

Low Tolerance Long Duration (LTLD) Stroke Demonstration Project

**Interim Summary Report
October 2005**

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1.0 INTRODUCTION

1.1 Background

The Coordinated Stroke Strategy in Ontario outlines a clear vision for stroke rehabilitation through establishing a coordinated approach to the delivery of stroke rehabilitation services. The key focus of this approach is to ensure that stroke survivors are able to access stroke rehabilitation in a timely manner, at the right level of intensity and for the right duration to maximize their functional and psychosocial outcomes following stroke.¹ The Greater Toronto Area (GTA) Rehab Network has been actively involved in several initiatives to support and promote the goals of the Coordinated Stroke Strategy since its inception. Most recently, a key area of focus has been Low Tolerance Long Duration (LTLTD) stroke rehabilitation.²

In the winter of 2004, the GTA Rehab Network held a Consensus Day Session that brought together stakeholders from across the province to achieve consensus on the program components of a stroke LTLTD rehab program and to develop a triage framework for determining patient need for LTLTD stroke rehab.³ Building on this work, in the fall of 2004, the GTA Rehab Network set out to address issues related to the accessing of LTLTD stroke rehabilitation. Currently, LTLTD stroke rehabilitation is not recognized by the Ministry of Health and Long-Term Care as a discrete rehabilitation program with designated funding. Instead, the availability of LTLTD stroke rehab is dependent on the programming decisions of individual organizations to allocate resources for this type of rehabilitation. However, the absence of designated funding presents a significant barrier for most organizations to make such programming decisions, as LTLTD services require an investment in specialized teams and longer length of stays. As a result, survivors are often transferred to settings that do not provide the rehabilitation they require and it is not unusual for stroke survivors to be discharged directly to long-term care without a trial of rehab.⁴ Since stroke survivors who require LTLTD stroke rehabilitation are typically older, this is a growing concern as the population ages.⁵

With these considerations in mind, the GTA Rehab Network set out to conduct an LTLTD stroke demonstration project to gain a better understanding of the characteristics and program and resource needs of LTLTD stroke patients. The findings of the project would be used to advocate for recognition of and appropriate funding for LTLTD stroke rehabilitation to the Ministry of Health and Long-Term Care (MOHLTC). It was anticipated that the project would demonstrate LTLTD stroke rehabilitation as a client-centred model of care that optimizes client functioning, reduces burden of care and is cost-effective in its use of resources and rehab beds.

This report provides a summary of the preliminary findings of the demonstration project. A more detailed analysis of data will be conducted at the end of the data collection period, the findings of which will be summarized in a final report in early 2006.

¹ Please see the report of the Joint Stroke Strategy Working Group's report, *Towards an Integrated Stroke Strategy for Ontario*, HSFO & MOHLTC, June 2000.

² See Teasell, R., Foley, N., Bhogal, S.K., Jutai, J., & Speechley, M., *Evidence-Based Review of Stroke Rehabilitation*, 2003.

³ For a summary of the Consensus Day Session, please see the GTA Rehab Network's report, *Low Tolerance Long Duration Stroke Rehabilitation Report*, June 2004.

⁴ See GTA Rehab Network, *Needs Assessment and Plan for Integrated Stroke Rehabilitation in the GTA*, February 2002.

⁵ Heart and Stroke Foundation of Ontario, *Stroke Rehabilitation Consensus Panel Report*, May 2000.

2.0 APPROACH

2.1 LTLD Stroke Demonstration Project Planning Subgroup

In June 2004, the LTLD Stroke Demonstration Project Planning Subgroup was convened to undertake the LTLD stroke demonstration project. The Subgroup represents collaboration among the following organizations:

- Network member organizations: Bridgepoint Health, Lakeridge Health and Providence Healthcare
- Castlerview Wychwood Towers, a not-for-profit long-term care home owned by the City of Toronto
- Toronto West Stroke Network, SCRIPT Project (Stroke Coordinated Referral Initiative Pilot Toronto)

2.2 Project Goals

The Subgroup determined the goals of the LTLD Stroke Demonstration Project as follows:

- To gain an understanding of the characteristics, resource needs and outcomes following LTLD stroke rehab for stroke patients in three different types of settings:
 - stand alone Complex Continuing Care (CCC)
 - Long-Term Care (LTC)
 - Acute Care with designated rehab beds and CCC beds.
- To increase awareness of the need for LTLD stroke rehab by incorporating the findings of the demonstration project in a business case to the MOHLTC to advocate for recognition of and appropriate funding for LTLD stroke rehab.

