3	4	5	6
I. Did you feel tired?	1	2	3	4	5	6

10. **During the <u>past 4 weeks</u>, how much of the time has <u>your physical health or emotional problems</u> interfered with your social activities (like visiting with friends, relatives, etc.)?**
(Circle one)

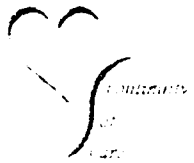
All of the time..... 1
Most of the time..... 2
Some of the time..... 3
A little of the time..... 4
None of the time..... 5

11. **How TRUE or FALSE is <u>each</u> of the following statements for you?**

(Circle one number on each line)

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. I seem to get sick a little easier than other people.	1	2	3	4	5
b. I am as healthy as anybody I know.	1	2	3	4	5
c. I expect my health to get worse.	1	2	3	4	5
d. My health is excellent.	1	2	3	4	5

APPENDIX E: Letter of Thanks to Subjects for Participation in this Study



<<<DATE>>>

<<<PATIENT NAME>>>
<<<PATIENT ADDRESS 1>>>
<<<PATIENT ADDRESS 2>>>
<<<PATIENT ADDRESS 3>>>

Dear <<<PATIENT NAME>>>,

I am writing to thank you for your valuable time as a participant in our research study entitled: "Transition from Hospital to Home: Promoting Continuity of Care for Patients with Congestive Heart Failure."

We have now completed the scheduled appointments with you. The information you have shared with us is an important part of this study. Your name and all of your responses are kept confidential. No identifying information will be used in any discussion of the study results.

A report will be prepared for our funding agency, the National Health Research Development Program and findings submitted to scientific/health related journals at the completion of the study later in 1998. We will be pleased to send you a summary of the findings from the study at that time.

It has been a privilege for myself and the research coordinator, Cynthia Toman, RN, to work with you over the last few months. We want you to know that without you, we could not have done this research. The research will demonstrate the importance of continuity of care needed from the patient and family perspective and hopefully will contribute to planning health care delivery in our region.

Sincerely,

Margaret B. Harrison
Principal Investigator, RN
Clinical Epidemiology Unit
Ottawa Civic Hospital
Tel : (613) 798-5555 ext. 3028

APPENDIX F: Subject Recruitment and Study Status Log

PATIENT # _____

Transition from Hospital to Home : Promoting Continuity of Care

for Congestive Heart Failure

PROTOCOL CHECKLIST - TRANSITIONAL CARE

EVENT		DATE	VARIANCE	EXPLANATION/RATIONALE
Eligibility Screen	yes/no			
Consent	yes/no			
Profile	yes/no			
Patient Chart flagged on unit	yes/no			
Assignment of Primary Nurse	#			
HCC notified of study patient admission	yes/no			
Home Care referral completed	yes/no			
T1 Pre-discharge	yes/no			
HCC notified of d/c	yes/no			
Nsg Consultation Letter completed & given to patient at	yes/no			
Education Map and book sent with patient	yes/no			
Discharge	yes/no			
Follow-up phone call made to patient	yes/no			
Documentation of phone advise	yes/no	_____		
Nurse Time Questionnaire	yes/no			
Return phone call from VON	yes/no	_____		
VON visits	#	_____		
T2	yes/no			
Retrieval of study material from patient's	yes/no			
T3	yes/no			
T4	yes/no			
Closure Letter sent	yes/no			

 Code : ☐ Shaded boxes contain information that may be available but not required for study protocol.

1001 TC	96.06.25	96.06.27	96.06.27	96.07.11	96.08.09
1002 UC	96.07.08	96.07.08	96.07.08	too ill	too ill
1003 TC	96.07.22	96.07.28	96.07.30	96.08.13	96.09.08
1004 UC	96.07.28	96.07.30	96.07.30	96.08.12	96.09.08
1005 UC	96.07.29	96.08.02	96.08.02	96.08.20	96.09.12
1006 TC	96.07.31	96.08.04	96.08.04	96.08.21	96.09.16
1007 UC	96.07.31	96.07.31	96.07.31	96.08.16	96.09.12
1008 TC	96.08.01	96.08.26	96.08.24	96.09.10	96.10.09
1009 TC	96.08.07	96.08.09	96.08.10	96.08.22	96.09.19
1010 UC	96.08.19	96.08.22	96.08.22	96.09.05	96.10.09
1011 TC	96.08.19	96.08.22	96.08.20	96.09.03	96.09.30
1012 UC	96.08.25	96.08.26	96.08.26	96.09.09	96.10.14
1013 UC	96.08.27	96.08.29	96.08.29	withdrew	withdrew
1014 TC	96.08.29	96.09.02	96.09.02	96.09.17	96.10.15
1016 UC	96.09.08	96.09.11	96.09.11	96.09.25	96.10.24
1017 UC	96.09.08	96.09.27	96.09.27	96.10.11	96.11.08
1018 TC	96.09.10	96.09.25	96.09.24	96.10.09	96.11.05
1020 UC	96.09.25	96.09.26	96.09.26	96.10.10	96.11.08
1021 TC	96.10.02	96.10.03	96.10.03	96.10.31	96.11.28
1022 TC	96.10.03	96.10.04	96.10.04	96.10.17	96.11.14
1023 TC	96.10.03	96.10.03	96.10.11	96.10.25	96.11.21
1024 UC	96.10.06	96.10.08	96.10.08	96.10.24	moved
1025 UC	96.10.07	96.10.12	96.10.11	96.10.25	96.12.02
1026 TC	96.10.07	96.10.09	96.10.10	96.10.26	96.11.21
1028 UC	96.10.25	96.10.29	96.10.30	96.11.13	death
1029 TC	96.10.28	96.10.31	96.10.31	96.11.15	96.12.18
1031 UC	96.11.02	96l11.06	96.11.06	96.11.20	96.12.18
1032 TC	96.11.20	96.11.20	96.11.20	96.12.05	96.12.31
1033 TC	96.12.01	96.12.04	96.12.02	96.12.18	97.01.20
1034 UC	96.12.04	96.12.04	96.12.04	96.12.17	97.01.16
1035 UC	96.12.11	96.12.17	96.12.20	96.12.30	97.01.29
1036 TC	96.12.13	96.12.13	96.12.13	96.12.27	97.01.24
1037 UC	96.12.14	96.12.14	96.12.14	96.12.31	97.01.28
1038 TC	96.12.16	96.12.16	96.12.16	96.12.31	97.01.28
1039 UC	96.12.18	96.12.20	96.12.20	97.01.10	too ill
1040 TC	96.12.22	96.12.23	96.12.23	97.01.07	97.02.07
1041 TC	97.01.02	97.01.03	death	death	death
1042 TC	97.01.08	97.01.09	97.01.09	97.01.23	97.02.19
1043 UC	97.01.12	97.01.13	97.01.13	97.01.28	lost to continue
1044 UC	97.01.13	97.01.16	97.01.16	refused to	refused to conti
1045 UC	97.01.30	97.02.03	97.02.03	refused	continue
1047 TC	97.02.25	97.03.03	97.03.05	97.03.19	97.04.16
1052 UC	97.03.19	97.03.21	97.03.22	97.04.08	97.05.09
1053 UC	97.03.23	97.03.28	97.04.01	refused to	refused to conti

1054 TC	97.04.03	97.04.09	97.04.10	97.04.24	97.05.20
1057 TC	97.05.06	97.05.06	97.05.06	97.05.21	97.06.20
1059 TC	97.05.15	97.05.20	97.05.22	97.06.07	97.07.02
1060 UC	97.05.19	97.05.23	97.05.23	97.06.04	97.07.02
2001 UC	96.06.27	97.07.01	death 96.07.11	death	death
2002 TC	96.06.28	96.06.29	96.07.01	96.07.16	96.08.14
2003 UC	96.07.01	96.07.01	96.07.02	96.07.19	96.08.13
2004 TC	96.07.08	96.07.09	96.07.09	96.07.24	96.08.21
2005 UC	96.07.16	96.07.16	96.07.16	96.08.01	96.08.29
2008 TC	96.08.02	96.08.06	96.08.06	96.08.21	96.09.17
2009 UC	96.08l16	96.08.19	96.08.19	96.09.04	96.09.30
2010 TC	96.09.05	96.09.08	96.09.08	96.09.19	96.10.17
2011 UC	96.09.06	96.09.12	96.09.06	96.09.25	96.10.28
2012 TC	96.09.09	96.10.01	96.10.02	96.10.17	96.11.14
2015 TC	96.09.15	96.09.17	96.09.17	96.10.03	96.10.30
2016 UC	96.09.22	96.10.29	96.10.30	96.11.12	96.12.13
2017 UC	96.09.24	96.09.26	96.09.26	96.10.09	96.11.08
2018 UC	96.10.10	96.10.11	96.10.11	96.10.24	96.11.20
2019 TC	96.10.11	96.10.17	96.10.17	96.10.31	96.11.28
2020 TC	96.10.15	96.10.21	96.10.23	96.11.07	96.12.03
2021 UC	96.10.18	96.10.21	96.10.21	96.11.07	too ill
2022 UC	96.10.28	96.11.05	96.11.15	96.11.27	too ill
2023 TC	96.11.03	96.11.07	96.11.06	96.11.21	96.12.19
2024 TC	96.11.07	96.11.13	96.11.14	96.11.28	96.12.28
2026 TC	96.11.13	96.11.13	96.11.13	96.11.28	96.12.27
2027 TC	96.11.16	96.11.19	96.11.19	96.12.05	death
2028 UC	96.11.16	96.11.22	96.11.21	96.12.05	97.01.03
2029 TC	96.11.25	96.11.30	96.12.03	96.12.12	97.01.10
2030 UC	96.11.27	96.12.06	96.12.06	96.12.19	97.01.23
2031 UC	96.12.01	96.12.06	96.12.08	96.12.20	97.01.17
2033 UC	96.12.04	96.12.07	96.12.07	96.12.23	97.01.23
2034 TC	96.12.08	96.12.12	96.12.12	death	death
2035 UC	96.12.09	96.12.09	96.12.09	97.01.09	97.02.04
2036 TC	96.12.13	96.12.13	96.12.13	96.12.27	97.01.24
2037 UC	96.12.26	96.12.27	96.12.28	97.01.13	97.02.07
2038 TC	96.12.30	96.12.31	97.01.01	97.01.14	97.02.11
2039 UC	97.01.03	97.01.07	97.01.04	97.01.24	97.02.22
2040 TC	97.01.08	97.01.24	97.01.24	97.02.07	97.03.04
2042 TC	97.01.24	97.01.28	97.01.27	97.02.10	lost to continue
2043 UC	97.01.26	97.01.30	97.01.30	97.02.11	97.03.11
2044 UC	97.01.30	97.02.14	97.02.14	97.02.28	97.03.26
2045 TC	97.01.30	97.02.04	97.02.04	97.02.18	97.03.19
2046 TC	97.02.07	97.02.07	97.02.07	97.02.21	97.03.21
2047 UC	97.02.18	97.02.18	97.02.18	97.03.04	97.04.03

