ONTARIO'S HOME FIRST APPROACH,

CARE TRANSITIONS, AND THE PROVISION OF CARE:

THE PERSPECTIVES OF HOME FIRST CLIENTS AND THEIR

FAMILY CAREGIVERS

by

Christine Adele Duff English

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Abstract

Home First is an Ontario transition management approach that attempts to reduce the pressure on hospital and Long Term Care (LTC) beds through early discharge planning, the provision of timely and appropriate home care, and the delay of LTC placement. The purpose of this qualitative descriptive study was to obtain descriptions from South Eastern Ontario Home First clients and their family caregivers of their experiences with and thoughts about care transitions, the provision of care, and the Home First approach. The goal was to enable insight into the Home First approach, care transitions, and the provision of care through access to the perspectives of study participants. Nine semi structured interviews (and one or more follow-up calls for each interview) with Home First clients discharged from hospitals in South East Ontario and their family caregivers were conducted and their content analyzed.

All participating Home First clients were pleased to be home from hospital and did not consider LTC placement a positive option. All had family involved with their care and used a mix of formal and informal services to meet their care needs. Four general themes were identified: (a) maintaining independence while responding (or not) to risks, (b) constraints on care provision, (c) communication is key, and (d) relationship matters.

Although all Home First clients participating in the study were discharged home successfully, a sense of partnership between health care providers, families, and clients was often lacking. The Home First approach may be successfully addressing hospital alternative level of care issues and getting people home where they want to be, but it is also putting increasing demands on formal and informal community caregivers. There is room for improvement in how well their needs and those of care recipients are being met. Health professionals and policy makers must ask caregivers and recipients about their concerns and provide them with appropriate resources and information if they want them to become true partners on the care team.

Acknowledgements

Table of Contents

List of Tables

List of Abbreviations and Glossary

ADL – Activity of Daily Living: Activities of daily living are the activities that people engage in to care for their everyday needs. "ADL" is commonly used, and is used in this thesis, to refer to those basic ADL activities (BADLs) that involve personal mobility (such as walking, transferring, and mobility aide use) and personal care (such as personal hygiene, eating, and dressing).

CCAC – Community Care Access Centre: Each of the 14 Ontario Local Health Integration Networks (LHINs) has an associated CCAC which is an organization legislated and funded by the Ontario Ministry of Health and Long-Term Care to coordinate and enable access to home care and other community services including Long Term Care (LTC). Most actual services are provided by workers employed by organizations contracted by the CCAC through a competitive bid process to provide the specified care.

CG – Participating Family caregiver of a CL: In this thesis, "CG" will mean a participant in this study who was the family caregiver of a CL at the time of the study.

CL – Participating Home First Client: In this thesis, "CL" will mean a Home First client who either participated actively in the study or whose information was supplied by a CG and included in the study findings.

CSS – Community Support Service: CSS refers to either the type of agency or the services they provide. CSS agencies are local non-profit agencies. They utilize volunteers to assist with providing many of their services. There are reasonable fees charged for some of the services which include things like meal provision, house and yard work, transportation to medical appointments, and friendly visiting. At the present time CSS agencies provide

home support (IADL) but not personal care (ADL) services. In the study area, information on and links to CSS agencies can be found at: www.4css.org

IADL – Instrumental Activity of Daily Living: These are all the many activities other than personal care that people do that allow them to live successfully in their homes and communities such as cooking, shopping, housekeeping, using available transportation and communication options, and managing their finances and medications.

LHIN – Local Health Integration Network: "LHIN" can refer to either one of 14 areas into which Ontario was divided in 2006 or the corresponding organization which was created within each area to coordinate planning and funding of health care across sectors (hospital, community support and clinics, and LTC) and foster innovation and collaboration between sectors in response to local needs and conditions. LHINs mange the funds which are provided by the Ontario Ministry of Health and Long Term Care to pay for local health care services (www.lhins.on.ca).

LTC – Long Term Care: In Ontario, "LTC" is used to refer to both the level of care provided and the facility providing care for institutionalized individuals who require a level of care that cannot be met in their homes through publicly funded services. LTC facilities are sometimes referred to as nursing homes.

PSW – Personal Support Worker: "Personal support worker" is the terminology used in Ontario to refer to the workers that provide personal care services to clients in home and institutional settings. In other areas they may be referred to as home support workers, home health aides, or nursing assistants. PSWs are not licensed professionals, but a registry for PSWs has recently been created in Ontario and registration may soon be

required for employment in sectors receiving provincial funding for service provision

(www.pswregistry.org).

SECCAC or SELHIN – South East CCAC/LHIN: The South East LHIN and CCAC serve the

towns, cities, and rural areas located within the counties of Frontenac, Hastings, Leeds

and Grenville, Lennox & Addington, Prince Edward, and portions of Lanark and

Northumberland in South Eastern Ontario. The research for this study was conducted in

this geographical area.

Chapter 1

Introduction

In this chapter I provide an introduction to the thesis beginning with a discussion of the context for and development of Home First and the philosophy and actions that underlie it. I then address the question of whether it is a philosophy, approach, or program. This is followed by information on how a Home First approach has been implemented in the area of the province in which this study was conducted. In the following section, I describe the events that led to my choice of research topic and some of my life experience which may have had an impact on the research results. The research purpose, goal, and question are then presented followed by an overview of the thesis.

Home First: Context, Description, and Evaluation

The demographics of Canada are changing and with them the pressures on its health care system. The average life expectancy is now over 80 for both sexes. An increasingly high proportion the population is over 65, and the proportion in the "oldest" age group (those over 85) is increasing even faster. There are presently more than half a million Canadians over 85 (1.5% of the population in 2005) and by 2056 there will be an estimated 2.5 million or approximately 5.8% of the population (Human Resources and Skills Development Canada, 2007). The prevalence of frailty, chronic disease, and associated disability increases with age and with it the need for medical care and formal and informal support with daily living activities.

Ontario has the lowest number of hospital beds per capita (2.5 per 1000) of any Canadian province and slightly less than one half of the average for the 34 Organisation for Economic Co-operation and Development (OECD) countries (Ontario Health Coalition, 2011). A lack of

available beds can result in delays in hospital admissions, cancelled surgeries, and emergency department backups. In Ontario in January of 2011, 18% of acute care beds were occupied by people waiting for an alternate level of care (ALC). Of these, approximately 8% were waiting for supportive housing or government funded home care, and half were waiting for placement in long term care facilities (Ontario Hospital Association, 2011) which have wait lists equal to almost one third of their total capacity (Ontario Association of Non-Profit Homes & Services for Seniors, 2010). Longer hospital stays increase the risk to patients of hospital deconditioning (Graf, 2006) and adverse events which in combination with longer stays result in an increased probability of long term care (LTC) placement on discharge (Ackroyd-Stolarz, Guernsey, MacKinnon, & Kovacs, 2009). Hospital care is more costly than LTC (Friedman & Kalant, 1998) which is more costly than home care (Hollander, Miller, MacAdam, Chappell, & Pedlar, 2009). Therefore, the ALC issue has financial as well as resource utilization and patient flow, safety, and quality of life impacts (LHIN Collaborative, 2011).

In 2008 an approach to reducing ALC numbers known as Home First was introduced in Ontario's Mississauga Halton Local Health Integration Network (LHIN) and demonstrated success in reducing the number of ALC days and LTC admissions in that LHIN (Starr-Hemburrow, Parke, & Bisaillon, 2011). Since that time the Home First approach or similar approaches have been mandated and implemented in all Ontario LHINs, and the LHIN Collaborative created a guide to facilitate implementation (LHIN Collaborative, 2011). There is some variability in stage of implementation and application of the approach across the province; however, "the key elements of the Home First philosophy must be consistently applied across all LHINs" (LHIN Collaborative, p. 7).

The provincial Home First philosophy statement is: "When a person enters a hospital with an acute episode, every effort is made to ensure adequate resources are in place to support the person to ultimately go home on discharge" (LHIN Collaborative, 2011 p. 8). The philosophy applies to all patients and is based on five principles:

- **Life changing decisions are better made in the home**. Home provides a patient with the most comfort for recovery along with lower levels of stress compared to hospitals…. Applying to a LTC home, if required, is a social process that should be done with family members/loved ones and is best done in a home setting.
- **People can choose to live at risk at home and in the community.**...It is important for patients and families to understand that there are inherent health and safety risks in every environment - whether they are in the hospital, in the community, or in their home. …Quality of life is not necessarily correlated with risk and is often higher when patients choose their destination and can reach home in a timely manner.
- **Institutionalized care presents risks that are not as prevalent in the home setting.** … These risks include contracting infectious disease, physical/mental deterioration and social isolation. …Home provides a more ideal environment for post-acute care.
- **Individuals and families have a role in partnering with health care providers to care for their loved ones.** The onus of responsibility to care for a patient does not only rest with care providers. Families/loved ones/primary care givers also have a large role to play in partnering with health care professionals to discuss and evaluate options for a patient's post-acute care, and potentially their on-going care in home.
- **Avoid "Ageism".** … Each client regardless of their age or state of well-being should be initially assessed for discharge home. (LHIIN Collaborative, p.9)

Home First is both an approach to discharge planning and to managing transitions between hospital, community living, and LTC. A goal of the approach is to ensure older people have the supports necessary to continue to live at home so that LTC placement can be avoided or delayed as long as possible. Only those people most in need of LTC and who can no longer be safely managed in the community should be admitted to a LTC facility. To be successful:

> Home First requires a major cultural shift in the behavior and mindset of all health care providers. Where previously the care process for high needs seniors was focused on identifying, facilitating and expediting their transfer to LTC homes, a paradigm shift is now required so that health care providers focus on sending these patients home with enhanced community support. (LHIN Collaborative, p. 6-7)

According to the *Home First Implementation Guide & Tool Kit* (LHIN Collaborative, 2011), implementation of the approach requires coordination and cooperation across multiple institutions and people:

- The LHIN must guide the implementation while ensuring support for the approach and that necessary resources are in place.

- Hospitals need to advocate for patients' return to the community, provide timely and appropriate discharge planning and communication about it, and limit functional decline in patients.

- The Community Care Access Centre (CCAC) is responsible for assessing patients while in hospital for community support needs and ensuring the availability of needed supports on discharge. They coordinate LTC placement and should stress that it is best done from the community and only when care needs cannot be reasonably met in the community.

- The Community Support Services (CSS) sector needs to adapt to provide additional services and capacity and to using more evidence based practices and assessments. Other health service providers need to become more aware of the services provided by CSS agencies and collaborate with them in care provision.

- Primary care physicians must be part of the process of determining the appropriate care location and support a return home where appropriate. Community physicians need to receive prompt notification of their patient's discharge so that they can support continued recovery at home.

- LTC facilities need to support community care through the provision of respite and convalescent beds, providing information on available community services, and minimizing the transfer of residents to emergency departments.

In the guide, the importance of involving patients and families in the discharge planning process is emphasized so that they clearly understand what to expect and can share information about what they can contribute, what supports they need, and any other factors that may influence care provision or discharge planning. It stresses that while it is important to make clear to patients and families that "staying in hospital is not a viable option" (LHIN Collaborative, 2011, p. 24), effective communication and education about the approach with and between health care providers, patients, family caregivers, and the general public is considered vital to the success of the approach and necessary to ensure that people do not feel "that patients are being forced out of the hospital in order to alleviate pressures, but rather recognize Home First as the person-centred philosophy that it is" (LHIN Collaborative, p. 16). Research is needed to evaluate if such communication is occurring and if people do feel like patients are being forced out of hospital.

Organizations involved with the approach are required to provide regular process and outcome performance metrics. "The outcome of Home First is a reduction in ALC, reduction in unnecessary ED visits and/or hospitalization, and reduced demand for LTC homes" (LHIN Collaborative, 2011, p. 16). Performance reports have supported those outcomes (LHIN Collaborative, Appendix C; SECCAC, 2011). Dr. David Walker, Ontario Provincial ALC Lead, in his the June 2011 report to the Minister of Health and Long-Term Care, *Caring for our Aging Population and Addressing Alternate Level of Care*, suggests that Home First should continue to be supported and that the CSS sector should be enhanced to relieve pressure on CCACs. The November 2012 report from the Canadian Institute for Health Information (CIHI), *Seniors and Alternate Level of Care: Building on Our Knowledge,* states:

> Initiatives such as Ontario's Home First Program are helping to reduce the amount of
> time seniors wait in hospital. This program aims to identify individuals at risk for
> residential care admission in order to provide adequate supports to enable a successful
> transition home (p.1).

5

The CIHI report references the Walker report which in turn refers to the Mississauga Halton

LHIN results for Home First also cited in the Implementation Guide (LHIN Collaborative, 2011).

I have been unable to locate any reports of independent research into the Home First approach or

any publically accessible studies that address the impact of the approach from the perspectives of

patients and families. I believe there is a need for such research on the Home First approach.

Home First: Philosophy, Approach, or Program?

To understand or evaluate Home First it is helpful to understand what it "is". In *Home*

First Implementation Guide and Tool Kit (LHIN Collaborative, 2011, p.4), it states that: "Home

First is an evidence-based, person-centred, transition management philosophy focused on keeping

patients - specifically high needs seniors - safe in their homes for as long as possible with

community supports." In *Home First in the South East Partnership Tool Kit* (SECCAC, 2011),

Home First is labeled an approach. I was advised by LHIN and CCAC staff to never refer to

Home First as a "program" as is done in the quote in the previous paragraph. I believe this

distinction is considered important as "program" usually implies a set structure and services. In

contrast, an approach or philosophy can be embraced by anyone and create change independent

of infrastructure, funding, location, or role. The results of a changed philosophy on or approach to

how people at risk of LTC placement are viewed and what services are appropriate for them can

potentially be more significant, and the methods for achieving them more diverse, than those of

any "program". However, with Home First, it is not in practice a simple or in some ways accurate

distinction as there is much about Home First that is systematic and planned. There are people

designated by the CCAC as Home First clients that are treated differently because of that

designation, and funding and procedures exist that support that difference. None the less, if the

philosophy of Home First is widely adopted, the changes set in place will potentially impact all

patients at risk of delayed discharges or LTC placement whether or not they are ever designated a

Home First client or receive different treatment because of it. Because there is little that

distinguishes the formal or informal care a Home First client receives from that of any other

person in a similar situation, most of what participants in this study had to say about their health

and care related experiences is not specific to Home First and can be applied to the more general

provision of care to the frail elderly. It can also provide insight into the Home First approach and

the extent to which Home First as it is being implemented supports and is supported by the

principles upon which it is reported to be based (LHIN Collaborative, 2011).

Home First in the Study Area

In the SELHIN, which was the study area, the Home First approach was implemented in

2009 starting in one hospital and then gradually extended to other hospitals. At the time of this

study, it was in place in four hospitals. To be eligible for a Home First discharge[1], admitted

hospital patients had to be at risk of being designated alternative level of care while waiting for

LTC placement (ALC LTC designation), have an informal caregiver able to direct care if they

were unable to do so themselves, have a home that provided a safe environment, and have no

behavioural or cognitive concerns making a return home unsafe. The most frequent barrier to a

Home First discharge is its refusal by the family of the patient (SECCAC, 2011). Home First

clients, like other CCAC clients, were eligible for many community supports. What they "got"

that was different as a Home First client was earlier and more intensive case management before

and immediately following discharge; a guarantee of home care services immediately on

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[1] In the Central East CCAC, hospital based CCAC case managers as part of the Home First approach meet with existing CCAC clients in the emergency department and are sometimes able to arrange care in the community that prevents hospital admission in the first place (CCAC b, 2012, p.13). In two hospitals in the study area similar efforts to reduce hospital admissions of the frail elderly from the emergency departments are made under a program known as easier+ (SECCAC, 2013).

discharge; and 30 days of free services such as meal provision, light housekeeping, and transportation to appointments provided by CSS agencies at some point during the first 90 days post-discharge and commencing as soon as within three days of discharge as desired by the client (SECCAC; 4CSS website: http://4css.ca/Home1st.html). A hospital based CCAC case manager was to be involved in consultations with the hospital care team early in the hospital admission and partner with everyone involved (including the healthcare team, patients, and their family) to identify and find solutions to concerns about a discharge home; a community based CCAC case manager was to meet with patients in their homes within five days of discharge (SECCAC).

Choice of Research Topic and Positioning the Researcher

I first learned of the Home First approach when I approached a SELHIN staff member for information on a different program which I was considering studying. The person I approached suggested that I study some aspect of the Home First approach instead. Both the SELHIN and the SECCAC had plans for studies on the approach which they wanted to have carried out; it was suggested that I consider undertaking one of them. Although neither study was appropriate for thesis research, it was agreed that a qualitative study of the approach from the perspective of patients and family caregivers would be worthwhile as their perspective was important to consider but often lacking. Staff at the SECCAC agreed to facilitate access to participants, and I proceeded to implement the present study.

My interest in conducting, and belief in the value of, the study was increased due to media coverage at that time of elderly people in Ontario being "pushed" out of hospital prematurely and/or with inadequate supports. A hotline had been set up by the Ontario Council of Hospital Unions and the Ontario Association of Speech Language Pathologists and Audiologists in July, 2011 to collect personal stories of such happenings. The hotline was promoted with

8

speaking engagements and press releases throughout the province during that summer and into the fall (Ontario Council of Hospital Unions, 2011). On September 23, 2011, CBC's Ontario Morning radio show presented the first of a documentary series by Mary Weins entitled "The Indignity of Aging: Crisis in Homecare" (Weins, 2011, September 23). It told the story of an elderly person sent home from hospital after a stroke with inadequate community supports. Such media coverage highlights the perceived need for changes to Ontario's health care system that is expressed by many residents of the province. It demonstrates the importance of studies which can provide a better understanding of the true impact of the implementation of approaches such as Home First (which could be viewed by some people as pushing patients out of hospital) on the lives of its target population, their families, and their care providers.

My interest in health care provision developed relatively late in life. My attitudes towards it are influenced by growing up in the US, my undergraduate training as an ecologist and animal behaviorist, my belief in the value of cooperative ventures, and my many years as a shepherd and mother. I completed a personal support worker (PSW) diploma as my daughters entered university. I then worked in community home care as a PSW for four years mainly with older people in rural areas. I enjoyed interacting with clients and hearing their life stories. I also became very aware of the challenges that they, care providers, and the health care system were facing. Before beginning my current studies, I spent more than a year as an occupational therapy student and a summer caring for my mother as she navigated the processes and decisions involved in receiving a hip replacement. Through conducting the study reported here, I hoped to again be entrusted with life stories and to generate information of value to improving the lives of people such as my former PSW clients. I believe that my age and background facilitated my interaction with participants, their comfort with my presence in their homes, and their willingness to share

9

their stories with me. I have attempted in this thesis to accurately present the experiences and concerns shared with me by participants; however, my background and interests must have had an effect on the data I gathered and the meaning I made of it.

Research Purpose, Goal, and Question

The purpose of this qualitative descriptive study was to obtain descriptions from South Eastern Ontario Home First clients and their family caregivers of their experiences with and thoughts about care transitions, the provision of care, and the Home First approach. The goal was to enable insight into the Home First approach, care transitions, and the provision of care through access to the perspectives of study participants.

The question guiding this research was: How do Home First clients in South Eastern Ontario and their family caregivers describe their experiences with and thinking about care transitions, the provision of care, and the Home First approach?

Thesis Overview

This chapter provided an introduction to Home First and context for the thesis project and my involvement with it. Chapter 2 provides a discussion of literature relevant to a consideration of the Home First approach and the lives of study participants. It discusses literature on the ALC issue, hospital discharge, post-discharge experiences and community care, and LTC placement and decision making about long term health care needs. Chapter 3 reports on the research approach and methods used in this study. Participant criteria and recruitment are discussed as well as the collection, transcription, and analysis of data. Discussions of strategies employed to ensure trustworthiness and address ethical concerns conclude the chapter. Chapter 4 presents the study findings. It begins with a description of participants and data sources, continues with a summary of descriptive findings by approach to or type of care provision, and finishes with a

presentation of thematic findings. Chapter 5 provides a discussion of the findings in relation to the literature and current and proposed health care initiatives. It then examines the strengths and weaknesses of the study and suggests topics for future research. It finishes with a brief summary and concluding remarks.

Chapter 2

Literature Review

In this chapter I review literature that provides a background for this study beginning with that related to the alternate level of care (ALC) situation in Canada and Ontario. I follow with studies related to the discharge process and the experiences of patients and family caregivers with life post-discharge and formal care. Finally, I consider some studies on LTC placement decision making and the substitution of community based care for facility care. These topics are relevant to an understanding of the Home First approach which: (a) was developed as a response to concerns about LTC bed shortages and the impact of frail elderly people waiting in hospital for LTC on ALC backlogs, (b) is a "transition management" strategy focused on facilitating the discharge of older people from hospitals and delaying their transition into LTC facilities, (c) is dependent on the adequacy of community care for this population, and (d) is based on the assumption that home is the optimal location from which to make decisions about and transition to LTC when care needs can no longer be meet in the community (LHIN Collaborative, 2011).

Alternate Level of Care (ALC) in Canada and Ontario

ALC is a descriptor that refers to the use of hospital beds by patients that no longer need the level of care provided in that setting and whose needs would be better served by an alternate level of care. In order to improve data collection and ultimately health care system performance, in July of 2009, Ontario adopted a standardized definition for ALC patients in acute and post-acute care hospitals (Alternate Level of Care, 2011):

> When a patient is occupying a bed in a hospital and does not require the intensity of resources/services provided in this care setting (Acute, Complex Continuing Care, Mental Health or Rehabilitation), the patient must be designated Alternate Level of Care (ALC) at that time by the physician or her/his delegate. The ALC wait period starts at the time of

designation and ends at the time of discharge/transfer to a discharge destination (or when the patient's needs or condition changes and the designation of ALC no longer applies). (Alternate Level of Care, 2011)

In 2012 the Canadian Institute for Health Information released a report on the ALC issue focused on Canadians over age 65 (Canadian Institute for Health Information, 2012). In it, ALC status and other data on seniors with new admissions to either a LTC facility or long stay home care were compared. The report found that: (a) More senior acute patients were discharged home (76.8%) than to LTC (9.7%); however, those discharged to LTC were about 4.7 times as likely to have spent time waiting in hospital and their median wait was 26 days which compared with 7 days for those going home; (b) 54% of ALC seniors were discharged to LTC, (c) patients admitted to LTC and/or having ALC days were older and less likely to have a spouse than those going home and/or having no ALC days, and (d) patients discharged home with ALC days were more apt to have been assessed as being at risk of LTC or caregiver distress than those who had no ALC days. The report mentioned Ontario's Home First Program as helping to reduce ALC days for seniors. It also commented that the key to reducing ALC in seniors and caring for seniors with complex needs at home is a strong system of formal and informal supports.

The report *Exploring Alternative Level of Care (ALC) and the Role of Funding Policies: An Evolving Evidence Base for Canada* (Sutherland & Crump, 2011) argues that high numbers of ALC patients contribute to inefficient use of hospital resources and an overall lower quality of hospital care. It postulates that the lack of financial incentives for hospitals to discharge ALC patients whose care costs are lower than those of acute patients could contribute to the ALC problem. It recommends a continued prioritization of initiatives to address the ALC issue, a change in funding mechanisms for health care provision, and measures to facilitate earlier discharges and lower demand for care in hospitals. The report recognizes the complexity of the

13

issues and the need to consider: (a) the shifting pressures on care providers as the location of care changes, (b) the geographical variations in available resources to provide services, and (c) the potential advantages to the integration of care. It suggests there is a need for an improved data/evidence base upon which to formulate recommendations for changes in clinical practice and funding approaches. The report mentions Home First as an Ontario program integrating hospital and home care and facilitating the transition between them.

