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# Articulating Program Impact Theory for the Comprehensive Home Option of Integrated Care for the Elderly (CHOICE)

by

**Corrine D. Truman** ©

A thesis submitted to the Faculty of Graduate Studies and research in partial fulfillment of the requirements for the degree of

**Doctor of Philosophy**

**IN**

**Medical Sciences – Public Health Sciences and Department of Sociology**

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled ARTICULATING PROGRAM IMPACT THEORY FOR THE COMPREHENSIVE HOME OPITON OF INTEGRATED CARE FOR THE FRAIL ELDERLY submitted by Corrine D. Truman in partial fulfillment of the requirements for the DOCTOR OF PHILOSOPHY in Medical Sciences-Public Health Sciences and Sociology.

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Date: Dec 20/1999

# DEDICATION

To my husband Roger
and my sons Evan and Colin
for their continued patience and support

# ABSTRACT

This study was undertaken to articulate program theory for CHOICE (Comprehensive Home Option of Integrated Care for the Elderly), an innovative, publicly funded, pilot program introduced in 1996 by the Capital Health Authority (CHA), one of seventeen regional health authorities in the province of Alberta. A modified stakeholder-social science approach similar to that suggested by Chen (1990) was used. Four qualitative research strategies: document review, field observation, stakeholder interview and literature review, were sequentially employed to develop a description and schematic model of CHOICE program theory. Areas of divergence between the information collected through document review and that collected through field observation, stakeholder interview and literature were identified, explored and reconciled to create a "best-fit" description and model of the chain of events that lead from the program actions to the ultimate program outcomes.

The study found that CHOICE combines elements found in a traditional Health Maintenance Organization (HMO), with elements and process components drawn from primary care and case management to deliver a broad range of home support, day program, and social and health services to its participants and their informal caregivers. This delivery model enables the program to: (1) provide program participants and their informal caregivers with an easily accessible set of comprehensive services appropriate for meeting the majority of the participants' basic health and social service needs; (2) support the development of long-term, therapeutic, multidisciplinary team/ participant/

caregiver relationships; and (3) create an environment that enables communication, partnership, and trust to flourish between the multidisciplinary team members.

The overall result of CHOICE is the provision of a level of care not possible within the traditional community based health and social service delivery system. CHOICE promotes improvement in the early detection of acute illness, continuous management of chronic illness, rehabilitation, maximization of self-care potential and risk management; all of which lead to improved participant health status and quality of life, and decreased informal caregiver stress. CHOICE also results in decreased reliance on the use of facility-based acute care emergency and inpatient services, and decreased use of ambulance, diagnostic, pharmaceutical and medical specialty services. At the same time there is increased use of primary medical and nursing services.

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I also wish to acknowledge the contributions of the other members of my supervisory committee, Dr. Herb Northcott, Dr. Tom Noseworthy, Dr. Billie Thurston and Dr. Vicki Strang, as well as those of my two external examiners, Dr. Glen Baker and Dr. Jose Arocha.

Finally, I would like to express my appreciation to the Capital Health Authority and the CHOICE program.

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# INTRODUCTION

Program evaluation is undertaken for one of three reasons: (1) to establish program accountability, (2) to aid program development, or (3) to develop knowledge (Chelimsky, 1997). The program evaluation described in this dissertation was undertaken in order to develop knowledge, more specifically to increase our understanding of how best to deliver community-based health and social services to the frail elderly.

Evaluations directed solely toward the generation of knowledge differ markedly from evaluation undertaken for accountability and/or developmental purposes (Chelmsky, 1997). Accountability evaluations ask specific questions about expected program outcomes. They include program audits, cost-effectiveness studies and the randomized, quasi-experimental, control group "black box" impact assessments traditionally associated with program evaluation. Developmental evaluations focus on improving program or institutional performance. They tend to employ what is often referred to as formative methods, which include program monitoring, performance measurement, case study, internal evaluation and empowerment evaluation[1].

Program evaluation directed toward the development of knowledge is, on the other hand, most often associated with academic research. This type of evaluation builds on a researcher's prior work, and is expected to contribute in-depth cumulative information in relation to a particular area of inquiry (Chelmsky, 1997). The larger purpose of this type of program evaluation is to increase our understanding about

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[1] Empowerment evaluation is a model of evaluation that uses evaluation concepts and techniques to foster improvement and self-determination (Mertens, 1998, p.225).

the factors underlying public problems, the fit between these factors and the policy or program solutions proposed, and the theory and logic (or their lack) that lie behind an implemented intervention or program.

This program evaluation focused on CHOICE (Comprehensive Home Option of Integrated Care for the Elderly), an innovative, publicly funded, pilot program introduced in 1996 by the Capital Health Authority (CHA), one of seventeen regional health authorities in the province of Alberta. The purpose of the evaluation was to articulate program theory for this program. In doing so it was expected that this study would accomplish two purposes. First, it would provide valuable insight and knowledge about the program to the program's funders, developers, managers and service providers. This knowledge and insight could then be used not only to guide ongoing program development and further evaluation of CHOICE, but also to inform replication issues that might impact the reproducibility of the program in different settings with different populations. Second, it would extend our understanding of the "how to" of program theory articulation.

## Limitations

The major limitation in this study was the nature of the access granted to the researcher. CHA and CHOICE management gave permission for the researcher to review program documents, conduct field observation at each of the program sites, and interview service providers, participants and their informal caregivers on an individual basis at a time and place convenient to them. The study was not expected to interfere in any way with the day-to-day operation of the program. In many instances provider, participant and informal caregiver interviews took place after working hours. In others they were scheduled around breaks or frequently interrupted by telephone calls and/or pages.

## Overview of the Dissertation

The dissertation has been organized into six chapters. Chapter One introduces the reader to the CHOICE program. It begins with a brief overview of the two American programs after which CHOICE is modeled, then goes on to describe the CHOICE program, and concludes with a review of the results of the CHOICE Pilot Project evaluation.

Chapter Two introduces the reader to program theory. It outlines and describes the three interrelated components that make up program theory and reviews two of the approaches that have been suggested for articulating program theory.

Chapter Three provides a detailed account of the study method. Each of the four data collection strategies (i.e., document review, field observation, stakeholder interview and literature review) used in the study are reviewed.

Chapter Four presents the articulated CHOICE program theory. It includes a detailed description and a schematic representation of the theory.

Chapter Five walks the reader through the process used to identify and reconcile areas of divergence in the information collected in order to create a "best fit" description and model of CHOICE program theory.

Chapter Six concludes the dissertation. It includes recommendations for others using this method to articulate program theory, and identifies several potential directions for future research.

# CHAPTER ONE – PROGRAM DESCRIPTION

Program evaluation begins with a program, a constellation of activities or actions that are expected to address or ameliorate an identified problem (Rossi, Freeman & Lipsey, 1999). This chapter introduces the CHOICE (Comprehensive Home Option of Integrated Care for the Elderly) program. CHOICE is designed to provide a full continuum of medical, rehabilitative, social and supportive services to the frail elderly who may otherwise be eligible for admission to a continuing-care facility and who are frequent users of acute care. The goal of the program is to maintain frail older persons in their own homes and communities as long as possible within the bounds of medical, social and economic feasibility (CHOICE Program Description, 1998).

The chapter begins with a brief overview of the two American programs after which CHOICE is modeled, On Lok (which means happy abode in Cantonese) and PACE (the Program for All-Inclusive Care for the Elderly). It then outlines the CHOICE program, and concludes by reviewing the results of the CHOICE Pilot Project Evaluation.

## On Lok

On Lok was pioneered in the early 1970s by a community-based nonprofit agency in the Chinatown/ Polk Gulch/ North Beach areas of San Francisco. It was the result of an attempt to incorporate multidisciplinary group practice, capitation and the assumption of risk within the confines of a comprehensive primary health delivery system directed toward the frail elderly. Five features distinguish On Lok's care provision (Ansak & Zawadski, 1984):

1. A clientele consisting of impaired and frail elders (55 years and over) who are nursing home (continuing care) eligible and likely to require custodial care for the rest of their lives.
2. Provision of comprehensive medical and social services by a group of specialists (physicians, nurses, therapists, and social workers) who work together as a multidisciplinary team.
3. The use of an adult day health center as a social center for participants and an efficient setting for the delivery of primary medical and social services.
4. Continued community residence for most participants, with an emphasis on frequent attendance at the day health center.
5. Capitation of Medicare and Medicaid reimbursements at a fixed amount per participant. On Lok is at risk for all cost over-runs, which includes the cost of continuing and acute care services provided to participants.

In 1982, an impact assessment of On Lok using a quasi-experimental constructed comparison group design was completed (Ansak & Zawadski, 1984). The impact assessment showed that, when compared to a similar group of individuals admitted to continuing care, On Lok participants had lower rates of acute and continuing care use, higher levels of functional independence, and required lower per capita levels of public funding. The results of this impact assessment were hotly debated. Some critics attributed On Lok's success to several "special non-reproducible circumstances"(Kane, Illston & Miller, 1992). On Lok served a fairly homogeneous population. Almost all of its participants were Chinese immigrants or of recent Chinese decent. Cultural norms such as greater deference to professional suggestion, belief in filial piety, or even epidemiological differences were thought to have confounded the evaluation results. In addition to this, all of the program's 300 participants resided within a 2.5 square mile area. At the time of the study this same area was also home to a large number of foreign physicians and nurses unable to obtain professional licenses in the United States, many of whom were willing to work as paraprofessionals with On Lok.

The debate surrounding the results of the impact assessment highlighted the need to replicate and re-evaluate On Lok with other populations. This replication became a reality in 1991, with a grant provided by the Robert Johnson Wood Foundation, under a risk-sharing arrangement with the American Health Care Financing Administration (Shen & Iversen, 1992). The replicated program was known as PACE.

## PACE

Between 1986 and 1990 a total of fifteen Medicare and Medicaid PACE site waivers were granted (Branch, Coulam & Zimmerman, 1995). Four of these PACE sites are not yet developed; eleven are in operation throughout the United States:

1. East Boston Neighborhood Health Center's Elder Service Plan, Each Boston, MA,
2. Beth Abraham Hospital's Comprehensive Care Management , Bronx, NY,
3. Richland Memorial Hospital's Palmeto Seniorcare, Columbia, SC,
4. Bienvivir Senior Health Services, El Paso, TX,
5. Community Care Org., Inc's Community Care for the Elderly, Milwaukee, WI,
6. Sisters of Providences's Providence Elderplace, Portland, OR,
7. Total Longterm Care Inc., Denver, CO,
8. Centers for Elders Independence, Oakland CA,
9. Rochester General Hospital's Independent Living for Seniors, Rochester, NY,

10. Sutter Health's Sutter Seniorcare, Sacramento, CA, and
11. Center for Senior Independence, Detroit, MI.

The catchment areas for the ten PACE sites now in operation range from 42 square miles to 1,400 square miles (Branch, Coulam & Zimmerman,1995). Enrollment ranges from 78 to 168 participants per site, and participants are predominantly whites and blacks, as well as a small numbers of Hispanics. Most participants are eligible for Medicaid and Medicare. Medicare-only participants, which account from 1% to 13% of the census per site, must pay the Medicaid PACE capitation rate out-of-pocket (this can range from $2,000 - $4,000/ month). Individuals who enter the program as private pay often deplete their assets rapidly and become Medicaid eligible (Van Steenberg, Ansak & Chin-Hansen, 1993). The PACE capitation rate guarantees Medicare a minimum 5% cost saving compared to the average fee-for-service participant cost.

Dr. R. L. Kane and Dr. L. G. Branch and their associates have been involved in an ongoing evaluation of PACE sponsored by the Health Care Financing Administration. Two articles have been published as a result of their continuing evaluation efforts. In the first article Kane, Illston and Miller (1992) reported what might be described as a descriptive case study evaluation of eight operating PACE sites. The evaluation focused on the progress that each site had made toward incorporating On Lok principles and philosophy. Two implementation issues were identified: the need to ensure sufficient program start up funds (estimated to be $1.5 million per program), and the need to attract and maintain sufficient numbers of participants. They also identified the difficulty of treating those with and without cognitive impairment in the same setting.

In the second article on PACE, Branch et al. (1994) reported what might also be described as a descriptive case study of nine operating PACE sites. Once again the evaluation identified the inability of the programs to reach and maintain optimum enrollment rates. The issue of "considerable implementation variability" making cross site comparison difficult was also raised in the report as was the possibility that the program was "cream skimming" (i.e., serving some individuals who were not at risk of admission to continuing care).

Ongoing comparison between the PACE sites has been facilitated through the development and implementation of the PACE minimum data set (Eng, 1996). The data set has the ability to collect and collate a wide variety of program specific information. Comparisons with the general Medicaid population (the majority of which are the well elderly) continues to show that PACE participants are admitted to hospital less frequently (2,399 hospital days/ 1,000 persons/year as opposed to 2,448), stay for shorter lengths of time (Average Length of Stay 4.9 days as opposed to 7.6), access emergency less often, and use fewer diagnostic services and prescription drugs.

## CHOICE

CHOICE was developed by CHA in partnership with two of Edmonton's largest continuing care operators, the Capital Care Group (CCG) and the Good Samaritan Society (GSS). During the early 1990s the CCG and GSS became interested in the possibility of replicating PACE in Canada. Representatives from both organizations travelled to the United States to initiate discussion and view PACE sites in Rochester, New York and Oakland, California.

Early in 1995, when Alberta's health system was regionalized and CHA assumed leadership of the CCG and GSS, several situational factors moved the idea of a Canadian replication of PACE forward. Sheila Weatherill, a champion of the PACE program, was appointed as the CHA Director of Continuing and Community Care for CHA. CHA sustained a loss in provincial funding and exceeded recommended provincial acute and continuing care bed targets of 2.4 acute care beds/ 1,000 population and 50 continuing care beds/ 1,000 population of those aged 65 years and over. Alberta Health directed the RHAs to invest in community-based services.

PACE administrators were not interested in developing a Canadian site. They agreed to provide consulting services for program development, and a three-year technical assistance agreement was established between CHA and the Milwaukee PACE site. In February 1996 the first of three CHOICE pilot program sites (Mount Pleasant) opened in Edmonton. The second site, Dickinsfield, opened in March 1996, and the third, Norwood, opened in December 1996. CHA is responsible for setting the overall directions and policy for the pilot program, and CCG (Dickinsfield and Norwood) and GSS (Mount Pleasant) are responsible for day-to-day on-site operations.

### Rationale

Five program rationale were identified in the CHOICE Program Description (1998):

1. There is a growing number and proportion of people over age 75 in the general population. This age group is expected to grow at a rapid rate as baby boomers reach their senior years. A large proportion of these individuals have one or more chronic illnesses (arthritis, diabetes, congestive heart failure,

dementia, chronic obstructive pulmonary or cerebral vascular disease). Chronic illness is generally associated with increased demands on the health care system.

2. The elderly value their independence and prefer to stay at home as long as possible. Alternatives to continuing care placement are desired.
3. Restructuring of the health system in Alberta has resulted in reduced availability of acute care beds. It is therefore important that the frail elderly do not use the acute care system unnecessarily.
4. The current system of care for the frail elderly is fragmented and difficult to coordinate. There is a need for innovative ways of meeting the health needs of this population.
5. Changes in the social support structure of families often lay the burden of caregiving for the frail elderly on elderly spouses and over-burdened families. A systematic approach which acknowledges the complexity of caregiving in day-to-day living, as well as, in the formal health care system is required.

Target Population

CHOICE targets the frail elderly who are eligible for admission to a continuing care facility who are frequent users of acute care. These individuals fall into one of four categories (CHOICE Program Description, 1998):

1. Functionally Frail - these individuals have a high need for personal care and are high users of home support services.
2. Medically Frail - these individuals demonstrate a high number of health conditions and are high health care service users on an after hours on-call basis.

3. Chronic Mental Illness (other than dementia) - these individuals often have special day program needs.
4. Dementia - because of the high stress levels among caregivers committed to maintaining their family members at home, care of those with dementia generally involves high use of family support and respite services.

Referral Process/ Eligibility Criteria

Referrals to the program are made to the CHOICE Intake Coordinator through the CHA Single-Point-of-Entry System. When a candidate's referral indicates the potential to benefit from the program, the CHOICE intake coordinator visits the candidate's home in order to collect additional information to ensure that the candidate meets the program's eligibility criteria, and share detailed information about the program with the candidates and their informal caregivers. In order to be eligible for admission to the program, candidates:

- are at risk for placement in long-term care,
- need assistance with ADL (activities of daily living: dressing, eating, toileting, grooming, bathing, transferring) /IADL (instrumental activities of daily living: shopping, handling finances, taking medications, preparing meals, transportation, using the telephone),
- have a support network committed to the candidate staying at home,
- have a history which includes frequent hospitalization and/or use of emergency,
- have a physician who is in agreement with the referral,
- have needs which cannot be met with less comprehensive (home care) services, and

- have needs which appear to be within CHOICE resources (CHOICE Program Description, 1998).

## Program Trial

Candidates who have met the eligibility criteria undergo a five-day program trial before being formally accepted into the program. During the first two years of operation approximately ten to 15 individuals per month were accepted for this five-day program trial. Each of the professional multidisciplinary team members (physician, pharmacist, physiotherapist, occupational therapist, nurse practitioner, recreational therapist, social worker, and home support coordinator) meet with and assess the participant and/or their informal caregiver during this trial. The occupational therapist and/or the home support coordinator also make an in-home visit. During the trial period candidates are expected to attend the program on a daily basis and take part in an extensive assessment process. During the first two years of operation (1996-97) the time between referral and the beginning of the assessment period ranged from two to four weeks. During 1998 all three sites had waiting lists. The number of individuals on the waitlist ranged from a low of 20 (January) to a high of 42 (September).

## Admission to the Program

Candidates who successfully complete the program trial are assigned to one of the three program sites on the basis of their residence postal code. The exception to this rule are participants who require a secure placement. These participants are admitted to the Mount Pleasant site, which contains a separate secured area on the second floor for those with dementia who exhibit wandering and/or disruptive behaviours. The maximum census for this secured area is 20 participants. The maximum census for the main floor

Mount Pleasant unsecured area is 75 participants. Currently Norwood has a census of 85 and Dickinsfield has a census of 75, making a total CHOICE census at all three sites of approximately 250 participants. Not all participants attend the program five days a week. The daily census in each site varies from between 50 to 60 participants. In 1996 and 1997 approximately 60% of the participants were male and 40% were female. The average age of participants was 78 years, with a range of 57 to 96 years.

## Core Program Elements

CHOICE program combines four core elements: (1) transportation, (2) day center, (3) health and social services provision, and (4) home support.

### 1. Transportation

Participants are transported to and from the day program/health clinic in mini-buses. Each bus holds approximately six participants either in fixed seating or belted in their wheelchairs, which are secured to the floor of the bus. Travel time to the program can range from a few minutes up to an hour or more depending on the bus route. Transportation for medical consultation, diagnostic services and other ancillary services is also provided as needed, (i.e., when family or friends are not available). Bus service is provided on a contract basis.

### 2. Day Centre

All participants attend the day health centre located at their assigned CHOICE site. The center is open five days per week, with participants attending between 9:30 and 4:00 p.m. The number of days that participants attend the centre each week depends on their needs as assessed by the multidisciplinary team. Day centre services include personal care and grooming, recreational and social activities, and a meal service. A typical daily day program schedule is outlined in table 1-1 below.

Table 1-1

Sample Day Centre Program Schedule

| Time | Activity |
|---|---|
| 09:00 - 10:00 | Participant buses arrive and unload |
| 09:30 –10:00 | Current events (newspaper reading), morning snack |
| 10:00-11:00 | Some sort of organized activity in the large activity room lead by one of the home support workers (e.g., boccia ball and bowling) |
| 11:00-11:30 | Exercise time in the activity room (participants sit in a circle and one of the home support workers leads the group) |
| 11:30-12:15 | Hot lunch provided |
| 12:15 –14:30 | Afternoon activity choice, e.g., gardening, crafts, discussion group, ceramics |
| 14:30 –16:00 | Social time, afternoon snack, bus arrival for the trip home |

3. Health and Social Service Provision

Individuals are not admitted to the CHOICE program unless their family physician is in agreement. A total of ten individuals have been denied admission to the program since its inception because their family physician was not in agreement. On admission to the program, participants are assigned to one of the CHOICE physicians. The participant's family physician may choose to receive written updates on the participant after admission to CHOICE. Twenty-four hour on-call is provided by the CHOICE physicians on a roster basis, and twenty-four hour on-call nursing services are provided under contract with CHA.

