Factors influencing post-stroke rehabilitation participation after discharge from hospital

Wei Koh, Christopher Barr, Stacey George

Aim: To explore what the obstacles are that deter patients from continuing stroke rehabilitation after discharge from hospital in Singapore.

Methods: In this qualitative study, individual semi-structured telephone interviews were undertaken and analysed using inductive thematic analysis. Thirty one stroke patients, who had been discharged from the hospital after inpatient rehabilitation (mean age=66.46 years, mean duration post-discharge=95.82 days), were interviewed.

Results: Five themes were identified as obstacles to post-discharge stroke rehabilitation including: the means to access rehabilitative services; lapse in discharge coordination; family members’ views and actions; discrepancies in expectation; and the perception that rehabilitation is simple. Participants indicated a need for timely and appropriate information, delivered according to their individualised needs.

Conclusion: Study findings revealed that the absence of a smooth transition through the continuum of stroke care and not having a common understanding of rehabilitation accounts for the lack of adherence to therapy recommendations. The results suggest that clinicians need to be more aware of their role in providing well-coordinated information about therapy. The study also highlighted the need to review the goal-setting processes that guide the course of rehabilitation. Goals should be more patient-centred to reduce the discrepancies in expectations of rehabilitation. There needs to be a greater involvement of carers in discharge planning to minimise the dissatisfaction in care arrangements and information delivery.

Key words: Rehabilitation Participation Discharge Singapore

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Greater participation in rehabilitation is associated with a higher percentage of improvement in activities of daily living and mobility (Paolucci et al, 2012). Therefore, knowing the factors that influence patients’ continuation in outpatient rehabilitation is paramount for quality improvement in clinical practice. An increased awareness of these factors will assist clinicians in building patients’ participation to ensure they achieve an optimal rehabilitation outcome.

There is a discrepancy in the factors cited by patients and health professionals that affect motivation to participate in rehabilitation. Patients with low compliance to rehabilitation reported a lack of support, not understanding the intervention, and receiving mixed messages from their health professionals as major factors that discouraged them from participating in rehabilitation (Maclean et al. 2000). A study with 32 health professionals revealed that the majority of clinicians felt that motivation is affected by clinical factors, e.g. severity of stroke, cognition and depression (Maclean et al. 2002). Half of the clinicians attributed motivation to an intrinsic personality trait of the patient. Only a quarter of the clinicians thought their behaviours could diminish patients’ motivation, while less than half mentioned the possible impact of the rehabilitation environment on patients’ motivation. Therapists also report routinely encountering patients who are difficult to engage in therapy (Lequerica et al, 2009) and rehabilitation professionals may also label patients according to their degree of motivation (Becker and Kaufman, 1995; Maclean et al, 2002). Since labelling a patient as unmotivated may negatively affect their rehabilitation outcomes (Maclean and Pound, 2002), it is important to investigate the contributory factors to patients’ lack of interest in continuing rehabilitation.

Best practice in stroke rehabilitation should address all the factors that are important to the patient (Peoples et al, 2011). However, there is a paucity of research exploring the determinants of motivation among the Asian population.

This study aims to gain insight into the reasons cited by Singaporean patients with stroke for not taking up recommendations to continue with rehabilitation after discharge from hospital, as very little is known about this specifically in Singapore. Gaining an understanding of the factors that hinder these patients’ participation will facilitate the discussion around how to empower rehabilitation professionals to cope with patients discontinuing rehabilitation.

