Home to Nursing Home:
Understanding Factors that Impact the Path Seniors Take

Final Report

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Nova Scotia Department of Health and Wellness, (PO #4500282537)

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Executive Summary

Background and research approach
The Continuing Care Strategy (2006) outlined a vision to adapt to Nova Scotia’s aging population by increasing services in the community to allow individuals to remain at home as long as possible. Despite these efforts, only 57% of the 2100 clients who applied for admission to residential care and were waiting at home were accessing provincial home care services. This report presents results of a study into the reasons why people approved for care in a nursing home do not receive home care, the ways the provincial home care program may need to adjust their services and what would help those waiting for nursing home placement in the hospital return to their home.

Between November 2013 and February 2014 a random sample of clients and a random sample of caregivers of clients who had been approved for admission to a nursing home participated in a telephone survey. Surveys were completed with 125 clients or their proxies (just over 80% were completed by proxies, largely due to the client’s cognitive issues) representing a 49% response rate of those contacted. Surveys were completed with 85 caregivers – nine of whom were part of the same case as the client, representing a 59% response rate. Participants were located throughout Nova Scotia with good representation by district health authority and by clients waiting for admission at home or in a hospital. Clients were more likely to be female and to live in their own home. Forty-three percent were low income and the median length of time on the waitlist, as of November 18, 2013, was 221 days. Seventy percent of the caregivers were female – caring for a mother/-in-law (40%) or a spouse (25%) and almost all were considered the primary caregiver (93%). Most had been providing a high amount of care (with over two-thirds providing 40 hours a week or more), the majority had been in this role for three years or more. One in five caregivers were at high risk of their caregiving situation breaking down. In addition to the telephone surveys, face-to-face interviews were conducted with clients/caregivers representing five different care situations.

Study results and recommendations
Generally, the main recommendation emerging from this study is that more effort should be made to support people to stay at home. Specific recommendations fall into three categories. Some recommendations are specific to the Continuing Care program while others are broader to better an understanding of the continuing care system.

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1 The proportion who received at least some Guaranteed Income Supplement
Address inadequacies in home care services

One of the strongest and most frequent points of advice provided by both clients and caregivers pertains to the need to improve the continuity of workers and scheduling of workers.

1. Improve delivery to better meet clients’ needs by: a) encouraging service providers (if not required when operationally feasible to do so) to make every effort to have workers consistently assigned to a client; and, b) considering the needs of the client and the caregiver when scheduling care work.

The most frequent type of home care services received by clients both before applying for admission to a nursing home and at the time of the survey were personal care and instrumental activities of daily living. The proportion receiving caregiver respite increased after applying for a nursing home, however, the respite hours were still not sufficient. It was primarily the caregivers, in giving advice to government, who suggested a system of direct funding. This would enable families to purchase service on their own thereby maintaining consistency in the workers; to access services such as home/yard work and transportation; and to support individuals who move to an assisted care facility to purchase more service to meet their changing needs.

2. Enhance the scope of supports by: a) providing more hours of support than is currently available and at needed times (e.g. nighttime) as well as more relief for caregivers; and, b) enabling clients to receive funding to purchase care services.

The role of the caregiver emerged throughout the study as key to supporting clients to remain at home, thereby preventing or delaying admission to a nursing home. Care situations are complex and without appropriate support, caregivers can burn out trying to do everything on their own before contacting the public home care program or other community supports.

3. Enhance targeted supports to family caregivers by: a) evaluating the existing approach being taken by Continuing Care to support caregivers to understand effectiveness; and, b) assessing the needs of family caregivers to obtain a fuller understanding of caregivers’ difficulties.

Results suggest that more attention to case management may prevent an application for admission to a nursing home for some individuals. Because of the instability of care situations in the community, health situations may be unnecessarily deteriorating due to infrequent communication between the client and the care coordinator. Clients and
caregivers would benefit from regular access to the care coordinators’ knowledge of services and supports to help them transition through the system.

4. Enhance case management by: a) increasing communication between the care coordinator, client and caregiver; and, b) developing better connections between the care coordinator and other points in the health system, such as primary care and acute care.

Address inappropriate referrals through education and procedural changes

Clients are being counselled to “go on the waitlist” even though they are not yet ready for nursing home placement, and by so doing they are increasing, and potentially inflating, the waitlist. In both surveys, about 50% of respondents (either clients or caregivers) would not accept a nursing home bed tomorrow if offered and another 14% replied “don’t know”. In 80% of the cases, this refusal was either based on the nursing home bed not being needed at this time or their desire to stay at home for as long as possible. Both physicians and care coordinators played a significant role in the decision to apply for admission to a nursing home. Forty percent of clients and caregivers identified their physician as being involved in the decision because of the “long wait” or because they felt there were no other options for their patient.

5. Educate physicians about home and community care by: a) developing a targeted campaign to increase awareness among physicians about the current admission process, the wait time and the range of home care options available; b) encouraging them to refer patients to care coordinators and other navigators; and, c) developing a targeted intervention for physicians about the detrimental impact of encouraging patients to go on the waitlist “just in case”.

In addition to care coordinators encouraging clients to apply for admission to a nursing home because of the “long wait”, there was some evidence to suggest that care coordinators did not view the client living at home with some level of risk as an option.

6. Increase training for care coordinators on ethical issues related to autonomy, decision making and the client’s right to live at risk.

There were a significant proportion of cases “not needing” a nursing home bed or “not wanting” a nursing home bed, and yet these individuals had been assessed for nursing home level of care. Health professionals who are encouraging individuals to apply for admission contribute to a waitlist that is not necessarily reflective of need. A process that is based on priority of need, as opposed to application date, may circumvent individuals from applying until they would be ready to accept placement.
7. Reprioritize access to a nursing home by: a) implementing a placement process that is based on priority of need as opposed to application date; and, b) considering the implications of the current option to defer placement.

Increase understanding of home care and living at informed risk

Improvements are needed in the general knowledge base of participants around the role of home care as a natural step in the support needs of older people and their caregivers. Embedded within some of the interviews was the assumption that one stays at home with family and the next step is to move directly into the long term care facility. The intermediary of receiving home care services, while increasing in public awareness, is still not an established pathway. In some cases, respondents indicated that they would prefer to move location to be cared for by strangers rather than having strangers come into their home. Concern was also expressed about the lack of socialization some individuals living on their own experienced.

8. Increase public awareness about options to nursing home admission by: a) increasing promotion about the benefits of home care services and the role of continuing care workers to keep people at home; b) promoting how home care services can help to support the local economy; and, c) increasing resources to mitigate social isolation of individuals living on their own.

In many of the cases, the theme of risk aversion was identified as a reason for needing nursing home placement. Caregivers felt challenged with being on site 24/7 and were concerned about the client’s capacity to live alone. At what point, and to what degree, should people have the right to choose to live at risk despite concerns about falling or safety. With an increasing number of baby boomers supporting their parents, it appears that they want the full extent of services possible with the least amount of risk. For them, this means living in a long term care facility where they feel their parent will be safe.

9. Begin public discussion of ethical issues such as autonomy and informed risk by: a) educating families and health care professionals about the acceptance of risk and client’s right to choose to live independently if s/he understands risk; and, b) support public conversations about varying levels of competency that older adults with dementia might experience and their continued right to make informed choices.
Section 1 - Introduction

1.1 Background

In an effort to provide appropriate, effective and sustainable support to our aging population, there is a need to provide more options for seniors to remain at home longer (by 2022 the population of Nova Scotians 75 years of age and older is expected to increase by 26%). Many jurisdictions are making program and policy changes to better support people to remain at home and in their communities longer. In the last two years, the Nova Scotia government has committed over $22 million to support the development and expansion of home- and community-based care initiatives.

The Continuing Care Strategy (2006) outlined a vision for the future of continuing care in Nova Scotia that includes more services in community to allow individuals to remain at home as long as possible. Although much of the focus over the past six years has been on building long term care beds, there is now a renewed focus on home and community-based supports.

The waitlist for residential long term care in Nova Scotia continues to grow. Many factors have contributed to this increase. In the fall of 2013, approximately 2,400 Nova Scotians were waiting for an initial placement into a long term care facility. Approximately 300 of these individuals were waiting in hospital, while the other 2,100 were waiting at home. In 2012-13, of those waiting at home, 57% were accessing provincial home care services at the time they were placed on the long term care waitlist. Of those receiving home support services, only 25% were authorized for intensive home support services (60 or more hours per month). Given this situation, there are a number of areas of inquiry – why are some people who are approved for nursing home admission not accessing provincial home care services? What would help enable those waiting in the hospital for a nursing home to return home? In what ways does the provincial home care program need to adjust its services to support individuals to remain in the community longer?

The results of this study are intended to provide information that will help decision makers to better understand these areas of inquiry. In particular, the project aimed to gather information from clients and caregivers of clients about the context surrounding their decision to seek long term care placement and the barriers for utilizing provincial home care services. Ultimately, the project’s goal is to identify the gaps in service and specific needs for support to prevent or delay entry into a long term care facility.
1.2 Methodology

Data that inform this report were collected through a questionnaire administered by telephone with a sample of clients and a questionnaire administered by telephone with a sample of clients’ caregivers. The clients and caregivers who participated in the survey were not connected to one another. In other words, they were not a client-caregiver pair (dyad relationship), but rather independent groups. In addition, interviews were conducted in person with a select group of clients and caregivers. The telephone surveys were completed between November 29, 2013 and February 26, 2014 by four project staff of the Nova Scotia Centre on Aging. In person interviews were completed between February 28, 2014 and March 25, 2014 by the researchers. The questionnaires used for the telephone survey and the guide to conduct the semi-structured in person interviews were developed in consultation with representatives from the Continuing Care Branch. Project staff were trained to administer the survey with special attention on how to respond to different scenarios they may encounter. They also participated in several debriefing sessions throughout the data collection period. The following provides an overview of the methodology employed for both the telephone surveys and in person interviews. For more information on the project’s methodology see Appendix C and Appendix D.

1.2.1 Sampling

The sample of clients and the sample of caregivers were derived from the Department of Health and Wellness database containing information on clients waiting for long term care as of November 18, 2013. Individuals approved for admission to a nursing home as of that date made up the original sample. There were no age restrictions. Clients approved for a Residential Care Facility were excluded, as were clients identified as “translator required”. Basic information on each client was provided to enable randomization of the file and selection of the client sample and the caregiver sample (i.e., Random Samples). This information included: Client ID, service address district (district health authority), client situation (waiting for long term care either in community or hospital), presence of caregiver and authorization of home care. The random sample of clients (N=520) was identified and a separate random sample of caregivers (N=551) was identified and returned to the Department for more complete case information to support the telephone survey work, including the client’s first and last name and telephone number on file.

The sample of cases to be considered for the interview portion of the project was derived from the completed surveys. The identification of case scenarios for the personal interviews was done in consultation with representatives from the Continuing Care Branch.

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2 Client survey-November 29, 2013 up to and including February 7, 2014; Caregiver survey-January 11, 2014 up to and including February 26, 2014.
3 Contractors obtained permission from Department of Health and Wellness Privacy Office to receive client information. As well, the contractors received Ethics Clearance for the project from Mount Saint Vincent University, File # 2013-046 (see Appendix A).
Researchers provided preliminary information on survey results and the following scenarios were deemed of interest:

- client approved for nursing home admission but not receiving any services from Continuing Care at time of application for housekeeping, meals, personal care (client perspective preferred rather than proxy)
- client approved for nursing home admission but comments reference "not ready yet" for nursing home or "managing okay with what I have" (client perspective preferred rather than proxy)
- client approved for nursing home admission and waiting in hospital to understand what contributed to admission and what supports may be required for client to return home
- caregiver experiencing stress and not able (increasing care need) or willing (burnout) to do more

1.2.2 Recruitment
On November 20, 2013, a letter from the Executive Director, Continuing Care Branch, Department of Health and Wellness was mailed to all clients on the waitlist as of November 18, 2013 using their mailing address identified in the Continuing Care database (as opposed to their service address). This letter provided information on the purpose of the project, information on the researchers engaged to complete the project, and a telephone number to call should the client wish to opt-out (see Appendix B). One hundred and thirty-two letters were returned to the Branch as "undeliverable" and more than 100 clients and caregivers contacted the Branch to discuss the project and their involvement.

For the interviews, researchers reviewed the completed surveys to identify potential cases to represent the above scenarios. Individuals who were considered had identified their willingness to be contacted for this purpose at the completion of the telephone survey. Researchers made direct contact with the identified individuals to review the purpose of the interview and gain permission to meet with them.

1.2.3 Survey process
Project staff telephoned the client and spoke to either the client him/herself or a representative (proxy). Caregivers were contacted through the client contact information as contact information for the caregivers was not available. In many instances, several attempts were made to establish contact. At the outset of the telephone call, the purpose for the call was discussed and consent was obtained. A file was established to track surveys

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4 In cases where caregiver called the Branch upon receipt of the letter to obtain more information or to affirm their interest in the study, contact information for the caregiver was obtained and used to contact the caregiver directly. In some cases, caregivers who served as proxy respondents in the Client survey provided their own phone numbers, and these were also used in the Caregiver survey to contact these cases, when/if these caregivers came up in the sample.
completed, call backs, refusals and those deemed unsuccessful. Tables 1a thru 1d provide information on calling results for both clients and caregivers.