In Ontario, as of January 2011, 17% of acute and inpatient beds (excluding paediatrics and obstetrics beds) were occupied by ALC patients, and 61% of these were waiting for a LTC placement (Ontario Hospital Association, 2011). Costa and Hirdes (2010) compared Ontario long-stay home care clients with ALC patients waiting for LTC placement. The majority of the ALC patients had lived at home prior to their hospitalization and the majority of those previously living at home had not been CCAC home care clients. In the ALC group, 80% were over age 75 and almost half were over 85. ALC patients tended to have more physical and mental health problems, reported falls, and functional impairments than the home care sample and were less likely to have a family caregiver living with them or able to continue caring for them. However, most were in a stable health condition and had no cognitive impairments while 39% had no major ADL impairments. Costa and Hirdes suggest that transitional care, supportive living options, and targeted and/or high intensity home care services might enable some ALC patients waiting for LTC to return to the community.

Another Ontario report (Change Foundation, 2011) also compared ALC patients waiting for LTC and home care clients. Using the Method for Assigning Priority Levels (MAPLe) priority level scale which is used by the CCAC, comparisons of patients' need for care were made. About one-third of both populations had moderate care needs. The report raises the

question of what determines whether a patient goes home or to LTC for patients in this need

range where people with similar levels of need are being managed in each setting. It suggests that

the availability of informal supports is often the deciding factor (Change Foundation).

Caring for our Aging Population and Addressing Alternate Level of Care (Walker, 2011)

is a report commissioned to examine the ALC issue in Ontario. The author recognized that he

would need to address broader issues relating to caring for Ontario's aging population to make

the findings regarding ALC useful. In the introductory section some of the factors discussed

match those foundational to the Home First approach such as: (a) the need to change the historical

emphasis on LTC placement of elderly patients from hospital without consideration of other

alternatives or their potential for recovery, and (b) the potential risks to patients and the hospital

system of inappropriately extended hospital stays. The report recommends changes and actions

across the continuum of care including an emphasis on: (a) further implementation of Home First;

(b) strengthening of the formal services upon which it depends to support older people and their

caregivers in the community; and (c) improved early identification, assessment, and support of

potential long-stay ALC patients.

Clearly, the ALC issue needs addressing and new approaches are needed. Home First is

seen as one such approach. The collection of quantitative performance metrics is part of the

Home First approach, and to date the data indicate that Home First has been successful in

reducing the number of ALC patients in hospitals in which it has been implemented while

readmission rates within 30 days for Home First clients remain similar to or lower than overall

hospital readmission rates (SECCAC, 2011).What is not clear is what the impact of the approach

is on the lives of patients and their care providers. I could not locate any published research

addressing this impact which is a primary focus of the present study

Hospital Discharge

Discharge Management

A patient's discharge home is considered "successful" by the health care system if the patient remains at home for an extended period post discharge with no emergency department or hospital admissions linked to the previous hospitalization. Therefore, one of the main outcome measures of research trials of discharge interventions is often a reduction in the rate of such readmissions. In the seminal randomized clinical trial (RCT) reported in Naylor et al. (1999), 363 older patients (over 65, mean age 75) at risk of readmission were studied. The intervention group received discharge planning and support from admission until four weeks after discharge from a geriatric advanced practice nurse who collaborated with patients, informal caregivers, other health care team members, and primary physicians to plan the discharge and implementation of appropriate post-discharge care. The nurse also provided patients and care givers with education, monitoring of progress, support through multiple visits, phone availability both while patients were in hospital and at home, and a final report of the patient history and current concerns which was also sent to others involved with the case. Patients in the intervention group had longer times to readmission and fewer readmissions with shorter associated length of stays than those in the control group for a cost savings of approximately $3,000 per patient over 24 weeks.

Another RCT (Coleman, Parry, Chalmers, & Min, 2006) included 750 patients over 65 years of age and utilized advanced practice nurses as transition coaches in an intervention designed to improve care transitions by providing support, education, and tools to enable patients and caregivers to be more active participants in their care over the long term. Information about, and access to, the tools used is available at (http://www.caretransitions.org). The intervention involved hospital and home visits and follow up calls, medication reconciliation, a personal

health record, promotion of follow-up visits with primary care physicians and strategies to optimize information gained from them, and training about "red flags" and responding to them. The intervention group had lower readmissions with a net cost savings to the hospital system of about $390 per patient over the 180 day period studied. The intervention led to improved patient self-management skills and its success was fostered by the positive ongoing relationship with the transition coach (Coleman et al.)

A third large RCT (Jack et al., 2009) included 749 general medical patients that as a group probably had less comorbidity and were younger (mean age 50) than participants in the previous two studies. A nurse collected information from the health care team and patient and created a booklet for the patient and a discharge summary for the team. The nurse coordinated with others, made post discharge appointments, reconciled medications, and provided patient education. Within a few days of discharge, a pharmacist called patients to follow-up on the discharge plans and medications and communicate any issues found during the call to the patient's primary care physician. Pharmacists found significant numbers of issues with or confusion about medications on their call backs. More intervention than control group patients attended a follow-up visit with their primary care physician. The intervention used about1.5 hours of nurse and .5 hours of pharmacist time per patient and showed gross hospital savings due to reduced readmissions of about $400 per patient. Information about the project can be found at: www.bu.edu/fammed/projectred/index.html.

Bauer, Fitzgerald, Haesler, and Manfrin (2009) reviewed literature on hospital discharge published in English after 1995 to identify best practices as they relate to impacts on frail older patients and their family caregivers. Findings from their review suggest that reductions in hospital length of stay make it harder to have time to develop an adequate discharge plan while the

reductions simultaneously increase the level of care needed by patients on discharge. They suggest that formulation of discharge plans can be impacted by inadequate or delayed communication between the health care team, patients, and family members; unavailability of formal community supports; and lack of a clear commitment by family caregivers to take on required care roles. Poor communication between health care providers within and across care settings was also found to negatively impact discharge outcomes. The findings demonstrate the high importance of the role of family caregivers to the success of discharges as well as the importance of involving them in discharge plans and providing them with the education and support necessary to perform their expanded care roles post discharge. Bauer et al. also identified the importance of starting the discharge process soon after admission and providing follow-up with patients and caregivers post-discharge. The review found that while many discharge interventions targeting a single issue did not significantly improve outcome measures, interventions which addressed many of these important aspects such as that of Naylor et al. (1999) can have a positive impact on outcomes. The review indicated that though many discharge management best practices were identified some time ago they are often not reflected in current practice (Bauer et al.). The results of this review and the RCTs discussed above suggest that changes in discharge strategies can have an impact on clinical outcomes, but they provide limited information on the experiences of patients and families. Outcome measures and intervention models need to be developed that include the costs and benefits to informal caregivers and families (Gitlin & Wolff, 2011).

The Home First approach as described in the implementation guide (LHIN Collaborative, 2011) includes interventions such as the initiation of discharge planning soon after admission, early involvement of family caregivers, and a home visit from a community case manager shortly

18

after discharge which are similar to interventions advanced in the above studies. Although readmissions are tracked, there are no currently available studies on how well the interventions are implemented in practice or their effects on Home First clients and their informal caregivers.

Participation in Discharge Planning

Patient and family participation in discharge planning is considered best practice. Many studies that have explored the discharge experiences of older patients or their family caregivers have found that they were often not included in the preparations for discharge (e.g. Foust, Vuckovic, & Henriquez, 2012; Grimmer, Moss, & Falco, 2004 a, b; LeClerc, Wells, Craig, & Wilson, 2002; McWilliam & Sangster, 1994) Studies also found that in some situations inclusion of or participation by patients and families simply meant that they were informed of decisions that had already been made by health care providers regarding their care, not that they had played an active part in the formulation of the discharge plan (Efraimsson, Sandman, Hydén, & Rasmussen, 2004; Roberts, 2002). Huby, Brook, Thompson, & Tierney (2007) and Efraimsson et al. suggest that system constraints often make a patient focus and true patient participation in discharge decision making impossible. Dill (1995) states that patient and family participation in discharge decisions is subject not only to system constraints but also to the individual health professional's socially constructed and context dependent understanding of: (a) the patient's competence, (b) who should be defined as "family" and with what expectations for their provision of care, (c) the importance of individual autonomy, and (d) the multitude of interdependencies of all involved. Complicating the issue of participation further, older patients themselves often limit their own participation for a variety of reasons (lack of medical knowledge, dependence on others for post-discharge support, poor health or limited perceived ability or eligibility to participate) and frequently relinquish control over discharge decisions to

19

professionals or family members (Huby et al.; McWilliam & Sangster; Roberts, Swinkels & Mitchell, 2008). Huby, Stewart, Tierney, and Rogers (2004) found that even though older patients might have strong views on discharge issues, their willingness to express them was context specific. When present at a discharge meeting patients might be talked about rather than with and could be intimidated by the number and status of other attendees (Rydeman & Törnkvist, 2006). Older patients sometimes viewed asking questions to professionals as criticism of them and chose not to share concerns or views with professionals who were part of a system with which they were reluctant to criticize or engage (Huby et al., 2004). In one study, older patients did not relate to the term "participation" and when they were asked about participation using other terms, interviewers "hit a blank wall of general satisfaction with the way things were" (Huby et al., 2004, p. 126). Roberts found that 18 of the 30 older patients interviewed wanted to be involved in decisions about their care, and 7 definitely did not want to be involved in decisions (usually citing their poor health as the reason). As participation in discharge planning depends on communication, it is noteworthy that only a third of older patients in that study felt able to communicate with their doctors, and only approximately two thirds of patients felt able to communicate with front line workers (Roberts).

In their study of what constitutes a "proper" discharge from a health care provider perspective, Bull and Roberts (2001), seem to provide mixed messages about providers' views of the importance of true participation by older patients and families in planning for discharge. The study found that the health care providers emphasized the importance of consultation with and information gathering from patients and their families when assessing discharge needs. However the actual formulating of a plan was done by the health care team once all assessments were complete. The plan was presented to the patient and family and "in situations where there was

ongoing dialogue regarding options and open communication, elders and family carers were likely to be happy with the plan" (p. 576). A case conference with the patient and family present might occur if they did not consider the plan to be acceptable. The study also found that some patients were not aware of aspects of the plan which were only discovered once they were home.

Communication and Information Exchange

Problems with communication and information exchange and with patient and family education were common findings in studies on hospital discharge. Foust et al. (2012) found that even though patients and family caregivers reported being generally satisfied with discharge instructions, they were vague about them. They also found that some family caregivers had difficulty getting information from or communicating with providers during the hospital stay and/or were never informed of the discharge timing. Little information was provided on follow-up appointments, or what to do and who to contact if there were problems. If discharge instruction documents were sent home, they were sometimes illegible or not understandable to nonprofessionals (Foust et al.). Dossa, Bokhour, and Hoenig (2012) found that there was: (a) a lack of information about care at home such as aide use and timing of interventions, (b) a lack of information on who to contact with concerns, (c) a failure of providers to return calls, and (d) poor communication between health care providers in different settings. McWilliam and Sangster (1994) found that family caregivers did not receive adequate training and often got conflicting information from different professionals who did not understand each other's roles well or what services they could offer. The study also found that there was a lack of information on the psychosocial issues that could be associated with illness, recovery, and giving and receiving care.

Information shortfalls for patients and their informal caregivers may not always mean that information was not offered or available at some point during the hospital or transition

21

period. Patients and caregivers may not have enough ability to foresee their information needs

and ask appropriate questions until they are engaged in life and care at home; patients and family

caregivers may also be feeling stressed or so focused on getting home and back to "normal life"

that they do not absorb or retain the information provided (Cain, Neuwirth, Bellows, Zuber, &

Green, 2012) Similarly, Grimmer et al. (2004 a, p.6) suggest that family caregivers may be so

"shell shocked" and have such "romantic notions" of the role they will be playing that they fail to

recognize their limits and needs or work with formal health care providers to get the information

and supports they require. The sheer volume or terminology and content of the information may

limit their ability to comprehend and retain it (Rydeman & Törnkvist, 2006). Patients and

caregivers are often reluctant to ask for information (McWilliam & Sangster, 1994). Better

methods for assessing information needs, ensuring access to information, checking uptake and

understanding, and providing options for post discharge access to information and support are

needed. Although some such methods were included in the successful discharge intervention

RCTs mentioned earlier in this chapter, they are often not implemented.

Experiences with Life Post-Discharge and Care Provision

Home is the preferred or only acceptable discharge location for many older people even

the very old and frail; however, it can be a "fragile option predicated on the willingness and

ability of the family to give care and also on the availability of formal services to support family

caregiving activity" (Popejoy, 2011, p.75). In Ontario in 2002, two thirds of community living

seniors over 85 were care recipients, and less than 1/3 of them were receiving only formal care

(Statistics Canada, 2002). Studies show that for the remainder, the vast majority of total care

(figures range from 70-90%) comes from family members (Guberman, 2004; Hollander et al.,

2007; Keating & Dosman, 2009). Policy shifts towards deinstitutionalization and market

managed care in Ontario have drastically increased pressures on families (Aronson, 2004a) and the voluntary sector, especially in rural areas (Skinner, 2008). In Ontario, 6% of seniors over 75 reported unmet care needs (Institute for Clinical Evaluation Services, 2010).

In the two following sections, studies relating to the experiences of older people and their informal (usually family) caregivers post-hospitalization are discussed. Studies documenting experiences with formal home care provision are also included in both sections.

Discharged Patients

Older patients want to get home from hospital, and Coffey and McCarthy (2012) found that in response to being asked simply if they were ready to be discharged, approximately 94% of their sample of over 300 older Irish patients with an arranged discharge said they were. However, when their scores on a more in-depth perceived readiness for discharge assessment tool were analyzed, the mean scores were just over the cut off for low readiness on the tool used. Patients with lower scores on the assessment used more formal and informal supports post discharge. Use of informal supports generally increased post discharge, and at six weeks 80% of discharged patients were receiving help with household activities and 40% with medication management from informal caregivers. Patients with poorer reported personal status (pain, strength, and energy) were more apt to be among the nearly 25% readmitted within six weeks.

A self-report survey study of 142 Swedish patients over the age of 80 and two weeks post discharge found that 20 % had been surprised by the discharge timing. Eighty percent were receiving help from informal caregivers, and 68% were receiving formal home help (28% of this group felt they needed more assistance, usually with shopping and cleaning). Sixty-six percent lived alone. Fifty-four percent reported that they had been managing well the whole time since discharge, while 10 % had struggled the whole time. The two factors found to be highly

23

correlated with managing well post-discharge were not being alone in their home on discharge and receiving formal home care which allotted sufficient time for social support and IADL assistance (Bragstad, Kirkevold, Hofoss, & Foss, 2012).

Grimmer et al. (2004 b) conducted a longitudinal study of nearly 100 older Australian patients at risk of unsuccessful independent community living. The study followed them for six months post discharge. By four months 55% had regained lost function and were living independently in the community. Nearly 20% had an unplanned readmission related to the previous hospitalization. Participants in the study reported little involvement in discharge planning and inadequate information received on their health condition and change in health status, medication management, self-care, community supports, or how to deal with practical issues once home. Participants' determination to maintain independence at times helped them deal with their situations but could compromise their safety or quality of life when it kept them from seeking or using beneficial supports. Formal services were not received for hours to months after the return home with longer delays for new users. Patients had problems meeting ADL and IADL needs in the first few weeks. IADL supports were usually seen as more needed than ADL services. For many participants the flexibility and responsiveness of privately accessed services over publicly funded ones outweighed the cost. Pain, fatigue, and loss of mobility were ongoing concerns. Some mobility aids had been prescribed, but about 25% were considered to be inappropriate. Some participants refused to use aids out of fear of dependency. Patients in general had little knowledge related to proper medication management for pain and many did not take prescribed medications out of concern for drug interactions or dependency. Patients were upset over lost abilities and had received little counseling on realistic expectations for recovery, how to deal with loses, or that the goal of rehabilitation was not always the full recovery of previous

function. Many participants' quality of life was negatively affected by their lack of community social engagement due to newly acquired and/or anticipated future health constraints.

In their qualitative study of the experiences during the first six to eight weeks after discharge home from hospital of 14 Ontario women over 75, LeClerc et at. (2002) found that discharge preparations had fallen "short of the mark" because the preparations had not included the women and did not provide them with the information and supports they needed for life at home. They were unprepared and therefore anxious about the duration and degree of the physical and emotional needs with which they struggled. Though many needed help with both ADL and IADL activities, some were reluctant to accept the formal assistance for personal care that was offered and/or were upset that government funded formal service provision did not generally include much IADL support. Participants relied on informal providers to fill the gaps in the formal provision of services; however, they worried about being a burden and the changes in relationships, roles, and independence associated with receiving informal care. They were reluctant to complain about care provision. With formal care they did not want to be seen as a "slave driver", felt the provider "knew best," or did not want to get anyone "into trouble." With informal care, they did not want to offend the caregivers, appear ungrateful, or jeopardize the care they were receiving. Participants were anxious about the normalcy of their experiences and recovery progress, the lack of available assistance at night, and potential falls. Four women were readmitted to hospital during the study. Participants had changed their daily patterns, physical environments, and social activities to cope with their fatigue and decreased mobility.

Themessl-Huber, Hubbard, and Munro (2007) interviewed 18 Scottish patients over the age of 80 with multiple hospital admissions from the emergency department. All of the participants saw their overall community supports as adequate and did not feel additional

supports would have affected their hospital admissions. However, almost one third of participants said they were reluctant to engage with formal services because they didn't want to be a bother, did not want to lose their independence or appear frail, were embarrassed, or preferred being helped by people with whom they were familiar. About one quarter of participants would have liked changes to the services they had received. The services did not meet their needs because their needs had changed (usually due to loss of mobility), the services offered were not the type desired, or the services were not flexible enough to adapt to individual life patterns and habits. The authors suggested that social engagement with, building the trust of, and inclusion in decision making of service recipients as well as offering flexibility in services were important in fostering the uptake and utility of formal services for the frail elderly.

Aronson (2004b) describes the experiences of 27 women receiving home care services in Ontario over a three year period. Although participants were not recently discharged and only around two thirds were elderly, their experiences were likely similar to those of Home First clients. Participants reduced exposing their decreasing functional ability to others by reducing social contacts both in and out of their homes. This decrease had negative impacts on their mental state and community integration. Participants expressed concerns about the exposure to home care workers of normally private spaces and activities and their need for assistance and loss of independence. They appreciated it when efforts were made by workers to be respectful and minimize exposure of their limitations. However, the all too frequent lack of consistency in who was providing care increased their sense of exposure. They valued feeling like their case managers and workers knew and respected their situations, histories, individuality, and physical space. It was important to participants to remain "in charge" of their lives by having input into their care and having their preferences respected. However, participants often found case

managers and workers unresponsive to their concerns. They were often reluctant to voice concerns or plead for needed care as they found exposing their need humiliating, were afraid of negative impacts on their services or workers, or believed it was pointless. When asked for feedback through surveys, participants mentioned saying that things were fine when they were not. The importance of the relational aspect of care provision (and therefore support for the workers that provide it) and of formal service providers understanding and having the resources to respond to the concerns of care recipients were emphasized.

In summary, the literature reviewed indicates that patients wanted to go home and remain as independent as possible, but they were often unprepared for and unrealistic about their needs and ability to manage post-discharge. They were dependent on assistance from formal and informal care providers. However, the services provided at times did not match their desires or adequately meet their needs, and they were reluctant to complain.

Informal Caregivers

Kane, Reinardy, Penrod, and Huck (1999) did a longitudinal study of the experiences during the first year post discharge of 307 family caregivers of older stroke and hip fracture patients in the US Midwest. It is a foundational study which includes both qualitative and quantitative information collected at multiple times and from both new and experienced caregivers of patients hospitalized for unanticipated acute events; many of its findings are probably relevant to the situation of caregivers of Home First clients. Kane et al. found that 39% of the participants were new to caregiving while 90% of the experienced caregivers had been providing care (often IADL assistance) for a year or more. Thirty-seven percent of caregivers were themselves over 65 with a mean age of 58. The median caregiving time was 28 hours at two weeks post-discharge (dropping to 12 at six weeks). However, many caregivers (40% at two

weeks and 18% at six weeks) provided more than 40 hours a week of support. At six weeks 93 % of caregivers reported getting assistance from at least one other family member; however, 36% believed they were the only family member that could adequately fill the primary caregiver role. Caregivers assisted with a large variety of ADL and IADL tasks. Although the number of tasks decreased over time, assistance with IADL tasks remained high and surprisingly few formal services were utilized. Problems with task performance were mentioned less often than psychosocial problems. Areas where education would have been beneficial were mentioned including medical and personal-care skills, accessing services, and dealing with emotions. At least half of respondents got a sense of achievement from their caregiving role. Many reported increased affection between them and the care recipient; however, caregiving could have both positive and negative effects on the relationships between caregivers, care recipients, or other family members. The most frequently reported negative effects of caregiving concerned financial and employment issues.

Grimmer et al. (2004 a) studied 24 Australian informal caregivers (four were not family members) for six months post discharge of an elderly patient. They reported that little effort had been made by professionals involved in the discharge to ensure participants were "fit" for the care role, and they had little choice in taking it on. "The greatest level of carer frustration, disorganization and worry occurred immediately post-discharge when the caring role was new, formal support services were not in place, local support services were unexplored and the patient was still unwell" (p. 4). By two to three months post-discharge things were more organized and more supports were in place. Many participants made up for early shortcomings in formal information exchange and care related education by acquiring information themselves from community sources, but they would have benefited from having it provided earlier. Many

28

caregivers had health concerns of their own which were sometimes made worse by the demands

of caregiving. Conflict between caregiver and recipient was a common theme and both were often

grieving the changes to their lives as a result of the recent acute event. All caregivers reported

lowered levels of social engagement which continued through the end of the study for half the

participants. In spite of ongoing declines in the health of many care recipients and the stresses of

caregiving, most caregivers were unwilling to consider LTC placement unless they had a health

crisis of their own which limited their ability to provide the necessary care.

Two Canadian studies (Sims-Gould & Martin-Matthews, 2010b; Wiles, 2003) examined

the relationship between informal caregivers of older care recipients and formal service providers.

Though the studies are not linked to recent hospital discharge they are still relevant to the

experiences of the caregivers of Home First clients. Wiles, in a study of 30 Ontario caregivers

utilizing formal supports, found a reluctance to ask for help, uncertainty about wanting

"strangers" in their home, confusion about available services or where to get information on

them, and a "need to be assertive, persistent, and well organized to get effective support" (p.194).

They were frustrated by the inflexibility of the services offered which often had seemingly

inappropriate eligibility requirements or did not match their needs. Their ability to have some say

in the timing of service provision was seen as positive, but the number of hours actually allotted

was often insufficient for needed tasks or to allow for respite. Established relationships with

workers were valued; however, poor working conditions for formal home care workers resulted in

staff turnover, lack of continuity of care, and the need for informal caregivers to engage in

frequent retraining of workers new to them. Wiles suggests that informal caregivers want to be

treated as co-workers or partners and as an important part of the healthcare team.