2048 UC	97.02.18	97.02.18	97.02.18	97.03.07	97.04.02
2049 TC	97.02.20	97.02.26	97.02.26	97.03.18	97.04.08
2050 TC	97.02.21	97.02.23	97.02.23	97.03.11	completed 1/2 -
2051 TC	97.02.27	97.03.03	97.03.05	97.03.25	97.04.16
2052 UC	97.02.27	97.02.28	death 97.04.05	death	death
2053 TC	97.03.06	97.03.11	97.03.11	97.04.04	97.04.23
2054 TC	97.03.07	97.03.10	97.03.10	97.03.26	97.04.23
2055 UC	97.03.11	97.03.17	97.03.17	refused	to continue
2056 UC	97.03.11	97.03.17	97.03.17	97.04.02	97.04.30
2057 UC	97.03.13	97.03.17	97.03.16	97.04.03	97.05.01
2059 UC	97.03.20	97.03.21	97.03.24	97.04.07	97.05.08
2060 TC	97.03.21	97.03.24	97.03.26	97.04.07	97.05.07
2061 UC	97.03.24	97.03.28	97.03.28	97.04.10	lost to follow-up
2062 TC	97.04.01	97.04.20	97.04.22	97.05.06	97.06.02
2063 UC	97.04.15	97.04.18	97.04.19	97.05.02	97.05.29
2064 TC	97.04.16	97.04.16	97.04.18	97.04.30	97.05.28
3001 UC	96.08.09	96.08.13	96.08.13	96.08.30	96.09.26
3002 TC	96.08.13	96.09.20	96.09.19	96.10.07	96.11.01
3003 UC	96.08.27	96.09.03	96.09.03	96.09.25	96.10.24
3005 TC	96.09.16	96.09.23	96.09.23	96.10.11	96.11.05
3006 UC	96.09.25	96.09.26	96.09.27	96.10.11	96.11.06
3007 UC	96.10.04	96.11.04	96.11.04	96.11.18	97.01.03
3009 UC	96.10.25	96.11.01	96.11.01	96.11.13	96.12.11
3011 TC	96.10.30	96.11.30	96.11.30	96.12.13	97.01.14
3013 TC	96.11.12	96.11.18	96.11.18	96.12.07	96.12.31
3014 TC	96.11.15	96.11.18	96.11.20	96.12.04	96.12.31
3015 UC	96.11.17	96.11.27	96.11.28	96.12.12	97.01.15
3016 UC	96.11.17	96.11.22	96.11.22	96.12.05	97.01.02
3017 TC	96.11.27	96.12.03	96.12.03	96.12.18	97.01.22
3018 UC	96.12.24	96.12.24	96.12.27	97.01.13	97.02.06
3019 TC	97.01.12	97.01.13	97.01.13	97.01.29	97.03.03
3020 UC	97.01.17	97.01.30	97.02.02	97.02.17	97.03.12
3021 UC	97.02.06	97.02.09	97.02.09	97.02.24	97.03.26
3022 TC	97.02.24	97.03.05	97.03.05	97.03.18	97.04.15
3023 UC	97.03.05	97.03.10	97.03.10	97.03.24	97.04.22

APPENDIX G: Ethical Approval

LOEB MEDICAL RESEARCH INSTITUTE
INSTITUT DE RECHERCHE MÉDICALE LOEB

OTTAWA CIVIC HOSPITAL
HÔPITAL CIVIC D'OTTAWA

UNIVERSITÉ D'OTTAWA
UNIVERSITY OF OTTAWA

March 7, 1995

Margaret Harrison
Nursing Research & Professional Development
1st Floor, Norman Patterson Building
Ottawa Civic Hospital

Dear Ms. Harrison:

Re: Protocol #94-225 **Transition from Hospital to Home for Congestive Heart Failure Patients: Promoting Continuity of Care**

I am pleased to inform you that your project (listed above) was reviewed by the Research Ethics Committee and approved. No changes, amendments or addenda may be made in the protocol or the consent form without the Research Ethics Committee review and approval.

Approval is valid for a period of one year ending March 7, 1996. The validation date should be indicated on the bottom of all consent forms and information sheets (see copy attached). Approximately one month prior to that time, a single renewal form should be sent to the Research Administration office.

The new guidelines of the Medical Research Council require a greater involvement of the Research Ethics Committee in studies over the course of their execution. You must maintain as part of your records copies of the signed consent form. As well, you must inform the Committee of adverse events encountered during the study, here or elsewhere, or of significant new information which becomes available after the Committee review, either of which may impinge on the ethics of continuing the study. The REC will review the new information to determine if the protocol should be modified, discontinued, or should continue as originally approved.

Sincerely,

Raphael Saginur, M.D.
Chairman
Research Ethics Committee

Encls.

1053 Carling Avenue, Ottawa, Ontario K1Y 4E9
Tel: (613) 761-4395 Fax: (613) 761-4920

Loeb Medical Research Institute
Ottawa Civic Hospital
1053 Carling Avenue
Ottawa, Ontario
K1Y 4E9

June 21, 1996

Ms. Margaret Harrison
Clinical Epidemiology Unit
C4, Ottawa Civic Hospital

Dear Ms. Harrison:

RE: **Protocol # : 1994225-01H** **Transition from Hospital to Home for Congestive Heart Failure Patients: Promoting Continuity of Care**

Renewal Expiry Date : **June 21, 1997**

Thank you for your letter of June 19, 1996 with a new information letter enclosed, as well as the Annual Renewal form. The information letter has been reviewed and approved. Approval for the above listed study has also been extended for one year. No changes, amendments or addenda may be made in the protocol or the consent form without the Research Ethics Committee review and approval.

Renewal is valid for a period of one year. The validation date should be indicated on the bottom of all consent forms and information sheets/letter (see copy attached). Approximately one month prior to that time, a single renewal form should be sent to the Research Administration office.

Medical Research Council guidelines require a greater involvement of the Research Ethics Committee in studies over the course of their execution. You must maintain, as part of your records, copies of the signed consent form. As well, you must inform the Committee of adverse events encountered during the study, here or elsewhere, or of significant new information which becomes available after the Committee review, either of which may impinge on the ethics of continuing the study. The REC will review the new information to determine if the protocol would be modified, discontinued, or should continue as originally approved.

Yours sincerely,

Raphael Saginur, M.D.
Chairman
Research Ethics Committee

APPENDIX H: Cited Publications authored by M. B. Harrison

Practice Guidelines for the Prediction and Prevention of Pressure Ulcers: Evaluating the Evidence. Applied Nursing Research, 9(1), 9-17.

Quality of Life as an Outcome Measure in Nursing Research. Canadian Journal of Nursing Research, 28(3), 49-68.

Hospital to Home Evidence-based Education for Congestive Heart Failure. The Canadian Nurse/L'Infirmière Canadienne,9(4), 36-42.

Practice Guidelines for the Prediction and Prevention of Pressure Ulcers: Evaluating the Evidence

Margaret B. Harrison, George Wells, Andrea Fisher, and Monica Prince

Clinical practice guidelines for the prediction and prevention of pressure ulcers (Agency for Health Care Policy and Research [AHCPR], 1992) were evaluated in a Canadian, university-affiliated, acute care hospital. Through a prospective study, the prevalence of pressure ulcers was determined, and pressure ulcer incidence was tracked to evaluate the accuracy of the Braden Scale for risk assessment. The prevalence rate for stage II or greater pressure ulcers was 13.6%; the rate was 29.7% when stage I (persistent redness) was included. In evaluating the Braden Scale's accuracy in predicting risk, the findings from this study were less favorable than previous reports. The total Braden score that appeared to have the best balance of sensitivity (67%) and specificity (66%) was 19. Several factors should be considered. The scale was implemented and tested hospitalwide with a wide range of patient diagnoses, age, and severity; the study was a cross-section of an existing population; and the levels of nursing care and type of staff vary between units ranging from critical to long-term care. This study highlights the need for individual settings to evaluate the AHCPR Guidelines for the Prediction and Prevention of Pressure Ulcers.

SKIN CARE is a fundamental component of basic patient care and reflects on the overall quality of care a patient receives in the hospital. The prevention and minimization of skin breakdown and pressure ulcers is an important aspect of this care and has been identified as a nursing research priority (Dennis, Howes, & Zelauskas, 1989). Given the current trends of higher acuity and an aging population in tertiary settings, an increased risk exists for skin breakdown during hospitalization. Considering the human suffering and the high cost of care and treatments for this condition, prevention and minimization of skin breakdown are increasingly important elements of basic nursing care.

BACKGROUND

Prevalence of pressure ulcers is defined by the National Pressure Ulcer Advisory Panel (1989) as the new and old cases of pressure ulcers assessed on a cross-sectional, one-time basis. Studies reported in the past 10 years provide estimates of pressure ulcer prevalence ranging from 4.7% (Allman et al., 1986) to 29.5% (Oot-Giromini et al., 1989). In a large prospective study of 148 U.S. hospitals, a 9.2% prevalence of pressure ulcers was reported (Meehan, 1990). Limited published information is available about the prevalence in Canadian hospitals. A recent report of 2,384 patients documented an overall prevalence of 25.7% based on a convenience sample from eight Ontario and Quebec facilities (Foster, Frisch, Denis, Forler, & Jago, 1992). The percentage of acute care patients with a pressure ulcer increased with age from 25% in the 60- to 69-year-old age group to 45% for those older than 80 years.

From the Department of Nursing Research, Division of Patient Services, Loeb Research Institute, Clinical Epidemiology Unit, Ottawa Civic Hospital; School of Nursing, Department of Epidemiology and Community Medicine, and Faculty of Health Sciences, University of Ottawa, Ottawa, Ontario, Canada.

Margaret B. Harrison, MHA, RN: *Nurse Specialist, Research and Evaluation, Division of Patient Services; Clinical Scientist, Loeb Research Institute, Clinical Epidemiology Unit, Ottawa Civic Hospital; Clinical Associate, Faculty of Health Sciences, School of Nursing, University of Ottawa, Ottawa, Ontario, Canada; and Doctoral Student (Nursing), Faculty of Health Sciences, McMaster University, Hamilton, Ontario, Canada.* George Wells, PhD: *Associate Director, Clinical Epidemiology Unit, Loeb Research Institute; and Associate Professor, Faculty of Medicine, Department of Epidemiology and Community Medicine, University of Ottawa, Ottawa, Ontario, Canada.* Andrea Fisher, MScN, RN: *Nurse Specialist, Quality Improvement, Division of Patient Services, Ottawa Civic Hospital; and Clinical Assistant, School of Nursing, Faculty of Health Sciences, University of Ottawa, Ottawa, Ontario, Canada.* Monica Prince: *Data analyst, Ottawa, Ontario, Canada.*

Address reprint requests to Margaret B. Harrison, MHA, RN, Loeb Research Institute, Clinical Epidemiology Unit, Ottawa Civic Hospital, 1053 Carling Ave, Ottawa, Ontario, Canada K1Y 4E9.

0897-1897/96/0901-0003$5.00/0

Agency for Health Care Policy and Research (AHCPR) Guideline

A multidisciplinary panel, funded by AHCPR, developed a clinical practice guideline related to pressure ulcer prediction and prevention in adults (AHCPR, 1992). This guideline offers a standard for evidence-based practice (Brunt, 1993). The guideline reflects the state of knowledge in this area of care, and the recommendations are based on published scientific literature. The following four main goals were established (AHCPR, 1992):

1. Identify at-risk individuals needing prevention and the specific factors placing them at risk.
2. Maintain and improve tissue tolerance to pressure to prevent injury.
3. Protect against adverse effects of external mechanical forces: pressure, friction, and shear.
4. Reduce the incidence of pressure ulcers through educational programs.

A multidisciplinary task force was established in a Canadian teaching hospital to develop and implement a skin care program based on the AHCPR Clinical Practice Guideline for the prediction and prevention of pressure ulcers (AHCPR, 1992). The task force identified the need for a pressure ulcer prevalence study and an evaluation of a risk assessment method as a first step to incorporating practice guidelines as a standard of practice and to begin addressing the prevention and management of pressure ulcers.

