

# SUBSTUDY 6

## DECISION-MAKING: HOME CARE OR LONG TERM CARE FACILITY

A Report Prepared for  
the Health Transition Fund, Health Canada

June 2000

---

National Evaluation of the Cost-Effectiveness of Home Care  
and



Faculty of Health Sciences,  
University of Ottawa  
Faculté des sciences de la santé  
Université d'Ottawa



To obtain additional copies of this report please contact either the National Evaluation of the Cost-Effectiveness of Home Care or the principal author:

National Evaluation of the Cost-Effectiveness of Home Care  
308 - 895 Fort Street  
Victoria, BC  
V8W 1H7  
Canada  
Tel: (250) 389-0123  
Fax: (250) 389-0105  
[info@homecarestudy.com](mailto:info@homecarestudy.com)  
<http://www.homecarestudy.com/>

Dr. Denise Alcock  
Dean  
Faculty of Health Sciences  
University of Ottawa  
Room 3028 - 451 Smyth Road  
Ottawa, Ontario  
K1H 8M5  
Tel: (613) 562-5432  
Fax: (613) 562-5437  
[dalcock@uottawa.ca](mailto:dalcock@uottawa.ca)

# SUBSTUDY 6

## DECISION-MAKING: HOME CARE OR LONG TERM CARE FACILITY

A Report Prepared for  
the Health Transition Fund, Health Canada

by Denise Alcock, RN, PhD (Principal Investigator)  
Elaine Gallagher, RN, PhD  
Elizabeth Diem, RN, PhD  
Douglas Angus, MA  
Jennifer Medves, RN, PhD (Candidate)

June 2000

---

National Evaluation of the Cost-Effectiveness of Home Care



and



Faculty of Health Sciences,  
University of Ottawa  
Faculté des sciences de la santé  
Université d'Ottawa





## PREFACE

The National Evaluation of the Cost-Effectiveness of Home Care is an integrated program of research including 15 studies, conducted across Canada. The overall program of research has been designed to generate information useful to administrators and decision-makers. The program of research examines whether or not home care is a cost-effective alternative to institutional care, that is to care in long term care and acute care facilities. In addition, the program of research is designed to provide an educational function to inform decision-makers and the public about home care, and to provide advice about issues related to the implementation of new and cost-effective home care initiatives. The overall research strategy is to conduct studies to:

- Examine if home care is a cost-effective alternative to institutional care, and if so, under what conditions it is cost-effective;
- Inform decision makers about the nature and scope of home care services across Canada. These studies provide a baseline of information about home care clients, costs, and utilization. This baseline is important because there is currently no national database on home care in Canada;
- Explore opportunities for potential savings in the institutional sector by substituting home care services. At present there are relatively few areas noted in the literature that indicate that home care is a cost-effective alternative to hospital care; and
- Provide decision-makers with information about some of the issues they may face if they try to implement new initiatives to enhance the cost-effectiveness of the health delivery system.

This study, Substudy 6, Decision Making: Home Care or Long Term Care Facility, was designed to identify factors that influence system efficiencies and to identify key factors which determine if clients will be cared for at home or in a long term care facility. Issues that decision-makers need to address when implementing programs to enhance quality of care and increase cost-effectiveness of continuing care services are identified.

Case managers/community care coordinators serve as gatekeepers to the continuing care system. It is they who facilitate the movement of clients from one care setting to another (acute care, home care, long term residential care). Substudy 1, Comparative Cost Analysis of Home Care and Residential Care Services, has demonstrated that home care can be provided at a lower cost than residential care, to similar clients, under certain circumstances. Therefore, the substitution of home care for residential care is critical to saving money and improving the efficiency and effectiveness of the health system. Substudy 6 provides information about issues which need to be addressed to bring about an effective substitution of home care services for long term facility care.

Neena Chappell, PhD  
Co-Director  
National Evaluation of the  
Cost-Effectiveness of Home Care

Marcus Hollander, PhD  
Co-Director  
National Evaluation of the  
Cost-Effectiveness of Home Care

## EXECUTIVE SUMMARY

Decision Making: Home Care or Facility Care is one of a number of studies which are part of the National Evaluation of the Cost-Effectiveness of Home Care project. Decisions related to home care versus facility care and the type and frequency of services offered through home care are influenced by case managers who assess client and family needs, plan, implement and monitor services. In order to 1) better understand the factors which determine if long term care clients will be cared for at home or in a facility; 2) examine the extent to which home care and facility care are substitutable and 3) identify the factors which influence clients in a long term care facility to return home, data were collected through focus groups and questionnaires from 89 case managers in urban and rural regions of five provinces in Canada. Content analysis of the qualitative data collected allowed for an in-depth view of issues and factors related to decision making. These factors were grouped according to the case management decision making conceptual model of Alcock et al. (1998) under organizational, system, client, informal provider, formal provider and case manager factors. An additional factor was generated by this study which was named ethical issues.

A wide range of factors promote the choice of care at home as opposed to care in a long term care setting. Organizational and system factors were reported across the five provinces as important factors influencing decisions. These range from public awareness of the provincial and regional policies and guidelines related to long term care; access to housing which accommodates for mobility problems, and is co-located with supportive services; to supportive communities (volunteers, meals on wheels, elder watch). Transportation for the elderly and disabled is a national issue. Day programs which provide health interventions, health monitoring, socialization and evening programs which provide respite care are under-utilized because of transportation difficulties. The financial well-being of the client or family is a factor in that home support services enable clients to remain in their homes and in some provinces these services are all or in part, the financial responsibility of the client or family. The lack of continuity of home support workers has influenced the decision of elderly clients to move into a nursing home because they cannot adjust to a continuous stream of different care providers in their home. Influences on home care versus placement decisions are discussed in depth under each of the following organizational, system, client, informal provider, formal provider, case manager and ethical factors.

Case managers across Canada agreed that the majority of long term care clients are appropriately placed and that there are not enough long term care facilities. However, valuable insight was gained into avoidance of early admission to long term care facilities and situations which influence the return of clients from facilities to their homes.

This report concludes with a proposed set of short term (1-2 years), and longer term goals (3 years or more). Meeting these goals will improve not only access to care and quality of care for long term care clients, but will also contribute to a more efficient system which will contribute to the cost-effectiveness of long term care in the home and in facilities.

## **ACKNOWLEDGEMENTS**

The research team gratefully acknowledges the assistance of the Ottawa-Carleton Community Care Access Centre case managers who piloted the questionnaire and the focus group guiding questions. The following individuals facilitated the data collection in each province : Dan Woodrow and Lee Drummond, British Columbia; Carol Slauenwhite, Jennifer Nagel and Steve Petz, Alberta; Sue Melrose, Saskatchewan; Laura Kokocinski, Kathy Stark and Kathy Desai, Ontario; Susan Howard, Ann Neatby, Betty McNab and Donna MacAusland, Prince Edward Island. Karen Benzies and Jennifer Schultz assisted Jennifer Medves with the focus group data collection in Alberta. Without the help of these individuals, the data collection would not have occurred within the time frame allotted for all the study. The participation of the 89 case managers and the 15 supervisors was critical to meeting the objectives of the study. The research team thanks the participants and their agencies for their generous sharing of time and information.

Funding for this study was provided by Health Canada through the Health Transition Fund, as part of the National Evaluation of the Cost-Effectiveness of Home Care project led by Drs. Marcus Hollander and Neena Chappell. The views expressed herein do not necessarily represent the official policy of Health Canada.

## TABLE OF CONTENTS

	<u>Page</u>
EXECUTIVE SUMMARY .....	i
ACKNOWLEDGEMENTS .....	ii
TABLE OF CONTENTS .....	iii
LIST OF TABLES .....	vi
INTRODUCTION .....	1
LITERATURE REVIEW .....	1
Organizational and System Factors Influencing Decisions to Provide Care at Home or in a Long Term Care Facility in the Five Provinces in the Study .....	1
Factors Influencing the Elderly Individual's Need for Long Term Care: The Disablement Process .....	3
Long Term Care in the Home or in Nursing Homes .....	5
The Elderly's Preference for Long Term Care .....	6
Informal Care Providers .....	7
Case Managers .....	8
OBJECTIVES OF THE STUDY .....	10
METHODOLOGY .....	10
Data Collection .....	10
Data Analysis .....	12
RESULTS .....	13
Demographic Information .....	13
FACTORS THAT INFLUENCE DECISIONS ABOUT THE CARE OF LONG TERM CARE CLIENTS .....	15
Organizational Factors .....	15
Ministry Partnerships .....	15
Regulations and Guidelines .....	15
Portability of Services .....	16
Common Tools and Language .....	16
Funding of Services .....	17
System Factors .....	18
Acute Care Resources .....	18
Access to Day Programs and Types of Programs .....	18
Respite Care .....	19
Palliative Services .....	20
Community Characteristics .....	20

Table of Contents (Continued)

Transportation	21
Housing	22
Access Issues	23
Substitutability of Home and Facility Care	23
Client Factors	24
Health Status	24
Environment	25
Financial Well-Being	26
Abuse	26
Family-Defined Needs	26
Client Choices	27
Case Management Issues Related to Family/Friend Care Giving	27
Families and Friends as Carers	28
Gender Issues and Care Giving	28
Stress and Care Giving	29
Families and Coping	30
Care Givers and Support	31
Care Giving and Financial Well-Being	31
Families and Proximity	31
Building on Existing Relationships	31
Offspring Relationships	32
No Family	32
Volunteers	33
Case Manager Factors	33
Case Managers' Perceptions of their Role	33
Timing of Referrals	34
Assessments and Planning	36
Providing Services: Implementation and Ongoing Monitoring and Evaluation	37
Care Providers	40
Access to Care Providers	40
Screening, Preparation and Remuneration of Home Support Workers	40
Professional and Support Services	40
Rural Care Providers	41
Services that Would Keep Clients at Home Longer	41
Ethical Issues and Dilemmas in the Case Management Role	41
Ethical Dilemmas Concerning Equity	42
Issues Related to Beneficence	43
Issues Related to Non-Maleficence	43
Issues Related to Autonomy: Consent, Living at Risk	44
Other Ethical Dilemmas	45
LIMITATIONS OF THE STUDY	46

Table of Contents (Continued)

SUMMARY AND IMPLICATIONS ..... 46

SUGGESTED NEXT STEPS ..... 51

REFERENCES ..... 55

APPENDICES

- APPENDIX A: FOCUS GROUP GUIDING QUESTIONS
- APPENDIX B: QUESTIONNAIRE
- APPENDIX C: ETHICAL CLEARANCE
- APPENDIX D: INFORMATION SHEET
- APPENDIX E: CONSENT FORM
- APPENDIX F: CASE MANAGEMENT DECISION MAKING CONCEPTUAL MODEL

**LIST OF TABLES**

	<u>Page</u>
Table 1	Educational preparation of case manager participants ..... 13
Table 2	Years of home care experience and years of case manager experience ..... 14
Table 3	Type of client profiles managed by participants by province ..... 14

## INTRODUCTION

This qualitative study examined the factors which, from the perspectives of case managers, determine if an adult client will be cared for through home care or in a long term care facility. It also examined the extent to which home care and facility care can be substituted for each other so that efficiencies can be obtained. Home care programs provide a substitution function for services provided by hospitals and long term care facilities; a maintenance function that allows clients to remain independent in their current environment rather than moving to a new and more costly venue; and a preventative function which invests in client service and monitoring at additional short-run but lower long-run costs (Canadian Home Care Association, 1998:1). Long term care has been described as “a range of services that address the health, social, and personal care needs of individuals who, for one reason or another, have never developed or have lost some capacity for self care. Services may be continuous or intermittent, but it is generally presumed that they will be delivered for the long term, that is indefinitely to individuals who have demonstrated need, usually by some index of functional incapacity” (Hollander, 1994:12). Decisions related to home care versus facility care, and the type and frequency of services offered, are strongly influenced by case managers who assess client and family needs, implement, coordinate, and monitor services (Alcock, Edwards & Morris, 1998). Case managers are also called community care coordinators; in this report only the title case manager is used.

Focus groups with case managers were held in rural and urban sites in five provinces: British Columbia, Alberta, Saskatchewan, Ontario, and Prince Edward Island. Structured individual interviews with administrators of long term care institutions and informal meetings with supervisors of the home care case managers were held to answer specific questions about the function and structure of long term care services in their region.

## LITERATURE REVIEW

The following literature review addresses selected topics which provide a contextual background for the study. The first section provides an overview of the organizational and system similarities and differences across the five provinces in the study. Since the majority of clients requiring home care or long term care in a facility are elderly, literature identifying the factors contributing to disablement of the elderly is summarized, as well as literature related to the elderly's preference for the location of care. The support of family and/or friends is a key factor in determining a client's eligibility for home care. Issues related to informal care providers are reviewed. Case managers are the key informants in this study and the final literature review section provides a brief overview of studies relating to case management.

### **Organizational and System Factors Influencing Decisions to Provide Care at Home or in a Long Term Care Facility in the Five Provinces in the Study**

An excellent overview of provincial and territorial home care programs is provided by Dumont-Lemasson, Donovan and Wylie (1999) in the Health Canada document entitled Provincial

and Territorial Home Care Programs: A Synthesis for Canada. The following is a summary of information from the document that is relevant to this project. Home care is included in the federal Canada Health Act as an extended health care service but is not publicly insured as are hospital and physician services. All provinces and territories provide and publicly fund home care services and their departments of health/social or community services control budgets and funding levels. British Columbia, Alberta, Saskatchewan and Ontario have legislation related to home care services. Prince Edward Island's home care services were established through an Order in Council. Home care services in British Columbia, Alberta, Saskatchewan and Prince Edward Island are the responsibility of local or regional health authorities. Ontario delivers home care through Community Care Access Centres.

Single entry functions such as assessment, case management and monitoring, and professional and home support services are mainly delivered by public employees in Saskatchewan and Prince Edward Island. Single entry functions plus all professional services are delivered by public employees and home support services are contracted out by agency or by client in British Columbia and Alberta. In Ontario, single entry functions are delivered by public employees or staff of publicly funded community agencies while professional and support services are contracted. Contracts are granted to for-profit and not-for-profit agencies. With the exception of Prince Edward Island, the other provinces in the study have some type of managed care for persons with disabilities. In the self-managed care system, persons (generally the young disabled) are funded to manage and pay for their own care requirements.

Case managers in British Columbia, Alberta, and Ontario are generally registered nurses; however, there are some occupational therapist, physiotherapist and social work case managers, especially in Alberta. In the other provinces, a variety of professionals are case managers.

The unregulated workers have a variety of titles such as home support worker, personal care worker, and home care aide and their training varies extensively from region to region. Many workers have little or no formal training in health or home care work.

Eligibility for home care services across the provinces includes: 1) proof of residence, 2) a comprehensive needs assessment, 3) the lack of availability of sufficient help from family or friends, 4) a home that is safe and suitable for health care delivery, and 5) the consent of the client or guardian. An official income assessment determines the financial contribution of the client for home support services in British Columbia, Alberta, Saskatchewan and Prince Edward Island. Ontario does not require a financial contribution from the client based on an income assessment. Upper cost maximums for home support are generally based on the comparable costs to care for the person in a long term care facility.

A major survey conducted by Anderson and Parent (1999) to examine the state of home care in Canada identified a number of organizational and system factors which must be addressed in order to provide better home care services to Canadians. The need for policy direction to guide home care development in Canada; inadequate funding; caregiver burden; issues related to care provider working conditions, wages, and training; the increase in acute care clients cared for at home; a reduction in home support services; pressure on the voluntary sector providing services for home

care clients and families; and the general lack of knowledge and lack of research were among the factors identified.

### **Factors Influencing the Elderly Individual's Need for Long Term Care: The Disablement Process**

Old age is associated with increased disability and an increased use of home care services (Alcock, Danbrook, Walker & Hunt, 1998) and institutional care. The population of Canada is aging as a result of decreased fertility and increased longevity (Denton, Geaver & Spencer, 1998). According to Statistics Canada (1999), the most vulnerable and fastest-growing segment of the senior population is the 85 and older age group. The number of people in this age group will quadruple by 2041. Women make up 70% of the group and 80% are widows. These women are the most likely to live alone (National Advisory Council on Aging, 1996), and also have a greater risk of poverty (Ulysse & Lesermann, 1997).

Effective health and social service planning is assisted by an understanding of the disablement process. One purpose is to identify the strategies that could ameliorate the process, and therefore should be part of a comprehensive home and community care system. The other, discussed in the next section, is to consider the disablement process in relation to the risk of institutionalization.

The greatest contribution to understanding changes that occur over several years has come from longitudinal studies. Although longitudinal studies on functional decline of elderly in Canada are limited, a systematic literature review identified 78 longitudinal studies on community living elderly in other countries (Stuck, Walthert, Nikolaus, Büla, Hohmann & Beck, 1999). Most of the factors identified are also found in Canadian cross-sectional surveys in recent years. Initiatives in Canada to identify factors related to healthy aging as well as disability have included the following surveys: 1986 and 1991 Health and Activity Limitation Surveys (HALS) (Statistics Canada, 1989; 1992); The Survey of Aging and Independence in 1991 (Statistics Canada, 1993); and the Canadian Study of Health and Aging (CSHA) in 1991 and 1992 (Canadian Study of Health and Aging Working Group, 1994). The populations involved in each survey varied. The 1991 HALS and the Aging and Independence surveys were limited to people living in the community. The 1986 HALS and CSHA included people living in institutions as well as those in the community.

To aid in the discussion of factors related to functional status decline, the factors are grouped into socio-demographic, physical disabilities and conditions, cognitive impairment and depression; and self-perceived health categories. It must be emphasized that although the categories are presented separately, frequently the discussion indicates a strong overlap both among factors within each category and across categories.

Consistently, surveys report that disability increases with age and occurs more in women than men. The disability rate for Canadians 65 years or older is reported as 46%, and for those 85 years or more, 70% (Statistics Canada, 1992). Although women live longer than men, they are burdened by more chronic health problems (Ulysse & Lesermann, 1997). In the 1986 and 1991 HALS, Raina,

Dukeshire and Lindsay (1998) found the factors associated with disability were: female gender; divorced, separated or widowed marital status; lower income; rented dwelling; and living alone.

The Havens and Finlayson (1999) study reports that Canada's age 85+ individuals are poorer than the other older age groups; the majority are widowed women living alone in an apartment; 41% of those aged 85 + reported no close friends (as compared to 30% of individuals ages 65 to 84); leisure activities both inside and outside the home decline in this age group and the decline is increased by reported poor health and decreased by education level. Low frequency of social contacts is also a risk factor for functional decline (Stuck et al., 1999)

The Canadian surveys reported geographical associations with disability in the 85+ age group. Individuals living in the Atlantic region and Yukon/North West Territories are at the highest risk for disability, followed by those living in the Prairies (Raina et al., 1998). In terms of provincial populations, the largest percentage of disabled aged 85 and over live in Manitoba and British Columbia (Havens & Finlayson, 1999).

The two HALS surveys assessed five types of physical disabilities: mobility, agility, hearing, seeing, and speaking (Raina et al., 1998). These surveys found that 40% of seniors 65+ had some level of physical disability and 80% of those were limited by mobility or agility. In addition, 70% of those disabled had both mobility and agility problems which is consistent with the co-morbidity disease burden described by Stuck et al. (1999). Hearing and seeing disabilities were found in less than 20% and speaking disabilities in less than 3% of those surveyed (Raina et al., 1998).