2.3 Scope of Project

The scope of this project has been circumscribed by the following considerations:

Limitations of Project

1. The project was developed with no external funding⁶ and conducted by staff at each organization that have coordinated their time to plan and conduct the activities required. The breadth of the project is also limited by the availability of human resources for data collection.
2. The project was designed as a short-term demonstration project to gather information about stroke survivors in LTLD stroke rehab programs. Findings of this preliminary work will be used to advocate for the rehab needs of this particular subgroup of stroke patient. The findings may also be used to clarify and determine the parameters of a more in-depth study in future.
3. It is beyond the scope of the project to determine an ideal model of inpatient LTLD stroke rehab or a single setting that is best suited to provide LTLD stroke rehab.

⁶ However, one of the participating organization, Castlerview Wychwood Towers, a long-term care (LTC) facility, received prior funding approval to conduct a two-year pilot study to provide LTLD stroke rehab in 20 beds to residents with severe stroke.

Limitations of Data Analysis

1. Data collection for this project is being conducted in two phases. Phase One involved a limited analysis of the data collected on full encounters that occurred during the first six months of the project (October 1, 2004 – June 30, 2005). In Phase Two, a more in-depth analysis with additional data elements will be conducted.
2. In the absence of external funding, a quality improvement approach was chosen that did not require an ethics review. Analysis of the data will be reported in an aggregated format of overall averaged data.

2.4 Project Design

Data will be collected on patients admitted to LTLD stroke rehab programs in the four participating organizations. These include:

- Bridgepoint Health (CCC beds)
- Providence Healthcare (CCC beds)
- Lakeridge Health (Acute care setting with designated rehab beds and CCC beds)
- Castlerview Wychwood Towers (LTC)

With the exception of Castlerview Wychwood Towers, the collection of data is part of an internal program evaluation of existing clinical practices. As a result, neither an ethics review nor patient consent was required at Bridgepoint Health, Providence Healthcare and Lakeridge Health. However, the provision of LTLD stroke rehab is a new service being piloted at Castlerview Wychwood Towers for residents in 20 beds at the facility. External funding was obtained to conduct the pilot and an ethics review process and patient consent were required.

Data collection has been conducted in two phases. Bridgepoint Health and Providence Healthcare began data collection on October 1, 2004. The second phase of data collection began in 2005 with Lakeridge Health beginning data collection in January and Castlerview Wychwood Towers in February 2005. Data collection continued at all organizations until September 30, 2005.

Data will also be provided by SCRIPT (Stroke Coordinated Referral Initiative Pilot Toronto). The SCRIPT Project of the Toronto West Stroke Network has developed a standardized rehab assessment and referral process for stroke patients in the GTA. Through SCRIPT, aggregate data on stroke patients in acute care settings enrolled in SCRIPT will be included.

Data Collection Indicators include:

- Functional Independence Measure (FIM™)⁷ scores and Minimum Data Set (MDS)⁸ scores on admission and at quarterly intervals
- FIM™ scores on discharge

⁷ FIM™ is a trademark of the Uniform Data System for Medical Rehabilitation, a division of UB Foundation Activities, Inc. The Functional Independence Measure (FIM™) assesses physical and cognitive disability in terms of burden of care. It includes an 18-item ordinal scale that measures independence in self-care, sphincter control, mobility, locomotion, communication and social cognition. The maximum total FIM™ score is 126. The maximum total motor FIM™ score is 91. FIM™ data is captured as part of the National Rehabilitation Reporting System developed by the Canadian Institute for Health Information.