**Table 1a: Client Survey (out of possible 520 clients)**

<table>
<thead>
<tr>
<th></th>
<th>Completed</th>
<th>Refusal</th>
<th>Unsuccessful</th>
<th>Not contacted</th>
<th>Not contacted due to letter returned as undeliverable</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>125</td>
<td>129</td>
<td>216</td>
<td>25</td>
<td>25</td>
<td>520</td>
</tr>
<tr>
<td></td>
<td>24%</td>
<td>25%</td>
<td>41%</td>
<td>5%</td>
<td>5%</td>
<td>100%</td>
</tr>
</tbody>
</table>

**Table 1b: Overview of Completed Surveys with Clients (N=125)**

<table>
<thead>
<tr>
<th>District Health Authority</th>
<th>Clients’ location while waiting for nursing home</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Community</td>
<td>Hospital</td>
<td></td>
</tr>
<tr>
<td>South Shore</td>
<td>3</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>South West</td>
<td>8</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Annapolis Valley</td>
<td>10</td>
<td>1</td>
<td>11</td>
</tr>
<tr>
<td>Colchester Est</td>
<td>10</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Cumberland</td>
<td>5</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Pictou</td>
<td>10</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Guysborough</td>
<td>4</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Cape Breton</td>
<td>23</td>
<td>8</td>
<td>31</td>
</tr>
<tr>
<td>Capital</td>
<td>34</td>
<td>2</td>
<td>36</td>
</tr>
<tr>
<td>TOTAL Completed</td>
<td>107</td>
<td>18</td>
<td>125</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Proxy respondent for client</td>
<td>104</td>
</tr>
<tr>
<td>Presence of caregiver</td>
<td>111</td>
</tr>
<tr>
<td>Client authorized to receive home care service</td>
<td>82</td>
</tr>
</tbody>
</table>

**Table 1c: Caregiver Survey (out of possible 551 caregivers)**

<table>
<thead>
<tr>
<th></th>
<th>Completed</th>
<th>Refusal</th>
<th>Unsuccessful</th>
<th>Not contacted</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>85</td>
<td>60</td>
<td>275</td>
<td>131</td>
<td>551</td>
</tr>
<tr>
<td></td>
<td>15%</td>
<td>11%</td>
<td>50%</td>
<td>24%</td>
<td>100%</td>
</tr>
</tbody>
</table>
Table 1d: Overview of Completed Surveys with Caregivers (N=85)

<table>
<thead>
<tr>
<th>District Health Authority</th>
<th>Clients’ location while waiting for nursing home</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Community</td>
<td>Hospital</td>
<td></td>
</tr>
<tr>
<td>South Shore</td>
<td>4</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>South West</td>
<td>3</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Annapolis Valley</td>
<td>8</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>Colchester East</td>
<td>8</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>Cumberland</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Pictou</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Guysborough</td>
<td>4</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Cape Breton</td>
<td>23</td>
<td>0</td>
<td>23</td>
</tr>
<tr>
<td>Capital</td>
<td>25</td>
<td>4</td>
<td>29</td>
</tr>
<tr>
<td>TOTAL Completed</td>
<td>78</td>
<td>7</td>
<td>85</td>
</tr>
</tbody>
</table>

Caregiver was proxy respondent for client | 9 | 11%
Client authorized to receive home care service | 58 | 68%

Telephone surveys were completed with 125 clients (or their proxy) which represents a 27% response rate\(^5\). However, if we consider only the clients who were successfully contacted, the response rate was 49%. Clients who were in the hospital within a one-hour radius of Mount Saint Vincent University were offered the option to participate in the survey in person with project staff. Telephone surveys were completed with 85 caregivers of clients which represents a 20% response rate. However, if we consider only the caregivers who were successfully contacted, the response rate was 59%. Nine caregivers (11%) who participated in the client survey as a proxy also completed the caregiver survey. A description of the survey respondents is provided in Section 2.

Project staff experienced significant challenges conducting the telephone survey. In many instances telephone numbers were incorrect or out of service, clients no longer lived at that number (moved to assisted living, nursing home or were hospitalized), clients were deceased, clients had difficulty understanding the purpose of the call after staff spent time reviewing the project (either due to hearing impairment or cognitive impairment)\(^6\), clients not acknowledging they were on a waitlist for care in a nursing home, clients were not interested

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\(^5\) Response rate is based on the number of completed surveys out of number of active client cases (contacted and survey completed, contacted but refused, unsuccessful contact).

\(^6\) Throughout the work, it became apparent that the information provided on clients’ cognition and hearing impairment was not as useful for the purposes of this survey as anticipated (two factors which can significantly influence survey administration). This contributed to extra time spent completing calls and having to reach proxies to complete survey.
in participating after staff spent time reviewing the project, clients or family members were unavailable at the time and asked to be called back, family members interjected the call and spoke on the client's behalf, etc. The completion of the survey itself took longer than originally anticipated due to the length of the final version of the survey, and staff having to repeat questions because respondents had difficulty answering. On average, the Client Survey took 30 minutes to complete (not including the time to review the survey or obtain consent). On average, the Caregiver Survey took 35 minutes to complete (not including the time to review the survey or obtain consent).

Due to the higher than anticipated unsuccessful contacts and refusals, analysis was undertaken to understand the extent to which survey respondents represented the respective samples on key descriptive variables. With respect to the clients, the sample may slightly underrepresent clients who did not live with a primary caregiver (the odds for completing the survey were 1.78 times higher for clients who lived with their primary caregivers compared to those who did not). With respect to the caregivers, more differences between those who completed the survey and those who did not complete the survey were present. The survey of caregivers may over-represent married clients who have a spouse as the primary caregiver. Further, the caregivers who responded to the survey were more likely to be referring to a client who lived with their primary caregiver and who was receiving home care.

Further, a significant number of client surveys were completed by a proxy (see Figure 1a). These proxy respondents were most commonly the adult daughters (45%) or the spouse (35%) of a client, but relationships included other family members, friends, and neighbours.

**Figure 1a: Proportion of Client Surveys Completed by Proxy**

![Pie chart showing proportion of client surveys completed by proxy: yes 83%, no 17%]

Reasons why someone else completed the survey on behalf of the client varied, with the majority of reasons associated with the clients’ cognitive capacity (see Figure 1b). Further, all cases in which the client was waiting in the hospital were completed by a proxy.
Proxy respondents were reminded to answer questions as they felt the client would respond. However, it is recognized that in some instances and for some questions this distinction for the proxy, who was often the primary caregiver, may have been difficult. To understand the potential impact on responses due to proxy participation, we investigated whether proxy respondents differed from client respondents on key variables. Throughout the analysis, we did not find significant differences. For example, there were no significant differences based on whether clients were receiving continuing care services before application or were currently receiving continuing care services, whether clients would accept a bed tomorrow, and the reason for application for admission to a nursing home.

Nine of the 85 caregivers who participated in the Caregiver Survey had previously participated in the Client Survey as a proxy. Therefore, almost all of caregivers who participated in the Caregiver Survey represent different care situations from those in the Client Survey. Caregivers were able to offer their own perspective on the situation as opposed to trying to frame answers on behalf of the client.

1.2.4 Interview process
Interviews were completed with one client and four caregivers (two as proxies for the client and two moreso representing their caregiver roles). Again, challenges were experienced securing individuals for the interviews (i.e., client deceased, caregiver unavailable, client/caregiver refused) and additional time was spent reviewing survey files to meet this
objective. While the client voice, rather than proxy voice, was desired this was not always possible due to the availability and circumstances of cases to choose from.

Interviews were conducted in person at a place convenient to the participant and most were audio recorded. Consent was obtained at the time of the interview. Interviews lasted on average 90 minutes. An overview of the situations included in the in person interview is provided in Section 2.

1.3 Organization of the report

Section 2 offers a descriptive overview of both the clients in the Client Survey and the caregivers who participated in the Caregiver Survey. As well, information on the situations in which individuals participated in the in person interviews is provided. Section 3 provides the results of respondents’ situation prior to the application for admission to a nursing home with respect to what types of support clients were receiving and from whom. Section 4 presents the results related to the application for admission to a nursing home. This includes information on the reason for the application, who was involved in the decision, extent of awareness of care options and a discussion of factors that may have prevented the application. Section 5 presents the results of what types of support clients were receiving at the time of survey and by whom. This section also examines their experience with continuing care services and provides information on the scope of service and delivery of service that may contribute to keeping the client at home longer. Section 6 presents the results of respondents’ advice regarding how government could better support people who want to remain at home longer. Section 7 offers recommendations based on key findings. Throughout the report, perspectives from both the Client Survey and Caregiver Survey are presented, sometimes in separate tables and other times in the same table. Relevant information from the interviews is offered where appropriate to illustrate and provide further understanding of key findings.
Section 2 - Who are the study participants

2.1 Continuing care clients who participated in survey

The average age of clients was 82 years. Less than 5% were either under the age of 65 or over the age of 95. Seventy percent of clients were female (see Figure 2a). Slightly more than half of clients’ marital status at the time of the survey was widowed (52%) (see Figure 2b), as compared to slightly less than half (48%) of clients in the original Continuing Care client database. This was not surprising given the age and health status of clients and their spouses. Slightly more than half of clients (54%) were living in their own homes at the time of the survey and 20% lived in someone else’s home (typically an adult daughter or son). Thirteen percent were living in an assisted living facility while 14% were in a hospital setting (see Figure 2c). Sixteen percent of respondents indicated that the clients’ living situation had changed since the application for admission to a nursing home.

Figure 2a: Gender of Clients (N=125)

![Gender of Clients Pie Chart]

Figure 2b: Marital Status of Clients at Time of Survey (N=125)

![Marital Status Pie Chart]
More than half of clients were not receiving the Guaranteed Income Supplement (GIS) (see Figure 2d) suggesting they would have higher incomes than those receiving OAS and GIS only⁷.

For clients, the median length of time on the waitlist for admission to a nursing home up until November 18, 2013, was 221 days (R=11 days to 1138 days). Almost all were identified as having a caregiver (89%) (Source: Continuing Care client database). Two-thirds were authorized to receive services from Continuing Care (Source: Continuing Care client database).

Income categories were derived from recoding responses to a list of potential sources of income (OAS, CPP, employment income, investment income, GIS, employer pension, other). Responses which included reference to spousal income were not included in our coding of this income as it would have been voluntary information and not asked consistently of all respondents.

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⁷ Income categories were derived from recoding responses to a list of potential sources of income (OAS, CPP, employment income, investment income, GIS, employer pension, other). Responses which included reference to spousal income were not included in our coding of this income as it would have been voluntary information and not asked consistently of all respondents.
2.2 Caregivers of continuing care clients who participated in survey

The average age of caregivers was 66 years and more than two-thirds were female (see Figure 2e).

Figure 2e: Gender of Caregivers (N=85)

Approximately half of cases involved an adult child as the caregiver and about 40% a spouse. Other family respondents were niece/nephew, sister-in-law and grandchild (see Figure 2f).

Figure 2f: Relationship of Client to Caregiver (N=85)
Almost all respondents (93%) identified as the clients’ primary caregiver. In 62% of the cases, the caregiver and client lived together, a number that was not surprising given the method of contacting the caregiver via the phone number on file for the client. Otherwise, caregivers tended to live close by (within a 30 minute drive), with only ten caregivers indicating that they lived 30 minutes or more from the person they supported. At the time of the Caregiver Survey, clients in seven cases were in the hospital and six were living in an assisted living facility (see Figure 2g).

Figure 2g: Living Situation of Client (Caregiver Perspective, N=85)

Most caregivers had been providing care for over a year, with three years or more of caregiving being a common situation. The weekly hours of support that caregivers provided was high; many estimated that they provided more than 40 hours per week (37%) or felt that the support they provided was around the clock or “24/7” (33%). Only eight caregivers provided minimal support (10 hours or less per week). On average, caregivers scored 1.2 on the Caregiver Risk Screen (scale 0-3) meaning many were at moderate risk of the caregiving situation breaking down. Close to 20% of the sample reported scores of 2 or higher, placing them in the high to very high risk categories. A number of caregivers scored higher on key items of the scale that indicate high risk – caregiver feels meeting care recipient’s needs no longer worth the effort, caregiver feels depressed, and caregiver feels he/she is losing control over life (see Figure 2h). As part of the protocol, following the questions on the Caregiver Risk Screen caregivers were asked whether they would be interested in receiving information on resources available to caregivers. Staff shared such information in 63% of the cases.
For the clients of caregivers who participated in the survey, the median length of time the clients were on the waitlist for admission to a nursing home up until November 18, 2013 was 214 days (R=4 days to 1104 days). About two-thirds (68%) of the cases were authorized to receive services from Continuing Care (Source: Continuing Care client database).

2.3 Individuals who participated in personal interviews

Personal interviews were conducted in different district health authorities. Descriptive information about the five cases in which individuals participated in a personal interview is:

CLARA – client who lives alone in own home, daughter helps, chronic health conditions but no dementia, “doing okay”, receiving some services from Continuing Care (i.e., housekeeping) [interview with client]

ANNE – wife of client who lives in own home, dementia, wife is caregiver, no services being received from Continuing Care, a lot of family support [interview with wife as proxy for client]

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8 Pseudonyms are used to protect individual from being identified.
MAX – family member of client in hospital but previously had been in own home with no services from Continuing Care, purchased private housekeeping services, dementia and injuries from fall [interview with family member as proxy for client]

BEATRICE – adult daughter of client who lives in own home, dementia and hip fracture due to fall, daughter is caregiver and lives approximately 30 minutes away, client receives personal care and housekeeping from Continuing Care [interview with adult daughter as caregiver]

DONNA – adult daughter of client who lives in daughter’s home, dementia and other health issues, daughter is caregiver, client receives services from Continuing Care (i.e., meal time, tuck in, caregiver respite) and purchases services privately (i.e., meal time, supervision, respite) [interview with adult daughter as caregiver]
Section 3 - Situation pre nursing home application

3.1 Receipt of services – Client perspective

The most commonly reported types of assistance clients were receiving prior to the application for admission to a nursing home are considered instrumental activities of daily living such, as housekeeping, grocery shopping, transportation, yard work/snow removal, and meal preparation (see Figure 3a). Between 80% and 90% of clients waiting for nursing home admission were receiving these types of supports prior to their application. Slightly more than half were receiving assistance with personal care (55%) and medications (59%). Information on frequency of support received or amount of support was not collected.