<table>
<thead>
<tr>
<th>Table 1. Questioning guide for telephone interviews</th>
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<tbody>
<tr>
<td>1. Were you being advised to continue to attend a rehabilitation programme upon discharge from the hospital?</td>
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<tr>
<td>2. Did you follow the recommendation?</td>
</tr>
<tr>
<td>3*. What makes you not want to continue rehabilitation?</td>
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<tr>
<td>4*. What had rehabilitation helped you with?</td>
</tr>
<tr>
<td>5*. What had rehabilitation not helped you with?</td>
</tr>
<tr>
<td>6*. Did the rehabilitation you received meet your personal goals of rehabilitation?</td>
</tr>
<tr>
<td>7*. Is there anything that you want to say and you didn’t get a chance to say?</td>
</tr>
<tr>
<td>*=Probing questions for subjects who indicated that they did not continue to participate in rehabilitation</td>
</tr>
</tbody>
</table>

**METHODS**

Data collection

This study took a qualitative approach, using telephone interviews with a purposive sample of participants. All patients with stroke who underwent rehabilitation and were discharged from a tertiary institution’s rehabilitation ward in Singapore between December 2012 and April 2013 were invited to participate in the telephone interviews. Potential participants were excluded if they did not understand spoken English, the official language of Singapore, or were non-permanent residents of Singapore. All of this study’s prospective participants spoke English and were either citizens or permanent residents of Singapore and so nobody was excluded from participating on the basis of language. The study was approved by the Centralised Institutional Review Board in Singapore and the Social and Behavioural Research Ethics Committee at Flinders University in Adelaide, Australia.

An advance letter was mailed out to the potential participants prior to telephone contact by the principal investigator (PI). The type of stroke each patient had and Functional Independence Measure (FIM) scores were obtained from clinical notes. Telephone interviews were held between 9 am and 6 pm daily between May and July 2013, with a maximum of six attempts to contact participants who did not initially answer the call (Vigderhous, 1981). The PI, who did not participate in patient care and had no previous contact with the participants prior to their telephone interviews, conducted one telephone interview per
Each participant’s verbal consent was obtained prior to commencing the interview. A number of questions were asked (see Table 1).

Participants who mentioned they did not continue their rehabilitation were further probed for the reasons that discouraged them from doing so. Participants were encouraged to comment on any aspects of their rehabilitation. In the cases where it was not possible for the participant to speak over the phone, their next of kin or carer who volunteered to speak on their behalf was interviewed. The PI took field notes of each interview immediately after the interview, in addition to the detailed verbatim notes that were taken during the interview.

**Data analysis**

The interviews were analysed using thematic analysis as described by Braun and Clarke (2006). The analysis was undertaken by the PI. The entire data set was used in deriving the thematic description and predominant themes of the topic. To ensure the validity and reliability of the results, data gathered from the interviews and field notes were compared to check for agreement in transcription (Berg, 1998; Liamputtong and Ezzy, 2005). The PI familiarised themselves with the contents of the interviews, and noted initial ideas from the data. Interesting features across the entire data were systematically coded, and collated into potential themes, using a data-driven coding process. The data were constantly re-organised and summarised to show patterns in the responses before they were interpreted. Themes were identified within the explicit meanings of the data, reviewed and refined using both the coded extracts and the entire data.

**RESULTS**

One hundred and eighteen patients with stroke were discharged from the rehabilitation ward between December 2012 and April 2013. Four patients were excluded from the telephone contact as they were non-permanent residents of Singapore. Telephone contact was attempted for 114 patients (see Figure 1), 68 patients were interviewed, and 46 patients were not interviewed (15 declined the interview, 19 points were unobtainable when telephone contact was attempted, and 12 had invalid numbers.

Of the 68 participants interviewed, 31 participants reported not following recommendations to continue their rehabilitation. Table 2 presents a comparison of participants’ characteristics, based on complete data available from the case notes (n=48). Twenty participants had incomplete case notes and were excluded from analysis. There was no difference in gender, type of stroke, or age between those who did and did not complete rehabilitation.