In a prospective study, prevalence of pressure ulcers was determined, and pressure ulcer incidence was examined during a 2-week follow-up period to evaluate the accuracy of a risk assessment scale. Patients were assessed for risk of pressure ulcers using one of the AHCPR Clinical Practice Guideline recommended tools, the Braden Scale (Braden, Demuth, & Bergstrom, 1987; Bergstrom, Braden, Laguzza, & Holman, 1987). Several studies have tested and used this scale in medical-surgical (Bergstrom, Braden, Laguzza, & Holman 1987; Salvadalena, Snyder, & Brogdon, 1992); critical care (Bergstrom, Demuth, & Braden, 1987); nursing home (Braden & Bergstrom, 1994); and mixed populations (Foster, Frisch, Denis, Forler, & Jago, 1992; Langemo et al., 1991). The purpose of the current study was threefold: to evaluate the ACHPR guidelines for general use in an acute care setting; to determine the extent of the problem with pressure ulcers, establishing a baseline measure to assess future improvements in care; and to evaluate the accuracy of the Braden Scale in a large, acute care setting.

METHODS

Population

The study population was the adult inpatient group from 28 nursing units in a 740-bed acute care setting. The institution is a university teaching hospital in Eastern Ontario, providing a range of tertiary services to a metropolitan as well as a large outlying catchment area of more than 800,000 people.

Sampling for Prevalence Study

In one 12-hour period (0600 to 1800) all individuals on the inpatient units of the hospital were examined for skin breakdown and assessed for risk of pressure ulcer development. This assessment was accomplished through the early morning census lists provided by the admitting department and by tracking admissions throughout the study day. The goal was to assess all patients in the hospital during the 12-hour prevalence period. The total study population on prevalence day (0600-hour census plus new admissions) was 815 possible subjects (Figure 1). The study was conducted midweek on a Wednesday to reflect most accurately the mix of new admissions, preoperative and postoperative cases, as well as long-stay patients. The September timing reflected usual patient flow, avoiding seasonal fluctuations encountered during the summer and winter breaks.

Sampling for Follow-Up Study

To assess the accuracy of a risk assessment method prospectively, patients would need to be followed for a period after the prevalence study. From the original prevalence group, 300 adult subjects were randomly selected for a 2-week follow-up study. Members of the survey team assessed subjects in the same manner as the prevalence day for risk and for new occurrences of pressure ulcers. This assessment was done 3 times weekly (Monday, Wednesday, and Friday) for 2 weeks. Early morning (0700-hour) assessments were conducted to capture data on patients being discharged. A 2-week time frame was selected as it more than encompassed usual lengths of stay of the study site.

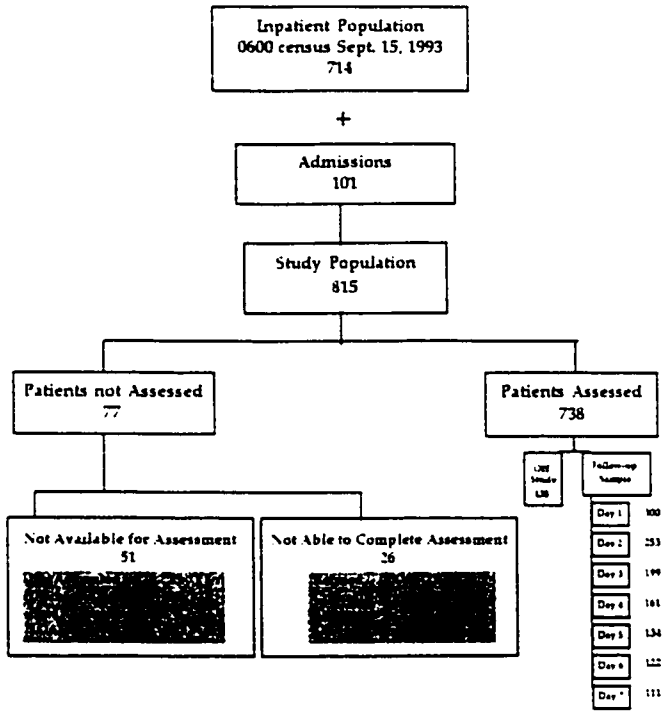


Figure 1. Skin care study population.

The number of subjects randomly selected from the prevalence day population was based on the sample calculations of previous studies assessing the Braden Scale (Bergstrom, Braden, Laguzza, & Holman 1987; Bergstrom, Demuth, & Braden, 1987; Salvadalena et al., 1992). In these previously reported trials, samples of 60 to 100 were used with relatively homogenous populations from one or two nursing units (e.g., medical, surgical, and intensive care units). Because the present study captured data from all nursing units in the institution, including intensive care, medical, surgical, psychiatric, continuing care, and obstetric areas, the sample size was increased by 50% (N = 150) to accommodate the heterogeneity. The discharge patterns over several months were reviewed to select a large enough random sample to ensure that at least 150 subjects would still be in the hospital at the end of the 1st week of the 2-week follow-up period. Based on recent discharge statistics, a sample size of 300 was selected.

Instruments

The Demographic and Clinical Profile Form captured information regarding patient age, sex, length of stay, admission diagnosis, any pressure relief devices in use, and type of nursing unit (surgical, medical, special services, or cardiac). The Prevalence Grid (personal communication, Bergstrom & Braden, August 14, 1989) was a tool used to identify 28 specific assessment sites and an additional "other" category for which skin integrity was to be assessed. An accompanying diagram detailed the 28 sites. If ulcers were present, descriptive information also was collected about the type of dressing treatments by site. The assessment checks were for "no symptoms" or staged according to an already developed staging classification. Stages I to IV were well defined by clinical characteristics (Table 1), and stage X was used when the stage could not be assessed because of the presence of necrotic tissue. Stage X, used in this

Table 1. Pressure Ulcer Staging Definitions

A pressure ulcer is any lesion caused by unrelieved pressure resulting in damage of underlying tissue. This impairment of skin integrity may result from the effects of pressure, friction, shear, or maceration. Pressure ulcers usually occur over bony prominences and are graded or staged to classify the degree of tissue damage observed.

Stage I. Pressure ulcer is defined as an erythema of intact skin. The reddened area remains reddened longer than 30 minutes after pressure is relieved.

Stage II. Pressure ulcer is defined as partial-thickness skin loss involving epidermis or dermis. The ulcer is superficial and presents clinically as an abrasion, blister, or swollen crater.

Stage III. Pressure ulcer involves full-thickness skin loss involving damage or necrosis of subcutaneous tissue that may extend down to but not through underlying fascia. This type of ulcer will most likely involve destruction of both subcutaneous tissue and fat. May include necrotic tissue, undermining, sinus tract formation, exudate, or infection. Wound base is usually not painful.

Stage IV. Pressure ulcer presents as a full-thickness skin loss with extensive destruction, tissue necrosis, or damage to muscle, bone, or supporting structures. Presents as a deep crater. May include necrotic tissue, undermining, sinus tract formation, exudate, or infection. Wound base is usually not painful.

Stage X. Includes ulcers that are covered with dark necrotic tissue (eschar). These ulcers are most frequently stage II or III ulcers and in some cases stage IV. Ulcers can only be graded once they have been debrided. (Clinical Practice Guidelines, No. 3, May 1992)

Data from (1) Agency for Health Care Policy and Research Publication (1992). *Pressure ulcers in adults: Prediction and prevention* (p. 3). Rockville, MD: U.S. Department of Health and Human Services; (2) Shea, J.D. (1975). Pressure sores: Classification and management. *Clinical Orthopaedics and Related Research, 112,* 89-100; and (3) EAET (1988). Dermal wounds. Pressure sores. *Journal of Enterostomal Therapy, 1,* 9-10.

and another Canadian study (Foster et al., 1992), was included to improve the reliability of the data collection considering the well-known difficulties in accurate staging of ulcers in the presence of eschar (AHCPR, 1992). Stage I was standardized to include a 30-minute recheck to confirm redness.

The Braden Scale (Bergstrom, Braden, Laguzza, & Holman, 1987; Braden, Demuth, & Bergstrom, 1987), one of two tools recommended in the AHCPR Clinical Practice Guidelines, was selected to assess risk of pressure ulcers in a standardized manner (AHCPR, 1992). The scale has an overall risk score derived from six subscales. The subscales, sensory perception, moisture, activity, mobility, nutritional status, and friction/shear, are scored from 1 (most at risk) to 3 or 4 (least at risk), for a maximum total score of 23 points. A risk cut-off score of 16, below which indicates a risk for pressure ulcer development, has been identified for acute care populations (Bergstrom, Braden, Laguzza, & Holman, 1987; Bergstrom, Demuth, & Braden, 1987). The AHCPR Guideline stresses, however, the evaluation of the risk cut-off score within individual settings.

Procedure

A survey team of 23 registered nurses conducted a head-to-toe skin assessment and administered the Braden Scale to consenting subjects. The surveyors were prepared through an education workshop that included an orientation to the study purpose and procedures, the use of data collection instruments, and a theoretical and practical "hands-on" component to stage ulcers and conduct risk assessment. The training films developed by Bergstrom and Braden were included in the workshop format. Reliability was assessed on a range of known cases where team members went to clinical areas, staged ulcers, and then had these assessments checked by a clinical expert (enterostomal therapist).

On prevalence day, the surveyors were divided into four data collection teams plus a validation team. Each had a team leader who was not directly involved in data collection to attend to administrative tasks, such as tracking admissions and discharges, and deploying surveyors. The team members were assigned to clinically familiar areas (e.g., critical care nurses to critical care areas) but not to their home units where they would know the patients. The enterostomal therapist was on call at all times if the surveyors required a second opinion on an assessment of ulcer stage.

The validation team, comprised of two registered nurse surveyors, reassessed a randomly selected subsample of 10% of the prevalence population to assess reliability. Correlation of the survey team and validation team on total Braden scores was calculated using Pearson's product moment correlation. Correlation of the survey team and validation team assessments was $r = .87$. The degree of association indicates a strong relationship between assessments.

The surveyors conducted a full skin examination and administered the Braden Scale for risk assessment on prevalence day. The risk assessment was completed using the chart, plan of care, clinical assessment, and consultation with the patient's assigned nurse to complete the data collection. The Braden Scale was administered in this manner because it closely emulates the way in which clinical staff would use such a scale if implemented institutionwide.

To determine the Braden Scale's accuracy in the setting, the same data (full skin assessment and administration of the Braden Scale) was collected in a 2-week follow-up on a Monday-Wednesday-Friday schedule by a subsample of the surveyors. They had no information of the subjects' prior risk scores, and with the number of surveyors, computer calculation of total scores, and the large number of patients in the study, the likelihood of bias by remembering an assessment was minimal.

To evaluate the Braden Scale and the risk cut-off scores, the sensitivity (i.e., percentage of all subjects who developed a pressure ulcer and were so predicted by the scale), specificity (i.e., percentage of all subjects who did not develop pressure ulcers and were so predicted by the scale), positive predictive value (i.e., percentage of subjects who were predicted to be at risk and did develop a pressure ulcer), and the negative predictive value (i.e., percentage of subjects who were predicted to be at low risk and did not develop a pressure ulcer) were calculated. The calculations are well described by Bergstrom, Demuth, and Braden (1987). Also, the receiver operator characteristic (ROC) curve displaying pairs of the true-positive percentage (sensitivity) and false-positive percentage (minus 100% specificity) corresponding to different possible risk cut-off scores for the scale was evaluated. The point on the ROC curve that is closest to the upper–left-hand corner of the figure, where the test has a perfect sensitivity and specificity of 100%, is considered the best cut-off point.

RESULTS

Subjects

Seven hundred thirty-eight of the possible 815 inpatients (91%) were surveyed on prevalence day. Study population statistics are displayed in Figure 1. Some patients were not available to be assessed because of discharge, being out on pass, or unaccounted at the time of study (n = 46; 5.6%). There was a small proportion of inpatients who were not assessed because of being in the operating room, being critically ill, undergoing prolonged diagnostic testing, or being treated (n = 5; <1%), or who refused participation in the study (n = 21; 2.6%).