Services not routinely available on-site are accessed through consulting or referral arrangements. These include: audiology, dental care, diagnostic imaging, laboratory, medical specialties, nutrition, optometry, ophthalmology, podiatry, psychology, respiratory therapy and speech-language pathology.

There is no penalty (i.e., financial charge) should a participant decide to access services outside of those provided by or coordinated by CHOICE (e.g., emergency services or other general/specialty physician services). Participants carry a card attached to their Alberta Health Care Card that identifies them as a CHOICE participant, and outlines how to contact CHOICE.

Two CHOICE sites contain sub-acute treatment beds, Dickinsfield (11 beds), Mount Pleasant (7 beds). Norwood participants access the treatment beds located in Dickinsfield and are transported there and back by mini-bus on a daily basis. Participants may stay at one of the CHOICE centers in one of the treatment beds while they receive treatment for an episodic illness, or upon discharge from acute care. These beds may also be used for the provision of respite services, and on occasion have been used to provide palliative care.

4. Home Support

Most participants require assistance within their homes in order to maintain their independence. They may also require help getting ready to attend the day center. Home support services include: meal delivery, personal care, adaptation of the home environment, provision of aids and home-making.

### Program Funding

The program is block funded by CHA. The amount received is adjusted to reflect the program census. This funding covers staffing, transportation, meal provision, supplies, medications and oxygen and respiratory therapy equipment. The program receives some reimbursement for physician services through the Provincial Physicians' Payment Schedule.

The cost of providing care per participant/ per day is not expected to exceed $60. The program currently costs $59.17 per participant/per day to provide. Physician salaries account for $3.81 of the per participant /per day cost or about $1,400/per participant/per year (J. Glass, personal communication, June 15, 1999). Detailed cost information for the other multidisciplinary team members is not presently available.

### Previous Program Evaluation

As a pilot project, CHOICE underwent an evaluation after its first full year of operation (1997). This two-part developmental/accountability evaluation was completed by an external team of evaluators under the direction of the CHOICE Evaluation Working Group, which included representation from Alberta Health, CHOICE, CHA, CCG and GSS. The purpose of the evaluation was to: (1) provide a comprehensive description of the program, (2) collaborate with program managers to develop a program specific information system for tracking clients and monitoring service delivery, and (3) determine the impact of the program on its participants in terms of quality of life, health status, and health service utilization.

A simple pre and post, "black box" research design was used to assess the impact of the program. The results of the impact assessment showed that CHOICE reduced:

- pharmaceutical claims by 86% or by about $1,000/participant per year
- inpatient acute care length of stay by 55%,
- inpatient acute care admissions by 30% and total cost by 52%,
- ambulatory care visits by 25% and total cost by 25%,
- billable medical specialist claims by 18%, or by about $260/participant per year,
- ambulance use by 11%, or by about $24/participant per year.

The impact assessment also showed that health status as measured by the SF-12 (Rand Corporation & J.Ware, 1990) did not change. Quality of life as measured by the Quality of Life Profile: Seniors' Version (QOLPSV) (Spitzer, 1980) improved, and participant and informal (family) caregiver satisfaction as measured with a tool developed for the study remained high.

Since the results of the impact assessment were released, CHOICE has received provincial and national recognition as an innovative, cost effective community-based model of care for the frail elderly who qualify for nursing home placement. It was recently featured on CBC's W5 television program (August, 1998), on CBC radio (February, 1999), and in Maclean's Weekly News Magazine (June 1999).

CHOICE's success prompted CHA's decision, in the fall of 1998, to disband the CHOICE Pilot Program Steering Committee and officially make the program one of several community and residential care options available to the frail elderly. Funding has recently shifted from home care to CHOICE, and CHA is currently developing a fourth CHOICE site to accommodate increased demand. CHA is also planning programs similar to CHOICE for other target populations known to be high users of health care services (e.g., those under 65 years of age suffering from chronic mental illness). Several other RHAs in Alberta have also expressed an interest in replicating the program, and CHA has been involved in discussions about CHOICE with health professionals and provincial departments of health in Ontario and British Columbia.

In summary, this chapter presented an overview of the CHOICE program. It identified the two programs upon which CHOICE is based, On Lok and PACE, and it described the rationale behind the program, the program's target population, referral process, and eligibility criteria. In addition it outlined the program trial and admission process, and provided a description of the core program elements. The chapter concluded by explaining how the program is funded and by reviewing the results of the pilot project evaluation completed on CHOICE.

# CHAPTER TWO - PROGRAM THEORY

This chapter introduces the reader to program theory. Program theory provides the means by which a researcher can delineate what is supposed to be happening in a program (Rossi, Freeman & Lipsey, 1999). In doing so, it enables a researcher to identify those aspects of a program most essential to effective performance.

As Figure 2-1 illustrates, program theory is composed of three interrelated components: a program's organizational plan, service utilization plan, and impact theory.

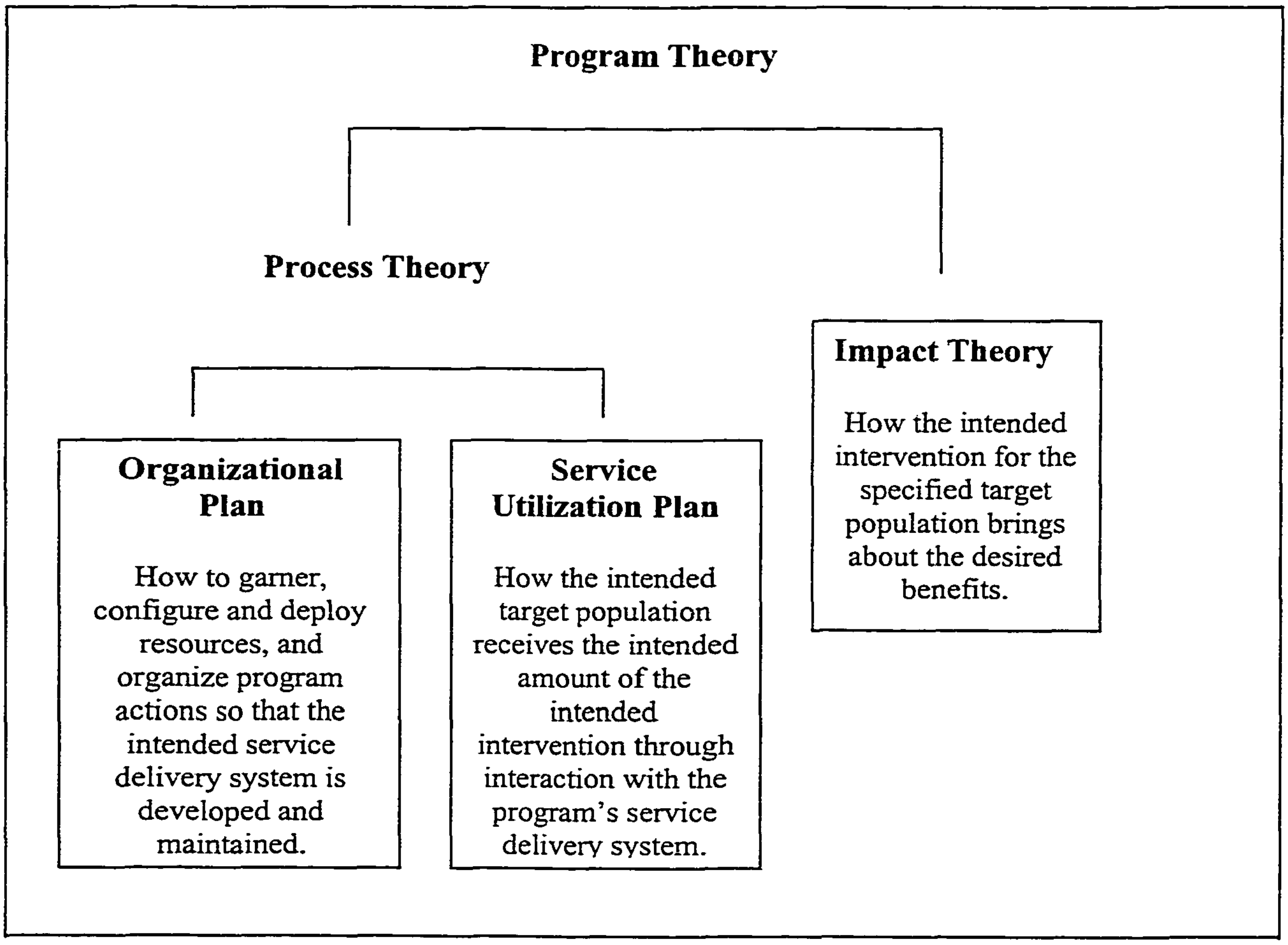

Figure 2-1.

The Three Components of Program Theory

The program's organizational plan and service utilization plan together make up the program's process theory (Rossi, Freeman & Lipsey, 1999, p. 101).

## Organizational Plan

A program's organizational plan is based on a set of beliefs, assumptions, and expectations about how the program will deliver services (Rossi, Freeman & Lipsey, 1999). It is articulated from the perspective of program management and outlines the actions the program is expected to perform, as well as the human, financial and physical resources required for that performance.

Articulating a program's organization plan allows a researcher to identify areas of congruence and incongruence between the program as conceptualized and the program as implemented. It provides an opportunity for a researcher to ask and answer the following types of evaluation questions:

- Is the program actually implementing the intended functions and activities in the intended way?
- Are the program functions and activities optimally configured for their purposes?
- Do the program functions represent appropriate standards of professional practice?
- Are the personnel sufficient in numbers or credentials for their assigned tasks?
- Is the program adequately resourced?
- What is the nature of the relationship between the program and its governing and/or advisory board?

## Service Utilization Plan

A program's service utilization plan is based on a set of assumptions and expectations about how the target population will make initial contact with the program, become engaged in the program and progress through the program (Rossi, Freeman & Lispey, 1999). It is usually depicted using some sort of flow chart which identifies the various possible paths program targets can follow from some appropriate point prior to first program contact through a point where there is no longer any contact. Articulating a program's service utilization plan allows a researcher to identify situations in which the program targets are not engaged with the program as intended. It provides an opportunity to ask and answer the following types of evaluation questions:

- Is the appropriate target population being served in sufficient numbers?
- Are there any barriers to entry into the program?
- To what extent is full appropriate service completed by an acceptable proportion of those beginning service?
- Is desirable follow-up contact made following service completion?

Figure 2-2 schematically depicts the CHOICE service utilization plan. In its first three years of operation (1996, 1997 and 1998) CHOICE received a total of 486, 340 and 299 referrals respectively. The bulk of these referrals (75%) came from home care coordinators. The other 25% came from acute care, rehabilitation and/or continuing care facilities (CHOICE Program Statistics, 1998). In 1997, 24% (118) of those referred to the program did not meet the eligibility criteria. The most common reasons for not meeting the eligibility criteria were: (1) candidate able to manage with current home care services, (2) candidate decided to apply for continuing care, and (3) candidate not

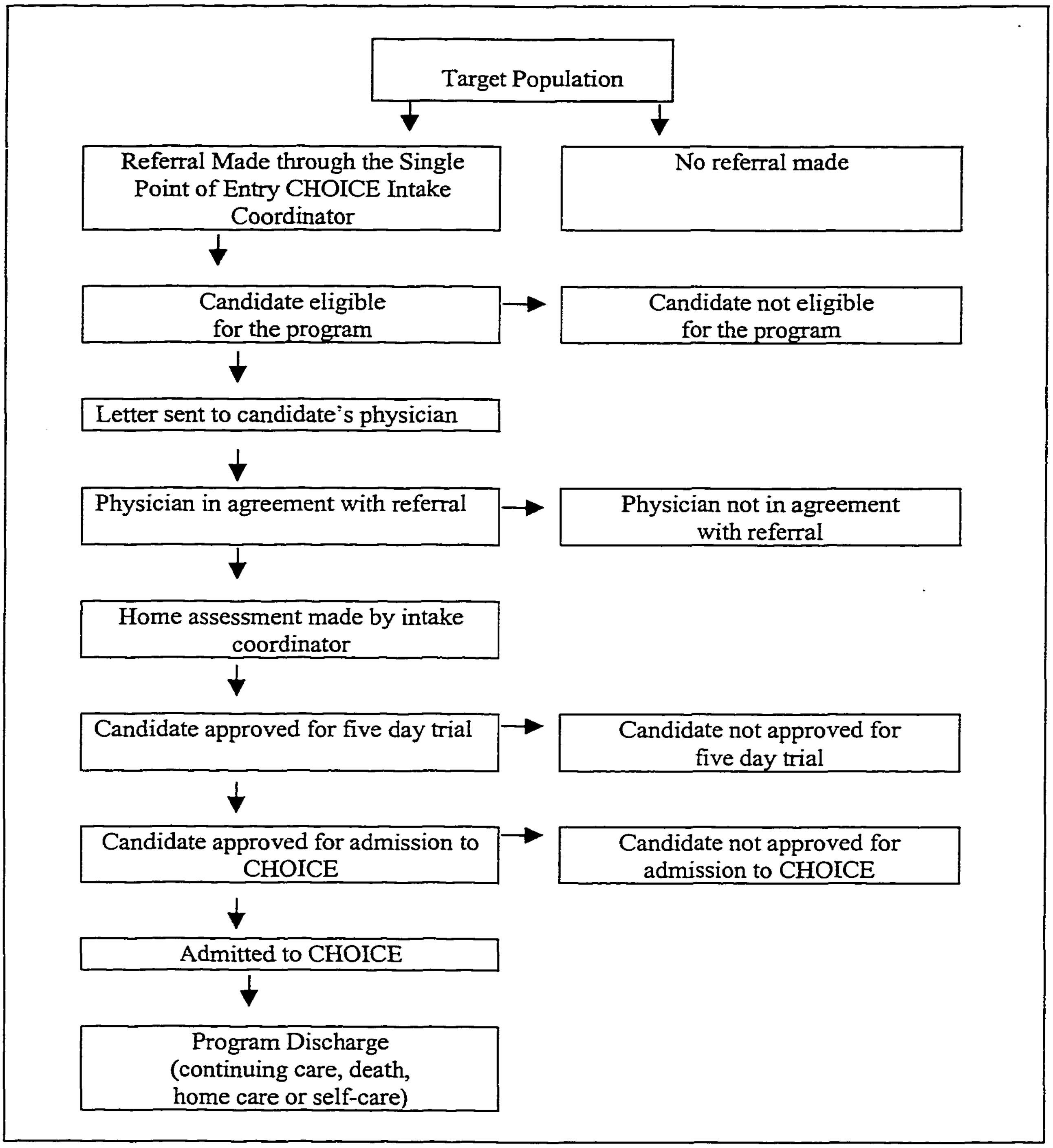

Figure 2-2.

CHOICE Service Utilization Plan

interested in CHOICE. Since the inception of the program, ten program candidates were found to be ineligible because their physician was not in agreement with the referral, and one was found to be ineligible due to the fact that their needs exceeded CHOICE resources (i.e., their need for continuous one-on-one supervision could not be accommodated within the confines of the program).

A total of 111 and 163 individuals were approved for the five-day trial in 1996 and 1997 respectively. All but one of these individuals completed the trial. Approximately 25% of those admitted to the program during 1996 were discharged during the same year, and approximately 60% of those admitted to the program during 1996 and 1997 were discharged by the end of 1997. In 1997, approximately 30% of participant discharges were as a result of admission to continuing care facilities and 30% were due to death. The remaining 40% of discharges were due to insufficient program resources, the participant's decision to withdraw from or comply with the program, or because the participant moved away.

CHOICE enrollees account for about 5% of CHA residents who qualify for continuing care placement. In 1997 approximately 5,000 CHA residents qualified for continuing care placement on the basis of the AAPI (Alberta Assessment and Placement Instrument)[2](Alberta Health, 1998A). Of these individuals approximately 3,550 or 70% were residents of continuing care facilities, and approximately 1,200 or 25% were living in the community and receiving assistance from home care. The remaining 250 or 5% were enrolled in CHOICE.

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[2] The AAPI is a comprehensive assessment tool developed by Alberta Health to coordinate assessment and placement functions for continuing care. Its purpose is to assist health care professionals to objectively and comprehensively identify clients needs and determine the most appropriate care and placement options

## Program Impact Theory

Program impact theory describes the chain of events that lead from the program actions to the ultimate program outcomes (Rossi, Freeman & Lipsey, 1999). As Figure 2-3 illustrates, program impact theory encompasses the program actions, intermediate and ultimate outcomes, and the action and conceptual hypotheses.

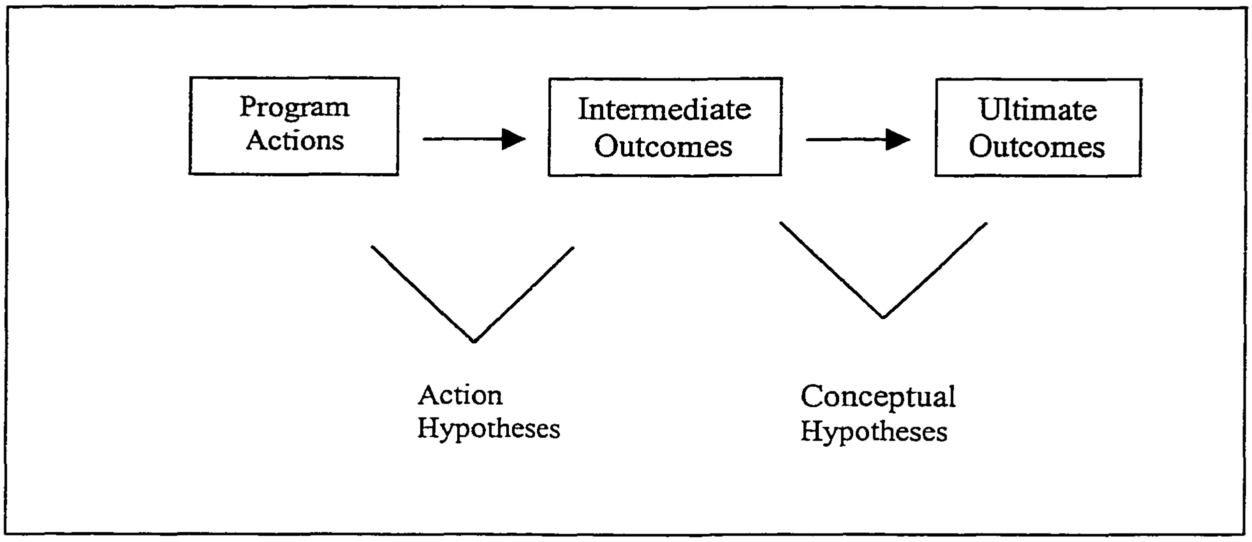

Figure 2-3.

Program Impact Theory

Action hypotheses and conceptual hypotheses represent different sets of assumptions about how a program produces its results (Rossi, Freeman & Lipsey, 1999). For a program to be successful both the action and conceptual hypotheses must be valid.

Action hypotheses relate to the ability of the program actions to activate the expected causal process. They link program actions to intermediate outcomes. Conceptual hypotheses relate to the ability of the intermediate program outcomes to

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available to meet their needs. Individuals with a score of D or greater on the seven point, A to G AAPI scale are considered to have needs appropriate for continuing care (Alberta Health, 1989).

impact the ultimate program outcome(s) as expected. They link the intermediate program outcomes to the ultimate program outcomes.

Action hypotheses tend to be program specific and are usually formulated by decision makers and/or program planners (Chen, 1990). Conceptual hypotheses tend not to be program specific, and are often drawn from the wider body of social science and/or health science literature. Take, for example, a public health program designed to improve birth outcomes by providing expectant mothers with information about the benefits of good nutrition and the dangers of smoking. The action hypotheses for this program are based on certain assumptions about how the program will provide expectant mothers with this information. This might include such things as developing and circulating an information pamphlet, or planning and delivering a group educational session. The program's conceptual hypotheses are based on certain assumptions about the relationship between the knowledge and behaviour change.