Figure 3a: Type of Service/Support Client Received Prior to Nursing Home Application (N=125)

Clients who identified receiving support prior to the application for admission to a nursing home were asked to identify the source, or sources, of that support. The source of support varied by type of support clients were receiving. However, for the most commonly identified types of support previously noted (i.e., housekeeping, meal preparation, transportation, groceries), family was the most commonly identified provider (see Figure 3b). Continuing

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9 Three of these cases were situations in which the client was hospitalized suddenly due to some acute situation but prior to had been in reasonably good health. Otherwise, clients were receiving on average assistance with 9 of the areas of support the survey covered (R=0.14; SD=3).
Care (CCS) was identified more frequently as a provider of “personal care” services and “relief for caregiver”\(^\text{10}\).

Figure 3b: Among Clients Receiving Specific Services/Supports Prior to Nursing Home Application (see Figure 3a), The Proportion of Cases From Each Source of Support(s)\(^\text{11}\)

Less than half of clients (43%) indicated they were receiving at least one service from Continuing Care. The odds of having received other continuing care services prior to the nursing home application were 3.19 times higher for clients who were at the time of survey living in their own home or someone else’s home compared to those clients in assisted living facilities or waiting in the hospital. No difference emerged between those who had been receiving continuing care services and those who had not been by client age, client marital status, client gender, client source of income, time on the waitlist, district health authority,

\(^{10}\) Responses to this question are interesting. For example, many individuals only identified receiving “housekeeping” or “personal care” from Continuing Care Services. This finding may be related to respondents (i.e., proxy in Client Survey) not including what they themselves are doing on a regular basis or responding to the question only from an “external source of support” perspective. It is likely that in many situations, these services are being received by continuing care workers and some other source.

\(^{11}\) The source of support is not included for adult day program, physiotherapy and occupational therapy services that some clients were accessing, due to the respondents’ difficulty with understanding from whom the service was being received.
presence of caregiver or relationship of caregiver. However, awareness of the Continuing Care program approached statistical significance, meaning that those who indicated they were aware of the publicly-funded program prior to application were more likely to be using continuing care services prior to the nursing home application.

3.2 Receipt of services – Caregiver of client perspective

Similar to the results above, the most commonly reported types of assistance the clients of caregivers surveyed were receiving prior to the application for admission to a nursing home were housekeeping, grocery shopping, transportation, yard work/snow removal, and meal preparation (see Figure 3c). A greater proportion of caregivers reported their client was receiving “relief for the caregiver” (respite) than the clients themselves.

Figure 3c: Type of Service/Support Client Received Prior to Nursing Home Application (Caregiver Survey, N=85)

The source of support identified by the caregivers surveyed followed a similar pattern as noted by clients. For the most commonly identified types of support noted above (i.e., housekeeping, meal preparation, transportation, groceries), family was the most commonly identified provider (see Figure 3d). Continuing Care was the main provider when receiving “relief for the caregiver” and “personal care”. Again, this response pattern may be due to the respondent answering this question without recognizing themselves as a source of support.
Figure 3d: Among Clients Receiving Specific Services/Supports Prior to Nursing Home Application (see Figure 3c), The Proportion of Cases From Each Source of Support (Caregiver Survey, N=85)\textsuperscript{12}

![Bar chart showing the proportion of cases from each source of support, with categories for CCS, CCS and other, Family, Private, VAC, Other, and specific services like Transportation, Housekeeping, and so on.]

Note: “CCS and other” means continuing care services and either family, private or VAC. “Other” does not include continuing care services.

Approximately half of caregivers (53\%) indicated that their relative was receiving at least one service from Continuing Care. No difference emerged between those who had been receiving continuing care services and those who had not by caregiver age, caregiver gender, caregiver and client in same household, distance between caregiver and client, relationship to client, Caregiver Risk Screen score, time on the waitlist, awareness of Continuing Care program, awareness of continuing care services or awareness of who to contact about continuing care services. The two variables where differences emerged were situations where the care coordinator reviewed care options and length of time as a caregiver. If the client was already receiving other continuing care services, the care coordinator was 3.4 times less likely to review options to the nursing home admission. This may be linked to an assumption that there were no other services available to support the situation other than the nursing home admission.

\textsuperscript{12} The source of support is not included for adult day program, physiotherapy and occupational therapy services that some clients were accessing, due to the respondents’ difficulty with understanding from whom the service was being received.
Further, the odds of receiving other continuing care services before application were 2.72 times higher in situations where caregiver had been providing care for less than three years compared to those who had been providing care for three years or more.

3.3 Receipt of support and services – Interviews with client and caregivers

Similar to the survey results presented above, at the time of application for admission to a nursing home all five of the cases which were included in the follow up interviews are cases in which family members were providing support to the client, especially with transportation, shopping/appointments, meals, and housekeeping. In Donna and Ann’s situation, they were also assisting with personal care and medications. Beatrice was assisting with medications as well.

In addition to family support, three of the five situations also involved receiving some services from Continuing Care at the time of nursing home application. Donna’s mother, who was diagnosed with dementia and lived in Donna’s home (in a suite downstairs), had home support workers a couple of times a week to supervise/assist with meals and she also had caregiver respite hours. Clara, who lived on her own in an apartment with multiple chronic conditions such as diabetes, hypertension and also has some mobility challenges, was receiving some light housekeeping. Beatrice’s mother who was diagnosed with Alzheimer’s and broke her hip last summer, lived on her own and was receiving personal care from Continuing Care.

Support services were also being purchased privately in four of these cases. Max’s relative, who was not receiving any continuing care services before her hospital admission, had hired someone to come in every other week for a few hours to assist with light housekeeping. Her eyesight was deteriorating and she was having difficulty seeing to keep her apartment clean. “She would have swept and cleaned but you would never know it,” commented Max. Similarly, in Ann’s situation where no continuing care services were being received, they were paying for housekeeping and elder sitting services privately on a weekly basis. This care was purchased privately from family members who were unemployed and unable to find work in their community. In Donna’s mother’s situation, in addition to Donna’s care and that being provided by continuing care services.
care services, someone was hired for light housekeeping and caregiver respite. Beatrice’s mother was purchasing Lifeline. She also had a support network – neighbours who checked on her (one of whom was a health care professional), church members and friends who took her church service, and daughters and sons-in-law who assist with instrumental activities of daily living. Beatrice also had a regular taxi driver who picked her up for her weekly physiotherapy appointment.

In Donna’s, Beatrice’s, Clara’s and Max’s situations, at the time of application for admission to a nursing home, foot care was accessed privately. Clara spoke about the importance of receiving this in-home service at some length. Following the death of her husband, she was surprised to learn that her husband’s medical plan would continue to cover the cost of this service for her. She recognized that because of her diabetes, proper foot care was important. Having access to this in-home service, especially in view of her mobility issues and that she has to rely on others for transportation, was recognized as being very helpful.

In Ann’s situation, services from Continuing Care were offered for her husband’s care by the assessor with a co-payment fee. “We got together and we said ok, do we want a bunch of strangers lookin after dad? He’s not that bad.. yet. But we don’t want strangers. He wouldn’t like that ... so we are going to pay and get our own caregiver like. I’d rather that.” Consequently, Ann had hired relatives such as siblings, children and grandchildren to provide her respite in the care of her husband.
Section 4 – Application for admission to a nursing home

4.1 Reason for applying for admission to a nursing home

When asked, “Why did you apply for care in a nursing home?” both clients and caregivers noted key reasons for applying. Approximately half of clients (55%) and caregivers (47%) surveyed referenced factors related to the client’s health situation and concomitant care needs (see Table 4a)\(^\text{13}\). Examples include:

“Getting to the point where not much other choice-bad memory, unable to do things on own. ...Husband [the caregiver] is getting older himself, won’t be able to care for her much longer.”

“Poor eyesight. Fell outside and broken bones. Ended up in hospital and had recovery problems. Dementia set in...couldn’t live alone and has no one to live with.”

“Too much care and primary CG [caregiver] couldn’t do it.”

“...she had a couple of falls because her balance was off. Went home and took another fall...her memory was slipping and she was mixing up her medications”.

These comments suggest the care needs at the time were not seen as being supported by options other than care in a nursing home. Comments from more than one-quarter of clients (28%) and more than one-third of caregivers (35%) related to their understanding of the “long wait” for nursing home admission. They wanted to be “on the list” should the need become more urgent. Examples include:

“Knew it would probably just be a matter of time before nursing home care was needed, so figured they should apply given long waitlist.”

“Because of long waiting list, precautionary measure.”

“...because it takes a long time and as time goes by he’s getting worse...”

“...in case anything happened to family caregiver. We needed a back up plan.”

“We knew she was declining and about the long list...we wanted to be proactive in case of another stroke.”

Less than 10% of clients and caregivers specifically referenced something related to caregiver stress or burden despite reference during most of the surveys to the need for caregiver relief.

\(^\text{13}\) Comments to the question were reviewed and codes established that represented the key themes.
Table 4a: Why Did You/Client Apply for Care in a Nursing Home? Frequency of Coded Responses by Clients Surveyed and Caregivers of Clients Surveyed

<table>
<thead>
<tr>
<th>Reason</th>
<th>Clients N=125</th>
<th>Caregivers N=85</th>
</tr>
</thead>
<tbody>
<tr>
<td>Concern about client’s health/well being/care needs</td>
<td>55%</td>
<td>48%</td>
</tr>
<tr>
<td>Planning ahead due to recognized long wait</td>
<td>28%</td>
<td>35%</td>
</tr>
<tr>
<td>Caregiver stress/burden</td>
<td>8%</td>
<td>9%</td>
</tr>
<tr>
<td>Reason not clear or unspecified</td>
<td>9%</td>
<td>8%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

When reasons for nursing home application noted in the Client Survey were examined by key descriptors no significant differences emerged for gender of client, age of client, marital status of client, source of income, district health authority, awareness of Continuing Care program, awareness of continuing care services, aware of who to contact about services, and whether a care coordinator or other health professional reviewed options at time of application.

However, clients whose reason for applying for admission to a nursing home was “concern about client’s health/well being/care needs” had a waitlist time as of November 18, 2013 that was significantly shorter (Med=179 days) compared to those whose reason was related to “planning ahead due to recognized long wait” (Med=342 days). This finding is likely related to situations in which higher care needs were present than could be seen to be met in the client’s living situation and with the existing caregiver support. For example, when clients who were waiting in the hospital were removed from the Client Survey data, while not statistically significant, the difference between those seeking nursing home care because of client’s “health/well being/care needs” and those planning ahead was smaller (Med=190 days compared to Med=342 days, p=.066). This finding may suggest that those waiting in hospital were doing so for shorter period of time likely due to a change in health that precipitated hospital admission. This may also be related to current government policy that enables clients on the waitlist from the community to defer an offer without penalty, an option that is not available for someone waiting in the hospital.

Similar to the client responses, caregivers who reported the reason for applying for their relative’s application to the nursing home was “concern about the client’s health/well being/care needs” were on the waitlist as of November 18, 2013 a median of 208 days compared to those whose reason was related to “planning ahead” (Med=313 days). However, this difference was not statistically significant.
4.2 Who was involved in decision to apply for admission to a nursing home

The involvement of others in the decision to apply for admission to a nursing home is more common than the client him/herself making the decision alone. Physicians were identified as commonly having a role in the decision. In situations when the client was not waiting in a hospital, more than 40% of clients and caregivers identified physician involvement (see Table 4b). It was noted in several cases that the physician suggested/encouraged application because of the “long wait” should the client’s situation change. In other instances, it was noted that a physician encouraged placement due to no other options for the clients’ level of care needs. Examples include:

“Too much care and primary CG [caregiver] couldn't do it. Geriatrician assessed him at hospital and too heavy care—must go to NH.”

“He was admitted to hospital and wife has health challenges so the DR [doctor] suggested he go on the list.”

“Dr...sees client twice yearly and has a nurse practitioner. He told caregiver spouse to do the application because of long waitlist.”

In 20 to 30% of cases, a care coordinator was identified as being involved in the decision (see Table 4b). Similar messages related to “long wait” and “lack of appropriate options” were attached to situations in which the care coordinator was involved in the decision. Examples include:

“Daughter wanted respite - [care coordinator] suggested she apply now due to 2 years wait”.

“Family applied based on her care coordinator who recommended they apply.”

“[Care coordinator] recommended we get on the 2 year waitlist.”

“Care coordinator said we should. I didn’t think I was ready.”