The conditions associated with physical disability are fairly consistent across studies and are: arthritis, osteoporosis, cardiovascular conditions, fractures/injuries, visual decline, and diabetes (Ebly, Hogan & Fung, 1996; Stuck et al; 1999). Alcock, Danbrook, et al. (1998) identified arthritis/osteoarthritis, stroke, fractures, and sepsis as the four most frequent diagnoses of clients on home care, and sepsis, osteoarthritis/arthritis, and stroke were related to the highest formal provider care costs. Between 1993 and 1998, *Chronic Diseases in Canada* published ten monographs on age-related diseases. Each of the monographs on the most prevalent physical conditions identify the importance of providing prevention strategies to reduce disability. These include: osteoarthritis (Rottensten, 1996); osteoporosis (Gordon & Huang, 1995); non-insulin-dependent diabetes mellites (Barcelo, 1996); and stroke/cerebrovascular disease (Gordon, 1993).

A key preventive strategy is to increase physical activity in the elderly, since a low level of physical activity and lower extremity functional limitation are associated with functional status decline (Stuck et al., 1999). Physical activity also reduces risk factors for arthritis and cardiovascular diseases. Raina et al. (1998) and Havens and Finlayson (1999) describe severe limitations in activities related to daily living such as walking, managing the stairs and providing self-care. Barriers to physical activity also need to be considered. The national Advisory Council on Aging (1996c) and Raina et al. (1998) identified the need for housing adaptations, assistive devices, and improved public transportation in order to help the elderly cope in their home environments.

According to the National Advisory Council on Aging (1996), disability arising from cognitive deficiency doubles from the 75-79 age group to the 80 to 84 age group and increases by

half again for those age 85+. The male population age 85+ appears to be most affected by stress (Havens & Finlayson, 1999), yet women are the most likely to seek professional help and medication to cope with stress. These medications may increase their risk of falling.

The overall prevalence of dementia increases after 65 years and continues to increase up to 106 years (Ebly, Parhad, Hogan & Fung, 1994). Although the total life expectancy for women is 26% more than for men, women have a greater burden of poor health and more than twice as many women as men are likely to live with dementia and in an institution (Hill, Forbes, Berthelot, Lindsay, McDowell, 1996; Hill, Forbes, Lindsay, McDowell, 1997).

Despite the actual disabilities that people experience, their attitude about their health can have a great impact on how well they function. Stuck et al. (1999) associated poor self-perceived health with functional status decline. In Canada, women age 85+ and those who have never married rate their health the worst. Those who are better off financially and have higher education tend to rate their health higher. Limitations in ability to perform activities, difficulty coping, feeling depressed and stressed contribute to a lower rating for health status (Havens & Finlayson, 1999).

In the review of the disablement process in this section, four factors amendable to change consistently emerged: physical activity, social interaction, support for caregivers, and adequate finances. Additional factors that also have potential to ameliorate the disablement process, are nutrition, smoking cessation, appropriate housing and transportation, and stress reduction. To address the predictors, prevention and supportive strategies need to be provided early in the home and community for those at increased risk for disablement. Making communities 'senior friendly' by providing accessible transportation, housing, and medical services would promote the physical and social activities that are crucial to health.

### **Long Term Care in the Home or in Nursing Homes**

As the disablement process progresses, the assumption is that people will first receive home care services and then, if their requirements in the home are beyond the availability of home care services, they are expected to be admitted to a nursing home. Home care services are expected to delay or prevent the use of nursing home care. That is not necessarily the case in practice.

Although there are major differences between the Canadian and United States health systems and therefore caution is required in making inferences from United States data, the largest randomized control trial of home care services is the United States National Channelling Demonstration. This study concluded that the people at the greatest risk of nursing home placement were not served and that home care services were largely additional services provided to people unlikely to ever use a nursing home (Kemper et al., 1988; Spector & Kemper, 1994).

Discrepancies between people receiving home care services and level of disablement also were found in Canada. A random sample of elderly home care users and nonusers in urban Nova Scotia and Newfoundland were assessed for limitations in activities of daily living (ADL), such as eating, walking, and toileting; and instrumental activities of daily living (IADL), such as using the telephone, preparing meals, and handling money (Cromwell, Rockwell, Stolee, Buehler, James,

Kozma & Gray, 1996). There were differences between the two provinces: 1) the prevalence of home care use was 24% in Nova Scotia, 11% in Newfoundland; 2) home care users in Newfoundland were more likely than nonusers to have cognitive impairment which was not the case in Nova Scotia despite the higher prevalence of cognitive impairment in the Nova Scotia sample; 3) in Nova Scotia 22% of home care users were ADL dependent similar to 20% who were nonusers, but in Newfoundland, 27% on home care were ADL dependent compared to only 8% of nonusers. In both provinces, only dependence in IADL was associated with home care use. However, in both provinces, most subjects who were ADL dependent did not receive services. Since dependence on ADL is an important risk factor for admission to institutional long term care, the authors conclude that there is a targeting to those with IADL and not a focus on substitution for institutional services. This suggests that the majority of the most dependent elderly people are not receiving home care.

Research over the last two decades into the risk factors associated with admission to a long term care institution now make it possible to fairly accurately depict the cluster of factors associated with institutionalization within a defined period of time (D'Agostino, Belanger, Markson, Kelly-Hayes, & Wolf, 1995; Jette, Branch, Sleeper, Feldman, & Sullivan, 1992; Rockwood, Stolee, & McDowell, 1996, Shapiro & Tate, 1988; Weissert & Cready, 1989). Although single predictors, such as age and gender, are significant, they are not particularly useful by themselves to plan for institutional services or prevention services in the home and community. Presently, the predictive variables in each of the risk profiles vary somewhat according to the data available and characteristics of the particular health system. For example, in the United States, people are more frequently than in Canada admitted to nursing homes for short term recuperative care (Jette et al; Rockwood et al; Shapiro & Tate). Some measure of social support, and functional and cognitive ability is consistently involved. As an example, Shapiro and Tate indicate a 62% risk of institutionalization within two and a half years for a person of 85 or older with no spouse at home, a recent hospitalization, living in retirement housing, one or more ADL and mental problems; compared to a 4% risk for a 85 or older person with a spouse at home and none of the other factors.

Functional or physical disability and the quality of informal support emerge as important amendable predictors of institutionalization. Three care giver characteristics: living separately from the patient, having conflicts because of a job, and being stressed by care giving, are also significant predictors of nursing home placement (Tsuji, Whalen & Finucane, 1995). The quality of caregiver support is even more crucial in cases of cognitive impairment and dementia (Philip, McKee, Armstrong, Ballinger, Gilhooly, Gordon, Mutch, & Whittick, 1997; Vernooij-Dassen, Felling & Persoon, 1997). The interventions to reduce risk, therefore need to strengthen existing networks and promote supportive ways for families, friends and neighbours to care for each other, including remuneration for informal care givers (Steinbach, 1992).

Both the disablement process and the risk for institutionalization have similar categories of predictors that must be considered together. To reduce the risk for institutionalization, home care programs must provide services to people at risk that address functional, cognitive and support needs if home care is to substitute for facility care.

## **The Elderly's Preference for Long Term Care**

Elderly people want what most people want: control over their own lives to the greatest extent possible. When elderly people who were at risk for institutionalization were asked what they would need to remain in their homes, their most important need was maintaining control (Krothe, 1997). They felt that going to a nursing home or moving in with family would remove that control.

Older participants in the National Forum on Health (1997) stated that they did not want to burden their children or spouses and that it was naive to consider that they would ever want to be cared for by family. They supported care in the home under the proviso that there is adequate, sustained funding and professionally trained care providers. When seniors are asked about their expectations regarding health care, the same themes of allowing individual control and adequate funding emerge. Interviews and focus groups with seniors generated common descriptive expectations of health services: efficient, sufficient, continuous, predictable, control and choice, acceptable, flexible and adaptable (Hollander, 1997).

## **Informal Care Providers**

Informal care givers are family and friends who provide services in the home on a voluntary basis. Most of the informal care giving is help with activities of daily living but as the care receiver's illness worsens, more assistance, either in a substitution or complementary model may be required (Logan & Spitze, 1994). This care is normally provided by paid health care providers (Houde, 1998). The decision to maintain a person in the home is dependent on the capacity of informal care givers to cope with the demands of the care receiver. The capacity is not simply time, but physical, emotional, social and financial. Informal care providers find making the decision to place a relative or friend in a long term care facility difficult. Their decision making is influenced by their values, beliefs, the expectations of care recipients and of the health care professionals.

The Canadian Study of Health and Aging (1994) states that approximately half of all people with dementia are living in the community and 98% have a care giver. The care givers in 94% of the cases are unpaid family members, relatives or friends who rarely use community services. The care givers of a person with dementia are more likely to experience chronic health problems and depressive symptoms than care givers of a non-demented person. The care giver of a person in the community is much more likely to feel burdened than the care giver of a person in a long term care facility despite the increased level of dementia in the nursing homes and other long term care facilities.

Informal care giving is usually linked to burden and early research tended to measure burden, identify stressors and examine interventions to help relieve the burden (George & Gwyther, 1986). Other studies examined the rewards of care giving (Kinney, Stephens, Franks, & Norris, 1995; Motenko, 1989). More recent studies have examined both the burden and the rewards (Lawton, Moss, Kleban, Glicksman & Rovine, 1991; Riedel, Fredman & Langenberg, 1998).

The physical, emotional, financial and social toll of informal care giving can be overwhelming (Robinson, 1990; Rosenheimer & Francis, 1992; Strang & Haughey, 1998). The

physical stress can lead to ill health of the care giver which may not be alleviated by adding funded community resources (Hawranik, 1985). Emotional changes occur over time when the carer and recipient relationship shifts, especially if there is significant dementia. The care giver burden can increase due to the decreasing quality of the relationship between carer and care recipient (Yates, Tennstedt & Chang, 1999). Care givers may be reluctant to seek support for themselves because of a reluctance to burden others, an inability to reciprocate, and the cost to others (Harrison & Neufeld, 1997). The financial burden can be overwhelming especially if services normally provided in institutions without user fees, involve significant monetary outlay, i.e., prescription drug charges, dressings and homemaking services. Care givers are usually women who may have to give up full time employment to provide care, juggle their own family commitments and suffer financial loss due to reduced income (Reynolds & Alonzo, 1998).

Adams (1996) describes the social toll as 'Social Death', influenced by three factors: the carer's anticipation of the death of the care recipient, diminishing awareness on the part of the care recipient and reduced response to the environment, and the apparent meaninglessness of the care recipient's life. The third factor is cited as the reason that institutionalization becomes more acceptable to the care giver. Collins, Liken, King and Kokanakis (1993) identified six themes that relate to loss experienced by care givers: loss of person, loss of hope, pre-death grief, expectancy of death, post-death relief and care giver reflections. The rewards include affection, commitment and reciprocity to the care receiver (Motenko, 1989), and allowing the care giver to show love, maintain intimacy and to nurture the care receiver (Riedel, Fredman & Langenberg, 1998).

The decision making processes by care givers to place the care recipient are multi factorial, complex and stressful, happen over time and are seriously contemplated (Strang, 1998). Making the decision to place the care recipient may be perceived as having failed as a care giver (Neufeld, 1998; Nolan, 1998). Nolan et al. (1996), suggests that in the United Kingdom context, the decisions are based on four processes: anticipation, participation, exploration and information. Nolan explains that the decision making process is rarely taken fully by the care giver but is greatly influenced by health care professionals. While there is a time of anticipation, the decision is actually taken at a time of crisis and under pressure. Care givers of hospitalized care recipients experienced pressure to make a decision quickly and care givers cite a lack of support from health care professionals. Penrod & Dellasega (1998), describe four experiential stages in the decisional process: uncertainty, surrendering to the system, urgency and validation of the experience.

For families and friends, the three values that rate highly in decision making about placement are care, security and psychological well-being (McCullough, Wilson, Teasdale, Kolpakchi & Skelly, 1993). The decision to place a family member in a long term care facility may not be grounded in the same values and beliefs as those of the recipient of care or of the health professionals (Coulton, Dunkle, Chow, Haug & Vielhaber, 1988).

### **Case Managers**

Case managers assess, plan, implement and evaluate the needs of their clients on a continuous basis (Alcock, Edwards & Morris, 1998). Although some case managers may assume this role exclusively, others work as service providers at the same time. The general goal of case

management is to improve the quality of care by decreasing fragmentation of services and maximizing the resources available for care (Barkauskas, 1994, p.8). Case managers work individually or as a team (Quinn, 1995; Warren, Puls & Fogelstrom-DeZeeuw, 1996). Different approaches to the assessment and delivery of case management have been defined: 1) site-based (e.g., hospital vs. community), 2) speciality defined (e.g., pediatric vs. oncology), 3) problem-defined (e.g., clients with high risk behaviours), and 4) referral-based case management (Warren, Puls & Fogelstrom-DeZeeuw, 1996). Working collaboratively with the client, the family and other members of the multidisciplinary team, the case manager acts as an advocate in facilitating community-based care in as cost-effective a manner as possible (Regional Municipality of Ottawa-Carleton Health Department, 1993).

Various aspects of case management have been discussed in the literature. These include case management models (Austin, 1988; Grisham, White & Miller, 1983; Roberts-DeGennaro, 1993); various aspects of the case management role (Williams, 1993; Rosenberg, 1995); and ethical issues related to case management (Wetle, 1992). Studies have addressed the cost-effectiveness of case management (Boyd, Fisher, Ware Davidson & Neilsen, 1996); the type of activities and time spent in clinical case management by nurses (Shuster & Cloonan, 1989); the attitudes of case managers regarding client-directed care (Mico, Hamilton, Martin & McEwan, 1995); the educational needs of case managers in long-term care (Applebaum & Wilson, 1988); and the characteristics of successful nurse case managers working in home care (Hilgendorf, 1996).

Fischer, Wilson Rollins, Rubin and McGinn (1993) evaluated a program to improve case managers' ethical decision-making skills. Feldman, Olberding, Shortridge, Toole and Zappin (1993) reviewed home health care records and presented nurses with case scenarios, questioning them as to whether they would maintain or terminate services. The most significant factor related to the duration of home care services was the client's age. Other influential factors were assignment of home health aides and a client diagnosis of arthritis or orthopaedic problems. There was a high level of consensus among nurses regarding continuation of service. Hagan Hennessy (1987) observed that a multidisciplinary case management team made decisions during case conference meetings by deriving a risk factor for each client. Client factors (i.e. stability of health condition, manageability of client, informal support/self-care competencies) were balanced against organizational resources (i.e. physical, personnel and vendor limits).

Abrahams, Capitman, Leutz and Macko (1989) provided case managers with case studies and explored the factors involved in care planning across different Social/HMO sites in the United States. They found differences by site in eligibility determination and in plans for allocation of care, as well as in the type and mix of service prescribed (Abrahams et al., 1989:725). Factors which influenced practice norms included differences in organizational structures and system differences across communities. Hagan Hennessy (1993) used factorial surveys to assess how members of a case management team decided upon placement for clients. The two factors used in making judgements were the client's condition (age; disease conditions; functional, cognitive, behavioural levels; informal assistance, etc.) and the availability of program resources. In developing a care plan, only client information was found to be important.

Case managers are central to the decisions made regarding the type of services provided to clients, and the frequency and location of services. Yet, there is scant research addressing the processes involved in case manager decision making or the factors which influence and are influenced by case manager decisions. Canadian studies to date are few. Lemire and Austin (1996) used qualitative methods to explore the different factors which had an impact on the development of care plans by six case managers in Edmonton, Alberta. The level of consensus among case managers in assigning services varied depending on the case scenarios. Factors believed to affect decision making included client/caregiver, case manager, program and system factors. Case managers were found to be uncomfortable with fiscal responsibilities in the development of care plans. Alcock, Edwards and Morris (1998) conducted focus groups with case managers in Ontario and New Brunswick. The case managers were also asked to respond in writing to case scenarios containing initial referral data and subsequently more complete client data. The information provided to the case manager at the time of referral was found to be important in the decision-making process regarding care provided. The factors which influenced the case manager's decisions were: the availability of resources, ministry or agency guidelines, the client's health condition, level of client and family coping, client's perceived goals and living conditions. The experience, knowledge, values and discipline of the case manager were also factors influencing the case manager's ability to make decisions. The case managers identified the difficult and the positive aspects of their work. Examples of the difficult aspects include making tough decisions related to client needs when resources are limited, dealing with long waiting lists for facility care or additional home care services, the lack of educational programs and support for themselves, and untangling the client's and family's wants from their needs. Positive aspects include personal interaction with clients and families and the opportunity for continuity of contact and follow-through on services, the diversity of the work, and the opportunity for relatively independent practice.

The majority of studies related to home care have been conducted in the United States. However, the establishment of home care service standards and guidelines in Canada must be informed by Canadian data which addresses regional variations. As home care continues to change and expand during these times of financial uncertainty, competent decision making by clients and their families will continue to be influenced by the case managers who remain central to the provision of coordinated and effective home care services.

## **OBJECTIVES OF THE STUDY**

1. To identify the key factors which determine if a client will be cared for through home care or in a long term care facility;
2. To identify the extent to which home care and facility care can be substituted for each other so that efficiencies can be obtained;
3. To identify the proportion of clients currently streamed into facilities who could be cared for at home with additional home care resources, by level of care; and the proportion of clients currently in long term care facilities who could be re-integrated into the community with additional resources, by levels of care.

## **METHODOLOGY**

### **Data Collection**

The key informants were home care case managers. Data were collected through focus groups, interviews, and a questionnaire. Due to monetary constraints and the overall mandate of the study within the large national home care evaluation project, data were collected in urban and rural sites of only five of the ten provinces and not in the territories. In British Columbia, the urban site was Victoria and the rural site Campbell River. In Alberta, the urban site was Calgary, the rural site Camrose. In Saskatchewan, the rural and urban sites were the Saskatoon Health Region. In Ontario, two sites London and Thunder Bay provided both rural and urban settings. In Prince Edward Island, data were collected in Charlottetown and Summerside. Focus groups with between three and eight case managers were held in each of the sites. Focus group guiding questions (Appendix A) and the questionnaires (Appendix B) were distributed to each member of the focus group prior to the commencement of the discussions. Focus group guiding questions as well as the questionnaires were piloted with case managers from the Ottawa-Carleton Community Care Access Centre. Individual interviews with managers of long term care institutions and informal meetings with supervisors of case managers were conducted to answer specific questions about the function and structure of home care services.

Study sites were identified by the investigators and the research assistant made contact with the senior manager of the home care services or case management services as applicable. Key individuals in the health authority were identified and appropriate administrative permission was obtained to conduct focus groups and interviews at each of the sites.

The proposal for the study was submitted for ethical review to the Health Ethics Review Board at the University of Ottawa. The ethical clearance from the University (Appendix C) was accepted by all participating provinces and the study was granted permission to proceed.

All data were collected in English. The focus groups were led by one of the research investigators and the research assistant. Information sheets (Appendix D), consent forms (Appendix E), and questionnaires (Appendix B) were available to the contact person at each site. Consent forms were signed prior to commencement of taping of the focus groups. All case managers agreed to the audio-taping of the focus groups and the supervisors interviewed also agreed to the audio-taping of their conversation with the researchers. Participants were asked not to sign their questionnaires, and they were assured that transcripts would not include the names of participants.

The focus groups were conducted in rooms close to the work place of the case managers at a time convenient for them. Their research participation time was paid by the health regions in which they were employed. Participants were welcomed by one of the investigators and the research assistant. The research assistant read the information letter to the participants and answered questions as appropriate. The participants were then invited to sign the consent form and complete the questionnaire. Participants were reminded at the start of the focus groups that they did not have to share information if they were uncomfortable and that the information would be aggregated prior to dissemination so that individuals could not be identified.

The focus groups were audio taped using two tape recorders, one as back-up in case of failure which occurred in one province. A list of guiding questions were given to each participant and the investigator used these to guide the focus group. The conversations were free flowing and the case managers were able to articulate many factors which influence their decisions. Focus groups lasted 1.5 hours and in each case had to be concluded due to work pressures of the participants. Senior managers told the investigators informally that when the participants returned to their work place, they expressed the positive benefits of taking part in the study.

