

Abstract

Purpose The purpose of this qualitative study was to enhance our understanding of the transition experience for clients with stroke and their carers during discharge and the first month at home.

Method Semi-structured interviews were conducted with five clients with stroke and their carers ($n=5$) at one month after discharge from stroke rehabilitation. Questioning in the interviews explored preparation for and the experience of the transition. Inductive thematic analysis was completed with the client and carer interviews and the resultant themes were compared. Basic demographic data were collected to allow description of the participants.

Results Five clients and five carers were interviewed one month after discharge to home. The analysis of the client interviews yielded three themes including: *rehabilitation was okay, it's a struggle*, and *supports and assistance*. The carer interviews also yielded three themes including: *the purpose of rehabilitation, life is different now*, and *looking to the future*.

Conclusions The clients and the carers all spoke of the positive aspects of rehabilitation but raised concerns about the limited ability to undertake daily tasks regularly and develop personalised routines in preparation for discharge. The daily routines at home were disrupted with clients taking longer to complete daily activities and carers juggling caring responsibilities with their own lifestyle. Overall, the results suggest that there is a need for stroke rehabilitation services to better prepare the clients and carers for transition to home.

Introduction

Transition is a term that represents the act of passing from one state to the next or an event that results in a transformation [1]. The lived experience following a stroke can be considered a series of transitions with the time of stroke event representing the first transition as the person becomes a patient in a hospital, with altered abilities and changes to their life roles. During recovery and rehabilitation, there are multiple transition experiences as the person moves along the continuum of care, returning to community living and their various life roles. The transition to home from inpatient services is an early and important transition for the client with stroke and their carer. The hospital-based rehabilitation services prepare people for a safe and expedient discharge to home with the ongoing care and support provided by community based services [2-4]. Despite this recognised continuum of care from hospital to community, stroke survivors have identified that this is a time when they feel inadequately prepared mentally and physically to return to their lives [5].

The first month at home represents a critical time for transition and there have been some studies exploring the transition experience during this time. An in-depth qualitative exploration of the psychosocial experience of transition to home identified that the first month was a time when clients experienced multiple psychosocial issues as they adapted to changes in their self, their social connectedness and their community participation [6]. In a separate study, Ellis- Hill and colleagues [7] interviewed stroke survivors and carers one month after discharge and identified that a good or poor experience of going home was related to mobility recovery and support from therapy services. They found that people were more likely to report a good experience if they felt they had momentum in their recovery, were well supported, and well informed. A poor outcome was perceived when momentum was lost, and people felt unsupported or uninformed. These studies provide some useful insights into early experiences at home from clients. However, there is scope for health

professionals to develop a more comprehensive understanding of transition to home during the first month from the perspectives of the client and their carer as a working partnership.

It has been identified that the first month at home represents a time when carers experience difficulties related to practical aspects of caring, concerns for safety, and changes to their own lifestyle [8]. The unexpected nature of stroke presents limited time to adjust to changes in relationships and roles and can be a time of great uncertainty, emotional distress, and burden [8 - 11]. Intervention programs have been developed which provide education and /or psychosocial support to prevent caregiver strain and depression [12 - 14]. