RESEARCH PAPER

Needs assessment of individuals with stroke after discharge from hospital stratified by acute Functional Independence Measure score

JULIE DAWN MORELAND¹, VINCENT G. DEPAUL¹, AMY L. DEHUECK², STEFAN A. PAGLIUSO³, DARRELL W. C. YIP³, BARBARA J. POLLOCK³ & SEANNE WILKINS⁴

¹Department of Physiotherapy, St. Joseph’s Healthcare, Hamilton, Ontario, Canada, ²Department of Physiotherapy, Joseph Brant Memorial Hospital, Burlington, Ontario, Canada, ³Hamilton Health Sciences, Integrated Stroke Unit, Hamilton, Ontario, Canada, and ⁴McMaster University, School of Rehabilitation Science, Hamilton, Ontario, Canada

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Abstract

Purpose. To determine the needs, barriers and facilitators of function in individuals with stroke after discharge from hospital. To examine the results stratified by the patient’s acute score (<41, 41–80, >80) on the functional independence measure (FIM).

Method. This was a cohort study of 209 patients who had been admitted to hospital because of stroke. Patients were interviewed following hospital discharge using a semi-structured interview and asked to complete and return a quantitative closed-ended survey.

Results. For most domains, frequencies of needs varied across the FIM groups. Combining all FIM groups, the interview showed needs related to: physical impairments (35%), time for recovery (33%), education (28%), medical advice (25%), therapies and services (21%), social needs (19%) and emotional needs (18%). From the interview, the most frequent barriers were physical impairments (55%) and emotional concerns (40%). Common facilitators were family support (54%), therapies and medical care (40%) and personal attitudes (22%). Additional needs from the survey concerned: IADL, mobility, ADL, recreation, finances, communication and employment. Additional barriers from the survey were: attitudes, social participation, environments and limited services.

Conclusions. There is a large and varied number of needs and barriers following discharge from hospital that have planning and advocacy implications for rehabilitation teams.

Keywords: Stroke, functional independence measure, discharge

Introduction

After stroke, individuals are usually hospitalised for medical care and stabilisation, investigations and rehabilitation if needed. To ensure adequate follow-up and community reintegration, it is important to understand the difficulties that are experienced once a person has been discharged from hospital.

Although there have been numerous studies of quality of life after stroke, there is little information available about the self-perceived needs of individuals soon after discharge from hospital. The majority of studies have been done in Europe or Asia with qualitative designs and small sample sizes. Two qualitative studies and one check-list survey (n = 35) reported the ongoing need for information and education following discharge from hospital [1–3]. Another finding of qualitative studies has been the need for emotional support and encouragement from peers [4] and professionals [3]. Although participants in Hong Kong [2] emphasised the need for spiritual rather than psychological support, Swedish [3] and British [5] qualitative studies found a need for support in managing stress, anxiety, fear and helplessness. These small qualitative studies explore in depth what needs may exist, however...
purposive sampling and small sample sizes limit generalisability of the findings. One larger checklist survey [6] of individuals receiving outreach nursing in The Netherlands found the top three needs to be physical, emotional and cognitive, however interpretation of the results is limited to those eligible for outreach nursing services.

In North America, a US study [7], surveyed 24 individuals about self-care needs using a checklist. These participants identified preventing falls, nutrition, staying active, managing stress and dealing with emotional and mood swings as important issues. The authors did not describe their sampling procedures and validity was compromised due to the low response rate (14%). A Canadian epidemiological needs assessment [8] using population-based data and evidence-based recommendations concluded that the need for effective services exceeded what was provided. However, services and interventions that had not been studied for effectiveness were not included in their analyses.

Overall, the literature on the needs of individuals with stroke in the short term following discharge is limited by small sample sizes, poor response rates and limited areas of focus. In addition, there is a paucity of studies in North America. Finally, there have been no studies that have examined needs stratified by the patient’s initial status.

The purpose of this study was to systematically and comprehensively identify the needs, barriers and facilitators of participation in individuals who had been hospitalised for stroke. To enable health care team members to anticipate and prepare for needs before discharge, we stratified needs based on the participants’ acute functional status. Ween et al. [9] found that in patients admitted to rehabilitation, those with an admission Functional Independence Measure (FIM) score of greater than 80 almost universally went home and those with an admission FIM of less than 40 were associated with discharge to a nursing home. On the basis of this information, participants were stratified into three FIM score groups (<41, 41–80, >80) as measured within 10 days of stroke onset.

Data were collected at three points: discharge, 6 months post-discharge and 1 year post-discharge. This report presents the findings at discharge and is summarised by domains to be of general use to rehabilitation teams.

Methods

Using Rothman’s and Gant’s definitions of needs assessment [10], this study was an assessment of felt needs in a target population. The target population was those individuals who were admitted to an acute care hospital with stroke. Four centers in urban settings in Canada participated in recruitment. The inclusion criteria were: greater than or equal to 18 years of age and availability of a translator if the participant or their caregiver did not understand or speak English. Patients were excluded if they had a transient ischemic attack. Previous stroke was not a criterion for exclusion. Consecutive patients meeting these criteria were to be approached, given information about the study and asked for their consent to participate. The Research Ethics Boards of all recruitment sites approved the study.

Sample size was calculated based on the assumption that a confidence interval of \( \pm 10\% \) would provide adequate precision for clinical interpretation of the frequency results. Allowing for a conservative, 37% dropout rate at 1 year due to attrition and deaths, the sample size target was 95 in each of the three FIM categories.

Demographic and clinical information were gathered within 10 days of onset of stroke. At this time, the patient’s physiotherapist or occupational therapist assessed the FIM. The FIM is a measure of activities of daily living (ADL) that has been extensively researched for reliability and validity in disabled populations including those with stroke. Inter-rater reliability has been found to be high with an intraclass correlation coefficient of 0.96 for the total score [11]. Therapists and research staff received standardised training and were required to meet FIM testing criteria.

Two methods were used to gather comprehensive information on perceived needs – (1) a semi-structured interview and (2) a comprehensive closed-ended quantitative survey. The primary method was the semi-structured interview of participants in their living setting within 1 month after hospital discharge.

The semi-structured interview was developed and pilot-tested in consultation with a multidisciplinary advisory team, with items from all domains of the International Classification of Function [12]. Item areas included: physical impairments, ADL, instrumental activities of daily living (IADL), participation in social and recreational activities, volunteer or paid work responsibilities, relationships with family and friends, communication, emotions, educational needs, thinking or remembering and needs for services. Questions were structured to first ask the participant if he or she had problems in an area, followed by what would be needed to overcome these problems. An example is: ‘Do you have any physical difficulties as a result of the stroke? If yes, what are they? What do you think you need to help deal with or overcome these difficulties?’ The interview finished with barriers to participation and enjoyment of life (i.e. physical, financial, environmental, emotional
and societal) followed by an open-ended question to elicit what had been most helpful in fulfilling their goals and meeting their needs. Prompts were written on the data collection forms to clarify the questions for participants who didn’t understand the question.

Trained research assistants conducted the interviews in the participant’s living setting. If the participant was unable to communicate in English, a family member or friend interpreted for them. For participants with expressive dysphasia, their closest caregiver was asked to answer on the participant’s behalf. The average length of interview was 1 h, varying between 30 and 90 min. The research assistant wrote down responses in detail during the interview.

To analyse these data, three investigators examined the interviews of 10 participants and devised a coding scheme for the content. Further interviews were examined until saturation of the codes was achieved. Two research assistants – a registered social worker with 20 years of experience and a senior occupational therapy student in an M.Sc. program independently coded the interviews to minimise bias and ensure completeness. For comprehensiveness, a code was entered if identified by either of the research assistants. The research assistants added new codes as needed. These were further checked by one of the investigators to ensure that only unmet needs were coded. Because of the large variance in responses to the interview, codes were concatenated into general domains. Frequencies and 95% confidence intervals were calculated for each domain using SPSS 11.5 and PEPI 4.04x statistical software.

The interview findings were supplemented by a closed-ended quantitative survey. The survey questionnaire with a pre-addressed stamped envelope was left with the participants after their interview. The items dealt with the same needs and barriers domains as the interview; however the magnitude of each need and barrier was scored on a five-point scale (0 = not a need, to 4 = very large need). There were 135 items related to needs and 25 items related to barriers. All questions were phrased to inquire about needs or barriers. An example item is given in Figure 1. For each need and barrier, the frequencies, 95% confidence intervals and the mean magnitudes (if scored > 0) were calculated using SPSS 11.5 and PEPI 4.04x. Reliability of the survey was investigated in a convenience sample of participants by having the research assistant administer the survey in person and asking the patient to complete it independently within the next 2 days and return it by mail. The prevalence-adjusted, bias-adjusted Kappa was calculated for each item using PEPI 4.04x statistical software.

Results

Study recruitment took place from October 2002 to February 2006. Because of deaths and low frequencies, we were unable to recruit the proposed sample size for the lowest FIM group (acute score < 41). Recruitment was stopped when 95 participants completed a discharge interview in each of the top two FIM groups (acute scores 41–80 and > 80). One participant was originally misclassified, hence there were 54 in the FIM group 41–80, 103 in the FIM group > 80 and 12 in the FIM group < 41. There were 32 dropouts before the discharge interview. Ninety-four individuals mailed back their survey (45%). The median number of days from discharge to interview was 19 (inter-quartile range: 12–31).

There were no statistically significant differences between the completers and the dropouts although the dropout group consisted of fewer who were married or had a partner, fewer who lived in their own home, more that lived alone and more that were previously employed. Overall, those that returned their survey were healthier, better educated, less dependent before their stroke and were less likely to have had multiple strokes.

The demographic and clinical data for participants in each FIM category are given in Table I. There were no statistically significant differences in demographic variables. As expected, their discharge variables were statistically significantly different. There were some clinically important differences. The < 41 FIM group were younger, had a higher frequency of pre-stroke employment, had a higher frequency of living in their own home pre-stroke, were more functionally independent pre-stroke and had a higher incidence of hemorrhagic stroke and multiple strokes.

The coding process of the interviews resulted in 98 codes for needs, 74 codes for barriers and 31 codes for facilitators. The codes were concatenated into eight needs domains, nine barriers and three main

<table>
<thead>
<tr>
<th>I need …</th>
<th>Not a need</th>
<th>A small need</th>
<th>Moderate need</th>
<th>A large need</th>
<th>A very large need</th>
</tr>
</thead>
<tbody>
<tr>
<td>To be better able to move around in bed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figure 1. Example of closed-ended survey question.
facilitators. We were able to gather test–retest data on the survey for 11 participants. Of the 160 items, $\kappa$ was indeterminate in 13 items. The median $\kappa$ was 0.75 and the inter-quartile range was 0.63–0.77 indicating substantial agreement [13].

In the FIM group $<41$, 33% of individuals had an expressive communication FIM score of less than four and required assistance from their caregiver to respond in the interview. A communication score of less than four occurred in five percent of the sample in the FIM 41–80 group and three percent in the FIM $<41$ group.

Interview responses

Needs domains occurring at a frequency of $>15\%$ are graphed in Figure 2 for each FIM group. Barriers are given in Figure 3 and facilitators are given in Figure 4. The confidence intervals show a large degree of overlap between FIM groups as our study was not powered to detect differences between groups.

Needs

From Figure 2, the largest difference between groups was for social needs with a frequency of 46% in the $<41$ FIM group, 24% in the 41–80 FIM group and 11% in the $>80$ FIM group. Combining all FIM groups, needs related to physical impairments occurred at a frequency of 31% and included: motor control, fitness, balance, energy, memory, vision, treatment for pain and incontinence. Thirty-three percent reported that they needed time to recover and 28% reported educational needs. Needs for education included: information on the cause and nature of the stroke, risk of recurrence and medication side effects. Need for medical advice and care was identified by 25% corresponding to the high need for education about stroke. Need for therapies was 21% and included speech language pathology, occupational therapy, physiotherapy and day hospital. Social needs were expressed by 19%. These included: need for new friends and contacts and need to do previously enjoyed activities. Nineteen percent expressed a need for services or assistance primarily for IADL such as home maintenance and transportation. Again, the $<41$ FIM group had much greater need for services at 38%. Emotional needs were also prevalent at 18% and included need for professional reassurance, emotional support, self-acceptance, understanding from others and counseling. The $<41$ FIM group had a markedly higher frequency of emotional needs (31%). An examination of the individual needs codes highlighted driving as a need in 14% of the middle FIM group and 17% of the highest FIM group.