Participants who reported they were non-compliant with rehabilitation recommendations significantly improved from their pre- to post-rehabilitation FIM scores (Wilcoxon Signed Ranked test, P<0.01). Twenty two interviews were conducted with patients’ next of kin who was involved in the direct care of the participant (15 with the son or daughter of the patient, 5 with their spouse, and 2 with their sibling). At the time of interview, the mean duration post-discharge in which significant improve-

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**Table 2. Participant characteristics**

<table>
<thead>
<tr>
<th></th>
<th>Continued with rehabilitation (n=20*)</th>
<th>Did not continue with rehabilitation (n=28*)</th>
<th>Statistic (P)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (male/female)</td>
<td>13/7</td>
<td>14/14</td>
<td>0.302 a</td>
</tr>
<tr>
<td>Type of stroke (infarct/haemorrhage)</td>
<td>16/4</td>
<td>23/5</td>
<td>0.851 a</td>
</tr>
<tr>
<td>Age (mean SD)</td>
<td>62.25 (9.79)</td>
<td>66.46 (12.01)</td>
<td>0.188 b</td>
</tr>
<tr>
<td>Number of days post discharge (mean SD)</td>
<td>85.85 (39.93)</td>
<td>95.82 (35.31)</td>
<td>0.368 b</td>
</tr>
<tr>
<td>Pre-rehabilitation FIM scores (median, range)</td>
<td>47.5 (18–85)</td>
<td>51.5 (18–103)</td>
<td>0.630 c</td>
</tr>
<tr>
<td>Post-rehabilitation FIM scores (median, range)</td>
<td>56.0 (23–92)</td>
<td>66.0 (18–120)</td>
<td>0.143 c</td>
</tr>
</tbody>
</table>

FIM = Functional Independence Measure; *indicates n where complete data sets were available; a=Chi-Square test; b=Independent sample t-test; c=Mann Whitney U
ments occurred was 95.82 days (SD=33.51). The participants who reported they were continuing their rehabilitation had a shorter mean duration in which significant improvements occurred post-discharge duration of 85.85 days (SD=39.93). These patients also demonstrated a significant improvement in their FIM scores after undergoing inpatient rehabilitation (Wilcoxon Signed Rank test \( P<0.01 \)).

Five themes were evident through inductive analysis of the transcripts from the participants who indicated that they did not continue with their rehabilitation. The five themes were: first, the means to access rehabilitative services; second, lapse in discharge coordination; third, family members’ views and actions; fourth, discrepancies in expectation; and fifth, the perception that rehabilitation is simple. Representative quotations are selected to present each theme.

The means to access rehabilitative services

Difficulties with mobility and transport to the rehabilitation centre precluded participation in post-stroke rehabilitation. The lack of means of transport and the associated costs were the chief barriers that hindered adherence to continuing post-stroke rehabilitation. Recommendations for further rehabilitation had overlooked the ease of the service user accessing services.

‘We didn’t go because my father cannot move. Have to call ambulance because he cannot move, so he can’t go’ Participant 14.

‘Money is a concern and also who to bring my dad to therapy’ Participant 19.

Affordability of rehabilitative services also had a direct influence on the continuation of rehabilitation. It is a practical factor considered by the participants in deciding whether to receive follow-on rehabilitation.

‘I say not [to continue as outpatient], I stay at home because no money. Rehab helps but no money’ Participant 21.

Lapse in discharge coordination

Existing gaps in the transition from inpatient to outpatient services were frequently cited as the reason for not continuing rehabilitation. Some participants fell through the unnoticed gap and were left waiting for follow-up rehabilitation.

Inadequate post-discharge follow-up may also have been a cause for this flaw in service delivery not being rectified.

‘They say “need [therapy]”, ask me whether I want to follow-up. I say “yes”, but I am still waiting. They say that someone will arrange for me. I am quite okay already, but still I am disappointed because nothing was done for me’ Participant 18.

‘We were discharged, but still waiting [for follow-up therapy], like it is not well planned’ Participant 23.

Data also highlighted the need for clinicians to review the appropriateness of the timing of information provision and education. The recommendations for further rehabilitation were found not to be explicitly understood by the interviewees.

‘I am unsure if we have appointment for therapy’ Participant 13.