Patients were grouped by nursing departments, and the hospital inpatient population on prevalence day was medical, 33% (n = 240); surgical, 31% (n = 231); special services, 18% (n = 136); and cardiac institute, 18% (n = 131). The patients ranged in age from newborn to 100 years of age. The mean age excluding newborns was 60 years (SD = 19). Fifty-one percent of the sample were male patients. Lengths of stays on prevalence day ranged from 1 day to 1 year in 99% of the population, with 1% being in hospital for more than 12 months.

Prevalence of Pressure Ulcers

Prevalence of pressure ulcers was found to be 29.7% (n = 219) (95% confidence interval: 26.4% to 33.0%) when all stages were included. The rate was 13.6% (n = 100) (95% confidence interval: 11.1% to 16.1%) with stage II or greater ulcer. Of those patients with an ulcer, 54% had stage I, and 46% had stage II or greater. Based on specific chart notations, 21% of patients with ulcers had acquired them before admission at the institution.

Accuracy of the Braden Scale

The data collected in the 2-week follow-up period was used to assess the accuracy of the Braden Scale. Of the 300 randomly selected subjects from prevalence day, 161 were still in the hospital 1 week later and were assessed. Figure 1 displays the follow-up sample.

To calculate the sensitivity, specificity, and positive and negative predictive values of the Braden Scale in the follow-up sample, the Braden score from prevalence day was used to predict pressure ulcer occurrence 1 week later. Only patients who were free of ulcers on prevalence day were included in this analysis. Although the specificity was 87%, the sensitivity of 38% was low at the identified risk cut-off score of 16, that is, a total score below which an individual is considered at risk for the development of a pressure ulcer (Bergstrom, Demuth, & Braden, 1987). Other possible cut-offs were calculated (Table 2) but revealed less than adequate sensitivity and specific-

ity. This finding was inferior in comparison with results reported in other studies (Bergstrom, Braden, Laguzza, & Holman, 1987; Bergstrom, Demuth, & Braden, 1987; Salvadalena et al., 1992). Positive and negative predictive values are provided in Table 2. The ROC curve for the current study is displayed in Figure 2.

To assess the Braden Scale further, a sample was assembled and selected with assessment protocols similar to groups that Bergstrom, Braden, Laguzza, and Holman (1987) and Salvadalena et al. (1992) had studied. For the prevalence group to be an incoming cohort like these other studies, the inclusion criteria for selection of this sample from the study population were on first assessment (prevalence day) the patient's length of stay was 3 days or fewer; newborns were excluded; no ulcers were present on the first assessment; and for ulcer-negative subjects, the first Braden assessment was used, and for ulcer-positive subjects, the Braden score immediately before ulcer development was used. Tables 3 and 4 display the sensitivity, specificity, and positive and negative predictive values for all stages, and for stage II or greater, respectively.

For all ulcer stages, sensitivity and specificity were plotted for the current study, as well as the Salvadalena et al. (1992) and Bergstrom, Demuth, and Braden (1987) results (Figure 3). The ROC curves for the current and Salvadalena et al. studies are similar and indicate an optimal score at a higher cut-off than the Bergstrom (1987) study. Neither attains the previously reported sensitivity and specificity levels even with these higher cut-off scores.

Given the acknowledged difficulties with the Stage I category, a further comparison was done with the Salvadalena et al. (1992) results using only stage II or greater (Figure 4). The ROC curves are similar for both studies, showing little improvement from the "all stages" group.

Table 2. Sensitivity and Specificity of the Braden Scale in Predicting Pressure Ulcers *(All Stages)* for Various Risk Cut-Off Scores in the Study Population Using the 1-Week Skin Assessment

Braden Score	Sensitivity (%)	Specificity (%)	PPV (%)	NPV (%)
9	0	100		88
10	5	100	100	88
11	10	99	67	89
12	10	99	50	89
13	14	98	50	89
14	14	97	38	89
15	19	93	29	89
16	38	87	30	91
17	48	81	24	91
18	48	73	20	91
19	67	66	21	93
20	67	51	16	92
21	81	38	15	94
22	86	23	13	92
23	100	0	12	

Abbreviations: PPV, positive predictive value; NPV, negative predictive value.

DISCUSSION

The prevalence of pressure ulcers (29.7%) found was somewhat higher than the Canadian study (25.7%; Foster et al., 1992). Both these rates are substantially higher than a comparable U.S. study of similar hospitalwide populations, using a prospective data collection and analogous staging criteria (Meehan, 1992). Two reasons may explain the difference in rates. The first is the difficulties in accurately capturing data on stage I ulcers. The way in which persistent redness is determined may vary (e.g., 24-hour, 1-hour, or 30-minute recheck of redness). In a single center study, it may have been more practical to maintain a consistent level of data quality control. Second, the recent, continuing shift to "sicker, quicker" hospitalizations with increasingly debilitated individuals along with the increasing mean age of hospital inpatients may be more significant now than in 1989 when the U.S. study was conducted.

In the current study, the total Braden score that appears to have the best balance of sensitivity (67%) and specificity (66%) is 19. These results are compared with two other recently published studies (Langemo et al., 1991; Salvadalena et al., 1992). The Salvadalena et al. (1992) results are similar to the current study and comparable in the ROC curves. Langemo and associates (1991) reported that the optimal sensitivity (64%) and specificity (87%) was attained at a lower cut-off score of 15 for acute care settings. For a score of 15, the current study results were 19% sensitivity and 93% specificity. This is a low accuracy in predicting risk for pressure ulcer occurrence. Although prevention is more cost-effective than ulcer management, prevention strategies in themselves are costly (e.g., nursing time and special pressure-relieving surfaces). It

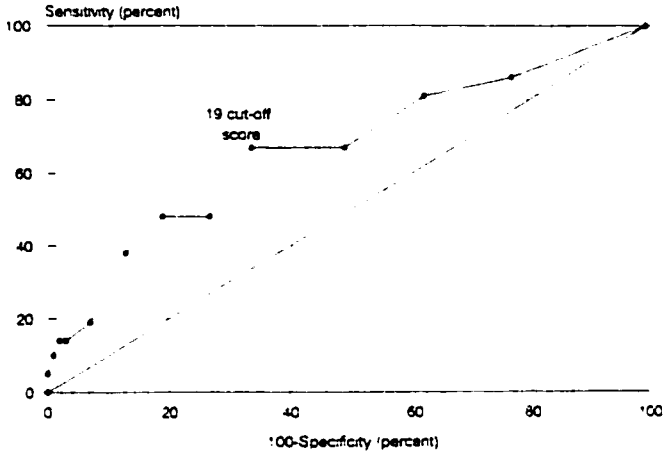


Figure 2. Receiver operator characteristic curves illustrate the sensitivity and specificity of Braden Scale for predicting pressure ulcers (all stages) in the study population using the 1-week skin assessment.

is imperative to predict with more precision those patients who should receive preventative measures. These findings are less favorable than previous studies using the Braden Scale (Bergstrom, Braden, Laguzza, & Holman, 198[illegible]; Bergstrom, Demuth, & Braden, 1987). Several factors may be influencing this result: the scale was implemented and tested hospitalwide with a large range of patient diagnoses, age, and severity; the study was a cross-section of an existing population; and the levels of nursing care and type of staff vary between units, ranging from critical to long-term care.

Because the results did not reach the same high sensitivity or specificity as previous reports, a sample was assembled that closely resembled the inclusion criteria of the other studies on general medical-surgical services (Bergstrom, Braden, Laguzza, & Holman, 1987; Salvadalena et al.,

Table 3. Sensitivity and Specificity of the Braden Scale in Predicting Pressure Ulcers *(All Stages)* for Various Risk Cut-Off Scores in a Subset of the Study Population Similar to Bergstrom et al. (1987) and Salvadalena et al. (1992) Studies

Braden Score	Sensitivity (%)	Specificity (%)	PPV (%)	NPV (%)
9	0	100	—	71
10	0	100	—	71
11	0	100	—	71
12	0	100	—	71
13	0	100	—	71
14	0	98	—	71
15	5	94	25	70
16	5	94	25	70
17	20	94	57	74
18	20	81	31	71
19	35	79	41	75
20	45	65	35	74
21	65	50	35	77
22	75	31	31	75
23	100	0	29	—

Abbreviations: PPV, positive predictive value; NPV, negative predictive value.

Table 4. Sensitivity and Specificity of the Braden Scale in Predicting Pressure Ulcers *(Stage II or Greater)* for Various Risk Cut-Off Scores in a Subset of the Study Population Similar to Bergstrom (1987) and Salvadalena et al. (1992) Studies

Braden Score	Sensitivity (%)	Specificity (%)	PPV (%)	NPV (%)
9	0	100	—	87
10	0	100	—	87
11	0	100	—	87
12	0	100	—	87
13	0	100	—	87
14	0	98	—	87
15	14	94	25	88
16	14	94	25	88
17	43	94	50	92
18	43	81	25	90
19	43	79	23	90
20	57	64	19	91
21	86	51	21	96
22	86	32	16	94
23	100	0	13	—

Abbreviations: PPV, positive predictive value; NPV, negative predictive value

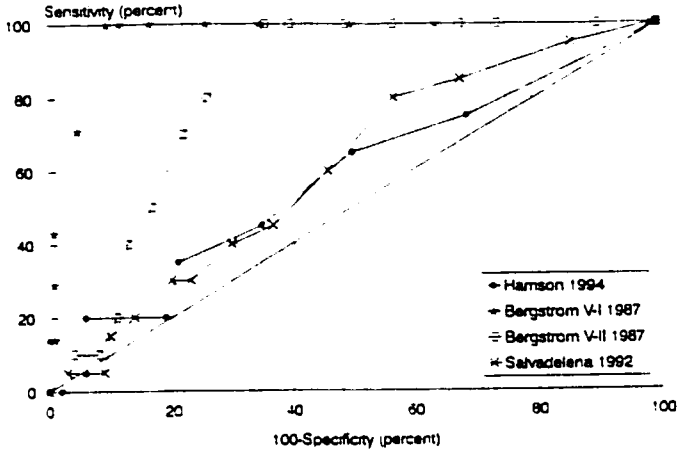


Figure 3. Receiver operator characteristic curves illustrate the sensitivity and specificity of Braden Scale for predicting pressure ulcers (all stages) in a subset of the study population similar to Bergstrom, Braden, Laguzza, & Holman (1987), and Salvadalena et al. (1992) studies.

1992). In this subsample, the current study results again were more similar to the Salvadalena et al. (1992) results than the Bergstrom, Braden, Laguzza, and Holman (1987) findings. In further comparing results for the optimal sensitivity-specificity balance with the Salvadalena et al. (1992) findings on stage II or greater ulcers, the cut-off scores are slightly improved for the Salvadalena et al. (1992) group (18) but worse for the sample (21) from this current study.

CLINICAL IMPLICATIONS

In evaluating the AHCPR Clinical Practice Guideline for Pressure Ulcer Prediction and Prevention in a setting having a variety of tertiary care inpatients, it was concluded the guideline provided a standard of care in assessing skin and documenting risk. The use of the staging classification provided a well-accepted and comparable outcome measure for the condition, and the Braden Scale assisted with risk assessment. However, using the total score of the Braden Scale for prediction of risk and implementation of prevention strategies would be difficult given the current study results of its accuracy and will require further evaluation.