Program impact theory is typically illustrated using some form of causal diagram. Each element in the diagram is either a cause or an effect. The linkages between the elements outline the chain of events beginning with program actions and ending with the expected change in the social condition(s) that the program ultimately intends to improve. These causal diagrams are often referred to as program logic models, program models, outcome lines, cause maps or action theory models.

In some instances program impact theory may be extremely simple. Take, for example, Alberta Health's new Palliative Care Drug Program. Until recently those receiving palliative home care services in the community were expected to pay for the cost of their medications privately, while those receiving palliative care services in an acute care facility were not. The out-of-pocket cost of medications in the community was identified as a barrier to expansion of community based palliative care service delivery. Alberta Health recently developed a palliative care drug program to address this barrier. The program provides public funding for palliative medications in the community. Figure 2-4 provides an outline of the impact theory for this program based on information contained in Alberta Health documents.

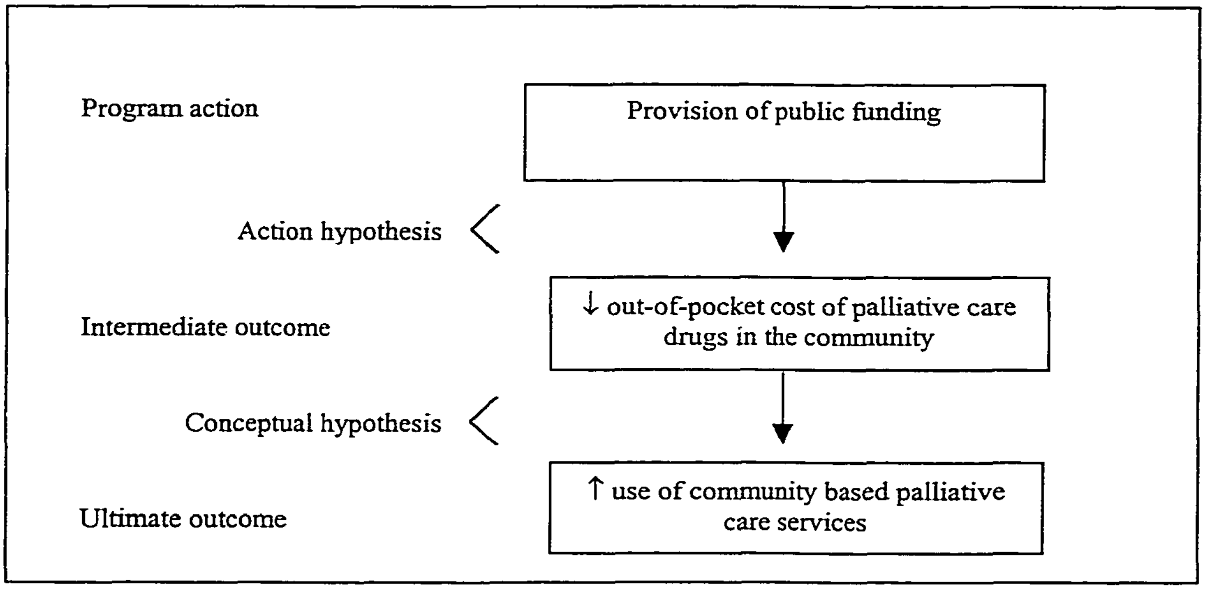

Figure 2-4.

Alberta Health's Palliative Care Drug Program Impact Theory Model

Alberta Health's Palliative Care Drug Program is based on the premise that decreasing the out-of-pocket cost of palliative care medications will result in an increase in the number of individuals who receive palliative home care services, and a corresponding decrease in the number of individuals who receive palliative care services in acute care facilities. The ability of this simple intervention to do so has yet to be shown.

In many other instances program impact theory is not as simple. It may include more than one program action and/or program outcome, and several intermediate steps between the two. Take, for example, CHA's SAYGO (Steady as You Go) program. This program is designed to reduce the incidence of falls in the well elderly. Figure 2-5 provides an outline of SAYGO program impact theory. This model, like the model of Alberta Health's Palliative Care Drug Program, is based on information contained in program documentation. It is not based on an evaluation of the program.

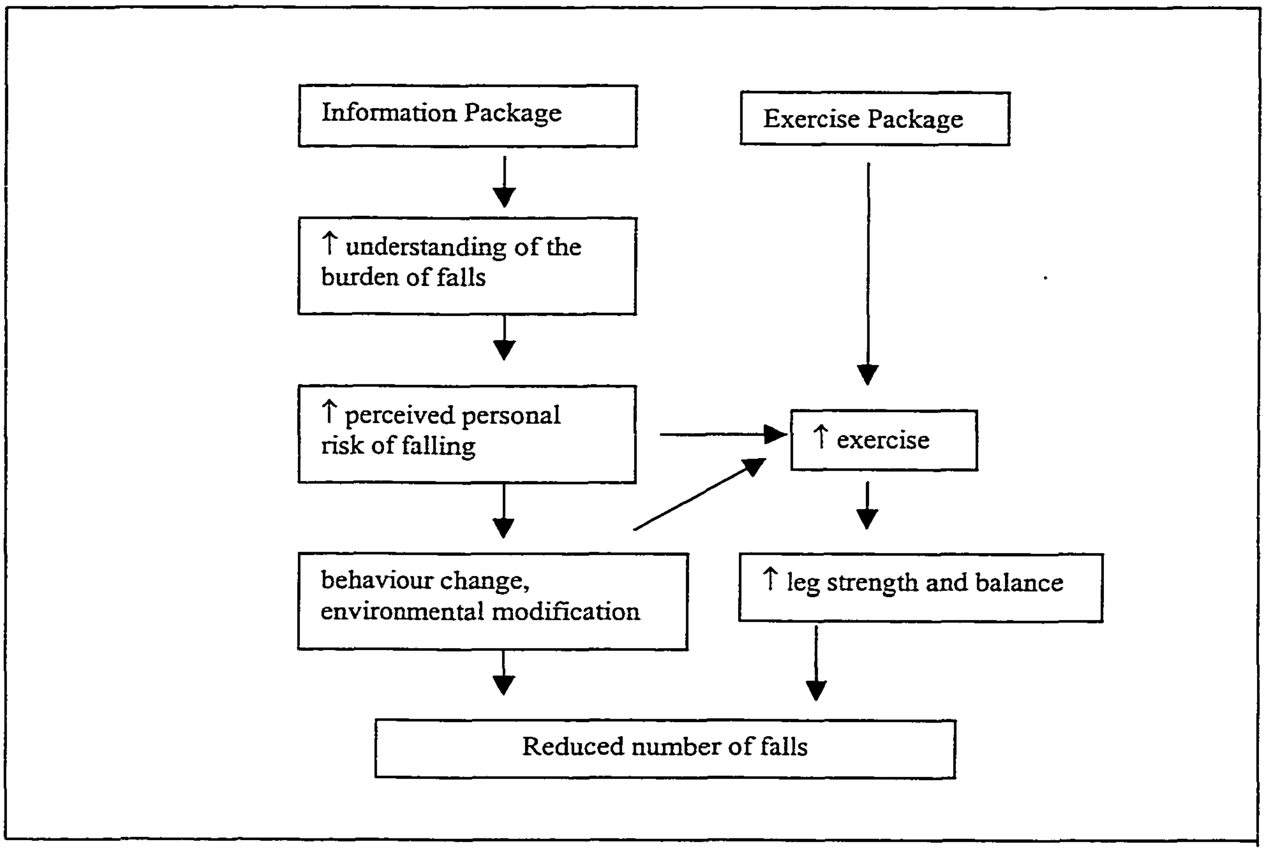

Figure 2-5.

CHA's SAYGO Program Impact Theory Model

SAYGO combines two intervention strategies to reduce falls in the well elderly: education and exercise. Community group leaders, who agreed to become SAYGO community group facilitators, are invited to attend an all day training session lead by two knowledgeable well seniors. At this training session the group facilitators receive an educational package and a videotaped exercise program. They are expected to take these back and share them with their community group members using a one day preset program format. The information package is expected to accomplish two purposes. First, to sensitize the community group members to the problem the program is designed to address, the personal, social and economic burden of falls, and second, to increase the participant's perceived risk of falling. This heightened sense of perceived personal risk is expected to result in the community group members taking specific actions, as identified in the program, aimed at reducing their personal risk of falling. These actions might include such things as: buying a new pair of winter boots with thick treads, getting a grab bar for their tub, letting the public works department know about the area of uneven sidewalk by the supermarket, attending the community group exercise session twice a week, or joining a Tai Chi class. Taken together, these actions are expected to result in a reduction in the potential number of falls that these individuals would have experienced had they not completed the program.

SAYGO action hypotheses rest on certain assumptions about the ability of the program's information package to increase the participant's understanding of the burden of falls, their perceived risk of falling, and their desire to make use of the exercise package. SAYGO conceptual hypotheses rest on certain assumptions about the ability of modification of risk and increased leg strength and balance to impact falling.

## Articulating Program Theory

Despite the fact that the first mention of the importance of program theory can be traced to the writings of Suchman (1967), Weiss (1972), and Fitz-Gibbon and Morris (1975), the program evaluation literature is exceedingly sparse when it comes to the "how to" of program theory articulation. What is known is based on the personal experience of a handful of evaluators such as Chen (1990), Weiss (1997) and Rossi, Freeman and Lipsey (1999). These individuals have suggested that evaluators employ a combination of inductive and deductive qualitative research strategies to articulate program process and/or impact theory.

Rossi, Freeman and Lipsey (1999) recommend that a researcher use a process of cooperative discovery among stakeholders to articulate program theory, and a comparative exploratory process to assess the plausibility of the program theory once articulated. Articulation involves a successive iteration procedure. Draft descriptions of the program theory are generated, usually by the researcher, discussed with knowledgeable stakeholder informants to obtain feedback, then refined on the basis of the discussion, and shown again and again to the appropriate stakeholders until there is little to criticize in the program theory description. The information contained in the program theory is based on the understandings of those that originate, plan, administer, and staff the program. The role of the researcher in this process is to collect, organize, and interpret the information as necessary.

Assessment involves standing back and objectively critiquing the articulated program theory. In order to do so a researcher is guided by a series of questions. The answers to these questions allow the researcher to make a judgment call about the plausibility or soundness of the articulated program theory. In some instances a researcher may choose to do this collaboratively with relevant experts and stakeholders in order to broaden the range of perspective and expertise upon which the judgment call is based. In other instances, depending on the expertise of the researcher he/she may choose to do it independently.

Rossi, Freeman and Lipsey (1999) outline four frameworks a researcher can use to assess the soundness of the articulated program theory: (1) assessment in relation to social needs, (2) assessment of logic and plausibility, (3) assessment via preliminary observation, and (4) assessment through comparison with research and practice. The nature of the questions asked in the assessment process is dependent upon the framework chosen.

Chen (1990) recommends that a researcher use a less cooperative approach to articulate program theory. He suggests that a researcher construct two parallel program theory models, the first using a stakeholder approach, and the second a social science approach. In the stakeholder approach, a researcher obtains clues or hints from relevant program documents and through interviewing multiple stakeholders. In the social science approach a researcher makes use of his/her knowledge of the social science literature, personal expertise and "first hand" experience of the program. The researcher then integrates the two understandings to create a "synthetic" or "best-fit" model of program theory for the program. Chen (1990) does, however, acknowledge that in some instances it may not be possible to integrate the theory produced using these two approaches.

Chen (1990) believes that impact theory based solely on uncritical acceptance of information contained in program documents and service provider interviews may not reflect the reality of a program. Vested interests on the part of those that fund and deliver a program may result in an over emphasis on the desirability as opposed to the plausibility of a program, and/or information collected from program stakeholders may not be sufficiently sensitive to capture the complicated causal processes underlying a program. Chen (1990) recommends that a researcher take steps to ensure that program theory is congruent not only with the program as observed, but also with impact theory that may have been articulated for similar programs, and with what is known in the literature about the problem the program has been designed to address.

In methodological terms the approach outlined by Rossi, Freeman and Lipsey (1999) and Chen (1990) is similar to that used for explanatory case study research (Yin, 1993,1994). Case study is the method of choice when the phenomenon being studied is not readily distinguishable from its context. It copes with the technically distinctive situation in which there will be many more variables than data points and relies on multiple sources of evidence, with data needing to converge in a triangulating fashion. Case study research may be exploratory, descriptive or explanatory. Explanatory case study research focuses on the identification of specific cause-effect relationships and seeks to explain which causes produced which effects (Yin, 1993, 1994).

Explanatory case study research is used by a detective to build a case or a coroner to explain how an individual did or did not die. Both make use of a wide range of investigation strategies to rigorously collect a broad base of evidence from a variety of sources. A set of standard procedures is employed to carefully examine and catalogue all of the collected evidence. An iterative inductive/deductive process is then used to cycle between the specifics of the case and the broader body of previous knowledge. Several plausible hypotheses explaining the links between the evidence are generated. Each hypothesis is tested against the available evidence. In some instances this may involve tapping into the knowledge and expertise of leaders in the field, and in others it may involve the collection of additional evidence. Any areas of divergence between the evidence and the hypothesized links assume a heightened sense of importance, and must be reconciled for the hypotheses to be considered plausible.

Explanatory case study research is rooted in an emergent realist paradigm. Emergent realists believe that reality exists and meaningful patterns are present in this reality, and that principled discovery, an iterative inductive-deductive or a "retroductive" process can be used to construct meaningful order (Mark, Henry & Julnes, 1998). As a method of study it is distinguishable from methods such as ethnography or grounded theory which are rooted in a constructivist paradigm, or experimental methods which are rooted in a positivist paradigm (Yin, 1994).

Explanatory case study is the method of choice for making explicit the theory behind a program, for understanding the context in which a program operates; for describing what is actually implemented in a program; for assessing the correspondence between what the program theory promised and what is actually implemented, for helping elucidate the processes that might have brought about program effects; for identifying some likely unintended consequences of the program; and for synthesizing the wisdom learned about a program of a set of programs with somewhat similar characteristics (Cook, 1997).

In case study research the validity of the explanatory model rests on the investigator's ability to build and maintain a chain of evidence (Yin, 1994). This conceptualization of causation is very different from that used in basic research. Experimental and quasi-experimental research designs are rooted in the counterfactual definition of causation (Mohr, 1995). The counterfactual causation argument goes as follows: if a set of activities, actions, etc. are delivered to one group of individuals (the treatment group) and not to another group of individuals (the control group), and if a statistically significant difference is found between the two groups in terms of the variable(s) of interest, then the delivered activities, actions, etc. are thought to be responsible for or the cause of the difference.

Regardless of the approach chosen to articulate program theory, a researcher needs to overcome two obstacles. The first obstacle relates to the fact that much of the information needed to construct program impact theory is implicit rather than explicit (Rossi, Freemam & Lissey, 1999). Health professionals, like may other professionals, tend to operate within the narrow confines of established discipline-specific intervention repertoires. Program design frequently involves configuring familiar "off the shelf" intervention strategies into service packages or programs that seem appropriate for addressing the identified health problem or issue. Programs are often developed on the basis of what Rossi, Freeman and Lipsey (1999) refer to as shared tacit knowledge. Tacit knowledge is routinized in the context of the program. It is rarely thought about or discussed, and must be drawn out piecemeal from program informants, available program documents, professional and research literature, and then synthesized by the researcher into a coherent whole.

The second obstacle relates to the availability of pertinent social science literature in relation to the program's action and conceptual hypotheses. Program evaluators have not done a particularly good job of accumulating substantive findings or drawing inferences about the programs and classes of programs that seem to work best in certain circumstances (Cook, 1997). Evaluators are typically commissioned to evaluate a specific program, not to review the literature on the classes of programs targeting a given problem. Very few compendia of "what has been shown to work and not work" exist. This can make any attempt to construct program impact theory solely on the basis of social science theory and knowledge difficult.

In summary, this chapter introduced the reader to program theory. It reviewed the three components that make up program theory, the program's organizational plan, service utilization plan and impact theory. It provided several examples of program theory and described two different approaches that have been suggested for articulating program theory.

# CHAPTER THREE - METHOD

This chapter describes the modified stakeholder social science approach (Chen, 1990) used in this study to develop a detailed description and model of CHOICE program theory. Four uniquely different data collection strategies: (1) document review, (2) field observation, (3) stakeholder interviews, and (4) literature review, were sequentially employed to gather a broad range of information about the program's actions, its outcomes, and the intervening links between the two. A successive iterative process similar to that recommended by Rossi, Freeman & Lipsey (1999) was then used to develop a preliminary description and model of CHOICE program theory based on the information obtained via stakeholder interviews. Areas of divergence and convergence between this model and the information obtained through document review, field observation, and literature review were identified and explored in order to create a "best fit" integrated description and model of CHOICE program theory. CHOICE process theory (the program's organizational plan and service utilization plan) was not fully articulated within the bounds of this study.

## Document Review

Document review provides an opportunity for a researcher to find out in a fairly efficient manner whether or not a program is based on an explicit conceptualization of program theory. Availability of such documented understanding does, however, vary greatly. As previously indicated, health professionals share discipline-specific intervention repertoires. In many instances the underlying causal beliefs upon which these repertoires are based have not been identified, questioned, or debated in the context of the program, and for that reason, will not be present in program documents (Chen, 1990; Rossi, Freeman & Lipsey, 1999).

In other instances the underlying beliefs may have been identified, but purposefully excluded from the program documents. Rossi, Freeman and Lipsey (1999) caution that all program documents are prepared for a purpose, and this purpose is rarely to describe and present program theory in a valid and straightforward manner. Most program documents are written to persuade some outside party to support the program. They present the official "program view" to funders, other professionals and/or the public.

In this study Six CHOICE program documents were selected for review:

1. CHOICE: Resource Manual (June 1998),
2. CHOICE Program Description (June 1998),
3. CHOICE Procedures and Protocols Manual (March 1998),
4. CHOICE Program Statistics for 1997 (April, 1998),
5. CHOICE Evaluation Project (November 1998), and
6. CHOICE promotional flyers.

A Document Review Data Collection Sheet (Appendix A) was used to guide the review process. Pertinent text in each of the documents was identified and photocopied. The photocopied text was then sorted into one of four broad categories: target population, program activities/actions, program outcomes, and intervening links between program activities/ actions and outcomes.

Although the CHOICE documents contained a description of the program services and several expected program outcomes, no mention of program theory was made, nor were any intervening links between the program services and the expected outcomes identified.

## Field (Program) Observation

Document review was followed by field observation. Field observation provides a researcher with an opportunity to describe the program setting, the activities that took place in that setting, the people who participated in those activities and the meanings of what was observed from the perspective of those observed. In doing so, it provides a balance to the inherent bias frequently found in program documents. Field observation provides a researcher with a very different program vantage point, one that can, in many instances, reveal a much different picture than that seen through program documents.

Field observation flows naturally through three identifiable stages: gaining entry, data collection, and closure (Patton, 1990). In order to successfully complete the first stage, gaining entry, a researcher needs to accomplish two things. First he/she needs to negotiate their way into the program, and second he/she needs to identify which observer role will be adopted for the study.

Patton (1990) identified several approaches a researcher can use to negotiate their way into a program. Two of these approaches, the known sponsor approach and the reciprocity model approach were used in this study. In the known sponsor approach a researcher uses the legitimacy and credibility of others to establish the researcher's legitimacy and credibility. In this study several individuals played a role in establishing the researcher's legitimacy and credibility. A member of the supervisory committee obtained written and verbal support for the study from CHA's CEO. One of the members of the evaluation team contracted by CHA to complete the two-part CHOICE developmental/accountability evaluation introduced the study to the program's steering committee and facilitated a meeting between the researcher and the program implementation coordinator. In response to this meeting the program implementation coordinator agreed to attend morning multidisciplinary team meetings at each of the program sites with the researcher in order to introduce the researcher to individual site managers and multidisciplinary team members.

Initial introductions to the site managers and multidisciplinary team members where followed by day long site visits. These visits not only provided an opportunity for the researcher to become familiar with each program site, but also an opportunity to lay the groundwork necessary for development of a mutually beneficial, or reciprocal relationship. A sense of reciprocity rests on the assumption of mutual beneficial exchange (Patton, 1990). A researcher obtains data through observation or interview, and those being observed or interviewed in return find something that makes their cooperation worthwhile (i.e., a feeling of importance from being observed or interviewed, the provision of useful program feedback, and/or assistance in some task).