“Spoke with care coordinator for precautionary/proactive measure. Home care only provides so many hours a month.”
Table 4b: Key People Involved in the Decision to Apply for Admission to a Nursing Home. Percent of Responses by Clients Surveyed and Caregivers of Clients Surveyed

<table>
<thead>
<tr>
<th>People Involved</th>
<th>Clients N=125</th>
<th>Caregivers N=85</th>
</tr>
</thead>
<tbody>
<tr>
<td>Client</td>
<td>5%</td>
<td>7%</td>
</tr>
<tr>
<td>Family</td>
<td>19%</td>
<td>32%</td>
</tr>
<tr>
<td>Physician</td>
<td>9%</td>
<td>7%</td>
</tr>
<tr>
<td>Care Coordinator</td>
<td>7%</td>
<td>4%</td>
</tr>
<tr>
<td>Other health professional (e.g., hospital social work, psychiatrist, geriatric nurse, nurse practitioner)</td>
<td>2%</td>
<td>2%</td>
</tr>
<tr>
<td>Client, family, physician</td>
<td>22%</td>
<td>23%</td>
</tr>
<tr>
<td>Client, family, care coordinator</td>
<td>11%</td>
<td>7%</td>
</tr>
<tr>
<td>Client, family, care coordinator, physician</td>
<td>12%</td>
<td>11%</td>
</tr>
<tr>
<td>Client, family, other health professional</td>
<td>4%</td>
<td>1%</td>
</tr>
<tr>
<td>Other</td>
<td>8%</td>
<td>5%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

Table 4c: Key People Involved in the Decision to Apply for Admission to a Nursing Home. Percent of Responses by Clients Surveyed and Caregivers of Clients Surveyed [Clients Waiting in Hospital Not Included]

<table>
<thead>
<tr>
<th>People Involved</th>
<th>Clients N=108</th>
<th>Caregivers N=78</th>
</tr>
</thead>
<tbody>
<tr>
<td>Client</td>
<td>6%</td>
<td>8%</td>
</tr>
<tr>
<td>Family</td>
<td>20%</td>
<td>31%</td>
</tr>
<tr>
<td>Physician</td>
<td>9%</td>
<td>8%</td>
</tr>
<tr>
<td>Care Coordinator</td>
<td>8%</td>
<td>4%</td>
</tr>
<tr>
<td>Other health professional (e.g., hospital social work, psychiatrist, geriatric nurse, nurse practitioner)</td>
<td>3%</td>
<td>3%</td>
</tr>
<tr>
<td>Client, family, physician</td>
<td>22%</td>
<td>23%</td>
</tr>
<tr>
<td>Client, family, care coordinator</td>
<td>13%</td>
<td>8%</td>
</tr>
<tr>
<td>Client, family, care coordinator, physician</td>
<td>13%</td>
<td>10%</td>
</tr>
<tr>
<td>Client, family, other health professional</td>
<td>3%</td>
<td>1%</td>
</tr>
<tr>
<td>Other</td>
<td>5%</td>
<td>5%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

Analysis was conducted to understand differences amongst the clients in terms of who was involved, by reason for the decision. For all clients (N=125), when the client or family was involved in the decision to apply for admission to a nursing home, the reason for the application was significantly less likely to be “concern about the client’s health/well being/care needs” compared to when the client or family was not involved in the decision (Odds Ratio=.38). In other words, there was more of a tendency for the doctor/health care

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14 This is a derived variable. Open ended comments were reviewed at the individual level, categories established which reflected the range of individuals identified, and then responses coded.
professional to be involved when the decision was related to client’s health/care needs. This same analysis with a sub sample which excluded clients who were waiting in a hospital (N=108) found no significant relationship between client and family involvement and reason for application ($\chi^2(2)=3.33$, p=.19).

### 4.3 Awareness of other continuing care services

For situations in which the client was not waiting in the hospital, approximately three-quarters of clients and caregivers reported being aware of the Continuing Care program and approximately two-thirds reported being aware of specific services available through the publicly-funded program (see Table 4d). These patterns were similar for the situations in which the client was waiting in the hospital (see Table 4e). A higher proportion of caregivers reported being aware of how to access services compared to the clients themselves (70% compared to 57%) (see Table 4d).

For situations in which the client was not waiting in the hospital, alternatives to nursing home placement were reviewed by the care coordinator at the time of application for admission to a nursing home in close to three-quarters of the client situations (72%) and higher in caregiver situations (80%) (see Table 4d). In about half of the cases other health professionals reviewed options to nursing home admission. In the majority of situations in which the client was waiting in the hospital, clients and caregivers report that options to admission to a nursing home were reviewed by a care coordinator or other health professional at the time of application (see Table 4e).

Table 4d: Awareness of Continuing Care Program and Services and Opportunities to Explore Options Other than Nursing Home. Percentage of Responses by Clients Surveyed and Caregivers of Clients Surveyed [Clients Waiting in Hospital Not Included]

<table>
<thead>
<tr>
<th></th>
<th>Clients N=108</th>
<th>Caregivers N=78</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aware of Continuing Care Program at time of application</td>
<td>78%</td>
<td>75%</td>
</tr>
<tr>
<td>Aware of continuing care services at time of application</td>
<td>70%</td>
<td>68%</td>
</tr>
<tr>
<td>Aware of who to contact about continuing care services at time of application</td>
<td>57%</td>
<td>70%</td>
</tr>
<tr>
<td>Care coordinator reviewed options at time of application</td>
<td>72%</td>
<td>80%</td>
</tr>
<tr>
<td>Other health professional reviewed options at time of application</td>
<td>51%</td>
<td>50%</td>
</tr>
</tbody>
</table>
Table 4e: Awareness of Continuing Care Program and Services and Opportunities to Explore Options Other than Nursing Home. Number\(^{15}\) of Responses by Clients Surveyed and Caregivers of Clients Surveyed [Only Clients Waiting in Hospital]

<table>
<thead>
<tr>
<th>Awareness of Continuing Care Program and Services and Opportunities to Explore Options Other than Nursing Home</th>
<th>Clients N=17</th>
<th>Caregivers N=7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aware of Continuing Care program at time of application</td>
<td>13</td>
<td>5</td>
</tr>
<tr>
<td>Aware of continuing care services at time of application</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td>Aware of who to contact about continuing care services at time of application</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>Care coordinator reviewed options at time of application</td>
<td>13</td>
<td>5</td>
</tr>
<tr>
<td>Other health professional reviewed options at time of application</td>
<td>10</td>
<td>3</td>
</tr>
</tbody>
</table>

4.4 Prevention of application for admission to a nursing home

When asked, “Looking back, is there anything that would have prevented you from seeking care in a nursing home?” the majority of clients offered comments that indicated nothing could have prevented the need for the nursing home application (81%). The response to this same question in the Caregiver Survey was less certain, although close to two-thirds (65%) made similar assertions regarding prevention\(^{16}\). This was a difficult question for both clients and caregivers to answer because of its “retrospective” nature, as well as the recognition that responses may have been framed by respondents’ understanding of available supports or services. For those individuals whose response was coded as “nothing would have prevented” and who provided a valid response (n=62 clients; n=23 caregivers), the most common reason given in both the Client Survey and Caregiver Survey was related to the “client’s health status” (39% clients, 39% caregivers). In other words, the health situation of a client (and presumably resulting care needs) was felt to be serious enough to warrant a nursing home placement.

Some clients (19%, n=21) and some caregivers (35%, n=25) did indicate that something may have prevented the need to apply for a nursing home bed (see Table 4f). For those individuals whose response was coded as “something could have prevented” and who provided a valid response (n=19 clients, n=23 caregivers) the majority of responses suggest that enhancements to services would have made a difference (i.e., broader range of services, more service hours, funding to purchase services).

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\(^{15}\) Not appropriate to report percentages due to low number of cases.

\(^{16}\) For both the Client Survey and Caregiver Survey, respondents who answered “don’t know” or whose response when reviewed by staff was “not clear” are not included.
Table 4f: Factors that Might Have Prevented the Application for Admission to a Nursing Home. Percentage of Coded Responses by Clients Surveyed and Caregivers of Clients Surveyed of those Offering a Valid Response

<table>
<thead>
<tr>
<th>Factor</th>
<th>Clients (n=19 out of 21)</th>
<th>Caregivers (n=23 out of 25)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Broader range of services</td>
<td>16%</td>
<td>30%</td>
</tr>
<tr>
<td>More service hours</td>
<td>21%</td>
<td>17%</td>
</tr>
<tr>
<td>Funding for home modifications</td>
<td>16%</td>
<td></td>
</tr>
<tr>
<td>Funding to provide care</td>
<td>11%</td>
<td>22%</td>
</tr>
<tr>
<td>Safety</td>
<td>11%</td>
<td></td>
</tr>
<tr>
<td>Client health status (e.g., not having fallen, no change in health)</td>
<td>26%</td>
<td>22%</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td>9%</td>
</tr>
</tbody>
</table>

There was a marginally significant relationship between those community-waiting clients who were currently receiving other continuing care services and who indicated that something could have prevented the nursing home application ($\chi^2(1)=3.63$, p=.06). The odds of a client indicating something could have prevented the application were 6.1 times higher for clients who were currently receiving other continuing care services compared to those clients who were not. The same relationship when analyzed for the caregiver sample did not find a significant difference.

4.5 Application for admission to a nursing home – Interviews with client and caregivers

Each situation involved in the follow up interviews present some insights into the level of awareness about other continuing care services and the key individuals involved in the decision to apply for admission to a nursing home. The influence of the physician and care coordinator was further exemplified in these cases. Moreover, for Clara as well as Max’s relative and Donna’s mother, the nursing home application could have been prevented either through direct services from Continuing Care or funding to enable the purchase of additional help. In the case of Beatrice’s mother, the application was primarily a result of the daughters’ initiative as the mother was in denial of needing home care let alone long term care. The impetus for the application for Anne’s husband primarily came from a physician and the lengthy wait for long term care. As no additional continuing care services were being used, only changes in the health professional’s interpretation of the waitlist would have altered the timing of the application in Anne’s case.
Clara did not want to go to a nursing home but her application was precipitated by her concern of not being a burden on her family and therefore she was planning for her future should her health condition deteriorate. She was aware of other continuing care services prior to the nursing home application and had been receiving a few hours of light housekeeping. She had made the decision on her own, but was dreading the point that she would have to move from her apartment - where she benefitted from a social network and familiarity with the community.

Since the time of nursing home application in the fall of 2012, Clara has required more support due to changes in her health. In part, some of her decline was attributable to her not receiving appropriate help and assistance with her meals which was very important to the regulation of her blood sugar. She commented that her care coordinator had not been in touch on any regular basis and that the additional service hours she was allocated, for help with meals and more housekeeping, were a result of trips to Emergency Department for acute situations. During one of her recent ER visits, she shared conversations she had with the doctor and another health care professional\(^\text{17}\) about her going to the nursing home. The doctor was of the opinion that she should be going to the nursing home now, while the other health professional talked to her about returning home and getting more service. While the health care professional’s message was preferred by Clara the rationale was perhaps inappropriately presented by this individual as Clara relates being told “it’s people like you that are taking up a bed in a nursing home when you could be at home.” This upset Clara because she certainly did not want to be taking up someone else’s bed if they needed it more. Following this ER visit, additional hours for housekeeping and meal time were added. In time, Clara may also require some assistance with personal care (dressing, bathing) and medication management but at the time of the interview, she was able to perform those tasks. Clara had family support and with improved case management and some additional services from Continuing Care, her desire to stay at home and her situation could be maintained for some time.

\(^{17}\) Participant unable to identify specific position/profession but likely the hospital social worker or hospital based care coordinator.
Max's relative’s application for admission to a nursing home arose after she was hospitalized due to injury from a fall. She had decided to go out of her apartment building on her own, which Max described as “poor judgement” on her part, and fell several blocks from her building. She had surgery and then moved to an Orthopedic Wing where she stayed for several weeks receiving treatment until ready for discharge. She also experienced, what he described as, “very agitated states” during her time in the hospital. At times she became very upset, agitated, experienced bad dreams and was reported to be “seeing things”. It appeared that her mental health changed dramatically during this time and while she may have been able to go home with some supports because physically she had gained, her mental state seemed to be more the concern. A doctor indicated that “she would not be able to go home on her own” so Max met with the hospital social worker to discuss discharge options – home care and nursing home. Max’s relative assumed she was going home but at times she was not aware of where she was. It did not seem feasible that she could return to her apartment and Max was unable to have her live with him. He would have continued to help her as best he could, but he talked about three barriers to the proposed services offered. One, was lack of nighttime supervision when she was known to get up through the night. Two, was his concern that the service plan could change with little notice (even within a day) and she would be on her own without necessarily the cognitive capacity to manage the situation. Finally, he spoke extensively about the lack of consistency in the workers who would be coming to help her and how he did not feel this would work for her given the trend that she becomes more confused within unstable/unfamiliar situations. He also spoke about her disposition being problematic with inconsistent workers. He described her as someone who a worker would need to get to know her ways and habits in order to best work with her. He talked about the homemaker they had hired and that it was working out. Max did not see this happening with a variety of workers coming and going.

Max's relative’s situation also offered some insight into how her hospitalization may have been prevented if she had been receiving more help at the time. Max's relative lived in an apartment complex where she benefitted from social interaction with other (similar to Clara), was mobile and was able to take care of her own personal care. Because of her eyesight, her ability to keep her apartment clean became a factor, as well as preparing meals and the task of eating itself (she had trouble manoeuvring utensils and would tend to eat “easy” things). Max admits that he was not aware or fully understood the public home care program and the situation may have been handled differently with more professional monitoring of her changing needs. The hours of the private homemaker were increased to help with more cleaning tasks around the kitchen, going through food in the fridge and providing some companionship. It was recognized, however, that her behaviour was becoming more unusual and she was not eating what he considered to be regular and well-balanced meals. He was also not fully aware of the degree of dementia that she was experiencing until her doctor mentioned to him offhandedly one day. Max commented that he did not feel there was sufficient attention or information given to what this condition could have meant to her.
situation (e.g., supervision and safety) and, again, had Max been more aware, he may have been able to help her to plan better. Also, it is difficult to confirm, but perhaps her increasing confusion was associated with poor nutrition which in turn could have contributed to her fall.

A fall also precipitated the application for admission to a nursing home for Beatrice’s mother. Her mother lived by herself and the two daughters lived about 30 minutes away. The nursing home application was limited to the facility that was located close to both of the daughters’ homes. The caregivers had looked into an assisted living facility, but found it too expensive. They were unaware that another nearby facility was also a long term care facility with private bedrooms, a feature they wanted.

The daughter described her mother as having a very independent personality. She was resistant to all formal outside help, but a son-in-law convinced her that she should accept some services in case she might need some in the future. The importance of consistency of staff emerged as a barrier to involving more home care services. Beatrice’s mother was receiving one visit for personal care (bath) and some housekeeping services. Her initial assessment allocated more services, but because Beatrice’s mother continually refused the workers to enter the home, the care coordinator reduced service.