Table I. Demographic and clinical characteristics according to acute FIM score.

<table>
<thead>
<tr>
<th>Acute FIM group</th>
<th>Open-ended interview responders</th>
<th>Survey responders</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$&lt;41$</td>
<td>$41–80$</td>
</tr>
<tr>
<td>$n=12$</td>
<td>$n=94$</td>
<td>$n=103$</td>
</tr>
<tr>
<td>Sex: male/female (%)</td>
<td>42/58</td>
<td>50/50</td>
</tr>
<tr>
<td>Age years: mean (SD)</td>
<td>66 (13)</td>
<td>74 (11)</td>
</tr>
<tr>
<td>Marital status: married or partner (%)</td>
<td>50</td>
<td>62</td>
</tr>
<tr>
<td>Living before stroke: own home (%)</td>
<td>92</td>
<td>79</td>
</tr>
<tr>
<td>Living alone before stroke (%)</td>
<td>25</td>
<td>23</td>
</tr>
<tr>
<td>Education: high school or greater (%)</td>
<td>60</td>
<td>63</td>
</tr>
<tr>
<td>First language English (%)</td>
<td>100</td>
<td>72</td>
</tr>
<tr>
<td>Employed pre-stroke (%)</td>
<td>33</td>
<td>18</td>
</tr>
<tr>
<td>Receiving home care services pre-stroke (%)</td>
<td>17</td>
<td>17</td>
</tr>
<tr>
<td>Independent ADL pre-stroke (%)</td>
<td>92</td>
<td>84</td>
</tr>
<tr>
<td>Independent IADL pre-stroke (%)</td>
<td>92</td>
<td>72</td>
</tr>
<tr>
<td>First stroke (%)</td>
<td>58</td>
<td>76</td>
</tr>
<tr>
<td>Cause: infarction/hemorrhage (%)</td>
<td>75/25</td>
<td>88/12</td>
</tr>
<tr>
<td>Side of hemiplegia: right/left/bilateral (%)</td>
<td>67/25/8</td>
<td>42/51/7</td>
</tr>
<tr>
<td>Number of comorbidities: mean (SD)</td>
<td>4.0 (2.7)</td>
<td>3.9 (1.9)</td>
</tr>
<tr>
<td>Acute FIM score: mean (SD)</td>
<td>34 (4.5)</td>
<td>64 (11.5)</td>
</tr>
<tr>
<td>Discharge location</td>
<td></td>
<td></td>
</tr>
<tr>
<td>– own home</td>
<td>45</td>
<td>58</td>
</tr>
<tr>
<td>– nursing home*</td>
<td>36</td>
<td>22</td>
</tr>
<tr>
<td>Discharge FIM score: mean (SD)†</td>
<td>74 (28.3)</td>
<td>99 (21.6)</td>
</tr>
<tr>
<td>Length of stay in days: mean (SD)†</td>
<td>121 (71.4)</td>
<td>65 (43.3)</td>
</tr>
</tbody>
</table>

Results are not given for survey responders with FIM scores $<41$ since there were only 4 respondents.

*FIM $>80$ is statistically significant ($p < 0.05$) from FIM $<41$ and FIM 41–80.