As clinical tools, the Braden Scale and its subscales are useful in the identification of risk factors to plan appropriate interventions. The inves-

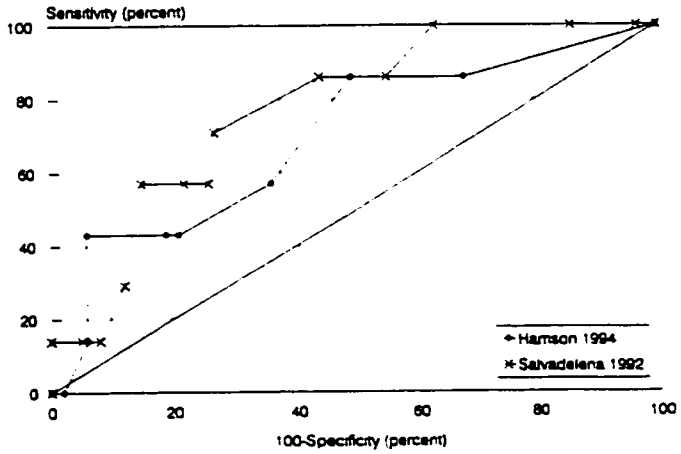


Figure 4. Receiver operator characteristic curves illustrate the sensitivity and specificity of Braden Scale for predicting pressure ulcers (stage 2 or greater) in a subset of the study population similar to the Salvadalena et al. (1992) study.

tigators recommend that for clinical use, nurses identify individual risk categories with low scores rather than relying on the total score. Although little information is available to suggest the magnitude or severity of risk for each category or combination of categories, Maklebust and Magnan (1994) reported that having an ulcer increased 22-fold in the presence of fecal incontinence, but only 10-fold in the presence of impaired mobility. This area is clearly one for future research.

The AHCPR Guideline has formalized and improved clinical assessment of skin integrity. Risk assessment, using the total score of the Braden Scale, requires further appraisal before using it as a tool to trigger institutionwide prevention strategies. Understanding how to best use the individual risk categories to predict risk for and plan interventions for pressure ulcer prevention holds the most promise for clinical application.

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Quality of Life as an Outcome Measure in Nursing Research *"May you have a long and healthy life"*

Margaret B. Harrison, Elizabeth F. Juniper, and Alba Mitchell-DiCenso

La qualité de la vie émerge comme un concept et un résultat importants dans les soins de santé. Les décideurs, les chercheurs, les cliniciens et le public en général estiment que la perception que l'on a de la qualité de la vie est une dimension importante de la santé d'une population ou d'une personne. La nature des sciences infirmières est telle que beaucoup de leurs résultats escomptés sont liés à l'amélioration de la qualité de vie des personnes et des populations. Le débat demeure ouvert sur la définition exacte de la qualité de la vie; un concept difficile à définir qui posera naturellement des défis aux moyens de le mesurer. Pourtant, cela n'a pas empêché la prolifération d'instruments de mesure de la qualité de la vie car le concept est reconnu comme un résultat clinique et de recherche de plus en plus important. Des progrès ont été accomplis pour clarifier et opérationnaliser le concept. Nous proposons un point de vue conceptuel qui sépare ce que la qualité de vie est de ce qui contribue à la qualité de vie. Cela permettra aux chercheurs en sciences infirmières d'envisager la qualité de vie comme un résultat dans leur évaluation des interventions en soins infirmiers. Dans les situations cliniques ou de recherche, pour ce qui a trait à la mesure, une définition opérationnelle de la qualité de la vie provient d'une définition de la santé. De là dérive une définition d'une qualité de vie liée à la santé. Pour mesurer les résultats, la définition opérationnelle est liée aux domaines importants pour la population étudiée et à l'intervention sanitaire particulière que l'on étudie. On présente également les questions soulevées concernant la mesure de la qualité de vie liée à la santé.

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Quality of life has emerged as an important concept and outcome in health and health care. Policy-makers, researchers, clinicians, and the public at large consider perceived quality of life to be an important dimension of the health of a population or an individual. The nature of nursing is such that many of its anticipated outcomes relate to improvement in the quality of life of individuals and populations. There continues to be debate about the actual definition of quality of life, and a concept that is difficult to define will naturally pose challenges to measurement. This has not impeded the proliferation of quality-of-life instruments, since the concept is recognized as an increasingly important clinical and research outcome. Progress has been made in clarifying and operationalizing the concept. We propose a conceptual viewpoint that separates what quality of life *is* from what *contributes to* quality of life. This will assist nurse researchers planning to use quality of life as an outcome in evaluating nursing interventions. In clinical or research situations, for the purposes of measurement, an operational definition of quality of life stems from a definition of health. From this is drawn a definition of health-related quality of life (HRQL). For the purpose of outcome measurement, the operational definition relates to the domains important to the study population and the particular health intervention under study. Issues that arise in the measurement of HRQL are also presented.

Quality of life has emerged as an important concept and outcome in health and health care. Policy-makers, researchers, clinicians, and the public at large consider perceived quality of life an important dimension of the health of a population or an individual (Campbell, Converse, & Rodgers, 1976; Kinney, Burfitt, Stullenbarger, Rees, & Read-Debolt, 1996). Nursing is, by its nature, holistic, supportive, and focused on the human response to a state of health (Ferrans & Powers, 1985; Padilla & Grant, 1985). Many of the anticipated outcomes of nursing practice relate to improvement in the quality of life of individuals and populations. As a result, quality of life and its measurement have become an important focus in the evaluation of nursing practice. This paper provides a conceptual viewpoint for quality of life as a nursing research outcome and outlines issues that arise in the measurement of health-related quality of life (HRQL).

Quality of Life as a Concept in Health and in Health Care

Following the deprivations of the Great Depression in the 1930s and the upheaval caused by World War II, the concept of quality of life emerged as a result of society's increased attention to achieving a "good life," rather than merely surviving (Campbell et al., 1976). The increased consumer awareness in North America since the end of World War II has had a significant impact on the health field. By the 1970s it was evident that the perspective of the patient was becoming an important consideration (McDowell & Newell, 1987; Ware, 1984). It is now possible to be biologically alive but socially dead (Edlund & Tandcredi, 1985). Technological and other medical advances have increased our ability to keep people alive longer. Society has put the quality of this extended

life under scrutiny, with debates over artificial life supports, euthanasia, and even the meaning and definition of death. Many available therapies offer similar morbidity and mortality outcomes but different effects on quality of life – for example, surgical or medical treatment of ischemic heart disease, chemotherapy or supportive care for advanced lung cancer. Individuals and families are becoming increasingly involved in decisions related to the quality, versus quantity, of life. The "provider paternalism" of the past is no longer widely accepted.

As a result of medical progress, people with chronic or long-term conditions are living longer and more people are surviving serious trauma and accidents (Ontario Ministry of Health, 1993; Strauss, 1984). The goal of their treatment is to maximize quality of life, by alleviating symptoms, maintaining or improving functional capacity, and retarding the progression of the underlying condition or incurable disease (Renwick, Brown, & Nagler, 1996; Stewart et al., 1989). Nursing provides support before, during, and after diagnosis and therapy. In the case of the chronically ill, nursing practice accompanies an individual (and family) on the journey through diagnosis, rehabilitation, and living with the condition day-to-day (Padilla & Grant, 1985; Rideout, 1992). Nursing interventions promote well-being, adjustment, and self-care, and their anticipated outcomes are primarily with improvements in quality of life. Nurses play a vital role in assessing and maintaining "health" for those with chronic or long-term conditions; thus they ultimately influence quality of life.

Quality of life will undoubtedly become an even more important concept in the next few decades. The incidence of chronic or long-term conditions increases as terminal ailments become curable and more individuals survive trauma. A larger aging population further increases the need for quality-of-life assessment. Chronic conditions are more common in the elderly (Kinney et al., 1996; Ontario Ministry of Health, 1993). Demographic data indicate that in Ontario, for example, by the year 2010 the proportion of people over 65 will increase by 68% (Ontario Ministry of Health, 1993, p. 9). The great expectations for technology and science have not been realized. Progress will be characterized by incremental gains in the management of major illnesses, rather than their cure. Thus the need for supportive care will continue to increase, as will its importance. For nursing, the challenge will be to evaluate the effectiveness of such interventions, which will require innovative outcome measurements beyond traditional morbidity and mortality endpoints (Jenkins, Jono, Stanton, & Stroup-Benham, 1990; Kinney et al.; Padilla, Grant, & Ferrell, 1992).

Quality of life offers one approach to this challenge, taking the individual's subjective assessment into account (Oleson, 1990). In a special report, Padilla and colleagues (1992) describe the "vital interest and commitment" of the nursing profession to conceptualizing and measuring quality of life: by actively promoting quality-of-life research (describing quality of life, developing measures, testing interventions); disseminating quality-of-life research through conferences and special issues of journals (for example, *Advances in Nursing Science*, *Seminars in Oncology Nursing*, and *Progress in Cardiovascular Nursing*); establishing pre- and post-doctoral training programs in HRQL; and offering awards for research excellence (Padilla et al.).

Quality of life has already become a major concern in planning, implementing, and evaluating health-care and social policies (see, for example, Spilker, 1990; Ontario's Health Plan in Ontario Ministry of Health, 1993; strategies for cancer care in Ontario Ministry of Health, 1994, and Ortho Biotech, 1993). As the next millennium approaches, decisions concerning quantity versus quality of life will become even more difficult and more prevalent, especially in view of the debt crises facing all levels of government. "Health is generally considered one of the most important determinants of overall quality of life which underscores the relevance of using quality of life as an ultimate outcome of health care" (McDowell & Newell, 1987, p. 205).

For the purposes of outcome measurement in nursing research, a number of practical questions arise: How can HRQL be defined in order to be helpful as a nursing research outcome? How can it best be measured? What are the key considerations in selecting an HRQL instrument?

Definition

The meaning of quality of life is a matter of much debate – even controversy. As yet, there is no agreed upon definition to guide health care and research (Ferrans & Powers, 1985; Gill & Feinstein, 1994; Kinney et al., 1996; McDowell & Newell, 1987; Padilla & Grant, 1985; Schipper, Clinch, & Powell, 1990; Spitzer, 1987). As one researcher bluntly states it, "Quality of life remains more a fashionable idea than a rigorously defined concept in the health sciences" (McDowell & Newell, p. 227).

The debate seems to have divided sociologists and some health researchers into two camps: those who support a broad concept of quality of life (Bergner, 1985; Campbell et al., 1976; Gill & Feinstein, 1994; McDowell & Newell, 1987; Strauss, 1984) and those who take a more pragmatic view, believing the parts can be reduced for purposes related to health-outcome measurement (Aaronson, 1988; Guyatt & Cook, 1994; Jenkins et al., 1990; Stewart & Ware, 1992; Ware, 1984). In the literature, terms such as health status, functional status, well-being, and life satisfaction are sometimes used interchangeably with "quality of life" (Spitzer, 1987), in other instances as components of an overall concept of quality of life.

There is general agreement on several theoretical aspects of quality of life. It is widely acknowledged to be a multidimensional concept (Ferrans & Powers, 1985; Jenkins et al., 1990; McDowell & Newell, 1987; Schipper et al., 1990; Spilker, Molinek, Johnston, Simpson, & Tilson, 1990; Ware, 1984; WHOQOL Group, 1993). Similar domains of quality of life have been identified by various researchers, and there is an emerging consensus toward the acceptance of four broadly identified domains: physical functional status, symptoms and side effects, social functioning, and psychological state (Aaronson, 1988; Schipper et al.). Examples of definitions and domains are found in Table 1. It is agreed that quality of life is a subjective, patient-perceived phenomenon (Gill & Feinstein, 1994; Guyatt, Feeney, & Patrick, 1993; Juniper, Guyatt, Willan, & Griffith, 1994; McDowell & Newell; Oleson, 1990; Strauss, 1984; Ware, 1984) that can change within the same individual over time (Guyatt, Deyo, Charleson, Levine, & Mitchell, 1989; Juniper et al., 1994; Juniper, Guyatt, & Jaeschke, 1990; Schipper et al.). The conceptualization of quality of life has progressed from a nebulous term about subjective feelings to an accepted concept – albeit, in terms of measurement, an evolving one.