⁸ The clinical characteristics of patients in Complex Continuing Care settings are reported using the Continuing Care Reporting System. Data is captured using the Rater Assessment Instrument MDS 2.0. The RAI MDS 2.0 is © interRAI Corporation, Washington, D.C., 1997 and has been modified with permission for use by the Canadian Institute for Health Information. (2002). The Minimum Data Set is used to collect administrative and socio-demographic information and to assess the care needs of patients in a number of functional areas. Information is collected on a quarterly basis.

- Factors contributing to discharge destination
- Pre-rehab discharge disposition
- Special Needs (e.g., tracheostomies, G/J tubes, Central/PICC line, etc.)
- Staffing Workload

Data collection was expanded beyond the information collected using the National Rehabilitation Reporting System data and Continuing Care Reporting System to allow for a more detailed understanding of the patients receiving LTLD stroke rehab. For example, capturing information on discharge destination provides only limited information regarding the outcome of LTLD stroke rehab. Discharge destination is also determined by the availability of social support within the home and/or in the community and inclusion of this information will enhance the analysis of the data. Similarly, inclusion of information on the presence of co-morbidities and special needs, which frequently differentiate patients in LTLD stroke rehab from those in a regular rehab program, will also add to the understanding of this rehab population group.

The Subgroup reviewed the feasibility of collecting data on the achievement of patient-identified goals. However, a number of complexities were identified that preclude the inclusion of tracking patient-identified goals. These include:

- Patient goals frequently shift during the rehab period and may or may not be documented consistently.
- The identification of realistic patient goals can be a complex process that would require in-depth audits of patient charts.

The availability of human resources to this project precludes such a level of analysis.

2.5 Data Analysis

To comply with privacy regulations, each organization will analyze its own patient-specific data and provide a summary report of its data based on a standardized data retrieval and analysis template developed by the Subgroup. The objectives of the data analysis are:

- To describe the patient populations who receive LTLD stroke rehab in facilities
- To gain a better understanding of the factors that may influence discharge destination
- To identify the factors that may influence functional outcomes and length of stay
- To determine the influence of rehab waiting time on functional outcomes, lengths of stay and discharge location
- To determine the optimal length of stay in LTLD stroke rehab relative to change in function
- To estimate the demand for LTLD stroke rehab

It has also been noted that FIM™ scores may not be sensitive enough to show change for scores less than 20, therefore it may be useful to conduct a Rasch analysis to convert each FIM™ score to a Rasch score.⁹ This will increase the sensitivity of the analysis to show smaller changes in function. The Subgroup will determine if a Rasch analysis is necessary and feasible once data has been collected.

⁹ A Rasch analysis is used to convert ordinal scores to linear measures with equal interval properties. See Heinemann, Allen W., Linacre, John Michael, Wright, Benjamin D. & Granger, Carl., Measurement Characteristics of the Functional Independence Measure, *Topics in Stroke Rehabilitation*, 1994:1(3):1-15.

3.0 PRELIMINARY FINDINGS

Findings provided in this interim report are restricted to patients with full encounters between October 1, 2004 and June 30, 2005. A full encounter refers to patients who were admitted and discharged within this time frame. The data indicators used for this preliminary data analysis are based on the National Rehabilitation Reporting System developed by the Canadian Institute for Health Information.¹⁰

3.1 CLIENT PROFILE

3.1.1 Number of Patients with Full Encounters

In total, data for 97 patients with full encounters was collected during the interim data collection period across all four settings (see Figure 1). The distribution of patients across gender was fairly equal with the percentage of male patients being slightly higher at 52%. The two largest cohorts of patients (n=67 patients and n=21 patients) were located in the complex continuing care settings whose data collection period began in October. The smallest cohort of patients (n=2) was found in the long-term care setting. This finding was likely owing to two factors. First, the data collection period in the long-term care facility began in February 2005. Second, in contrast with the other settings, residents admitted to the LTLTD stroke rehab program in the long-term care facility were required to pay a co-payment fee. The availability of publicly-funded LTLTD stroke rehab programs in the other settings adversely affected recruitment of residents for the program.