‘I don’t know if therapy is offered. I am waiting, hoping to have some therapy for my wife’ Participant 6.

Family members’ views and actions

The presence of a family member, who is not necessarily involved in the direct care provision were potential facilitators or inhibitors for the continuation of rehabilitation. In some cases, where the patient was generally reluctant to continue their rehabilitation, the patient’s children acted to implement rehabilitation based on their own beliefs that participation in rehabilitation is beneficial.

‘She doesn’t care if she goes or not [to day rehabilitation centre]; need prompt to go. We want her to go as it is good for her. I think she also enjoys herself there’ Participant 25.

This influence of power and authority within the family dynamics may not always be optimal for rehabilitation. Patients and some carers, who are not the next of kin, but who served as a nominated spokesperson during the patient’s admission, felt stranded and expressed their helplessness and need of assistance.

‘I missed two appointments as my son forgot’ Participant 3.
‘My brother holds all the appointment card, so I don’t know when is the next appointment. Can you help me?’ Participant 14.

‘I don’t know what happened, my brother was the main spokesperson then, and my dad was discharged with no therapy follow-up. The doctor got recommend[ed], [I get] home therapy, can you help me?’ Participant 19.

Discrepancies in expectation

Some participants did not see the need to continue with the recommended rehabilitation as they perceived that rehabilitation was not holistic. This was due to their concerns not being addressed during inpatient rehabilitation.

‘Rehab is good, but knee problem not address’ Participant 22.

‘Work stress caused my ill health. Stress management not taught, it is up to us to cope’ Participant 2.

While some participants felt discouraged from continuing rehabilitation due to unmet needs during their rehabilitation, others reported that the therapy intensity was not comparable to their expectations, leading them to seek alternatives to their therapy recommendations. There was a mismatch in the intensity of rehabilitation between what the clinician felt was appropriate for the patient and what the patient deemed suitable.

‘I do on my own, brisk walking and swimming, rehab is too light for me’ Participant 20.

‘We were recommended to community hospital but feel that it is not sufficient intensity. We got a personal physio at home for therapy’ Participant 9.

Despite the statistical significance in the improvement in FIM scores after inpatient rehabilitation, some patients were deterred from continuing rehabilitation as they did not feel the gain from their rehabilitation programme.

‘Rehab is not helpful, no improvement, no seeing him getting better. Sometimes the body will go in front, and fall, can’t straighten him up’ Participant 14.

‘It [rehabilitation] doesn’t help. How to say ... the method doesn’t work, for example, my hand my arm can’t really lift up, but their way of teaching old citizen to keep moving doesn’t work for this kind of sickness’ Participant 18.

Another factor contributing to non-continuation of rehabilitation was the discrepancy between the suggested rehabilitation needs by the referring therapist and the perceived rehabilitation needs of the patient by the step-down (community) rehabilitative service provider. One participant mentioned being denied the need for further rehabilitation by the step-down rehabilitation centre despite being convinced by the referring therapist of his potential for further improvement with rehabilitation.

The perception that rehabilitation is simple

Rehabilitation was seen and understood as mere exercises by most participants.

Table 3. Characteristics of participants who continued with rehabilitation (n=20)*

<table>
<thead>
<tr>
<th></th>
<th>n (%)</th>
<th>Mean (SD)</th>
<th>Median</th>
<th>Min–max</th>
<th>Shapiro-Wilk test</th>
<th>Wilcoxon Signed Ranked test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (male; female)</td>
<td>13 (65); 7 (35)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type of stroke (infarct; haemorrhage)</td>
<td>16 (80); 4 (20)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>62.25 (9.79)</td>
<td>63.0</td>
<td>40–81</td>
<td></td>
<td>P=0.886</td>
<td></td>
</tr>
<tr>
<td>Days post-discharge (n)</td>
<td>85.85 (39.93)</td>
<td>85.5</td>
<td>26–147</td>
<td></td>
<td>P=0.205</td>
<td></td>
</tr>
<tr>
<td>Pre-rehabilitation FIM scores</td>
<td>47.5</td>
<td>18–85</td>
<td></td>
<td></td>
<td>P=0.091</td>
<td>P=0.000</td>
</tr>
<tr>
<td>Post-rehabilitation FIM scores</td>
<td>56.0</td>
<td>23–92</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