Toward Conceptual and Operational Clarity

The challenge for nurse researchers in using quality of life as a primary or secondary outcome will be to achieve conceptual and operational clarity. The qualification of HRQL would facilitate nurses planning to use quality of life as an outcome when evaluating nursing interventions. Conceptually this approach represents a separation of what quality of life *is* from what *contributes to* quality of life (Stewart, 1992). In clinical or research situations, health, for the purposes of outcome measurement, can be viewed as contributing to overall quality of life, and health care as contributing in some way to the person's health. An operational definition of quality of life should stem from a definition of health, and this definition of health should be in philosophical accord with the ethic, standards, and mission of the profession or discipline.

Table 1	*Selected Themes of Quality of Life*	
Source	**Quality-of-Life Definitions**	**Domains**
Ferrans & Powers (1985, p. 17)	A person's sense of well-being stemming from satisfaction or dissatisfaction with the areas of life that are important to him/her	1. Health and functioning 2. Socio-economic 3. Psychological 4. Family
Gill & Feinstein (1994, p. 619)	Personal perception of health status and/or non-medical aspects of one's life	1. Health-related factors – important clinically – important to patient 2. Non-medical aspects
Guyatt & Jaeschke (1990, p. 37)	The wide variety of subjective experiences related to health	1. Symptoms 2. Physical function 3. Emotional function
Schipper et al. (1990, p.16)	The functional effect of an illness, and its consequent therapy, upon a patient, as perceived by the patient	1. Physical and occupational function 2. Psychological state 3. Social interaction 4. Somatic sensation

(cont'd)

Table 1 (cont'd)	*Selected Themes of Quality of Life*	
Source	**Quality-of-Life Definitions**	**Domains**
Ware (1984); Ware & Shelbourne (1992)	Personal health status and factors such as family life, finances, housing	1. Physical functioning 2. Role functioning – physical 3. Bodily pain 4. General health 5. Vitality 6. Social functioning 7. Role functioning – emotional 8. Mental health 9. Reported health transition
WHOQOL Group (1993, p. 153)	An individual's perception of life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and relationship to salient features of their environment.	1. Physical health (bodily states and functions) 2. Psychological health 3. Level of independence 4. Social relationships 5. Environment

A modification of the broad World Health Organization (WHO) definition, "Health is a resource which permits individuals to achieve their aspirations and cope with or change their environment" (WHO, 1986; personal communication, A.S. Macpherson, McMaster University, Sept. 9, 1996), may be how many nurses would define quality of life. From such a position, one can address the contribution that health-care and nursing interventions might make toward achieving a state of health. A definition of HRQL could then be drawn: a person's "perception of their health status and aspects of their life considered important in relation to their expectations of 'normal' living" (Harrison, 1996). This definition encompasses the notions of a subjective evaluation of one's life against what is normal; an acknowledgement of expectations against natural capacity; and meeting personal goals by narrowing the gap between one's expectations and one's achievements (known as Calman's gap – Calman, 1984). It is recognized that health care and health professionals are limited in what they can change or affect. For the purpose of outcome measurement, the operational definition is more restrictive and situationally specific (Waltz, Strickland, & Lenz, 1991). In the case of HRQL this relates to the domains important to the study population and the health intervention under investigation.

Measurement

Types of HRQL Instrument

There are two types of HRQL instrument, generic and specific. Generic instruments provide a summary of health status, functional status, and/or general quality of life. Specific instruments focus on problems associated with single disease states, patient groups, or areas of function (Guyatt et al., 1993; Guyatt, VanZanten, Feeney, & Patrick, 1989). Generic instruments assess a spectrum of quality-of-life components or domains and are applicable to a variety of populations. Specific measures concentrate on particular conditions or populations. A growing number of researchers have found it necessary to develop specific instruments because the generic measures fail to capture the specific quality-of-life issues associated with the condition of interest – for example, inflammatory bowel disease (Guyatt, Mitchell, et al., 1989) or asthma (Juniper, Guyatt, Ferrie, & Griffith, 1993; Marks, Dunn, & Woolcock, 1992). Additionally, instruments may need to be generated to be developmentally appropriate and specific to a condition – for instance, asthma in children (Juniper et al., 1996).

Another approach is to modify generic instruments for use with particular populations, as Ferrans and colleagues did to create cardiac and cancer versions of their quality-of-life index (Bliley & Ferrans, 1993; Ferrans, 1990; Ferrans & Powers, 1985). However, this approach should be used only with the collaboration of the original developer and with a good understanding of the psychometric issues.

Guyatt and colleagues developed a taxonomy for HRQL measures and evaluated the strengths and weaknesses of each (Guyatt, VanZanten, et al., 1989). A number of authors have systematically catalogued generic and specific quality-of-life measures (Gill & Feinstein, 1994; McDowell & Newell, 1987; Spilker et al., 1990).

Generic measures. These questionnaires are designed for use with patients with any medical condition. Probably the most commonly used and the best validated are the Medical Outcomes Study Short Form 36 (SF-36) (Stewart, Hays, & Ware, 1988; Ware & Shelbourne, 1992), the Sickness Impact Profile (SIP) (Bergner, Bobbitt, Carter, & Gilson, 1981), the Nottingham Health Profile (Hunt et al., 1980), and the McMaster Health Index Questionnaire (Sackett, Chambers, MacPherson, Goldsmith, & McAuley, 1977). Although each health profile is designed to measure all important aspects of HRQL, each does so in a different way. For instance, the SF-36 comprises 36 questions aggregated into two major health attributes (physical health and mental health). In contrast, the 136-question SIP has two domains (physical and psychosocial), which can be combined into one overall score.

The main advantage of generic instruments is that the burden of illness can be compared across medical conditions. However, because they need to be broadly comprehensive to cover all conditions and diseases, they may fail to measure the specific and important impairments associated with any one condition. For instance, the SIP tends to focus on severe impairments (feeding, dressing, etc.) that may not apply to patients with less debilitating illnesses. In addition, there is growing evidence that generic measures may not be responsive to small but important changes when used to assess the effect of an intervention (Hawker, Melfi, Paul, Green, & Bombardier, 1995; Rutten van Molken et al., 1995).

Specific measures. The recognition that generic instruments are often insufficiently responsive to changes or differences in HRQL that are important to individuals has led to the development of specific

instruments, for both adults and children. The strength of specific instruments is that they focus on the areas of function that are most important to patients. Their weakness is that the degree of impairment cannot be compared across conditions.

Evaluating the Quality of HRQL Measures

The essential properties of reliability and validity in a high-quality HRQL instrument are well agreed upon (Feinstein, 1987; Fitzpatrick et al., 1992; Fletcher, Gore, & Jones, 1992; Guyatt, VanZanten, et al., 1989; McDowell & Newell, 1987; Ware, 1987). Reliability is the ability of the instrument to consistently provide similar results when used on the same population in similar circumstances. Validity is its ability to accurately measure what it is intended to measure. McDowell and Newell offer detailed methods for generally assessing these key attributes, including the appropriate statistical tests and a rating framework (p. 8). Particular attention must be paid to certain attributes with HRQL instruments, depending on their purpose. A discriminative measure must be reliable and have cross-sectional construct validity. An evaluative instrument must be responsive and have longitudinal validity.

Face and content validity. When selecting an instrument, the researcher must first ensure that it has face and content validity; that is to say, that the instrument appears to measure what it is intended to measure and that the items in a questionnaire have been selected using recognized procedures so that all the areas of function considered important by patients will be captured. Unlike other outcome measures, HRQL questionnaires – particularly specific measures in which items have been selected by clinicians – rarely meet this criterion, because some impairments that patients consider important have been omitted.

In order to address clinically important issues of face and content validity, Feinstein (1987) suggests "sensibility" criteria for the questionnaire: applicability, clarity and simplicity, comprehensiveness, unlikelihood of bias, and elimination of redundant items. Feinstein argues that a sensibility screen judges instruments, rather than mathematically testing them. This would be in addition to empirical appraisals carried out in the selection of HRQL instruments.

Once content validity has been established, the measurement properties are examined to ensure that the instrument is capable of carrying out the intended task. Instruments that are to be used in cross-sectional studies (e.g., surveys) require different measurement properties from those to be used in longitudinal studies (e.g., clinical trials) (Guyatt, Kirshner, & Jaeschke, 1992).

Discriminative Instruments

These instruments are used to distinguish among individuals or among groups of patients – for example, among individuals who do or do not have a chronic condition such as congestive heart failure (CHF), or, within a CHF population, among those who have mild, moderate, or severe impairment. Discriminative instruments are most commonly used in screening and in cross-sectional surveys. Their essential measurement properties are reliability and cross-sectional construct validity (Guyatt et al., 1992).

Reliability. The signal-to-noise ratio is a simple method of deciding which measurement properties will be required in a particular situation. The "signal" is the true difference or change that is to be measured, and the "noise" is the variance, unrelated to the true signal, that will interfere with the detection of the signal. Discriminative instruments must be able to detect differences among individuals or among groups of patients. Therefore, the signal is the between-subject difference at one point in time. The noise that will tend to mask this signal is the within-subject variance. The test statistic usually used to express the relationship between the signal and the noise for discriminative instruments is the intraclass correlation coefficient (ICC), which relates the between-subject variance to the total variance (Cronbach's alpha, which measures the internal consistency, does not give an indication of this property).

Cross-sectional construct validity. Where there is no gold standard against which to determine whether the instrument is actually measuring what it is intended to measure, the developer puts forward hypotheses or constructs, which, if met, provide evidence that the instrument is valid. The most common approach is to demonstrate that the various domains of the new HRQL instrument correlate in a predicted manner with other indices of severity and with other HRQL instruments (see Table 2).

Table 2
Measurement Properties Necessary for Evaluative and Discriminative Instruments

	Discrimination	Evaluation
Signal	Between-subject differences	Within-subject differences related to true within-subject change
Noise	Within-subject differences	Within-subject differences unrelated to true within-subject change
Signal-to-noise ratio: descriptive term	Reliability	Responsiveness
Construct validity	Cross-sectional	Longitudinal

Source: Assessment of asthma control: Quality of life. In N.C. Thomson & P.M. O'Bryne, *Manual of asthma control*. London: W.B. Saunders, 1995.

Evaluative Instruments

These instruments are required to measure longitudinal change in an individual or within a group of patients and are often used in clinical trials. The essential measurement properties of evaluative instruments are responsiveness and longitudinal validity (Guyatt et al., 1992).

Responsiveness. Evaluative instruments must be responsive to small but clinically important changes that occur either spontaneously or as the result of an intervention. The signal is the true within-subject change over time, and the noise is the within-subject variance unrelated to the true within-subject change. The relationship between the two represents the responsiveness of the instrument (Guyatt, Walter, & Norman, 1987).

Longitudinal construct validity. Evaluative instruments also require longitudinal validity. Any change in score must reflect a true change in HRQL. Longitudinal validity is usually demonstrated by showing that changes in the various domains of the new HRQL instrument correlate in a predicted manner with changes in other outcome measures, such as disease severity and generic HRQL.

Interpretability

An additional requirement, "interpretability" (Juniper et al., 1994; Juniper et al., 1990; Juniper, Guyatt, & Griffith, 1993), deals with interpreting the clinical importance of a change in a quality-of-life score and the smallest difference in a score that patients would perceive as important. Repeated experience with a wide variety of physiological measures allows clinicians to interpret results meaningfully. For instance, the experienced clinician will have little difficulty interpreting a blood pressure change of 20 mmHg or an increase in respiratory rate of 20 breaths per minute. In contrast, the meaning of a change in score of 1.0 on an HRQL instrument is not obvious, not only because there are no units, but also because health professionals seldom use HRQL measures in clinical practice and each instrument has its own scoring system.