One of the challenging issues for Beatrice’s daughter was constant worry that her mother would fall again. She had the Life line service, but as Beatrice lived 30 minutes away and neither she nor her husband drove at night, it was a worry. Beatrice used to call her mother every night, but since she had come to realize that her mother did not remember her calls, she had reduced their frequency. The physical design of the home may have been an issue in this situation although it was not identified as a specific problem by Beatrice. The mother appeared to use three floors in the home due to the location of her bedroom, television, and kitchen.

Donna had purposively built a suite in her home so she could care for her mother and neither she nor her mother wanted her to be in a nursing home. In this situation, the main factor precipitating nursing home application was “planning for the future” should Donna become unable to continue to support the increasing care her mother would require. Over the previous two years, Donna had her own health problems. Her mother was not involved in the decision to apply for admission to a nursing home. Donna had experienced a lot of guilt about the application process, but saw this planning as a safety net for her mother. She took time to research and visit several nursing homes to ensure the ones on her list were ones she was comfortable with. Since the time of nursing home application, Donna’s mother had received more hours from Continuing Care and Donna had increased the hours of the private caregiver. While they lived in the same house and Donna continued to help her mother in many ways (prepared meals, medications, personal care), she was comforted from knowing someone was with her mother during meals, getting her ready for bed, etc. Donna described a positive and supportive relationship with the care coordinator. Either
Donna called or the care coordinator called her to discuss service adjustments, but Donna was aware that there was a maximum to what she could receive through Continuing Care despite her mother’s increasing care needs and her own reduced capacity to provide direct care.

Donna spoke at length about the challenges she faced with the workers not being able to administer medications to her mother (despite her willingness to sign a waiver relinquishing them of any responsibility). This would have been of great help to her situation as her mother required medications twice a day with meals. While the workers could get the pills out of the dossier and tell her mother to take them, they could not administer them. On many occasions, the pills were not taken and this was very frustrating and upsetting to Donna. She also spoke about the lack of workers’ ability to prepare meals as part of the service. Again, this would be a great help to the situation but was not available. So Donna prepared meals and froze them so the workers were able to “heat and serve”. Donna wanted her mother to be able to stay with her but required more service. If she could get more home support hours and respite, she would in turn purchase more service from her private caregiver herself so more hours each week would be covered.

In the case of Anne and her husband, the concern of having strangers coming into their home to take care of him was paramount to the refusal to accept home care services. Also significant was the large extended family that lived in the surrounding community and from whom Anne purchased services. The initial assessment from Continuing Care occurred in the fall of 2012 following a specialist appointment. Her husband had been on medication to stabilize the dementia but his condition began to deteriorate. Anne recalls the geriatrician saying “I think it’s time for you to apply for the home, cause I think he’ll be in a home in two year’s time.”

In addition to having the support for family and friends, Anne’s positive nature was evident in the discussion on the caregiving situation. She recalled a time not long after the diagnosis when her husband stopped in the middle of a sentence, “he went right blank and sad.. and I said [husband’s name] this is our life from now on...This is our future... pause.. we can have two choices right now. You feel like crying and I feel like crying but we can either cry, and every time this happens, we’ll cry; or we can laugh about it and make a joke about it.... Now what do you want to do? We’ll laugh about it. And after that there is no more problem with it, we would just laugh.”

Anne carried a tremendous responsibility in this client’s situation. She was trying to maintain as much positivity and functionality as possible. For example, she stood outside the shower only providing cues rather than helping her husband with bathing, determined that he would remember what to do with soap and face cloth, razor and shampoo without cueing. Although her physician and others have suggested that she should obtain a respite bed in a nursing home for a week to have a break, she does not want to leave him with others.
Section 5 - Usage of home care services and nursing home need

5.1 Receipt of services – Client perspective

The most commonly reported types of assistance clients were receiving at time of survey were housekeeping, meal preparation and planning, transportation and grocery shopping. In fact, more than 90% of clients were receiving assistance with these instrumental activities of daily living (see Figure 5a).

A greater proportion of clients were receiving personal care services at the time of survey than at the time of application for admission to a nursing home. Similarly, there is a noted increase in the proportion of clients who reported receiving relief for their caregiver between the two points in time. This may be an indication of increasing care needs that occurred during the waiting period for admission to a nursing home or that the contact with Continuing Care regarding nursing home admission triggered this service to be put in place.

Figure 5a: Type of Service/Support Client Received at Time of Survey (N=125)

No significant differences emerged for those currently receiving other continuing care services and those who were not at the time of survey by gender of client, marital status,

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Note re “Funding”: The question was worded “Funding to hire care provider” however all responses offered that pertained to client/caregiver receiving money are included here (e.g., Caregiver Benefit, Caregiver Allowance).

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source of income, district health authority, time on waitlist, presence of caregiver, awareness of Continuing Care program at time of application, aware of continuing care services at time of application, aware of who to contact about services, whether care coordinator reviewed options at time of application, and receipt of continuing care service before application. The odds of currently receiving services were 2.30 times higher for clients living in someone else’s home compared to clients living in their own home. Odds of receiving continuing care services increased when clients lived in their own home or someone else’s compared to those living in assisted living facilities.

The source of support varied by type of support clients were receiving. However, for the most commonly identified types of support noted above (i.e., housekeeping, meal preparation, transportation, grocery shopping) family was the most commonly identified provider (see Figure 5b). Continuing Care was identified more frequently as a provider of “personal care” services and “relief for caregiver”.

Figure 5b: Among Clients Receiving Specific Services/Supports at Time of Survey (see Figure 5a), The Proportion of Cases From Each Source of Support

Note: "CCS and other" means continuing care services and either family, private or VAC "Other" does not include continuing care services

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19 The source of support is not included for adult day program, physiotherapy and occupational therapy services that some clients were accessing, due to the respondents’ difficulty with understanding from whom the service was being received when not paying for directly through a private provider.
5.2 Receipt of services – Caregiver of client perspective

Similar to results above, the most commonly reported types of assistance the clients of caregivers surveyed were receiving at the time of survey were housekeeping, grocery shopping, transportation, yard work/snow removal, and meal preparation (see Figure 5c). Likewise, a greater proportion of caregivers reported that the client was receiving personal care services at the time of survey than at the time of application for admission to a nursing home. Similarly, there is a noted increase in the proportion of clients receiving relief for their caregiver between the two points in time.

Figure 5c: Type of Service/Support Client Received at Time of Survey (Caregiver Survey, N=85)

No significant differences emerged for those currently receiving other continuing care services and those who were not at the time of survey by gender of caregiver, relationship of client to caregiver, time on waitlist, length of caregiving, client in own home compared to somewhere else, client in same house as caregiver, Caregiver Risk Screen score, awareness of Continuing Care program at time of application, aware of continuing care services at time of application, aware of who to contact about services, and whether care coordinator or other health professional reviewed options at time of application for admission to a nursing home admission. However, the odds of currently receiving services were 5 times higher for
those were also receiving services before application for admission to a nursing home compared to those who were not.

The source of support for the services currently received that were identified by the caregivers followed a similar pattern as noted by the clients. For the most commonly identified types of support being received (i.e., housekeeping, meal preparation, grocery shopping, transportation), family was the most commonly identified provider (see Figure 5d). Continuing Care was the main provider for those receiving “relief for caregiver”.

Figure 5d: Among Clients Receiving Specific Services/Supports at Time of Survey (see Figure 5c), The Proportion of Cases From Each Source of Support (Caregiver Survey)²⁰

²⁰ The source of support is not included for adult day program, physiotherapy and occupational therapy, services that some clients were receiving, due to the respondents’ difficulty with understanding from whom the service was being received.
5.3 Experience with current services and need

Both clients and caregivers were asked to identify what additional types of support would be needed to keep the client at home longer. Respondents could identify more than one type of support. Common responses that were consistent across both respondent groups were services such as personal care, foot care, physiotherapy, relief for caregiver, and funding (see shaded areas in Table 5a). Responses related to “funding” included several references to support with expenses of assisted living facilities, hiring of some (or more) private help, and to offset expenses for supplies. Two individuals referenced the need for nighttime help, which they felt would be very expensive.

Table 5a: Types of Additional Support Needed to Stay Home Longer (Client and Caregiver Perspective; Clients Waiting in Hospital Not Included)

<table>
<thead>
<tr>
<th>Service</th>
<th>Client (178 responses)</th>
<th>Caregiver (155 responses)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Housekeeping</td>
<td>7%</td>
<td>7%</td>
</tr>
<tr>
<td>Meal planning</td>
<td>6%</td>
<td>6%</td>
</tr>
<tr>
<td>Meal preparation</td>
<td>7%</td>
<td>6%</td>
</tr>
<tr>
<td>Personal care</td>
<td>9%</td>
<td>9%</td>
</tr>
<tr>
<td>Foot care</td>
<td>8%</td>
<td>10%</td>
</tr>
<tr>
<td>Grocery shopping</td>
<td>2%</td>
<td>3%</td>
</tr>
<tr>
<td>Transportation</td>
<td>6%</td>
<td>7%</td>
</tr>
<tr>
<td>Yard work/snow removal</td>
<td>3%</td>
<td>5%</td>
</tr>
<tr>
<td>Home maintenance</td>
<td>6%</td>
<td>2%</td>
</tr>
<tr>
<td>Medications</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Physiotherapy</td>
<td>8%</td>
<td>10%</td>
</tr>
<tr>
<td>Occupational therapy</td>
<td>4%</td>
<td>5%</td>
</tr>
<tr>
<td>Adult day program</td>
<td>6%</td>
<td>6%</td>
</tr>
<tr>
<td>Relief for caregiver</td>
<td>8%</td>
<td>9%</td>
</tr>
<tr>
<td>Supervision/support</td>
<td>3%</td>
<td>3%</td>
</tr>
<tr>
<td>Funding</td>
<td>10%</td>
<td>9%</td>
</tr>
<tr>
<td>Other</td>
<td>6%</td>
<td>4%</td>
</tr>
</tbody>
</table>

In addition to the items above, as part of the “other” category several respondents made reference to the need for “companionship”, “friendly visitors” or “social interaction” as a beneficial support.

Analysis of both clients and caregivers who said they may benefit from an additional support for the client to stay home longer was completed in relation to whether they were currently
receiving that support from Continuing Care\textsuperscript{21} (e.g., client said yes to needing housekeeping by whether they were receiving housekeeping from continuing care service; client said yes to meal planning by whether they were receiving meal planning from continuing care service, etc.). For clients, there was no significant relationship for any of the additional supports identified by whether they were already receiving the support\textsuperscript{22}. For caregivers, similar findings emerged except the odds of caregivers identifying they needed funding was 4.23 times higher in situations where funding was currently received ($\chi^2(1)=4.68, p<.05$). This was likely due to their situation benefiting from the existing financial support to purchase help and recognizing the importance of receiving more funding to purchase additional support.

In the Caregiver Survey an additional question was asked specific to additional supports. Forty-three percent of caregivers responded “yes” when asked specifically “Given the support you provide to your [relative], do YOU, as a caregiver have a need for support?”

The most commonly identified response was “relief/time away” to give him/her a break (see Figure 5e). There was interest in receiving funding to be able to purchase more help with approximately 15% of caregivers identifying this type of support specifically in this question.

Figure 5e: Types of Support Needed for Caregiver (Caregiver Perspective, N=33)

Clients and caregivers were both asked to comment on what changes to continuing care services would be helpful in keeping the client at home longer. The most common response pertained to how services are delivered. Close to 30% of both clients and caregivers identified the importance in having the same workers come to their home. Consistency in workers often related to situations in which cognitive impairment was present and changes

\textsuperscript{21} This was done for supports expected to be available from CCS such as housekeeping, meal planning, meal preparation, personal care, foot care, medication assistance, adult day program, caregiver relief and funding.

\textsuperscript{22} Results should be used with caution as cell violation for some cross tabulations exist.
in routine and setting could be disruptive. Similar to previous findings, caregivers identified the need “relief for the caregiver” and both respondents indicated the need for “more hours of service”.

Figure 5f: Changes in Continuing Care Services to Help Keep Client at Home [Hospital waiting clients not included]
5.4 Nursing home need

Slightly more than one third of clients (37%) and caregivers (36%) surveyed indicated that, if offered a bed tomorrow, they would accept it. Conversely, approximately half of clients (49%) and caregivers (51%) indicated they would not accept a bed (see Figure 5g and Figure 5h).

The most commonly identified reason when willing to accept a bed was related to perceived need of the client (see Table 5b). It was not clear if these responses would be different if more services were available or whether nursing home was viewed as the only option for the circumstances. A few individuals indicated “non need” responses such as the client wanting to go to the nursing home or that the client/caregiver did not want to decline bed (even though perhaps client situation may not need nursing home yet). For example, in a couple of cases coded as “desire to go to nursing home” comments referenced that the client was willing and comfortable about going, the benefit of having more activities or stimulation, or increased sense of security.

The most commonly identified reason when willing to accept a bed was related to perceived need of the client (see Table 5b). It was not clear if these responses would be different if more services were available or whether nursing home was viewed as the only option for the circumstances. A few individuals indicated “non need” responses such as the client wanting to go to the nursing home or that the client/caregiver did not want to decline bed (even though perhaps client situation may not need nursing home yet). For example, in a couple of cases coded as “desire to go to nursing home” comments referenced that the client was willing and comfortable about going, the benefit of having more activities or stimulation, or increased sense of security.