The data were transcribed verbatim with all proper names removed. Transcripts were verified by a review of the tapes with the written transcripts by a person other than the transcriber. The interviews conducted with senior managers of home care facilities and supervisors of the case managers were taped and notes taken from the data. The purpose of these interviews was to obtain information with respect to the organisation of the community services and to check information that was obtained in the focus groups that appeared contradictory or required clarification. Questions put to managers of long term care facilities concerned placement procedures, the ability of residents to manage in a community setting with more resources, and the difficulties experienced by the long term care managers to re-integrate residents into more suitable settings. The managers provided a useful reflection on community services and generally articulated the same decision making processes identified by case managers.

### **Data Analysis**

The statistical package SPSS 6 was used to generate the descriptive statistics from the questionnaires. Simple cross tabulations were used to compare across provinces such items as the years in home care and age and experience of case managers. The sample size is not large enough for inferential statistical analysis, and the majority of the data is qualitative.

Focus group interviews were audio taped, transcribed verbatim, checked for errors and distributed in paper format to the researchers. Content analysis (Brink & Woods, 1989) of the qualitative data collected during the focus groups allowed for an in-depth view of issues and factors related to case management decision making across provinces. A two day meeting was held and researchers reported their independent analysis of the content to others in the group. Common themes were identified and were grouped into the following categories: rural versus urban; organizational factors; system factors; client factors; informal care providers; volunteers; case managers; care providers; ethical dilemmas; outcomes of care; blockages to care; and finances.

Each main category had a number of sub-categories. For example, the focus group data identified a number of sub-categories under system factors such as: the influence of acute care resources, access to day programs, access to respite care, availability and type of palliative services, community characteristics, housing, and transportation.

Following analysis and initial coding the researchers identified one hundred and sixty four separate categories. Common themes were formed which grouped the various categories and subcategories of information (Morse, 1994). Further analysis and discussion resulted in merging of some categories and grouping of similar content (Miles & Hubberman, 1994).

The categories and themes were congruent with those found by Alcock, Edwards and Morris (1998) and their case management decision making conceptual model (Appendix F) was used to guide the analysis of the data. Ethical issues/dilemmas was identified in this study as an additional factor influencing the decision making of case managers. The qualitative analysis software programme NUD\*IST version 4 (Non-Numerical Unstructured Data Indexing Searching and Theorizing) was used to help organize the data into manageable components and assist the investigators to describe the decision making processes.

The data generated by the focus groups reflects the perspectives of the case managers. Within the results section all direct quotations from case managers are in italics.

## RESULTS

### Demographic Information

The eighty-nine participants completed a questionnaire that enabled the researchers to describe the case managers who took part. The average age of participants was over 40 and the gender distribution was 87 females and 2 males. The participants consisted of 65 Registered Nurses, 1 Registered Psychiatric Nurse, 12 Social Workers, 3 Physiotherapists, 2 Occupational Therapists, 1 home support worker, 2 teachers and 3 who did not define their discipline. Their level of educational preparation is provided in Table 1.

**Table 1: Educational preparation of case manager participants**

Province/Education	Diploma	Bachelor	Masters
British Columbia (14)	3 (3)	11 (9)	2 (2)
Alberta (12)	7 (7)	9 (5)	0 (0)
Saskatchewan (10)	9 (4)	14 (6)	1 (0)
Ontario (23)	10 (10)	12 (12)	1 (1)
Prince Edward Island (7)	7 (6)	3 (1)	0 (0)

The numbers not in brackets include all case managers; the numbers in brackets indicate the number of nurses in each category for a total of 66 nurses (65 RNs plus 1 RPN).

As noted in Table 2 most case managers in the study have more than five years of experience in home care and all provinces have experienced case managers. In one focus group, a participant was on orientation to case management and the focus group discussion was considered a beneficial learning experience. She noted at the conclusion of the focus group that she had learned a great deal about the day to day management of clients with complex needs.

**Table 2: Years of home care experience and years of case manager experience**

Province/ Years of experience	Less than 2 years	2-5 years	6-9 years	10-13 years	More than 13 years
British Columbia	0(1)	2(3)	4(5)	7(3)	2(4)
Alberta	1(1)	2(3)	5(5)	2(2)	5(5)
Saskatchewan	0(0)	2(4)	3(5)	7(5)	11(10)
Ontario	1(1)	6(6)	2(5)	9(9)	5(2)
Prince Edward Island	2(2)	0(0)	2(3)	2(3)	3(1)

The numbers not in brackets indicate the number of participants with the years of experience in home care identified in the column (n=85, four case managers did not answer the question). The numbers in brackets indicate the number of participants with the years of case management experience identified in the column (n=88, one case manager did not answer the question).

Case managers were asked to categorize their case load into acute, long term, palliative, target specialty, or a mixed case load. Prior to the study it had been anticipated that case managers would be designated as either acute care case managers or long term care case managers as is the case in some jurisdictions. In fact, across the country, case managers reported that their practice was mixed and also mixed in terms of rural and urban (see Table 3). With these mixed case loads, they often provided palliative case management as well.

**Table 3: Type of client profiles managed by participants by province**

Province	acute only	long term only	acute and long term	palliative only	acute, long, palliative	acute, long, palliative, and convalescence
British Columbia	0	6	0	0	10	0
Alberta	0	2	8	0	6	0
Saskatchewan	3	5	5	1	8	2
Ontario	0	0	1	0	19	0
Prince Edward Island	0	0	0	0	8	1

(n=85, 3 Ontario and 1 PEI case manager did not answer the question)

Of the 89 participants that completed all or part of the questionnaire, all remained the extra 1.5 hours to participate in a focus group.

## **FACTORS THAT INFLUENCE DECISIONS ABOUT THE CARE OF LONG TERM CARE CLIENTS**

### **Organizational Factors**

#### Ministry Partnerships

In provinces that have separate ministries of health and social services, case managers provided examples of the need for better partnerships in order to offer total client care. The examples given often involved disabled clients for whom housing, transportation and social services are managed by the Ministry of Social Services. Case managers working within the Ministry of Health address only the medical needs, and see benefits to the clients if the ministries could share resources to address total client needs. Case managers advocated for integrated care plans to avoid duplication of services and to pool resources to fill gaps in service provision.

#### Regulations and Guidelines

Each province has regulations and guidelines for community-based care, both in the home and in a long term facility, and each region providing community care has its own guidelines. Provincial regulations and guidelines may be interpreted differently in adjoining regions so that access, frequency and type of provider can differ region to region.

*We all regionalize differently, so our structure's different, way different. This leads to inequities in care across regions: So why can't you give my mom homemaking when she comes to visit me for three months, in (neighbouring region) they can.*

There is concern that the guidelines have not adapted to the increased level of client acuity and therefore are no longer responsive to client needs. Regular review of guidelines is required in order to ensure that current needs are addressed.

*Initially guidelines were reviewed annually, but the case loads got so big, it just wasn't feasible..we are out there enforcing the regulations and then an appeal is done and won..it makes you feel devalued.*

Case managers across the country spoke of their frustration in following the guidelines concerning access to services and frequency and type of services, only to have the client or family complain to the regional administrators or to the ministry representatives and have their demands met.

*Much more political so they will go to their MLA or MP or will write to our managers .. very assertive.. you know get a lawyer, threaten lawsuits some of us have had that happen to us..they go to the media. The squeaky wheel gets the oil.*

The case managers are often the people who have to inform the recipients of changes to the guidelines and they lamented that there is rarely a written communication backup.

*You know we changed the criteria for heavy care so you tell them, but (administration) is not going to put anything in any kind of publication about what the criteria are to make your job easier you just go and tell them one person at a time and deal with it.*

Communication appears problematic in other situations as well:

*Well what they did they eliminated the home support program that here was being run by city social services and instead of replacing it with something they just stopped it and they sent all their clients a letter telling them to call us (the home care agency).*

Case managers across the country identify the need for clear written regulations and guidelines that are communicated to the public, particularly to service users, and that are respected in appeal processes.

### Portability of Services

Home care service portability was an often raised issue. Elderly parents cannot move to another province to live with a daughter or son for the summer and thus give the more permanent care provider a break because the regulations for funding of services requires residency in the province and the mechanisms for funding of service transfers province to province are difficult to master. Also, services are not available across the country in a uniform way. The different models of day programs, respite care, acute care and long term care make comparisons as well as portability difficult.

### Common Tools and Language

Although assessment tools for admission to long term care facilities are being developed or already in use across the country these tools cannot be used to compare populations across the country because there is no standard assessment tool. Each tool varies somewhat, possibly to accommodate regional differences. Some case managers stressed that *you can never put down the real picture on a document*. Language describing clients varies as well. For example, in Saskatchewan, a special care home is the provincial nursing home and accommodates level 3 and 4 clients. A personal care home is private, not subsidized and since a level 2 client cannot access a special care home, the client would have to pay for personal care home accommodation. People are also confused by name changes:

*Daughters are care giving long distances and are totally confused by a national health care system where every province and every city is different.*

Name confusion can cause a great deal of anxiety in the system for clients. *We have recently gone through this thing of changing our name from home care co-ordinator to community care co-ordinators and home care to community care..they changed my name to transition services out of the hospital and so I will tell you..an 80 year old said to me ' I am not a transient dear, I have a home all I need is some home care'.* People do not understand what home care services are and what the role of home care providers entails. Case managers identified the costs associated with name

changing and stated that the money could be used in more effective ways. *You have to have the up and coming name or what ever when I think that money could be better put to use. Let's settle on a name, let's keep it and let's utilize it.* It may not matter what case managers are called, clients will use a nomenclature that they can understand: *Yeah as far as people are concerned you are their nurse or their PT, one case manager said I am their OT nurse.*

### Funding of Services

Case managers across the country spoke of the financial constraints of the health care system and particularly as it relates to funding for services in the home. They spoke of the organizational restructuring that resulted in shifting more care into the community but without adequate shifting of funds.

*The only thing that has come from the hospitals into the community is the clients themselves.*

*What we hear is that there is more money going into home care and yes there is more money but what they don't mention is that these people are much heavier care.*

When asked whether home care is less expensive than residential care, the following is a case manager's response:

*Depends on how much care they need. If they need 24 hour care then that is \$10,000 a month certainly..money is the factor..the government can't have everyone at home at \$10,000 a month.*

Another case manager suggested that we think about what it costs to have a long term care client in a hospital..*think about what it costs to be in hospital \$400 or \$500 a day. You get these people home, get them some help..I'm sure its going to be cheaper.*

Another message about the funding of services in the home which was a common theme across the country was with regard to the client's contribution. *..we could keep more clients at home if they would help financially.* For example, it was suggested that if a client could top up the home support services for an extra day a week it would prevent admission to a residential facility. However, some elderly clients believe that it is their privilege to be cared for in a residential facility.

*Clients believe going into a facility means that they don't pay anything..they don't know there is a cost to them on a daily basis.* Education about the financial realities of services at home or care in various types of long term facilities should be offered to the healthy adult population so that well informed choices can be made.

Sometimes the client may be better cared for in a residential setting and have more opportunities for socialization, but the family cannot afford to give up the pension cheque which would go toward care in the facility.

Case managers have great respect and concern for the informal providers: *We tend to be off-loading a lot of financial burden and care giver burden to the family with the criteria that have been developed.*

## **System Factors**

Factors which determine where long term care will be provided and how much care as well as by whom, are influenced by the availability of a number of inter-related resources in the client's community. These include the status of acute care facilities serving the community, appropriate housing, transportation, access to day programs, long term care facilities, professional and non-professional resources.

### Acute Care Resources

There is general agreement across the country that health care reform has downloaded acute care to community settings without the necessary investment in community-based services to make the new system work. Acute care clients discharged into home care are priority clients and therefore extend the waiting times for services for the long term care client cared for at home by an informal provider who needs help. The acute care personnel in some provinces make the referral for acute care clients upon admission to acute care services or shortly thereafter. These system changes have added to the work load of the case managers.

*If you are not walking two days after your stroke they want a level of care done and they don't want a level of care done to see if you are going to stabilize and improve.*

### Access to Day Programs and Types of Programs

Various types of day programs were identified across the country. Some provide recreational activities for clients, others provide direct care or monitoring, and yet others are not day programs but night programs which permit the families of clients with dementia to get a night's sleep. In rural areas, case managers wished for traveling day clinics so that clients did not experience the cost and inconvenience of traveling long distances for regular follow-up. Day programs offer care-givers respite on a regular basis. *I think we need to augment our day programs too so that we don't have to have care givers or care providers stuck in with them 24 hours 7 days a week.* However, sometimes persuading a person to go to a day program is difficult:

*I mean their families have tried two or three times, they've gone with the person to the centre, they've been there you know, two or three times and it's still not working.* For informal care givers this can cause much upset: *why can't the husband go and enjoy himself instead of causing such an uproar when he goes, you know, they have to take him out. he just won't stay.* If clients in the region are fiercely private or independent, day programs are not the solution. A community day care centre did not attract clients because in that community people were fiercely private: *It required a person going out of the home into another setting and the people who would qualify for that sort of thing didn't want to be seen as people who require that service.* Day programs used in

conjunction with such services as wound clinics, or within a special care home were more favorably perceived.

Day programs can be perceived as extra work for the informal provider:

*Mobility is very hard in winter even though you have day care programs..to get the person ready, out to the car, transferred into the building, back home again, like you might as well stay home .. it's too much for the care givers to do.*

### Respite Care

Respite care is offered both in the home and out of the home. Lack of opportunity to access respite often leads to placement due to care giver burnout.

*I think more respite would help because the care givers sometimes just need like a weekly night sleep and a weekly day off.* Short term respite on a regular basis was cited frequently as a need. In one area respite beds are booked 15 months ahead. The number of days of respite that is paid for by the public system varies from region to region. Respite beds in hospital or a long term care facility are not always viewed as an asset because respite clients are not the facility's priority and do not receive the same level of care as at home; therefore some deteriorate and are more difficult to manage when they return home.

Respite in the home means that the care giver has to leave the home *but they don't always want to do that, like it would be nice for that client to be taken by the home support worker to go shopping and do whatever so that he (the care giver) can put his feet up on the couch and watch TV.* The lack of flexibility in terms of respite care regulations was evident in many examples offered by case managers even though respite care hours per client vary considerably across the country. For example, a three hour limit gave one care provider in a rural area one hour to drive to the town, one hour to shop and one hour to return home ...exhausted! Even in regions with more liberal respite hours, there are weekend restrictions:

*Even if they use their limit of 24 hours a week for respite for the wife to get out..you can only have service every second weekend for respite. So even if they wanted to go to church which may be very important for a family member, it is limited to twice a month.*

A case manager with flexibility in respite care planning stated that she can provide more home care services each week to clients who get respite for a week a month:

*It works well for us because it offsets the hours, I have quite a few people on that program and they..go one week of the month into (name of lodge) so they are not requiring support services and I can put all my hours into three weeks instead of four. One week a month of respite while providing the needed rest also enables the family member to stay at home.*

*A lot of people cope really well if they have a planned respite admission into a facility for say one week out of every four weeks and it sort of gives their family time to recoup and continue on.*

There was disagreement as to whether cultural factors presented a barrier to the provision of respite services:

*I think some ethnic groups have a hard time accepting respite..it has been their culture to keep their people at home and they find it very very difficult even to put them in for a week, Mom or Grandma gets so upset. Other case managers did not perceive any differences related to cultural factors.*

### Palliative Services

Palliative services include services by various care providers which enable a dying person to remain at home. Palliative care services are delivered differently across the country. In some areas a case manager plans care for all palliative care clients but in most jurisdictions palliative care is simply added on to the case load. Palliative care clients generally receive as much home care as needed. The budgeted amount is above the normal home care budget per month, however, sometimes only for the last few weeks or months of life.

*Well it's a catch twenty-two right, so now you say well you know that's palliative, that person is palliative but it's not really imminent so we're not going to give you very much now but when you're a little closer to death then we'll be able to give, you know it's just so tacky.*

Case managers negotiate services with a number of volunteer and service providers such as the Cancer Society and Hospice visitors in order to offset the home care services.

The level of palliative care provided in the home has increased but *it is a difficult thing for people to understand you don't die in hospital any more.* People go into hospices or hospital for symptom management and then return home. Returning home can be a burden for families if medications are not covered so the incentive to keep people in their home may not be there even though home care will provide support. Case managers articulated other difficulties providing care for the acute palliative care clients and those who have long term terminal illnesses.

*The brain tumour person who doesn't have major symptoms but needs supervision and some nursing care.. they don't probably get up to a level 4 so they are slipping through the cracks..there is no real place for some of the terminally ill clients.*

### Community Characteristics

Community characteristics and history play a role in determining home care usage. In communities that have the seniors' residence co-located with nursing homes there is a perception that travel costs are lower and the quality of life for the elderly is enhanced. This is particularly true when one spouse is in the nursing home and the other is not. *I have lot of people in the lodge whose*

*spouse is in the nursing home and because of proximity they are able to go back and forth and it is quite a healthy sharing. The opposite is true when there is a distance between the two: My lodge is far removed from any nursing home miles and miles away and my dear people who have to go in, and the spouse then has to take the bus for 20 minutes and or take a taxi so psychologically they feel distance. There is concern for the elderly who, even though they live in a city, may be socially isolated because of winter conditions when winter months come along they are sort of trapped in their home because of the ice and snow and cold and their friends are in the same boat. Some communities are able to alleviate the loneliness of elders by helping them get to community centres: a lot of my people go to the (name of centre) that has an East Indian afternoon on a Wednesday and all the women go in a bus which helps.*

Gated communities as well as being criticized by case managers as unhealthy and elitist were described by one case manager as places *where people can artificially create a homogenous environment of people with somewhat the same amount of money, somewhat the same amount of health, somewhat the same 'I want things to be perfect,' what I call the vacuuming the drive way syndrome.* These communities do not tolerate differentness and seniors requiring care can be pushed out. Case managers expressed the view that communities that are more heterogeneous tend to look after seniors better: *She happened to be the only one who was extremely elderly and it was really fun to see her. You would see all the little children with her walker and it was like a normal part of the environment. An elderly senior who wandered was protected by his community: The community became the watch dogs for him so he went down to the seniors centre took part in the activities and would head back home. Everybody knew that he was going back home and they kept an eye out 'you turn at this corner' you know and he would see his house and then he would be okay.*

In remote areas case managers articulated the characteristics of the people who choose to live there. *They're fiercely independent, I mean, they want as little interference from the outside world as possible, they want to stay home.* Case managers who live and work in the same community recognize that this can be a hindrance in that they are never not at work. *I have had calls New Year's day at 7 in the morning, you know, the doctor's away, so they know you're there and it is very difficult to set limits.* Other health care professionals can also impose on the case managers because they live in a particular community: *the doctors call them at home um 'could you do this could you do that' and that is because we live in a small community and every body knows everybody.*

### Transportation

Our Canadian transportation system poses problems for our elderly in many regions. *Transportation is a big problem for people to get from A to B even to get to the doctor's or to get blood work done. Like you have somebody who needs the handivan to go from the main town to the next little town waiting for the lab it costs something like \$160 to have your blood drawn you know.*

In rural and remote areas the transportation issues are compounded because the bus may be used for other services: *The doctor's appointment is not at a time when the Handivan can run or when the Handivan is available because they use the Handivan for disabled children and take them to and from schools.*

Even in cities, bus services can be difficult to access: *If you live on the south side and you needed to go to the north side you'd have to catch three buses and you might have to walk a block and a half to catch the bus.* Transportation to and from community services has dealt a blow to programs. *We had access to beds overnight for sleep and it was used so little that the program was terminated..one thing was transportation they had to get these people to the bed by.. and there is no Handivan running at night at 7 o'clock, there was no way to get them to the bed..so the program died.*

Several case managers stressed that day programs and transportation must be planned together. Centralized well-attended programs would reduce current day program costs.