Sims-Gould and Martin-Matthews (2010b) studied the experiences of 52 informal caregivers of older care recipients utilizing home support services in British Colombia. They found a general dissatisfaction with the bureaucratic nature of service provision, its inflexibility, and the lack of needed IADL services. Participants emphasized the importance of the relationships that were established between workers and care recipients and the importance of the affective and social support they provided. The informal caregivers were involved with formal caregivers through providing "assistive care" when they worked together to perform tasks requiring two people. They worked sequentially when one set the stage for tasks performed by the other or when the informal caregiver performed quality assurance and monitoring of the work done by formal care providers. Informal caregivers are "filling the gaps" in the formal support system due to reduced hours and lack of continuity of workers. The formal and informal care systems are dependent on each other to share the care to meet the needs of older care recipients who also participate actively in the process. "Older clients and their families are not just consumers of service but rather contributors to this dynamic care system" (Sims-Gould & Martin-Matthews, p. 42).

In summary, family caregivers reported that their needs or ability to provide care had often not been considered during discharge planning, and communication about care needs and services was often lacking. Most were committed to their role and many continued to provide many hours of care in spite of their own health issues. They also mentioned issues with the types, amounts, and flexibility of the formal services which were provided. The need for a partnership between formal and informal caregivers and the frail elderly to meet their care needs was clear.

Long Term Care Placement

Two of the professed goals of the Home First approach are moving decision making about and transitions to LTC from hospitals to clients' homes, and reducing or delaying LTC placement. These goals raise questions about how LTC placement decisions are made and the options for and pros and cons of managing people at risk of LTC placement in the community.

Placement Decisions

There is usually little preplanning or discussion of LTC placement between informal caregivers and the older people they care for. Nolan et al. (1996) found that placement was so negatively viewed that nobody wanted to think about it; if caregivers had considered it, it was often covertly and with feelings of guilt. Duboise, Dubuc, Caron, Raîche, and Hébert (2009) in a Quebec study of nearly 600 older adult (over 75 years) and informal caregiver dyads found that in around two thirds of cases neither person had thought about LTC placement; when one had, the other often had not. When informal caregivers seek LTC placement for the person they care for it is often the result of a crisis after an extended period of caring, and it is usually because they perceive themselves as no longer able to provide adequate care or cope with the demands of caregiving, (Caron, Ducharme, & Griffith, 2006; Davies & Nolan, 2003; Ryan and Scullion, 2000). A Canadian report by the Change Foundation (2009) on LTC placement following hospitalization found that preplanning for longer term care needs had seldom occurred and that information and assistance provided by health care providers to enable decisions were inadequate. The report suggests that having hospitalization be the event that triggers discussion and planning for longer term care needs or LTC placement is a failure on the part of the system to initiate discussions that are often difficult for older people and families to begin due to conflicting emotions and negative views of available options (Change Foundation). When informal

caregivers must make decisions about LTC placement from hospital, an already traumatic process is made worse by the added pressure, short time frames, emotional impact of the acute event, and limited ability of the care recipient to participate (a situation made worse if there has been no preplanning) (Nolan et al., 1996; Ryan & Scullion, 2000). Care recipients often feel that doctors or others have made the decision for them and, even if they are present at discussions, they may not be able to hear or understand the options presented or actually exercise choice (Hicks, Sims-Gould, Byrne, Khan, and Stolee, 2012; Jorgensen, Arksey, Parsons, Senior, & Thomas, 2009; Nolan et al., 1996). Decisions made from acute care settings may not allow for adequate recovery or time for proper assessment of functional abilities and may be unduly influenced by medical models of care and physician input; community or long term rehabilitation settings allow for a more appropriate and client centered assessment of long term care needs (Moats, 2006).

LTC Placement versus Community Care

In 2011-2012, the median wait time for a LTC bed in Ontario was 98 days (Auditor General, 2012). One way to reduce pressures on LTC beds, the length of LTC wait times, and ALC-LTC numbers is to provide supports in the community to delay or forestall the perceived need for LTC placement. Studies show that the number of people actually requiring a level of care only possible in a LTC home setting may be much lower than that which is indicated by current LTC wait list and ALC-LTC numbers. One Ontario study found that 35% of ALC-LTC patients had care needs no greater than some clients being successfully supported with CCAC home care services (Change Foundation, 2009). Williams, Challis, et al. (2009) found by matching the assessed needs of those on Ontario LTC wait lists with hypothetical care packages that around a third of people could be cost effectively and safely managed at home using community supports if there was adequate community capacity to provide such support. The

32

study also found that an additional 10 to 20 % could be managed successfully in supportive housing while approximately 20% could be safely managed only in LTC (often due to the lack of an informal caregiver combined with cognitive deficits). In a 2006 study from the Netherlands, van Bilsen, Hamers, Groot, and Spreeuwenberg (2006) interviewed 67 older people on LTC wait lists and found that 88% would refuse a bed offer if it was not for their first choice facility, 34% would refuse even their first choice, and around 40% felt that admission was not actually necessary. When I recalculated the refusal rate including 26 people that had refused to participate in the study due to poor health, and I assumed they would accept an offer, the refusal rate was still 25% and perceived lack of need 29%. In a US study, Marek et al. (2005) showed that 78 older participants receiving well integrated nursing and home supports in the community had better functional outcomes over an 18 month period than 78 matched participants with initially similar needs being cared for in LTC facilities.

From the above, it seems likely that LTC placement may not be necessary for many of the people presently on wait lists for it in Ontario, and the alternatives for community care may be cost effective and actually provide for better client outcomes; however, the costs and benefits to informal caregivers are not always considered. Hollander, Chappell, Havens, McWilliam, and Miller (2002) took a very detailed look at costs and benefits to clients, informal caregivers, and the formal system for community versus LTC facility care. They found similar perceptions of overall quality of life between clients in both settings. Hundreds of hours of care by informal caregivers continued to be provided annually to LTC facility dwelling clients. However, the time informal caregivers spent providing care in facilities was much less than that spent caring in the community and the difference became larger the more dependent the care recipient became. Based on their survey instruments, although objective measures of burden were lower for

caregivers of those in LTC, their emotional burden was higher than that of those caring in the community (Hollander et al.). The monetary cost of care provision was much lower in the community unless caregiver time was figured at replacement wage costs and the user fees charged to facility patients were not included in the cost calculation in which case the costs became similar (Hollander et al., p. 65). When considering the substitution of community care for facility care for older people in the context of ALC pressures and post-acute care needs and the limited funding and capacity for community care, it is important to ensure that there is no erosion of support (including IADL support) for home care clients who require long term support the erosion of which could result in an increase in hospitalizations, spiraling demands for LTC care, and increased system costs (Hollander, Miller, MacAdam, Chappell, & Pedlar, 2009). In encouraging community care for elderly clients, it is important that for those clients and caregivers for which LTC placement is the preferred or only viable option, the already difficult decisions to seek LTC placement which are often already colored with a sense of failure or guilt are not made more difficult (Nay, 1995; Nolan et al., 1996).

Summary

This literature review has shown that the issues of ALC patients waiting in hospitals for LTC placement and long wait lists for LTC placement are of concern in Ontario. The Home First approach has been developed as part of the attempt by health care providers to deal with these two issues. Performance metrics which have been collected on some health care system outcomes indicate that it is successful. However, little is known about its effects on clients and informal caregivers. The literature on some discharge interventions has shown cost savings for the healthcare system, but little evaluation of the effects on patients and their caregivers has been undertaken. The review of literature on patient and caregiver experiences post-discharge

34

identified many areas for potential improvement in the provision of formal services. An

exploration of LTC placement decisions and the possibility of substituting community care for

LTC for some clients seems to support the Home First philosophy's contention that hospitals are

not an ideal place to make LTC placement decisions and that there is a potential to provide

suitable community supports for people considered at risk of or waiting for LTC placement.

There is a lack of information on the post-discharge experiences and thinking of Home First

clients and their informal caregivers. The present study attempts to reduce this information gap.

Chapter 3

Research Approach and Methods

Research Approach

This is a qualitative descriptive study reflecting a social constructivist worldview. As discussed by Creswell (2009), this worldview holds that people seek to understand their experiences. The understandings they develop are complex and constructed through interaction with other people and their physical, social, historical, and cultural environments. He suggests that constructivist researchers seek to learn about and interpret these understandings through communication with and observation of the people involved in the experience while remaining aware of the reality of the researcher's unavoidable influence on all aspects of the research and evaluation process. In keeping with Creswell's suggestions for conducting qualitative research:

- I considered the multiple perspectives of all those involved in the study and the Home First approach, and during reporting recognized the diversity of participant views.

- I interviewed participants in their homes and interacted with them multiple times.

- I was open about my values and biases and sensitive to those of the participants.

- Portions of the thesis were written in the first person (see also Webb, 1992), and quotations from participants were used to illustrate some findings.

- Procedures and study details evolved over the course of the study, and inductive reasoning guided analysis.

Sandelowski talks about naturalism in her 2000 and 2010 articles on the qualitative description approach to research. She states that: (a) naturalism often provides the philosophical or theoretical basis for a qualitative descriptive study, (b) that naturalism presupposes that there is

a reality to be perceived, and (c) that the study should be conducted with as little manipulation or preconceived expectations as possible. A naturalistic belief is foundational for this study and is compatible with its constructivist worldview: there is a reality out there, but one's view of it is shaped by many influences. In keeping with these beliefs, I have based my study on interview data which I view as reflecting the reality of the participants' situations (probably a mixture of subjective and objective reality/facts). Interviews were semi structured and questions open ended to reduce my influence on the responses to them and the accounts provided by participants. "There is nothing trivial or easy about getting the facts, and the meanings participants give to those facts, right and then conveying them in a coherent and useful manner" (Sandelowski, 2000, p.336). She suggests usefulness is often the goal of qualitative descriptive studies. I will provide a report documenting the study findings to study participants and Home First partner organizations. It is my hope that the findings will prove of use to these organizations in their evaluations of the Home First approach and their provision of services to the elderly and their caregivers.

The research protocol originally submitted for this study stated that the study would utilize a narrative inquiry approach. Narrative interviewing can be empowering for the participants and allows them to express themselves and make sense of or justify events in ways that more traditional questioning does not (Holloway & Freshwater, 2007). Though participant narratives may not always reflect empirical fact, they represent emotional and experiential reality and may provide insight into aspects of the participant's situation that the researcher had not considered or asked about (Overcash, 2003, Wiklund-Gustin, 2010). A narrative approach was initially deemed appropriate for this study as the intent was to access personal experience in a non-exploitive way. Narratives often reflect change over time, and I was interested in the ways in which the experiences and decision making of participants changed over time from the precipitating health

event through the hospitalization and the first few months after the return home. I was also attracted to narrative research as I have long enjoyed listening to life stories.

As the study progressed, however, I realized how large a portion of the interview data I was obtaining was more simply a response to questioning than a "narrative". As I pondered how I would eventually analyse the data being collected, I realized that I would not be doing a typical narrative analysis. I also realized that my study was presented in the research protocol sent for ethics approval and in the Information and Consent Form (Appendix A) as a study of the Home First approach, community care, and decision making about housing and care needs. It was not presented as a study that, as is often implied by narrative analysis, would interpret the philosophical, sociological, or psychological levels of the meaning found in the interview narratives. I believed that it would be unethical to use data in such ways which were not anticipated by the participants (Sandelowski, 2011). I concluded that while an interest in narrative had been valuable in formulating the study and data gathering, the study should be considered a qualitative descriptive study. Sandelowski (2000) states "qualitative descriptive studies offer a comprehensive summary of an event in the everyday terms of those events" (p. 336); that it "is especially amenable to obtaining straight and largely unadorned . . . answers to questions of special relevance to practitioners and policy makers" (p.337); and "that there is no mandate to re-present the data in any other terms but their own" (p. 338). As my goal in the study was to describe participant experiences and thinking in order to answer questions of relevance to the providers of community care for the frail elderly, the methodology seemed appropriate. Sandelowski (2000) also stated that qualitative description like other forms of qualitative analysis could have overtones of other methods. This study did retain narrative overtones as narrative approaches and participant narratives were important components of it.

Participant Criteria and Recruitment

Participant Criteria

Participants were adults over 65 (and/or their caregivers) who were discharged from hospital as part of the Home First approach during a one and a half month period beginning approximately three months before the start of recruitment. Both Home First clients and/or their caregivers were recruited to increase the number of potential participants and hear "both sides of the story" as I believed their views on the discharge and their post discharge needs and experiences could potentially be quite different. I chose three months post discharge as the time frame, as by that point significant recuperation might have occurred, the impacts of service provision would have been experienced, changes to care provision might be occurring with the ending of funded CSS services, a re-evaluation of long term possibilities for care needs and provision might be occurring, and the discharge experiences would still be relatively fresh.

The target number of participants was 10. This number was thought to provide an opportunity to learn from a heterogeneous sample of people and be realistic to recruit and study within the limits of available time and resources. This sample size is similar to the participant numbers found in some of the qualitative studies I reviewed during planning for the thesis or referenced in it (such as Efraimsson et al. 2004; Moats, 2006; Ryan & Scullion, 2006; Tanner, 2010). The sample had to be an opportunistic one as there was only a small number of Home First clients eligible for participation and there were constraints on access to them and information about them for reasons of confidentiality. I had to work through a "gate keeper" because potential participants might lack information about their status as a participant in the Home First approach and so could not be recruited independently. Because of these restrictions, I was not, as is considered ideal in qualitative studies, able to do purposeful sampling in order to recruit people

with a predetermined range of experience to enhance the richness of the information available

from them (Patton, 2002). In spite of this, the sample I ultimately obtained did reflect a

potentially information rich range of participant characteristics.

Inclusion criteria were that participants be: (a) 65 or older and recently discharged Home

First or a family caregiver of such a person; (b) presenting themselves as willing and able to

remember and talk with me in English about their health and care related experiences.

Recruitment

To access potential participants I worked with staff at the South East Community Care

Access Centre (CCAC) which had access to the contact information of potential participants and

was willing to support recruitment as they believed the study could produce useful findings. I

delivered stamped, sealed envelopes to them for addressing and mailing to the 36 people (or a

caregiver of that person if that was the contact person of record) discharged during the target

dates. The envelopes included a letter from the SE CAC explaining their interest in the study

(Appendix B) and an invitation brochure (Appendix C) that requested that those interested in

obtaining more information and/or participating call a toll free number or send an email which

would connect them with the investigator. About two weeks after the mailing, since only one

person (who did agree to participate) had contacted me in response to it, a staff member at the

SECCAC made calls to the people who had been mailed information[2]. People were reminded

about the mailing, offered a new copy of it, and asked if they would like to be called directly by

the investigator (script in Appendix D). Six participants were recruited as a result. One of these

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[2] The person making these calls informed me before completing the last of the calls that of those she had
already called three of the Home First clients had been readmitted to hospital, one had a fallen and
sustained a life threatening injury, some could not be reached, one did not want to do it as they had just
participated in a survey, and one said they were not up to participating.

was a primary CG who asked to have two secondary CGs participate in the interview. Two

family caregivers (CGs) were recruited by me through participating Home First clients (CLs).

Ultimately, eleven people participated actively in the study and information was obtained about

seven CLs (for more information see Participants and Data Sources, p. 48 and Table 1, p. 49).

Data Collection and Analysis

In Person Interviews

After an initial phone conversation with participants to describe the study and arrange for

an interview, I conducted and digitally recorded nine in-person interviews (see the table on page

49) in the homes of Home First (HF) clients and/or their primary caregiver about 2.5 to 4.5

months post-discharge. Before the interview, the Information and Consent Form (Appendix A)

was discussed and read by or to the participant and signed. In three cases, both a care recipient

and one or more caregivers participated. The inclusion of more than one person in an interview

was done to accommodate the desires of the participants. I hoped that doing so might help make

"visible the complex, relational character of the experiences under consideration" (Holstein &

Gubrium, 1995, p.66).

In order to insure that relevant topics were not missed, at some point during interviews I

referred to an interview guide (Appendix E) and question list (Appendix F). The actual questions

asked in an interview were context specific and generated in response to the information received

from the participant (Holstein & Gubrium, 1995; Seidman, 1998). My initial questions were very

open ended in an attempt to allow the participants to talk about that which was most significant to

them. I used follow-up questions or prompts to clarify information or encourage further

exploration of topics of importance to the study (Rubin & Rubin, 2012). Accounts were sought

about the situation prior to the hospitalization, hospital experience, discharge planning, post

41

discharge experiences, and plans for the future which were related to health and care provision

issues. The Home First approach was discussed and explained to participants during the

interview. In keeping with suggestions by Holstein and Gubrium and Rubin and Rubin, I

purposefully kept the interviews somewhat conversational and included some reciprocal sharing

of experience to encourage rapport and elaboration on their experiences by participants.

The recorded interviews ranged in length from about 1/2 hour (an individual interview

that was a follow-up interview immediately after a longer joint one) to 2 1/2 hours with an

average length of about 1 1/3 hours. Wenger (2003) suggests that informal visiting may be done

after an interview to show appreciation of the participant's contribution and to ease the transition

for them from the intense sharing of the interview to the leave taking. Therefore, I usually

encouraged some off topic conversation beyond the end of the recorded interview. Before I left

the interview location: (a) participants were asked if they had anything else they wanted to say or

any questions, (b) permission was sought for further contact if required to clarify unclear content

or to confirm findings and for a follow-up call one month later, (c) participants were encouraged

to contact me (which none did) if they had questions or concerns, and (d) participants were

thanked for their time and offered a copy of a booklet on navigating the health care system.

Follow-up Calls and Emails

For the study population there is a high potential for: (a) significant changes in health

status over a short period of time, (b) continuing adjustments to a possibly altered life situation

post-hospitalization (Grimmer et al., 2004 b), (c) actual or anticipated changes in service

provision as enhanced Home First services decrease, and (d) change in LTC admission status or

planning. Therefore, I contacted participants by phone about one month after the in-person

interview to find out if their life situation, health, or thoughts about care provision had changed

42

over the intervening weeks. One of these calls was conducted for each of the original in-person interviews (where there were multiple participants at an interview only one of them was willing to receive a follow-up call). All of these calls were digitally recorded (with permission) except for one during which I forgot to turn on the recorder and had to rely on notes written after the call. These calls provided an opportunity for me to ask any questions that had occurred to me during the transcription of the interview and for participants to add any information they felt had been missed. It also allowed me to learn what if anything of relevance to the study had changed during the intervening weeks.

During the initial interview, all participants agreed to later contact if there were questions on my part related to the study or for feedback from them on a preliminary summary of the study. Six email messages were exchanged with a total of three participants. A dozen such calls in addition to the one month follow-up calls were made to a total of seven participants and some of these were recorded. Most of these calls were made in response to questions raised during my data analysis. They also included calls made to a CL following a respite stay at a retirement home and to a CG following the LTC placement of her husband because I believed getting feedback from them following these events could provide information of significance to the study.

Timing of Data Collection

The interviews occurred three months to four months post discharge. Contact was made up to nine and a half months post discharge with the participants who reviewed the preliminary summary. Follow-up calls and emails occurred throughout the intervening months.

Documenting the Research

I produced a research diary in which I documented the progress of the study and some of my thinking about it. For each participant, a data sheet was created which included their

43

demographic data, contact information, notes recorded after all calls and interviews, copies of emails exchanged, a list of codes used in transcriptions to protect confidentiality, and questions which occurred to me during my transcription or analysis of their data.

Transcription

Transcription overlapped with continued data collection. I transcribed all of the digitally recorded in-person interviews and some of the phone conversations (notes on content were written as I listened to the recordings that I did not transcribe). QSR International's NVivo 9 data management software was used to assist with data analysis. I did my initial transcription into a Microsoft Word document. I then reviewed the document while I again listened to the recording, corrected any transcription errors, and adjusted formatting and sectioning of the transcript to allow import into NVivo and audio linking within it. Although the process was time consuming, the multiple reviews it included gave me confidence in the accuracy of the transcripts and increased my familiarity with the data. During the transcription process, I removed identifying information and made notes in the participant file of questions raised or thoughts to follow up on. Following the transcription of each of the interviews, a summary was written.

Data Analysis

Data analysis was an ongoing process (Creswell, 2009) that began following my first phone contact with participants as I thought about the information they had provided. All of the interviews involved at least an hour of travel time each way, and I pondered the interview or listened to the recording as I drove home. Once all of the initial interviews were transcribed, I began their analysis using content analysis which is the strategy commonly used for qualitative descriptive studies (Sandelowski, 2000). This involved identifying, classifying, and finding common meanings in the transcript data (Patton, 2002), and, as defined by Morse and Field

44

(1995), "analysis by topic" (p.140) or category. I began by coding the transcripts; that is, I read through them and linked each segment to the topic/category/code to which it was related. Codes were not predetermined but were created as topics were identified in the data (Sandelowski, 2000). Earlier coded transcripts were rechecked later to ensure that nothing belonging to a more recently created code had been missed. The coding was descriptive (for example: PSWs, Hospital Stay, Aids, Medication, Family Support) and was done to allow for further more analytical coding and to look for commonalities across participants or codes (Miles & Huberman, 1984). I was then advised by my thesis committee to concentrate on reading and rereading material and focusing on what "jumped out" at me as important which I did while also looking for commonalities, progressively condensing the material, and questioning and refining my understanding of potential findings. This stage of analysis went beyond providing a descriptive summary of the data and became thematic analysis or the search for themes. Themes are "common threads that extend throughout an entire interview or set of interviews" and "significant concepts that link substantial portions of interviews together" (Morse & Field, p. 139-140). I chose to carry data analysis through to the identification of themes even though Sandelowski (2000) states that "the expected outcome of qualitative descriptive studies is a straight descriptive summary of the informational contents of the data" (p. 338-339) with no requirement to re-present it further.

Trustworthiness

The terms used to describe various aspects of the quality or trustworthiness of qualitative research methods and reporting (rigour, credibility, dependability, qualitative reliability, qualitative validity) and their definitions vary depending on the source, but the recommended

45

strategies for insuring trustworthiness are quite consistent (Liamputtong, 2009). I employed many of these recommended strategies as well as others to insure this study's trustworthiness:

- I kept a research diary and copies of document drafts to provide an audit trail. I also kept field notes and memos. All of these documents were included in data analysis.

- I consulted participants about questions that arose during data transcription or analysis.

- Three participants wanted to review and approved a preliminary summary of the study.

- The prolonged period of involvement with participants allowed for documentation of changes in their life situations and their understandings of the changes.

- The participants had intimate knowledge of the relevant topics and opportunities to freely and fully express their views during the multiple interactions with me.

- My use of interview and question guides increased the probability of having obtained representative data from all participants.

- By personally doing the transcribing and rechecking the transcription against the original recordings, I reduced the possibility of transcription errors. Doing both the data gathering and analysis enabled me to remember and include a consideration of nonverbal and environmental clues in my analysis of interactions.

- Including both CLs and CGs in the study allowed for both a wider perspective on topics of interest and the triangulation of findings between the two groups.

- I believe my sex, age, and experience working as a PSW were assets in developing rapport with participants and in turn my ability to collect meaningful data from them.