†All groups are statistically significantly different ($p < 0.05$).
Barriers

From Figure 3, the largest differences between groups were for dependence (46% < 41 FIM group; 39% 41–80 FIM group; and 9% > 80 FIM group) and communication barriers (23% < 41 FIM group; 8% 41–80 FIM group; and 2% > 80 FIM group). Combining all FIM groups, the most frequent barriers were related to physical impairments (55%). These primarily included motor control, fatigue, aphasia and visual loss. Emotional barriers emerged as the next most frequent issue.
These included fear of another stroke, fear of falls, depression, boredom, lack of confidence, difficulties adjusting to change, frustration and anger. ADL, IADL and dependence issues occurred at frequencies of 30, 24 and 25%, respectively. Environmental barriers were encountered by 21%. These were predominantly because of stairs and winter weather. Financial barriers were reported by 19%. Finances were barriers to appropriate housing, aids, services, programs and transportation.

An examination of the individual codes showed inability to drive was reported as a barrier by 15% of the <41 FIM group, 15% of the 41–80 FIM group and 22% of the >80 FIM group. For the 41–80 and >80 groups, fatigue (21%, 30%) and inability to walk (28%, 18%) were important barriers.

Facilitators

Facilitators were only probed in the interview. There were three main facilitators: family and friend support (54%), therapies and medical care (40%) and personal qualities (22%). The primary codes for personal qualities were determination and having a positive attitude.

Survey responses

The closed-ended surveys elicited many more needs and different needs than the interviews. Because there were only four surveys returned by the individuals with acute FIM scores of <41, these were not analysed. The results for needs and barrier domains with a frequency of >15% are given in Figures 5 and 6. The weighted mean magnitude of needs and barriers for each domain were similar varying between 1.7 and 3.0 for the 41–80 FIM group and 1.7 and 3.2 for the >80 FIM group. Most needs occurred in the moderate to large range.

Needs

From Figure 5, large differences in needs between the groups occurred for IADL (95%, 61%), mobility (92%, 59%), ADL (87%, 51%), recreation (87%, 37%) and finances (69%, 37%) for FIM group 41–80 and FIM group >80, respectively.

Combining both FIM groups, needs with a frequency of >50% were physical impairments (85%), medical advice (80%), IADL (76%), mobility (73%), emotional concerns (72%), ADL (67%), social issues (65%), need for services (63%), recreation (59%) and financial needs (51%).

Individual survey needs items with a mean score of ≥2.0 (moderate to very large need) for physical impairments were standing balance (66%), better motor control of upper extremity (69%), better motor control of lower extremity (62%), to feel less fatigue (66%), to be able to carry things (56%), to reduce spasticity (54%), improve vision (41%), improve sleep (37%), decrease pain (36%) and relief from dizziness (32%).
Figure 5. Frequencies and 95% confidence intervals for need domains from the survey.

Figure 6. Frequencies and 95% confidence intervals for barrier domains from the survey.
High scoring (≥2.0) needs for medical and therapeutic help were physical therapy (49%), occupational therapy (42%) and stroke education (42%). Other services included: forum to interact with others who have had a stroke (40%), advice on driving (39%), suitable place to exercise (33%), nutritional education (32%), help with home maintenance (31%) and accessible public transit (31%).

High scoring (≥2.0) IADL items were need to be able to: cook (48%), write (47%), clean (42%), reach for items (42%), shop (42%), do laundry (37%) and do yard work (36%). For employment, the most frequent need was to perform tasks more quickly (31%). ADL items included: driving (48%), bathing (41%) and dressing (35%).

Mobility needs scoring ≥2.0 were: standing for long periods of time (58%), getting down and up from the floor (56%), walking outdoors (52%), stair climbing (48%), walking in crowded places (47%), tub transfers (44%), car transfers (39%), indoor ambulation (39%) and ability to pick items up off the floor (39%).

Emotional needs scoring ≥2.0 concerned: forgetfulness (43%), feeling of being a burden (39%), boredom (34%), financial worries (33%) and confusion (30%). High frequency social and recreational needs were: hobbies (38%), reading (32%) and ability to visit (31%). With respect to communication, ability to speak was the most frequent response (34%).

High scoring (≥2.0) responses for needs related to financial and government assistance included ability to deduct non-medical expenses (for example costs of services) from taxes (45%) and government recognition of their needs (33%).