*It would be more practical rather than have little satellite programs all over to have increased spots in the city and have transportation provided for these people to be pulled into something functioning well.*

### Housing

Across the country there is a lack of seniors' housing. *What we need are more retirement villas or homes..we need a step between home and the long term institution.* Housing that is suitable for those who are not able to manage stairs is hard to find as described by one case manager:

*There's only one apartment .. that has an elevator..so seniors living in apartments are going to have to do stairs.* In another city there was only seniors housing and facility care and nothing in between for those who would have benefitted just from having communal dining facilities.

*You know like their own little apartment but maybe with a common dining room or something..that kind of arrangement.*

Waiting lists for suitable accommodation vary across the country but the wait is often unbelievable: *I understand anywhere from about a year for a little bachelor versus 15 years for a two bedroom apartment.* In another part of the country for a senior complex *the waiting list is five years and the other one is a little more like 8 or 10 years.*

Housing for seniors who need minimum care would benefit from co-location with residential care settings and nursing homes. A case manager described a private facility thus:

*It is a private community, privately run, has a nursing home, has regular apartments and also has a residential area. It has a dining room, a beautiful dining room, cafeteria, stores, doctors offices, huge swimming pool and it is all contained within one building that has crossovers so that the seniors don't have to go out in the winter.*

Flexible care buildings permit clients to remain relatively independent but permit the efficient use of home care resources.

*I have found that what has been of benefit has been the flexible care buildings and that if you have got a high number of people that are high risk in an area..If you have got flexible care you can afford to flex care and they can drop in four or five times a day but you are still not using a lot of time but you are checking up.*

### Access Issues

Case managers are faced with access issues on a daily basis. Access for their clients into services in the community, into institutions, into acute care settings and access back out into home settings from institutions. Many case managers chasing too few resources makes the problem worse. As there are not enough resources, wait lists become the problem and they have to be managed and evaluated periodically. The paradox of the wait list is that when case managers know that a wait list is long they are not inclined to recommend the service to their clients and therefore do not add them to the list. This means that the administrators may not have an accurate picture of service requirements.

Case managers suspect that wait lists are used to control costs. Family members may phone and request help with the personal care of a relative and be told *a nurse will contact you within the week to do the assessment and she will go out but there is a three month waiting list and you are expected to either sponge bath or purchase the service ....and sometimes you don't even get the service, what you get is a bath chair.* In most areas across the country there are waiting lists for home support services. Case managers often suggested that with more day hospital access, clients could be managed at home because the day hospital programs act as respite for care givers.

People can wait in acute care beds for places in long term care institutions. These clients can and often are placed ahead of clients in the community: *The hospital clients have priority even over community urgent clients.* They are labeled as bed blockers and *in acute care hospital there's no programs, it is not a good environment for them.* Some areas maintain two lists for clients awaiting placement; the regular list and the emergency list. The wait times vary as well: *I mean our emergency wait lists are now three months and it used to be one week you could get someone into care..the term emergency is an oxymoron.* Concern over waiting lists can be compounded when a facility closes or when bed numbers are not increased. In one area *a private nursing home decided to close..and that really upset the apple cart right across the province.* The need to manage the waiting list became very difficult as other nursing homes were temporarily granted extra beds and the placement committee had a difficult role determining who needed the next vacant bed the most.

Waiting lists for placement are a major concern for case managers. When clients have waited on a list for a particular institution and a place either does not become available or their health status changes they may not go to the facility they have prepared themselves to go to: *We have to put down their name on waiting lists so long in advance and it sets up a mind set.. that is where you are going.*

### Substitutability of Home Care and Facility Care

Case managers were asked if there were people who were in institutions who could be at home with services. Surprisingly case managers felt almost all the people who were in long term

care institutions should be there, but they could all recount stories of those who had come back into the community. Several stories were told of families who became so overburdened a long term care institution was seen as the only alternative but when families recovered they wanted their loved ones home again. *Placement happened because the daughter actually was burned out. And she started to have some real health problems and so Mum went into care and she is now coming home again with extended care.* Another story was of a husband who burned out *one of my ladies in one of my facilities was admitted on an emergency basis because the husband was absolutely at the end of his rope but once she got in there and he had a good rest at home, ..well suddenly the whole world looks brighter and he felt more capable of coping..so he discharged her from the facility and now has her at home again.* Occasionally, the reason for coming back to the community is financial *I have had a couple of clients coming out of long term care facilities because the spouse that they have been living with is used to, is dependent on both pensions in order for them to stay in their own home and now with one person in the facility they can't manage on one pension.* Clients return to the community because they don't like the facility and sometimes because access to alcohol is restricted in the facility.

Health delivery systems that are constantly changing provide daily challenges to case managers as they try to negotiate adequate services for their clients. Overall, clients who are in long term care institutions are appropriately placed since they are frail by the time they are admitted. The problem for case managers is that the sick elderly are often discharged home from hospital before they can manage, particularly when they are not able to access convalescent beds. The acute care system is one of *hurry, hurry, hurry* and the elderly are often pushed out or into institutions without allowing them time to recover. There is no uniform method of accessing home care services and there is a lack of information for clients who are trying to access care in the community. While there has been an increase in case managers the resources they are trying to access for clients have not increased to the extent required so waiting lists for services, particularly home support services, are the norm across the country.

### **Client Factors**

The themes generated by the focus group data concerned client health status, age, special needs, environment, vulnerability to abuse, financial well-being, tool assessed needs, family defined needs, client choices and client support system.

### Health Status

Throughout the country, case managers agree that the medical acuity of home care clients and their complexity of care has risen considerably over the period of their personal practice as home care managers.

*Criteria for home care admission has changed. Folks are running into more trouble and the expectation is that we have our finger on what is going on..a lot more intensive case management..people having to find alternatives because they can no longer access long term care facilities like they did 5 or 6 years ago. Families having a real difficult time at home and we can*

*no longer offer them options. What used to happen is higher case loads had lower risk clients, now heavy case loads and all intense.*

More professional resources are required and the treatments are more expensive. Resources are going into intravenous therapy and ventilator services. There are more older clients, more palliative care clients, and more clients in long term care interim beds that cannot get services in the community because of a lack of resources. The under 60's with mobility problems (quadriplegia, etc.) who used to go into institutional settings are now maintained through home care. Obtaining placement for clients with special needs has become extremely difficult. The case managers indicated that they are managing long term care needs by crisis, there are not enough residential facilities and the waiting lists are long. Physically disabled individuals have difficulty finding appropriate accomodation. Some residential facilities cannot accommodate individuals with gastric-tubes or even those with special diets.

*When people come to us they are in crisis..almost time for long term care. With dementia within a 3-4 month period we are looking for placement. A lot of families want 24 hour service. As a case manager you have a 2 hour visit with people in crisis, 4 hours of paper work plus 2-3 hours to get the plan off the ground.*

Another informant said that because of the lack of long term care facilities, clients wait until there is an emergency and then go into hospital. Case managers state that all they can do for the special needs clients is advocate for them ..the severely compromised stroke patients with feeding tubes, oxygen, stay in hospital longer and do not get rehabilitation services. The clients which create the most concern are those that residential facilities say they can not handle, the client with a mental health problem plus diabetes and incontinence, those with psychotic behaviour and suicidal tendencies, patients with Huntington's Chorea. Across the country case managers spoke of the difficulty meeting the health care needs of those who suffer substance abuse.

### Environment

The support of the community is a factor in the client remaining at home. Some communities pick up the wanderers and take them home. Clients who have always lived in isolated environments in rural areas particularly do not adjust well to residential living and prefer to take greater safety risks by remaining at home. Communities that have invested in senior housing with accessible bathrooms, on site support workers and support packages that can be purchased (daily delivered meals, bathing assistance etc) enable their seniors to remain in the community longer. It is particularly difficult to find appropriate accommodation for alcoholics since residential facilities do not want them. *I can think of three men that could go into the community if they had daily socialization and counselling and someone to help them through the hills and valleys..they are likeable men with a horrible disease that people do not want to deal with.*

The rigidity of some long term care facilities also creates environmental barriers. For example:

*Because one of my clients who is on a special diet has a mental disorder she will eat anything..the facility would not take my diet order..a physician rewrote the diet..another would not admit a Chinese man even though his wife assures us he will eat Western food..they said no.*

### Financial Well Being

Although the financial well being of the client is obviously a factor in being able to afford to augment care, many seniors have difficulty spending money on themselves *they want to save it for their old age*. When financial resources are limited, and supplies such as DEPENDS are costly, the financial adjustment made may be in terms of food supplies.

*We have defined scrooge in using dressings at home. We have seniors on \$840 a month, add medications and some gauze..we don't throw out a 4x4.*

Case managers spoke of individuals making choices to go into a long term care facility who could have been cared for at home because the long term care facility was subsidized.

### Abuse

The most vulnerable clients are those with borderline competence. Prince Edward Island has an adult protection program. However, some clients are difficult to protect as suggested in this British Columbia example:

*A lady who lived on the beach had parties with teenagers who drank her liquor and stole her silver..they took advantage of her but in a way she liked it.*

### Family-Defined Needs

Defining family support is sometimes difficult. The example is given of the elderly husband who is an alcoholic and says he can manage his wife's care but leaves her in bed all day. Several conflicts were identified related to family choices:

*The hospital pushes placement and the family pushes to get them home. I know they will do better at home..hospitals don't see how much better they do in their own surroundings.*

Case managers also expressed concern that families are sometimes reassigned to the same agency whose staff stole from their relative. Theft was an issue raised by at least four case managers who advocated for security checks on care providers as a requirement by all agencies. The workload of case managers is increased every time the client and/or family, after assessment, planning and confirmation of the decision for a relative to go into a long term care facility, change their decision. Families also threaten case managers with intervention from the local politician if the needs as they define them are not met. Ethnic groups have difficulty accepting respite care and some families feel responsible and follow the paid caregiver around to ensure that care is given properly. Decisions are comfortable for some families only once they see that their family member has settled into a facility

and is a whole lot brighter, the diet is healthier and the medications are being taken on time and they have a degree of socialization. Case managers speak of the holiday visitors:

*Families who live far away come home at Christmas and want to fix it. If the daughter is an RN the focus is on the physical care, if a PT it is on mobility.*

Movement from the residential facility into the home is generally the result of family lobby or the client does not have access to alcohol. *Most cannot leave long term care but there is always the one or two that can.*

If there is no family, and the person is incapable of making the decisions, the role of the community (case manager, physician, long term care facility staff, home care agencies) becomes central to the decisional process regarding the best site for care of the individual.

### Client Choices

The young would rather live at incredible risk than enter a long term care facility with elderly residents. Even for seniors the nursing home is perceived as the end of the road. A case manager remarked:

*We guide people along a continuum..you get your support worker, then respite care, and if it gets too much for you we place you..that's our story but it isn't theirs..if they had their choice my families would keep the person at home.*

The majority of the clients are the elderly and their choice is to remain at home. A 97 year old woman is quoted as saying: *My leg just stopped and I am not going anywhere but heaven, nothing in the middle.*

One case manager indicated that a couple can be put into a long term care facility only if they both need care whereas there used to be the option of keeping the couple together if only one required the placement. People need more choices. People who can no longer stay in a private facility and have to move to a shared room find it quite traumatic. When family members want to move a parent closer to them it frequently turns into a disaster. *We want to fix everything but people have choices and sometimes they do not make the best ones. Old people do not want to be told that they cannot have a beer and that they can only have one bath a week. The client does not care if she falls or drops dead in the garden..she just wants to garden.* Alternatively, there are clients who feel they have worked hard all their lives and deserve nursing home or other facility care even if they do not need it.

### **Case Management Issues Related to Family/Friend Care Giving**

The case managers identified a number of issues related to how their work impacts on - and is impacted by - family and other informal care givers. Their accounts clearly point out that not all clients they serve have such care providers, and that even among those who do have families, the

quality of care provided by such persons differs significantly depending on such factors as their motivation, age, proximity, health, knowledge and past relationships.

### Families and Friends as Carers

Case managers perceive families and friends of their clients as vital to the decisions regarding care management. A case manager described a triumvirate of care involving the client, the family and the health care system:

*What the client can do for himself, what are his resources, what the family can do, and what we have available to provide for them. Those are the three things.* Another noted that overall, families provide as much as 85% of the help given to people at home. *The ones we are getting are the ones who don't have those resources for whatever reason.*

Family members are expected to carry out their care-giving roles without remuneration. One case manager described the financial burden that this causes:

*I find that is one of the biggest downfall is that we expect families to do all this stuff without any kind of remuneration whatsoever. There are family members who are willing to take care of their parents and do a good job..but they may have to give up their job or go part time and we have this mind-set that if you are in any way related to the person we will not pay you. We would rather have someone who has no knowledge of them, no idea what they were like before, come in and do that. Like under some guise we are doing them a favor.*

Each family is unique in terms of needs. Parents of multiple needs children who become adults are particularly disadvantaged. One case manager noted: *The pediatric model is all encompassing and then they get booted into the adult world all of a sudden and things are no longer covered. They don't get the same level of assistance but now they have a dependent adult with multiple needs.*

Rural families were thought by one case manager to give more care to family members. It seems to be a mind-set in the farming community that the elderly member of the family will be looked after.

### Gender Issues and Care Giving

Several issues related to gender and care giving arose in the focus group interviews. It was frequently noted that wives and daughters were most likely to be the designated carers. Often it is a combination of the two. *I have had cases where the husband has done a lot of the care but that is a rarity.* Another claimed *more than 80% of care givers are women.*

A case manager expressed the view that it is: *Almost like we are going back to when women really didn't work outside the home and they looked after the elders.* But then she paused and after an uncomfortable silence said *we are almost going back to that except now the women are working outside the home full time somewhere and, ah, they are still the care givers.*

These gender-related issues and roles pertaining to care-giving practices are changing as societal values change. A shift is also noted in the way men are becoming involved:

*I have been surprised recently...some males were better care givers than the females and in actual fact, I think that our generation of men will do hands on care more than our parents generation because their roles were very much more defined.*

A case manager made an interesting and somewhat troubling observation that in her view male care givers are treated more favorably in our long term care system:

*There is definitely a trend in the health care system to rescue male care givers and not female care givers. A client was recently discharged and the doctor claimed that he had no support at home because he only had three sons. I was quite flabbergasted. I have noticed that particularly in dementia we tend to as a largely female profession rescue the men care givers more than the females. Like the man can't do this and the man can't do that.*

### Stress and Care Giving

The case managers reinforced the well-known fact that caring for a relative or friend in the home can be stressful. It can interfere with sleep patterns and social patterns and can over time result in the total inability to cope.

*Sometimes we start out with one sick person who needs the care and they have a spouse who is the same age and maybe as many medical problems..and by the time we are finished we have two people who need care. I think it is really sad when you do that to the spouse.*

Another informant noted that *no one is tracking the health of the care giver. They go into caring for demented people with three illnesses and come out with six, and there's no tracking of that. They are not considered in the equation at all..and that is more costly to health care.*

Making the family part of the “official equation” was a theme that arose quite often in the focus groups. For some, the issue relates to situations where the client falls short of the eligibility requirements for facility placement but the health of the care giver is failing.

*When you have a care giver whose health is at risk, you feel like you are juggling. It's we'll try this for a while and then we'll try that and jiggling to always find a better mix for the person to help the family cope.*

Not all families want to engage in care giver roles. It was also clear that families experience continuity in their relationships, so that if there has always been disharmony, this will often continue on into later life and can complicate the sorting out of who will care for whom. A case manager even felt that some families will say anything to get their family member into placement *if they really want this person out of their life and out of their house.*

The case managers reported frequent encounters with families who had in their opinion “burned out”. It was particularly troubling for one who believed that *in a way we are promoting care giver burnout [because] we are not giving them the support they need.*

Immobility of the client, and in particular the inability to transfer, was seen to be a triggering factor for care giver burnout. And nights were seen to be a problem. *If they can't get any sleep at night they are not going to last long.* More than one case manager said that they had seen instances of care givers dying before the client they are caring for.

*There are more and more demands being put on the family and friends and neighbours and what you will often see is the elderly person just plugs along and does fine and you will have the care giver that dies.*

There was a sense among many case managers that they had the potential capacity to prevent crises and burnout among families, and conversely if they had that ability, perhaps they were to blame for families falling apart under the stress. This is quite a burden to carry, as the following excerpt reveals:

*It's a difficult decision when you know that one extra eight hour shift or a little bit more service would make a whole lot of difference in that person's life and its not available. ...so they can have a break..we cannot do that type of thing..we have to work within the framework..it doesn't meet the individual's needs.*

### Families and Coping

While most of the case managers spoke in highly positive terms about the roles of family carers, it was clear that they did not see all families coping equally well. As one said:

*I think it is not everyone has the ability to care for someone..well we all knew that this one particular lady could not cope and the doctor knew and the nurse knew but what do they do? They send [her husband] home..but we have to watch we don't get judgmental in this job and not everybody's cut out to be a mom and not everybody's cut out to be a care giver.*

The case managers talked about the value of respite care as an aid to coping of family carers. They believe that respite in the form of short term admissions to facilities might have prevented permanent placement in several situations.

Placement often entails guilt, particularly when it violates trust or promises that have been made such as: *I had told Mom I would never put her in the Nursing Home.* Some families appear to feel less guilt using respite care, day care or home care services, compared to putting their relatives into long term care. But even these programs induce feelings of guilt for some families..*maybe it's the admitting they need help, that they are having a hard time.* Some people just seem to be remorseful that they are not able to do all of what they believe they should be doing for their loved one. They may put off asking for help until they are in crises and then its *almost time for long term care..its placement issues that we are looking at.*

### Care Givers and Support

Clients receive physical and emotional support during direct care visits or through telephone contact. When one client was asked how many nurses had been in to visit his terminally ill wife, he said that he had only seen two, and the rest were by telephone only. According to the case manager *..they called him everyday on the long weekend and that's all he needed to know. That was a life line. A telephone call is not too hard. Mutual support is encouraged among clients.. trying to get the families to support each other and maybe provide some tradeoff that way.*

### Care Giving and Financial Well-Being

Several case managers expressed the view that families should pay for some of the support they receive. However, some families keep an elderly relative at home because they rely on the relative's income.

*In my area with a lot of low income families cost does factor into what their options are. There have been situations where they have kept the spouse at home because financially they could not handle having that spouse go into a long term care facility even though it was physically too hard on them to provide the care. They would have to pay. Like if they can't, they would lose that second income at home...some would lose their homes. Or young families I have worked with where Dad or Grandpa is home and they have come to be dependent on that pension cheque. If they put him into a nursing home, then all the money goes to providing his care there and that family is devastated.*

### Families and Proximity

Living near or far from aging parents or relatives affects the nature of the care giving relationships which are formed and maintained. Living nearby certainly has its obvious advantages. Mixed housing complexes afford a range of living options. For instance, a case manager described the advantages for people living in a lodge next door to the nursing home where their spouses are living. Proximity enables frequent visits. Families living far apart have their unique struggles. Families that can only visit on holidays *want to fix everything over the holidays*. It is difficult when adult children want to uproot their aging parents and move them closer to where they are living, as one family was quoted as saying *just so we can keep an eye on them*. A case manager states:

*Time and again I have seen this to be an absolute disaster..I have tried hard to talk to the kids, so that they're aware that quite often this isn't in their parents best interest*. However, in some families, such arrangements have worked out.

### Building on Existing Relationships

Family members do not become carers in a void. They usually evolve into the role, building on existing relationships. They are already a daughter, a spouse, a son or a daughter-in-law, and thus need to undergo changes in roles and relationships. Many different arrangements exist. Often these relationships are symbiotic or reciprocal. One case manager talked of her 85 year-old client who is

caring for a mentally challenged daughter who is 50. *Without each other, neither women could be there, but that is almost typical of our case load.*

Spousal relationships can become quite complicated when one party is required to change roles and become the carer of the other. Case managers believe there are more 90 year-old spouses giving care now than ever before, and that it is quite startling what some of them can do. When alcohol or drugs are involved, care giving becomes complicated. Care giving puts stress on a marriage, but also affords opportunities for closeness and bonding. Strangers can never know the client's patterns and idiosyncrasies in the way a spouse does.