- My background and personal interest in the study were both an asset and potential source of bias to it. However, they were made clear to participants; I was reflexive about them throughout the study; and they were identified and discussed in the thesis document.

- I used quotations from participants to illustrate the findings in reporting on the study and provided contextual description while respecting the need to maintain confidentiality.

- Findings were developed through prolonged and repeated immersion with the data.

- Before finalizing my determination of descriptive findings and themes, I returned to the original transcripts to check for congruence between my findings and the transcript data.

- In an attempt to find or evaluate any discrepant cases, findings were checked against each participant's data and my understanding of their situation.

- The conduct of the research and resulting thesis were deemed appropriate by members of my supervisory committee, all of whom are experienced qualitative researchers.

Ethics

Prior to my initiation of the study, approval was obtained from the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board. A detailed discussion of how potential ethical concerns would be addressed was included in the research proposal that was submitted for review. Written consent was obtained from all participants prior to the initial interview and further verbal consent was obtained before each phone conversation. Participants were free to terminate their involvement or decline to provide information (or have it deleted from the data base) at any time. Pseudonyms were used in data storage, analysis, and reporting. An email address and toll-free number for contact with me and the phone numbers of the chairman of the ethics review board and my thesis supervisor were provided to participants. All personally identifiable digital participant data was encrypted during storage.

Chapter 4

Results

In this chapter I describe the participants and data sources from which the findings were obtained. I then present an overview of descriptive findings organized by topic: the Home First approach itself and then different types, locations, or providers of care. Thematic findings are presented in the following section. The chapter ends with a brief summary of findings.

Participants and Data Sources

This study was based on interviews with Home First clients (CLs) discharged from hospital over a one month period and/or with family caregivers (CGs) of study CLs. Five CLs participated actively in the study. A sixth CL, Harold, had cognitive impairments that prevented his participation, so information was obtained from his wife (who was his primary caregiver and the CCAC's contact of record) and two sons. A seventh CL's information was provided by her daughter, the CCAC contact of record. The CL, Mary, was present at the interview but chose to participate minimally due in part to a hearing impairment. Two other CGs agreed to participate after giving permission to CLs for me to contact them about the study. All CLs lived in different parts of the SELHIN and received home care services coordinated by the South East CCAC. Two of the CLs lived in rural areas and five in small to midsized towns. Five of them had had at least one additional hospitalization in the previous year. Three had stays in more than one hospital during the most recent period of hospitalization. They were discharged home from five different hospitals one of which was outside of the SELHIN boundary. All of the women CLs had been hospitalized for fall related fractures. The three men had been hospitalized for cardio-vascular or neurological issues. Additional information on participants can be found in the following table.

Table 1: Participants and Data Sources

Home First Clients

Name[1]	Age	Marital Status	Lives in/with	Data Sources[2]	Discharge to Last Data
Mary	90-94	widow	House with daughter and son-in-law	**Dorothy**	9 months
Mollie	85-89	widow	Retirement home	Private interview, 2 calls	4 months
Melanie	80-84	widow	Apartment in a relative's home	Private interview, 4 calls and **Debbie**	8 months
Martha	75-79	married	Apt. with husband	Private interview, 3 calls, 1 email	9.5 months
Harold	90-94	married	House with wife	**Wilma, Steve**, and **Sam**	8.5 months
Fred	80-84	widower	House alone	Private interview, 2 calls	4 months
Frank	65-69	unknown	With daughter at discharge, then alone	**Donna** and joint interview with her	8 months

Caregivers

Name[1]	Age	Marital Status	Role, Status, Other Information	Data Sources[2]	Discharge to Last Contact
Dorothy	70-74	married	Daughter CG of **Mary** CSS volunteer until became CG	Interview (Mary present) 2 calls, 3 emails	9 months
Debbie	55-64 (est.)	married	Daughter CG of **Melanie** Cares for grandchildren, pets, and livestock	Private Interview 1 call, 2 emails	8 months
Wilma	85-89	married	Wife CG of **Harold** Chronic health condition	Joint interview with Sam & Steve, 4calls	8.5 months
Sam	55-64 (est.)	unknown	Son of **Harold** and Wilma, Retired	Joint interview - Wilma and Steve	6 months
Steve	55-64 (est.)	married	Son of **Harold** and Wilma, Employed	Joint interview - Wilma and Sam	3 months
Donna	40-44 (est.)	divorced	Daughter CG of **Frank** Mother of pre-teen child Chronic health condition	Joint interview - Frank & Private interview, 2 calls	8 months

1. All names are pseudonyms. To add to the information content of names referred to in the thesis,
 the first letter of the name is associated with the relationship between CL and CG: For CLs, M = mother,
H = husband, and F = father of the CG. For CGs, D = daughter, W = wife, and S = son of the CL. (Note for
3 CLs the reference CG did not participate in the study.) Bolded names in the fourth or fifth columns are
the corresponding CG or CL of the person in the first column. 2. Number of calls does not include initial
calls to arrange for interviews.

<center>**A Summary of Findings by Topic**</center>

This section contains a summary of what participants told me about their recent health and care related experiences. I first present findings that relate to the Home First approach itself and then describe findings as they relate to different types, locations, and providers of care.

Home First Approach

Few participants had heard of the Home First approach. For those that had, it was usually just associated with the 30 days of free CSS services that CLs were offered post discharge. For all of the participants, the approach was a success in that the CLs, all of whom wanted to continue living in homes in the community, were able to do so. None was re-hospitalized prior to my interview with them. During the 4 to 9.5 month period of my contact with them, two CLs had short term hospital admissions and one was placed in a LTC facility and had a hospitalization post LTC placement. By the end of my contact with participants, one was palliative.

It is impossible to know for sure what the discharge timing or destination would have been for any of the CLs in the study in the absence of the Home First approach. However, Dorothy stated that Home First had "been a good thing as far as I'm concerned." She felt that without the push from Home First to have Mary wait for LTC in the community, she would have gone into LTC. Instead she moved in with Dorothy who reported things were "fine," and Mary reported, "It's great to be here with my daughter."

Formal Care

Hospitalization.

All CLs had entered hospital from a hospital emergency department, and for three of the CLs, their treatment required them to transfer between two hospitals. All had experience with previous hospitalizations and/or chronic conditions. When Martha was asked if the recent

<center>50</center>

hospitalization had altered her thinking about her situation, she replied that she had just thought, "here we go again." Three CGs mentioned that a hospital stay had improved the CL's health status beyond just addressing the presenting problem by also providing an opportunity to become aware of and address pre-existing medication or nutritional issues. No one mentioned issues with hospital based infections or deconditioning, but concerns regarding food, beds, boredom, or the exhaustion inherent in the large number of people involved with care were mentioned by one or more CLs. A lack of adequate communication in the hospital between patients, caregivers, doctors, and nurses was mentioned by some participants. Different understandings of, and failures to communicate about, the probable hospital care trajectory resulted in misunderstandings about discharge timing and CGs being unprepared for the discharge.

Discharge.

The views of CGs and CLs on the discharge process were generally somewhat different and will be discussed below.

Client views of the discharge.

All CLs wanted to go home and none expressed concerns about their readiness to do so. However, Fred was not informed adequately about who would be taking him home, or that a different agency from that which had formerly been providing his homecare would provide it post-discharge. This left him confused and upset. Eventually he did manage to get services reinstated from the agency and workers with which he had established positive relationships before his hospitalization. None of the other clients had complaints about their discharge. Martha thought she might have benefited from more rehabilitation in hospital, but still wanted to get home. When asked about her discharge, Melanie just said that she knew her discharge date a few days ahead and that the meeting about it "was very good."

Caregiver views of the discharge.

All of the CGs had concerns about the timing of discharge. They felt that they were not ready for it and/or that the CL was not ready. They did not feel included in discharge planning. They felt they had simply been "told" what was going to happen and some felt that the hospital just wanted to "get rid of" the CL. There was poor communication about the timing of discharge including a failure to notify CGs when expected discharge dates changed. One CG reported problems with access to and information on medications on one of several discharges. Two CGs reported a lack of adequate information on the services that would be provided on discharge.

In spite of the many concerns that CGs had about the discharge, in all cases CLs did manage to transition to the community without an adverse health event or the need for an early readmission, and formal services were in place right away on discharge. For the one CL for whom the discharge was across LHIN boundaries, the CG reported that the case manager at the hospital handled things well and made all necessary calls to ensure a smooth transition and have formal services in place.

Community case management.

All of the CLs had CCAC community case managers who took over their case from the CCAC hospital based case manager who had given them the Home First designation. They would also have had a case manager associated with any agency (such as the agency contracted by the CCAC to provide home support services) actually sending in people to provide care. It was not clear how many if any of the participants actually understood the differing roles of people and who to call if there were concerns. Three CLs mentioned receiving a visit from a CCAC community case manager shortly after their return home and no one reported further visits from case managers. Six participants did mention talking with, or calls from, case managers; however,

it was not always clear which agency they were from. One CL mentioned conflict with a case manager, and three participants mentioned positive relationships. One CL suggested that she would appreciate having contact "ordered" (that is regularly scheduled) with her case manager rather than have to initiate contact herself as she was not good at "asking". No participant expressed certainty about how hours of formal care were allotted or why changes in hours had occurred.

CCAC provided professional services.

The professional services that were arranged and funded by the CCAC for CLs included in-home nursing, physical therapy and occupational therapy. Four participants mentioned having received home nursing services at some point and all were satisfied with them. The visits provided social as well as medical support to CLs. All of the CLs had received a limited number of home visits from a physiotherapist. Instructions were provided for continuing with exercises after the end of the short period of therapist visits; however, CLs varied in their willingness to continue with the recommended exercise programs after they were no longer being supervised by the therapist. Continued supervision of the prescribed exercises was provided for one CL by a CG and for another by a PSW for a short period of time. Three participants mentioned having received occupational therapy services but in all cases the therapists were simply doing safety evaluations and found little that needed addressing.

CCAC provided home care/personal support services.

The main service organized and funded for CLs by the CCAC was home care (also known as home or personal support) which was delivered by personal support workers (PSWs). Three CLs had been receiving some PSW services immediately prior to their recent hospitalization. All CLs received some PSW assistance post-discharge. All study participants

were grateful for the social and instrumental support provided by PSWs, and there was at least one reference to a positive relationship with a PSW for all CLs in the study. One CG that ultimately was very appreciative of the PSW support she and the CL had received, mentioned that initially she had been uncomfortable with having strangers in her home and handling her things and with accepting her own need for assistance.

For all of the CLs there was an initial period post-discharge when there was inconsistency in the timing of PSW visits and in which PSW was providing the care. Once CLs had been home longer, timing and people became more consistent. Consistency in who provided care contributed to the development of positive relationships and the establishment of routines and was valued by participants. If timing of visits was inconsistent it was not only inconvenient for CLs or their CGs, but could pose health and safety issues if it interfered with timely safety or medication compliance checks by a PSW or altered the timing of assistance with a meal which had medications associated with it. In spite of such concerns, participants were often forgiving of late workers or missed visits as they understood the scheduling and travel challenges facing PSWs. For two CLs, concerns were voiced about the pressure on PSWs to provide the specified care in the hours allotted for its provision, and for three CLs, about the amount of time allotted for their PSWs to travel between clients. Both situations led to rushed care provision and/or a failure of CLs to ask for or receive the mandated care. One CG chose to take over the provision of evening care which often came at inconvenient and unpredictable times, and was able to exchange those evening care hours for flexible respite hours. One CL chose to discontinue help with meal preparation but was not permitted to substitute assistance with house cleaning which she found more difficult to manage without assistance but is no longer provided by the CCAC.

54

PSWs can contribute to client health and safety. Two CLs commented on their unwillingness to risk showering alone due to fear of falling and one reported that a PSW had identified a potential pressure sore which had allowed for proactive treatment. Two CGs mentioned PSW assistance with CL medication compliance while one CG was concerned about their failure to monitor it. This CG also reported receiving contradictory information from different people working for the same agency about what PSWs were allowed to do with regard to monitoring medication compliance or assisting clients with medications. Two CGs mentioned that CLs were more receptive to having some types of care provided by PSWs than by family members.

Community support service (CSS) organizations and formal IADL supports.

CLs were offered 30 days of free CSS social and IADL support services post-discharge due to their Home First status; however, only four CLs made any use of this offer. All CLs received at least some social support and IADL assistance from informal caregivers and so did not choose to utilize some similar CSS services. One CL did not need CSS services as similar supports were provided by her retirement home and one hired house cleaning privately from a neighbour rather than access it through a CSS agency. Two CLs were already receiving IADL supports including Meals-on-Wheels through other publically funded support programs for which they had ongoing eligibility (SMILE and VIP, see pages 89-90). Three other CLs utilized CSS meal provision (either Meals-on-Wheels or a frozen meal program); however, participant evaluation of the quality of the meals varied greatly. Two CLs used CSS assistance with house cleaning, transportation, and/or shopping. One CL valued visiting with the CSS workers that came in but declined their help with any chores (her CG viewed their visits as providing respite from her caregiving responsibilities). Only one CL continued with any CSS service that was no

55

longer being funded for them; however, one CL repeatedly expressed a desire for more help with house cleaning but could not afford to purchase it. The CL on the SMILE program was frustrated that the agency providing services refused to accommodate his need for assistance with banking and purchasing some items, and therefore he was forced to rely on the informal assistance of a neighbour.

Informal Care

Assistance from friends and neighbours was only reported by two CLs. In one case, the use of such assistance may have resulted from the lack of any local family members to provide help combined with the CL's long residence in the neighborhood and established relationship with neighbours.

All CLs had family members actively involved with their lives. The only CLs who did not report family involved in regular instrumental support at home were one CL who had no family members living close by and one who lived in a very supportive retirement home setting. However, both were in frequent contact with children who provided episodic care and emotional support. All CLs had multiple family members (and sometimes multiple generations) involved with providing some type of support. One family member usually had primary responsibility for the CL's informal care and/or organizing their formal supports. Other family members often provided the primary caregivers with respite, help with certain tasks, and support in making decisions. The highest amount of informal care was provided when the CL and CG lived together and the CG believed they could not leave the CL unattended due to concerns for their safety . This was the situation for three CLs at the time of discharge. In all three cases the importance of respite (an opportunity to get away from caregiving duties) was mentioned by the CGs.

Self-Care

In this section I discuss self-care as it applies to both CLs and CGs. I am defining self-care as the care people provide for themselves. I believe this includes providing for a person's own physical needs, but that it applies as well to attending to factors important to self-esteem and emotional well-being. As discussed in this section, self-care also means refraining from doing things that would have negative impacts on a person's physical, mental, or emotional well-being.

All CLs had been dependent on formal services during their recent hospitalization and had all been and remained dependent on the services of formal and informal caregivers to enable them to return home and remain there for as long as possible. A CL's ability and willingness to contribute to self-care was the determining factor in how much ADL and IADL support and supervision CLs required from others regardless of the setting. However, what was understood to be appropriate or safe behavior was not always consistent between formal and informal care providers and CLs. When the self-care performed by CLs was perceived by their CGs to be inadequate (that is, when CLs did things which CGs viewed as risky or failed to do things CGs saw as important to their health or safety), it increased the CG's perception of the CL's need for support and therefore the emotional and/or instrumental demands of their caregiving role. Some CLs expressed negative feelings about pressure CGs put on them to modify their behaviour.

CGs had to care for themselves in order to maintain their own physical and mental health and to be able to continue to care for their loved ones. This need for CGs to care for themselves was accentuated for the CGs who had chronic health conditions. One mentioned cancelling appointments with her own doctor as she could not leave the CL unattended. For CGs, self-care included finding some respite from caregiving. Respite could mean a trip away or simply a short trip to the store, time in the garden, or a meal out with a family member.

Participation in personally valued activities contributes to well-being; however, all participants had been forced to give up or modify some such activities since the recent hospitalization. The ability of participants to take care of themselves and to do the things important to their physical, mental, and emotional health, was influenced by multiple external and internal factors which will be discussed below.

Internal barriers and facilitators to self-care.

Internal barriers and facilitators to self-care are factors located inside the individual such as their physical status, mental abilities, attitudes, and emotional state.

Physical factors impacting self-care. All of the CLs and at least two CGs had heath related physical conditions that limited their self-care or care giving activities. Problems were mentioned with chronic conditions, mobility, balance, endurance, and pain which limited the activities they could undertake. Two CLs had given up engaging in a long enjoyed indoor hobby and three participants had needed to curtail valued gardening activities due to changes in physical function. One mentioned missing being able to shop for herself due to her physical limitations. All CLs were dependent on mobility aids post-discharge. Although all of them had seen improvements in physical function since their recent acute event, none had returned to their pre-hospitalization levels.

Mental, attitudinal, and emotional factors impacting self-care. Barriers to self-care could be mental, attitudinal, or emotional as well as physical. A lack of awareness of or reluctance to admit limitations, cognitive issues, or an unwillingness to change attitudes and long standing behaviours sometimes resulted in CLs acting in ways that other people perceived to be unsafe or contrary to the CL's long run well-being. However, such refusal to admit limits, although posing risks, may also be a form of emotional self-care.

58

Emotional self-care, that is, caring for one's emotional well-being, is a vital part of self-care. Some CLs commented on the importance of maintaining a positive attitude in spite of times when things appeared bleak. The one CL who reported being depressed also reported losing interest in maintaining her home.

When self-motivated to continue to do former occupations, CLs could be creative and persistent although they were not always successful. CLs did eventually have to recognize limits and accept assistance with the necessary tasks of daily living. They also had to give up cherished activities and hobbies, but found other ways to fill their time and occupy their minds. They read, watched TV and DVDs, listened to music, played bingo on the computer, joked with their PSWs, and talked with family members on the phone among other activities.

External barriers and facilitators of CL self-care.

External factors influencing CLs' self-care ability included things such as weather, the accessibility of the physical environment, the availability of appropriate assistive devices or products, and the formal and informal care provided (which were discussed above). Where a CL lived and their financial situation influenced both their need for and the availability of formal and informal support. External factors interacted with each other and with internal self-care factors.

Accessibility and aids. A CL's ability to care for their needs was influenced by environmental accessibility and their use of aids. All CLs were no longer driving and so were dependent on others for transportation including that required for access to medical appointments and shopping areas. All of them were dependent on mobility aids post discharge though several of them had not been before their recent hospitalizations. One CL often refused to use her walker which increased her risk of falls. The need to use a mobility aid hampered the ability of two CLs to sweep their homes. Three CLs could no longer access the upper level of their homes due to

59

their inability to manage stairs. One CL talked of the lack of accessibility in his community and to his church which had an impact on his ability to meet his practical and spiritual needs. One CL's ability to exercise and get around outside her rural home was limited by the rough and steep terrain and lack of smooth walking surfaces that would accommodate her walker.

Place of residence. A change in a person's abilities can result in a decision to change their place of residence to better enable them to maintain some degree of self-care and therefore independence through decreased environmental demands or increased environmental supports in the new location. The four women CLs had all experienced one or more such moves in recent years in many cases accompanied by their husband. Two had moved to apartments close to family support and two had moved to supportive seniors residences.

The three male CLs had not moved recently. All wanted to stay in their homes until death. All had decreased environmental demands by moving their bedrooms onto the ground floor rather than moving to a different home when they could no longer manage stairs. For one CL there was no toilet on the ground floor and his self-care ability was undermined by his dependence on formal help with emptying his commode. However, he felt his home was vital to his emotional wellbeing, and established relationships with neighbors increased his access to informal assistance which helped compensate for his increasing difficulties with self-care.

Financial situation. A CL's financial situation had an impact on their ability to provide for their own care and influenced the formal care options they could access. One CL was able to afford to live in a very supportive retirement home which provided the formal services she required at no cost to her family or the public. In contrast, another CL's inability to pay for prescription medication compliance/blister packaging made him unable to manage his own medications and increased the burden on his CG and risk of a medication related adverse event.

60

Long Term Care (LTC)

Two CLs were on LTC wait lists at the time of their recent hospitalizations. In their cases, accessing the wait list had been precautionary, done as insurance against a possible or probable future increase in their care needs at which time the woman's assisted living facility and the man's spousal caregiver might no longer be able to meet those needs: In one case a LTC bed offer was received and accepted five months post-discharge. The CG would have preferred to wait a few more months but could not risk the consequences of a refusal. In the other case an offer two months post discharge was refused but a new application was planned as insurance against future changes in the health of either the CL or CG. None of the participants had a positive view of LTC; however, one CL did mention that LTC placement some years earlier of her hospitalized husband had been an easy decision as LTC was preferable to hospital care. None of the male CLs were willing to even consider LTC as an option and all stated they would prefer to die than be placed. The women CLs resisted thinking about placement and did not see it as imminent; however, all of them accepted that it might at some point be necessary. The CGs wanted to support the CLs in their desire to remain in their present homes, but recognized the possibility of the CL having increasing care needs, the constraints on their own caregiving abilities, and the limited availability of formal supports. They knew that these could eventually lead to a LTC placement.

Summary

The participants in this study provided accounts of their experiences with a variety of health conditions and care provision situations. Participants had little knowledge of Home First per se but much to say about their experiences with and thoughts about the provision or receipt of care.

Thematic Findings

According to DeSantis and Ugarriza (2000), "Themes make explicit the implicit meaning of dialogue, behavior, and events. . . . Themes are representations of important aspects of, and issues in, the lives of peoples. These aspects and issues should give rise to and prioritize health care interventions" (p. 367). I identified four general themes which appeared to me to be central to the experiences reported by participants and important to consider when evaluating and designing health care provision. The themes were: (a) maintaining independence while responding (or not) to risks, (b) constraints on care provision, (c) communication is key, and (d) relationship matters. Although they are presented as separate themes, they were actually interrelated in the lives of study participants and therefore the study data. Consequently, some of the material presented to illustrate the theme under consideration will also link to additional themes or to the findings discussed by types of care. Much of the material on self-care discussed in a previous section of this chapter could equally well have been discussed under the first theme presented below which relates to independence and risk. (The ability to care for oneself is linked directly to, and is in some ways seen as equivalent to, the ability to live independently. As self-care abilities decrease, the risks of independent living increase.) The sections on barriers to self-care could similarly have been discussed under the theme of constraints on care provision.