**Barriers**

From Figure 6, the 95% confidence intervals were overlapping for each domain. Combining both FIM groups, barriers with a frequency of >50% were physical impairments (87%) and emotional barriers (68%).

The following were barrier items with a mean magnitude of ≥2.0: lack of energy (75%), weakness (69%), balance (67%), fear of having another stroke (63%) and fear of falling (51%). Others were: lack of confidence (45%), attitudes of other people (34%), finances (33%), lack of knowledge about stroke (31%) and aphasia (31%).

**Discussion**

The reported needs reflect areas covered by multiple rehabilitation disciplines. The interview is the most compelling source of information because it likely represents the needs that are foremost on the minds of individuals with stroke soon after discharge from hospital. The closed-ended survey elicited many more needs. Although the survey items may have facilitated recall of needs, the items in the survey were limited to those areas that were felt to be important by the multi-disciplinary panel rather than those of importance to patients.

This needs assessment was not powered to detect differences between FIM groups and hence statistical significance testing is not reported. Although it might be expected that the highest functioning FIM group would not have as many needs, in this group, needs related to medical advice and education were slightly higher than the other two groups. The lower FIM groups had more needs related to emotional issues, services and social participation. Although discharge planning usually addresses these issues in all FIM groups, the lowest FIM group may need special attention to these areas. Additional concerns that presented as barriers in the lower FIM groups were communication, employment and environmental accessibility. The proportion of participants previously employed in the lowest FIM group was larger which may explain the results regarding employment.

In the interview, the need for services had an overall frequency of 19%, but ADL and IADL barriers had frequencies of 30% and 24%. This compares to a sub-analysis of the Canadian Community Health Survey that was conducted in 2000–2001 [14]. Cloutier-Fisher found that only 33% of the need for assistance with ADL was met. In a review of qualitative studies, McKevitt et al. [15] identified service interface problems that resulted in gaps in care especially for personal care services. Therefore, ensuring a seamless transition from hospital to home needs to be seen as a priority by inpatient and community based rehabilitation teams.

As might be expected, needs and barriers related to physical impairments had the highest frequency and many felt that they needed time for recovery to occur or therapies to facilitate recovery. The most frequent survey items in the physical impairment domain were balance, motor control of the extremities and fatigue, each with a prevalence of ~80%. Walking and driving were not as important for the <41 FIM group but being dependent on others was a concern for the <41 and 41–80 FIM groups. This suggests that more research and development are needed in the area of assistive technologies.

The need to relieve or cope with fatigue was commonly reported. Although fatigue has been recently recognised as being prevalent in 40–57% of individuals with stroke, there appears to be only...
one study of attempted treatment [16]. Further investigation into the mechanisms of fatigue and its treatment are needed for this highly prevalent symptom.

There was an average self-reported need for therapies of 21%. This is consistent with the epidemiological study of Hunter et al. [8] in which 25% of the need was not met for speech language pathology, occupational therapy and physiotherapy. With hospital length of stays being shortened and limited access to multidisciplinary and single service outpatient rehabilitation programs, teams and therapists may perceive a need to ration existing services among patients. Evidence of cortical [17,18] and functional changes [19–21] in patients given therapy months after stroke onset compel clinicians and health service planners to consider the ongoing potential for improvement of individuals at this stage of recovery.

All FIM categories showed a need for more information about stroke including the nature and cause of their stroke and risk of recurrence. The need for education is consistent with findings from other qualitative research [15]. Information is often given to patients in the early phase following stroke, but patients may not retain the information because of being overwhelmed by the occurrence and consequences of the stroke. Stroke education has been evaluated in randomised controlled trials that have shown an increase in recipient knowledge and satisfaction, but no change in emotional or functional outcomes [22,23]. Patient preferences for means of delivery of education have also been studied [5,24]. Despite these studies, the need for education has a high frequency suggesting that research findings need to be translated into clinical practice. Following discharge, family doctors may be able to play a role in education, answering residual questions, making referrals and ensuring that secondary preventive measures are taken. In a study in the UK, Hare et al. [5] conducted focus groups with individuals with stroke and reported that they viewed Primary Care as the first point of contact for any information or problems. Thus, it is important that family doctors are aware of the needs of individuals with stroke and the resources that are available to meet these needs.