### Offspring Relationships

Relationships between adult children and their parents change when parents become frail. The case managers thought it was important to treat each case on its own merit.

*It would depend on the individual case because I had a mother who was 101 and her daughter, who was her care giver, was in her 80's. The daughter was dementing but thought she could care for her mother, who in turn was completely mentally intact. That was a unique situation so both of them did go into care and actually the daughter was quite an asset to the staff. They went in together cause they just couldn't separate them.*

Such success stories were not always the case. A case manager painted a sad picture of financial abuse by a son, which left his mother in serious financial difficulties.

### No Family

Occasionally the case managers find there are no family members available for care giving or the family network has *disappeared into the woodwork*. They described feeling awkward, having to stand in as makeshift family. *It is not considered part of our job, but in a few cases there was no other person to take them (to the Nursing Home) so we had to do it. And when they do not want to go, it puts you in a bit of a space..some of them need help just to get out and get their groceries. We don't often do that but.*

Transportation is a particularly difficult issue when there are no family members available. They may need help to get groceries or go to appointments – and homemakers are usually not allowed under their contracts to provide such services. People without families have no one to check in on them, and the case managers expressed issues concerning safety for such clients.

*If you can only provide a couple of hours of homemaking a day and the person doesn't have any family, and you know that person will probably fall and break their hip or go outside and lock the door and freeze to death, or leave the stove on, you would rather see these people in a nursing home. If you had the resources in there you wouldn't feel that way.*

## Volunteers

The case managers expressed the view that the pool of volunteers available to assist seniors is *drying up*. Small communities are particularly noticing this shortage, as there are often more seniors and handicapped persons than volunteers and the volunteers tend to be involved in many other things so are not always available.

*For palliative and for cancer clients, there is almost unlimited volunteers compared to very limited volunteers for the elderly..the friendly visitors and help with shopping has pretty much eroded in the last two or three years. That puts a huge hole in services.*

A volunteer program to drive seniors to appointments was thought to be working well, in part, because the senior pays for gas and the driver's lunch, if it is over a meal time.

## **Case Manager Factors**

### Case Manager's Perceptions of their Role

Case managers (also called home care coordinators) stated that their role involves initial assessment, planning and implementing services and ongoing monitoring and evaluation, to promote the effective and efficient use of home care services. Aspects of their role affect placement decisions. Whether case managers are seeing clients for the first or twentieth time, they are constantly considering their client's ability to manage safely at home. When a care giver is involved, that person's health and safety is also considered.

Case managers across the country did not describe themselves as having a streaming or directive role. They emphasized that their role was not to make the decisions, but to provide information so that clients and families could make informed decisions:

*Our role is to support the families and make them aware of their options. Not to do the problem solving or decision making for them. So I spend a lot of time going over that. A lot of our role is to provide information to people because if they have the information they can make good decisions on their own. We are not the ones that say that you have to go anywhere and that is not our role.*

There are situations in which some case managers perceive the need to provide more direction, especially to families that were unaware of the client's limitations:

*I am finding that there are a fair number of people who you are trying to direct because of your clinical knowledge of progression. [They] are stuck on it for whatever reason and you have to try and redirect them and sometimes you can't wait for the crisis to happen.*

Families do not want to hear the word "nursing home" spoken before the client even though that is what is needed. *So that makes the job harder when you are the one that has to say..well, this is reality.* Families feel guilty making these decisions and need help in these situations. Case

managers weigh the costs and availability of services with the risk of the client's health and safety, yet even if home care resources are available, the home is not always the best place, especially if the health of the care giver is also considered. Also, case managers state that *there comes a point in time when a client can't be managed one on one or maybe one on one isn't the best..especially if they're not the kind of person who would go to a day program.* The situation described above seemed to relate consistently to confused clients and their families. Those people were not getting their needs met on home care. Two case managers in different provinces explain the stress on the care giver:

*I think another set of people who fall through the cracks are those that are early Alzheimer's and needing care but according to the way our assessment for long term care is set up is based very highly on physical need..mentally and emotionally they are not able to cope at all. Their care giver is at very high risk of burn-out and we are ending up with two (clients) instead of one.*

*I have a dementia specialty case load and often very stressed care givers.. someone is up all night. They (the clients) are not quite at the elopement risk that would qualify them for a special care home. They can't afford a private care home. You have got elderly care givers with health at risk. I find that, that impacts in a stressful way, coz you are juggling..to always find a better mix.*

These descriptions indicate that if the client or caregiver's health or safety are at risk, case managers will direct the client and family toward placement and are particularly stressed when the clients do not meet the criteria for admission. On the other hand, case managers may be forced to direct a person to placement who could be managed at home, if more services were available, or if the case manager had more time to organize the services.

Case managers spend considerable time informing physicians, clients and families about the eligibility criteria, the services that are available, the role of the case manager and correcting misconceptions that people have gained from the media, neighbours, family or friends about home care and case managers. There is a perception that home care has received a lot of funding and that families can rely on home care to cover all costs for care in the community.

*When we tell them there is a limit to the number of hours they can have and beyond that they will have to pay privately, we get asked..well what is this 'closer to home' about? I understood it was cheaper to stay at home and now you are telling me I have to pay for some of this.*

### Timing of Referrals

Case managers working with or in hospitals say they are expected to work miracles. Sometimes, within a few hours, they have to find and put in place services for a client whom they have just met. They lament that some hospital professionals *do not have a clear understanding of our role.* Referrals are often not received in sufficient time to prepare the client, family and services prior to discharge:

*The frustrating thing I find is for people who weren't existing clients coming on. You have got to figure out if they can go home but you haven't seen their home and the description of what happens in that home isn't always accurate.*

Case managers identified two aspects of the placement process from which they were often excluded. One was placement assessments that were done on people in the hospital, the other was the approval of placement for people who were not receiving home care services.

*I think the hospitals are a little bit quick to go the placement route too. I am not sure if it's because, well they're taking up the acute bed for one thing, but I also wonder if, if they are just not looking at the whole person and only looking at their diagnosis, medical..I think what they should do is have community care to do the placement papers in the hospital.*

Hospital professionals were perceived as too quick to decide that people in the hospital were permanently confused rather than temporarily disorientated because of illness, medications or strange surroundings. Community-based case managers who know the client in the community can add a valuable dimension to the decision-making. Increasingly, community-based case managers are doing the placement assessments in hospital. A case manager relates the example of input from a case manager who knew the client:

*We saw a medical condition but weren't seeing all the other stuff and when you came in and said "Oh, my gracious, she was out gardening last week"..that is a brand new condition and we had no idea.*

Even if they do not know the person, case managers indicate that they are much more aware of community resources that could be used to support the person in the community. Since they are not employed by the hospital, hopefully they would be in a better position to resist hospital pressure for a quick placement solution to clear the bed rather than a potentially more time consuming process to return the client to the community.

Although community-based case managers have become much more integrated into hospital teams planning the client's discharge, many case managers perceive a gap between hospital liaison staff and themselves. Examples from two different provinces:

*The liaison at the hospital hasn't changed in so many years..we are still educating the same groups and face exactly the same barriers that we were 10 years ago.*

*It's a lot of work we do with educating our colleagues.*

In contrast to expecting that only the case managers in the hospital can arrange and prepare the client and family for discharge, some described case conferences and team work in hospitals:

*As team members in the hospital, we meet at rounds weekly and identify people who are going to be in need of some type of support..we work very closely with the team.. that is best for the client to prepare for going home.*

Regular and early case conferencing in the hospital provides the opportunity to adequately prepare the client and family for discharge. As well, it provides an opportunity to orientate the

hospital professionals to the client's home environment and the resources that are available in the community. Case managers thought the system had failed if the reason for their first visit was to complete placement papers. It was frequently suggested that a trial on home care be considered prior to placement. From one end of the country to the other, they talked about people waiting too long or not knowing about options other than placement:

*We're quite frequently going out because we're being asked to do papers. These people don't even have one service from the community, but they want papers done! ..they will say..well, I want to go to a nursing home. So we will have to back away and get them to see exactly what their needs are..perhaps other resources like day care and assistance from families..then they can stay in their own homes..if it is 16 to 18 hundred a month for a nursing home bed.. I say well you weren't spending this money at home and if you want to look at how you can spend that and fit that into your monthly schedule, you may not need to do the papers right now.*

*We get the referral ...for going to the nursing home and you say..you need some help right now, let us help and they say they are not ready to accept it yet..I went through a bunch of files on placement..there must be 235 there, there is 50% there that don't have home care.*

In these situations, either the public is not aware of home care services or care in the home is not a preferred option. More communication to the public about home care services may prevent or delay placement. People may be more resigned to accepting placement because of its similarity to hospital and medical care, yet they may not anticipate the effect of losing their personal freedom. Sometimes a case manager will hold a person's place on home care for a short period when admitted to a nursing home:

*If I have an inkling that this person going in is really unsettled, we can place them on hold from our end for up to a month.*

With their place on hold, the client can return home and be put directly on the same services without going on the waiting lists. One way to ensure that clients applying for placement understand the benefits and limitations of both home care and placement is to require trial periods for both situations.

### Assessments and Planning

Case managers view the initial assessment in the home as crucial to their ability to provide appropriate services for clients. The time needed ranges from a minimum of an hour to two hours face-to-face contact. They feel that an in-depth assessment for a community referral is necessary so they could move beyond the superficial concerns..*not only looking at now but sort of what's in the long term and often we can deal with the crisis on the spot.* The face to face contact also fosters closer communication over time:

*Face to face, they know who they are talking to so they would be more apt to phone us and say. You know, this is what happened to-day, what do you think?*

Planning occurs along with the assessment of the client and the availability of family supports. The case managers provide options so that clients and families can make decisions. Often the planning and decision making is not straightforward. People are confused because they do not understand the system and they are experiencing a considerable amount of stress:

*They don't understand what is available and what isn't..start from the beginning again, you reinvent the wheel every time and I think that is a shame..I still find a lot of people are completely confused..families are traumatized by all the changes and information. We find we have a crucial role to help them sort out who is who and try to be with them to co-ordinate the services so they understand what is available to them..next week you need to present the same stuff..they want to know again and again what the options are coz they are so stressed out they can't keep it in perspective so there is a lot of that. It is very time consuming.*

The confusion and frustration of families emphasize the need for case managers to have patience, conflict resolution skills, and time. The time put initially in the process lays the groundwork for an ongoing supportive relationship.

The financial resources of the client and/or family also influence planning if home support services are required. In some provinces home support services are only available if privately funded. In other provinces a means test determines the services available at provincial expense. If the client or family is able to pay for home support services, the implementation of these services is more rapid and more sustainable.

#### Providing Services: Implementation and Ongoing Monitoring and Evaluation

After the assessment and plan, services are implemented, monitored and evaluated. As case managers repeat the process with each new admission, clients and caregivers already on the caseload must be maintained and additional assigned tasks completed. The determination of the amount of work involved in coordinating the services for a caseload takes into account the number of people on a caseload at any one time, the number of new admissions, the complexity of the cases, the availability of professional services and the availability and coping level of the informal care giver. As well, case managers report additional community services that are not part of their official caseload, but a part of their professional responsibilities.

Case managers as a whole stated that administrative tasks, restrictions caused by criteria or guidelines, lack of resources (funds or services), and the size of their caseloads were the major obstacles to their efficiency as case managers. They are handicapped by poor clerical and technical support. Many case managers are expected to do all documentation themselves, including writing the same name and particulars on several forms:

*The paperwork is phenomenal. We could see probably at least a third to a half again as many people if we did not have the paper work..It would be more cost effective in the long run if they spent some money on technology.*

Computer support is either not available or not designed for their needs. Determining and managing waiting lists takes time away from organizing services. Case managers recognize the burden wait lists put on families and the costs in their time:

*We've gone to the waiting lists to handle our excessive over spend, over expenditure with homemaking hours because we don't want to have to go out and say unilaterally that we're cutting hours. A lot of time we seem to spend on helping manage the wait lists.*

The actual productive time of case managers could be increased if the administrative tasks were reduced. Clerical support, computers and client/family-oriented publications would free them to spend more time working with clients and service providers.

A considerable amount of time is consumed implementing the plan that has been worked out with the client and family: *You're two hours in the home, if all goes according to plan..and then two or three hours follow-up just to get that initial plan off the ground.*

Advocating on behalf of the client with community agencies and service providers is a large part of the role while attempting to implement the planned services. The statement of one case manager summarized what many were saying:

*We are often trying to stretch the boundaries of what different agencies will provide. [We say]: This isn't enough for this person. We need this. Can I get more? I think maybe I spend an awful lot of time on that sort of thing .*

In addition, time-consuming advocacy is sometimes necessary with their own supervisors when they feel that someone needs more than can be provided in the guidelines. A less frequently mentioned advocacy role is *to point out the holes in the system..we have to be able to say..that this is too big a hole for it to remain and to work towards that change.*

The lack of funds or professional resources also affects the implementation of needed services. *Sometimes I feel my role is just to put a Bandaid on it and it (the problem) goes to the community. Not that that's right, but just the system that's in place.*

Insufficient services result from reduced funding, lack of trained personnel such as homemakers, and changes in an agency's mandate. Whatever the reason, the resulting waiting lists are difficult: *We have to try to find alternative resources for people and that has made it quite difficult not only for us but for the clients who are waiting for those services.*

Both planning and implementation are easier if the client and family is willing to pay for services beyond what is allowed by home care. On the other hand, case managers report that they *can spend an awful lot of time trying to find a service that the client can afford.*

Even if the assessment and plan is appropriate, the actual care the client and family receives frequently is less than optimal. The amount, frequency, and availability of services was identified as a constant problem everywhere. Case managers spend a considerable amount of time trying to

piece together an inadequate service package. Clients and their families not only have to handle the burden of inadequate services, but often lose the services of the busy case manager during the lengthy waiting period. Time pressures and the absence of backup assistance limit the case managers' ability to provide ongoing monitoring and evaluation.

*I would like to see smaller caseloads so that we could have a better handle on the clients that are out there because quite often I don't get to see them regularly as I should..the only visits I was getting to make are the ones that they really needed me ..as far as the regular assessments, people who were declining, you might miss those until they became a crisis*

*I am responsible for that person and no one else is going to pick up the slack..if I am sick, nobody is going to come and take my place..as the list gets longer, your stress level goes up higher and higher..I'm basically the only one.*

In at least two provinces, case managers noted that additional case managers were hired for hospitals but none for the community and as well they had to cover in the hospitals. They were also lost to their areas when they were covering for evenings and weekends in the home care office.

*It's not even like you have a hundred percent coverage in your area, you don't. You're being asked to go here, go there, go everywhere. Because of their time limitations, they often talked about being required to work under the premise that no news is good news because reassessment visits have become a low priority. Case managers depend on families and the service providers to let them know when a client needs to be reassessed: I assume that everything is fine and there are no problems until the service provider gets in there and calls and is identifying problems.*

However, that situation makes them uncomfortable. They worry that a client's condition may deteriorate without being noticed and they will be unable to prevent a crisis. Much of their organizing and monitoring time concerns homemaking services. Case managers recognize the irony of spending the most time controlling the cheapest per hour service. However, they recognize the importance of the service. Lack of access to 24 hour homemaking was the service that was most frequently linked to inability to cope on home care. Although they spend a considerable amount of time managing homemaking hours, they frequently can not provide optimal service.

*If you can't put in blocks of time.. maybe you can send somebody in six times a day. Maybe it will be four different people and it is difficult for, especially elderly people, with any cognitive dysfunction at all just to cope.*

The location of their practice also affected how able they were to provide services. In rural areas when the case manager does not live in the area, most of the contact occurs over the phone. It is also difficult in rural areas to have access to day programs, specialists, or short visits from home makers. On the other hand, case managers in rural areas felt that they worked more as a team and had better communication than those in urban areas.

## Care Providers

### Access to Care Providers

The care providers most central to the provision of home care according to the case managers are the nurses and home support workers. A shortage of nurses was acknowledged in some regions of the country and the anticipation of a greater shortage looms:

*There is a real fear that we have a lot of staff in both long term care and home care moving towards retirement..how to replace the trained staff?..will the younger generation want to take on this type of workload? In small communities in particular, nurses who live in the community are frequently called at home.*

### Screening, Preparation and Remuneration of Home Support Workers

There was concern that since home support workers are giving personal care previously provided by nurses that early identification of risk is not happening (e.g. no reporting of swollen ankles, shortness of breath). Conflict management between family and worker is also a case management function and takes time on the part of the case manager to resolve. Case managers appeal for better screening of applicants for positions as home support workers, more standardized education, less casual and more full time positions, access to in-service and levels of pay that reward education, experience and performance. Clients and home support workers that work well together form a bond which becomes very difficult to break when an agency no longer retains the contract for services with home care. Several instances were given of clients deciding at the time of loss of the home support worker to go into a long term care facility. However, there appears to be better continuity of assignment between home support workers and clients than between nurses and clients and this is true primarily across urban settings.

*There may be a different nurse every visit..they don't know those people and people don't rely on them in the same way.*

### Professional and Support Services

Pharmacists have relieved nurses of much of medication management by prepackaging the daily doses of medications. There is agreement that the assignment of professional providers is heavy at the beginning but once the teaching and the safety issues are addressed and the support system is in place then the professionals are withdrawn. In some settings Physiotherapists and Occupational Therapists, after the initial assessment and establishment of a care plan, teach restorative therapists who provide the service to long term care clients. Most home care visits are related to physical care or enabling independence. Even though a primary need may be psychological support, visits are rarely for that purpose. Social workers deal with the *really complex cases or a crisis* and help resolve accommodation issues. Case managers admitted that they increase home support services when they are worried about someone and cannot get out to see them. It was suggested that shorter more frequent visits by a home support worker would be more beneficial to some clients. Shorter visits are not happening in some regions because payment for one hour per

visit is expected. Fewer home support services are required if adult day care, transportation, meals on wheels and other substitutes for a home support worker visit are available. Professionals determine for the most part the duration and frequency of their service whereas the amount of homemaking is controlled by the case manager.

### Rural Care Providers

Rural home care teams appeared to have long term memberships, better communication and evidence of partnership of professional and home support workers. In winter, case managers frequently had to do assessments and monitoring by telephone and rely on the home care nurse in the community to do the paperwork for long term care and to contribute to the assessment.

### Services that Would Keep Clients at Home Longer

Case managers agreed that more home support services would keep clients at home longer and they especially expressed the need for low cost cleaning services. Seniors are reluctant to pay for cleaning services and require a clear explanation of cost alternatives if they choose to enter a nursing home.

*It is fascinating to see how the elderly think..they will say if you take away my homemaker who is 2 hours a week and does my vacuuming, I will have to go to a home..that will cost them \$1500 a month..if they pay a cleaning service it won't be \$1500 a month.*

In terms of keeping people at home a case manager said: *It used to be that there was a service that would enable seniors to stay at home..home maintenance, yard work, wall washing, window washing..all those things not seen as health services..now house work is not a health service so they make the decision to move into a facility sooner than they need to..I see that as not preventative.*

### **Ethical Issues and Dilemmas in the Case Management Role**

The case managers interviewed for this study described a wide range of values-related issues and conflicts that arise in their day-to-day work. This section will discuss the ethical issues and concerns as described by the case managers, according to five themes identified in the focus group data: values-based ethical issues and dilemmas, beneficence, non-maleficence, autonomy and power imbalances, and rights versus responsibilities.