FIM=Functional Independence Measure; * n=37 (20 data sets were valid for statistical analysis as 17 were incomplete)
Rehabilitation was being perceived as simple, common-sense knowledge, which could be easily self-replicated or substituted without engaging a therapist, but instead using the help of therapy devices or domestic helpers. The expertise of exercise prescription and activity grading by the clinicians was undermined as participants did not understand the reasoning behind their therapy prescription. Self-prescribed or self-replicated exercises were believed to be comparable to the prescriptions of a therapist and assisted in achieving similar therapeutic outcomes.

‘Rehab is simple exercises’ Participant 14.

‘He went once [for outpatient rehabilitation service] and say he can do on his own so no need to go. I think doctor want him to go, but he insist he no need’ Participant 29.

‘We are advised for physio, but we did not do. We are doing at home, we buy the cycling machine, the one I saw her using. I feel that this is sufficient’ Participant 11.

‘The maid accompanies to do exercise at home, bending legs while holding on at the window’ Participant 24.

‘We do our own rehab, the maid helps with the ranging at home’ Participant 12.

There was also a greater emphasis on other means to facilitate post-stroke recovery than on rehabilitation. The use of medications and acupuncture was believed to be contributing more to their recovery compared to rehabilitation.

‘We bought the machine [for therapy], what is important is follow-up with doctors. I take medication so it helps. Medication helps me more’ Participant 8.

‘Rehab helps but I feel that the improvement is due to the Chinese acupuncture’ Participant 19.

**DISCUSSION**

This study was an exploratory investigation to provide initial information on the reasons given by Singaporean patients with stroke for not taking up the recommendations to continue rehabilitation. Telephone interviews were employed to ensure a high response rate (59.6%) compared to the use of questionnaires or in-person interviews (Sturges and Hanrahan, 2004; Carr and Worth, 2011). Despite the limitations of the methodology, including relatively short interviews, and the absence of visual cues for communication of emotions and feedback (Novick, 2008; Irvine, 2011; Lechuga, 2011), this mode of data collection allowed an open and free discussion of thoughts that may not be easily discussed through in-person interviews (Mitchell and Chaboyer, 2010).

The interviews revealed several themes. With the current user-pay healthcare system, it is not surprising that financial concerns are being raised. The participants also raised the issue of transport to and from the rehabilitation centre, and the need for transport to be arranged, which warrants attention. It is crucial that clinicians consider the ease of accessibility of post-discharge services during discharge planning, and that they make the various means of transport and mobility known to both patients and carers.

A common theme in this study was the dissatisfaction with the transition from inpatient care to outpatient follow-up. The absence of an effective continuum of stroke care was revealed to be an obstacle for the continuation of rehabilitation. Greater understanding is needed to clearly articulate the processes that impacted the smooth transition between services.

The results also suggested that patients and their carers may be inadequately informed of the necessary follow-up. Patients and carers are selective in their needs for information provided by clinicians by only absorbing information that they deem relevant (Van Veenendaal et al, 1996; Wachters-Kaufmann et al, 2005). The use of active involvement instead of passive information delivery to patients and their caregivers during the education process have been emphasised as the desirable method of information dissemination (Kalra et al, 2004; Smith et al, 2008). While more research is needed to evaluate the timelines of information provision, potential interim services, e.g. support groups and counselling services, should ensure there is ongoing support readily accessible to patients who are discharged.