Maintaining Independence while Responding (or not) to Risks

In spite of their recent hospitalization and increased mobility impairment following it, all CLs were determined to continue to perform former activities and assert their independence as much as possible. One CG stated:

> I think a lot of people would be fearing losing their independence and don't want to give that up, and I think there's probably a general thing that goes with almost everybody that they are the last person to realize their own limitations.(Sam)

A CL's desire to maintain independence or control over his or her life was at times accompanied by a lack of awareness of or reluctance to admit limitations, cognitive issues, or an unwillingness to change attitudes and long standing behaviours. This could result in CLs acting in ways that were, or at least other people perceived to be, contrary to the CL's own best interests. Melanie has cognitive and mobility issues but values her independence; her daughter commented:

> She went to the garage, and there's a staircase with no railing. And she went up the stairs because she knew there was a heater up there. But, she went up. She did all that when no one was home. So, rather that ask . . . us, we drop by frequently; she did that on [her own], and to me it was quite a bad decision. Nothing happened to her. And that's her answer, I'm fine, so there's no problem. (Debbie)

Frank, who has increasing breathing problems, resisted the advice of his doctors: "He was told like, 'Come on, you gotta quit smoking;" and he said, 'that's the last thing I'll do'" (Donna). Wilma, the wife of a CL with dementia who was unable to provide his own personal care, said: "If it was up to him, he wouldn't have the PSWs coming in at all." She also commented on her own reluctance to admit to limits to her physical ability to care for both the CL and herself. Such refusal to admit limits and accept ones need for assistance, though posing risks, may also be a form of emotional self-care. Debbie commented on Melanie's desire for independence and the risks involved in her reluctance to use her walker as well as on the possibility that effective communication about walkers could change Melanie's relationship with hers:

> She resents the walker. . . . I don't understand that because, to me it's a sign . . . [of] independence. . . . It's the reverse of what she thinks. Without the walker, she's going to fall and then we're back to where we were. . . . If [only] one of the OTs could come in and give her some kind of an idea that it was enabling her to be independent, but she cannot, she has not been able, no matter what we say, look at it that way. . . . I understand how it must be, I can't imagine how it must feel, you know, she no longer drives, she no longer can get her own groceries, she can, she can still make decisions, but she doesn't have much control over anything. (Debbie)

The data from Fred provides many good examples of the independence and risk theme.

Fred told me proudly that he was still actively engaged with his cooking, laundry, and banking.

However, he recognized when the risks of continuing with some activities were unacceptable:

> I wanted to go in the garage the other day . . . [to get] my snips. It's stupid, and I said [to myself], "You can't even get out the front door, how [come] you want to go to the garage?. . . It's not a good thing to do it alone." The doctor told me, "Don't you go anywhere alone!" So that's why I cannot go upstairs. I'm tempted so many times to go upstairs by myself, but I know if I do, and I fall, that's the end of it. So, you gotta be dumb [to do it]. (Fred)

He also commented: "I gave up driving voluntarily. I could have driven longer, but then I did it

on a voluntary basis . . . cause I could have killed somebody." However, he came into conflict

with a CSS case manager over burning candles before a photo of his wife, a ritual for him of

many years duration:

> That really bugged the hell out of me. That candle was there every day. . . . I loved my wife; so, if I want to see her face every day (that's why the candle is there) and think about her, that's my prerogative. . . . They're trying to take that away but I [will] fight like hell. (Fred)

His relationship with his deceased wife, the ritual with the candle, and the CL's feeling of control

over it were all important to him; and he had evaluated and accepted the potential risks involved.

Although some CLs were determined to remain in a home they had occupied for many

years, other CLs had moved within the past few years to housing situations that put fewer

demands on them for maintenance, were more accessible, or offered more options for support; the

move therefore increased their ability to live independently and reduced the risks of doing so.

However, all CLs saw a future move to a LTC facility as a negative option and equated it with

giving up the independence they valued. Fred talked of visiting friends at a LTC facility and

watching residents walk to lunch like "ducks in a row" and he continued:

> I don't want to go, maybe it's the attitude, first of all you lose your personality, in there. You lose your freedom of speech . . . you cannot go where you want, you cannot eat when you want, you gotta get up when they want. (Fred)

In spite of their desire to support CLs in their desires to remain at home, at times the risks involved with maintaining a CL in the community could become too big for CG's to accept or manage. Wilma made the difficult decision to place Harold in LTC: "I've come to the conclusion now that I couldn't manage him at home…if he has these [spells], what am I gonna do, you know? Especially if they're in the middle of the night" (Wilma). However she also commented on the difficulty of decision making when the factors involved with balancing his desire to remain at home with the associated risks and benefits to all involved were hard to determine and impossible for him to comprehend:

> In one way, it would have been easier[3] if he'd gone directly . . . when he was in the hospital, because, he knew he wasn't well then. But, see, then, with the care he was getting, the PSWs in three times a day and the VON coming twice, two and three times a week, he was getting the care here, and he was improving. And, that I think it made us all stop and think and wonder if we were doing the right thing. . . . But then [if he stayed home], he wouldn't have been doing any more than he was before. He wouldn't have been walking. [The CLs mobility improved after admission due to the exercise he got walking to meals]. (Wilma)

Melanie's family members were close to their limits for providing her care. The biggest concern they had was over the risks involved with her failure to consistently take her medications as prescribed. She preferred pills in bottles but had not demonstrated an ability to take them reliably. They decided that unless she was willing and able to consistently take compliance packaged medications, they could not "help her look after herself or look after her where she is" (Debbie).

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[3] Wilma clarified for me that the placement decision would have been easier from hospital, but only if placement could have occurred quickly. A prolonged hospital stay would have been hard on everyone.

Constraints on Care Provision

The need for assistance by CLs, in spite of the desire by all of them to remain as independent as possible, was due to constraints on their ability to provide their own care because of physical or mental impairments: "I couldn't even fix the blinds, because I can't climb" (Fred); "I was doing my own shopping, but it's hard to do it because I can't breathe that good anymore" (Martha); "She's having trouble with her memory . . . she does get confused. . . . Sometimes you can tell that . . . the decisions she's coming to are not maybe the best" (Debbie).

Likewise, regardless of the type of care assistance provided, all formal and informal caregivers also had constraints on their ability to provide care. Participants frequently mentioned the time pressures on PSWs which constrained their ability to provide care and to communicate and build positive relationship with clients. Molly said:

> There's just not enough time for them to communicate beyond what has to be said. I just feel so sorry for them; I don't know how they ever squeeze their traveling in and keep their appointments. . . . So, I'm always aware of that. So, I've never ever tried to delay any of them. (Molly)

Similarly, Donna commented:

> It's crazy, the girls only have one hour to come in here, get him up, get him dressed and washed and everything, in one hour. Make his bed, sweep his floor, whatever she's allowed to do. And then they're running out the door. . . . You know, they say one of the biggest problems, too, is loneliness in people. . . . How much time can you really talk and bath and you know it's just like: get you done, throw you back down, and away I go. It's gotta be more. I think even an hour and a half would be better, if they don't want to give him the two hours, you know . . . cause I mean people move slow. (Donna)

To which, Frank replied: "Shame to see them [PSWs] rush around;" and talked about the totally unrealistic travel times allotted for PSW travel between clients.

Participants were aware of the constraints imposed by the health care system on service availability, and some mentioned that they could not expect more services or hours of care than

they were currently getting. Donna commented that her case manager knew she needed more help, but said, "I know, [but] we just can't give you the hours."

CGs had conflicting demands on their time and energies. Some had health issues of their own. Donna mentioned missing her own medical appointments as she had no one to care for her father while she was away. She also had a pre-teen child whose needs she had to attend to. Other CGs also had caregiving responsibilities for other family members:

> I know we're retired, so theoretically we don't have anything to do; it's just that we do have, you know? There's a, I have a calendar full of things. I, we, have my grandchildren coming next week. . . . We have them for four days." (Debbie)

Personal financial constraints affected the ability of some participants to access services. Donna had to hand fill dosettes as Frank could not afford to have medications blister/compliance packaged. She commented that the cost was not covered and that, "There's not much out there to help. The government wants people to stay home and get better, cause it's, well, cheaper for them then the hospital, but they don't give you the resources just to do it" (Donna). Martha was unable to afford assistance with the house cleaning she was no longer capable of doing to care for herself and her visually impaired husband.

The ability of some family members of CLs to provide care was constrained by the lack of geographical proximity of their residences. Geography also impacted the availability of some formal services such as Meals-on-Wheels and the demands imposed on PSWs for travel between clients.

Communication is Key

Throughout the study there were examples of the importance of good communication or the issues associated with poor communication. Donna mentioned communication frequently. When talking about her father's hospitalizations she commented:

> One thing I will stress … the doctors, if they know a family member is taking care of them [a patient], they should really talk face to face … not through nurses or anything else, and explain to them exactly what's going on, especially if they're gonna be coming home. And I know . . . there are time limits, too, but still if you want to keep them out of the hospital, then you better start communicating with the caregiver a little better. (Donna)

In her and her father's recent experiences, she felt that poor communication between different health care providers (such as between the family doctor and hospital doctors) and between health care providers and Frank and her had resulted at different points in inadequate or inappropriate treatments and in confusion about discharge, medications, his care needs, and service provision. Donna also mentioned that the foreign accent of one hospital doctor made him hard for Frank to understand which was frustrating for him.

A lack of adequate communication in the hospital between patients, caregivers, doctors, and nurses was mentioned by other participants. Melanie and Debbie believed that Melanie had a partly healed fracture reinjured by improper handling during her hospitalization because the need to protect the limb was not properly communicated to care providers. Fred was unnecessarily kept on thickened fluids because his admitting doctor prescribed them and did not follow-up or adequately communicate with him or nurses about how long they should continue with the practice. Dorothy experienced poor communication during two discharges; for the first, she learned of a changed discharge date only after seeing the new date on a hospital white board; before the second, a doctor had expected Mary would have a stay in a rehabilitation setting but changed his opinion when the nurses did not feel it would be useful. However, the change in plans was not communicated to Dorothy who had been told to expect the longer stay and therefore made commitments that would conflict with her caregiving role on Mary's discharge.

In contrast, participants also provided examples of positive communication. Donna reported: "The surgeon was very very good, though, I can't complain about him. He [Frank]

68

really liked him, too. He explained himself very thoroughly. He phoned me, talked to me on the phone for quite some time, wanted to know Dad's history." Several participants mentioned good communication and relationships with case managers; however, even in those cases, there was still a lack of communication about how services were allotted or modified. Debbie mentioned a change in formal health care providers' communicative behavior after they recognized and responded to a change in Melanie's ability to manage her own health care:

> Often now I get phone calls. The pharmacy calls . . . they call me. They call Mom, but they call me. The doctor's office calls me just so that [I know], which is fine. You know, it just means that there's a follow up. It's good, because sometimes she wouldn't tell me and then I wouldn't know. (Debbie)

Debbie was trying to be proactive in addressing Melanie's longer term care needs by facilitating communication between Melanie and her many family caregivers about their concerns and possible solutions to meet everyone's needs. She planned a family discussion about the care related issues when everyone would be present during a holiday gathering. Melanie's inability to remember information that was communicated to her about medications and activities of daily living was putting her at increasing risk of adverse events. For example, she did not recall important medication and heating control information and did not respond to notes her daughter had posted throughout the home reminding her to wear her emergency call pendant and take her medications.

Communication with health care professionals and between family members and CLs regarding planning future care needs and possible LTC placement was mentioned by Wilma and Donna. Wilma had been receiving pressure from her husband's doctor for a couple of years to place her husband on a LTC wait list due to his increasing cognitive impairment. She had also received some advice from professionals on her own options for placement. However, Wilma and her sons still did not have a clear picture of the details of community service provision or the LTC

placement process. Though Harold had clearly communicated his desire to remain at home, he was not considered competent to make that decision and was unable to comprehend the need for placement in spite of efforts to communicate with him about it. Donna mentioned that the CCAC case manager had communicated her willingness to assist with the LTC placement process when appropriate; however, Frank had clearly communicated with Donna his unwillingness to be placed, and Donna respected his decision so no application for LTC was made.

Communication of concerns about care provision on the part of its recipients is important to the delivery of appropriate care. Voicing concerns was compromised for some participants by a lack of understanding of who to communicate with about them: "At the beginning we were getting the agencies mixed up, that's probably not uncommon cause we had different people coming in at different times, and til we got them sorted out, but as far as what we need to do, or who we need to contact, it was not very clear" (Dorothy). Most study participants also appeared to be reluctant to complain or ask for desired changes. Even when talking with me about a problem, they usually included something positive as well. Some of the reluctance was due to their gratitude for the care they received and some to their empathy for their workers and understanding of the constraints on the worker's provision of care. Dorothy commented:

> Well a couple of times, you know, we didn't get notified that somebody wasn't coming, and then, you know, we did it ourselves. But, we also realize that, especially in the winter time, you don't know what somebody else's having to deal with weather wise. So, you know, it's all ok. I mean we were just glad to be getting the assistance so weren't going to complain about anything. (Dorothy)

When I asked Melanie if she had contacted her case manager about a concern, she replied, "I think it [would] be nice if contact was ordered rather than me have to ask for it. I'm not very good at asking." Debbie mentioned during different contacts with me that she was concerned about the inability of PSWs to monitor Melanie's medication compliance and Life Line pendant use. She

was also concerned about the irregularity of the timing of visits. However, she had not communicated her concerns with either the case managers or PSWs involved with Melanie's care. Martha mentioned a nurse who had been rude and disrespectful; however, she said she did not complain to anyone about it as she never saw her again and did not want to get her into trouble.

Some participants had complained about or requested changes in care provision. Wilma had to request a change in PSWs when Harold refused to have a PSW back after a negative interaction. Fred, Donna, and Frank mentioned having voiced concerns about care to case managers or other health care professionals with mixed results. Donna and Frank explicitly chose to participate in this study in order to voice concerns about the health care system and potentially contribute to positive change in it.

Relationship Matters

There were examples throughout the study of the impact of interpersonal relationships on caregiving and quality of life. As caregiving is itself a type of relationship and is influenced by other aspects of the relationship between the care giver and receiver, it is to some extent a subtext to many of the findings in this thesis.

The long standing relationships made possible by continuity of care were seen as important to participants. Established relationships can improve communication and decrease the impact of time constraints on care provision. Several participants commented on the advantages of established relationships with doctors. Debbie mentioned a situation in which an established relationship with a doctor contributed to access to a prescription without the need for an appointment; and for Fred, a quick alteration in a care plan while in hospital was made possible when he caught the attention of a doctor he knew. Donna said, "It's so much easier to have your own doctor because she knows your history." However, she also said, "We were told to change

71

doctors . . . and I talked to him [Frank] and he said well maybe I should because she is never around . . . and we were going to change . . . but then, he had her for so long, and then he started feeling guilty about it." This illustrates that there can also be negative impacts from the long term nature of a relationship that is no longer beneficial.

When PSWs work with clients for long periods of time as they often do, strong relationships can develop. Participants mentioned the importance of these relationships. Fred said, "Now, the bond between those people [his PSWs] and myself is unbreakable cause they're so good." The type of relationships that developed depended not just on continuity of provider, but also on who the worker was and how the job was done. Martha commented,

> Well there's one PSW that I really like. And she does what I really want her to do the way I want it done. And some of them don't seem to really care that much. They come do the job, that's it…. I mean, they're friendly enough, but there's always one you want to pick out…. Same as when I was in the hospital [there] was always a favorite nurse ….They seem to be a little bit friendlier, little bit more caring. (Martha)

For most of the CLs in the study family members provided much of their care. Although the long standing relationship between them was often an asset, it could at times complicate or be a constraint on the caregiving role when that role required a changed way of relating. Debbie commented:

> It's just it's more difficult. If it was, if I was looking after Anna, it would be easier, because she's my daughter. . . . I always told her what to do. . . . [My sister] gets frustrated and then she'll say, "Well, just tell Mom she has to do it." And I said, "It's alright to say that, but," I said, "when you're actually trying to do it, it's not that [easy]."

For Molly and her children, who all lived nearby and had maintained strong ties with her, there had been less need to change their relationship to one centered around care provision because she had chosen and could afford to live in a supportive retirement home. She commented, "I just get gentle little drops," rather than pressure from them to "steer" her in response to any concerns they might have. They continued to enjoy social time together and talked with each other daily.

Participants varied in their desire to have opportunities to socialize with others and the types of interactions they valued. Dorothy missed the socializing she had done during the many volunteer activities she had given up in order to care for her mother. Fred clearly enjoyed visiting with his PSWs: "We always have a half an hour chat." After describing a positive interaction with a man and his children who came to his door soliciting for a charity, Fred said, "[It] was nice. Those are the good things in life, the good days." In contrast, although Frank appreciated the positive relationship he had established with his PSWs, he stated that he was a loner and had no interest in simply socializing. Mary, who had moved in with her daughter on discharge, rejected having formal visits from a CSS worker, but valued being able to interact with her grown grandchildren when they came home to visit their parents.

Other types of relationships in addition to interpersonal ones also mattered. A person's relationship or attitude to their situation and self was important to their mental state and therefore quality of life and ability to care for their emotional and physical needs. The continuity of their relationships with former occupations such as hobbies or cooking for themselves was important for participants in maintaining a sense of self. For example it was important for Mary to continue to be able to read, Marjorie to garden, Frank to get out and mow his lawn, and Fred to cook for himself and listen to familiar music.

CLs' relationships with their homes could have an impact on their quality of life and be an asset or constraint on care provision. In spite of accessibility issues with his home, Fred was determined to remain in the home he had shared with his wife and children and renovated himself many years before. He considered it vital to his emotional wellbeing and commented, "There's so much in here that brings back memories. Every little nail, you know? All the things you always remember." The fact that Fred had lived in the same home for half a century and had a long

standing relationship with some neighbours likely facilitated their supportive roles which complemented the many formal supports that enabled him to continue to live there. Like Fred, Martha and her husband were struggling to maintain their independence in their present location in the face of increasing impairments. During my early contacts with her, she repeatedly mentioned her concerns about housekeeping and a desire for assistance with it. Unlike Fred, they did not have a long established relationship with their home as they had lived in their present apartment for only three years. Although Martha admitted that it had practical advantages over her former residence, she did not feel at home now. She explained, "I've always lived in a house. This is an apartment." She had not developed a positive relationship with the apartment or with any of her neighbours in the building which may have contributed to the depression which she was experiencing during my later contacts with her and which was having a negative impact on her interest in maintaining her home. Martha said: "I gotta get motivated and do something. I don't care right [now] if I don't do any house work. I got no motivation for that." This was a change from two months earlier when she had said, "I do a little bit each day myself to keep it tidied up. Try to do the floors one day and dust next day . . . I have to push my walker around, too, but it works out."

The experiences of two participants illustrate how establishing a relationship with a supportive living facility in advance of a need for that type of living situation may be advantageous. Molly spent time visiting her husband in a convalescent care room in a retirement home and was so favorably impressed by the facility that she told her family she would move there when the time came. She initiated the move a couple of years later and became an active participant in life at the retirement home. Melanie spent a week in a retirement home respite bed while her family caregivers were on a holiday. Though a move was not yet imminent, because she

had enjoyed her stay there, both she and her family were more comfortable discussing retirement homes as an option and were able to communicate more easily about future care needs.

Summary

The participants in this study represented a range of demographic variables and provided accounts of their experiences with a variety of health conditions and care provision situations. As the explicit goal of the study was to access the perspectives of CLs and CGs to gain insight into the Home First approach and care provision, the findings presented in this chapter are largely descriptive. Participants had little knowledge of Home First per se but much to say about their experiences with the provision or receipt of care. In this chapter, their experiences are first reported by in relation to Home First and then by location, type of care, or participant role. Four general themes crossing all of these categories and important to any discussion of the provision of care were discussed in the final sections of the chapter. General themes were: (a) maintaining independence while responding (or not) to risks, (b) constraints on care provision, (c) communication is key, and (d) relationship matters.

Chapter 5

Discussion and Concluding Sections

In this chapter I discuss the study findings in relation to relevant literature and the principles and goals of Home First. I first explore the Home First approach as it relates to hospital discharge and LTC placement followed by a section relating the approach to health care funding, and system change. The discussion continues structured around the four themes identified in the findings. Sections on the strengths and limitations of the present study and suggestions for future research follow. The chapter finishes with a brief summary of the thesis and concluding remarks.

Discussion

Home First, Hospital Discharge, and LTC Placement

From the point of view of the Home First clients who participated in this study, and to the extent that the approach in fact expedited their discharge to home rather than to LTC, Home First is a positive approach. The choice Home First offered CLs to return home in spite of potential risks in doing so was seen as positive by all of the CLs as they wanted to go home and felt ready to be discharged. Even though patients who say they are ready to go home may not actually be as ready as they claim to be (Coffey & McCarthy, 2012), for all of the CLs participating in this study, they at least did not need to be readmitted to hospital soon after discharge. Only one CL voiced any complaints about the discharge which is similar to the general satisfaction of patients with discharge found by Huby et al. (2004). Although all CGs were supportive of an eventual return home from hospital by their family member, they generally had more concerns than did CLs about their own or the CL's readiness for the discharge, the risks involved, and the discharge process itself (Grimmer, Moss, & Gill, 2000). Such concerns on the part of family caregivers may

76

account for the finding in SECCAC data that the most common barrier to a Home First discharge was family refusal of it (SECCAC, 2011). Similar to findings in the literature (Foust et al., 2012; Grimmer et al. 2004 a), none of the CGs had much input into discharge options, and in most cases there was little advance notice of discharge timing. Some CGs felt that little concern was shown during the discharge process for either their needs or those of the CLs. These findings clearly differ from the "partnering" with caregivers and clients and "person-centred" philosophy claimed to be central to Home First (LINC Collaborative, 2011; SECCAC).

As is a goal of the Home First approach, the combination of informal and formal supports available immediately post discharge did allow all of the CLs to make a successful transition back to homes in the community to stay or wait for LTC placement. Although the demands for care placed on informal CGs did go up post discharge, all CGs expressed more concerns about the constraints on their ability to provide the needed care than any unwillingness to attempt to provide it. This demonstrates the willingness of at least some family caregivers to engage as care partners with health care professionals and in that respect supports the Home First approach. What is less clear is how much the health care system and health care professionals are ready to partner with family caregivers as equal partners in care and how much they are viewed largely as resources to be exploited when dealing with economic and other system constraints (Lévesque et al., 2010, Ward-Griffin & McKeever, 2000).

As is usual for older people, all CLs valued their independence and had negative views of LTC (Aronson, 2006; Cheek et al., 2006; Ryan, McCann, & McKenna, 2009). Although none of the CLs had positive views of LTC placement, women were willing to admit that it might someday be required while men were adamant they would never go. How many CLs actually would have been discharged to LTC from hospital prior to the initiation of Home First is not

77

known; however, for those that would have been, the approach has clearly made a positive contribution to their lives by preventing or at least delaying LTC placement.

In the one case in which a CL did enter LTC five months post-discharge, the primary CG said that the wait at home was preferable to a long wait in hospital but a placement at the time of discharge from hospital might have been easier for both the CL and family. She would actually have liked to delay placement for a few months once an offer came but could not risk refusing the bed[4]. As a goal of Home First is to delay LTC admission for as long as possible, a mechanism for allowing people to postpone placement following a bed offer such as is currently available in Nova Scotia[5] might improve the approach. Another participant mentioned that the placement of a family member into LTC from hospital some years earlier had not been a difficult decision as LTC was preferable to hospital care. These two cases contrast with literature which comments on the difficulties of placement from hospital especially when there has been no preplanning for such a transition (Nolan et al., 1996; Ryan & Scullion, 2000). The examples suggest that the Home First assertion that decisions about placement are better made from home is not supported in some patient situations.

Participants, especially CLs, were reluctant to preplan for or even think about potential LTC placement. This is not unusual (Change Foundation, 2009; Duboise et al., 2009). In the five cases represented in this study in which the CL was not already on a LTC list, only one family had clearly initiated the process of planning for longer term care needs following the hospital

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[4] In Ontario a refusal would result in a removal from the wait list and a need to wait six months before reapplying to start again at the bottom of their priority level list unless there was a significant change in their need for admission.