Table 5b: Reasons for Accepting Nursing Home Bed Tomorrow if Offered (Client and Caregiver Perspective, Coded based on open ended comments)

<table>
<thead>
<tr>
<th>Reason</th>
<th>Client</th>
<th>Caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing home level of care needed now</td>
<td>34%</td>
<td>52%</td>
</tr>
<tr>
<td>Client in hospital</td>
<td>24%</td>
<td></td>
</tr>
<tr>
<td>Desire to go to a nursing home</td>
<td>16%</td>
<td>9%</td>
</tr>
<tr>
<td>Not to miss opportunity/risk deferring</td>
<td>3%</td>
<td>13%</td>
</tr>
<tr>
<td>Client willing, but no choice</td>
<td>5%</td>
<td>13%</td>
</tr>
<tr>
<td>Other</td>
<td>18%</td>
<td>13%</td>
</tr>
</tbody>
</table>

Similarly, perceived lack of clients’ need for nursing home care was commonly referenced when offering an explanation as to why they would not accept a bed tomorrow (see Table
5c). As well, both clients and caregivers commonly noted the desire to maintain the situation at home as long as possible. Responses provided that were coded as “negative attitude towards nursing home” referenced the state of other residents (“bibs and drooling”), terrible food, anticipated decline once admitted due to different care, or not liking institutions.

Table 5c: Reasons for Not Accepting Nursing Home Bed Tomorrow if Offered (Client and Caregiver Perspective, Coded based on open ended comments)

<table>
<thead>
<tr>
<th>Reason</th>
<th>Client</th>
<th>Caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing home level of care not yet needed</td>
<td>43%</td>
<td>48%</td>
</tr>
<tr>
<td>Negative attitude towards nursing home</td>
<td>3%</td>
<td>16%</td>
</tr>
<tr>
<td>Desire to stay at home as long as possible</td>
<td>38%</td>
<td>32%</td>
</tr>
<tr>
<td>Other</td>
<td>15%</td>
<td>4%</td>
</tr>
</tbody>
</table>

When examining key descriptors to understand these response patterns better (not including hospital waiting clients), no significant differences emerged for clients who said they would or would not by gender of client, age of client, marital status of client, source of income, time on waitlist, district health authority, awareness of Continuing Care program, awareness of continuing care services, whether care coordinator or other health professional reviewed options at time of application, and reason for nursing home application. Significant differences did exist, however, based on where the client was living at time of survey. The odds of the client not accepting a bed were 4.2 times higher when living in their own home compared to clients living in someone else’s home or an assisted living facility.

Further, no significant differences emerged for caregivers who said they would or would not accept a bed tomorrow by (not including hospital waiting clients) gender of caregiver, time on waitlist, length of care, whether client and caregiver in same household, change in client health, awareness of Continuing Care program, awareness of continuing care services and whether care coordinator or other health professional reviewed options at time of nursing home application. Significant differences did exist, however, based on caregiver age and whether client had gone to the emergency department since applying for admission to a nursing home. The age of caregivers who would accept a bed was significantly lower (M=61 years, SD=11.95) than caregivers who would not accept a bed (M=68 years, SD=10; p<.05). The odds of accepting a bed were five times higher when community waiting client had gone to the ER compared to if the client had not gone to the ER.
5.5 Home care usage and need for nursing home admission – Interviews with client and caregivers

At the time of survey, both Clara and Donna’s mother were reporting an increase usage of continuing care services since the application for admission to a nursing home and in both cases, while family were still involved, Continuing Care was also now involved in meal preparation. For Clara, this increase in service came as a result of an ER visit and discussion with hospital staff before being released. She was initially upset about the idea of these workers coming into her home to do this service, but it appeared that she misunderstood what the workers would be doing, and once this was further discussed with her daughter and son-in-law, she was fine with the arrangements. She would also be open to receive more services if it meant she could stay in her apartment longer. She was aware that she could call the care coordinator and discuss her situation at any time but appears to be the kind of person who would not do so unless in a crisis. It appeared that she would benefit from more regular contact by the care coordinator to assess the need for more service. For Donna, ongoing communication with the care coordinator about Donna’s health and a fall that her mother experienced since the time of application, necessitated the increase in service.

Both Clara and Donna discussed what type of supports would be needed to keep the client at home longer. For Donna, it was additional hours for personal care as her mother’s care needs have increased and Donna is unable to lift or assist with transfers. For Clara, it was more assistance with meals, medication management, and some personal care (e.g., dressing, bathing).

Donna spoke at length about the good relationship she and her mother have with the workers assigned to her case. She reported that there seemed to be regularity in the staff and her mother responded well to these workers – viewing them as “friends” coming over to visit with her. Her mother has no problem with the workers helping her get ready for bed (washing, changing into bed clothes) but would not allow them to put her to bed – this she insisted that her daughter did. Donna felt that this was an important part of her day where she and mother go through a routine associated with her “tuck in”. She also spoke at length about

| Clara-client in own home with multiple chronic health conditions, receiving continuing care services |
| Anne-caregiver of spouse with dementia, not receiving continuing care services |
| Max-family member of client in hospital |
| Beatrice-caregiver of mother in own home with dementia, receiving continuing care services |
| Donna-caregiver of mother with dementia, mother lives with caregiver, receiving continuing care services |
the need for workers to be able to administer medications. Workers were present during the times when her mother was to take her medication and assisted by getting the pills out of the dossier, but they were unable to give the pills to her mother. This meant that on many occasions her mother did not receive her required medications.

In most of the care situations involved in the interview, the client would not accept a bed tomorrow if offered. For example, at the time of the survey, Clara, Donna, Beatrice and Anne would not accept the bed if offered tomorrow. There was a similar response pattern at the time of the interview except for Donna’s mother whose situation had further deteriorated and was recently hospitalized. Given Donna’s health situation, and that a bed was being offered in her preferred facility, arrangements for her mother’s admission were being made.

At the time of the survey, neither Beatrice nor Anne’s situation had increases in services. In Beatrice’s situation with her mother, the continuing care services had actually decreased as her mother continually refused to accept regular home care services. When asked what could be done to reduce the need for nursing home care and allow her mother to stay longer in her home – consistency of staff was mentioned as was the need for 24-hour supervision. Her mother was very reluctant to accept the need to move to a long term care facility. Beatrice suggested what her mother really wanted was for one of the daughters to move in with her. They had tried to provide this level of care on a temporary basis shortly after she fell and broke her hip, but this care arrangement was not manageable.

Beatrice did not feel that they would accept a bed if offered tomorrow, but she believed her mother would need one soon. She and her sister had power of attorney and she felt, that if necessary they might have to make that decision for nursing home entry despite the mother not being in agreement.

Anne would not accept a nursing home bed tomorrow for her husband. She felt she was managing okay for now with the family help and with paid support coming from extended family members. She thought that they would have to eventually have someone come to help him shower and would do this before moving him to a facility. So for Anne, there will be a time when outside formal help from Continuing Care will be necessary. She also felt that while she did not need the bed at the time of interview, it was likely that by the fall of 2014 that they would.

For Max’s relative, a bed would be taken tomorrow, if offered, both at the time of survey as well as the time of interview. It had been almost a year and he described the Alternate Level of Care unit as initially unsatisfactory conditions and an environment that was not supportive of her needs. The last few months, however, had improved. There was more routine and structure to her day, she was getting the assistance from staff that she needed, and the 4-5 staff who worked on the unit came to know how to manage her. However, he anticipates that getting her settled into a nursing home as being good for her at this time. He commented that the situation he, and other families with someone in the unit, have
endured over the past year was not acceptable. From his “caregiver” perspective he would have benefited greatly from more information about her health situation and the expected progression of her decline as well as having more information about the system [referring to both home care services and nursing home admission process] and how it worked. He felt that the “system” left things to the last minute when it was a “crunch” or “crisis” and it made making the decision required of him difficult to make. On repeated occasions he commented on “not knowing if he made the right decision” or “how to know what is the right decision”.
Section 6 - Advice to government

At the conclusion of the survey, clients and caregivers were asked "If you could give the government one piece of advice about how to better support people who want to remain at home, what would it be?" While not all respondents took advantage of this opportunity, likely due to fatigue as well as having had opportunity to comment on many of these issues already, some did (and sometimes offered more than one piece of advice). Interestingly, comments were similar between the client respondents and caregiver respondents. Generally, the main message from most of the study participants was that more effort should be made to support people to stay at home.

6.1 Client Survey

Less than three-quarters of client respondents provided advice to government to help people stay at home longer. Responses were reviewed and coded into eight categories (see Figure 6a). The eighth category contained responses where advice applicable to more than one of the other categories was given, or where relevant advice was given but it did not fit in any of the other categories.

The most common recommendation was changes to continuing care services. This included: broader range of services, more hours of service, more flexible hours, improved dependability or reliability of services, and staff continuity. The second most common advice was financial support: either to support clients at home generally, or for specific things like assisted living or relating to ability to purchase one’s own care privately. A closer look at the responses in the “Other” category reveals that several respondents mentioned both service changes and financial support, and that comments were often interrelated due to their experience (or messages heard about delivery of services) and preferring to manage the situation on their own.
6.2 Caregiver Survey

Similar to client respondents, less than three-quarters of caregiver respondents provided advice to government to help people stay at home longer (72%). Service changes and financial support again ranked high (see Figure 6b). As with the Client Survey, several responses in the “Other” category included both service changes and financial support.
Other suggestions from clients and caregivers included improving training of continuing care assistants, tax credits, and subsidizing expenses such as home heating.

6.3 Discussion of advice offered by key point

Service changes:

The strongest piece of advice centred on the amount and the consistency of home care services. Amount of care encompassed assessing and delivering more hours of support and, for some, over a wider range of hours, even to considering 24/7. The advice was often just simply “give more care” or “hire more people”. Others were more specific: “Home care is only good if it is available 24 hours” and another client commented “Need to offer overnight care to give caregiver a break.”

Many discussed the difficulty of coping with staff inconsistency both in terms of multiple workers (particularly difficult for persons with dementia) and the time of day that they come. As a caregiver explained, “Make support more consistent so that paid caregivers actually get to know clients. [There is a... ] Much better system in England, where same staff come to the home daily. Having many different CGs [caregivers] coming in and out of home when person has dementia is very difficult for people and families.”

The struggle with the time of day involved both consistency and the broadening of service provision to offer more flexible hours. As one client stated, “More consistency on timing—same time every day so that individual (client) and their family caregiver don’t have to guess about when they are coming in.” This problem was not always viewed as the fault of the worker. In fact, one caregiver believed it to be more of a system-level issue in terms of scheduling commenting, “CCS [continuing care services] schedulers should be familiar with geography, so CCAs [continuing care assistants] actually have the time to get to clients. They end up using their CG [caregiver] time travelling instead of caring for clients.”

Having consistent workers was identified often by both clients and caregivers. For example, “Don’t know what mother (the client) would be like with a different person. Not receiving the same quality of care/people don’t know what way the client likes to have things done [when there is] constantly a different person”. It was recognized that better training of the workers was an important contributing factor. Several commented about the inexperience of the “younger workers” and others called for a personality test to ensure that the workers had the compassion needed to work in this field.

Financial support:

About one in five clients and caregivers referenced the need for more financial support in offering advice to the government. Some used broad terms like “affordability of being at home”. When specific examples were identified, the advice led in many directions from
financial support for caregivers, issues with the high costs of medication and additional services (e.g., respite care and assisted living), to calls for direct funding where the families hired the workers directly.

At the broadest level, the need to provide additional funding to the household was consistent. One client commented, “Affordability- it can become very costly to keep a person at home. Province doesn’t do enough to ensure people with dementia can stay at home...”. Similarly from the caregiver perspective, one simply stated, “Additional funding to be able to keep people at home. Makes big difference to caregiver and client when same people are coming into home but that all boils down to money.”

On the other hand, some respondents were realistic about the limitations of home care. A client proxy stated, “Should make a determination if it is in the best interest (to stay at home) think the focus is heading in the wrong direction. Yes, in some cases people can and should stay at home, but when you need 24 hour care you should have to pay out more than they have coming in.”

There were a number of respondents who would favor a direct funding approach – typically to facilitate an improvement in consistency. As one client suggested, “Provide money to hire caregivers. Relying on government employees isn’t consistent. Better off to have families given money to manage services themselves”. Another client simply stated, “help with money/funding because then it becomes easier to hire”.

The caregivers were particularly vocal in the need to increase direct financial support to family/friend caregivers. As one stated, “Pay the caregivers: That’s the only advice I could give; you need money to be able to care for people at home.” It was obvious that some caregivers had analyzed available options when commenting, “No matter how willing, if you (the caregiver) can’t stay at home because you have to work, it’s not doable.“ Among a couple of respondents who were recipients of the Caregiver Benefit, more money was suggested but for very different reasons. One caregiver focused on the wage replacement approach when she commented, “When you are giving up your job to save the government for only $400 a month, that’s not enough.” Another emphasized what additional services an increase in the Benefit could help provide such as, “More funding available to keep her at home. $400/month is very helpful because it’s not taxable but that only pays for her medications. There are still a lot of other things that need to be paid for. ... Cost of heating/fuel went up which really affected them financially. Now operating on reverse mortgage. Funding would be a Big Help.”

Clients, in particular, spoke more about these additional costs associated with remaining in the home. A small number focused on the need for more financial assistance with home modification. As one client explained, “I had applied for a ramp but I couldn’t get it...we were over the cut-off so they don’t want to do it. Home repairs so they can stay in the home longer.” Another suggested that financial help would be helpful to offset expenses related to...
necessary home remodelling to keep the client at home. One client identified the increased costs he incurred because of living in a rural area, [The advice was to have] “less running around, everything costs. I've got to travel a lot in this rural area. Lots of time and money. Services closer to home or more money.”