Additionally, the various unmet needs participants reported suggest that the goal-setting process for stroke rehabilitation was moreclinician-centred or system-centred rather than patient-centred. The discrepancy in perception of functional recovery post-stroke is a barrier that needs to be overcome. Patients
viewed recovery as regaining their pre-stroke status or gaining the ability to adapt to their new life situation, yet clinicians tend to focus on improving activity levels or reducing the impairment post-stroke (Rosewilliam et al, 2011). Since education is essential to arriving at goals and for establishing the expectation for behaviours, goal-setting with the patient and carers can be used as the platform for ascertaining the focus and direction of rehabilitation. While it is recognised that not all goals desired by a patient will be realistic and attainable (Reuben and Tinetti, 2012), the investment of time in shared decision making is an opportunity for the clinician to explain and address issues around stroke rehabilitation. Since the participants identified therapists and nurses as the next most important source of information second to physicians (Hafsteinsdottir et al, 2011), it may be beneficial to conduct a thorough assessment of the patient and carers’ educational needs and develop a plan to meet those needs.

Participants demonstrated limited knowledge of rehabilitation and made no mention of the impact of the rehabilitative environment on their motivation to continue rehabilitation. A clearer understanding of rehabilitation by patients and carers can be established to facilitate adherence to therapy recommendations for optimising functional benefits. It is important that patients and carers understand therapy as complementary and do not to dismiss it as an alternative means of stroke recovery. It can also be inferred that participants had limited understanding of the rationale behind each intervention strategy. It has been suggested that clinicians need to be more aware of their role as educators, and to provide therapy information that is coordinated and delivered as a reinforcement of the rationale of therapy to the patients (Wachters-Kaufmann et al, 2005).

This study also highlighted that the routine of having a family member nominated as the spokesperson for the patient during admission, who may not be involved in the care provision post-discharge, can jeopardise the rehabilitation needs of the patient. The social support within the family context can affect the amount of support the carer receives (Ell, 1996). There needs to be a clear communication and mutual understanding of the burden of care as well as the ability of the carer to meet care needs. Individuals who do not receive direct care provision may have unrealistic expectations of family members’ care-giving behaviours. Misguided family support can increase carer strain and be an impediment to the continuation of rehabilitation. This finding is consistent with other literature, revealing that the needs of the carers for patients with stroke have been overlooked and they are often being excluded from the decision and discharge planning process (Low et al, 1999; Cobley et al, 2013). The involvement of carers in discharge planning can minimise dissatisfaction with care arrangements and information needs, which is valuable in diminishing the negative effects from the high stress levels carers face (Gillespie and Campbell, 2011). Therefore, it is imperative to ensure the primary carer is included in the decision making process during discharge planning. Further research is required to evaluate the best means to empower caregivers as spokespeople.

Despite the rich data gained on factors which influence the continuation of rehabilitation following stroke in Singapore, the study has its limitations. The interviews with the small sample provided a comparable breadth of data, but depth of detail may be lacking compared to in-person interviews (Irvine, 2011), and may not represent the non-English speaking population. The findings are subjected to biases as they are based on participants’ reports and that of their proxies. Carers of stroke survivors report having inadequate stroke-related knowledge (Simon et al, 2008). Thus, the results of this study might have been influenced by a lack of understanding of stroke on the part of the carer. The study results might also be skewed towards reflecting their care-giving experiences as many carers for patients with stroke feel that they are failing as carers (Gillespie and Campbell, 2011). Nonetheless, the results suggest the decision over whether the person with stroke continues to seek services is largely dependent on their carers and one third of stroke survivors require a full-time carer (Steiner et al, 2009).
CONCLUSION

The qualitative interviews in this study provided insights into the experiences of Singaporean stroke patients that led to their discontinuation of rehabilitation. It is revealed that the obstacles that stop patients from participating were largely extrinsic factors stemming from the gaps in the stroke care continuum, such as a lapse in discharge coordination. This study emphasised the need to empower carers of stroke survivors, the need to review current goal-setting processes for rehabilitation and the need to establish a common understanding of rehabilitation practice between patients, their carers and the clinicians.

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