Gaining entry also involves identifying the role that a researcher will assume during the field observation. In field observation, the extent to which a researcher is, or is not, a participant in the program being observed varies. As it was inappropriate in this study for the researcher to be involved as either a multidisciplinary team member or a participant, a spectator role was adopted. Multidisciplinary team members were informed of the researcher's presence at morning meetings, and multidisciplinary team members' and participants' questions about the researcher's presence or about the nature of the study were responded to on an individual, *ad hoc* basis.

The second stage of field observation, data collection, involves several "trade-offs" related to the focus and scope of the observation period, no observer can observe everything. In this study, observation time was directed toward observation of a broad range of day program and health clinic activities at all three CHOICE sites, including the Mount Pleasant secured area. Notes pertinent to these observations were written during the observation time and typed out each evening. These notes were reviewed and discussed with a member of the supervisory team on a daily basis to ensure that the information being recorded in the field notes was appropriate for the purpose of the study.

As a researcher approaches the third and final stage of field work the focus changes. Data gathering gradually gives way to interpretation and then confirmation (Patton, 1990). Possible explanations about what is happening begin to show up in the field notes, and the researcher makes a conscious effort to seek out incidents that support or contradict these explanations. During this stage of field observation confirmation centered on the nature of the interactions between the participants, between the participants and the multidisciplinary team members, and between the multidisciplinary team members at morning meetings.

Field observation was officially terminated when it became apparent to both the researcher and the committee member that no new or contradictory information was being collected. A total of 22 hours was spent in field observation.

## Stakeholder Interviews

Tapping into the firsthand knowledge and experience of program stakeholders through the use of in-person interviews provided a third vantage point from which to view CHOICE. In-person interviews offer several advantages over document review and field observiaton. They allowed this researcher to tailor the line of discussion to the expertise of the individual(s) being interviewed, to probe and explore issues in depth, and to engage the stakeholder(s) in careful reflection about how a program "works".

A total of 49 in-person stakeholder interviews were conducted for this study. These interviews were held with a broad range of individuals connected with and impacted by CHOICE. The stakeholders included: CHA's CEO, CHA's Manager of Continuing and Community Care Services, CHOICE's Single-Point-of-Entry Coordinator, CHOICE's implementation coordinator, CHOICE site managers (n=2), and CHOICE multidisciplinary team members (n=24), participants (n=6), and participant's informal (family) caregivers (n=13). Multidisciplinary team members, participants and informal caregivers were selected from all three CHOICE program sites.

Interviews were conducted either in the staff member's office, in a private on-site interview room, or in the participant's home. Each interview was tape recorded, and lasted between 30 and 90 minutes. Individual stakeholders were purposefully selected for interview as the data collection period progressed using two selection criteria: (1) potential to provide information, and (2) potential respondent differences that might be expected to effect how the stakeholders experience the program. Patton (1990) refers to this as maximum variation sampling.

The informal caregiver stakeholders included both genders, employed and retired, and both spouses of, and children of, CHOICE participants attending all three program sites, including the secured Mount Pleasant area. The CHOICE participant stakeholders included those who were functionally and medically frail. Although the program is designed to target four basic groups of participants: those who are functionally or medically frail, those with dementia, and those with chronic mental illness, participants from the first three groups comprised approximately 90% of the participant population (CHOICE Evaluation Project, 1998). Participants with chronic mental illness who attend the program tend to suffer from what might be termed "milder" mental illness (e.g., anxiety disorders or mild depression). As one of the managers interviewed explained, "We have to turn away a lot of mental health issue referrals because the day program piece doesn't have the level of professional support service and the level of the high intensity one-to-one that these sort of people need."

Three basic interview approaches can be used: (1) general interview guide approach, (2) informal conversational interview, and (3) standardized open-ended interview (Patton, 1990). These approaches differ in the extent to which interview questions are pre-determined and thus standardized beforehand. A general interview guide approach was used in this study. A set of interview questions was prepared ahead of time as a general guide, but the order and exact wording of the questions was dependent on the stakeholders' responses. Copies of the interview questions used for the multidisciplinary team members, informal caregivers and participants can be found in Appendixes B, C and D. Questions used for the CHA's CEO, CHA's Manager of Continuing and Community Care Services, CHOICE's Single-Point-of-Entry

Coordinator, CHOICE's implementation coordinator, and the CHOICE site managers were developed specifically for each of these interviews.

During the interview process it quickly became apparent that the general interview guide approach did not work well for some members of the participant group. This was not totally unexpected given the characteristics and health status of this stakeholder group. An adapted "storytelling" informal conversational interview approach was substituted for these participants.

All taped interviews were transcribed and verified by the researcher. An interview summary for each of the transcribed interviews was then completed (Appendix E). Transcripts of the first three interviews and several subsequent transcripts were reviewed with three members of the supervisory committee. This review process accomplished three purposes. First, it provided an opportunity for the researcher to examine and improve her interview skills as the study progressed. Second, it ensured that the questions being asked elicited the type of information needed for the study, and third, it provided a check to ensure that the researcher was correctly identifying and extracting text units from each of the transcripts.

The text units identified on the first three interview summary sheets were used to prepare provisional descriptions of the program activities/actions, outcomes and possible intervening links. These initial descriptions were transferred to 4"x 6" coloured cards, which were then arranged on a cork wallboard. Arrows were added to illustrate potential causal pathways. The original text units associated with each card were placed in envelopes and pinned to the appropriate card on the wallboard for ease of reference. One of the members of the supervisory committee reviewed the text units associated with each of the cards with the researcher at this stage of the study, and on a regular basis thereafter.

Additional stakeholder interviews and further analysis of the transcripts then proceeded in an iterative manner similar to that described by Rossi, Freeman and Lipsey (1999). As each additional interview was completed and transcribed, additional text units were identified, coded and allocated to the appropriate envelopes and cards on the wallboard. The initial description of the program components captured on each of the coloured cards was updated on an ongoing basis to reflect this additional information. Memos were used to capture insights about the cards, arrows and their placement on the wallboard as the model evolved.

During this stage of the analysis informal "member checking" was done (Guba & Lincoln, 1989). This involved sharing preliminary and subsequently more informed iterations of the developing program theory with members of the stakeholder groups. For previously interviewed individuals this was accomplished in an informal manner. For individuals not yet interviewed this type of discussion was initiated at the conclusion of the interview. This information obtained through this member checking process was captured in memos, which were later added to the appropriate card or arrow on the wallboard. Stakeholder interviewing and member checking continued until no additional information was obtained.

Two final checks were then undertaken to ensure that the wallboard schematic faithfully represented the information collected via the stakeholder interviews and the member checking process. This involved rereading all of the cut text units and memos attached to each of the cards and arrows on the wallboard, and then rereading the cut text units not linked to the wallboard model.

## Literature Review

Literature review provided yet a fourth vantage point from which to view the CHOICE program. Literature review and field observation are seen as a way of balancing the bias inherent in document review and stakeholder interview (Chen, 1990). Identifying areas of congruence between the articulated program theory and what is known in the literature increases a researcher's confidence in the articulated program theory (Rossi, Freeman & Lipsey, 1999).

In this study, literature review and stakeholder interviews proceeded simultaneously. The literature review was guided by the evolving identification and refinement of the wallboard model. As each outcome and intervening link was successively identified and refined, appropriate literature was sought, retrieved, reviewed and sorted by program component (4"x6" wallboard card or arrow). Areas of congruence and incongruence between the literature and the wallboard model were noted in memos.

The literature review included published and unpublished reports relating to On Lok and PACE, as well as a wide range of articles, journals and books addressing managed care, case management, integrated health service delivery models, utilization review, home care, continuing care, day programming, primary care, caregiver burden, and quality of life.

## Putting It All Together – Addressing Divergence

Viewing a program from several vantage points has a great many advantages, but it also has one very large drawback, all views are not the same. While Chen (1990) acknowledges this can create some difficulties for a researcher, he defends the merit of integrating both approaches in one study. He believes that program theory based on a number of viewpoints is superior to that based on only one.

Chen (1990) suggests that a researcher manage divergence between view points in one of three ways, by: (1) accepting that one view of program theory is superior to the other and basing the model on that view, (2) accepting that the differing views cannot be reconciled and developing different descriptions and models of program theory, or (3) exploring and explaining the differences in order to create a "best fit" description and model of program theory.

The wallboard model of CHOICE program theory developed from the stakeholder interviews became the starting point for this phase of the study. The photocopied text from the document review, the field observation field notes and the literature review memos were reviewed and added to the appropriate card or arrow on the wallboard model. The information attached to each of the cards and arrows were reviewed and areas of convergence and divergence were noted. Any card or arrow containing divergent information was then further explored. Areas of divergence were resolved and a best-fit description and model of CHOICE program theory was developed.

In this chapter the modified stakeholder – social science approach (Chen, 1990) used in this study to develop a detailed description and model of CHOICE program theory was described. Each of the four qualitative data collection strategies, document review, field observation, stakeholder interview and literature review were outlined, and the process used to develop the "best fit" integrated description and model of CHOICE program theory was detailed.

# CHAPTER FOUR - CHOICE PROGRAM THEORY

Chapter four provides a detailed description of CHOICE program theory. It is divided into four sections. Section one describes the program actions, or the services that CHOICE delivers to the program participants and their informal caregivers, and the service delivery model used by the program. Section two identifies the intermediate outcomes and explores the action hypotheses that link the program actions with these outcomes. Section three identifies the ultimate program outcomes, and explores the conceptual hypotheses that link the intermediate and ultimate program outcomes. The last section of the chapter, section four, presents the schematic model of CHOICE program theory developed as a result of this study.

## Service Components and the Service Delivery Model

CHOICE delivers a wide range of health and social services to its participants and their informal caregivers. These services can be grouped into one of four program service components: (1) home support, (2) day program, (3) health service, and (4) social service. Table 4.1 provides a summary of the actions found in each of these four program components. The remainder of this section then provides a detailed description of these service components, and an overview of the service delivery model used by the program to delivery these services.

Table 4.1

CHOICE Program Services by Program Service Delivery Component

| Component | Program Services |
|---|---|
| Home Support Service Component | • Personal care light housekeeping<br>• Delegated nursing tasks<br>• Self-care, ADL and IADL<br>• Risk assessment and management |
| Day Program Service Component | • Therapeutic activities<br>• Recreational activities<br>• Entertainment, outings and celebration (birthdays, holidays)<br>• Participant Council<br>• Personal care (bathing, toileting, hairdressing, foot care)<br>• Meal provision (lunch, bag suppers), Laundry service<br>• Transportation to the day program |
| Health Service Component | • Participant assessment, diagnosis, treatment, health monitoring, medication dispensing and administration, rehabilitation, health promotion, health education, palliation<br>• Respite, treatment bed management, acute care coordination, medical specialty medical service coordination, ancillary health service provision (dentist, denturist, seating clinic)<br>• On-call, after hour health service provision<br>• Informal caregiver education and support<br>• Transportation for medical, diagnostic and ancillary health services |
| Social Service Component | • Procurement of benefits and entitlements<br>• Preparation for placement, advanced directives, trustee and guardianship<br>• Participant, informal caregiver and family: education, support and conflict resolution<br>• Respite services<br>• Housing and community living issue resolution |

## Home Support Component

Home Support Workers (HSWRs) under the direct supervision of a Home Support Coordinator provide most of the in-home support services. These HSWRs are responsible for the provision of in-home personal care, light housekeeping and a host of delegated nursing tasks as required. One of the Home Support Coordinators explained:

> *They (the HSWRs) get people up, help them get dressed, do sponge baths, peri-care, catheter care. They put on pressure stockings, assist with medication. Everything is pre-poured so they assist with the dosettes. Any medication that is in vials they don't assist with because they can't pour medication from vials but they can handle pre-poured medication. If the person cannot physically take it out of the dosette they would do that for them. If all that a person needed was to be queued, here is your dosette, it's Monday, take your Monday A.M. meds, than they would do that. They put on medicated ointments, they help with nail care, just filing, they don't do any cutting, they help with side stream medications, nebulizers, blood sugar checks with glucometers, some meal preparation, like breakfast, making something small for the person's lunch... prepare a sandwich and leave it in the fridge or open a can of soup and leave it in a bowl so it can be put in the microwave. Then they will do light housekeeping duties, nothing heavy, tidying up a bathroom, cleaning up a tub, wiping up the floor or sink. Making beds, tidying up the person's room, tidying up the kitchen, sweeping floors, and they can mop floors, but they have to have the proper equipment like a mop and a pail, they don't get down on their hands and knees an scrub floors or wash walls. There are certain instances when we will go in and do heavy homemaking just because it will benefit the participant because the condition of the home is poor and it's affecting their health.*

In addition to the HSWRS, the occupational therapist and occasionally the physiotherapist also have a role in the provision of home support services. Their focus is in-home assessment of participant self-care potential, ADL and IADL assessment, and risk management. One of the occupational therapists summarized their role in the delivery of home support services in the following way:

> *I mainly look at self-care, ADL and IADL. I look at ... can they dress themselves, can they bathe themselves, can they get on and off the toilet, can they get in and out of bed. I do a lot of home visits looking at that and exploring and seeing what we can do to help these people be as independent as possible. So I'm looking at environmental assessments, accessibility, can they get in and out of their house, transportation issues in terms of wheelchairs, equipment at home, what can we put in to make them safe or help them do things by themselves, equipment, grab bars, benches and raised toilet seat, home renovation issues, those kind of things.*

### Day Program Component

As with the home support component, the bulk of day program component services are provided by HSWRs under the supervision of the recreational therapist. The day program component also includes transportation services to and from the day program. As one recreational therapist commented:

> *We provide a wide variety of activities for them at the centre as well as therapeutic activities that are targeted for specific populations. For instance, we do a sensory stimulation program that targets individuals that are Alzheimer type or quite demented as they are not usually getting a lot of socialization at the centre or stimulation. I run a fully-alive program that targets people that have gone through a lot of losses. I also do a community kitchen program which is a program which targets individuals who are at home alone and no one is there to assist them to make dinners, we provide bag lunches (take home meals) for them. We do a program that allows these people to make a meal and we package it up and freeze it and they take it home the next week. We do a participant council, which is a council of eight participants who meet every month... and they act as liaisons for the rest of the participants, they have a say on recreational activities and little concerns, little beefs that they have. We have two special programs that we run with a volunteer, zipper art and a ceramics program. We have wood working program and a craft program. We do out trips...We provide their meals at lunch time so they get a nice hot lunch. Individuals who may require some assistance with laundry, rather than sending someone home we do it at the centre. If someone requires a bath (needs special equipment or additional help to that provided at home) we do it at the centre on the days they come.*

### Health Service Component

A mix of health professionals (physiotherapist, occupational therapist, pharmacist, physician, clinic manager/clinical nurse specialist, on-call nurse, and LPNs (licensed practical nurses) and HSWRs provide health services. Each health professional is responsible for providing a set of discipline specific services. HSWRs are responsible for delivery of health services as delegated to them by the health professionals.

Health services can be provided in the participant's home, in the day center in either the health clinic or day program area, or when participants are admitted to the program's sub-acute treatment beds. In a participant's home this might involve administering medication or changing a dressing. In the health center it might involve completion of a regularly scheduled physical exam, and in the sub-acute treatment beds it might involve intravenous therapy or continuous monitoring.

In addition to the provision of "hands on" health services, this service component also includes medical specialty referral, acute care service coordination, ancillary health service coordination, and transportation for diagnostic and referral services.

The following interview excerpts provide an overview of the various services provided in this program service component. A physiotherapist summarized their role in the following way:

> *I try very hard to keep people functional, functioning, mobile, transferring. Trying to keep them walking, trying to help with pain, falls. We have an awful problem with falls. You know doing balance exercises, trying to improve balance. My role mainly revolves around function. Primarily to keep them as functional as possible, so if pain is preventing function or getting in the way of function then I would try to get them stronger. If it's their range of motion, or their balance, then those are the particular things that I am looking at that impact their function and their ability to stay at home and be as independent as possible.*

One occupational therapist described their role as follows:

> *I do all the cognitive testing; I do assessments for dementia and perception testing. I look at pressure stockings. I do dopplers here with the nurse, I do feeding and swallowing assessments and make recommendations on diet or referral out to get a fluoroscopy or getting a dietician in.*

The pharmacist's role was described as including:

> *Each week I check the dosettes that have been prepared by the technician. I check for accuracy and drug interaction and completeness of the order. I field any drug information questions that the team has, but also the participants and families. Once a week I get together with the physician for a drug review. We discuss any issues that are outstanding*

A physician described his role as follows:

> *As the physician I am responsible for the medical care of the participants. I try to ensure that the patients hopefully stay at home as long as possible, try to avoid sending them to emergency as much as possible and keep them out of acute care, and when they end up in acute care to try and get them out as quickly as possible.*

The clinic manager/ clinical nurse specialist role was described by the clinic manager/clinical nurse specialist as:

> *I function as the clinic supervisor with RN skills to facilitate and direct my staff who are three LPNs and a clinic attendant in the delivery of care, so I don't do much hands on, I do a lot of delegation, direction and teaching. You have to decide who the doctor is going to see, where the time is best utilized, who you can manage, who the doctor can mange. I do a lot of triage, sometimes I might get a call if the on-call nurse is not sure...I make sure that the supplies are available, that everything is here for the after hours staff... I spend a lot of time with hiring and orientation.*

The on-call nurse's role was described in the following way:

> *I'm the on-call nurse and the weekend and evening coordinator. Instead of having people call an ambulance...we go out and see them first and determine whether or not its something we can treat at home or bring them into a treatment bed or they have to go to the hospital. If somebody is in distress they call the program number; there's a program number for each site with a 24-hour answering service. Depending on what the person says the answering services will call the on-call nurse, we will then call them and do telephone triage and determine whether or not it is something that needs to be seen right now or can wait till the next business day or if they actually need to go to the ER then and there. Based on what the home support coordinator find during the day we also go out in the evening to show HSWRs how to do certain parts of care or to delegate certain tasks to them and go through them with them...On evenings and nights I am classified as a supervisor (for the LPNs managing the sub-acute care treatment beds) they'll come to me with any concerns, or if something occurs during the night they'll contact me.*

Social Service Component

The social service component is delivered by the social worker. At times the social worker works in partnership with the physician. The services provided by the social worker include the procurement of benefits and entitlements, application for placement, preparation of advanced directives, and making trustee and guardianship arrangements. In addition, the social service component also encompasses a set of less concrete activities centering on participant and informal caregiver psychosocial issues. As one social worker put it:

> *A big part of the role is one of education for the family about various illnesses, particularly the dementia, and how they cope with care giving, 60% of my time is more with families than directly with participants. For the participant a lot of it is easing their anxiety around admission, and if they don't have social supports, then it could mean, I am the one paying the utility bills or being the emotional support. It's a pretty wide range, from the very practical to emotional distress.*

In addition to the services identified in the four service delivery components, CHOICE also includes a wide range of supportive services provided by the program receptionist, clinic clerk, clinic secretary and day center supervisor. The program receptionist is responsible for the telephone, transportation arrangements, checking participants in, keeping track of participant schedule changes, and other routine paper work. The clinic clerk and clinic secretary provide support services to the physician and clinic nurse. The day center supervisor is responsible for staffing and day program management.

### Service Delivery Model

CHOICE uses what can be described as a multidisciplinary team, case-management model to deliver this broad range of home support, day program, health and social services to its participants and their informal caregivers. Each multidisciplinary team includes a program manager, center supervisor, home support supervisor, social worker, physician, clinic nurse, clinical nurse specialist, pharmacist, occupational therapist, physiotherapist, and recreational therapist as well as several LPNs and HSWRs. All team members are salaried and housed centrally in the day program/health clinic to which they are assigned. Figure 4-1 illustrates the program components and the service delivery model.