Many of the dilemmas for case managers stemmed from their unique role at the interface between the clients and the long-term care system. As gate-keepers for the system, they are expected to identify the real needs of clients on the one hand, but are bound by agency rules, system shortfalls, and provincial policies in terms of what can be offered to meet those needs. Clients who fall short of service level specifications may cause the greatest concern. As one case manager described:

*A lot of the really difficult decisions are made for us, which sometimes makes it more difficult for us because we are the bearer of bad news. If someone doesn't meet admission standards on a*

*particular day, then it's our responsibility to let them know the decision that's been made. You have to think of a very sensitive way of presenting to a client something that maybe you don't agree with and you have to sort of back up that decision as if you do agree with it.*

Another informant expressed concern about the large numbers of people on the waiting lists for home care services.

*You don't want to have to go out and say we are unilaterally cutting hours on everybody. You know there is a limited number of hours and money in this budget and until someone improves, dies or goes into a facility and frees up those hours, [we cannot serve new clients on waiting lists].*

Another way of picturing this type of conflict for the case managers is to understand their need to both economize as well as humanize their decisions. They deal with real people and feel that others may only see them as bottom lines or numbers.

*They are a number and a bed and they have got to get in and get out and my hardest thing is to get up in the morning and come in and say to people we have got to get your loved one out of here [hospital] and they fall apart..it just really goes to the core of what your ethical beliefs are. ..the hardship that I see everyday, it takes its toll.*

### Ethical Dilemmas Concerning Equity

One value, which the case managers described frequently, was that of "equity" in relation to services for their clients. They identified particular groups of clients for whom this was particularly problematic such as families with special needs children who then become adults. These particular clients have all-encompassing care when treated in a pediatric model, but find the services suddenly become extremely limited when the child legally becomes an "adult".

Another example of equity conflict arises when case managers are forced to decide which client's needs should be given priority. They are generally instructed to make objective decisions based on client needs. In reality, this may not occur for a variety of reasons. For example, two clients may have similar service requirements in relation to facility placement, but one may be placed first if there are no supportive families to *pick up the slack*. *You put the others on a waiting list but it is not like it is a rush..it is the coping skills of whatever circle is around that person*. Examples were provided which suggested that people with high needs for care often are assigned lower priority than those with fewer needs, because they have family support.

Case managers also commented on the disparity between private versus public facilities. When clients in private facilities can no longer be maintained there because they need more professional care, the move to a publicly funded facility can be quite traumatic, given the need for shared rooms and fewer amenities. *They may not even have a choice of which facility to transfer to.*

Rural communities are facing particular problems with inequities in service provision:

*In this district, you're trying to go out and visit once every six to eight weeks if that. In the winter you can't even do that because of the weather, so you are doing the assessments over the phone and you don't really get a good idea. Crises management is all that's really being done. Ideally, case managers need to live in the actual town that they are providing service for.*

One of the greatest challenges for case managers is deciding how to divide the finite service pie. The actual mix of services offered is changing. Clients in continuing care are experiencing higher and higher acuity levels and some are now getting intensive services such as intravenous and ventilator services. Yet at the same time, there are people who could stay at home with *just a little bit of homemaking and reassurance that they have some help. Or maybe they just need a bath and someone to come in once a week but must wait six to eight weeks because of others who have more acute needs.* So a dilemma evolves between offering a few people intense services versus serving many people with smaller amounts of service. The timing of services also presents conflicts for the case managers. More than one informant expressed the belief that if home support were provided earlier, costly admissions for serious outcomes such as injurious falls could be prevented for frail older people, but budgetary restrictions do not allow this in many jurisdictions. There was also debate about enabling family members to provide more care by paying them.

#### Issues Related to Beneficence

Case managers, like other professional workers, are bound by the ethical notion of beneficence – the need to do good for their clients. One case manager spoke of her feelings of having only put Band-Aids on when much more was needed. *Being nurses, we have that protective part that we want to make sure everyone is safe.*

The issues of wanting to “do good” can be related to “when” the services are provided. A particular group which pose challenges in this regard is palliative patients. An informant noted that even though someone is classified as palliative, they may live for five or more years and the case manager is challenged with how to apportion care over the long term. This suggests that little distinction is made between clients termed palliative and for whom death is imminent, and the terminally ill who require longer range care planning.

Some case managers expressed a desire for more education in order to improve their capacity to serve their clients. As one person noted:

*We're being placed in a lot of positions where we're helping families make difficult decisions or there is no family member and the person is quasi competent. Sometimes we're feeling we don't have all of the knowledge or skills needed in these areas such as risk management. We need more education about who to turn to and when.*

Others talked about having to advocate on behalf of clients, even when their supervisors don't agree. *Like if you feel the client needs more than the home care guidelines say you can provide. You have to advocate because you really feel it will make a big difference.*

### Issues Related to Non-Maleficence

In addition to the idea of doing good, case managers are mandated by the principle of doing no harm or “non-maleficence”. They expressed concern about having to make decisions on behalf of clients, when the outcomes could prove potentially harmful. A case manager described serving a client who in her words was blind and eccentric and who needed to be transferred to a public facility when the operator of the private home she was in felt she could no longer be cared for there.

*So we did move her and it is not working and I don't have a setting for this lady that is going to work and I know it will kill her. It will absolutely kill her mentally and she will..die. And it is sad.*

Other case managers worried about the negative impact that health reform in their region may have on clients. One informant said that some of her clients were going to need to have a change of homemaker agency following the bidding competition for these services and she was concerned about the negative impact that would have. She claimed *That [changing agencies] will be a challenge for sure.*

The case managers were also cognizant of “doing no harm” to other workers in the long term care system. There were clients whom they described as potentially dangerous and who they believed imposed a risk to other workers going into the home. *There are times..you can't put professionals at risk [in these situations].*

### Issues Related to Autonomy: Consent, Living at Risk

A number of ethical issues were described by the case managers under the general heading of autonomy. The first of these was the issue pertaining to freedom of choice. A case worker described some of the issues here as follows:

*Well it makes it more difficult if they are not competent. When you have to intervene and say you really need to do this. It makes it tough. And if they seem cognitively able to know that they are signing a consent form to go into long term care. I mean you just don't want to push somebody out of their home...but it is sometimes very difficult to make sure that they are able to grasp what they are signing and they are agreeing that that is what it has come to. That they really aren't able to be at home anymore. I find that a tough one.*

Case managers also talked about client's rights to live at risk. One said that for her, this area poses the biggest ethical challenges. She said people are quite loathe to declare clients incompetent to make their own decisions and as a result, she has clients out there whom she knows could be at risk but feels powerless to do anything about it. *You can do nothing.*

Case managers also expressed their belief in people's right to refuse services but at the same time, they experienced frustration when people refused services that they felt could be beneficial.

*I think maybe the first lesson you learn is that you cannot tell a person what services they must take. It has to be their decision..and we learn to accept the fact that they may refuse to accept all the services we know they could benefit from.*

### Other Ethical Dilemmas

Maintaining professional standards of ethical practice can be a challenge in the real world. As one case manager said *upholding the standards of our profession won't always uphold the standards of our employer.* Another commented, *I know it's a job but it goes beyond that. We work with people who are struggling with serious problems.*

Case managers described the periodic need to bend or break the employer's rules in carrying out the case management role. One example would be *padding things in my goal setting,* presumably to increase the amount of service which someone may be entitled to.

*You lie to get things that you want. We are just working the system. That is what every coordinator does.*

A more troubling practice which one case manager described was to base the level of client service on the amount of time and effort needed by the case manager.

*Some of them don't drive or take buses and we are finding it is hard to get that service. Sometimes I take the easy way out. I will say this is just too much effort and not cost effective for my time to put this many hours of coordination in to get services..our case loads are getting so unmanageable we sometimes take the path of least resistance..so we will put them in a Nursing Home because it is just too time-consuming to do anything else.*

Prioritizing time presents daily challenges for the case managers. One case manager described constantly feeling guilty for not being able to squeeze just one more person in during the day as she sits in her car, eating her lunch, on her way to her next appointment.

Knowing when to intervene on a client's behalf can pose a challenge, as the case managers balance their clients' rights to autonomy with their own responsibilities. An excellent case example was presented in relation to a woman who was deemed competent by the public trustee to give her son her money, but who was falling deeply in debt because certain bills were not being paid.

*We worked around it..the physician and I got together and he approached her and said do you realize that you owe \$3,000 to this facility? So she said where is my money going? Well, your son is spending it, to which she replied, let's stop it. The social worker took her to the bank and so it let us provide her with a reality check..we were lucky cause otherwise that bill would have grown and who knows what would have happened to her.*

One of the hardest decisions case managers have to make is deciding when their responsibility ends. One person in the study noted described her dilemma here as follows:

*What is our responsibility when we pass this on to a family member or make a doctor aware of it and they don't follow up? Somehow we always feel that we are holding the bag. And if something happens, is this going to come back to us? And if it does, where do we stand?*

## **LIMITATIONS OF THE STUDY**

For the items on the questionnaire which asked case managers the number of clients on their case load, the level of care of clients, the number of clients they perceived to be inappropriately placed and the number of clients for whom home care could have been offered had the resources been available, case managers had to provide “guestimates”. Because the responses were “guestimates” they were not included as data. The pilot group was able to answer these questions because members of the group had computerized and accessible data files. It was assumed that all case managers across the study sites would have similar rapid access to information on all their clients. Several case managers in the study sites indicated that in order to answer these questions they would have to go through all their files by hand and categorize all their clients according to our definitions of high, low and medium levels of care. For some case managers this could mean going through up to 400 files. The fact that case managers have little clerical help and that computer documentation for home care is not fully developed (in one setting 24 case managers had access to one computer) is a major contributing factor to their inability to answer these questions. However, the questions proved useful in raising lively discussion. Case managers indicated that they gained insight into their own practice by participating.

Although data were collected at two sites in each of the five provinces, the variations in delivery systems, interpretation of regulations and availability of resources across regions, highlights that if more sites had been visited a fuller picture of the long term care situation across Canada would have been developed. Also, comparisons across provinces could not be made without a loss of anonymity of participants because of the limited number of study sites in each province. The consent form signed by participants in the study ensured that responses to questionnaires and statements made within focus groups would remain anonymous. For this reason, the method of qualitative analysis used in this study generated common themes across all focus groups. Quotations were chosen because they best reflected the message across the theme.

## **SUMMARY AND IMPLICATIONS**

### **The key factors which determine if a client will be cared for at home are:**

- provincial policies which assure access to and funding for home care services
- health status of the client..does not require 24 hour care
- availability of an informal provider...proximity of family members
- health status of the informal provider
- access to appropriate professional providers
- access to home support workers
- financial well-being of the client and/or family to provide additional home support
- access to reasonable cost home maintenance services (e.g., lawn mowing, snow removal)
- living in a supportive community (volunteers, meals on wheels, elder watch etc.)

access to seniors' housing which accommodates for mobility problems  
inexpensive and direct transportation to and from day or night programs and medical appointments  
access to respite care on regular basis for informal care givers  
client and family level of independence and coping  
home environment judged to be safe to accommodate level of care required by client  
convalescent beds available so client makes transition from hospital to home with some ability to cope at home  
reasonable waiting list for home care services and equitable positioning of community-based applicants and hospital-based applicants for home care services  
non-access or long waiting lists for long term care facility  
willingness of client/family to have services provided in the home

**The factors which influence the choice of care in a long term care facility rather than at home are:**

home environment not safe for the provision of home care services or for the client's well being  
client requires 24 hour care  
home care unable to provide full service package required to meet client needs  
client with mobility problems, inability to transfer, and/or incontinence which contributes to informal provider burn-out  
client lives alone, has no family or only informal care provider is frail  
insufficient or ineffective support for care givers (e.g., home support, day programs, other respite programs)  
in some provinces, client assessed by means of standardized tool and identified as requiring care in long term care facility  
elderly client cannot cope with non-continuity of care providers and chooses admission to a facility  
lack of understanding on part of client and family of cost differences between home care and long term care facility..believe institutional care is their right and will not cost them  
client and family unwilling to pay for additional support services that would enable the client to stay at home  
home care case managers not part of hospital discharge planning team (*system has failed if first visit is to do placement papers*)  
acute care environment pushed for long term care placement  
lack of community supports (seniors' housing, transportation, meals on wheels etc.)  
client and family in crisis..no previous contact with home care or home care unable to monitor because of heavy case loads so preventive action not taken

**Factors which influence long term facility care clients to return home are:**

a period of respite has permitted informal providers to recover from exhaustion and other stressors and to lobby for the return of their relative  
the client's residence has been adapted to accept the client with mobility problems

adequate home support workers have been found to provide care at home  
the client has chosen to return home because of the rigidity of rules in the facility,  
especially those pertaining to alcohol consumption  
a respite care program for the informal providers has been established  
the client has completed a convalescent period following acute care hospitalization and  
is now assessed to be able to cope at home

Case managers stressed that with few exceptions, clients in long term care facilities are appropriately placed. They lamented the fact that there are long waiting lists for places in long term care facilities which contribute to health status decline in informal care providers.

The factors which promote the choice of care at home as opposed to care in a long term care setting are extremely varied. Independent individuals who live in communities where residents take the responsibility to ensure that the individual with memory loss takes the right turn to walk to his home and where meals on wheels and day or night programs are available have a community safety net that facilitates care at home. Remaining at home is further facilitated by the availability of housing which accommodates for mobility problems and/or permits home care services to provide shorter but more frequent visits. Seniors apartment buildings housing several home care clients, allow home support workers and professional providers to spend several hours in the building. Since there is no time wasted on transportation between visits, care providers can make shorter more frequent visits and the support system becomes even stronger. The financial well-being of the client and family also contribute to the ability to remain at home longer. Case managers frequently lamented that just one more day of home support services would have enabled the client to remain at home. If clients or their families can afford and are willing to pay for the additional help, then the client remains at home.

Adequate respite care is a central factor in the provision of long term home care. The case managers want to prevent "burn-out" in informal providers but state that what they are forced to do is crisis management because there has been inadequate or no respite planning. The regulations about respite care vary across provinces and across regions. There needs to be more flexibility in the respite care regulations so that the informal provider who needs to take a shower and go for a three hour nap is not forced to leave the house in order to access respite care. Case managers who have the flexibility to provide one week of respite care every month and can augment support services for the remaining three weeks by using the extra hours of home support not used in week four can keep their clients at home longer. This ability to be flexible benefits the clients and saves the system in the long run because the extra home support hours and the respite care are less expensive per month than the approximately \$500 per diem for residential care. There was considerable discussion about the quality of respite care if clients are admitted to busy facilities where they are low priority clients. In these circumstances clients are known to regress emotionally and physically, the family feels guilty for placing the client for respite care and has to work toward getting the client back to the pre-admission level of functioning. Emergency respite care which may be required if the informal care provider becomes ill or hospitalized presents both a care provider resource and financial crisis for home care case managers. There is not enough flexibility in the system to respond to crises.

Day programs offer some respite and can also offer opportunities for socialization, provide health care interventions such as gait training and dressing changes, and health status monitoring. The problem is the underutilization of day programs. It appears that the ethnic groups that provide centralized day programs and transportation to and from the programs are highly successful. However, for clients sensitive to having others learn of their disabilities or who are just not sociable, these programs are a hardship for the informal providers rather than a relief. The clients object to going and the exercise of getting the clients dressed and transported is too much for the informal provider.

Night programs for clients who require attention during the night or who are wanderers was touted as a welcome relief for informal providers but again transportation and location of the program is the problem. Case managers suggested that well managed programs in centralized locations with transportation provided to and from the program would encourage greater use of both the day and the night programs.

Transportation across Canada is an issue, especially for the elderly and the disabled. Particularly in sparsely populated regions, trips to a diagnostic laboratory or to visit a medical specialist can be very costly and time consuming. An example given by a case manager was a cost of \$160 to a client just for transportation for a laboratory visit. Perhaps mobile diagnostic units and specialty services which rotate through small communities would not only be cost-effective for the clients but also would serve to reach more individuals and have a greater early risk detection value.

Case managers across the country agreed that the majority of clients in long term care facilities are appropriately placed. These clients would present safety concerns if they remained at home; their acuity level and complexity of care are too much for the family to handle and if 24 hour home care resources are required the cost is higher at home than in a residential facility. There are however a few clients who do return home after a stay in a residential facility. Some of these clients according to the case managers were too hastily placed because of pressures by hospital personnel who do not fully understand the client's and family's ability for self-care and who did not allow sufficient time for the rehabilitation of the client in a protected convalescent environment before making the judgement that the client can not be cared for at home. Other clients could have avoided residential placement if there had been accessible and sufficient respite care for the informal provider.

Although the advantages of regular and well planned meals and opportunities for socialization were identified as beneficial to some clients who appear to "revitalize" once they enter a residential facility, there were several examples of lack of flexibility in residential management which made people want to get out or did not permit them to be admitted. Not being allowed to have alcohol in the facility was a repeated example. Case managers identified specific populations of clients that were difficult to place because nursing homes could not manage their multiple diagnoses. Some residential facilities could not or would not cope with special diets. In addition there are populations of clients such as the elderly with substance abuse problems, Alzheimer clients, the young disabled and clients with Huntington's Chorea for whom long term care residential care is very difficult to access. In some provinces the lack of long term care beds particularly for special populations requires attention. In at least one province a special effort is made to place both spouses

in the same facility if placement for both is desirable. This is not the situation across the country, so not only do spouses suffer separation but family have more travel time and less opportunity to spend less time with their family members who are in residential facilities a distance apart.

An issue for long term care regardless of the location of the care is the availability of both professional providers and home support workers. In many regions the greatest need is for screened and educated home support workers. Across all five provinces, it was indicated that there are insufficient opportunities for educational preparation of home support workers. Programs that exist have limited admissions, in one province only 24 students are admitted per year, yet case managers stated that if there were 200 graduates the system would absorb them immediately. Because of the increasing responsibilities associated with home support services, the need to ensure that there is an educational program to prepare these workers and an infrastructure to support their work in the community is critical. Because of case manager workload, home support workers are often the monitor for elderly clients and in order to visit the clients regularly, home support workers are sometimes assigned tasks which in fact the client may not need. Since most agencies assign a minimum of one-half hour per client, the quick ten minute check-up visit is not possible. As one case manager stated *what some people need is a quick visit and we are still pretty stuck on having to pay someone for an hour.*

Home support workers are predominately employed on a casual basis. The remuneration is less for work in the community than in institutional settings. Therefore there is enormous turnover of home support staff as they find permanent employment in residential facilities. Administrators should be concerned if health status monitoring is either overtly or covertly becoming the role of home support staff who are not educated to assess clients and who because of their casual employment status and rapid turnover as employees of community care agencies, do not get to “know” the patient and family either.

The professional providers, particularly the registered nurses and the rehabilitation specialists, are also in short supply in several regions and as one case manager stated, the professionals are aging and not enough new graduates are choosing to work with long term care clients. Because of cost and availability of professionals, professional services are terminated more quickly than home support services. In one region, there were only two full time nurses to do senior’s assessments, nursing home placements, adult protection, scheduling of home dialysis and after hour nurses. In this same region there is only one physiotherapist to provide care for all clients on home care. The physiotherapist indicated that she does the assessment, provides the care plan, teaches the family and in a good situation gets back to see the client and family within 4-6 weeks. Across the country the lack of mental health specialists is another major concern. The need for psychogeriatric care is increasing; fewer in-patient psychiatric beds plus a movement to community-based care for clients with mental health problems has created a community care crisis because the expertise is not available in the community to appropriately serve these clients.

The request for proposal process in order to assign responsibility for services to both for-profit and not-for profit agencies in some provinces has interrupted continuity of service provider almost as much as the casual employment status of the service provider. Other difficulties in maintaining continuity of service provider appear linked with unionization of the professional

providers who work on a seniority policy. For example, the most senior nurse at the agency will be assigned the clients rather than the nurse who has already made contact with the family and already provided 2-3 visits. The focus is on the provider's privileges rather than what is best for the client. The exception to the problem of lack of continuity appears to be in rural settings. Consistently case managers spoke of better communication, more team work and more continuity of provider in rural settings. The drawback for both providers and case managers in the rural setting is that they are always on call because they generally live in the community.