[5] In Nova Scotia a person waiting in the community for placement has a one-time option to, when they receive a placement offer, defer it for up to 90 days and re-enter the wait list at any time during the 90 days with their original/former access date used in determining current level (Nova Scotia Department of Health and Wellness Continuing Care Branch, 2011).

discharge. Even that discussion was motivated not by the hospitalization but by new concerns. The reluctance to engage in preplanning for LTC raises questions as to how often the planning for LTC placement that the Home First philosophy postulates should best be done from home in consultation with the family will actually occur post-discharge. Discussions about the future may be easy to delay when there is a feeling the crisis has passed and families are anxious for life to get back to normal (Cain et al., 2012). Ways to encourage consultation about future care needs and to facilitate discussion at earlier stages in the care trajectory need to be developed and implemented (Change Foundation). Older people may be more open to suggestions for meeting changing care needs which come from health care professionals than from family members (Change Foundation). Research has also shown that placement recommendation by health care professionals or others can relieve some of the negative feelings of older people and their caregivers which are associated with placement by justifying a placement decision (Caron et al., 2006, Cheek et al., 2006, Nolan et al.1996; Ryan & Scullion, 2000). Rather than encouraging preplanning, the emphasis which the Home First approach and the health care system place on aging at home could actually make placement discussions and decisions even more difficult for older people and their informal caregivers than they already are by increasing the sense of failure and guilt often associated with LTC placement (Nay, 1995; Nolan et al.).

Home First, Health Care Funding, and System Change

Issues of health care funding and system change have relevance to the evaluation and implementation of the Home First approach. According to Gitlin and Wolff (2011), hospitals, physicians, and other health care professionals will be unlikely to make the paradigm shift that is needed to include families and clients as true partners in care and meet their care related needs unless health care funding is changed to provide the resources and create financial incentives for

formal care providers to make the changes required to do so. Findings in this study support the need for change in some cases in the relationship between clients and families and health care providers and in the services available to them.

Two CLs expressed concerns over a lack of ongoing formal IADL support. These CLs like many Home First clients were post-acute CCAC clients and are also, or will likely become, long stay CCAC clients. There are concerns that funneling home care funds into post-acute care programs such as Home First, even if they appear to address their intended goals, may actually have negative system effects in the longer term (Hollander et al., 2009). This would be due to the consequent reduction in the funding that addresses the support needs of home care clients with long term care needs who may then enter the acute and LTC system as a result of service cutbacks and resource shortages (Hollander). The Central East CCAC report comment that "the success of Home First has meant a significant impact on our budget . . . measures will be required [to balance it]" (CCAC, 2012 b, p. 4) may exemplify the impetus for such a reallocation of funds.

CLs ability to contribute financially to their care ranged from being able to afford private care in a high quality retirement home to not being able to afford a few hours of house cleaning or compliance packaging for their medications which they would have had to pay for privately. All had received government funded services for the provision of personal care assistance, but not all of them were at risk of adverse events due to a lack of public funding for that or other needed services. This may indicate the need for systemic funding changes to improve the accessibility and equitability of supports for health related care. One such change is included in the Sinha (2013) report which recommends that the Ontario government consider changing home care to allow for the inclusion of some means testing of clients in determining the allocation of services.

The Sinha (2013) report also recommended changing the role of CSS agencies to include the provision of personal as well as home support services. Study participants were at times confused by the provision of services by both the CCAC and CSS agencies. Managing and adjusting to a number of providers from different agencies was sometimes challenging. If changing the scope of CSS service provision were to increase continuity of care and service integration it could be of benefit both to clients and to the PSWs that, according to participants, are presently finding it hard to find consistent work, sufficient hours of employment, and manage travel between clients (similar to the situation in New Zealand, see King, Parsons, & Robinson, 2012). Sinha included a recommendation to promote volunteerism by older adults. CSS agencies are experienced in recruiting and managing volunteers. If they are given an even wider role in supporting older people in the community, they might be able to find ways to include and support volunteer roles for people such as the CG that had given up extensive volunteer activities with seniors and was missing the social interactions such activities offered.

The findings from this study include examples of situations in which participant needs were not met or the needs of the health care system appeared to be paramount (such as the feeling by some CGs that hospitals just wanted to "get rid of" CLs). Ceci and Purkis (2013) document a shift in Canadian health care funding and planning from an emphasis on meeting individual human needs to meeting those of the health care system. They suggest this shift was justified on financial grounds and its success measured by industrial standards of efficiency and evaluated based on quantitative outcome data. Some people challenge this trend and advocate for a system based on human needs, rights, and a concern for others which will have to be evaluated by more qualitative means (Ceci & Purkis). The Home First approach was developed in response to system level concerns about ALC numbers; however, it professes to be a person-centred approach

81

(LHIN Collaborative, 2011 p. 4). How well it can address both human and system needs requires assessment both by the quantitative outcome measures being collected by agencies providing services and more qualitative studies such as this one.

Maintaining Independence While Responding (or not) to Risks

Maintaining as much independence as possible is a common desire of older people (Cheek et al., 2006; Tanner, 2010) as it was for all CLs. "Independence" is relative, with the definition applied by older people to their situations often changing to include options for assistance from others or a reduction in their engagement in former activities as their health and functional abilities decrease (Tanner). Maintaining some degree of client independence/self-care ability is critical to the Home First approach as it enables clients to return home and stay there. The approach explicitly recognizes the risks involved for clients in living at home but also that their quality of life may be higher there than in an institutional setting (LHIN Collaborative, 2011, p. 9). However, the approach also explicitly excludes from eligibility for the program those patients with cognitive or behavioural issues that would make a discharge home unsafe (SECCAC, 2011). Cognitive impairment is a major threat to independence (Williams, Challis, et al., 2009) and it was a factor in the placement of the one CL who entered LTC. It was also seen as potentially jeopardizing the ability of another family to continue to manage a CL at home unless she agreed to comply with interventions to increase her safety there.

Programs Supporting Independence and Reducing Risk.

Study findings that some CGs felt clients were not ready for discharge suggest that some participants would probably have benefited from options for further rehabilitation before discharge to the community. One approach to reducing ALC days, premature LTC placement, and the risks and burdens of early discharge is providing options for patients to regain or improve

their self-care ability before returning home through stays in convalescent and transitional care

beds in LTC facilities or retirement homes. Patients may be more willing to agree to a short term

placement for convalescence than they would to one they view as permanent (Nolan et al., 1996).

Short stay accommodation to provide for respite care may also reduce the risk of crisis hospital or

LTC placements due to caregiver burnout. An increase in all of these types of short stay beds is

included in recent recommendations for health system change in Canada and Ontario (Sinha,

2013; Sutherland, 2011; Walker, 2011). Such beds may have the added benefit of providing an

opportunity to encourage preplanning for longer term care and housing needs and stimulate

discussion between older people and their family members. This was the case for two study

participants who had positive experiences with short stay beds in retirement homes.

Although most study CLs had some improvement in their condition after they returned

home, none had achieved their pre-hospitalization functional or mobility levels, and for some

there were ongoing concerns about the loss of self-care ability and mobility. A continued decline

in function could result in increased care needs and pressure on the formal and informal support

systems or LTC placement[6]. Restorative care approaches to the provision of home care have

shown success in improving the self-care abilities of program recipients and also the job

satisfaction of the formal care providers delivering the programs (King et al., 2012; Rabiee &

Glendinning, 2011). According to Rabiee and Glendinning the approach is most beneficial for

those recovering from falls (as were four of my study participants) and requires a desire on the

part of service users to improve their independence (a desire most CLs expressed). A restorative

care or other rehabilitative approach to home care provision might improve client function,

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[6] Ironically, one CL's mobility declined at home and actually improved after LTC placement due to the enforced exercise when going to the dining area from his room.

reduce learned dependency in the post-discharge period, increase the ability of clients to engage in personally meaningful activities, and contribute to the Home First goal of supporting independent community living.

Being able to direct one's own care or having an appropriate informal caregiver willing and able to do so are eligibility criteria for a Home First discharge in the study area (SELHIN, 2011) and are necessary for maintaining any degree of independence once an older person is no longer able to provide their own care. Six of the seven CLs had family members providing significant assistance with care management and IADL support. Without any of this assistance, two CLs would have clearly required LTC placement, and it is unclear how many of the others would have been able to return to the community without more extensive supports than are presently available through Home First in the study area. An innovative program has been initiated in the Wellington Waterloo LHIN to address situations in which informal care is inadequate or lacking for at risk older people referred by hospital emergency departments and discharged home. Intensive Geriatric Social Workers (IGSWs) are assigned to appropriate older clients lacking adequate informal help post-discharge. IGSWs interact closely with clients until the client's immediate health situation has stabilized, appropriate formal care is in place, and any required changes in living situation/location have occurred. They do the types of things a family member would often assist with such as accompany clients to medical appointments and touring retirement homes with them. They have proven successful in reducing LTC placements (Heckman, McKinnon-Wilson, Hillier, & Manderson, 2011; Weidner, 2010).

Constraints on Care Provision

The efforts of all care providers are constrained by factors over which they have little control. The older person's ability to provide their own care is constrained by many factors such as

physical and cognitive impairments and lack of financial resources. Case managers have

constraints on their ability to provide appropriate supports to their clients related to health care

system and agency policies, funding levels, and the availability of appropriate human resources.

Study participants were aware of and spoke about some of those constraints. Participants in this

study reported that their PSWs were constrained in their work both by what care they are allowed

or mandated to perform as well as by the time allotted for care and travel (Sims-Gould & Martin-

Matthews, 2010a, b). The Home First approach itself is constrained by its dependence on the

active participation and support of health care professionals in hospital and community settings as

well as on the willingness of informal caregivers to support the discharge and provide care in the

community. The study findings show that some informal caregivers are willing partners in the

provision of home care but that they also have constraints on their ability to provide it (Sims-

Gould & Martin-Matthews, 2010b). For many CLs, the efforts of multiple family members

involved with their care were at times compensating for each other's constraints on their ability to

contribute to it.

Case management: Managing constraints on care.

CCAC case managers are the gatekeepers for government-funded personal care and home

support in Ontario. Here, as in other parts of Canada, a shortage of time and resources constrains

the ability of case managers coordinating such care to develop relationships with clients and

understand their needs, monitor changes in their situations, or offer the optimal level and type of

services (Diem, Alcock, Gallagher, Angus, & Medves, 2001; Randall, 2007). Skilled case

management is vital to the success of the Home First approach through ensuring barriers to

discharge are recognized and addressed and needed supports are in place to reduce the potential

risks inherent in the discharge home of elderly patients. Study participants were grateful for the

85

formal assistance they had received and some described positive relationships with case managers. Ideally case managers are able to juggle the constraints on care provision (present from the level of the health care system to that of client self-care) and somehow provide the supports required for maintaining independence and reducing the risks of living at home for their clients. However, a need for improvements in case management is suggested by reports from participants in this study of a lack of input into and information about discharge, confusion about who to contact about concerns with services post-discharge, misunderstandings or conflict with case managers, and concerns about or lack of services or information regarding them. A constraint on the provision of optimal or integrated case management for study participants may have been that they had to deal with a hospital and a community CCAC case manager as well as case managers from all agencies actually providing care in the community.

The formal services CLs received were not consistent across CLs and some participants expressed confusion or frustration over how or what services were allotted. Peckham (2009) found that most Ontario CCAC case managers considered both the client and their primary family caregiver as a unit of care and adjusted services accordingly. However, she found that there was no uniform way to assess such units of care and that how care was allotted varied between case managers in terms of how care provision changed due to the presence or absence and needs and resources of family caregivers. Case managers need to constantly adjust services provided due to changing system mandates and local service demands (Peckham). The idiosyncratic and ever changing nature of formal service provision through the CCAC increases the importance of positive relationships and good communication between case managers and clients and their informal caregivers.

CLs and CGs in this study reported some unmet care needs. Diem et al. (2001) stated that cognitively challenged and/or frail elderly clients (such as all clients in my study population) were the most difficult to support and that there was often a mismatch between what could be provided and their needs. Recently introduced higher service maximums (Government of Ontario, 2008) in Ontario have reduced constraints on allotting care and enabled CCAC case managers to provide the level of services required to support an approach such as Home First. However, some participants in this study still expressed concerns about the time allotted for care, type of services provided, and communication about service provision and availability. Only very limited contact with case managers was reported by most study participants, and for some their case managers did not appear to clearly understand their situation/needs. The constraints on the time available for CCAC case managers to devote to high needs clients such as those designated Home First, may lessen as CCACs move to a new Client Care Model. In the new model, each case manager will handle cases from only one of five client classes differing in the intensity of navigation and support needs which will be reflected in the size of the case manager's case load (CCAC, 2012a). Hopefully a smaller case load for complex clients such as many Home First clients will allow time for the good communication and the development of the positive relationships between CCAC case managers and clients and informal caregivers that this study has found to be important and sometimes lacking.

IADL supports: Compensating for constraints on self-care.

As was evident in the reports of some study participants, the ability or inability to engage in familiar IADL, leisure, or social activities around their homes and communities had implications for their emotional well-being and quality of life (Aronson, 2002; Lum, Williams, Sladek, & Ying, 2010; Tanner , 2010). The inability of older people to perform IADL tasks

87

decreases their ability to care for themselves and is increasingly being recognized as triggering the need for assistance from others and increasing their risk of adverse events, hospitalization, or LTC placement if adequate IADL support is not provided (Chen & Thompson, 2010; Heckman et al., 2011; Hollander et al., 2009; Markle-Reid et al., 2008; Williams, Challis, et al., 2009). An increasing focus on post-acute care and current fiscal constraints have affected the availability of publicly funded IADL and social supports in spite of their recognized value (Hollander et al.). The CCAC now provides only very limited IADL support to its clients. The Home First approach as operationalized in the SELHIN recognizes the importance of such supports through the offer to Home First clients of 30 days of IADL services provided by local CSS agencies post-discharge with the normal user fees waived for the client; however, only 69% of Home First clients served by the SECCAC were referred for CSS services and only 64% of those offered services took advantage of them (SECCAC, 2011). Themessl-Huber et al. (2007) suggests that formal community services may be refused because they are inflexible and do not correspond to client needs. CSS provision of scheduled visitors was declined by some CLs as not of interest to them but was highly valued by another CL. For the four CLs who utilized few if any Home First funded CSS services, the services were already provided from other formal or informal sources or were for other reasons of no interest to them. Financial considerations constrained the continued use of CSS services for the three CLs who did utilize significant amounts of the funded services and who would have benefited from longer term access to funding for them. The lack of uptake of CSS services by Home First clients does not mean that the formal provision of IADL services is not important to or needed by many clients but that there may have been a lack of congruence between the needs and preferences of the clients offered the services and what was actually offered to them.

Study participants mentioned situations in which IADL supports of importance to them such as house cleaning or shopping for certain items were not permitted by either a private agency or the CCAC in spite of fitting within the allotted hours of care. In response to such situations, home care case managers or workers sometimes partner with clients to "bend the rules" to accommodate client desires for IADL assistance and work around system or agency constraints (Aronson, 2002; Aronson & Sinding, 2000; Goar, 2012; Sims-Gould & Martin-Matthews, 2010a). A new program called "Changing the Conversation" has been put in place in the Toronto Central CCAC that makes accommodating client wishes "the rule" for PSWs who are now required to ask clients what they would like done for them during the allotted time. The approach removes the former constraints on their flexibility to provide more varied IADL assistance if it is requested (CCAC, 2012 c; Goar, 2012).

The effectiveness of Home First in maintaining clients in the community long term is dependent on ensuring ongoing and flexible formal IADL support for those in need of and desiring it[7]. To accomplish this, some Home First clients are referred (although actual access is limited due to a current wait list) to a program initiated in the study area in 2008 known as SMILE (Seniors Managing Independent Living Easily). Ongoing access to the SMILE program pre- and post-discharge enabled one of the study participants to live at home in the absence of local family support. After extensive community engagement in the planning process, SMILE was developed to flexibly meet the IADL needs of the frail elderly. The program was modeled in part after the Veterans Independence Program (VIP) which provides self-directed funding for

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[7] In the US long standing successful IADL support programs are New York State's Nursing Home Without Walls (NHWW) program and Ohio's Pre-Admission Screening System for Providing Options and Resources Today (PASSPORT) program (Miller, 1991; New Your State Government, 2013; Ohio Department of Aging, 2011). Quebec has developed the Program of Research to Integrate Services for the Maintenance of Autonomy (PRISMA) approach (Hébert et al., 2010, Williams, Deber, et al., 2009).

eligible veterans to purchase IADL services. SMILE provides a budget to clients after assessing their needs and allows them to choose their desired services and service providers; it includes a self-directed care option (SECCAC, 2008). Reducing the wait list for the SMILE program through securing additional funding for it (or perhaps through a change in eligibility to include a means test) might enable more low-income Home First clients to live successfully in the community.

Communication is Key

The importance of, and frequent lack of, good communication and access to appropriate information across the spectrum of care settings and trajectory of care experience was apparent in study findings. Study participants provided examples of both good and bad communication between various health care providers, between themselves and health or home care providers, and between family members. Although it does not remove the need for someone to insure further or more appropriate access to information, it is possible in some of the cases in which participants mentioned that important information had not been provided to them, that it had been provided but they had not retained it (Cain et al., 2012; Diem et al., 2001). Cognitive issues impacted the ability of some CLs to retain or respond appropriately to information communicated to them.

Communicating concerns about care.

One of the things that stood out for me in the participant accounts was a reluctance to complain about poor or inadequate care (Aronson, 2004b, 2006; LeClerc et al., 2002). Even in cases where participants responded to my probes with concerns about the care they had received, and in which a request for changes to the services provided appeared to me to be justified and potentially productive, there were few examples of participants voicing complaints to health care providers or advocating for change. Tanner (2010) suggests that the tendency of some older

90

people to try to be positive about their situations and not bother others may make them unwilling

to advocate for themselves and may therefore increase their risk of receiving inadequate care

especially in a resource scarce system. The good communication which study results and the

literature reviewed showed to be key to good care is not possible when clients and informal

caregivers are unwilling to talk honestly about their needs and concerns with each other and with

formal service providers.

In spite of participant reluctance to express their concerns about care provision to their

health care providers, they were willing to share at least some of them with me. Byrne, Sims-

Gould, Frazee, and Martin-Matthews (2011) mention the difficulty of evaluating health care

services and the high levels of satisfaction often found in surveys. Using qualitative data from

interviews with older home care recipients and their family caregivers, they found that although

almost three-quarters of respondents reported a general satisfaction with their care, over one-third

of them qualified their response with a negative aspect or an "it depends." The issues in service

provision that they were able to identify using qualitative methods were similar to those found in

this study, were important to consider in the evaluation of services, and might have been missed

in most surveys. For program evaluation they recommend the use of open-ended questions and

qualitative methods such as those used in this study.

Relationship Matters

As was the case with communication, the quality of relationships between and among

formal health care providers, clients, and informal caregivers has impacts across the spectrum of

care settings and trajectory of care experience. The Home First approach depends on the

existence of supportive relationships between health care professionals, informal caregivers and

discharged patients. However, CGs clearly did not feel that they had been partners in discharge

decisions and planning but had just "been told" what was going to happen. This is contrary to the partnership relationship postulated to be part of the approach (LHIN Collaborative, 2011). Some CGs did report positive relationships with case managers although some also reported confusion over who to contact about services and a reluctance to complain to case managers when there were concerns about services. The study findings suggest that by different case managers or at different times, CGs were viewed as either partners in, or resources for, care provision (Levesque et al., 2010) or as part of a unit requiring the provision of care (Peckham, 2009).

Participants reported both positive and problematic relationships with physicians both in hospital and community settings and in one case both types of relationship with the same physician. They also provided examples that showed impacts on the quality of care and health outcomes that linked directly to the quality of those relationships.

The most important relationships for CLs and those that had the most impact on their quality of life and ability to remain at home were generally those with PSWs or other home support workers and with their family caregivers. When writing about the care provided by PSWs, Aronson (2004b, p. 95) stated: "The inseparability of practical assistance from its personal and social context is a forcible reminder that the relational context of care is critical to its quality." All CLs mentioned PSWs or other home support workers with whom they had positive relationships. For many CLs the social interactions were an important or even the most important component of the care provided and strong friendships developed between workers and CLs (Gill, White, & Cameron, 2011; Ryan et al., 2009; Sims-Gould & Martin-Matthews, 2010a, b; Tanner, 2010). Although strong relationships developed between participants and workers over time, there could be initial concerns about having "strangers" in their homes (Ryan et al., 2009; Wiles, 2003). Participants expressed concerns about the challenging conditions under which PSWs

worked (Wiles, 2003). CGs at times worked as co-workers or partners with PSWs but also monitored the quality of the care provided by them (Sims-Gould & Martin-Matthews, 2010b). CLs could be more willing to accept assistance from PSWs than from family members.

The relationships between CGs and CLs were sometimes complicated. They often had differing views of situations in which needs for safety and independence had to be balanced. The caregiving role required a sometimes difficult modification of former parent-child roles (Abel, 1990). CLs were often concerned about being a burden on their children (Cahill, Lewis, Barg, & Hillary, 2009). Family caregiving extended across multiple generations and included people related by both blood and by marriage.

For one CL perhaps his strongest relationship was with his home and the artifacts and memories it contained (Clough, Leamy, Miller, & Bright, 2004; Tanner, 2010). The happiness that his return home gave him is evidence of a successful outcome of the Home First approach that would not have been captured in the quantitative outcome measures routinely kept on it.

Strengths and Limitations of the Study

During planning for this study there were concerns voiced by some health care providers that participation in the study might be biased towards people upset with their care and therefore more willing to participate. As only one CL/CG dyad actually "vented" to me about health care issues, these concerns were unfounded. In fact, I believe the sample is likely biased in the opposite direction; I suspect that people for whom the approach had not "worked" were either too ill or stressed to participate[8]; were not approached to participate as they were again in hospital, had been admitted to LTC, or had to move to an unknown location; or were reluctant to

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[8] Grimmer et al. (2000) found that the non-responders to his discharge survey were significantly older and had been in hospital longer than responders.

93

participate due to a lack of understanding of my independence from the CCAC (who had initiated

the contact with them) or other health care providers about which they had complaints[9]. If the

sample is biased in a positive direction, it makes the study findings of some shortcomings in the

Home First approach and the provision of formal care more likely to be not unique to study

participants and even more important to address.

The total number of participants was small but provided rich data and was adequate for a

short descriptive study. There was no opportunity to do purposeful sampling as is often

recommended for qualitative studies. However, the sample was quite varied and represents many

of the variables for which I would have selected if I had been able to do so. It does lack ethnic or

cultural variety, male primary care givers, participants at both extremes of the personal wealth

spectrum, or CLs who had an early hospital readmission. I was not able to include as participants

any CGs for some CLs or all of the CGs for any of the CLs. Likewise, two of the CLs had little or

no direct participation in the study and data on their direct experience are lacking. However,

having both CG and CL perspectives represented in some cases is a strength of the study and

allowed for some triangulation of findings between their accounts. I was unable to confirm many

of the factual details of participant narratives including those related to the provision of formal

services such as the amounts, types, and timing of the care provided. In some cases the members

of a care dyad reported some events differently from each other. However, it was the subjective

experience, not objective details of participant experience, that was the focus of the study.