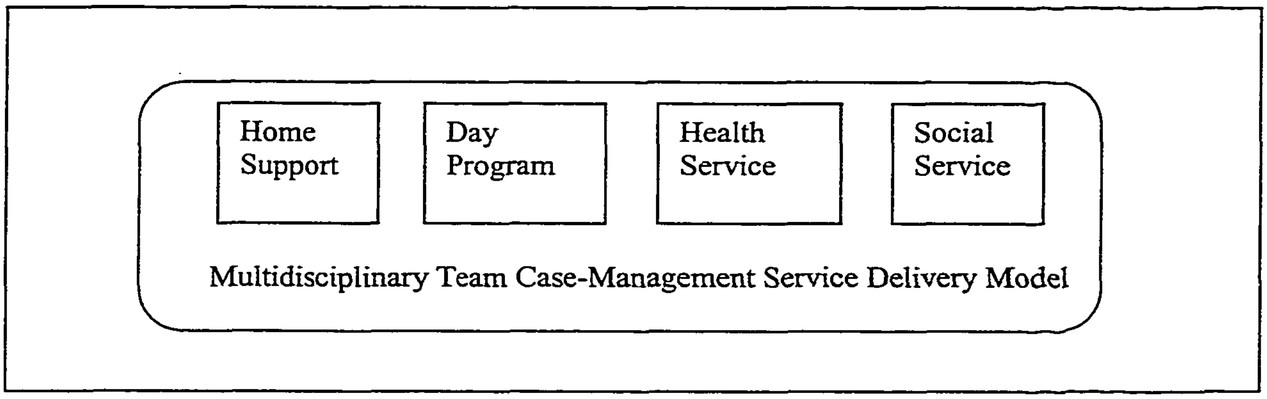

Figure 4-1.
CHOICE Program Components and Service Delivery Model

Morning multidisciplinary team meetings, which last from one to one and one half hours, are held Monday to Friday. These meetings are used to: (1) update the multidisciplinary team about services provided by the on call nurse, (2) review potential participants before their five day trial period begins, (3) make admission decisions, and (4) review participants on a three month or as needed basis (An excerpt of the field notes taken at one of these morning meetings can be found in Appendix F). At these morning meetings the HSWRs and LPNs, with the exception of the lead health clinic day center LPN, are represented by the home support supervisor and the center supervisor. The home support supervisor and the center supervisor relay team meeting information to the HSWRs and LPNs. Family case conferences are organized on an "as needed" basis.

Each multidisciplinary team is responsible for case management for its roster of participants (i.e., assessing, planning, delivering services or ensuring that services are delivered, and evaluating the effectiveness of the delivered services). On admission to the program each participant is assigned to one member of the multi-disciplinary team.

This team member acts as the official communication link between the team, the participant and the informal caregiver.

## Intermediate Program Outcomes

These four program service components delivered using this service delivery model produce three very important intermediate outcomes:

1. Provision of an easily accessible set of comprehensive services appropriate for meeting the majority of the participants' basic health and social service needs.
2. Development of a long-term, therapeutic, multidisciplinary team/ participant/ caregiver relationship.
3. Creation of an environment that enables communication, partnership and trust to flourish between the multidisciplinary team members.

### Accessible, Comprehensive Service Delivery

CHOICE provides its participants and their informal caregivers with an easily accessible set of comprehensive services appropriate for meeting the majority of the participants' basic health and social service needs. As the daughter of one participant stated:

> *What we found so convenient was everything, he was cared for totally ... the doctor, haircuts, dentist, feet, his medications were sent home ... under any other program we would have still gone to doctors and gone to the pharmacy. I just found that I couldn't do all that running. And mom can't [do it], she doesn't drive...*

Another multidisciplinary team member commented:

> *That the doctor is right here means that from home they don't have to call on a relative or neighbour to take them to the doctor. The fact that the pharmacist is right here and the medications are dispensed right here means that they don't have to get to the drug store, the fact that the nurse is here, the fact that they can have their vital signs monitored. The fact that we can get them to an x-ray, that*

> *the lab comes twice a day to collect blood samples ... it's very, very comprehensive.*

Participants rarely have to go outside the program to deal with other service providers or to obtain additional health, social, recreational or home support services. The program is a "one-stop-service-shop" for basic medical, nursing, rehabilitation, pharmacy, social, recreational, personal care, home support and transportation services.

Development of Long-term, Therapeutic Relationship

The service delivery components delivered using this service delivery model also support the development of a long-term, therapeutic, multidisciplinary team/ participant/ informal caregiver relationship. As three of the service providers, a social worker, and two physicians explained:

> *For so many of these people we catch things before they are caught in the community. There are several participants we can tell that they have a bladder infection just by their behavior. We can see somebody with a slightly elevated temperature and know they have a history of pneumonia and they are starting.*
>
> *You get this very important personal picture of a patient. If you have got the personal picture of a patient and you know you have had a chance to discuss their personalities a little bit so that you can understand what the illness means to this person then you can offer quality of care. Without understanding what the illness means to the patient you can't offer that and in the communication we have here we can gather that whole picture a lot faster and maintain it. Does that make sense?*
>
> *When we have a participant referred to us we start to look at their overall needs and from a team perspective so we identify what we feel this person's needs are. Then we talk with them, maybe not always as much as we should, we're trying to get better on that. Then we try to work with them to what they see as their needs and what we see as their needs to determine, and you can't work at a whole bunch of things at a time so we are trying to set what is most important for the participant and what we think are the most pressing. If we can't keep them medically stable then they can't do, if PT is their big thing or RT is their big thing then they can't participate. So it changes depending on how frail or more frail*

> *they are at the time. I think it is probably a combination of team and the participant or family together, to decide what is the most difficult. Maybe the most difficult is strengthening and PT and if that is their big focus then we have to try to keep them medically well enough so PT can work with them. I think it is on a one to one, its each person is different and then we have to look at their overall and decide where to go and what they want.*

This long-term, therapeutic, multidisciplinary team/ participant/ informal caregiver relationship leads to improvements in the continuity and coordination of care.

Communication, Partnership and Trust

In addition to the provision of an easily accessible, comprehensive set of services, and the development of a long-term therapeutic relationship, the CHOICE service delivery components and the service delivery model also creates an environment that enables communication, partnership and trust to flourish between multidisciplinary team members. As several of the service providers, a clinic manager, two of the physicians, and a recreational therapist, commented:

> *Communication is paramount; there is an information role that attaches to everything that happens out of the clinic. It maybe just so far as giving a piece of information that the other team members may not have or putting it in a different light so that they may have so a comprehensive understanding about a person's health issue...It's continuity and integration of the other disciplines, in the care that they are providing, I see someone and I'll bring it to my team members to say this is happening how can we help support this participant, and so it's drawing in their skills and expertise and abilities to help that person stay in the home whether it's physician, OT, PT , RT community home support. There is a lot of that kind of coordinating that goes on.*

> *...you need communications among the team members, if you've got a PT an OT a social worker how do you communicate if you are not in the same building you spend your life on the phone it doesn't work. I think if you look at a community based program you have to recognize that...I think that's why CHOICE works, one program and one doctor.*

> *Every morning we have a team conference where we are listening to everybody's approach on a certain one or two patients that have come up for review in the team conference meeting so each day we do hear everyone's point of view on that*

> *and I think that helps with everybody speaking the same language, the communication is there to understand what we are trying to realistically achieve for these chronically ill people. I interact frequently with the nurses who may already have done an assessment on different people who are presenting with clinical symptoms and they, if you like, triage and say would I see them or not they sometimes can handle small wounds and abrasions and things that are happening that just need a little clarification and communication without the patient seeing me, but then we may have questions about changing medication or insulin doses and then they may need to just communicate that on patients that I'm not actually going to see that day, we have that constant communication.*
>
> *I think with a team you get more people who are truly committed to a cause. Ultimately they have the same goal so you have more people working but they also bring their own personal flavour to it so you're problem solving and decisions are globally answered, like issues you have are done globally because you have so many people that have different backgrounds and different disciplines, but also different people so it just somehow makes it easier. A social worker doesn't have a very strong background so can't answer [certain] questions but with a physician there who has that medical focus and the pharmacist, that part gets answered. The playing field is a little easier and you have more people to make a better decision for that participant.*

An environment of communication, partnership and trust between the multidisciplinary team members enables the CHOICE multidisciplinary team to develop participant specific, as opposed to discipline specific, care plans for the delivery of comprehensive, coordinated, participant centered care.

This type of environment also results in increased understanding and appreciation among team members for the knowledge and skills that each brings to the team, as well as the development of some "unexpected" working relationships. One of the pharmacists commented:

> *I actually end up working with the home support coordinator. I didn't realize that there would be a role there when I first came. I would have never known that I would end working with the home support coordinator.*
>
> *I spent my whole career talking to doctors on the phone, I mean that is all I've ever done, there is very little personal discussion, which happens here, which is*

> *nice, whether it's with the nurse or the doctor, you have conversation. It's just not the quick telephone call.*

One of the physicians also stated:

> *The social worker frequently is present with me with family members because a lot of the time we are talking about legal issues and boundaries of competency, and you know, she knows a lot more about that than I do, so we put our heads together on where the medical and the social lines cross and present as a pair.*

Communication and coordination of care were further facilitated by the availability of phone mail, computer generated participant check-lists, and participant care plans. These computer generated check-lists and participant care plans were used to review participant medication profiles and treatment plans, and to ensure that scheduled diagnostic tests, off site visits, scheduled reassessments, and ongoing monitoring is completed as planned. The on-call nurse for the Dickenfield and Norwood sites also have access to a lap-top computer containing up-to-date participant demographic and diagnostic information, informal care giver information and current participant care plan information. Figure 4-2 identifies the program actions and the three articulated intermediate program outcomes for CHOICE.

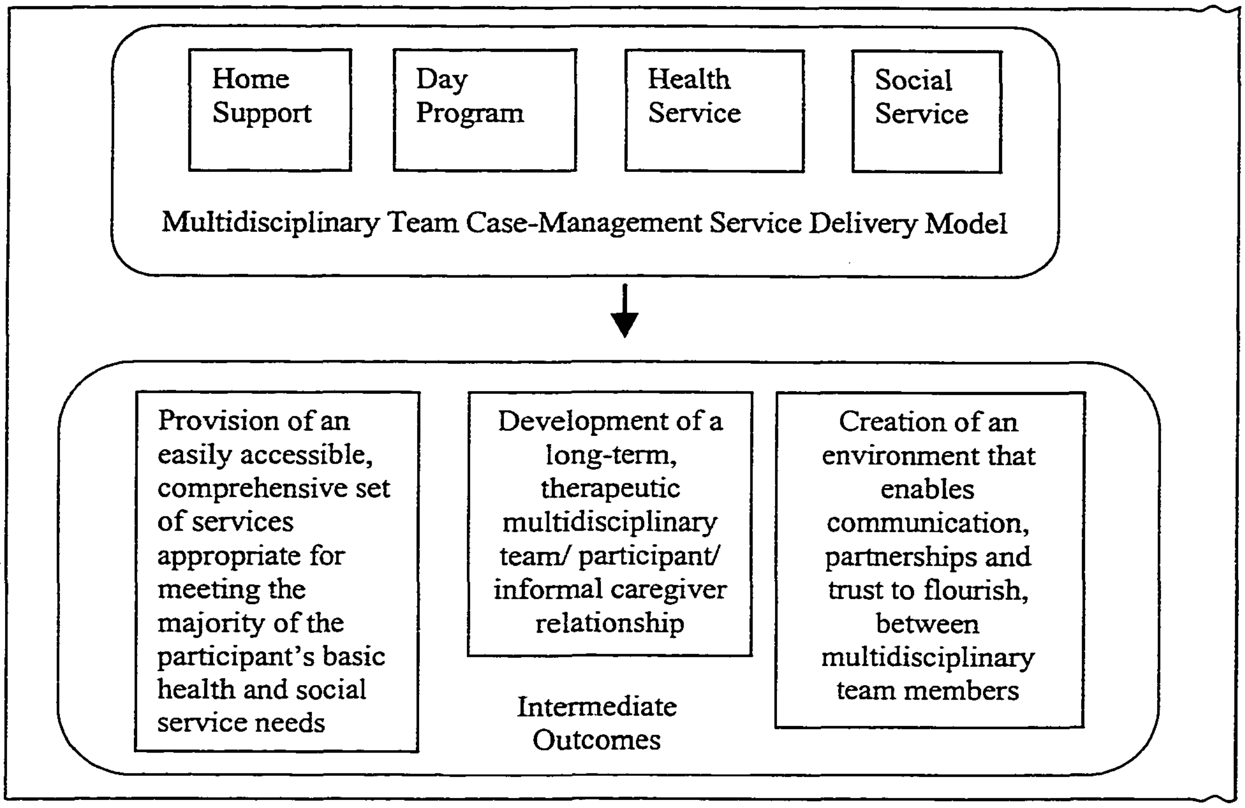

Figure 4-2.
Intermediate CHOICE Outcomes

## Enabling Conditions and Factors

Four "enabling" conditions or factors were identified as being important for CHOICE to achieve these intermediate outcomes. These included: (1) the availability of qualified, experienced general practitioners/family physicians who are willing to work on a salary basis as a member of a multidisciplinary team, (2) expanded scope of practice for the RNs, LPNs and the HSWRs, (3) a supportive management style, and (4) the fact that home support services are provided by the program and not contracted privately.

1. Physician Availability

All of the CHOICE physicians had a keen interest in working with the frail elderly. They were experienced general practitioners/ family physicians that had pursued additional education opportunities and/or training in the management of chronic illness and/or gerontology, and were willing to work on a contract basis as a member of a multidisciplinary team of health professionals. One program manager commented:

> *We found that some physicians came in expecting this to be a cake walk, and we had people who certainly were adequate physicians but didn't have the clinical skills ... the people they were dealing with were very complex. A couple of them said "I'm scared, quite frankly I'm scared." I don't have what it takes to do this and they voluntarily withdrew and we had to terminate a couple because they were dangerous. So you know you combine all those factors and it's just been extremely difficult and we are still not out of the woods we are still having trouble with physicians. Some physicians come in and they do not want to participant as equal partners in an interdisciplinary team if they can't be king of the hill they don't particularly want to play in that sandbox.*

2. Expanded Scope of Practice

CHOICE has expanded the "traditional scope of service provision" for its RNs, LPNs and HSWRs. As one of the on-call RNs explained in the following exchange (R = respondent, Q = question):

> *R: I look at what I do and try to define it, when somebody asks I say I'm doing outpost nursing within Edmonton with a certain population, and they go that's impossible.*
>
> *Q: Tell me about that because I don't understand.*
>
> *R: If you go up north there's a certain protocol for medication that can be given within certain guidelines and the outpost nurse is allowed to prescribe them within that guideline. We are developing that within the program here as well. We do have some standing orders, like gravol, suppositories, certain antibiotics, and so on. Then I don't have to page a physician get an order and try and track down a pharmacist.*
>
> *Q:Because the medications are here in stock?(nods) And you would just tell the clinic nurse and the doctor would sign the order?*

> *R: yes*

One of the LPNs describes her thoughts in the following way:

> *I really enjoy it. Not everybody that would want to do it, because it is a lot of added responsibility but it is nothing that we are not trained to do... its much different ... you're basically in charge and responsible for initially assessing them and their care and everything, their medications, just about everything other than management... we are responsible for making sure that they are on a proper diet ... if they are not eating ... same with elimination. We're responsible for making sure like if they need, a lot of them have never used an incontinent product ... I really enjoy it ... if you are working in the treatment beds they have insulin, they are preloaded now but by fall we will be drawing up the insulin. We have the clysis and we have IVs and most everybody who works here knows how to use the IV pump. We have our own ECG machine and we do that.*

One of the HSWRs put it this way:

> *Q: I know they have really expanded the role of HSWRs. Does that create any kind of problem?*
>
> *R: Not on the whole because they feel really comfortable asking for help or direction, like we know we can always go to the HSWR supervisor, and say I don't really feel comfortable can you go through it with me again and it's not a problem and we do get an opportunity to do blood sugars and stuff in the center and be supervised that way and if you are really uncomfortable with anything then someone will go with you or there is the on call nurse. There are a lot of HSWRs that didn't have a lot of medical background of whatever so you could see that it would be challenging. I think the more they do it and the more they do they feel more confident in the skills they are getting.*

To be done successfully this expansion of scope and delegation of duties did require that appropriate support in terms of education, follow-up and continuing support be available on an on going basis. As one clinic nurse explained:

> *You have to be able to be clear, systematic step wise in your delegation so that they basically get the reader's digest version. That might mean using a whole different vocabulary because as a professional you are used to talking the lingo. You need to be able to have the assurance as a professional that the person you are delegating the task to has been able to successfully demonstrate to you that they understand the directions and they're able to carry out the directions as put forth. There is a risk that sometimes you'll miss a step. If you have taught*

> *someone how to do eye drops for 15 different people and it's the same person learning for the 15th time that this is how you do a particular eye drop for a different Mr. S some of that learning is going to stay with them. Their memory does not get erased. They will know that they will have to wash their hands, but in keeping with the professional standard that is established through my licensing body I will need to review with them that their hands need to be washed. So there is a time element that is attached to delegation. I think some people can find that frustrating. They have to keep saying it over and over so there is a tendency to say by the time I get done explaining it I could have done it myself, so probably that's a big issue. Personally if I've got 15 people who have had cataract surgery and they have to have eye drops 4 times a day I don't want to be the person that is doing those 15 eyes for the next three week. There is not enough of me to go around. I have to delegate that and be assured that the checking mechanism that goes with delegation is critical and is being followed up, and the health monitoring and the management and the co-ordination and continuity that I talked about earlier is sustained.*

3. Supportive Management

CHOICE management was also willing to share decision-making and accept a higher level of patient risk than traditionally found in continuing care. As one physiotherapists commented, "*I give management the credit because really and truly they are very progressive in thinking.*" One of the social workers put it this way:

> *Here we are allowed to be connected to changes... we're asked out opinions and we're listened to and I have never had that happen before...maybe it's because of XX(the manager. She is very good about bringing everything to us and asking in return. Certainly it has a lot to do with the way she is because if she wasn't a very good connecting rod between them and us it wouldn't happen. We can get things done and changed faster than any other place I have worked. I've never felt that what I was saying was wasted or worthless or nonsense.*

Or as one of the recreational therapists commented:

> *You need to look at that person and realize how complex their life is aside from the medical issues and how they are able to stay in the community and how we work with them and put our own values, morals, standards, ethics aside and allow them to take a risk and try to support them any way we can but within boundaries.*

4. Provision of Home Support Services

One of the home support coordinators explained the importance of having home support services provided by the program and not contracted through a private agency.

> *I have worked with private agencies. I really have difficulty with them; I hate it because I can't communicate with the girls (HSWRs) so I don't know what is going on in the homes. I can't get that feedback and to me that is what makes home support work so well in this program, it's because I have direct contact with the girls, I make zillions of phone calls all the time to keep in touch with them based on new updates. That private setup is real tough...*

From a social worker's perspective:

> *I get great information from the HSWRs, they get to know the people in their homes and they see what is happening and are in there a lot and are going to do physical jobs but they can pick up a lot of emotional stuff that is going on and the family doesn't know it, so they bring me issues of one type or another. The HSWRs will just pop through the door and I'll get little notes sometimes in my mailbox.*

## Ultimate Program Outcomes

These three intermediate program outcomes: (1) provision of an easily accessible set of comprehensive services appropriate for meeting the majority of the participants' basic health and social service needs, (2) development of a long-term, therapeutic, multidisciplinary team/ participant/ caregiver relationship, and (3) creation of an environment that enables communication, partnership and trust to flourish between the multidisciplinary team members, enable CHOICE to produce several more distal or ultimate outcomes. These outcomes include: an improvement in the overall provision of care, a shift in the participants' previous use of health services, an improvement in the participants' health status and subsequently their quality of life, and a decrease in informal caregiver stress.