Several administrative blockages to the provision of optimum long term care have been identified. Better collaborative planning between Ministries is required so that clients who receive services from more than one Ministry do not have double the bureaucracy and have a more continuous and comprehensive care plan as a result of collaboration. Currently, young disabled individuals who reach their provinces' cut-off age for receipt of services from the Ministry of Social Services experience a sudden drop in services not because they do not need them anymore but because they are now transferred to a different Ministry for their care. For the young adult receiving services from both the Ministries of Health and Social Services, the lack of coordination between the two sets of service providers means either duplication of service or not getting maximum service because resources are not shared and service planning is not collaborative. A similar example provided by case managers relates to veterans who are served in part by Veteran's Affairs.

It is surprising to observe that regulations can be interpreted differently in adjacent regions so that access, frequency of service and type of care provider assigned can differ across regional boundary lines. At least within provinces there should be common guidelines pertaining to home care services and eligibility for residential care. It would be enormously useful if assessment tools used to determine eligibility for residential care were standardized across Canada. There are inequities across provinces and across regions in terms of access to home care services and the kind and frequency of services provided. There are also inequities in terms of access to long term facilities, and to supportive housing. Case managers across the country strongly urged administrators to provide clear written regulations and guidelines to the public. Public education about home care services and the various kinds of facility care, is essential. Currently case managers are faced with appeals related to the services which they could not provide according to regulations and guidelines. These appeals are often won by clients who have political connections. Case managers are seeking public education so that they are not the sole targets of complaints because of the resource restrictions they must communicate to clients and families. Public education about the cost of residential care compared to the cost of supplementing home support services would help clients and families to be introduced to alternatives before they face a crisis and must make a decision without either the necessary facts or the time to make a good decision.

## **SUGGESTED NEXT STEPS**

In order for clients and their families to make the best choices about care alternatives and in order to offer cost-effective services, a number of issues must be addressed. The following goals for action over the short term (1-2 years), and longer term (3 years or more) should be considered:

### **Short Term Goals**

1) Ensure that provincial home care policies and guidelines are interpreted uniformly across the home care jurisdictions of each province.

Rationale:

There should not be significant differences in access to services or the array of services available across the various regions of a province. Clear written policies and guidelines diminish appeal processes aimed at augmenting services.

2) Ensure that provincial home care policies and guidelines are reviewed regularly.

Rationale:

Policies and guidelines must remain relevant and enable services to be available to manage the increasing acuity and complexity of care provided in the home.

3) Foster the development of integrated health systems within each provincial region.

Rationale:

Appropriate rehabilitative/convalescent care may prevent unnecessary placement in a long term care facility. Assessment of clients in the acute care setting by community-based case managers may avoid early admission to a long term care facility. Each region must explore ways to reduce pressures across the health delivery system in order to ensure equitable access to the most appropriate level and location of care.

4) Establish home care health human resource planning strategies for each province.

Rationale:

Health human resource planning for home care and facility care must be undertaken in each province so that appropriate education programs and a targeted recruitment process can be initiated to ensure adequate numbers of appropriately prepared health professionals and home support workers to serve long term care clients. Attention must be given to maximizing the continuity of the home care provider, particularly for elderly clients. Lack of continuity of provider has been identified as a reason for admission to a long term care facility.

5) Work toward inter-provincial adoption of standardized assessment tools and classification systems for long term care clients.

Rationale:

Several provinces are developing a long term care assessment tool and use a classification system. Cooperation across the provinces to develop and adopt a common tool and classification system would reduce duplication of tool development and facilitate the collection of comparable data across the provinces.

- 6) Provide public information about long term care options.

Rationale:

Detailed written information should be available to people when they want/need the information. They should be informed of long term care alternatives, cost implications and access procedures.

- 7) Develop a philosophy, policies and protocols to address unmet long term care needs.

Rationale:

Waiting listing for services are common across the country. However, the credibility of waiting lists is tainted by years of “gaming” in the system. Clear policies and protocols to manage unmet needs are required with accompanying documentation of process and outcomes.

- 8) Encourage home care agencies to provide an efficient documentation system.

Rationale:

Case managers across the country are managing large case loads with a minimum of clerical support or access to computers. Minimizing documentation time and ensuring easy access to client information will ensure more direct contact time with families and clients.

### **Longer Term Goals**

- 1) Encourage the development of national-provincial/territorial model programs which include evaluation components.

Rationale:

Health care delivery is a concern of each province and territory, but the home care/long term care issues facing the provinces/territories are similar. There is concern on the part of Canadians that there is no portability of services across jurisdictions. Respite programs are essential to enable clients with complex needs to stay at home. There is currently major variation in regulations across the provinces and regions and little flexibility in the interpretation of the regulations regarding respite care. There is a lack of long term care facilities and home care programs for special needs clients with mental health, substance abuse and certain debilitating conditions such as Huntington’s Chorea.

The establishment of programs which are evaluated across sites for “best practices” relating to respite care, day programs, mobile services, special needs etc . . . would permit universal guidelines to be developed as a resource to all Canadian deliverers of long term care.

- 2) Encourage joint care planning for clients served by more than one Ministry.

Rationale:

For provinces with more than one Ministry involved in the provision of care, clear working relationships should be defined in order to maximize service to clients, reduce bureaucracy, and provide comprehensive services at shared and possibly lower costs. An alternative is to put all services under one Ministry.

- 3) Encourage the development of communities which are friendly to seniors and the disabled.

Rationale:

Certain community characteristics (seniors’ housing, accessible and affordable transportation, neighbourhood watch for the elderly, meals on wheels, friendly visitors) help those requiring home care to stay at home longer. Community development projects that establish a supportive environment for home care recipients must be encouraged. Appropriate housing for individuals with mobility problems is a serious concern across the country. Communities must become more sensitive to the hardships experienced by special populations with regard to transportation.

- 4) Facilitate national-provincial/territorial discussions which would result in the development of guidelines with regard to client/family funding related to home care.

Rationale:

Home care has become a substitute for hospital care for many clients, for example, those in palliative care. The burden of paying for medical supplies, medications, transportation to and from medical appointments and home adaptation costs, have placed an enormous burden on families and is not conducive to their choosing to keep their relative at home. In addition, working family members must cope with loss of work hours in order to compensate for a lack of home support services.

## REFERENCES

- Abrahams, R., Capitman, J., Leutz, W., & Macko, P. (1989). Variations in care planning practice in the Social/HMO: An exploratory study. The Gerontologist, 29(6), 725-736.
- Adams, T. (1996). Informal family care-giving to older people with dementia: Research priorities for community psychiatric nursing. Journal of Advanced Nursing, 24, 703-710.
- Alcock, D., Danbrook, C., Walker, D., & Hunt, C. (1998). Home care clients, providers and costs. Canadian Journal of Public Health, 89(5), 297-300.
- Alcock, D., Edwards, N., & Morris, H. (1998). Home care case management. Perspective from the home front. Journal of Case Management, 7(4), 167-173.
- Anderson, M., & Parent, K. (1999). Report on Home Care in Canada. A study conducted by Queen's health policy research unit for the Canadian Association for the Fifty-Plus. Final Report. Queen's Health Policy Research Unit. Kingston, Ontario.
- Applebaum, R. A., & Wilson, N. L. (1988). Training needs for providing case management for the long-term care client: Lessons from the national channelling demonstration. The Gerontologist, 28(2), 172-176.
- Austin, C. D. (1988). History and politics of case management. Generations, 12(5), 7-10.
- Barcelo, A. (1996). Monograph series on aging-related diseases: VIII. Non-insulin-dependent diabetes mellitus. Chronic Diseases in Canada, 1-20.
- Barkauskas, V. H. (1994). Case management within home care: Old ideas and new themes. Home Healthcare Nurse, 12(1), 8.
- Boyd, M. L., Fisher, B., Ware Davidson, A., & Neilsen, C. A. (1996). Community-based case management for chronically ill older adults. Nursing Management, 27(11), 31-32.
- Brink, P. J., & Wood, M. J. (1989). Descriptive designs. In P. J. Brink and M. J. Wood (Eds.), Advanced Design in Nursing Research (pp. 123-140). Newbury Park, CA: Sage.
- Canadian Home Care Association. (1998). Portrait of Canada: An Overview of public home care programs, p. 1.
- Canadian Study of Health and Aging Working Group. (1994). Study methods and prevalence of dementia. Canadian Medical Association Journal, 150, 899-913.
- Collins, C., Liken, M., King, S., & Kokinakis, C. (1993). Loss and grief among family care-givers of relatives with dementia. Qualitative Health Research, 3(2), 236-253.

Coulton, C. J., Dunkle, R. E., Chow, J. C-C., Haug, M., & Vielhaber, D. P. (1988). Dimensions of post-hospital care decision-making: A factor analytic study. The Gerontologist, *28*(2), 218-223.

Cromwell, S., Rockwell, K., Stolee, P., Buehler, S., James, B., Kozma, A., & Gray, J. (1996). Use of home care services among the elderly in Eastern Canada. Canadian Journal on Aging, *15*, 413-26.

D'Agostino, R., Belanger, A., Markson, E., Kelly-Hayes, M., & Wolf, P. (1995). Development of health risk appraisal functions in the presence of multiple indicators: The Framingham Study nursing home institutional model. Statistics in Medicine, *14*, 1757-70.

Denton, F., Geaver, C., & Spencer, B. (1998). The future population of Canada, its age distribution and dependancy relations. Canadian Journal on Aging, *17*, 83-109.

Dumont-Lemasson, M., Donovan, C., & Wylie, M. (1999). Provincial and territorial home care programs: A synthesis for Canada. Minister of Public Works and Government Services Canada. Ottawa: Health Canada.

Ebly, E., Hogan, D., & Fung, T. (1996). Correlates of self-rated health in persons aged 85 and over: Results from the Canadian study of health and aging. Canadian Journal of Public Health, *87*, 28-31.

Ebly, E., Parhad, I., Hogan, D., & Fung, T. (1994). Prevalence and types of dementia in the very old: Results for the Canadian study of health and aging. Neurology, *44*, 1593-1600.

Feldman, C., Olberding, L., Shortridge, L., Toole, K., & Zappin, P. (1993). Decision making in case management of home health care clients. Journal of Nursing Administration, *23*(1), 33-38.

Fischer, J. M., Wilson Rollins, C., Rubin, S. E., & McGinn, F. (1993). The ethical case management practices training program: An evaluation. Rehabilitation Education, *7*, 7-16.

George, L. K., & Gwyther, L. P. (1986). Care-giver well-being: A multidimensional examination of family care-givers of demented adults. The Gerontologist, *26*, 253-259.

Gordon, M. (1993). Monograph series on aging-related diseases: III. Stroke (cerebrovascular disease). Chronic Diseases in Canada, 64-89.

Gordon, M., & Huang, J. (1995). Monograph series on aging-related diseases: VI. Osteoporosis. Chronic Diseases in Canada, 1-23.

Grisham, M., White, M., & Miller, L. S. (1983). Case management as a problem-solving strategy. Pride Institute Journal of Long Term Home Health Care, *2*, 21-28.

Hagan Hennessy, C. (1987). Risks and resources: Service allocation decisions in a consolidated model of long term care. The Journal of Applied Gerontology, *6*(2), 139-155.

Hagan Hennessy, C. (1993). Modelling case management decision-making in a consolidated long term care program. The Gerontologist, 33(3), 333-341.

Harrison, M. J., & Neufeld, A. (1997). Women's experiences of barriers to support while care-giving. Health Care for Women International, 18, 591-602.

Havens, B., & Finlayson, M. (1999). Analysis of Canada's oldest old: From the survey of aging and independence. [On-line] Division of Aging and Seniors, Health Canada. Available: [www.hc-sc.gc.ca/seniors-aines/seniors/pubs/havens\\_e](http://www.hc-sc.gc.ca/seniors-aines/seniors/pubs/havens_e).

Hawranik, P. (1985). Caring for aging parents: Divided allegiances. Journal of Gerontological Nursing, 11(10), 19-22.

Hilgendorf, P. M. (1996). Profile of the successful home health nurse case manager. Nursing Management, 27(10), 32Q-R, 32U-V.

Hill, G., Forbes, W., Berthelot, J., Lindsay, L., & McDowell, I. (1996). Dementia among seniors. Health Reports, 8, 7-10.

Hill, G., Forbes, W., Lindsay, L., & McDowell, I. (1997). Life expectancy and dementia in Canada: The Canadian study of health and aging. Chronic Diseases in Canada, 18, 166-7.

Hollander, M. J. (1994). The Costs, and Cost-Effectiveness, of Continuing Care Services in Canada. Ottawa, Ontario: Queen's-University of Ottawa Economic Projects (Working Paper No. 94-10).

Hollander, M. (1997). Assessing the impacts of health reforms on seniors, Part 1. Ottawa: National Advisory Council on Aging.

Houde, S. C. (1998). Predictors of elders' and family caregivers' use of formal home services. Research in Nursing and Health, 21, 533-543.

Jette, A., Branch, L., Sleeper, L., Feldman, H., & Sullivan, L. (1992). High risk profiles for nursing home admission. Gerontologist, 32, 634-40.

Kemper, P., Brown, R., Carcagno, G., Applebaum, R., Christianson, J., Corson, W., Danstan, S., Ganneman, T., Harrigan, M., Holden, N., Phillips, B., Schore, J., Thronton, C., Wooldridge, J., & Skidmore, F. (1988). The evaluation of the national long term care demonstration. Health Services Research, 23, 1-174.

Kinney, J. M., Stephens, M. A. P., Franks, M. M., & Norris, V. K. (1995). Stresses and satisfactions of family caregivers to older stroke patients. Journal of Applied Gerontology, 14, 3-21.

Krothe, J. (1997). Giving voice to elderly people: Community-based long-term care. Public Health Nursing, 14, 217-226.

Lawton, M. P., Moss, M., Kleban, M. H., Glicksman, A., & Rovine, M. (1991). A two factor model of care-giving appraisal and psychological well-being. Journal of Gerontology: Psychological Sciences, 46, P181-P189.

Lemire, A. M., & Austin, C. D. (1996). Care planning in home care: An exploratory study. Journal of Case Management, 5(1), 32-40.

Logan, J., & Spitze, G. (1994). Informal support and the use of formal services by older Americans. Journal of Gerontology, 49, S25-S34.

McCullough, L. B., Wilson, N. L., Teasdale, T. A., Kolpakchi, A. L., & Skelly, J. R. (1993). Mapping personal, familial and professional values in long-term care decisions. The Gerontologist, 33(3), 324-332.

Micco, A., Hamilton, A. C. S., Martin, M. J., & McEwan, K. L. (1995). Case manager attitudes toward client-directed care. Journal of Case Management, 4(3), 95-101.

Miles, M. B., & Hubberman, A. M. (1994). Qualitative Data Analysis (2<sup>nd</sup>. ed.). Thousand Oaks, CA: Sage.

Morse, J. M. (1994). `Emerging from the data`: The cognitive processes of analysis in qualitative inquiry. In J. M. Morse (Ed.), Critical Issues in Qualitative Research Methods (pp. 23-43). Thousand Oaks, CA: Sage.

Motenko, A. K. (1989). The frustrations, gratifications and well-being of dementia care-givers. The Gerontologist, 29, 166-172.

National Advisory Council on Aging. (1996a). Age and disability. Info-Âge [on line]. Available: [www.hc-sc.gc.ca/seniors-aines/issues/english/pubs/info\\_16e.htm](http://www.hc-sc.gc.ca/seniors-aines/issues/english/pubs/info_16e.htm).

National Forum on Health. (1997). Canada health action: Building on the legacy, II. Ottawa: Minister of Public Works and Services.

Neufeld, A. (1998). Commentary on care-givers' experiences in making placement decisions. Western Journal of Nursing Research, 20(6), 725-727.

Nolan, M. (1998). Commentary on caregivers' experiences in making placement decisions. Western Journal of Nursing Research, 20(6), 727-730.

Nolan, M., Walker, G., Nolan, J., Williams, S., Poland, F., Curran, M., & Kent, B. C. (1996). Entry to care: Positive choice of fait accompli? Developing a more proactive nursing response to the needs of older people and their carers. Journal of Advanced Nursing, 24, 265-274.

Penrod, J., & Dellasega, C. (1998). Caregivers' experiences in making placement decisions. Western Journal of Nursing Research, 20(6), 706-732.

Philip, I., McKee, K., Armstrong, G., Ballinger, B., Gilhooly, M., Gordon, D., Mutch, W., & Whittick, J. (1997). Institutionalization risk amongst people with dementia supported by family caregivers in a Scottish City. Aging and Mental Health, 1, 339-345.

Quinn, J. (1995). Case management in home and community care. Journal of Gerontological Social Work, 24(3/4), 233-248.

Raina, P., Dukeshire, S., & Lindsay, J. (1998). Prevalence, risk factors, and primary causes of disability among Canadian seniors: An analysis of the 1986 and 1991 Health and Activity Limitation Surveys. Annals of Epidemiology, 8, 402-409.

Regional Municipality of Ottawa-Carleton Health Department. (1993). Towards a Better Understanding of Home Care. Ottawa: Author.

Reynolds, N. R., & Alonzo, A. A. (1998). HIV informal care-giving: Emergent conflict and growth. Research in Nursing and Health, 21, 251-260.

Riedel, S. E., Fredman, L., & Langenberg, P. (1998). Associations among care-giving difficulties, burden and rewards in care-givers to older post-rehabilitation patients. Journal of Gerontology: Psychological Sciences, 53B, P165-P174.

Roberts-DeGennaro, M. (1993). Generalist model of case management practice. Journal of Case Management, 2(3), 106-111.

Robinson, K. (1990). The relationships between social skills, social support, self-esteem and burden in adult caregivers. Journal of Advanced Nursing, 15, 788-795.

Rockwood, K., Stolee, P., & McDowell, I. (1996). Factors associated with institutionalization of older people in Canada: testing a multifactorial definition of frailty. Journal of the American Geriatrics Society, 44, 578-82.

Rosenberg, C. (1995). Controversies in case management. Journal of Long-Term Home Health Care, 14(3), 37-42.

Rosenheimer, L., & Francis, E. (1992). Feasible without subsidy? Overnight respite for Alzheimer's. Journal of Gerontological Nursing, 18(4), 21-29.

Rottensten, K. (1996). Monograph series on aging-related diseases: IX. Osteoarthritis. Chronic Diseases in Canada, 92-107.

Shapiro, E., & Tate, R. (1988). Who is really at risk of institutionalization? The Gerontologist, 28, 237-245.

Shuster, G. F., & Cloonan, P. (1989). Nursing activities and reimbursement in clinical case management. Home Healthcare Nurse, 7(5), 10-15.

Spector, W., & Kemper, P. (1994). Disability and cognitive impairment criteria: Targeting those who need the most home care. The Gerontologist, 34, 640-651.

Statistics Canada. (1989). Health and Activity Limitation Survey (microdata user's guide: adults in households). Ottawa: Minister of National Health and Welfare.

Statistics Canada. (1993). Aging and independence: Overview of a national survey. Ottawa: Minister of National Health and Welfare.

Statistics Canada. (1992). Health and activity limitation survey 1991. Ottawa: Minister of National Health and Welfare.

Statistics Canada. (1999). Statistical snapshots of Canada's seniors. (Prepared for the Division of Aging and Seniors). [On-line]. Available: [www.hc-sc.gc.ca/senior-aines/seniors/pubs/factoid/en/factoid.htm](http://www.hc-sc.gc.ca/senior-aines/seniors/pubs/factoid/en/factoid.htm)

Steinbach, U. (1992). Social networks, institutionalization, and mortality among elderly people in the United States. Journal of Gerontology, 47, S183-90.

Strang, V. (1998). Commentary on caregivers' experiences in making placement decisions. Western Journal of Nursing Research, 20(6), 723-725.