Program awareness:

About seven percent of the caregivers and clients gave advice to the government on the need to improve or increase awareness of home care services and, in some cases, specific suggestions were identified. As one client suggested, “[we need information on] where to start, it’s a very emotional and confusing time.” Many spoke about the lack of awareness of the services to support seniors to stay in their own home. “You don’t hear of services, but apparently they are available. How would they know that? It’s not well-publicized to seniors.” And others suggested that this awareness is necessary before a crisis occurs. As one client advised, “To get more public awareness to people before they need it. Maybe television or pamphlets in hospital. What help is available before urgent or target over 65, then this applies to you.”
Section 7- Recommendations

Generally, the main recommendation emerging from this study is that more effort should be made to support people to stay at home. Specific recommendations emerging from the results fall into three categories. The first area specifically addresses the main question – what are the gaps in service and the specific needs for support to enable people to delay entry into a long term care facility? These recommendations propose direct changes in service delivery, coordination and scope in the Continuing Care program. Next, suggested actions are proposed to address inappropriate referrals. The third category of recommendations are presented to increase an understanding of home care and living with informed risk.

Address inadequacies in home care services

The central theme at the core of this study’s results is the clients’ and caregivers’ desire to have the person stay at home for as long as possible given safety, financial considerations and available supports. At the outset, it is important to recognize that recommended changes to usage patterns reflect both direct changes in operation and administration to make such services more accessible and attractive to clients and caregivers. Indirect changes involve changes in attitudes from clients/families regarding the acceptance of outside help and the choice to live at informed risk.

1. Improve delivery to better meet clients’ needs:
   - Many of the participants spoke about the inconsistency of workers coming into the home and the challenges that this creates. Service providers should be strongly encouraged (if not required when operationally feasible to do so) to make every effort to have workers consistently assigned to clients.
   - Clients and their caregivers discussed challenges with scheduling regarding inconsistency in scheduling and not knowing when workers are arriving. Service providers should be strongly encouraged to consider client and caregiver needs and situations when scheduling care work.

As outlined in Section 6, one of the strongest and most frequent points of advice provided by both clients and caregivers pertains to the need to improve the continuity of workers assigned and reliability of the scheduled time.

2. Enhance the scope of supports:
   - A direct funding approach was identified by some participants as a way to improve home care services by enabling clients and caregivers to receive funding to purchase care services as needed.
• More hours of support was identified. Reference was made to having access to more than is currently available such as hours through the night and more relief for caregivers.

The most frequent type of service received by clients both before applying for admission to a nursing home (Section 3.1) and at the time of the survey (Section 5.1) were personal care and instrumental activities of daily living. Use of physiotherapy and occupational therapy was minimal. Despite increased calls for more relief for caregivers, some of the programs offered such as adult day programs, were only used in a minority of cases. One area where use of services changed between the time of application and time of the survey was the increased use of respite services. Yet, many noted that the hours for these services were still not sufficient. It was primarily the caregivers, in giving advice to government, who suggested a system of direct funding. This would enable families to purchase services thereby maintaining consistency in the workers (See Section 6.2). The direct funding approach could also enable access to instrumental activities of daily living such as transportation and home/yard maintenance, and support individuals who have moved to an assisted care facility to purchase more service to meet their changing needs.

3. Enhance targeted supports to family caregivers:
• Continuing Care has made a concerted effort to support caregivers by enhancing respite services, establishing a financial support benefit, and providing funding to enhance information and support activities. These activities should be formally evaluated to measure expected outcomes as well as to better understand opportunities to enhance them and identify any barriers to accessing these supports.
• Access to continuing care services is through the client assessment process. Assessing caregivers’ needs, independent of the clients’ needs, has been demonstrated to improve the efficacy of support services to caregivers. Understanding caregivers’ difficulties will support better decision making about how to target limited resources.

The role of the caregiver emerged throughout the study as key to supporting clients to remain at home, thereby preventing or delaying admission to a nursing home. Most caregivers were providing care for over a year, with three years or more being common, and the weekly hours of support caregivers reported was high. Particularly, the in person interviews highlighted family caregivers who were doing whatever possible to delay admission to the nursing home. However, without appropriate support, caregivers can burn out trying to do everything on their own before contacting the public home care program or other community supports. As noted in Section 2.2 many caregivers were at risk of the caregiving situation breaking down. Despite best efforts to improve support for caregivers, the complexity of care situations requires a comprehensive understanding to better match needs with supports.
4. Enhance case management:
   • In recognition of the instability of care situations in the community, more frequent contact between client/caregiver and care coordinator is needed. Currently, this practice appears most prevalent when an acute situation arises, or when a caregiver or client is assertive. Yet, health situations may be unnecessarily deteriorating due to infrequent communication and reassessment of needs.

Results suggest that more attention to case management may prevent an application for admission to the nursing home. Clients and caregivers would benefit from a fuller understanding of options early on and how home care services would be delivered to help decision making about the nursing home application (Section 4). As well, close to two-thirds of caregivers were interested in receiving more information on available supports that they may not have been aware of (Section 2). It is evident that a better connection between the care coordinator and other points in the system such as primary care and acute care would benefit the client and caregiver in helping him/her transition through the system. Further, much information in the client database accessed for the project was not up-to-date and this could be improved with more frequent contact with the client.

Address inappropriate referrals through education and procedural changes

Clients are being counselled to “go on the waitlist” even though they are not ready for nursing home placement, and by doing so, they are increasing, and potentially inflating, the waitlist. In both the Client Survey and the Caregiver Survey, about 50% of respondents indicated they would not accept a nursing home bed tomorrow if one was offered and another 14% stated “do not know” to this question. In 80% of the cases, this refusal was either based on the nursing home bed not being needed at this time or their desire to stay at home for as long as possible. Both physicians and care coordinators were reported to have played a significant role in the decision to apply for admission to a nursing home.

5. Educate physicians about home and continuing care:
   • In recognition of the key role that physicians have in the decision to apply for long term care, a targeted campaign is needed to increase awareness among physicians about the application process and wait time as well as the range of other continuing care services available. They need to be encouraged to refer patients (and their families) to care coordinators and available navigators to assist in making an informed decision.
   • Targeted intervention to physicians is needed to increase awareness of the detrimental impact of encouraging people to go on the waitlist for long term care “just in case”.

Home to Nursing Home, Final Report, June 2014
As noted in Section 4, physicians were identified as being involved in the decision to apply for admission to a nursing home in 40% of client and caregiver surveys. In several cases, participants reported that it was the physician who suggested and/or encouraged the nursing home application because of the “long wait”. In other instances, it was noted that physicians encouraged the application due to their belief that there were no other options for their patients' level of care.

6. Increase training for care coordinators on ethical issues:
   - Increased training on issues related to autonomy, decision-making and client’s right to live at risk is needed for care coordinators to better support clients to make informed decisions about their care.

As outlined in Section 4, care coordinators were identified as playing a role in the decision to apply for admission to a nursing home in 25-30% of the cases. There was some evidence to suggest that the care coordinator did not view the client living at home with some risk as an option. Interestingly, results suggested the probability of having received continuing care services prior to the application was almost three and a half times higher in situations when the care coordinator did not review options compared to when the care coordinator reviewed options.

7. Reprioritize access to a nursing home:
   - Given that many people are on the waitlist because it is a long wait period for admission to a nursing home, and not because they would accept nursing home care, an admission process is needed that is based on priority of need as opposed to application date.
   - Consider the implications to the waitlist of the current policy which allows clients to defer an offer of placement.

In this study, there were a significant proportion of cases in this study “not needing” a nursing home or “not wanting” a nursing home bed and yet these individuals have been assessed for nursing home level of care and placed on a waitlist for the next available bed. The domino effect is then evident through the health professionals who are encouraging people to “get on the list because it is a two year wait”. A more rigid placement process that is based on priority of need as opposed to “time on the waitlist” may then circumvent clients from applying until they would say yes to “take a bed tomorrow if offered”.

Home to Nursing Home, Final Report, June 2014
Increase understanding of home care and living at informed risk

8. Increase public awareness about options to nursing home admission:
   - Increased public education on the benefits of home care services, the important role of continuing care workers in helping to maintain an individual in their own home, and the level of education/training workers receive.
   - Communicate key messages that the home care program can support the local economy, especially in rural areas.
   - Increase resources to mitigate social isolation in the community.

Clients who lived in their own home or with others were three times more likely to have received home care services than were clients in assisted living and hospital facilities. Embedded within some of the interviews was this assumption that one stays at home with family and the next step is to move directly into the long term care facility. The intermediary of receiving home care services, while increasing in awareness, is still not an established pathway. Indeed, it is ironic that many clients seem to prefer to move location to be cared for “by strangers” than to have “strangers” come into their own home to give them care. In addition, some caregivers expressed the importance of socialization and activities. The lack of such stimulation at home was viewed as a reason for admission to a nursing home. Reduction in the social isolation of older adults in the community is an important goal.

9. Begin public discussion of ethical issues such as autonomy and informed risk:
   - Educate about right to live at risk is needed with families, physicians and other health care professionals. Acceptance of risk and clients’ right to choose to live independently if s/he understands risk, needs more attention.
   - Support public conversations about the varying levels of competency that older people with some form of dementia might experience and their continued right to make informed choices.

In many cases, the theme of risk aversion was identified as a reason for needing nursing home care. Caregivers felt challenged with being on site 24/7 and were concerned about the client’s capacity to live alone. At what point, and to what degree, should people have the right to choose to live at risk despite concerns about falling or safety. With an increasing number of baby boomers caring for their parents, it appears that they want the full extent of services possible with the least amount of risk. For them, this is living in a long term care facility where they feel their parent will be safe.
Appendix A - Ethics Certificate
Certificate of Research Ethics Clearance

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<th>Effective Date</th>
<th>November 18, 2013</th>
<th>Expiry Date</th>
<th>November 17, 2014</th>
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File #: 2013-046
Title of project: Home to Nursing Home: Understanding Factors that Impact the Path Seniors Take
Researcher(s): Pamela Fancey
Supervisor (if applicable): n/a
Co-Investigators: Janice Keefe
Version: 1

The University Research Ethics Board (UREB) has reviewed the above named research proposal and confirms that it respects the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans and Mount Saint Vincent University’s policies, procedures and guidelines regarding the ethics of research involving human participants. This certificate of research ethics clearance is valid for a period of one year from the date of issue.

Researchers are reminded of the following requirements:

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<th>Any changes to approved protocol must be reviewed and approved by the UREB prior to their implementation.</th>
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<th>Info: REB.SOP.113</th>
<th>Policy: REB.POL.003</th>
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Dr. Daniel Séguin, Chair
University Research Ethics Board

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Tel 902 457 6350 • Fax 902 457 2174
www.msvu.ca
Appendix B – Letter to Clients
On Department of Health and Wellness LETTERHEAD

November 2013

Dear Client,

The Continuing Care Branch, Department of Health and Wellness is aware that many clients are waiting for a nursing home bed and the number continues to grow. In order to better understand the need for nursing home beds as well as the services needed to better support people in the community, we are interested in gathering information about the factors that contribute to an individual’s decision to apply for a nursing home bed.

We are pleased to share with you that we have engaged researchers at the Nova Scotia Centre on Aging, Mount Saint Vincent University to undertake a project that will gather critical information to support our planning decisions. The Mount’s Centre on Aging has expertise in the field of home care and nursing home care and has a strong reputation for its high-quality work.

The project the Centre on Aging has been engaged to do involves a survey to be completed by many of our clients such as yourself, and in some cases family and friend caregivers of our clients throughout Nova Scotia. The survey will be conducted over the telephone and expected to take no more than 20 minutes. In some instances, surveys may be administered in person as well. Researchers will be contacting clients and caregivers from November 2013 through to January 2014 until a sufficient number of participants are reached. If contacted, you will be asked questions that cover topics such as: the support you currently receive (type, amount, from whom), need for other support, changes in health status, and reasons related to applying for nursing home admission. Should you be contacted and choose to participate, your participation in the survey is completely voluntary and you are free to stop the interview at any time, or refuse to answer certain questions. Safeguards are being put in place to protect the confidentiality of your responses and be assured that the services you currently receive through Continuing Services or your nursing home admission will in no way be affected by whether or not you participate in the survey.

Our goal at the Continuing Care Branch is to support Nova Scotians to achieve and maintain their maximum independence. The information that will be available to us as a result of this project will support decisions to ensure the services offered are appropriate to our clients’ needs yet contribute to a sustainable health system. If you would like further information about the project, please contact Shannon Giles at the Continuing Care Branch, (902) 424-5129, or by email, shannon.giles@gov.ns.ca. You can also let Shannon know by Wednesday, November 27th, 2013 if you do NOT wish to be contacted about this project.

Sincerely,

Ruby Knowles,
Executive Director
Appendix C – Survey Methodology

Sample Selection

In October, 2013, an application to access Personal Health Information from the Continuing Care SEAscape client database was approved by the Privacy and Access Office, Department of Health and Wellness.

Staff with the Continuing Care Branch prepared a file, from the Continuing Care client database, on November 18, 2013 that reflected the clients who were approved for nursing home admission as of that date. All ages were included. The only exclusion pertained to those identified as “translator required” (N=36). The file contained 2383 cases, and for sampling purposes, included client information from the following fields:

- Case Record Number
- Location of Client (home, hospital, elsewhere)
- DHA of Client
- Presence of Caregiver
- Receipt of Home Care Services from DHA

The records in the file were randomized using SPSS (Statistical Package for Social Sciences) software and a sub-sample was selected. To achieve the original target for completed surveys with clients, a sample of 662 cases of clients was selected to make up the initial pool (28%). The original file of 2383 cases was also used to determine a separate sample of caregivers by selecting only the cases where a caregiver was noted as being present (Field used was “Presence of Caregiver”). Of these 2184 cases, the file was randomized using SPSS software and a sub-sample selected. To achieve the target for completed surveys with caregivers, a sample of 669 cases was selected to make up the initial pool (30%). Both files with the Random Samples were returned to the Continuing Care Branch for additional fields to be added at the client level to support the survey work.