### Improved Care

CHOICE results in the provision of a level of care not possible using a traditional community-based health and social service delivery system. From the service providers' perspective "improved care" was the result of having access to complete up-to-date on-going assessment/monitoring information, and the ability to access and initiate appropriate health, social and home support services in a timely manner. As one of the physicians explained in the following exchange:

> *R: The single biggest thing is that you have is the physical presence and the communication. I've been in family medicine 18 years. I had a large geriatric population, and I could no longer get physiotherapy. If I wrote a referral to try and get them physiotherapy they would go on a waiting list for a few weeks, and then when they went in they might be seen once or twice, and the physiotherapist would say I can't do anything for this patient they need to go to another program, and all those programs were full and had long waiting lists. So it was a very frustrating experience because there were just no physiotherapists left out there that were easily accessible. So that was one big thing, and then the social issues, and the legal thing. The competency problems were always frequently coming up, and the home care interaction with me as a family physician. I never saw a home care nurse at all, face to face. I would speak to the voices, but I never knew their faces. When you are faceless you don't communicate in the way you should about a patient's care. You don't get this very important personal picture of a patient. If you have got the personal picture of a patient and you know you have had a chance to discuss their personalities a little bit, you can understand what the illness means to this person. Then you can offer quality of care. Without understanding what the illness means to the patient you can't offer that. With the communication we have here we can gather that whole picture a lot faster and maintain it. Does that make sense?*
>
> *Q: Do you think a GP in his office in the community can provide the quality of care to this patient population?*
>
> *R: No, No absolutely not. They are capable of doing it, and there are a lot of GPs out there that think exactly the same way that I do, but they face the same frustrations that I did when I was out there in practice. You make do with the second best. It's not the end of the world if Mrs. Smith does not get her physio that week, but it feels very uncomfortable not to do the best for your patient. I know that moving in here and being able to get that physio therapy that day or started off in such a quick easy way is much less stressful on the caregiver. If you have got to sit and wait for care to occur from other caregivers in the other disciplines (professionals) it's stressful on the caregiver as well as poor treatment for the patient...You get a resultant quality of care here that you just can't get out there.*

Or as two other physicians commented:

> *There is the comprehensiveness that allows me to do things that would otherwise not be possible, for instance putting patients on medications and feeling well assured that the compliance is going to be much better because you have dosettes. You have people monitoring the dosettes. You have a pharmacist who is very in tuned with what is going on and keeps me up to date when such a patient is or is not taking their medication. If they are not taking their medication we find out about it quickly. The things that are a complete mystery out in the community, this patient is on the drug and yet still having seizures and I don't understand why they are still having seizures, are cleared up here. We know they are taking their medication or we know they are not. A lot of the mystery is stripped away and things become somewhat easier. You can do things because you have other team members, other supports that you are talking to right away. Working out in the community as a physician you try to work with home care, but the fact is that home care is this huge vast immense mechanism, and so it is extremely difficult to partner with them. Occasionally you get one patient where home care and you are both so involved that you are having constant discussion and that is a partnership role, but usually most of the time the left hand does not know what the right hand is doing, and so things get duplicated or things get misrepresented or the physician just has no real idea about what the true problems are.*
>
> *The other thing is that it is much easier for me to initiate something because I can quickly go and talk to the physio or the social worker or whatever, give them a phone call leave a message and say I'm thinking this what do you think. We talk about it the same day, or the next day and bang. Where a physician in the community, first of all it often waits till the end of the day, well good luck getting anyone at the end of the day, you may be in your office at 5:30 but all the other health disciplines have closed their offices at 5 or 4:30 or whatever. So you end up sending off faxes, or that sort of thing, and then you wait days or weeks before someone reads it gets back to you, and it's certainly never the same person twice. There is also a trust issue out in the community. Physicians don't trust other health disciplines. You get to know the people (other professionals) here, their areas of interest, their limitations.*

Improved care was similarly described by the informal caregivers. As the following exchanges illustrated:

> *R: Well, another thing we had a problem with was, he (her regular GP) was giving her high blood pressure pills. It almost seemed like sometimes he would give her too much and other times not enough. The dosage, I mean at one time her blood was so thin she would stand up and fall, I mean I didn't know this but there are blood vessels that close that push the blood up to your head to keep you from passing out. Her blood was so thin and she had gone to the hospital for that and then they realized that her blood pressure pills were too strong, and he was*

> *always adjusting always adjusting it. Ever since she has gone to the CHOICE program we haven't had that problem.*
>
> *Q: So does she take her own medications?*
>
> *R: No, home support comes in there with a dosette. She can't take them on her own. She will forget or she'll take them and think oh, I didn't take them oh I better take them now.*
>
> *Q: So they are locked, and the home support worker has the key and will give them to her.*
>
> *R:Yes, she was over medicating herself sometimes too, and he (her regular GP) never caught it. He said oh "she is not taking her pills properly". So that's why he kept adjusting it. So now she has been going to the CHOICE program we don't have that problem anymore.*

A second informal caregiver explained:

> *R: She gets bladder infections, and she would get really sick and by the time we would take her to the doctor it had progressed really far. He (the CHOICE physician) actually managed to catch it before it advanced, before she got too sick, which was pretty good. So that is a lot better than before.*
>
> *Q: So before CHOICE with her regular GP that didn't happen?*
>
> *R: Well she'd have to get sick, she'd have to tell us, and we'd have to take her to the doctor and by this time she's kind of let it go a little bit farther too ...*
> *by having him around it's caught a lot sooner, or if there is a flu going around or something is happening it's caught a lot sooner than what had happened before, and things are checked into right away.*

An improvement in care was the result of the multidisciplinary team's ability to: (a) detect and manage acute illness in a timely manner, (b) work with participants and their informal caregivers to continuously manage chronic illness, (c) maximize the participants' self-care potential through the provision of rehabilitative and adaptive services, and (d) manage risk in the community.

Health System Impact

CHOICE also leads to a shift in the participants' previous use of health care services. As several of the physicians explained:

> *When a patient goes to acute care I will call them, call acute care the next day, to find out what the problem is, how severe it is and if there is any great need to keep them there. If there isn't then let's get them back here into one of our sub-acute care treatment beds as soon as possible. If it's a little more severe and they're going to end up in acute care for awhile, then I'll usually try to make an effort and go over there and see them at least once or twice, just to make sure that things aren't getting out of hand in terms of investigations.*

> *I explain what we are and then I explain that we have sub-acute treatment beds and that we are capable of doing this, this and this. Now if they are a two person assist that is probably beyond our resources because we only have one person on at night. But otherwise if they're just needing some time to rehab to convalesce, then let's bring them back to our treatment bed. I have yet to hear anyone unhappy with that. They have their tight beds as well, so when you hear I have a bed and I'm willing to take them even though they still have the IV, the oxygen, side-stream or whatever... We have taken care of people with pneumonia, with quite severe congestive heart failure with kidney infections, with the things that are classically considered to require a medical admission.*

> *I think if on-call were missing we would need to rethink fundamentally what we do and how we mange risk. I'm sending home someone today who has had an insulin reaction and they've been stable now for 3 ½ to 4 hours. If on-call weren't there they wouldn't be going home. I would have sent them to the hospital but I know that on-call is there and I know they will make 2 care calls tonight to that person to ensure that they've remained stable and they will reinforce the instructions that I've given to that family and participant. I am confident that with the guidelines that on-call has been given that should A, B or C happen they will have received direction from me as how to I want them to mange A, B, or C, and initiate the steps to make that happen.*

> *When I'm on-call I might get telephone calls frequently from the nurses who have the initial contact from the patient or the relative about a problem that may have arisen and generally speaking it's fairly straight forward what we have to do and the majority of the patients of course we know quite well so it's not too difficult to make some decisions over the phone. On occasion where I haven't known the patient and there has been some concern about whether or not they should go to the hospital I will either go and do a house visit or I will see them in the treatment bed that is available at Dickinsfield or Mount Pleasant. I have been to those places on a weekend on-call to cover those types of cases.*

One of the on-call nurses explained in this exchange:

> *Q: Do you have participants who just go directly to ER?*
>
> *R: We have a couple of people that are like that. They don't feel that we can accommodate what they want not what they need. So it becomes a want and need process and eventually when the ER doctors go, why are you here again a few times or they don't get treated the way they think they should they change their behaviour. Sometimes it takes a few times, but usually I have to talk them into going to ER.*

One of the informal caregivers explained:

> *She used to call 911 pretty often. It wasn't really necessary. Like I mean she would end up at the hospital with a bad case of the flu, or even a bladder infection or whatever, not knowing what else to do. Now that has gone way down. Now if something like that happens she has a button she can press and the on call nurse will phone me or she will go over there to check up first and if it seems like it's serious then she will go to the hospital.*

CHOICE produces this shift in health service utilization by providing comprehensive case management, 24 hour on-call, and sub-acute care services. The program's on-call component diverts participants from using facility-based emergency (ambulatory care), ambulance services and medical specialty services on a demand basis. The availability of sub-acute beds reduces their use of inpatient acute care services by supporting early hospital discharge, providing a holding area for continuous observation, and allowing the program's multidisciplinary team to treat a range of medical conditions that traditionally result in admission to an acute care hospital (e.g., congestive heart failure, urinary tract infections or pneumonia). It is, however, important to note that this shift away from facility-based ambulatory and inpatient care services is accompanied by an increase in the provision of non-fee-for-service primary medical care as provided by the program's physicians.

## Participant Impact

Improved care (i.e., early detection of acute illness, continuous management of chronic illness, maximization of self-care potential, and risk management) has a direct impact on the participants' health status. As several participants explained:

> *I love working in my shop (woodworking room). I like interviewing people (member of the participant council) and checking people and asking if they need help. I look out for any new ones coming like this morning where I was when you asked to talk to me, that fellow there he just came and is walking around and nobody seems to be bothering about him. I talk to him and he doesn't speak much. I don't know if he can't talk but he shook hands with me and was pretty happy. I like to help everybody, they all need help just like me.*

> *We have this program where we make things, you might have seen them in the front, the wolf is mine. I made two other things that I have given to my daughter and son-in-law. I'm making another for my son. He likes Indians, he'll like it.*

> *It's something to do a couple of days a week. It gets me out two days a week. Very seldom do I go anywhere else. I think I was only out in the back yard three times this summer, terrible. I could probably get out more if I forced myself more, but you don't.*

> *Today is lunch making. I get dishpan hands, I wash the dishes. There are two or three of us who don't participate in making lunch so the staff said okay you can wash the dishes. I wash and Joe rinses. It seems like you have a lot of laughs around here. The last time Joe got water dumped down the front of him. I said the next time we do the dishes you got to wear your bathing suit. He is a good guy. The look on his face was priceless.*

One of the informal caregivers commented:

> *It gives him something to do. Before he was just sitting in a chair all day, he couldn't even see the TV, he was so depressed, he was right on the edge...at first he didn't like it at all. It's something new and when you're used to doing stuff all your life and then all of a sudden you're just helpless...everybody likes him down there, he looks forward to it.*

A social worker put it this way:

> *They make friends, they get to know one another, they get this support. Joe doesn't show up tomorrow, one of us is phoning, so it gives you that sense of purpose ... some of them refer to us as the club or as work ... our people are so busy trying to get hold of them at times. Joe is in having a bath at two o'clock.*

> *He's leaving on the bus at 3, I won't be able to see him till Wednesday. Or they are doing something with the PT, or they are out on an appointment, or their daughter is visiting, or they're down with the doctor ... it gives you back a purpose, and it's a hard purpose because we make heavy demands, 30 below the bus is coming at 8 o'clock for an 82 year old and she'll come muffled up and the first week she sleeps because she is so tired and then she gets into it and the mood goes up ... one guy couldn't walk and now he uses a walker... it gives you back that purpose in life and it means you can stay at home. You're still able to do it.*

One of the recreational therapists described it this way:

> *CHOICE gives them an opportunity to meet other people who are in the exact same position that they are in and dealing with the same kind of issues, and it allows them somewhere to go each day. A lot of them went to work all the time now they don't work they're retired, it's been twenty odd years since they have worked and they can't do what used to fill up their time post retirement. They get on a bus and they go to where they know someone is going to help them with a bath, look after their nails, they get a good meal, their medications. Somebody is looking out for them but allowing them to live in their own home and make their own choices. Have that opportunity to socialize, meet new people because lots of times the only time that they ever leave the house is to come to CHOICE. Its too difficult for the family to take them out or they don't want to go out. They get caught up in that little circle and the four walls get really closed in. It gives them a reason, hey somebody knows if I'm not here and somebody knows who I am, and so that makes them feel important.*

The end result of improved health status for the program participants was an increased potential to engage in a range of activities that improved their quality of life, such as exercise, proper nutrition, recreation, and socialization. These activities allow participants to develop a personal sense of belonging and purpose.

## Informal Caregiver Impact

The program also has an impact on the participant's informal caregivers through its ability to reduce caregiver stress. One of the social workers stated:

> *A lot of the task is to sit here and listen, to truly listen and hear what they have to say and accept what they have to say regardless of my feelings about what they are saying, and then try to work through, maybe to a compromise situation. One of the biggest issues with caregivers is to listen to them talk about how tough it is.*

The daughter of one of the informal caregivers indicated:

> *Well, lots of the days he went she just laid and rested and then other days, she has a four wheeled cart so she'd go out for coffee. She has a couple of sisters here and they would go out...just things like that to try and recoup her energies for the evening.*

Two of the informal caregivers talked about the program

> *If we asked XX (one of the service providers) ... he'd tell us different things when we were in to have a meeting with him, you know once a month. And he gave us good idea. Like he said to mom once, you don't tell Joe that you are putting him out, he is going to a program so you can get your rest and he can stay at home. It's the way of presenting it.*
>
> *I just shipped her out the door and let them do their thing. I felt confident that they were doing a good job there, that she was secure there. I felt that she was well looked after and I appreciated that and was grateful for that...she talked a lot about her dancing and the musicians so she had probably more fun there than she would have, I don't see the opportunity for her to have that kind of stimulation and entertainment, so that was a good thing for her. I think it was quite a useful thing I'm glad it's there, it's well worth it. The other thing I liked is that they looked after her physically very well. Like when she, they were monitoring her fairly well I thought and she was fairly healthy. I thought that there was a time when she was starting to cough a lot more and I thought she was going to get pneumonia again, but they kept up her treatments and sent me everything that I needed and they helped her recover.*

CHOICE impacts ongoing caregiver stress in two ways: by (a) providing informal caregivers with physical assistance with and/or relief from their care giving responsibilities, and (b) providing the information and emotional support necessary for them to continue in their caregiving role or to terminate it when they can no longer continue.

In some instances it was not possible or feasible to maintain the participant in the community. Two of the service providers and one of the informal caregivers explained:

> *When a person is admitted to the program we always meet with the person most closely connected to them at that time. So they get a clear understanding of the program and what we can offer, because frequently our participants may not understand on a cognitive level and appreciate what we can do for them, it's the*

> *caregiver that is needing the relief. They want to keep the person at home but they need the relief so we have to get on track. So we interact with them right at the start. It's not infrequent that I'll do several phone calls a day to different family members to touch base about changes in medications, or if I'm worried, or if I've heard a worry on their side they may have communicated it to the nurse and the nurse communicated it to me, I phone the family member. If there are particular families where a lot of stress is going on and they've got brothers and sisters, the caregivers have got brothers and sisters who are all not infrequently having differences of opinion as to how mom or dad's care should be handled we get them into a family case conference. We get them in and talk to the whole crowd and try to get some understanding all round as to what we are trying to achieve and what's realistic and what isn't.*
>
> *It took me about six months to realize that I needed to use the respite system. The first couple of times I used it, it was because I had to go out of town and then I used it to take a weekend off, suffered tremendous guilt all weekend but decided yeh, this was a good move... I'll be using it again at the end of August...I find that very useful especially for me because I do have a challenging job.*
>
> *The first time somebody places their relative in respite, the family doesn't get any respite. They are worried about them, then they find out that dad or mom or wife or whoever the individual hasn't fallen apart, and comes home, and 9 out of 10 times they come home as if they have never been away, and they think oh, they can book more respite, so its getting used to us, another team outside of the family sharing the burden of care...its getting them used to letting go, and it helps the caregiver get a bit of a life...so it's that breaking. It is in some ways a transition.*

In instances when it is not possible for the participant to remain in the community the program helps the informal caregivers "let go" or prepare for the participant's eventual move to continuing care. During its first two years of operation, 36% and 30% of participants entered continuing care.

## Modeling CHOICE Program Theory

Attempting to model CHOICE, which is in essence a primary health and social services delivery system for the frail elderly, using a two-dimensional box and arrow diagram like the one illustrated in figure 4-3 below, was challenging. CHOICE combines several structural elements found in a traditional Health Maintenance Organization (HMO):

- capitation (census based block funding),
- salaried physicians,
- a participant registry,
- first contact - gatekeeping,
- the use of non-specialist first contact physicians, and
- vertical integration (sub-acute care treatment beds).\

It then adds additional structural and process components integral to primary care[3] and case management[4]

- provision of a set of easily accessed community based health and social services appropriate for addressing the majority of basic health and social needs of the program participants,

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[3] For this study primary care was defined as the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, practicing in the context of family and community (Institute of Medicine, 1996).

[4] Case management was defined as the process of planning, organizing and monitoring the services and resources needed to respond to an individual's care needs (American Hospital Association, 1983).

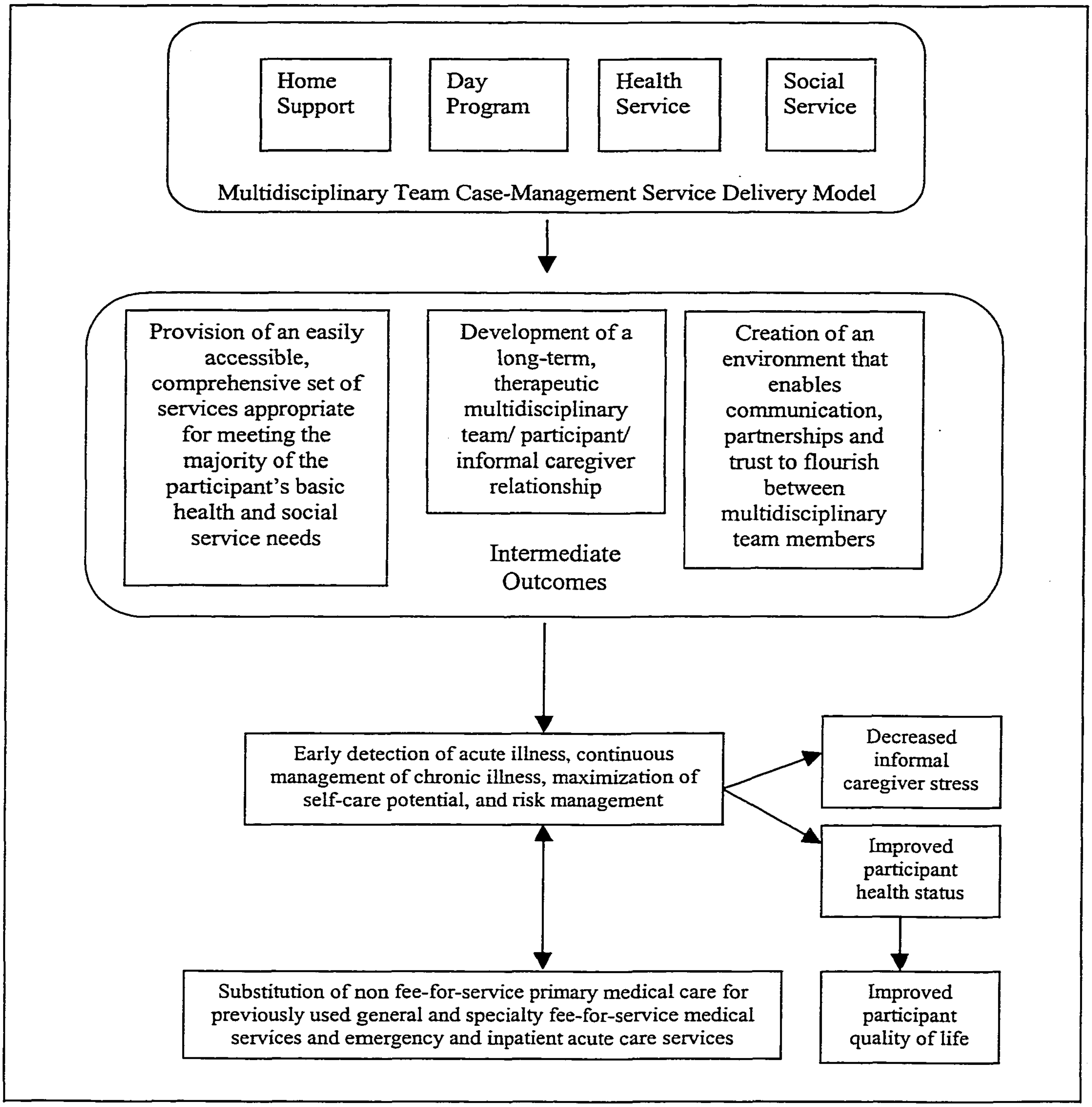

Figure 4-3.