Strang, V. R., & Haughey, M. (1998). Factors influencing the caregiver's ability to experience respite. Journal of Family Nursing, 4(3), 231-254

Stuck, A., Walthert, J., Nikolaus, T., Büla, C., Hohmann, C., & Beck, J. (1999). Risk factors for functional status decline in community-living elderly people: a systematic literature review. Social Science & Medicine, 48, 445-469.

The National Advisory Council on Aging. (1996c). Seniors and disabilities. Expression, 11, 1 [on line] Available: [www.hc-sc.gc.ca/seniors-aines/seniors/pubs/disabled.htm](http://www.hc-sc.gc.ca/seniors-aines/seniors/pubs/disabled.htm).

Tsuji, I., Whalen, S., & Finucane, T. E. (1995). Predictors of nursing home placement in community-based long-term care. Journal of the American Geriatrics Society, 43(7), 761-766.

Ulysse, P., & Lesermann, F. (1997). Population aging: An overview of the past thirty years. Division of Aging and Seniors, Health Canada: Ottawa.

Vernooij-Dassen, M., Felling, A., & Persoon, J. (1997). Predictors of change and continuity in home care for dementia patients. International Journal of Geriatric Psychiatry, 12, 671-7.

Warren, B. H., Puls, T., & Fogelstrom-DeZeeuw, P. (1996). Cost-effectiveness of case management: Experiences of a university managed health care organization. Journal of Medical Quality, 11(4), 173-178.

Weissert, W., & Cready, C. (1989). Toward a model for improved targeting of aged at risk of institutionalization. Health Services Research, 24, 485-510.

Wetle, T. (1992). A taxonomy of ethical issues in case management of the frail older person. Journal of Case Management, 1(3), 71-75.

Williams, J. K. (1993). Case management: Opportunities for service providers. Home Health Care Services Quarterly, 14(1), 5-40.

Yates, M. E., Tennstedt, S., Chang, B-H. (1999). Contributors to and mediators of psychological well-being for informal caregivers. Journal of Gerontology: Psychological Sciences, 54B(1), P12-P22.



**Decision Making: Home Care versus Residential Care  
Focus Group Guiding Questions**

1. Describe your case management role. What functions do you perform? What is the scope of your responsibility?
2. How do you decide if a client is cared for in the home or in a long term care facility? Generally speaking what are the main factors that determine the decision you make concerning the category of provider, the type of intervention, or the frequency and duration of care? How do you decide if a client can stay in home care or has be transferred to a long term care facility?
3. How has your role as a case manager changed over the past five years?
4. What resources do you need to keep clients in the community instead of transferring them to long term care facilities?
5. Do you accept clients from long term care facilities into home care? If so, what factors determine that the client can be cared for at home?
6. If you had different or more resources how many clients could you accept from long term care facilities? What percentage of this is your current client base? What sort of resources would you need (e.g. personnel, equipment)?
7. What would you change, if you could, about the management of home care as it is now managed in your province?
8. What are the most difficult decisions you make as a case manager?
9. How much opportunity is there to save money by providing care at home rather than in a long term care facility?
10. Is there anything else you would like to say about the topic of case management?

**Decision Making: Home Care Versus Residential Care  
Demographic Sheet and Questionnaire**

Thank you for agreeing to participate in this study. Please note that you are **not** required to identify yourself on this questionnaire. Answering the following questionnaire helps us to learn more about case managers across Canada. Please check the appropriate answer for the following questions:

There are a total of 18 questions in this booklet.

Please check in which province you currently work

British Columbia

Alberta

Saskatchewan

Ontario

Prince Edward Island

How would you describe your practice?

Rural

Urban

Rural and Urban

1. Age:            Less than 25 years            26-30 years  
                              31-35 years            36-40 years  
                              41-45 years            46-50 years  
                              More than 50 years

2. Gender:
- Female                      Male

3. Discipline:
- Registered Nurse  
Registered Psychiatric Nurse  
Registered Practical Nurse  
Licensed Practical Nurse  
Social Worker  
Physiotherapist  
Occupational Therapist  
Speech Therapist  
Respiratory Therapist  
Nutritionist  
Home Support Worker  
Other (please specify) \_\_\_\_\_

4. Employment Status:
- Part time  
Full time  
Job share

5. Education background:
- Please indicate the level of education you have completed to date.

Diploma  
Bachelor  
Masters  
PhD

6. How many years have you spent as a Case Manager/Assessor?

- Less than 2 years
- 2-5 years
- 6-9 years
- 10-13 years
- More than 13 years

7. How many years have you spent working with Home Care clients?

- |                    |             |
|--------------------|-------------|
| Less than 2 years  | 2-5 years   |
| 6-9 years          | 10-13 years |
| More than 13 years |             |

8. What is the category of your case load at the present time? (Check off more than one if applicable).

- Acute Care
- Long Term Care
- Acute Care and Long Term Care
- Palliative
- Other (please specify) \_\_\_\_\_

9. What is the approximate size of your case load at the present time?

- Less than 20 clients
- 20-50 clients
- 51-100 clients
- 101-200 clients
- 201-300 clients
- More than 300 clients

10. To what extent do you feel overworked at this time? (Choose one)

- Not at all
- Somewhat
- Moderately
- Extremely

11. Do you provide direct service (e.g. nursing care, social work care) to clients in addition to your case management responsibilities?

Yes

No

---

**We are interested in knowing your opinion about the percentage of clients who given more resources could be cared for in home care instead of in a long term care facility.**

Below are the definitions which may help you answer the questions.

High level of Care

Care that is provided by professionals and support staff on shift and/or at least daily and intensive care services.

Medium level of care

One to two visits a week provided by professionals and/or support staff.

Low level of care

One to two visits a month provided by professionals and/or support staff.

12. For how many clients do you provide case management in an average month?

\_\_\_\_\_

In the last month how many clients have you admitted and discharged from your case load?

Admit \_\_\_\_\_ Discharge \_\_\_\_\_

13. Using the above definitions of high medium and low care what is the approximate number on your case load in each category?

high level of care \_\_\_\_\_

medium level of care \_\_\_\_\_

low level of care \_\_\_\_\_

14. If you had more financial resources in home care how many of the clients that you transferred in the last year to long term care facilities could you have managed in home care?

Less than 10

10 - 50 clients

More than 50 clients

Please state the approximate percentage that number is of your total case load last year.

\_\_\_\_\_ %

Of this percentage could you categorise how many were:

high level of care \_\_\_\_\_

medium level of care \_\_\_\_\_

low level of care \_\_\_\_\_

15. If you had more resources in home care do you know how many of the clients in acute care facilities could be managed in home care. ( For example alternative level of care clients).

Less than 10  
10 - 50 clients  
More than 50 clients

Please state the approximate percentage that number is of your total case load last year.

\_\_\_\_\_ %

Of this percentage could you categorise how many were:

high level of care \_\_\_\_\_

medium level of care \_\_\_\_\_

low level of care \_\_\_\_\_

16. Due to lack of resources, other than financial, in Home Care in the past year how many clients have you transferred or admitted to Long Term Care Facilities that could have been cared for at home?

Less than 10  
10 - 50 clients  
More than 50 clients

Please state the approximate percentage that number is of your total case load last year.

\_\_\_\_\_ %

Of this percentage could you categorise how many were:

high level of care \_\_\_\_\_

medium level of care \_\_\_\_\_

low level of care \_\_\_\_\_

17. In your opinion what are the three most important determinants of the decision to advise clients that a long term care facility is appropriate when compared to home care? Please tick the three boxes.

1. Number of hours funded to provide services in a given week for each client
2. Clients level of coping
3. Family level of coping
4. Availability of other professionals to provide services for home care clients
5. Financial constraints of family
6. Client living alone
7. Incontinence
8. Other (i.e. geographic)

18. If you have any further comments about decision making processes that you wish to make please use the space below.

---

---

---



Université d'Ottawa University of Ottawa

Faculté des sciences de la santé      Faculty of Health Sciences  
Cabinet de la doyenne              Office of the Dean

CERTIFICATION OF INSTITUTIONAL HUMAN RESEARCH  
ETHICS COMMITTEE  
FACULTY OF HEALTH SCIENCES

This is to certify that the Institutional Human Research Ethics Review Committee of the Faculty of Health Sciences has examined the research proposal **from Dr. Denise Alcock from the School of Nursing** for the project *“Decision Making: Home Care versus Residential Care (sub study 6 of The National Evaluation of Cost-Effectiveness of Home Care)”* and concludes that, in all respects, the proposed research protocol meets the appropriate standards of ethical acceptability, at a **Category 1A** level.

---

MEMBERS OF THE COMMITTEE

<u>Name (Optional)</u>	<u>Position held</u>	<u>Department of discipline</u>
Victor Boucher	Professor	Audiology and Speech-Pathology Program
Claire-Jehanne Dubouloz	Professor	Occupational Therapy Program
Mark Grenier	Student	School of Human Kinetics
Roch Paquin	Member-at-Large	
François Tremblay	Professor	Physiotherapy Program
J. Roger Proulx	Chair	Human Research Ethics Committee
Jocelyne Tourigny	Professor	School of Nursing
Julian Roberts	Professor	Department of Criminology

SIGNATURE

27/11/98

[Signature]

Date

Committee Chairperson - J. Roger Proulx, Ph.D.



Université d'Ottawa    University of Ottawa

Faculté des sciences de la santé    Faculty of Health Sciences  
Ecole des sciences infirmières    School of Nursing

**Research Project: *Decision Making: Home care versus Residential Care***

**Principal Investigator:** Denise Alcock, RN, PhD, Dean Faculty of Health Sciences, University of Ottawa.

**Co-Investigators:** Elaine Gallagher, RN, PhD, School of Nursing, University of Victoria.  
Doug Angus, MA, Faculty of Administration, University of Ottawa.  
Liz Diem, RN, PhD, School of Nursing, University of Ottawa.

This study is a sub study of a project entitled A Program of Evaluation Research on the Cost-Effectiveness on Home Care Services in Canada which has been funded by Health Canada and will be conducted in five provinces: British Columbia, Alberta, Saskatchewan, Ontario, and Prince Edward Island.

Case Managers will be asked if they would be willing to take part in a focus group with other case managers from their respective offices. In each province 2 focus groups in rural areas and 2 focus groups in urban areas will be conducted. Participants will be asked to read the information letter and the consent form. If participants have any questions the research assistant will answer the questions. Individuals who agree to participate will be asked to sign the consent form. Groups of 4-6 Case Managers will meet with a researcher and research assistant and discuss the issues surrounding decision making as it relates to the elderly and the multi-needs people. The focus for this study is the multiple needs and elderly population. The focus groups will be audio-taped and transcribed word for word with proper names taken out so that individuals will not be identifiable. The transcripts will not be shown to managers, nor will they listen to the audio-tapes. Only the researchers will listen to the audio tapes. Audio tapes and data will be kept in a secure place accessible only to the research team and will be destroyed after seven years.

Key individuals who work in long term care facilities and those responsible for managing care in the community may also be interviewed .

The time commitment for the study is approximately 60 to 90 minutes and will be conducted at a time convenient to participants and the work schedule. Case managers may benefit from their participation in that they may gain insight into their own practice by being able to reflect on their decision making. Completing the demographic form and questionnaire poses a very low level of psychological/social risk because the forms are coded and do not reveal the names of the participants. The decision to take part in this study is voluntary and case managers may withdraw from the study at any time without being penalized. A Case Manager`s decision to take part in this study will not affect her/his employment status in home care.

Management will not be present at focus group meetings and the identity of individual case managers will be protected when reporting all findings.

Responses to the questionnaires will remain anonymous. Some of the statements case managers make may be used in papers or conference reports, however, the identity of those who made the statements will be protected. A low level of psychological/social risk and discomfort may occur for those who are uncomfortable voicing certain opinions in the presence of co-workers during the focus group and are worried about confidentiality in the group. All information will be held confidential except when professional codes of ethics and or legislation require reporting. Case managers can choose not to answer any questions that they do not wish to answer. This study will identify what decisions are being made for certain clients, and what factors are related to such decision making. This data will shed light on the critical role that case managers play in planning and distributing home care services.

The chairperson of the Human Resource Ethics Committee who provided initial ethical clearance for this study is Dr. Roger Proulx, Faculty of Health Sciences, University of Ottawa. He can be reached at (613) 562-5800 extension 4251 if you have any questions/comments. Ethical clearance for your province was obtained from ..... and the contact person is ..... The mailing address for Dr. Alcock is Faculty of Health Sciences, University of Ottawa, Roger Guindon Hall, Room 3028, 451 Smyth Road, Ottawa, Ontario, K1H 8M5.

If you are interested in taking part in this study, please send off the bottom portion of this page to \_\_\_\_\_ who is the contact person for your organisation. That person will pass the information onto Dr. Alcock. This will give us an idea of the number of case managers interested in participating before we travel to collect data for the study. If you have any questions, please do not hesitate to contact Jennifer Medves, RN, MN (Research Assistant) 613-562-5800 extension 8447 or Denise Alcock, RN, PhD 613-562-5432. All participating agencies will receive a copy of the findings.

---

**Research Project: Decision Making: Home Care versus Residential Care**

**Name and Agency of Case Manager:** \_\_\_\_\_

**I am interested in participating in the focus group discussion:** \_\_\_\_\_



Université d'Ottawa    University of Ottawa

Faculté des sciences de la santé  
Ecole des sciences infirmières

Faculty of Health Sciences  
School of Nursing

**Research Project: *Decision Making: Home Care versus Residential Care***

**Principal Investigator:** Dr. Denise Alcock, RN, PhD, Dean Faculty of Health Sciences, University of Ottawa.

**Co-Investigators:** Dr. Elaine Gallagher, School of Nursing, University of Victoria.  
Doug Angus, Faculty of Administration, University of Ottawa.  
Dr. Liz Diem, School of Nursing, University of Ottawa.

This study is a sub study of a project entitled A Program of Evaluation Research on the Cost-Effectiveness on Home Care Services in Canada funded by Health Canada and will be conducted in five provinces: British Columbia, Alberta, Saskatchewan, Ontario, and Prince Edward Island.

The goals of this study are to:

8. To identify the key factors which determine if a client will be cared for through home care or in a long term care facility.
9. To identify the extent to which home care and facility care can be substituted for each other so that efficiencies can be obtained;
  - To identify, by level of care, through the opinion of case managers, the proportion of clients currently streamed into community based long term care facilities who could be cared for at home care with additional resources;
  - To identify, by level of care, through the opinion of case managers, the proportion of clients currently in hospitals and acute care facilities who could be cared for at home care with additional resources.

Data from this study will be collected through focus groups, interviews and a questionnaire. The focus groups and interviews will be audio-taped and then transcribed. Identification of participants is not required on the questionnaire and focus group and interview transcriptions will not include any names used by participants in the groups.

The time commitment for participation in this study will be approximately 60 to 90 minutes and will be conducted at a time convenient to the participants. Management will not be present at the focus group meetings and will not have access to the transcripts. Any publication arising from the findings will protect the identity of all participants.

Participation in this study is voluntary and participants may withdraw at any time without reprisal.

The chairperson of the Human Resource Ethics Committee who provided initial ethical clearance to this study is Dr. Roger Proulx, Faculty of Health Sciences, University of Ottawa. He can be reached at (613) 562-5800 extension 4251 if you have any ethical questions/comments. Dr Alcock, the principal investigator can be reached at 613 562 5432 or by e-mail at [dalcock@uottawa.ca](mailto:dalcock@uottawa.ca). The mailing address is Faculty of Health Sciences, University of Ottawa, Roger Guindon Hall, Room 3028, 451 Smyth Road, Ottawa, Ontario, K1H 8M5.

---

I, \_\_\_\_\_, the undersigned, have read the consent form and agree to participate in the research study, *Decision Making: Home Care versus Residential Care*. I have had any and all questions answered to my satisfaction and understand that a copy of this consent form will be provided to me.

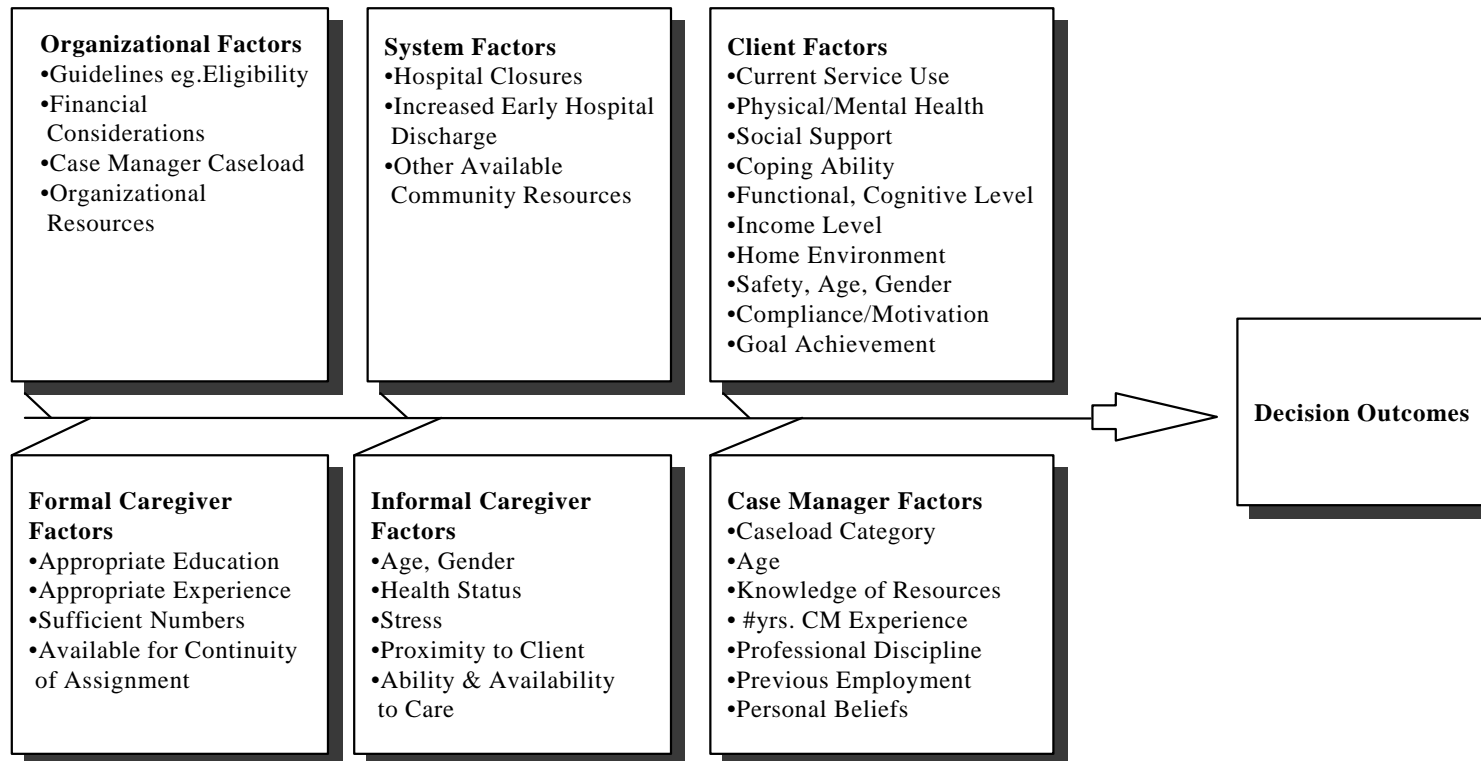
\_\_\_\_\_ Date

\_\_\_\_\_ Signature of Case Manager

\_\_\_\_\_ Signature of Research Assistant

APPENDIX F

# Case Management Decision Making Conceptual Model



Factors derived from clinical experience & factors found in the following articles: Lemire & Austin (1996); Feldman, et. al., 1993; Hagan Hennesy, 1987; Hagan Hennesy, 1993; Abrahams, Capitman, Leutz & Macko, 1989.