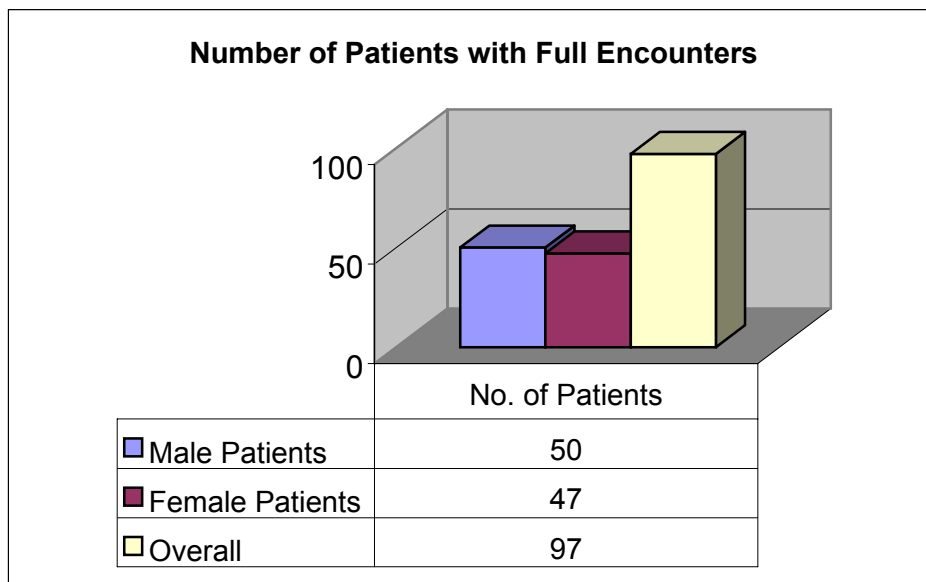


Figure 1: Number of Patients with a Full Encounter

3.1.2 Age

The majority of patients admitted to the LTLTD stroke rehab programs fell into two age categories. Fifty-three percent were 75 years of age or older; forty-two percent of patients were between 55 and 74 years of age (see Figure 2). Five percent of the patients were between the ages of 18 to 54. The average overall ages ranged from 73 to 81 years; the average age of female patients was generally older than that of males.

¹⁰ See the Rehabilitation Minimum Data Set Manual, Canadian Institute for Health Information, 2004.

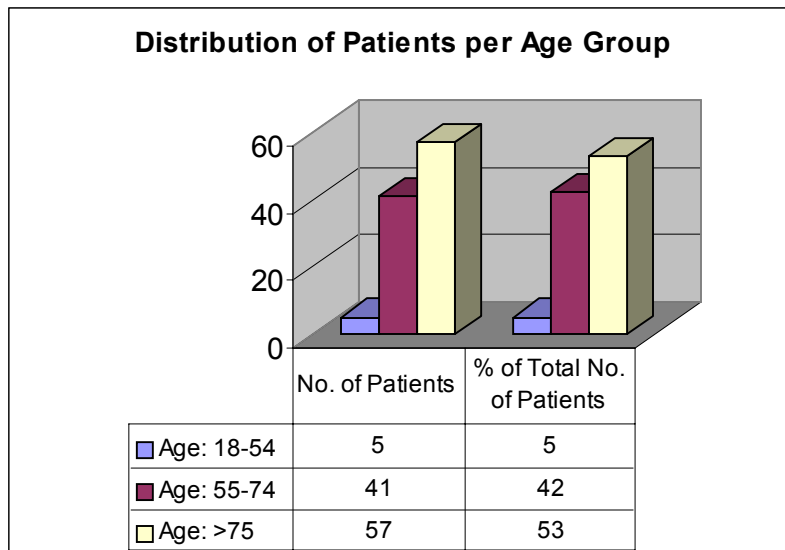


Figure 2: Number of Patients per Age Distribution Category

3.1.3 Pre-Admission Living Arrangements

Ninety-three percent of patients were living in a home setting prior to admission. Of these, 40% were living with their spouses, 32% were living with family members and 21% were living alone. A smaller percentage of patients (7%) were living in a facility before admission (see Figure 3). A comparison of data across gender shows that of the patients who were living with their spouses before admission, the overwhelming majority was male (76%). The reverse gender situation was found for patients living alone before admission. That is, 70% of patients living alone were female. The number of patients who were living with family before admission was equally distributed across both genders. Of the number of patients living in a facility before admission, all were female (see Figure 4).