As the interviews were two and a half to four and a half months post-discharge, some

details surrounding it may have been forgotten or confused by participants, or their attitudes

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[9] The one person I was able to talk with who refused to participate did so because of concerns on her caregiver's part about any involvement with "my agency" that they had had trouble with.

towards the discharge may have been affected by events occurring post-discharge. However, it is a strength of the study that I engaged with participants on multiple occasions which allowed me to question them about previous data and them to volunteer new information. I was able to follow them for up to nine and a half months post-discharge and learn more about the long term impact of the discharge and how care needs and thinking about LTC placement changed over time.

This study is based on the experiences of participants in one area of Ontario at one point in time. The Home First approach is operationalized differently in each LHIN and each LHIN is at a different stage in its implementation of the approach. The approach involves a culture change, and such change takes time. Therefore, the findings of the study might have been different if the study had been done at a different point in time or location.

I am a novice researcher and completed this study with minimal support or feedback from more experienced researchers whose additional input might have resulted in somewhat different or richer study findings and analysis. My experiences as a PSW and student occupational therapist have influenced my interactions with the study participants, the information they shared with me, and the perspective from which I viewed that information. However, I believe the influence of my background was positive by increasing participants' comfort in their interactions with me and my insight into the questions relevant to the study. Although a different primary researcher or research conditions or participants would have produced a study different in some respects, that possibility is inherent in all qualitative research. Ultimately, the data collected were rich and descriptions of the thoughts and experiences of the participants with the Home First approach, care transitions, and the provision of care were obtained which can contribute to insight into these topics. The study findings appear to be congruent with those of the existing literature and will contribute to it.

95

Suggestions for Future Research

Questions that future research on the Home First approach could seek to answer include: (a) What are the consequences of the approach for the funding of other services, that is, to how LHINs and CCACs balance their budgets to fund Home First; (b) what is the impact on PSWs of caring for recently discharged patients and meeting the service guarantees which are a component of the program; (c) when and why do family caregivers refuse to cooperate with a proposed Home First discharge[10]; (d) what do patients that were readmitted to hospital soon after a Home First discharge and/or their caregivers say about the approach; (e) why do Home First clients refuse or choose to utilize CSS services?

More general topics in need of future investigation that were suggested to me by findings from this study include: (a) the networks of family members involved in caring for a family member, (b) episodic and long distance care provision, and (c) ways to improve involvement of families in discharge planning and preparations (Gitlin and Wolff, 2011 also suggest similar research needs). There is a need to encourage discussion between older people and their families and formal health care providers about planning for longer term care needs and possible LTC placement; research is needed on the present situation and possible interventions to meet this need. A study finding that intrigued me was that all three male CLs stated that they would rather die than enter LTC while women could accept that even though it was not a positive option it might be a necessary one. If further investigation showed this to be a general difference in attitude, research into male attitudes might provide insight into ways to make the transition to LTC less stressful for men if it does become necessary.

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[10] I have been informed that such a study is currently being undertaken by the SELHIN.

Summary and Conclusions

All participating Home First clients remained at home for an extended period post-discharge and were pleased to be there. All had family involved with their care and used a mix of formal and informal services to meet their ADL and IADL needs. Although the care provided by formal health care providers contributed to enabling the discharge home and extended stays there for all Home First clients, a true partnering by formal providers with clients and their families for care provision was often lacking. Four general themes were identified from study findings which highlighted: (a) the high value CLs placed on maintaining their independence and the issues this raised around acceptable levels of risk, (b) the need to attend to and address the multiple constraints which exist on the provision of care whether formal, informal, or self; (c) the importance of, yet frequent lack of, good communication between formal health care providers themselves, formal providers and clients and families, and within families; and (d) the key role of the quality of relationships (whether between different people or people and their internal or external worlds) in the outcomes of interactions involving them.

Although the Home First approach may be reducing hospital ALC levels and getting people home where they want to be, it is also putting increasing demands on formal and informal community care provision. There is room for improvement in how well the needs of care providers and recipients are being met. To meet their needs and promote positive health system change, better ways need to be found to learn from people across the spectrum of care receipt and care giving about their lives and concerns and to provide them with the information and supports they need so they can become true partners in a process that improves the quality of life of everyone involved.

97

References

Abel, A. (1990). Daughters caring for elderly parents. In Gubrium, J. F., & Sankar, A. (Eds.), *The Home Care Experience: Ethnography and Policy* (pp. 189-206). Newberry Park, CA: Sage Publications.

Ackroyd-Stolarz, S., Guernsey, J. R., MacKinnon, N. J., & Kovacs, G. (2009). Impact of adverse events on hospital disposition in community-dwelling seniors admitted to acute care. *Healthcare Quarterly, 12 Special Issue*, 34-39.

Alternate Level of Care (2011). Cancer Care Ontario. Retrieved from https://www.cancercare.on.ca/cms/One.aspx?portalId=1377&pageId=43214#def

Alzheimer Society Ontario (2012). *First Link®: Your first step to living well with dementia.* Retrieved from http://www.alzheimer.ca/on/~/media/Files/on/PPPI%20Documents/ASO-First-Link-report-Web03-12.ashx

Aronson, J. (2002). Elderly people's accounts of home care rationing: Missing voices in long-term care policy debates. *Ageing and Society, 22*(4), 399-418.

Aronson, J. (2004a). "Just fed and watered": Women's' experiences of the gutting of home care in Ontario. In Grant, K., Amaratunga, C., Armstrong, P., Boscoe, M., Pederson, A. & Wilson, K. (Ed.), *Caring for/caring about: Women, home care, and unpaid caregiving* (pp. 167-183). Aurora, ON: Garamond Press.

Aronson, J. (2004b). 'You need them to know your ways': Service users' views about valued dimensions of home care. *Home Health Care Services Quarterly, 22*(4), 85-98.

Aronson, J. (2006). Silenced complaints, suppressed expectations: The cumulative effects of home care rationing. *International Journal of Health Services, 36*(3), 535-556.

Aronson, J., & Sinding, C. (2000). Home care users' experiences of fiscal constraints: Challenges and opportunities for case management. *Care Management Journals, 2*(4), 220-225.

Auditor General (2012). *2012 Annual report of the Office of the Auditor General of Ontario*: *Long-term-care Home Placement Process* (Chapter 3, Section 3.08). Retrieved from http://www.auditor.on.ca/en/reports_en/en12/308en12.pdf

Bauer, M., Fitzgerald, L., Haesler, E., & Manfrin, M. (2009). Hospital discharge planning for frail older people and their family. Are we delivering best practice? A review of the evidence. *Journal of Clinical Nursing, 18*(18), 2539-2546.

Bragstad, L. K., Kirkevold, M., Hofoss, D., & Foss, C. (2012, February 10). Factors predicting a successful post-discharge outcome for individuals aged 80 years and over. *International Journal of Integrated Care, 12.* Retrieved from http://www.ijic.org

Bull, M. J., & Roberts, J. (2001). Components of a proper hospital discharge for elders. *Journal of Advanced Nursing, 35*(4), 571-581.

Byrne, K., Sims-Gould, J., Frazee, K., & Martin-Matthews, A. (2011). "I'm satisfied . . . but":
Clients' and families' contingent responses about home care. *Home Health Care Services
Quarterly, 30*, 161-177.

Cahill, E., Lewis, L., Barg, F. & Hillary, H. (2009). You don't want to burden them: Older adults'
views on family involvement in care. *Journal of Family Nursing, 15*(3), 295-317.

Cain, C. H., Neuwirth, E., Bellows, J., Zuber, C., & Green, J. (2012). Patient experiences of
transitioning from hospital to home: An ethnographic quality improvement project.
Journal of Hospital Medicine, 7(5), 382-387.

Canadian Institute for Health Information. (2012, November). *Seniors and alternate level
of care: Building on our knowledge.* Retrieved from
https://secure.cihi.ca/free_products/ALC_AIB_EN.pdf

Caron, C. D., Ducharme, F., & Griffith, J. (2006). Deciding on institutionalization for a relative
with dementia: The most difficult decision for caregivers. *Canadian Journal on Aging,
25*(2), 193-205.

CCAC (2012 a). *Client Care Model*. Retrieved from http://www.ccac-ont.ca/Upload/ww/General/
BoardMeetings/2012/Presentations%20at%20Board%20Mtgs/2012-Apr-
25%20CCM%20presentation%20Final.pdf

CCAC (2012 b). *Our Report to the Community: 2011-2012.* (Central East CCAC). Retrieved
from http://www.ccac-ont.ca/uploads/Our-Report-To-The-Community-2011-2012/
BF325F19C5A5DCB9D497DEA4F202C8A7/Annual%20Report_2011-12_FINAL.pdf

CCAC (2012 c). *Toronto Central CCAC: Changing the Conversation, one client at a time.*
[Media release] Retrieved from http://www.ccac-
ont.ca/Upload/toronto/General/MediaRelease-CTC.pdf

Ceci, C., & Purkis, M. E. (2013). Means without ends: Justifying supportive home care for frail
older people in Canada, 1990-2010. *Sociology of Health & Illness, 33*(7), 1066-1080.

Change Foundation (2009, June 9*). Catch 22. Having Their Say and Choosing Their Way
Project: Report 2: People's experience going to long-term care after being hospitalized.*
Retrieved from http://www.changefoundation.ca/site/wp-
content/uploads/HTSLTCHfinal.pdf

Change Foundation (2011, February). *Because this is the rainy day: a discussion paper on home
care and informal caregiving for seniors with chronic health conditions*. Retrieved from
http://www.changefoundation.ca/site/wp-content/uploads/ElderlyInformal.pdf

Cheek, J., Ballantyne, A., Gillham, D., Mussared, J., Flett, P., Lewin, G., Vandermeulen, S.
(2006). Improving care transitions of older people: Challenges for today and tomorrow.
Quality in Ageing and Older Adults, 7(4), 18-26.

Chen, Y., & Thompson, E. A. (2010). Understanding factors that influence success of home- and
community-based services in keeping older adults in community settings. *Journal of
Aging & Health, 22*(3), 267-291.

Clough, R., Leamy, M., Miller, V., & Bright, L. (2004). *Housing Decisions in Later Life.* New
York: Palgrave McMillan.

Coffey, A., & McCarthy, G. M. (2012). Older people's perception of their readiness for discharge

      and postdischarge use of community support and services. *International Journal of Older*

      People Nursing. doi:10.1111/j.1748-3743.2012.00316.x

Coleman, E. A., Parry, C., Chalmers, S., & Min, S. J. (2006). The care transitions intervention:

      Results of a randomized controlled trial. *Archives of Internal Medicine, 166*(17), 1822-

      1828.

Costa, A. P., & Hirdes, J. P. (2010). Clinical characteristics and service needs of alternate-level-

      of-care patients waiting for long-term care in Ontario hospitals. *Healthcare Policy, 6*(1),

      32-46.

Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods*

      approaches. Thousand Oaks, CA: Sage.

Davies, S., & Nolan, M. (2003). 'Making the best of things': Relatives' experiences of decisions

      about care-home entry. *Ageing & Society, 23*(04), 429-450.

DeSantis, L., & Ugarriza, D. N. (2000). The concept of theme as used in qualitative nursing

      research. *Western Journal of Nursing Research, 22*(3), 351-372.

Diem, E., Alcock, D., Gallagher, E., Angus, D., & Medves, J. (2001). Looking beyond caseload

      numbers for long-term home-care case managers. *Care Management Journals, 3*(1), 2-7.

Dill, A. E. P. (1995). The ethics of discharge planning for older adults: An ethnographic analysis.

      Social Science & Medicine, 41(9), 1289-1299.

Dossa, A., Bokhour, B., & Hoenig, H. (2012). Care transitions from the hospital to home for patients with mobility impairments: Patient and family caregiver experiences. *Rehabilitation Nursing, 37*(6), 277-285.

Dubois, M., Dubuc, N., Caron, C. D., Raiche, M., & Hebert, R. (2009). Is there agreement between Canadian older adults and their primary informal caregivers on behaviour towards institutionalisation? *Health & Social Care in the Community, 17*(6), 610-618.

Efraimsson, E., Sandman, P. O., Hydén, L., & Rasmussen, B. H. (2004). Discharge planning: 'fooling ourselves?'– patient participation in conferences. *Journal of Clinical Nursing, 13*(5), 562-570.

Foust, J. B., Vuckovic, N., & Henriquez, E. (2012). Hospital to home health care transition: Patient, caregiver, and clinician perspectives. *Western Journal of Nursing Research, 34*(2), 194-212.

Friedman, R., & Kalant, N. (1998). Comparison of long-term care in an acute care institution and in a long-term care institution. *Canadian Medical Association Journal, 159*(9), 1107-1113.

Gill, L., White, L., & Cameron, I. D. (2011). Interaction in community-based aged healthcare: Perceptions of people with dementia. *Dementia, 10*(4), 539-554.

Gitlin, L. N., & Wolff, J. (2011). Family involvement in care transitions of older adults: What do we know and where do we go from here? *Annual Review of Gerontology and Geriatrics, 31*(1), 31-64.

Goar, C. (2012, April 3). How to deliver 'patient-centred' health care in Ontario. *thestar.com* Retrieved from http://www.thestar.com/opinion/editorialopinion/2012/04/03/ how_to_deliver_patientcentred_health_care_in_ontario.html

Government of Ontario (2008). *Ontario regulation 164/08*. Retrieved from http://www.e-laws.gov.on.ca/html/source/regs/english/2008/elaws_src_regs_r08164_e.htm#

Graf, C. (2006). Functional decline in hospitalized older adults: It's often a consequence of hospitalization, but it doesn't have to be. *AJN the American Journal of Nursing, 106*(1), 58-67.

Grimmer, K. A., Moss, J. R., & Gill, T. K. (2000). Discharge planning quality from the carer perspective. *Quality of Life Research, 9*(9), 1005-1013.

Grimmer, K., Moss, J., & Falco, J. (2004 a). Becoming a carer for an elderly person after discharge from an acute hospital admission. *The Internet Journal of Allied Health Sciences and Practice, 2*(4). Retrieved from http://ijahsp.nova.edu/articles/ vol2num4/grimmer-carer%20issues.pdf

Grimmer, K., Moss, J., & Falco, J. (2004 b). Experiences of elderly patients regarding independent community living after discharge from hospital: A longitudinal study. *International Journal for Quality in Health Care, 16*(6), 465-472.

Guberman, N. (2004). Designing Home and community care for the future: Who needs to care? In Grant, K., Amaratunga,C., Armstrong, P., Boscoe, M., Pederson, A., & Wilson, K.

(Eds.)*, Caring for/caring about: Women, homecare, and unpaid caregiving* (pp. 75-90).
Aurora, ON: Garamond Press.

Hébert, R., Raîche, M., Dubois, M. F., Gueye, N. R., Dubuc, N., & Tousignant, M. (2010).
Impact of PRISMA, a coordination-type integrated service delivery system for frail older
people in Quebec (Canada): A quasi-experimental study. *Journals of Gerontology Series
B: Psychological Sciences & Social Sciences, 65B*(1), 107-118.

Heckman, G., McKinnon-Wilson, J., Hillier, L., & Manderson, B. (2011). *Developing an
integrated system of care for frail seniors in Waterloo Wellington: Results of a
consultation process to identify system strengths and gaps*. Paper submitted to Waterloo
Wellington Local Health Integration Network. Retrieved from
http://www.waterloowellingtonlhin.on.ca/uploadedFiles/Home_Page/
Board_of_Directors/Board_Meeting_Submenu/08.1%20-
%20Heckman%20ISC%20for%20Seniors%20Report%20Oct20%202011.pdf

Hicks, E., Sims-Gould, J., Byrne, K., Khan, K. M., & Stolee, P. (2012). "She was a little bit
unrealistic": Choice in healthcare decision making for older people. *Journal of Aging
Studies, 26*, 140-148.

Hollander, M. J., Chappell, N., Havens, B., McWilliam, C., & Miller, J. A. (2002) *Substudy 5:
Study of the costs and outcomes of home care and residential long term care services*. A
report prepared for the Health Transition Fund, Health Canada. Retrieved from
http://www.homecarestudy.com/reports/full-text/substudy-05-final_report.pdf

Hollander, M. J., Chappell, N., Prince, M. J., & Shapiro, E. (2007). Providing care and support

      for an aging population: Briefing notes on key policy issues. *Healthcare Quarterly,*

      10(3), 34-45.

Hollander, M. J., Miller, J. A., MacAdam, M., Chappell, N., & Pedlar, D. (2009). Increasing

      value for money in the Canadian healthcare system: New findings and the case for

      integrated care for seniors. *Healthcare Quarterly* 12(1), 38-47.

Holloway, I., & Freshwater, D. (2007). Vulnerable story telling: Narrative research in nursing.

      Journal of Research in Nursing, 12(6), 703-711.

Holstein, J. A., & Gubrium, J. F. (1995). *The active interview.* Thousand Oaks, CA: Sage.

Huby, G., Brook, J. H., Thompson, A., & Tierney, A. (2007). Capturing the concealed:

      Interprofessional practice and older patients' participation in decision-making about

      discharge after acute hospitalization. *Journal of Interprofessional Care, 21*(1), 55-67.

Huby, G., Stewart, J., Tierney, A., & Rogers, W. (2004). Planning older people's discharge from

      acute hospital care: Linking risk management and patient participation in decision-

      making. *Health, Risk & Society, 6*(2), 115-132.

Human Resources and Skills Development Canada (2007). *Addressing the challenges and*

      opportunities of ageing in Canada. Retrieved from http://www.unece.org/fileadmin

      DAM/pau/_docs/age/2007/AGE_2007_MiCA07_CntrRprtCAN_e.pdf

Institute for Clinical Evaluation Services. (2010). *Aging in Ontario: An ICES chartbook of health service use by older adults.* Retrieved from http://www.ices.on.ca/file/AAH Chartbook_interactive_final_2010.pdf

Jack, B. W., Chetty, V. K., Anthony, D., Greenwald, J. L., Sanchez, G. M., Johnson, A. E., Manasseh, C. (2009). A reengineered hospital discharge program to decrease rehospitalization: A randomized trial. *Annals of Internal Medicine, 150*(3), 178-188.

Jorgensen, D., Arksey, H., Parsons, M., Senior, H., & Thomas, D. (2009). Why do older people in New Zealand enter residential care rather than choosing to remain at home, and who makes that decision? *Ageing International, 34*(1), 15-32.

Kane, R. A., Reinardy, J., Penrod, J. D., & Huck, S. (1999). After the hospitalization is over: A different perspective on family care of older people. *Journal of Gerontological Social Work, 31*(1-2), 119-141.

Keating, N., & Dosman, D. (2009). Social capital and the care networks of frail seniors. *Canadian Review of Sociology, 46*(4), 301-318.

King, A. I., Parsons, M., & Robinson, E. (2012). A restorative home care intervention in New Zealand: Perceptions of paid caregivers. *Health & Social Care in the Community, 20*(1), 70-79.

LeClerc, C. M., Wells, D. L., Craig, D., & Wilson, J. L. (2002). Falling short of the mark. *Clinical Nursing Research, 11*(3), 242-263.

Lévesque, L., Ducharme, F., Caron, C., Hanson, E., Magnusson, L., Nolan, J., et al. (2010). A partnership approach to service needs assessment with family caregivers of an aging relative living at home: A qualitative analysis of the experiences of caregivers and practitioners. International Journal of Nursing Studies, 47(7), 876-887.

LHIN Collaborative (2011). *Home First implementation guide & toolkit.* Ontario: Queens Printer. Retrieved from http://www.lhincollaborative.ca/uploadedFiles/ LHIN_Collaborative/Home%20First%20Implementation%20Guide%20and%20Toolkit %20Feb%202011_Final_updated%2020110409.pdf

Liamputtong, P. (2009). *Qualitative research methods /* (3rd ed. ed.). South Melbourne, Vic.; New York: Oxford University Press.

Lum, J., Williams, A. P., Sladek, J., & Ying, A. (2010). *Balancing care for supportive housing: Final report.* Canadian Research Network for Care in the Community. Retrieved from http://www.crncc.ca/knowledge/related_reports/pdf/ Balancing%20Care%20for%20Supportive%20Housing%20Final%20Report.pdf

Marek, K. D., Popejoy, L., Petroski, G., Mehr, D., Rantz, M., & Lin, W. (2005). Clinical outcomes of aging in place. *Nursing Research, 54*(3), 202-211.

Markle-Reid, M., Browne, G., Weir, R., Gafni, A., Roberts, J., & Henderson, S. (2008). Seniors at risk: The association between the six-month use of publicly funded home support services and quality of life and use of health services for older people. *Canadian Journal on Aging, 27*(2), 207-224.

McAiney, C., Hillier, L., & Stolee, P. (2010). *First Link Demonstration Project: Final Evaluation Report*. Submitted to: Alzheimer Society of Ontario. Retrieved from http://www.akeresourcecentre.org/files/FirstLink/FLDP_Evaluation_Report.pdf

McWilliam, C., & Sangster, J. (1994). Managing patient discharge to home: The challenges of achieving quality of care. *International Journal for Quality in Health Care, 6*(2), 147-161.

Miles, M. B., & Huberman, A. M. (1984). *Qualitative data analysis: A sourcebook of new methods.* Beverley Hills, CA: Sage.

Miller, J. A. (1991). *Community-based long-term care: Innovative models.* Newbury Park. CA: Sage Publications.

Moats, G. (2006). Discharge decision-making with older people: The influence of the institutional environment. *Australian Occupational Therapy Journal, 53*(2), 107-116.

Morse, J. M., & Field, P. A. (1995). *Qualitative research methods for health professionals*. (2*nd ed*.). Thousand Oaks, CA: Sage.

Nay, R. (1995). Nursing home residents' perceptions of relocation. *Journal of Clinical Nursing, 4*(5), 319-325.

Naylor, M. D., Brooten, D., Campbell, R., Jacobsen, B. S., Mezey, M. D., Pauly, M. V., & Schwartz, J. S. (1999). Comprehensive discharge planning and home follow-up of

hospitalized elders. *JAMA: The Journal of the American Medical Association, 281*(7), 613-620.

New York State Government (2013). *Long Term Home Health Care Program*. Retrieved from http://www.health.ny.gov/health_care/medicaid/program/longterm/lthhc.htm

Nolan, M., Walker, G., Nolan, J., Williams, S., Poland, F., Curran, M., & Kent, B. C. (1996). Entry to care: Positive choice or fait accompli? Developing a more proactive nursing response to the needs of older people and their carers. *Journal of Advanced Nursing, 24*(2), 265-274.

Nova Scotia Department of Health and Wellness Continuing Care Branch (2011) *Facility Placement Policy*. Retrieved from http://www.gov.ns.ca/health/ccs/ltc/ policyManual/Facility_Placement_Policy.pdf

Ohio Department of Aging (2011). *PASSPORT Medicaid Waiver Program*. Retrieved from http://aging.ohio.gov/resources/publications/profile_passport.pdf

Ontario Association of Non-Profit Homes & Services for Seniors (2010). *Long Term Care waitlists growing – Homes challenged to respond*. Retrieved from http://www.oanhss.org/AM/Template.cfm?Section=Home&%20TEMPLATE=/ CM/ContentDisplay.cfm&CONTENTID=7345

Ontario Council of Hospital Unions (2011) *Senior care tour*. Retrieved from http://www.ochu.on.ca/senior_care.html

Ontario Health Coalition (2011). *No vacancy: Hospital overcrowding in Ontario, impact on patient safety and access to care.* Retrieved from http://www.web.net/ ohc/hospitalbedsreport.pdf

Ontario Hospital Association (2011). *Alternative Level of Care (ALC): OHA ALC Survey Results: January 2011.* Retrieved from http://www.oha.com/CurrentIssues/Issues/eralc/ Documents/OHA%20ALC%20Survey%20Results%20%28Jan%202011%29%20- %20at%20Jan%2021.pdf

Overcash, J. A. (2003). Narrative research: A review of methodology and relevance to clinical practice. *Critical Reviews in oncology/hematology, 48*(2), 179-184.