Social and emotional issues are complex. They can result from deficits as a result of the stroke lesion, such as cognitive and communication impairments, reaction to changes in roles and dependency, environmental barriers and social stigma [25]. Social needs were highest in the lowest FIM group and interview codes included needs for social contacts, new friends and ability to do previously enjoyed activities. It is not clear how to address these needs. In a review of psychosocial interventions, Knapp et al. [26] (2000) found that existing studies are not adequately designed to conclude whether the psychosocial interventions are effective or not. As social isolation is a serious concern that may cause or potentiate depression, more developmental and evaluative research is needed.

Although emotional needs were expressed by 18% in the interview, emotional barriers emerged as the second most important barrier at 40%. This is consistent with the findings of Hochstenbach et al. [27] in a study of community living individuals with stroke at a mean of 10 months following stroke. More than 40% of the respondents reported dependent behaviour, depressed mood, being more focussed on oneself and anxiety. A further look at our data showed that fear of another stroke (63%), worries about health (43%) and depression (38%), had the highest frequency although they did not have a mean score of ≥2.0.

Fear and anxiety may be related to coping and lack of confidence. In our study, lack of confidence was reported as a barrier by 45% in the survey. In a qualitative study of coping post-stroke, Rochette et al. [28] concluded that changing how a situation is perceived may be the most effective way of coping. This suggests the use of cognitive restructuring interventions. The model of chronic diseases self-management education which incorporates self-efficacy appears promising in this regard [29], however, Kendall et al. [30], in a randomised controlled trial, did not find any effect on the Stroke Specific Quality of Life Scale except for family roles and fine motor tasks. No significant effects were found for the remaining psychological, social and physical measures. Given that only one study of chronic diseases self-management has been published, further research is needed on self-efficacy and cognitive restructuring interventions.

Other barriers were generally consistent with needs. Barriers that did not correspond to needs were environmental and financial barriers. Finances were needed for services including transportation, therapeutic programs and assistive devices. Environmental barriers were predominantly due to stairs and accessibility issues.

The primary facilitators that were identified were family support, medical and rehabilitation care and personal characteristics such as determination and positive attitude. This suggests the need for research on how rehabilitation and service providers can develop, reinforce and channel these characteristics during inpatient rehabilitation and during the process of community reintegration.

There are some limitations of this study. There were only 12 individuals in the lowest FIM group, therefore precision of the frequency estimates for this
group is low and generalisability is limited. Although individuals in the FIM <41 group had a higher frequency of multiple strokes, their demographic characteristics were more favorable (younger age and more previously employed), hence our sample may have under-estimated needs for this group. Our sample was from an urban Canadian setting with cultural backgrounds primarily associated with having English as a first language. Needs may differ for those in rural settings, in different health care systems and in other cultures. Our response rate for the quantitative survey was low at 45%. For this reason, greater emphasis should be given to the results of the open-ended interview. In the case of individuals with communication problems, the closest caregiver was asked to respond on the participant’s behalf. The use of caregiver responses was negligible in the top two FIM categories, however it was 33% in the lowest FIM group. In studies of proxy-patient agreement in individuals with stroke, proxies have been found to report more disability than patients [31,32]. This would have the potential effect of over-estimating needs in the lowest FIM group.

Conclusions

The results have implications for rehabilitation teams, primary care, service planners, stroke support groups, health care funding bodies, lobbyists and researchers. Regardless of level of acute function, participants reported substantial needs following discharge from hospital. There was a high degree of need related to physical impairments, education, medical advice and therapies, as well as social and emotional needs. Detailed discharge planning and continued advocacy for ensuring that adequate and affordable services are available are important. Although many of the results might have been intuitively predicted, the extent of educational, social and emotional needs and barriers was unexpected. Newer areas of research are indicated regarding post-stroke self-efficacy, cognitive restructuring and how to promote determination and positive attitudes and their role in community reintegration.

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