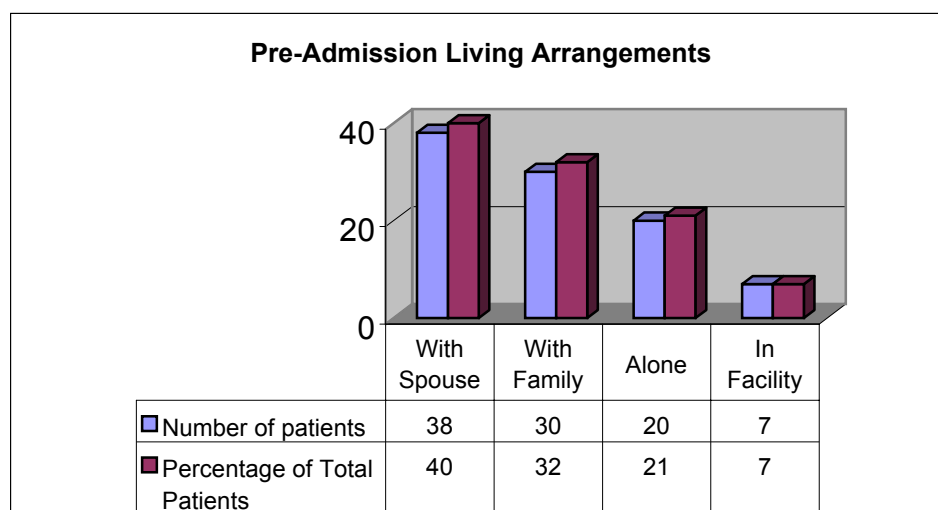


Figure 3: Pre-Admission Living Arrangements
(Data for two patients are unavailable.)

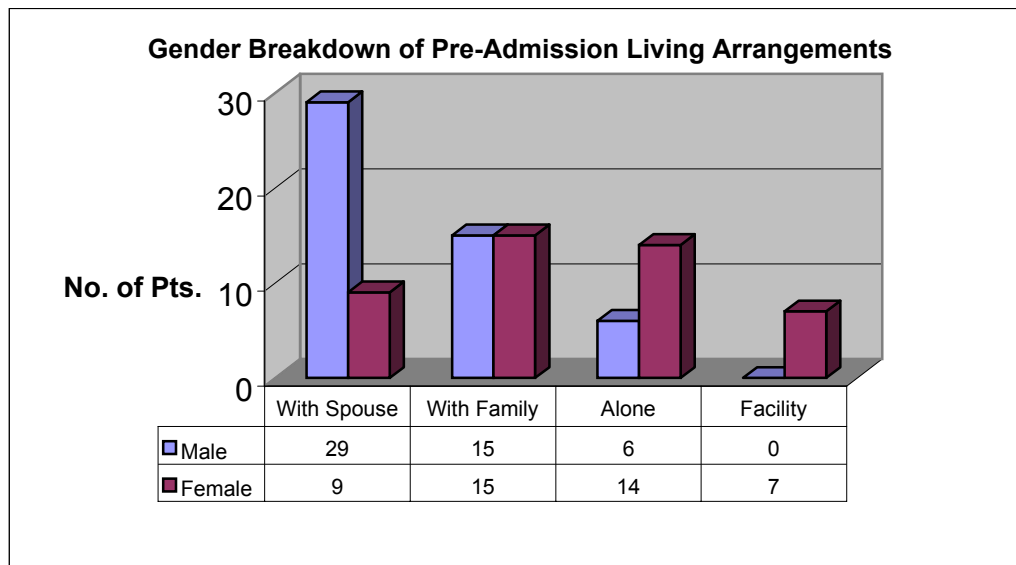


Figure 4: Pre-Admission Living Arrangements According to Gender
(Data for two patients are unavailable.)