A few weeks after survey work had begun it was decided that clients classified as “pending” and approved for a Residential Care Facility were to be removed from the study. For the clients, this was done through checking individual Client Identification Numbers made available from the Branch with the Random Sample File of clients and removing 142 clients23. The work on the Caregiver Survey had not started when this decision was made, so another file with clients (as of November 18) without those classified as either RCF or pending was provided by the Branch. After these adjustments to the study’s criteria were made to the Random Sample files the sample size for the clients and the caregivers was reduced (see Table C1).

23 At this point, surveys had been completed with four individuals who were approved for a Residential Care Facility and their surveys were removed from the completed file.
Table C1: Overview of Original and Adjusted Sample Files

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<tr>
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<td>2184</td>
<td>669</td>
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<td>November 18 adjusted</td>
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<td>520</td>
<td>1279</td>
<td>551</td>
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Table C2: Overview of Clients from Original Continuing Care Database (Sample File, N=1403)

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<th>District Health Authority</th>
<th>Clients’ location while waiting for nursing home</th>
<th>Total</th>
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<tr>
<td></td>
<td>Community</td>
<td>Hospital</td>
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<td>South West</td>
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<td>TOTAL</td>
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Presence of caregiver 1279 91%
Client authorized to receive home care service 803 57%
Table C3: Overview of Caregivers from Original Continuing Care Database (Sample File, N=1279)

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<th>District Health Authority</th>
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</tr>
<tr>
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<td></td>
</tr>
<tr>
<td>TOTAL</td>
<td>1067</td>
<td>212</td>
<td>1279</td>
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| Presence of caregiver     | 1279      | 100%     |
| Client authorized to receive home care service | 718 | 56% |

Recruitment and Promotion

On November 20, 2013, a letter about the project was sent from the Continuing Care Branch to all clients originally identified in the November 18, 2013 file (see Appendix B). The letter was sent to the clients’ mailing address as opposed to the service address. The letter provided an opportunity for clients to opt-out of the project by contacting the Continuing Care Branch. Staff at the Branch received numerous calls/emails from either clients or their caregiver indicating they wanted to be removed from the project. This information was communicated to the NSCA Project Lead (or her designate) and individual cases were removed from the survey pool. These cases were treated as “refusals” and no call was placed to either the client or the caregiver. In other cases, these calls resulted in different contact information and this information was communicated to the Project Lead (or her designate) and noted in the calling file. Other callers were seeking more information about the project. Branch staff replied to most calls/emails, but in some instances information about the caller was not provided and a call back was not possible.

The November 20th mail out also resulted in mail being returned from Canada Post marked “undeliverable” (i.e., 132 letters). For these letters, Branch staff checked the Sample File that had been provided to NSCA in the event the client was part of the calling pool. If so, this information was communicated to NSCA Project Lead (or her designate) and these clients were excluded from the calling pool.
In addition to the individual letter, Branch staff also provided information about the project to Managers, Continuing Care Services through email communication and during meetings on at least two points in time.

Survey Call Protocols

Protocols for NSCA staff were established for making contacts with clients and caregivers. A classification system that described the status of cases during the calling process was also established.

A file for the Client Survey and the Caregiver Survey was established in Excel software to monitor the calling process. Each file had four worksheets (e.g., Unassigned, Completed, Refusal, Unsuccessful). In addition to the fields provided on each client from the Continuing Care database, staff used additional columns to make notes regarding the status of the case and moved cases within the file to different worksheets depending on the status of the case.

Client Survey:

For clients who were not identified as “hospital” clients the following protocol was followed:

1. Once a case was considered ready to be contacted (having verified it was not one of the cases communicated by the Branch), a Respondent Identification Number was assigned to the case. NSCA staff then called the telephone number on file after having reviewed information about the client (e.g., district, cognitive impairment, hearing impairment, date of application, caregiver name, care coordinator name).

2. If there was no answer, up to two more attempts were made and each time this information was recorded in the Excel file. On the 3rd attempt, if no contact was made and an answering machine was available, a scripted message was left which included a telephone number (local and toll free) for call back if they wished to participate. A note was made within the Excel file about whether a message had been left and this case was moved to the “unsuccessful” worksheet. If a call from the client/caregiver was received following the message, the case was “reactivated” and the calling protocol followed again.

3. If someone called the project office providing information about a specific person to call regarding the client’s situation, the same protocol of three attempts to reach this individual was followed (see #2 above).

For clients who were identified as “hospital” clients, the following process was followed:

1. Once a case was considered ready to be contacted (having verified it was not one of the cases communicated by the Branch), a Respondent Identification Number was assigned to the record and NSCA staff called the telephone number on file. One staff
member handled all these cases to provide consistency in the communication with the client/caregivers, hospital staff and care coordinator.

2. In some cases, the telephone number on file was a nursing station at the hospital. For these cases, NSCA staff would inquire about the clients’ situation (telephone available, health status, availability of caregiver) hoping to gather sufficient information to decide how to proceed.

3. In some cases, the telephone number on file was disconnected, or no one answered, or NSCA staff received insufficient information from the hospital staff, NSCA staff contacted the care coordinator identified on client’s file to confirm the status/location of the client.

4. If the client was in a hospital within one hour radius of the University the opportunity to have the survey administered in person was offered. Despite this option, no surveys with clients waiting in a hospital were completed in person.

5. If the survey was unable to be completed, a note was made within the Excel file and the case was moved to the “unsuccessful” worksheet.

Caregiver Survey:

For caregivers of the clients who were not identified as “hospital” clients the following protocol was followed:

1. Once a case was considered ready to be contacted (having verified it was not one of the cases communicated by the Branch, or a situation where information gathered through the Client Survey indicated that the client had died or moved to long term care), a Respondent Identification Number was assigned to the case and NSCA staff called the telephone number on file. In most cases this was the client’s telephone. However, in some cases, another contact and/or telephone number was available because of information conveyed during the call/email to the Branch following the initial recruitment letter.

2. If there was no answer, up to two more attempts were made and this information was recorded in the Excel file. On the 3rd attempt if no contact was made and an answering machine was available, a scripted message was left which included a telephone number (local and toll free) for call back if they wished to participate. A note was made in the Excel file and this case was moved to “unsuccessful” worksheet. If a call from the caregiver was received following the message, the case was “reactivated” and the calling protocol followed again.

NSCA staff called between 9:30 and 12:00 noon and from 1:00 to 4:30, Monday through Friday. Several Saturday shifts were organized as well as one evening shift through the week which ran from 6:30 to 8:30 pm. All efforts were made to have a staff person call an individual back at a requested time.
Classification of Cases for Client Survey and Caregiver Survey

Completed – Cases in which the survey was successfully administered with the client (or his/her proxy) or with the caregiver.

Refusal – Cases in which NSCA staff made contact with the client (or his/her proxy) or with the caregiver and the individual refused to participate. In some instances, refusal occurred before staff had an opportunity to talk about the project and in other instances, the participant refused after staff had shared information about the project. Other cases that were classified as “refusal” were cases in which the client or his/her caregiver contacted the Branch and advised they did not wish to participate in the survey.

Unsuccessful – Cases in which NSCA were unable to make contact with the household due to:

- wrong telephone number or disconnected telephone
- situations in which clients had died
- situations in which clients had moved to long term care
- situations in which clients had moved to an assisted-living facility and contact information not provided to staff
- situations in which NSCA staff were unable to communicate satisfactorily with client due to a hearing, speech or cognitive issue and no proxy was available (potential cases for caregiver survey in these instances were considered unsuccessful as well as contact for the caregiver was through the client and it was decided that a repeat contact may cause confusion)
- situations in which someone had called the Branch after receiving the recruitment letter and it was unclear whether the client/caregiver was willing to participate.

Unassigned – Cases in which NSCA staff did not make contact with the household.

Survey Start and End Dates

Client Survey – NSCA staff began calling clients on November 29, 2013, and concluded calling clients on February 7, 2014 (last survey was completed on January 27, 2014). During the Christmas break, calling was discontinued after Friday, December 20, 2013, and resumed on Friday, January 3, 2014.

Caregiver Survey – NSCA staff began calling caregivers on January 11, 2014, and concluded on February 26, 2014. The protocol of three attempts to the household continued up to the last day, but the protocol of leaving a message to call back was stopped early in the last week.

The delay in starting to administer surveys with caregivers until early January was intentional to enable staff ample time to focus on the Client Survey file. Concern about the response
rate emerged early on in the process when NSCA staff noted several challenges such as the number of attempts required to successfully make contact with a household; clients’ recollection of the letter received; the number of cases in which staff were unable to complete the survey with clients due to hearing or cognitive issues, etc.

**Questionnaire – An Overview**

A separate questionnaire was developed for clients and a separate questionnaire was developed for caregivers of clients. For the most part, both questionnaires contained the same topics and questions. In a few places, the Caregiver Survey was modified to capture the caregiver perspective specifically. In addition, the Caregiver Risk Screen was added to the Caregiver Survey to help gauge the level of caregivers’ risk. Both questionnaires were developed in consultation with representatives from the Continuing Care Branch. Sections included:

Section 1 - Participant Background [This section captured demographic information such as age, sex, marital status, sources of income (client survey only), living arrangement.]

Section 2 – Awareness and Use of Home and Community Supports [This section focused on their situation prior to making an application for admission to a nursing home in terms of the type of support they were receiving and from whom, to what extent they were aware of continuing care services, to what extent home care options were discussed with them when applying for a nursing home bed, extent of contact with care coordinator or other health professionals who may have discussed home care services with them.]

Section 3 – Clients in the Community [This section was asked of clients waiting in the community for admission to a nursing home. It included questions about their situation at the time of the survey in terms of the type of support they were receiving and from whom, their need for supports to stay at home longer, and changes to continuing care services that would be helpful. In the Caregiver Survey the 12 items as part of the Caregiver Risk Screen were asked.]

Section 4 – Clients in the Hospital [This section was asked of clients waiting in the hospital for admission to a nursing home. It included questions about the length of time in the hospital, reason for admission, their need for supports to have kept them at home longer, and changes to continuing care services that would be helpful.]

Section 5 – Other [This section was asked of all participants in the Client Survey and the Caregiver Survey. One question offered them an opportunity to share anything about their situation or the decision to apply for admission to a nursing home that had not been previously discussed. The second question asked them specifically to give advice to the government about how to better support people who want to remain at home.]
Section 6 – Follow Up [This section asked whether they would be willing to be contacted for a follow up interview.]

Survey Data Preparation and Analysis

Information from completed surveys was entered into two separate files in SPSS (Statistical Package for Social Sciences) software. No name or contact information was identified on the survey, however, a Respondent Identification Number for the survey that staff assigned was also entered into the Excel file used to track the calling process. In this way, information between the survey file and the original client file could be made, if required.

Comments to open-ended questions were reviewed in their original format and common themes identified. Several codes were established to collapse comments into a more manageable format to support analysis.

Statistical Procedures

Univariate and Bi-variate analyses were employed on the survey data. For some analysis, the cases of clients waiting in hospital were excluded or reviewed separately.

Descriptives such as frequencies, means, medians and standard deviations were used to explore individual variables.

Chi-square test of independence (X²) was used to assess the relationship between categorical variables, meaning if two variables are significantly dependent then they are related to one another (p value is less than .05). The odds ratio was used to provide information on the strength of the relationship between two categorical variables, meaning the closer the odds ratio is to 1, the weaker the relationship.

T-test was used to assess whether the means on continuous variables were different for two groups. For example, the average number of days on the waitlist for those clients receiving continuing care services was compared to those not receiving services.

One-way analysis of variance was used when more than two groups of participants were analyzed to assess whether the means on continuous variables were different. For example, the average number of days on the waitlist was compared by clients’ whose reason for application was coded as “anticipatory-related”, “caregiver stress related” or “concern about client’s health/needs”.

Home to Nursing Home, Final Report, June 2014
Case Selection

In early February, 2014, approximately three-quarters of the completed client surveys had been entered into the data file and a number of caregiver surveys had been completed thereby providing reasonable insight into the range of cases in the study. The Project Lead met with staff to discuss their observations about the cases completed and a preliminary review of the aggregate data was conducted to help identify care situations that may be of interest for the in person interviews. A communication was sent to Branch representatives on February 5, 2014, providing information about six possible scenarios that had emerged.

The researchers met with Branch staff to discuss the possible scenarios and four scenarios were identified.

The researchers reviewed the data file to identify relevant cases to represent the scenarios.

Recruitment

Once a pool of cases had been identified for each scenario, and verified that the individual indicated their willingness to be contacted for a possible follow up interview, the Project Lead reviewed the completed survey to gain a better understanding of the situation to ensure its fit with the follow up interview objective. A short list of cases was identified and the researchers contacted one individual for each scenario. During this call, information about the follow up interview was conveyed and initial consent received to meet with the client/caregiver in person to formally obtain informed consent and conduct the interview.

In several of the original cases identified for follow up, the researchers were told upon contact that the individual was unable to participate. Reasons for their refusal included: client had died since survey, no longer interested, or no longer felt the survey was relevant to their situation. Attempts to one individual were discontinued after two calls to the household and a message left with an invitation to call the researchers if interested.

The pool of potential cases was revisited and alternate cases had to be identified. A similar contact process as above was followed until an interview was completed for each scenario.

Start and End Dates

The researchers conducted five in person interviews with clients or their caregivers between February 21 and March 24, 2014.
Interview Guide – An Overview

The questions used for the in person interview covered the main areas of inquiry from the survey (e.g., situation prior to application for admission to a nursing home, current situation, experience with services, what is needed to support client to stay home) with specific probes that enabled the researcher to ask and elicit more understanding depending on the circumstances and relevancy of the situation.

Data Preparation and Analysis

With the exception of one interview, all were audio recorded. Two of the first interviews were transcribed. The transcripts and researchers’ notes were analyzed.