CHOICE Program Theory Model

- longitudinality, or the development of an ongoing relationship between service providers and program participants over time,
- use of a multidisciplinary team of health professionals (including physicians), social service professionals and paraprofessionals to plan and deliver services,
- expanded scope of practice and delegation of duties to paraprofessionals,
- extensive formal and informal information sharing between service providers, participants and informal caregivers,
- provider initiated participant assessment,
- ongoing scheduled multidisciplinary team case review, and
- development of a participant/informal caregiver centered as opposed to discipline specific participant care plans.

What very quickly became apparent in attempting to model CHOICE is that CHOICE works by combining a number of elements. Its success cannot be traced to any one action or activity. It is the combination of elements that together impacts the how, where and when of care provision and which, in the end, results in change in the participants' previous health service utilization patterns.

This combination of elements and components enables CHOICE to:

1. create a bounded, easily assessed, service delivery system through which a comprehensive set of appropriate health and social services is delivered to the program participants;
2. support the development of a long-term therapeutic provider/participant/informal caregiver relationship that promotes early

detection of acute illness, continuous management of chronic illness, maximization of self-care potential and risk management; and

3. create an environment that enables communication and partnership to flourish between multidisciplinary team members, participants and informal caregivers.

Taken together these intermediate outcomes result in the provision of timely, coordinated quality participant care, which in turn impacts:

1. the participant by improving their health status, and increasing their potential to engage in a range of activities that improve their quality of life;
2. the participant's informal caregivers by providing relief and support in managing their day-to-day care-giving responsibilities; and
3. the health system by substituting non fee-for-service primary medical care for previously used general and specialty fee-for-service medical services, and emergency and inpatient acute care services.

In summary, this chapter provided a detailed description and a schematic model of CHOICE program theory. It included a detailed description of the program service components and the service delivery model. It outlined the three action hypotheses and the conceptual hypotheses or the process by which the action hypotheses produce the identified program impacts. The chapter concluded by presenting the "best-fit" schematic model of CHOICE program theory developed as a result of this study.

# CHAPTER FIVE – RECONCILING DIVERGENCE

This study was undertaken in order to articulate CHOICE program theory. Program theory describes and models the chain of events that leads from program actions to program outcomes. Successful creation of a best-fit description and model of program theory is dependent upon the researcher's ability to create a convergent, plausible representation of reality. This requires that a researcher identify, explore, and reconcile any differences or divergence in the information collected from a variety of sources. This chapter outlines the process used to reconcile divergence in the information collected through document review in order to create a "best-fit" description and model of CHOICE program theory.

## Convergence

The information collected through field observation and stakeholder interviews was easily integrated into a congruent, convergent plausible representation of reality. The interactions observed between the participants, between the participants and multidisciplinary team members, and between the multidisciplinary team members at morning meetings, complemented and supported the information collected during the in-person stakeholder interviews. In no instance was a difference found between what was seen and what the stakeholders said was happening. Nor were any differences found between the information collected from each of the various stakeholder groups through in-person interviews. Program recipients (participants and informal caregivers), service providers (multidisciplinary team members), and management (CHOICE management and CHA management) all provided similar versions of the same story.

The information retrieved through the literature review provided support for the emerging description and model of CHOICE program theory in an entirely different way. As hypotheses explaining the links between the program's actions/activities and outcomes were generated, pertinent literature was identified, retrieved, reviewed and sorted by program component. In many ways the retrieved literature played the role of "devil's advocate". It forced the researcher to critically think about each of the components and the intervening links identified in the evolving wallboard model from a different perspective. In doing so the literature acted to increase confidence in the model as an unbiased representation of reality.

The literature retrieved in the areas of primary health care (Starfield, 1992, 1998), managed care (Kongstvedt, 1996), and case management (Austin & McClellend, 1996) was particularly useful in this regard. Several of the text units selected from the interviews and the intervening action hypotheses identified in the evolving wallboard model mirrored concepts and/or explanations identified in the literature (e.g., access, comprehensiveness, longitudinality, gatekeeping, assumption of risk, and case management).

The literature also provided support for several of the conceptual hypotheses identified in the wallboard (e.g., the role that easily accessible, comprehensive, longitudinal service provision plays in shifting service provision to the community and improving the quality of care) (Starfield, 1998), and the role that case management plays in improving the coordination and integration of care (Austin & McClellend, 1996). In this study the information extracted through the literature review was congruent with and supportive of the evolving wallboard model of CHOICE program theory.

## Divergence

Divergence centered on the information extracted through the document review, specifically in relation to: (1) the program's target population, (2) the expected program outcomes, and (3) CHOICE's comparability with PACE.

### Target Population

The CHOICE Program Description (1998) identified the functionally frail, the medically frail, those with chronic mental illness, and those with dementia as the program's target population. The field observation and stakeholder interviews revealed that a good deal of differential targeting in relation to these four groups existed. Those with chronic mental illness and advanced dementia were frequently excluded in the selection process. This difference was explained by one of the program managers:

> *CHOICE is really intended as a replacement for continuing care particularly at the typical entry level end ... it really is to pick up where home care has to leave off because their care needs become too complex or too unscheduled or too comprehensive for home care to continue to manage well in the community. So it's a replacement for that end and I think what we found was that the target has become more defined as we have gone on. We are seeing the functionally frail stable type of participant that you expect to find in continuing care. What we are seeing that we maybe didn't expect in the numbers we are seeing and is perhaps one of the best target groups is the people with quite a number of chronic conditions. I think [they]can probably be managed better in CHOICE than in continuing care because of the presence of a primary medical service right on site. And I think the referring community has just by experience begun to define who the best participants are, primarily those two groups. We are also seeing people with dementia fairly mid stage that need some kind of secure kind of environment. We certainly have them, I'm not sure we manage them or the mental health population, which we are currently taking a look at. I think that the program per se is most successful for the early end of continuing care participants and the medically complex.*

Two further areas of concern related to the target population centered on the participant's willingness to comply with the program as outlined, and the availability of a reliable, capable informal caregiver. In 1996 and 1997 approximately seven percent (n=11) of individuals admitted to the program were later discharged because they were "unwilling to comply with their service plan". These individuals continued to "doctor shop" outside the program, refused to use the on-call program component, repeatedly accessed emergency directly, and/or refused to attend the day program as scheduled.

In other instances, when no reliable capable informal caregiver willing to partner with CHOICE to reasonably manage after hours participant risk, admission to the program was refused, and application for continuing care placement made. One of the physicians explained:

> *For example,e some people might come with the expectation that when their mom and dad comes into the program that we look after everything to the degree that even at weekends we might give them 24 hour care and obviously that's not the way this program runs. We would hope that family members would still be involved with their mother or father and that they will still maintain a certain amount of supervision themselves at weekends for those people who need it.*

It seems that CHOICE is in reality targeting two of the four originally identified population groups, the functionally frail and medically frail, then selecting from those two groups those willing to comply with the program as outlined, who have an available, reliable, capable informal caregiver willing to partner with the program.

### Expected Program Outcomes

The second area of divergence in the information collected through the document review related to the nine expected program outcomes identified in the June 1998 Program Description (p.3):

1. improved health status through early intervention and health promotion,
2. reduction in medical visits by improving access to needed non-medical services,

3. avoidance of unnecessary or premature institutional placements, thereby improving quality of life and reducing system costs,
4. reduced medical utilization,
5. improved accountability to consumers through the provision of an integrated and comprehensive point of health support within the region,
6. reduced use of acute care days,
7. improved effective use of existing resources through a streamlined screening system and referral system,
8. increased consumer satisfaction , and
9. expansion into a managed care system.

Table 5-1 compares the above nine expected program outcomes identified in the CHOICE Program Description (1998) with the program outcomes identified through the stakeholder interviews and supported by the field observation. Several differences between the two exist, the most notable being the failure of the expected outcome list to include the provision of comprehensive, accessible, coordinated patient centered care, the development of long-term, therapeutic multidisciplinary team/participant/informal caregiver partnerships, or a reduction in caregiver stress. Part of this oversight might be explained by the fact that the program's planners did not make an attempt to explicate program theory for CHOICE while planning the program. CHA viewed CHOICE as a Canadian replication of PACE. The need to explore how CHOICE may or may not have been expected to produce similar results to PACE might not have been viewed as necessary. Or, it could be due to the fact that the nine expected program outcomes identified in the CHOICE Program Description (1998) were extracted from

Table 5-1.

A Comparison of Program Outcomes Identified in the Document Review with Those Identified Though Stakeholder Interview

| Articulated Program Outcomes (stakeholder interviews) | | Expected Program Outcomes (document review) |
|---|---|---|
| The provision of comprehensive, accessible, coordinated patient centered care | ↔ | Not an identified program outcome |
| Development of long-term, therapeutic multidisciplinary team/participant/informal caregiver partnerships | ↔ | Not an identified program outcome |
| Possibly some short-term delay in institutionalization for selected participants through the reduction of caregiver stress, the provision of physical assistance with, or relief of, care giving responsibilities, and/or the provision of the emotional support | ↔ | Avoidance of unnecessary or premature institutional placements, thereby improving quality of life and reducing system costs |
| Improved health status through early detection of acute illness, continuous management of chronic illness, rehabilitation, maximization of self-care potential and risk management | ↔ | Improved health status through early intervention and health promotion |
| Increased use of first-contact primary care medical services and decreased use of facility-based acute care emergency and inpatient services, and a corresponding decrease in ambulance, diagnostic, pharmaceutical and medical specialty services | ↔ | Reduction of medical visits by improving access to needed non-medical services.<br>Reduced medication utilization<br>Reduced use of acute care days |
| Improved quality of life for the participants | ↔ | Not an identified program outcome |
| A reduction in caregiver stress | ↔ | Not an identified program outcome |

various CHOICE Pilot Program Steering Committee meeting notes by the external evaluator who prepared the document (B.Christie, personal communication June16, 1999). Several members of the CHOICE Pilot Program Steering Committee Steering had either visited PACE sites, been involved in negotiating the three-year technical assistance agreement with the Milwaukee PACE site, and/or reviewed PACE documentation.

Another difference between the two is the role the program was expected to play in avoiding institutionalization. It was thought that CHOICE would result in avoidance of unnecessary or premature institutional placement by maintaining individuals in the community for as long as possible. The stakeholder interviews revealed that this was not the case. In this instance, literature related to the determinants of institutionalization provided insight and helped reconcile this difference. Several social-demographic and health related characteristics such as: age (>85 years), living alone, having no children or children not living close by, having minimal social support and/or limited assistance for the performance of IADL (independent activities of daily living (e.g., shopping, banking, etc), and having a high level of functional disability or cognitive impairment have been found to be related to institutionalization (Branch & Jette, 1982; Shapiro & Tate, 1988). These characteristics can be used to describe the individuals CHOICE has difficulty coping with; that is, individuals who require extensive after hours coverage to remain safely in the community. One of the home support coordinators put it this way, "*If somebody is here five days a week and they are getting four hours of home support in the evening and a couple in the morning, I mean they're placement.*" It seems that CHOICE has the ability to delay institutionalization for some types of participants and informal caregivers, but the program can in no way be considered as a substitute for continuing care for the frail elderly population.

A further area of incongruence between the expected and the articulated program outcomes related to participant health status. Although improved health status was identified as a program outcome in both the documentation and the wallboard model, the route by which it was achieved differed. Both the program documentation and the articulated program theory identified early identification and treatment of acute care illness as playing a role in improving health status. The program documentation failed to identify appropriate management of chronic illness and disability, rehabilitation, maximization of self-care potential or risk management as playing a role. The importance placed on the role of health promotion identified in the program documentation was also not supported in the wallboard model.

Appropriate management of chronic illness and disability, rehabilitation, maximization of self-care potential and risk management are critical components of CHOICE's success. The most common diagnoses recorded for CHOICE participants in descending order of frequency included: hypertension, osteoarthritis, cerebral vascular accident, mild depression, chronic obstructive pulmonary disease, diabetes mellitus, congestive heart failure, anemia, atrial fibrillation, peripheral vascular disease, coronary artery disease, osteoporosis, cognitive impairment and myocardial infarction (CHOICE Program Statistics, 1997). Something more than a focus on the early identification and treatment of acute care illness and health promotion is required in order to optimize participant health status for this population.

Once again the literature helped reconcile this difference. Optimizing health status for those with chronic illness requires that an individual successfully complete four tasks (Wagner, Austin and Von Korff, 1996):

- engage in activities that promote health and build physiological reserve, such as exercise, proper nutrition, social activation and sleep,

- interact with health care providers and systems and adhere to recommended treatment protocols,
- monitor their own physical and emotional status and make appropriate management decisions on the basis of symptoms and signs, and
- manage the impact of the illness on their ability to function in important roles, on emotions and self-esteem and on relations with others.

Service delivery models that support the completion of these four tasks share five common elements (Wagner, Austin and Von Korff, 1996):

- the use of explicit client-specific plans and protocols,
- the reorganization of the practice to meet the needs of patients who require more time, a broad array of resources and closer follow-up,
- systematic attention to the information and behavioral change needs of patients,
- ready access to necessary expertise, and
- supportive information systems.

The stakeholder interviews and field observation confirmed that, not only were the above five elements present in CHOICE, but also that the program supported participants in accomplishing each of the four tasks necessary to optimize health status. Whether or not failure to include appropriate management of chronic illness and disability, rehabilitation, maximization of self-care potential or risk management as expected program outcomes in the CHOICE Program Description (1998) is unknown.

Another area in which the documented program outcomes differed from the actual outcomes was in relation to health service utilization. The CHOICE Program Description (1998) identified two program utilization outcomes, reduced medical visits and reduced use of acute care days. The first outcome was not achieved; the program actually resulted in a 127% increase in the use of general practitioner/family physician services (CHOICE Evaluation Project, 1998). The second outcome, reduced use of acute care days was achieved. CHOICE resulted in a decrease in the number of separations (30% reduction), total inpatient days of stay (55% reduction), and outpatient visits (25% reduction), but added to this was also decreased use of ambulance (11% reduction), diagnostic, pharmaceutical (86% reduction), and medical specialist services (18% reduction) (CHOICE Evaluation Project, 1998).

### PACE and CHOICE

A third area of divergence uncovered as a result of this study centered on the comparability of CHOICE with PACE. CHA describes CHOICE as Canada's first replication of PACE (CHOICE Resource Manual, 1998). In reality, as Table 5.2 illustrates, several important differences exist between the two programs (CHOICE Evaluation Project, 1998).

Three of the most notable differences are: the assumption of risk, the level of vertical integration, and the nature of program funding. Assumption of risk relates to the fact that PACE is responsible for assuming the cost of any acute or continuing care services provided to its participants; CHOICE is not. Vertical integration relates to the fact that PACE contracts with acute and continuing care to provide needed services, and then continues to be actively involved in the management of participant care during acute and continuing care admissions. PACE participants are not discharged when they require continuing care services, but move in and out of continuing care on an "as needed" basis. When CHOICE participants access acute care services they are cared for by the acute physician assigned to them, CHOICE physicians serve as a conduit for information exchange with the acute care physicians, but do not continue to be involved in day to day management of care. When CHOICE participants are admitted to continuing care they are discharged from CHOICE. Funding relates to the fact that PACE is funded under a managed-care capitation system while CHA provides block funding to CHOICE.

Table 5.2

Differences Between CHOICE and PACE

| | PACE | CHOICE |
|---|---|---|
| Assumption of financial risk | Program assumes full financial risk for all types of health services, including acute and continuing care. | Program does not assume any financial risk for acute or continuing care. |
| Vertical Integration | Program establishes contracts with acute and continuing care service providers. Providers continue to be actively involved in participants care while in acute and continuing care. | Program does not establish contracts with acute or continuing care. Providers do not continue to be actively involved in participants care in acute care. Participants are discharged from the program upon admission to continuing care. CHOICE includes a sub-acute bed and emergency on-call component, whereas PACE does not. |
| Funding | Capitation funding. | Block funding. |
| Eligibility | PACE is available for Medicare participants and for others wishing to individually purchase the services. No single-point-of-entry system exists for PACE. | CHOICE is available to all who meet the eligibility guidelines and for whom the program is assessed to be the most appropriate service alternative. CHOICE referrals proceed through home care coordinators via the single-point-of-entry system before being forwarded to the CHOICE intake coordinator. |

A further difference between the two programs relates to eligibility. PACE is available to Medicare recipients and others who wish to pay for the services out-of-pocket. CHOICE is a publicly funded program available to all who meet the eligibility guidelines and for whom the program is assessed to be the most appropriate service alternative. All CHOICE referrals proceed via Alberta's single-point-of-entry system for continuing care.

The magnitude of these differences between the two programs brings into question not only CHA's decision to consider CHOICE to be a replication of PACE, but also CHA's belief, as expressed in the program documents, that CHOICE would achieve comparable outcomes to those achieved by PACE. A review of the CHOICE program statistics (1997) for the 1996 and 1997 indicated that CHOICE participants make more use of continuing care and have a lower rate of death in place than do PACE participants. In 1996 and 1997, 36% and 23% respectively of all CHOICE participants were discharged to continuing care facilities. Less than seven percent of PACE participants use any continuing care facilities on a monthly basis (On Lok, 1993). In 1996 and 1997 approximately 20% of CHOICE participants died in place. Approximately 70% of PACE participants die in place (On Lok, 1993). Unfortunately further comparison of PACE and CHOICE participants in terms of other types of health and social service utilization was not possible as more detailed client specific utilization data were unavailable.

The other difference between the two programs, participant eligibility, also raises concerns about the comparability of the two programs. Since its inception PACE has constantly had difficulty meeting and maintaining per site enrollment quotas (Branch, Coulam & Zimmerman, 1995). At the time of writing, all three CHOICE sites had waiting lists. This difference leads to questions as to the comparability of the service utilization plans for both programs.

## Explaining the Difference

It is not unusual for a researcher to find, as was found in this study, that the "official" program view and the "real" program view differ (Rossi, Freeman & Lispey, 1999). The health service field is replete with vague programs based on what seemed like a good idea at the time, or an expedient method for dealing with political pressure, or a quickly written proposal for external funding. In many instances these programs were never fully conceptualized to begin with (i.e., the program goals were never clearly identified, the actual intervention was never described in detail, and/or the links between the intervention and the goals were never articulated or questioned). In others instances some of the original conceptualization work may have taken place, but the program was allowed to evolve and develop over time until the program being delivered bears little resemblance to the program originally envisioned.

In this study divergence between the official program view, as outlined in the program documents, and the real program view, as developed from field observation, stakeholder interviews and supported by the literature review, was attributed to the lack of up-front program conceptualization, or perhaps in this situation re-conceptualization would be a better word. CHOICE program theory was not articulated during program development. CHA viewed CHOICE as a replication of PACE even though PACE and CHOICE differ in several fundamental ways. The result of this oversight is that the program goals and the intervening mechanisms identified in the CHOICE program documentation reflect those developed for PACE, not those of CHOICE.

Failing to adequately conceptualize program theory before undertaking an impact assessment can be risky when divergence exists between the expected program outcomes and the actual program outcomes. It may result in a program being labeled as unsuccessful, when in reality it may be producing some very valuable but unexpected outcomes. Or, it may result in a program being judged to be less successful than it really is, as was the case with the 1997 CHOICE impact assessment, which failed to capture the full extent of the program's success.

In summary, this chapter outlined the process used in this study to reconcile divergence between the information collected via the document review with that collected through field observation, stakeholder interview and literature review. The next chapter concludes the dissertation. It includes a summary of the main findings of the study, makes recommendations for others wishing to use this method to articulate program theory, and identifies several potential areas of future research.