Two approaches have been suggested for interpreting HRQL data (Lydick & Epstein, 1993). The "distribution-based" approach is based entirely on the statistical distribution of the results, the most commonly used being the effect size, which is derived from the magnitude of the change and the variability in stable subjects. The disadvantage of this approach is that there is still no indication of whether the effect is important to the patient. In the "anchor-based" approach, the changes in quality-of-life measures are compared, or anchored, to other clinically meaningful outcomes. A minimal important difference (MID) is defined as "the smallest difference in score in the domain of interest which patients perceive as beneficial and would mandate, in the absence of troublesome side-effects or excessive cost, a change in the patient's management" (Juniper et al., 1994). One method of determining the MID is global rating of changes. Briefly: on a global rating of change questionnaire, a person with asthma, for example, is asked whether he or she has experienced change in HRQL since the last visit. To obtain the MID, the researcher calculates the change in HRQL score that corresponds to the smallest global change that patients consider important. On the St. George's Respiratory Questionnaire the MID was determined by asking patients, at the end of a clinical trial, whether they felt the treatment was effective (Jones & Lasserson, 1994).

Feasibility

Feasibility of the instrument concerns the practical factors that arise in administering the tool and, given the subjective nature of HRQL, are highly consequential in the selection of a quality-of-life instrument. Consideration should be given to the means of administration. Paper-

and-pen self-report instruments may be a challenge for older, sight-impaired people. Telephone interviews are difficult for hearing-impaired subjects. Administration of questionnaires by trained interviewers is resource-intensive and therefore costly, but ensures compliance and minimizes errors and the number of missing items (Guyatt et al., 1993). Long surveys or batteries of instruments impose additional risk to recruitment and retention of subjects. Instruments that have been used successfully elsewhere may challenge particularly complex medical populations. A pilot test on the study population is advisable, even with established instruments. Poor instrument feasibility is costly and will endanger successful completion of the study.

On a practical note, many adequately developed and tested instruments (for example, Ware's SF-36 instrument and Ferrans's Quality of Life Index) come with a manual to guide administration, data entry, and analysis, providing detail that is not possible in the published accounts of the measurement. The researcher should ask the developer for full documentation.

When a patient is unable to participate, a surrogate respondent, usually the family member closest to the patient, may be asked to complete the questionnaire on behalf of the patient. Comparison of responses provided by patients and provided by close relatives has shown a correlation of 0.55 between the two sets of responses and a difference greater than 6 on a 100-point scale for 50% of the patients (McCusker & Stoddard, 1984). A relative may not be able to discern the individual's response accurately; therefore, surrogate responses must be interpreted with care. Other research with children has shown that a parent can have a very poor perception of the child's HRQL (Guyatt, Juniper, Feeney, & Griffith, in press).

The Choice: Generic, Specific, or Both Types of HRQL Measure

The choice of a generic or a specific quality-of-life instrument, or both, depends on the question under study. Use of both types is warranted in the following circumstances: to measure the effect of an intervention (specific) *and* the evaluated actual burden of illness experienced by individuals (generic); and to measure the effect of an intervention (specific) when there is uncertainty whether the specific instrument will capture all areas of interest *or* when the specific instrument is fairly new and the measurement properties are not well established. A well-established generic instrument may have poor responsiveness yet still be preferable to a specific measure that proves to have inadequate measurement properties.

Table 3 *Comparison of Use of Generic, Specific, and Multiple HRQP Instruments*

Instruments	Strengths	Limitations
Generic Summary of HRQL (Guyatt, VanZanten, et al., 1989) Capture important differences in health in any adult population (Ware, 1987)	Global/comprehensive: full range of domains relevant to quality of life Applicable to wide variety of populations Comparability, generalizability Established reliability and validity Total and subscale score measures available Single instrument, improves feasibility Short-form versions improve feasibility	May not focus adequately on area of interest May not be responsive Overuse within certain populations Many indices are long, posing feasibility problems
Specific Focus on problems associated with single disease states, patient groups or areas of function (Guyatt, VanZanten, et al., 1989)	Unidimensional: focus on aspects of primary interest – function, age, condition, disease Increased responsiveness Clinically sensible Single instrument, improves feasibility	Application limited No comparability possible across conditions Less established validity and reliability
Multiple Capture information on global and specific aspects for quality of life or multiple specific aspects Greater proportion of conceptual domain of quality of life will be tapped (Jalowiec, 1990)	Triangulation of measurement approaches Enhanced conceptualization of domains Comparability across studies and populations Improved specificity and sensitivity to QL data High responsiveness and reliability	Multiple tools, more variable, larger sample Questionable practicality/feasibility Potential for missing data Difficulty interpreting relationships between variables Redundancy Mixed strengths with reliability and validity

Source: Guyatt et al., 1993; Guyatt & Jaeschke, 1990; Guyatt, VanZanten, et al., 1989; Jalowiec, 1990; Juniper et al., 1990; Ware, 1987

Some disadvantages of using both a generic and a specific measure are lack of practicality and feasibility; poor reliability of multiple forms due to incomplete or missing data; redundancy or non-comprehension; increased need for sophisticated statistical expertise in interpreting multivariate statistics; and difficulty interpreting complex relationships or contradictory results. The strengths and limitations of the generic, specific, and multiple-instrument approaches are summarized in Table 3.

If both a generic and a specific measure of HRQL are used, the investigator should declare a priori which measure is the primary outcome and what degree of change will be considered a clinically important difference.

Development of New HRQL Measures

The development of any new instrument is a science in itself. The development of an HRQL instrument takes a number of particular steps: identification of all possible suitable items; reduction of this list to the most frequently applicable and most important items; formulation of these items into specific questions or statements; pretesting of the instrument for clarity and completion time; and testing of the instrument for its psychometric properties, including reliability, validity, and responsiveness. While published resources for instrument development may provide guidance (Guyatt et al., 1992; Juniper et al., 1990), the researcher is advised to link up with an expert in measurement development.

Summary

There continues to be debate about the definition and dimensions of quality of life, but there is general agreement that it is a subjective phenomenon that changes over time. With respect to its measurement, significant progress has been made over the past two decades in its acceptance and use in clinical trials as an important outcome measure, and in the development of explicit guidelines for the selection and development of quality-of-life instruments. The decision framework in selecting an instrument is a stepwise one: determining the purpose of the instrument (evaluative or discriminative), identifying the type of instrument (generic or specific), and assessing the instrument's measurement properties and feasibility.

Nursing is by its nature supportive and focused on the human response to a health state. The anticipated outcomes of nursing interventions often relate to elements of quality of life. Because of nursing's broad scope, its evaluation requires the frequent use of quality-of-life measurements. The concept of quality of life as an outcome for nursing studies has been examined from two broad viewpoints: conceptual advancement and measurement progress. HRQL and its components of well-being, adjustment, and functional capacities offer promise as appropriate and sensitive outcomes for evaluating nursing interventions.

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HOSPITAL TO HOME
EVIDENCE-BASED EDUCATION FOR CHF

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Photo: Tony Postma

As Ottawa nurse researchers working with congestive heart failure patients have found, a knowledgeable client may be the best way to ensure continuity of care.

Congestive heart failure (CHF) is a significant health problem in Canadian adults and continues to be a leading cause of morbidity and mortality.[1] It has been cited as the most rapidly growing category of cardiovascular disorder.[2] There is little likelihood that patients experiencing CHF will leave the health care system until death. Typically, they move between health care sectors, being repeatedly admitted and discharged from each. In our system today, where institutional and community sectors are separately organized, separately funded and poorly linked at the point of service delivery, these patients are at high risk for discontinuity of care.

Continuity of care depends on a successful transition from hospital to home, a transition best managed when patients and their families are informed about their condition and knowledgeable in self-management.[3] Unfortunately, health care restructuring has negatively affected both teaching and learning. Hospital length of stay is often very brief, less than 24 hours in some cases. These shortened hospital stays result in less time for psychosocial support and patient and family education. There is also less opportunity for consultation and communication between different health care providers.

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Recently, nurse researchers at the Ottawa Civic Hospital set out to solve at least one part of the discontinuity problem: patient and family education. To gain a comprehensive understanding of the issues from the perspectives of all the stakeholders, our development process needed to involve practitioners in both the institution and the community as well as the individuals and families experiencing CHF.[1] Our final product would have to fit both the home and hospital environments and be transportable between them. Also, to move evidence into practice, the research evidence on CHF education would need to be available and accessible to nurses in both settings.

Building the evidence base

As a starting point, we examined existing CHF guidelines. What we found most useful were the guidelines developed by the Canadian Cardiovascular Society Consensus Conference and the Agency for Health Care Policy and Research (AHCPR), which used science-based methodology and expert clinical judgement to develop specific guidelines for patient assessment and management of CHF.[2] The AHCPR guidelines reflect the current state of knowledge on effective and appropriate care. Particularly valuable to us were the topics suggested for education and counselling.

Our next step was to learn more about the needs of our clients (patients and their families) and the practice environments of the nurses. Through nursing focus groups and informal interviews with patients, we identified and validated the learning needs in both the hospital and community settings. Patients described a tremendous level of fatigue following an exacerbation of CHF. One man commented, "I keep waiting for a better day [with energy], and it just never comes." For this reason, patients often do not feel ready for teaching during the increasingly short hospital stays. Their energy must be conserved for physiological stability to be regained. The educational process needs to be flexible and adaptable to their readiness for learning, which may be after the hospitalization event. Many of these patients commented that they would not attend group sessions or clinics for follow-up learning. Reasons were given related to fatigue, mobility issues, transportation arrangements and costs. This group is increasingly elderly and living alone with a variety of social supports. For some persons, the support is provided by a neighbour or friend who may be equally elderly. The type of support may range from phone calls to cooking and assisting with physical care. Therefore, these caregiving persons need to also be part of the education process and learn how to assist in assessment and management of CHF. One person described how she relied on her neighbour for food preparation and food shopping. For another person, a friend organized and assisted with her medications on a daily basis. From this patient input, we realized that the educational program would need to be portable to the patients' homes and would need to include the informal network of caregivers as identified by the patients themselves.

Because the abilities to self-care and self-assess are critical if these patients and families are to detect early changes and make appropriate decisions about seeking further nursing and medical care, we asked our focus groups to identify what resources were being used. We also sought out any resources developed by groups involved in public education about health and lifestyles, such as cardiac support groups.

We discovered that very few resources about CHF were available, and fewer still were accessible in patient care environments. In evaluating the resources for comprehensiveness and readability, we found that they provided fairly general information and this was not appropriate for guiding patients through a structured learning program or for assisting with self-management as identified in the AHCPR practice guidelines. The materials typically focused on a few narrow components of CHF instead of being comprehensive; they also tended to emphasize medical and pharmacologic interventions and were lacking other important strategies for CHF management. In addition, readability recommendations for this population had not been met.

Our research indicated that patient learning works best when multiple strategies are used and that outcomes do not depend on high levels of sophistication or technology

We consulted with experts in patient education and practice trends (such as care maps and clinical paths for specific populations) for vali-

dation of our findings in the practice context. We also consulted with multidisciplinary team members — physiotherapists, nutritionists and pharmacists — to gain input from other care providers who commonly interact with the CHF population. All these team members have educational components within their practice, but consistency is needed in educational content and process, across disciplines and across health care sectors, for optimal patient learning.

We also identified economic and practical limitations. A range of educational technology is available: brochures, diagrams, booklets, audiotapes, videos, computer-assisted learning and the Internet. Our research indicated that patient learning works best when multiple strategies are used and that outcomes do not depend on high levels of sophistication or technology. Therefore, we decided that a low-technology approach would be most economically feasible and most appropriate for the CHF population. They are often challenged by sensory deficits and may or may not be able to use some of the newer technologies such as videocassette recorders or Internet web sites.