3.1.4 Level of Functioning on Admission

The functional level of patients admitted to the LTLD stroke rehab programs was determined by examining total average FIM™ scores and total average motor FIM™ scores. The average admission FIM™ scores ranged from 39.6 to 73 points (maximum 126). The overall weighted average admission FIM™ score was 57.4. In general, the functional status of patients as measured by average FIM™ scores on admission was slightly higher for male patients. There was less variability among the average admission motor FIM™ scores across organizations with scores ranging from 21.5 to 38 points (maximum 91). The overall weighted average admission motor FIM™ score was 33.32 (see Figure 5).

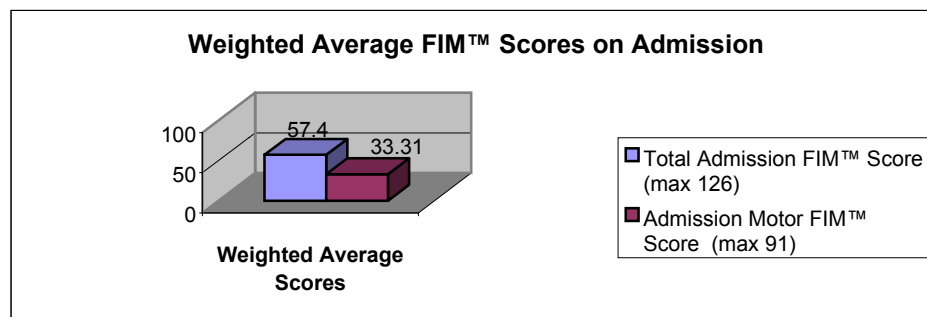


Figure 5: Weighted Average Admission FIM™ Scores

Data regarding patients' pre-admission health conditions present at the time of admission were also collected. According to the National Rehabilitation Reporting System, these co-morbidities include any health conditions or complications "which delay, interrupt or compromise effectiveness of the rehabilitation program or represent high medical risk disorders."¹¹ The patients admitted to the LTLD stroke rehab programs had a number of medical co-morbidities with an average range from 5 to 7 (see Figure 6).

¹¹ See the Rehabilitation Minimum Data Set Manual, Canadian Institute for Health Information, 2004.

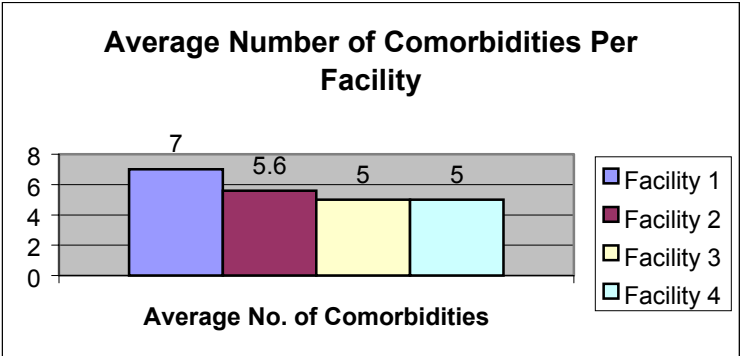


Figure 6: Average Number of Co-morbidities in Each Facility

4.0 PATIENT OUTCOMES

4.1 Level of Functioning on Discharge

The functional status of patients on discharge was measured using the change in total FIM™ scores and change in motor FIM™ scores between admission and discharge. The overall change in average FIM™ scores ranged from 4 to 26.8 points with an overall weighted average change in total FIM™ scores of 17.17. The change in average total FIM™ scores was greater for female patients than male patients. The change in average motor FIM™ scores ranged from 4 to 24.2 points with an average weighted change in average motor FIM™ scores of 16.85 (see Figure 7). The change in average total FIM™ and motor FIM™ scores was greater for females in three settings.