Patton, M. Q. (2002). Two decades of developments in qualitative inquiry: A personal, experiential perspective. *Qualitative Social Work, 1*(3), 261-283.

Peckham, A. L. (2009). *Caring for caregivers: Balancing formal and informal care for frail older persons.* University of Toronto (Canada)). *ProQuest Dissertations and Theses, ,*105. Retrieved from http://search.proquest.com/docview/89263848?accountid=6180. (89263848).

Popejoy, L. (2011). Complexity of family caregiving and discharge planning. *Journal of Family Nursing, 17*(1), 61-81.

Rabiee, P., & Glendinning, C. (2011). Organisation and delivery of home care re-ablement: What makes a difference? *Health & Social Care in the Community, 19*(5), 495-503.

Roberts, K. (2002). Exploring participation: Older people on discharge from hospital. *Journal of Advanced Nursing, 40*(4), 413-420.

Rubin, H. J., & Rubin, I. S. (2012). *Qualitative interviewing: The art of hearing data.* (3rd ed.). Thousand Oaks, CA: Sage.

Ryan, A. A., McCann, S., & McKenna, H. (2009). Impact of community care in enabling older people with complex needs to remain at home. *International Journal of Older People Nursing* 4, 22–32.

Ryan, A. A., & Scullion, H. F. (2000). Nursing home placement: An exploration of the experiences of family carers. *Journal of Advanced Nursing, 32*(5), 1187-1195.

Rydeman, I. B., & Törnkvist, L. (2006). The patient's vulnerability, dependence and exposed situation in the discharge process: Experiences of district nurses, geriatric nurses and social workers. *Journal of Clinical Nursing, 15*(10), 1299-1307.

Sandelowski, M. (2000). Focus on research methods-whatever happened to qualitative description? *Research in Nursing and Health, 23*(4), 334-340.

Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing & Health, 33*(1), 77-84.

Sandelowski, M. (2011). When a cigar is not just a cigar: Alternative takes on data and data analysis. *Research in Nursing & Health, 34,* 342-352.

SECCAC (2008). *A plan to help seniors stay at home.* Retrieved from

http://www.southeastlhin.on.ca/uploadedFiles/Public_Community/

Health_Service_Providers/APlantoHelpSeniorsStayatHome_February2008.pdf

SECCAC (2011). *Home First in the South East partnership tool kit.* Retrieved from

http://www.ccac-ont.ca/Upload/se/General/HOME%20FIRST/

Home%20First%20Manual.pdf

SECCAC (2013). 4CSS Information about Community Support Services - easier+. Retrieved

from http://www.southeasthealthline.ca/displayservice.aspx?id=73589

Seidman, I. (1998). *Interviewing as qualitative research: A guide for researchers in education

and the social sciences.* (2nd ed.). New York: Teachers College Press.

Sims-Gould, J., & Martin-Matthews, A. (2010a). Strategies used by home support workers in the

delivery of care to elderly clients. *Canadian Journal on Aging, 29*(01), 97-107.

Sims-Gould, J., & Martin-Matthews, A. (2010b). We share the care: Family caregivers'

experiences of the older relative receiving home support services. *Health and Social Care

in the Community, 18*(4), 415-423.

Sinha, S. K. (2013, January 8). *Living longer, living well: Highlights and key recommendations

from the report submitted to the Minister of Health and Long-Term Care and the Minister

Responsible for Seniors on recommendations to inform a Seniors Strategy for Ontario.*

Retrieved from http://www.health.gov.on.ca/en/common/ministry/

publications/reports/seniors_strategy/docs/seniors_strategy.pdf

Skinner, M. W. (2008). Voluntarism and long-term care in the countryside: The paradox of a threadbare sector. *Canadian Geographer, 52*(2), 188-203.

Starr-Hemburrow, L., Parks, J. M., & Bisaillon, S. (2011). Home first: Reducing ALC and achieving better outcomes for seniors through inter-organizational collaboration. *Healthcare Quarterly (Toronto, Ont.), 14*(1), 70-76.

Statistics Canada (2002). *Table 1.4: Prevalence of receiving care for long-term health problems, care receivers aged 65 and over, by sex and age group, Ontario, 2002.* Retrieved from http://www.statcan.gc.ca/pub/89-583-x/t/th/t1/4152853-eng.htm

Sutherland, J. M., & Crump, T. C. (2011, September) *Exploring alternative level care (ALC) and the role of funding policies: An evolving evidence base for Canada.* CHSRF Series of Reports on Cost Drivers and Health System Efficiency: Paper 8. Retrieved from http://www.cfhi-fcass.ca/publicationsandresources/researchreports/ commissionedresearch/11-09-20/29f5b70f-e94f-4986-9455-231888e40f4a.aspx

Swinkels, A., & Mitchell, T. (2008). Delayed transfer from hospital to community settings: The older person's perspective. *Health & Social Care in the Community, 17*(1), 45-53.

Tanner, D. (2010).*Managing the ageing experience: Learning from older people*. Bristol, UK: The Policy Press.

Themessl-Huber, M., Hubbard, G., & Munro, P. (2007). Frail older people's experiences and use of health and social care services. *Journal of Nursing Management, 15*(2), 222-229.

114

van Bilsen, P. M., Hamers, J. P., Groot, W., & Spreeuwenberg, C. (2006). Demand of elderly

    people for residential care: An exploratory study. *BMC Health Services Research, 6*:39.

    Retrieved from http://www.biomedcentral.com/1472-6963/6/39

Walker, D. (2011, June 30). *Caring for our aging population and addressing Alternate Level of*

    Care. Report Submitted to the Minister of Health and Long-Term Care. Retrieved from

    http://www.health.gov.on.ca/en/common/ministry/publications/reports/walker_2011/

    walker_2011.pdf

Ward-Griffin, C., & McKeever, P. (2000). Relationships between nurses and family caregivers:

    Partners in care? *Advances in Nursing Science, 22*(3), 89-103.

Webb, C. (1992). The use of the first person in academic writing: Objectivity, language and

    gatekeeping. *Journal of Advanced Nursing, 17*, 747-452.

Weidner, J. W. (2010, Aug. 4). Geriatric services workers connect at-risk seniors with help. *The*

    Record. Retrieved from http://www.therecord.com/living/article/

    293807--geriatric-services-workers-connect-at-risk-seniors-with-help

Weins, M. (Producer) (2011, Sept. 23) *The indignity of aging: Crisis in Homecare*. Ontario

    Morning [Radio program]. London, ON:CBC. [Audio file]. Retrieved from

    http://www.cbc.ca/ontariomorning/episodes/2011/09/23/

    the-indignity-of-aging-crisis-in-homecare-1/

Wenger, G. C. (2003). Interviewing older people. In Holstein, J. A., & Gubrium, J. F. (Eds.),

    Inside interviewing: New lenses, new concerns (pp. 111-130). Thousand Oaks, CA: Sage.

Wiklund-Gustin, L. (2010). Narrative hermeneutics: In search of narrative data. *Scandinavian Journal of Caring Sciences, 24*, 32-37.

Wiles, J. (2003). Informal caregivers' experiences of formal support in a changing context. *Health & Social Care in the Community, 11*(3), 189-207.

Williams, A. P., Challis, D., Deber, R., Watkins, J., Kuluski, K., Lum, J. M., & Daub, S. (2009). Balancing institutional and community-based care: Why some older persons can age successfully at home while others require residential long-term care. *Healthcare Quarterly (Toronto, Ont.), 12*(2), 95-105.

Williams, A. P., Deber, R., Lum, J., Montgomery, R., Peckham, A., Kuluski, K. et al. (2009). *Mapping the state of the art: Integrating care for vulnerable older populations.* Canadian Research Network for Care in the Community Report. Prepared for: Ministry of Health and Long -Term Care and Canadian Institutes for Health Research. Retrieved from http://www.crncc.ca/knowledge/related_reports/pdf/MappingtheStateoftheArt.pdf

Appendix A

Information and Consent Form

March 27, 2012

Letter of Information & Consent Form
Post-Hospitalization Narratives of Home First Clients
and Their Care Givers: What Can They Teach Us?

Principal Investigator: Christine English, MSc Candidate

Faculty Supervisor: Dr. Margaret Jamieson, PhD, Chair

Occupational Therapy Program

Invitation to Participate: You are invited to take part in a research study which will use stories about your experiences to better understand the effects on older people and their caregivers of a hospital discharge approach called "Home First". You were, or the person you are caring for was, discharged as part of this approach. You may tell your own story or agree to let someone tell it.

Purpose of the Study: The study will try to learn about the Home First approach and related services from the point of view of older people and their caregivers. It will also try to learn how their thinking about housing and care options may change after a discharge. The study results may suggest ways to improve Home First and programs for older people and their caregivers.

Participation and Withdrawal: Taking part in this study is completely voluntary. This information and consent form will be reviewed with you. You will have a copy to keep. You may ask questions at any time. Whether you take part in the study or not will not affect your eligibility for any medical treatment, health care, home care, or community support services that you receive now or may receive in the future. You may decide not to answer any question or provide more information for any reason at any time. If you change your mind about having said something, it will not be used in the study if it is still possible to remove it.

Summary of What Will Happen: After some general information has been exchanged, you will be asked for stories about your experiences which relate to this research. An audio recording will be made. You will be asked questions like: a) "Please tell me the story of your recent health event and its effects on your life." b) "Describe what a typical day was like for you shortly after the return home." c) "Describe how you feel now about being at home (or the discharge home even if no longer living at home) and the timing of the discharge." How long the interview takes will depend on how much you want to share, but it may take an hour or more. You can stop or take a break if you want. After the researcher leaves, she will review her notes and make a written copy of the recording. She may contact you if she has questions about them.

117

Because a lot can change in the first few months after a hospital stay, she will contact you about a month after the interview to find out if or how your situation or plans have changed. At this time, you may also be asked for your opinion on findings from the research so far or to clarify something you said earlier. Later, you may comment on a preliminary study summary.

A final report of the study results will be given to any study participants who would like a copy. Copies will be given to organizations involved with Home First. A thesis, to be written as part of the researcher's Master of Rehabilitation Science degree, will be based on the study. Information from the study may also be used in one or more presentations or published articles.

Requirements to be in the Study: The person providing the stories must be willing and able to communicate about post-hospitalization experiences and other information that will be helpful in understanding them. There must be a suitable location or phone option for the interview.

Possible Risks of Participation: There are few risks to you from being in this study. You may feel some uneasiness about meeting someone new and sharing stories of your life or personal and health information with her. Unpleasant memories or emotions may arise while you share your stories. You cannot use time you spend with the researcher for other activities. You may find the interaction tiring.

Benefits of Being in the Study: The benefits of being in the study are hard to predict. You may get pleasure from sharing your stories and contributing to health care research or to someone's education. You may learn something about yourself or gain insight into your situation through telling your story. If there should be changes in service provision in the near future related to this study, you or others may benefit directly from them.

Confidentiality/Privacy: To protect your privacy, you will be identified only by a pseudonym (false name) on any shared data or references to you in written materials or presentations. Any information that would allow you to be identified will not knowingly be included in reporting study results. However, it is possible that someone who knows you well could identify you from a story you told that was reported. Any personally identifiable digital data will be password protected and/or encrypted during storage. Other identifiable data will be kept in a locked location with restricted access. Data will be stored by the Queen's Department of Rehabilitation Therapy for 5-7 years and will then be destroyed. Some anonymized data may be kept longer.

Approval for the Study: This study was reviewed for ethical compliance by the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board.

This study has been granted clearance according to the recommended principles of Canadian ethics guidelines and Queen's policies.

2

Additional Information and Consents:

1. How would you like to share your information?   By telephone _____

 Face to face _____ Location _____

I will participate through my care giver/receiver but do not want to be interviewed. _____

2. Are you willing to have interviews and phone conversations audio recorded?

Yes _____ No _____ NA _____

3. Are you willing to have digital photos taken of you or your environment to help C. English remember the details of your situation and connect you with your data? She will ask you for verbal permission before any photo is taken. Photos will be deleted once the study is completed. They will not be shown to anyone else or used any other way unless you are contacted and choose to give written permission for that use.

Yes _____ No _____

4. Do you agree to be contacted by C. English by phone and/or e-mail to be asked about changes to your situation (about a month after the interview) or to clarify what you have told her (during the duration of the study)? You can decline to respond at the time any request for further information is made. You may request at any time not be contacted again.

Yes _____ By phone: _____ By e-mail: _____ No _____

 5. Summaries of the stories you have shared, information about your situation, or direct quotations of your words may be used in the reporting of this study. Would you like to be contacted for consent before being quoted in any reporting of the study?

Yes _____ No _____ N/A _____

 6. To protect privacy, a false name will be used when reporting any study information related to you or anyone you mention and to identify your data. Please choose how you would like be identified (not required).

I would like to be identified as _____in my data and any reporting of it.

7. Do you wish to comment on a preliminary summary of the study? Yes _____ No _____

    Do you wish to receive a final report of the study?   Yes _____ No _____

If "yes", provide an e-mail or postal address: _____

_____
3

Consent for the study: Post-Hospitalization Narratives of Home First Clients and Their Care Givers: What Can They Teach Us?

Participant Statement and Signature:

As a volunteer participant, I have read and understand the information and consent form for this study. Any purposes, methods and language I do not understand have been explained to me. I have been given sufficient time to consider the above information and to seek advice if I choose to do so. I have had the opportunity to ask questions which have been answered to my satisfaction. I understand that I can withdraw at any time, without any consequences. I understand that my participation will be known only to the researcher and that my data will be used only for the purposes mentioned in the information provided to me in this document. I am voluntarily signing this consent form and will receive a copy of the form for future reference.

If I am dissatisfied with any aspect of the study, or have questions, concerns, or negative events related to it, I am encouraged to contact the principal investigator or her supervisor.

Christine English, MSc Candidate and Principal Investigator

                       At: (1-800) 649-1569   (c.english@queensu.ca)

Dr. Margaret Jamieson, PhD, Faculty Supervisor

                       At: (613) 533-6088   (m.jamieson@queensu.ca)

If I have questions regarding my rights as a research subject I can contact: Dr. Albert Clark, Chair, Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at (613) 533-6801. By signing this consent form, I am indicating that I agree to participate in this study.

_____

Signature of Participant   Date

_____

Signature of the Principal Investigator   Date

Statement of Investigator:

By signing this consent form, I confirm that I have carefully explained the nature of the above research study to the subject. I certify that, to the best of my knowledge, the subject understands clearly the nature of the study and the demands, benefits, and risks involved to participants in this study.

_____

Signature of the Principal Investigator   Date

Appendix B
Letter Sent to Potential Participants by CCAC

South East Community Care Access Centre

1471 John Counter Blvd.

Kingston - Ontario - Canada - K7M 8S8

www.se.ccac-ont.ca

Date xxxx

Dear Community Care Access Centre client and/or their caregiver,

Enclosed with this letter is an invitation for you to take part in a research study of the new provincial hospital discharge approach known as "Home First". The Community Care Access Centre is aware that you or a person you care for was discharged as part of this approach. The access centre is mailing the invitation to participate in the study for the researcher in order to protect your privacy.

The researcher, Christine English, is a graduate student in the School of Rehabilitation Science at Queen's University. She is not associated with the Community Care Access Centre in any way. The access centre will have no influence on her research or how the results are reported. However, the access centre will receive a summary of the results.

I believe that Christine's study is worthwhile. Its results will contribute to our and other health and home care service providers' ongoing evaluations of our services. The information you provide to Christine will improve our understanding of what is being done well now and things that could be done better in the future. This will contribute to the provision of higher quality care and services for you and other people like you.

Please read the enclosed invitation. If it interests you, you can then contact Christine directly to take part in or learn more about the research.

Sincerely,

xxxx, xxxx

South East Community Care Access Centre

Phone: xxxx

Enclosure

You are invited to share your experiences about life after a hospitalization.

Your help is needed to provide meaningful information for use in research about a new hospital discharge approach called "Home First". This approach influenced a return home from the hospital of you or a person you care for.

Why sharing your experiences is important.

To better understand how well needs are being met after a hospital stay, it is important to hear directly from people like you about your experiences. A better understanding will contribute to efforts to improve Home First and the associated services which are available to you and others in situations like yours.

Sharing your experiences is easy.

If you decide to contribute to this research, you will tell the researcher about your experiences over the phone or in person at a place you choose. She will contact you again a month later to see if your situation has changed or if you have more information you want to share.

The Researcher: Christine English, PSW, MSc candidate

Christine worked as a personal support worker doing home care for four years after her daughters were grown. She learned from this work about the challenges faced by people like you. She decided to enter university to explore ways to reduce those challenges. A thesis, which is a requirement of her degree, will be based on her research.
Christine is looking forward to talking with you!

Supervised by: Margaret Jamieson, PhD, Chair, Occupational Therapy Program, School of Rehabilitation Therapy, Queen's University

To learn more, please contact Christine.
Call free: 1-800-649-1569   E-mail: c.english@queensu.ca

Being part of this research is voluntary. Only the researcher will know if you choose to participate. You may change your mind and withdraw at any time. *This study has been granted clearance according to the recommended principles of Canadian ethics guidelines and Queen's policies.* If you have questions about this or your rights if you participate in the study, contact: Dr. Albert Clark, Chair, Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at (613) 533-6801

Appendix D

Telephone Follow Up Script

Telephone Follow Up Script - Home First Study - Queens University

Hello, would (…….NAME) be available. Good Morning/Afternoon, my name is xxxx
and I'm calling from the South East Community Care Access Centre.
Approximately 2 weeks ago, the SECCAC mailed to your home an invitation to participate in a
Home First research study being conducted by Mrs. Christine English at Queen's University.
Mrs. English is a Master of Rehabilitation Science student and has worked as a personal support
worker for four years and is now enrolled at Queens University to further to explore better ways
to support older people and their caregivers.   The SECCAC believes this study to be very
worthwhile and so is assisting Mrs. English in recruiting participants. I feel it is important for you
to know that to protect your privacy, I do not know who will be participating in the study, nor
should you inform me of whether or not you are willing to participate in this study. I do know,
however that Mrs. English requires more participants for her study. Do you recall receiving a
letter and invitation to participate in this study (**YES/NO**)?

YES (received letter)	NO (did not receive letter)	
Very good. Would you be interested in hearing a brief summary of the study now? (**YES/NO**)	May I offer to mail this is out to you? **(YES/NO)**	
	YES 1. Would you mind confirming your address? 2. Would you be interested in hearing a brief summary of the study now? **(YES, Continue)**	**NO** 1. Would you be interested in hearing a brief summary of the study now? (If **NO**, go directly to **NO or Continue**) **YES, CONTINUE or NO (not interested)** Thank you for taking the time to speak with me today and I hope you have a good day.

YES, CONTINUE

"It is a research study in which older clients and their caregivers will share with the researcher, information about their experience since their hospital stay. This is being done to better understand the effects of a hospital discharge approach called Home First. You or the person you are caring for was discharged as part of this approach. If you decide to participate in the study, Mrs. English will talk with you either by phone or in person at a location of your choice. Then, after about a month, she will connect with you again to see if any things have changed for you. The results of this study will contribute to continuing efforts to improve Home First and the services associated with it. **(CONTINUE)**

NO or CONTINUE

If you would like more information on the study or to participate in it, we are requesting that you contact Mrs. English **OR** if you would like, I can have Mrs. English contact you directly. I could give her your number and perhaps tell her what the best times to call you are. Would you like her number?

YES	NO	
Her number is **1-800-649-1569 and her name is Christine English**	Would you like me to have her call you?	
	YES	**NO**
	Is there a time that would best suite you for Mrs. English to call you? Thank you and if you have any other questions or concerns, Mrs. English could assist you with these. Again, thank you for taking the time to speak with me and I hope you have a good day.	Thank you for taking the time to speak with me and I hope you have a good day.

Note: This script was created by staff at the SECCAC based on a draft I had provided and was approved by me before it was utilized.

Appendix E
Interview Guide

Interview Guide

These may require changes depending on the individual circumstances of the participant and may evolve over the course of the study....wording may need adjusting to account for the type of participant (Home First client or caregiver).

1. Please tell me the story of your recent health event and its effects on your life. (as needed prompt for information on initial and current expectations of implications, feelings about the need for a hospitalization, concerns about the return home)

2. Describe what a typical day was like for you shortly after the return home. (or similar questions about before the hospitalization, now, or at a point in an imagined future)

3. Describe how you feel now about being at home (or the discharge home if no longer living there) and the timing of your return home.

4. Tell me about the care/services you have gotten from people other than family or friends since the discharge and why you chose to receive them. Include stories about actual events such as times you got either unusually good or bad help from a care/service provider.

5. Describe your current thinking about your preferred living situation and options for care provision. How has your thinking been affected by your experiences since the event that resulted in the recent hospitalization.

Appendix F
Questions for Interview

Questions of Interest

- What is the influence of prior hospitalizations or long standing health conditions on the participant's understanding of and reaction to their present situation?

- What were the participant's expectations for, experiences with, and reactions to the discharge process and Home First approach?

- What has been participant's experience with CCAC and CSS services both before and after the most recent hospitalization? How does this impact their decisions about community living and providing for their care needs?

- How do participants describe their thinking and feelings about, planning for, and experiences with LTC admission?

- How well are the current health care and support needs of participants being meet?

- What changes would participant's recommend to Home First and more generally to the provision of services for the elderly and their care givers?

- How involved were participants in the planning for discharge and choice of services to be provided? What had they assumed would be their discharge destination? Did they feel comfortable with the decisions made? Did they feel pressured to return home or to return home earlier than desired? Did they feel their concerns were "heard"?

- What aspects of the discharge plan do participants believe have and have not worked for them and what changes would they recommend? Have these beliefs changed over time?

- Were participants receiving CCAC services or utilizing CSS services prior to hospital admission? Did this impact their comfort with anticipated service adequacy post discharge and therefore their comfort with the discharge plan?

- How satisfied are the participants with current CCAC and CSS services? How do they describe their relationships/experiences with the multiple agencies and people providing these services? Do they plan to continue using CSS services when they must pay for them? Do they have fears about managing with reduced services as/if they are cut back? What other supports would be/would have been useful to them? Have they utilized any additional formal or informal supports to meet their current needs?

- How well do participants feel they are managing at home now? How is this different from before the hospitalization or immediately following it? Have recent events changed their attitude towards their ability to live independently/continue to provide needed care?

- How do they describe their approach to planning for future care needs, factors influencing their decisions, sources of information on options?

- What had been participants' thoughts about a move to an assisted living facility or long term care placement before the recent hospital stay? How have recent events changed their attitudes towards such a move? If they have decided on LTC placement, what are their thoughts about the admission process