# CHAPTER SIX – SUMMARY, RECOMMENDATIONS AND FUTURE RESEARCH

This chapter concludes the dissertation. It has been divided into three sections. Section one summarizes the study findings. Section two reviews the method used for the study, and makes recommendations for other researchers interested in articulating program theory. Section three identifies potential areas of future research, both in relation to CHOICE, and in relation to other health service and program initiatives directed toward the frail elderly.

## Summary of the Findings

Fragmented is perhaps the most accurate way to describe how health and social services are traditionally provided to one of our most vulnerable populations, the frail elderly (those over the age of 64 who have one or more chronic illnesses, e.g., arthritis, diabetes, congestive heart failure, dementia, chronic obstructive pulmonary or cerebral vascular disease). Service recipients and their informal caregivers are confronted with a confusing array of health and social services provided by a wide range of professionals and para-professionals, all of whom are linked to a variety of institutions and service agencies. These institutions and service agencies use different selection criteria, frequently have incompatible or overlapping service jurisdictions, and tend to have different funding and accountability structures. The result is inappropriate costly use of medical specialists, acute care facilities, and continuing care institutions (Bergmen, Beland, Lebel, Conrandriopoulos, Tousignant, Brunelle, Kaufman, Leibovich, Rodriguez, & Clarfield, 1997).

Since the early 1970s a small number of alternative service delivery initiatives have been developed in an attempt to improve service integration and decrease cost. These initiatives include the Darlington Project in the United Kingdom; the Abel reform initiatives in Sweden; the development of SHMOs (Social Health Maintenance Organizations) and the On Lok, and PACE programs in the United States, and the development of the SIPA (Système de services intégérs pour personnes gée s en perte d'antonomie) and CHOICE programs in Canada (Bergmen et al., 1997).

This study was undertaken to develop an understanding of how one of these initiatives, CHOICE, impacts the provision of health and social service delivery for the frail elderly. It found that CHOICE combines elements found in a traditional Health Maintenance Organization (HMO) with elements and process components drawn from primary care and case management to deliver a broad range of home support, day program, and social and health services to its participants and their informal caregivers. This delivery model enables the program to: (1) provide program participants and their informal caregivers with an easily accessible set of comprehensive services appropriate for meeting the majority of the participants' basic health and social service needs; (2) support the development of a long-term, therapeutic, multidisciplinary team/ participant/ caregiver relationship; and (3) create an environment that enables communication, partnership, and trust to flourish between the multidisciplinary team members.

The overall result of the program as delivered was the provision of a level of care not possible within the traditional community-based health and social service delivery system. CHOICE promotes improvement in the early detection of acute illness, continuous management of chronic illness, rehabilitation, maximization of self-care potential and risk management; all of which lead to improved participant health status and quality of life, and decreased informal caregiver stress.

The program also produces a change, or shift, in the participants' use of health care services. CHOICE decreases reliance on medical specialist and facility-based emergency and inpatient acute care services, thereby leading to a corresponding decrease in the use of ambulance, diagnostic, and pharmaceutical services. CHOICE accomplishes this service shift by increasing the participants' consumption of first-call, non fee-for-service, primary medical care.

Four enabling factors play a role in CHOICE's ability to produce these results: (1) the availability of qualified, experienced general practitioners willing to work on a salary basis as a member of a multidisciplinary team, (2) expanded scope of practice for the program's RNs, LPNs, and HSWRs, (3) supportive management, and (4) the fact that home support services are not contracted privately.

## Review of the Method

The method used for the study was drawn from the field of program evaluation and based on the work of Chen (1990) and Rossi, Freeman and Lipsey (1999). It involved use of a stakeholder-social science approach similar to that recommended by Chen (1990) which four qualitative research strategies: document review, field observation, stakeholder interviews and literature review, were employed to develop a "best fit" description and schematic model of CHOICE program theory.

Unlike previous efforts to articulate program theory, which have most often been undertaken within the confines of an evaluability assessment[5], this study was completed on the heels of recently completed "black-box" impact assessment which showed that CHOICE was successful in reducing health service utilization and improving the quality of life of its participants (CHOICE Evaluation Project, 1998). Articulating program theory in this context forced the researcher to deal not only with the expected (the document review), but also with the possible (the literature review), and the actual (the field observation and stakeholder interview). In doing so, this study provided a concrete example of an attempt to broaden our understanding of the "how to" of program theory articulation. It answered Lipsey and Pollards' (1989) call for researchers to "explore and demonstrate the power of the theory-driven approach through a range of actual applications that provide practical models or exemplars to illustrate the advantages as well as the details of how it is done"(p.327).

Although not feasible in this study, two additional data collection strategies should be considered by others wishing to articulate program theory in a similar context, the use of focus groups and an expert panel. Focus groups should not be viewed as a substitute for in-person interviews, but in addition to. In-person interviews offer several advantages over focus groups. They allow a researcher to tailor the line of discussion to the individual, and to follow where the individual being interviewed leads. They are ideal for providing one-on-one encouragement and support for those who have difficulty speaking in a group. They enable a respondent to talk about sensitive subjects in private, and they can be conducted in the comfort of the respondent's home at a time that suits

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[5] Evaluability assessment is a systematic process for examining a program (or a proposed program) to assess its structure, determine the plausibility of it achieving its intended goals, the evaluability those goals,

them best. A combination of in-person interviews followed by separate focus groups for each of the stakeholder groups is recommended. The in-person interviews could be used to develop the tentative wallboard model of the program theory. Focus groups could then be used to present the tentative model to each stakeholder group. The placement of the cards and arrows, the description of program components, and the identification of intervening links could have been reviewed, discussed and clarified with each stakeholder group using focus group strategies.

This study could also have benefited from the use of an expert panel. Researchers often tend to work with a variety of programs each of which is designed to address a variety of issues using a variety of strategies. No one individual can be expected to become an expert in everything. This study alone involved reviewing literature in the areas of managed care, case management, integrated health service delivery models, utilization review, home care, continuing care, day programming, primary care, caregiver burden, and quality of life. Having a panel of experts act in the role of "devil's advocate" would have been beneficial.

## Potential Areas of Future Research

Two areas of future research were identified as a result of this study. The first area centered on the need for further evaluation of CHOICE, and the second on future efforts to increase our understanding of how best to deliver health and social services to the frail elderly.

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and the utility of conducting an impact assessment of the program at some future time (Smith, 1989).

## Further Evaluation of CHOICE

What typically happens in the field of program evaluation is that once an evaluation has been completed and a program found to be “successful”, additional evaluation is considered unnecessary. Further evaluation of CHOICE is important for three reasons. First, this study found that CHOICE was differentially serving its target population, the frail elderly. There is a need to identify which sub-population of the frail elderly is best served by a program like CHOICE, and which is better served by home care or continuing care.

Second, there is a need to track changes in health service utilization for the program’s participants on an individual, not an aggregate, basis, as was done in the 1998 “black box’ impact assessment (CHOICE Program Evaluation, 1998). Being able to identify individual changes in utilization is important for identifying the type of participant for whom the program is most successful.

Third, there is a need to complete an additional impact assessment of the program using a broader range of outcomes than those used in the 1998 “black box” impact assessment (CHOICE Program Evaluation, 1998). Several of the outcomes identified in the articulated program theory model were missed in this assessment. These include: the provision of comprehensive, accessible, coordinated participant centered care, the development of long-term therapeutic, multidisciplinary team/ participant/ informal caregiver partnerships, improved care through the early detection of acute illness, continuous management of chronic illness, rehabilitation, maximization of self-care potential and risk management, delayed institutionalization, and the reduction of caregiver stress. A more complete impact assessment should be undertaken. This would involve operationalizing and measuring a much wider range of intermediate and final program outcomes. A quasi-experimental design with one or two comparison group(s) drawn from home care and/or continuing care, and a cost-benefit analysis could be added to this impact assessment.

How Best to Deliver Health and Social Services to the Frail Elderly

In addition to the ongoing need for further evaluation of the CHOICE program, future research efforts also need to be directed toward increasing our understanding of how best to deliver health and social services to the frail elderly. This type of comparative research is particularly relevant given Alberta Health's vision for health system reform. In its recent Review of Selected Trends in Health Status, Health System Performance and Socio-Economic Indicators, Alberta Health (1998B) outlined its vision of future health system options for the frail elderly in the following way. Traditional continuing-care facilities will provide services to individuals with the highest care needs, the majority of whom will have dementia and mental health problems. Community-based care will expand to serve the needs of the functionally and medically frail elderly, and support a growing number of informal caregivers. A range of innovative day support and respite programs will develop in response to increased caregiver burden. The overall challenge will be to determine how best to meet the range of seniors' needs and ensure that families are not overburdened and, at the same time control publicly funded costs.

If health service providers in Alberta are to meet the challenge set out by Alberta Health, then health system reform needs to be partnered with systematic evaluation. Researchers need to explore, document, and evaluate program theory in relation to these new innovative programs for the frail elderly. If this does not take place, those who plan service delivery programs are in danger of falling into the trap of once again configuring "off the shelf" intervention strategies in an attempt to meet new challenges without critically analyzing the underlying assumptions and explanations of how, when or why the selected intervention may or may not be expected to achieve the desired results.

## Closing Remarks

Cook (1997) sees the field of program evaluation as resting on a metaphorical three-legged stool. The first leg of the stool, methodology, has received a great deal of attention. The second leg, the analysis of evaluation theory, and the third leg, systematic synthesis of evaluation findings, have received much less attention. Evaluations such as this one, which focus on the development of knowledge, are particularly valuable. Developing knowledge about the program theory that underlies a program or intervention is a necessary pre-requisite of any attempt to produce compendia that synthesize evaluation findings.

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# Appendix A: CHOICE Document Review Data Collection Sheet

Document Reviewed:________________________________________

Date: _______________

1. How was the target population described?
   Page #s: __________________________________

2. Was any mention of program theory found?
   Yes No
   If yes, where? Page #s: __________________________________

3. Did the document identify specific program activities or actions?
   Yes No
   If yes, where? Page #s: __________________________________

4. Did the document identify any specific program outcomes?
   Yes No
   If yes, where? Page #s: __________________________________

5. Did the document identify an intervening links between the two?
   Yes No
   If yes, where? Page #s: __________________________________

## Appendix B: CHOICE Multidisciplinary Team Member Questions

1. What type of clients does the program target?
2. To what extent do you think you are reaching your target population?
3. Are there certain types of clients that should not come to CHOICE?
4. What specific needs does the program address?
5. How does CHOICE meet these needs?
6. What tasks do you perform with the program?
7. What is your role in the program?
8. How do you work with the other program staff in your role?
9. What problems, if any do you need to overcome to perform these tasks?
10. What are some of the challenges in working in a multidisciplinary team?
11. Are any other organizations or persons outside of CHOICE involved with you in performing these tasks? Do you contact professionals or organizations outside of CHOICE in your role?
12. Does anything need to be changed to improve working relationships? Either within the team or with people or organizations outside the program?
13. How do the tasks you perform affect the clients?
14. How do the tasks you perform affect the informal caregivers?
15. How do the tasks the other multidisciplinary team members perform affect clients?
16. How do the tasks the other multidisciplinary team members perform affect informal caregivers?
17. Does the program have any negative effects?
18. Is there anything else I should know about the CHOICE program?
19. How is CHOICE different from other places you have worked?

Question changes/ memos

1. dropped after the first three interviews because I inevitably got the party line
2. dropped after the second interview because I don't think staff had the information to answer this question
3. New question added after the first interview
4. Used throughout the interviews with good results
5. This question was frequently dropped because the information was provided in the previous question

6 & 7. A second question was often needed to get the stakeholder to think in more global terms, used throughout with good results

8, 9, & 10 Used throughout with good results

11. Used selectively depending on the stakeholder's role, second question often needed to clarify
12. . Used throughout with good results, second question often needed to clarify
13. &14, often dropped, answer received in response to questions 6
15. & 16 dropped after the first interview these questions involved too much supposition, and I did not feel comfortable having them answer for other staff members
17. New question added after the first interview. Almost always got something like "interesting", "good question", "I hadn't thought about that"
18. Used throughout with good result.
19. New question provided some of the best reflective information

## Appendix C: CHOICE Informal Caregiver Questions

1. Can you tell me a bit about (participant's name) decision to come to CHOICE?
2. Questions to confirm where participant attends the program?, How long?, How often?, What types of services?, You are (participant's name) ..... ?
3. How has CHOICE helped you?
4. What types of things do you do on the days (participant's name) goes to CHOICE?
5. What types of things do you do on the days (paricipant's name) doesn't go to CHOICE?
6. Does (participant's name) talk to you about CHOICE ?
7. Is there anything that needs to be changed about the program?
8. What kind of help were you getting before CHOICE?
9. How is CHOICE different from (type of help previously receiving)?
10. Is there anything else you would like to tell me about CHOICE?

Question changes/ memos

1. good question, used throughout, frequently elicited a review of the client's whole health history and had to redirect to present situation
2. provided information for me to personalize and tailor the interview to the informal caregiver, nice easy conversational opening
3. good question, provided a wealth of information, often used probes to clarify the information being provided
4. good question, used throughout
5. good question, used throughout
6. good question, provide a wealth of information, often used probes to clarify the information being provided
7. difficult question, reluctance to criticize the program often surfaced
8. new question added after the first interview
9. new question added after the first interview, provided a wealth of reflective information
10. usually reiterated the program's good points, a nice way to get closure

# Appendix D: CHOICE Participant Questions

1. How did you decide to come to CHOICE?
2. How long have you been coming, How often, Where and who do you live with?
3. What types of help do you get from CHOICE?
4. What do you do at CHOICE?
5. What do you like about CHOICE?
6. What does (informal caregivers's name) do on the days you come to CHOICE?
7. What do you do on the days you don't come to CHOICE?
8. What kind of help did you used to get before CHOICE?
9. How is CHOICE different from (type of previous help)?
10. Does anything about CHOICE need to be changed?
11. Is there anything else I should know about CHOICE?

Question changes/ memos

1. good questions, used throughout, but had to frequently redirect, got the participant's whole life story
2. provided information for me to tailor and personalize the interview
3. hard to get more than a one or two word answers with some participants
4. good question, got some reflection
5. usually answered in question 4, or I got a one word answer
6. good question received some excellent information
7. good question received some excellent information
8. good question
9. got some good reflective information
10. some reluctance to talk about any problems, the food and buses were always mentioned
11. nice closure question

In three out of the six participant interviews it was difficult to work through a list of questions. In these instances I switched to a storytelling approach (i.e., can you tell me about your day today since you got up this morning?). Can you tell me about a day like (substitute yesterday or day of the week) when you didn't come to CHOICE?, and tried to refocus on the questions whenever I could in the flow of conversation.

# Appendix E: CHOICE Interview Summary

Stakeholer: _____ Date: ________________ Place: ________________________

General impression of the interview.

What questions seemed to work well?

What questions did not seem to work well?

1. What information was provided about the target group?
Line numbers:

2. What specific program activities/actions were identified?
Line numbers:

3. What specific program outcomes were identified?
Line numbers:

4. Were any intervening links between activities/actions and outcomes identified?
Line numbers:

## Appendix F: Morning Team Meeting Field Notes for Day Three

XXX, one of the center's LPNs is chairing the meeting today. As with the other meetings everyone is sitting around the table in the meeting room, and the telephone is on the table. The meeting begins by having everyone listen to the telephone messages left by the on call nurse.

One telephone message this morning, one of the clients fell on the floor and was left on the floor for two hours by the son until the home support worker arrived. Discussion as to how to handle "inappropriate" behaviour of son, concerns regarding willingness of son to be client caregiver. Social worker will be talking with son to get a better feel for the situation.

The group now turn to the clinic secretary who provides an update on who remains in hospital, and who will be going for tests today. Group discussion about client with cognitive impairment who was in hospital for the insertion of a PEG? tube (stomach tube) ensues – the client ended up being discharged without procedure being performed because wife changed her mind at the last minute. Three clients are going for outside appointments today: ultra sound, pulmonary function and cystoscopy.

The group now engage in a free flowing discussion of issues and concerns.

1. One of the new admissions is coming from Home Care. He has been receiving home support services through them via a nursing agency. The CHOICE assessor identified some undesirable behaviour on the part of the home support workers: "patronizing attitude" toward client and CHOICE staff. Need for an adjustment period for new client identified.

2. Concern raised by physiptherapist about return of a client recently discharged from acute care and their loss of mobility while in hospital.

3. Issue of a client who is very dependent upon home support services that are not considered to be necessary by staff, difficulty of decreasing service levels dicussed.

There is a client review and a new admission review scheduled for today.

Client Review (completed every four months)

The review begins with the chair presenting a brief client medical and social history. She refers to the client chart and shows the client's picture to the group.

As in previous client admission and scheduled reviews, a "professional" approach is being used (each professional provides specific types of information about the client followed by group input and discussion).

Social worker - client was considering a change in his place of residence, but it did not happen

Recreational therapist - activities client has been participating in

Clinic Nurse - client has COPD and Parkinson's Disease, some difficulty with a drug interaction (Parkinson drugs depressed his respiration). Client seems to be going from one important date to another, concern expressed regarding what will happen when his wedding aniversary is over in July, will he become depresssed as he has been in the past. Client uses a communication book in which he writes his feelings.

Physician - difficulty of using slow release Parkinson's drugs because of decreased effectiveness compared to q3hr administration. Physician has consulted with Dr. XX a movement disorder specialist regarding meds.

Physiotherapist - comes to physiotherapy room on his own, is able to set dates and identify goals with PT. Wife can't manage him in wheelchair. She has spent some time with the wife helping her to get him in and out of the care without injuring herself. Daughter is not receptive to any teaching at present.

Home Support Coordinator- review of services and monthy foot care, no changes recommended.

Occupational Therapist - Safety, has not fallen recently, wife has been taught to lift safely. Client tends to do what he likes to do so will probably continue to use wheelchair and expect wife to help him and lift him. Has a sunken room in house, and does not have appropriate railings in home, possible move to a different residence, but expense might be an issue.

LPN - some urinary dribbling, no constipation, weight has been stable, but a big man who has no interest in losing weight. Attends five days a week

Throughout the round table discussion the client's paperwork has been updated by the site manager, client goals for the next meeting are agreed upon by the group based on the issues they brought to the table, and a reassessment date for the client is set for October.

<u>Review of Client for admission after five day trial</u>

The CHOICE intake coordinator begins this portion of the meeting by reviewing the potential client with the group. The OT has made a home visit, the intake coordinator has made a pre-admission visit, and social worker will be visiting the informal caregiver at their home later today.

The professional approach is used once again, with each of the people at the table presenting specific kinds of information to the group.

LPN – the client (who is a diabetic) uses sugar (five or six packages) and wants extra sweets at meal times. They tried to remove sugar from his table but he took it form another table. Discussion of how to handle this situation. Not feasible to take all sugar away, no easy solution proposed. Dr. indicated that this man is an ex-alcoholic and these individuals tend to crave sugar ++.

Social Worker - family dynamics between this man's wife and his sister are not the best. The sister comes to the program, wife does not want him to spend time with her at program because although she has not seen her for three years she thinks she will be a bad influence on him. Six children, but no one child identified as a primary support.

Recreational Therapist - client has difficulty with language cognition at times and "might be gravitating to first language. He has a hearing aid but refuses to wear it and cannot hear unless screamed at. Does not participate in any group activities. Brings a book and reads. He is a smoker and is at some risk because he has some cognitive impairment. Possibility of using a smoking apron discussed.

Physician - client on no drugs but has quite a few past diagnoses that need to be investigated. Mini mental 21/30, long term psychiatric history of depression.

Physiotherapist - balance 48/56 . ADL seems able to do most things. Wife helps him downstairs to basement and he is supposed to bathe himself, question as to how well he is doing this, dicussion about getting him to have a bath at CHOICE.

Home Support Coordinator - wife expressed difficulty in her ability to cope, The cleanliness of her home is very important and she has had to drop her standard in order to take care of him, but does not want to have anyone come into her home to clean. She sees it as having a stranger in her home.

Group discussion, decision made to admit client for three days a week, one of which will overlap with his sister.

Overall

As with the other meetings, the participants are sitting comfortably in a relaxed manner around the table, there is a good deal of banter back and forth, everyone refers to each other by first names, there is no set order of speaking, everyone is listened to and solutions and actions are arrived at as a group. One person records the information in the client's chart.