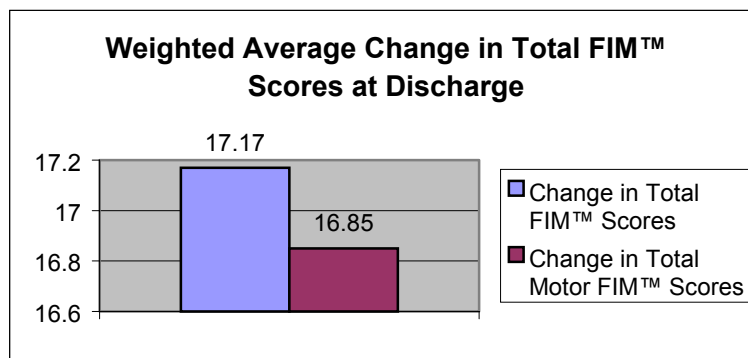


Figure 7: Weighted Average Change in Total FIM™ Scores

4.1.1 Discharge Living Setting

Another measure of patient outcome is the discharge living setting of patients following LTLD stroke rehabilitation. An analysis of the preliminary data findings shows that 54% of patients were able to return to their home. One female patient was discharged to an assisted living setting¹² and 29% of patients were discharged to a long-term care facility. Of these, the majority (61%) was female. Sixteen percent of patients' discharge living setting was categorized as "Other" and of these, 67% were male (see Figures 9 and 10).

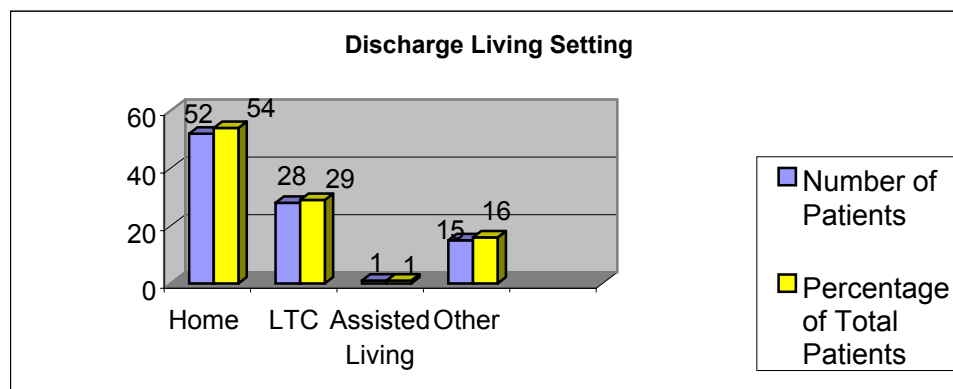


Figure 9: Discharge Living Setting

¹² An assisted living setting includes a group home, retirement home or supervised living setting. See the National Rehabilitation Report System Manual, Canadian Institute for Health Information, 2004.

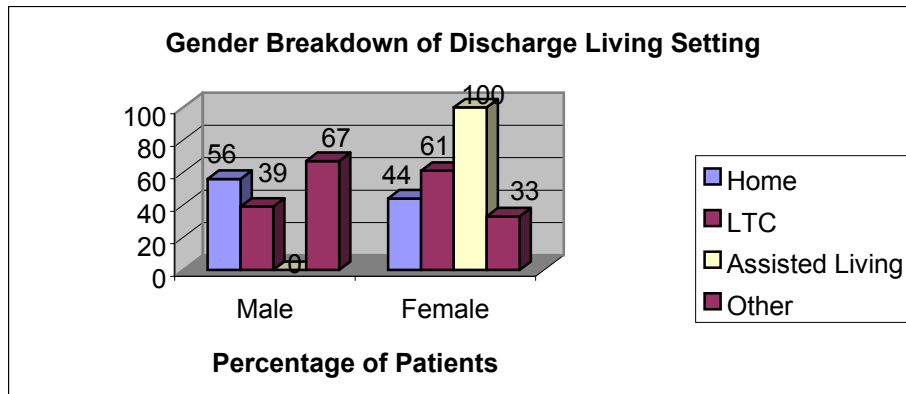


Figure 10: Discharge Living Setting According to Gender

A closer examination of the data concerning the patients who were able to return home reveals that 35% required supportive services. A comparison of the data for all patients who went home, regardless of whether they required supportive services, shows that a greater percentage of these patients were male. (See Figure 11)