The educational program, while designed to respond to the needs of patients and families dealing with CHF, is flexible enough to fit into a variety of nursing routines and settings

Finally, we conducted comprehensive and systematic literature searches to identify research on the process or CHF educational content. We looked for references to supportive care delivery, CHF interventions and practice guidelines (medical and nursing), patient education, education of the elderly, education across health care sectors, the development of educational materials and the teaching role of nurses. From the database searches, an annotated bibliography was created; this continues to be brought up-to-date every six months.

Traditionally, patient teaching has been founded on adult learning theories and principles that have been adapted for health ca We found specific literature on teaching learning in elderly populations," as well research that compared the effectiveness of p ticular teaching strategies.[9] In addition, su this educational program would be innova for the nurses, requiring changes in usual pr tice, it was necessary to improve our unc standing of how research is integrated i practice. Some of the common barriers ide fied in the literature were lack of time, lack awareness of research sources for specific t ics, self-perceived inadequacy in understand research reports, inadequate facilities (or acc to the facilities) for literature searching and l of peer support.[9] We realized that we neec an approach that would address these barrier

Designing the program

The educational program we developed, wl designed to respond to the needs of patie and families dealing with CHF, is flexil enough to fit into a variety of nursing routi and settings: general medical units within co munity and teaching hospitals, ambulatory community settings, small rural hospitals large urban centres.

Partners in Care for Congestive He Failure is a program that is evidence-based content, structure and process. It brid health care sectors and fits within current pr tice environments. It has the potential to int act with clinical paths, standards and clini practice guidelines.

The program focuses on prevention, self-c assessment and self-management with emphasis on function rather than deficits includes both general content and content t has been individualized to each learner. Bo patients and their families are included as lea ers, and it is readily available and accessible both.

The guiding principles of Partners in C were based on a synthesis of the theory a research literature. These principles, shar with nurses in an orientation to the progra were that adult learning theories provide foundation to facilitate and enhance the lea ing potential in elderly populations; physic psychosocial and cognitive readiness are nec sary for learning to occur; effective learnir requires active participation; learning that personally relevant and meaningful to the in vidual is more easily acquired and is retain longer; and the learning plan must be design to meet individual needs. During that same o entation, opportunity was provided for discu sion and clarification. The feedback provide by these nurses helped us to refine the guid lines and validate their appropriateness for th CHF population. We gained further validatio

LOEB RESEARCH INSTITUTE

Partners in Care Education Map: Congestive Heart Failure©

PROFILE:

Patient's name

Address

Phone number

Instructions:
At the top of the column for each module: sign your name, status, and the date of teaching
If material needs to be re-taught, continue to add name(s) and date(s) appropriately.
For each session, initial in the column as each component is completed
General content is in the patient education booklet, organized by modules.

NURSING:	MODULE #1	MODULE #2	MODULE #3
	Nurse's signature and date:	Nurse's signature and date	Nurse's signature and date:
Assessment	___ level of prior learning ___ patient perception/readiness ___ learning challenges	___ review of activity sheet #1 ___ respond to questions arising ___ level of understanding achieved	___ review of activity sheet #2 ___ respond to questions arising ___ level of understanding achieved
Planning	___ decision on readiness to learn ___ strategies to meet learning challenges (identify these at top of page 2)	___ decision to re-teach previous session ___ decision to progress ___ learning strategies in place	___ decision to re-teach previous ses ___ decision to progress ___ learning strategies in place
Interventions	Teaching content: ___ overview of the teaching program ___ the heart as a living pump (basic anatomy, physiology) ___ personal responsibility ___ controllable aspects of CHF ___ present Activity sheet #1	Teaching content: ___ principle components of CHF management ___ specific signs/symptoms from patient's experience ___ self-monitoring skills ___ present Activity sheet #2	Teaching content: ___ patient's medications for CHF management ___ patient's related cardiac medicati ___ non-prescription medications us the patient ___ signs/symptoms of high and low potassium (if required) ___ use of the medication record ___ present Activity sheet #3
Evaluation (patient outcomes)	___ verbalizes readiness to learn ___ acknowledges personal involvement	___ identifies self-monitoring skills relates individualized signs and	___ identifies personal medication management components: name.

Current Medications:

Previous CHF status:
Present CHF status:
Learning challenges:

Strategies for meeting challenges:

Designated learner(s):
(Client, family member, other caregiver)

MODULE #4

Nurse's signature and date

___ review of activity sheet #3
___ respond to questions arising
___ level of understanding achieved

___ decision to re-teach previous session
___ decision to progress
___ learning strategies in place

Teaching content:
___ diet in the management of CHF components of weight control, salt and sodium, fat and cholesterol, fluids, use of alcohol
___ food preparation
___ planning for special occasions
___ changes in appetite
___ present Activity sheet #4

___ identifies main CHF dietary components
___ recognizes relation of diet to own signs/symptoms
___ recognizes importance of changed appetite
___ evaluates current dietary practices

MODULE #5

Nurse's signature and date:

___ review of activity sheet #4
___ respond to questions arising
___ level of understanding achieved

___ decision to re-teach previous session
___ decision to progress
___ learning strategies in place

Teaching content:
___ role of exercise, rest and energy conservation in CHF
___ reflection on present levels
___ benefits
___ techniques for use
___ related self-monitoring skills
___ present Activity sheet #5

___ identifies self-monitoring aspects
___ identifies preferred techniques
___ participates in self-monitoring skills

MODULE #6

Nurse's signature and date:

___ review of activity sheet #5
___ respond to questions arising
___ level of understanding achieved

___ decision to re-teach previous session
___ decision to progress
___ learning strategies in place

Teaching content:
___ Stress management, relaxation and environmental influences
___ related self-monitoring skills
___ techniques for use
___ present Activity sheet #6

___ identifies personal situations of stress
___ identifies own preferred coping techniques

MODULE #7

Nurse's signature and date:

___ review of activity sheet #6
___ respond to questions arising
___ level of understanding achieved

___ decision to re-teach previous se
___ decision to progress
___ learning strategies in place

Teaching content:
___ resources and support systems f CHF
___ patient role
___ professional's role
___ community resources
___ present wall chart guide for dail self-care activities

___ identifies personal sources of su
___ identifies community resources continued learning about CHF
___ review of draft forms for patien education related to CHF

The primary tool of Partners in Care is an education map, which is also the nurses' documentation form. There is an education booklet for individuals and families, as well as a clinicians' resource manual, which summarizes the evidence.[7] The education map is set up as a grid, with learning modules listed horizontally across the top and nursing process elements listed vertically down the left side.

The nursing process elements serve as the nurses' guide to the assessment, planning, implementation and evaluation of the learning process for individual clients. The map is a one-page, double-sided form with space for the patient profile and individual learning challenges and strategies to be identified.

The format is similar in style to clinical pathways, which are currently under development to manage care in a variety of patient populations. Unlike clinical pathways, however, the progress through the education map is based on learners' and nurses' mutual assessment of the learning process, rather than events or points in time, such as "day one postoperatively." The form can easily be faxed between nurses and settings to provide continuity of care and consistency in teaching.

Each module on the education map corresponds to a module in the patient education booklet. The booklet, which serves as a guide, is based on CHF knowledge and treatment related to the self-management and self-care items recommended in the AHCPR practice guidelines. The map realistically recognizes that learners may be at different levels of motivation and capability and may need to be directed to supplemental materials.[8]

The CHF content is organized into seven modules, each of which includes specific material on themes of management (rather than cure), the learner's responsibility for self-management and the development of the self-care skills required for monitoring and self-management. The focus is on maximizing heart function and quality of life. The information progresses from general to specific within each section. Areas are provided to ensure that the content is individualized to each learner, and each module includes an activity sheet to encourage the learner to participate in the process.

The clinicians' resource manual was created to provide the evidence underpinning the program in a user-friendly format. The manual facilitates nurses' application of research to practice and supports the use of potential strategies when teaching challenges develop.[9] The supporting evidence is provided in several forms to meet the needs of different users. First, a shadow document summarizes the state and content. Second, the literature has been organized into structured abstracts for a more critical appraisal. Third, because most clinical settings are not yet equipped with access to on-line professional literature, hard copies of the primary source documents are contained in the manual for users wanting to read them. The binder format of the resource manual is inexpensive and portable.

Implementing the program

Partners in Care is currently being used in a large-scale clinical trial as part of a supportive intervention for promoting continuity of care. Patients in the transitional care group of the study are introduced to the education booklet in the hospital. The primary nurse guides the patient's and family's progress through the program using the education map, on which all learning assessment, teaching and evaluation are documented. There is no specified rate at which a learner must progress. The amount of content and the pace of learning are jointly decided by the learner and the nurse. Although the material is sequentially structured, individual modules can be taught out of sequence depending on the learner's readiness and needs (for instance, an unexpectedly early discharge may necessitate going immediately to the medications or exercise component).

With the current rapid rate of discharge, we have found that by the time the patient is stable and ready to learn, there may be time only to introduce the program. At discharge or transfer of care to the community, the patient is given the booklet, the education map and a nursing consult letter. The patient hands on this material to the home care nurse, who continues guiding the patient through the learning program. The home care nurse also documents the patient's progress on the education map.

From first implementation, we asked patients, families and clinicians for feedback on the structure, content and format of the program materials. Although the content has not changed, the format has continued to evolve into a more user-friendly product. Revisions such as a larger font size and a different organization of the charts have been incorporated as the materials have been reprinted.

We envision further development of the educational materials that will incorporate an evaluation of effectiveness in various settings, including community practice settings, teaching hospitals and community hospitals. We would also like to see research that applies this prototype to different populations within diverse language and cultural settings, as well as research that evaluates the appropriate timing of educational

De l'hôpital à la maison: un programme d'éducation pour les patients atteints d'insuffisance cardiaque globale. Les infirmières chercheures de l'Hôpital Civic d'Ottawa ont conçu un programme appelé *Partners in Care* afin de promouvoir la continuité des soins entre l'hôpital et la maison pour les patients atteints d'insuffisance cardiaque globale. Elles visaient avant tout à dispenser aux patients et aux membres de leur famille un programme d'éducation fondée sur des données probantes.

Afin d'établir les normes de soin et d'éducation appropriées, les chercheures se sont inspirées des lignes directrices élaborées par l'*Agency for Health Care Policy and Research* ainsi que des recommandations formulées par la Société canadienne de cardiologie dans le cadre de la conférence visant à établir un consensus sur le diagnostic et la gestion de l'insuffisance cardiaque. Des entrevues menées auprès des clients et des groupes de réflexion composés d'infirmières ont servi à définir les besoins d'apprentissage. On a également consulté des experts en éducation des patients et tendances de la pratique, ainsi que d'autres fournisseurs de soins de santé (p. ex., physiothérapeutes, nutritionnistes, pharmaciens) qui ont des contacts réguliers avec les patients atteints d'insuffisance cardiaque globale. Les ressources diponibles ont été évaluées.

À la fois général et personnalisé, le programme *Partners in Care* porte avant tout sur la prévention, l'évaluation de l'autosoin et l'autogestion, et met l'accent sur les fonctions plutôt que sur les déficiences. Les patients et les membres de leur famille sont considérés comme des apprenants. Le programme comprend trois éléments: un plan d'éducation qui sert de guide à l'infirmière et lui permet de noter les progrès accomplis, le livret du patient ou de sa famille qui sert de ressource personnelle; et le guide des ressources à l'intention des cliniciennes.

programs within the illness experience. We believe that the Partners in Care program has the potential to guide the standard for care not just in CHF patient education, but in a much broader context. ■

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