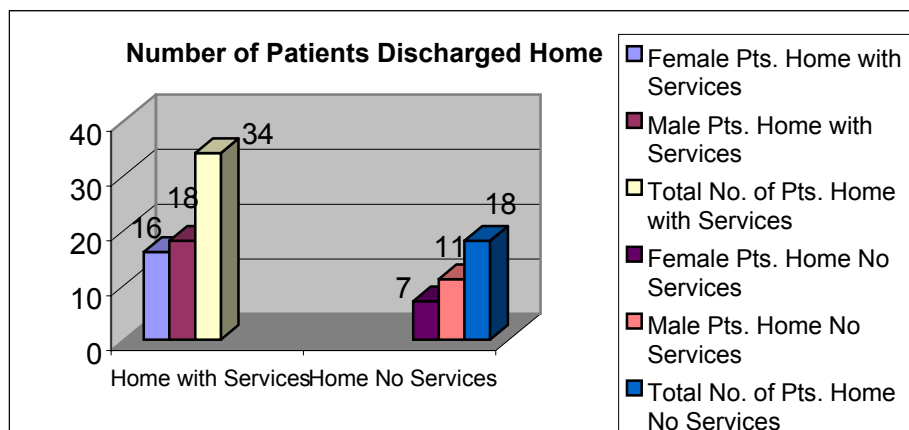


Figure 11: Number of Patients Requiring Services When Discharged Home

4.1.2 Average Length of Stay

The overall average length of stay ranged from 75.5 days to 205.96 days across the four settings with a weighted average length of stay of 110.47 days. An examination of the patient population in each setting showed that the longest overall length of stay occurred in the setting whose patient population had the highest average number of co-morbidities and the lowest average FIM™ scores on admission. As a result, these patients were more medically complex and at a lower functional level on admission. In each facility, the average length of stay was greater for females than for males.

5.0 SUMMARY AND ANALYSIS

This interim report highlights a number of issues in this initial review of LTLD stroke data.

According to these preliminary findings:

- Both male and female patients were admitted to LTLD stroke rehab programs with fairly equal representation.
- Although a few patients younger than 54 years of age required LTLD stroke rehab, the majority of patients were 55 years or older with a slightly larger representation in the over 75 year age category. The final report will explore a number of patient characteristics and indicators within in each age category in greater detail.
- Almost all patients were living at home before stroke onset. Over half of the patients were able to return home following LTLD stroke rehab.
- Although there was wide variation in level of functioning among patients on admission to LTLD stroke rehab, patients admitted to the LTLD stroke rehab program were medically complex with a number of co-morbidities present on admission. The impact of the presence of these co-morbidities on functional outcomes and length of stay will be explored in more depth in the final report.
- The average length of stay varied considerably among organizations and the preliminary findings suggest that level of functional status on admission and number of co-morbidities may affect the length of stay in LTLD stroke rehab. The analysis of data for the final report will include a comparison of FIM™ and MDS scores in each three-month period to determine when the greatest change in FIM™ scores tends to occur. It is anticipated that this level of analysis will help to determine the optimal length of stay in LTLD stroke rehab.
- Patients demonstrated an improvement in their level of functioning as measured by changes in average FIM™ scores between admission and discharge, with females showing more improvement in their outcomes than males. Interestingly, a greater percentage of patients who were able to return home were male while there was greater representation of female patients among those who were discharged to residential care. The extent to which the availability of social support at discharge influences discharge destination will be explored in more detail in the next report.

6.0 NEXT STEPS

The data collection period for the LTLTLD Stroke Demonstration Project concluded on September 30, 2005. Each organization will conduct an analysis of its own data and provide a summary report of its aggregated data to the GTA Rehab Network by the beginning of December 2005. The findings of these organization-specific data summaries will be further analyzed, published in a report and used to prepare a business case to inform the Ministry of Health and Long-Term Care about the service needs of survivors of severe stroke and LTLTLD stroke rehab.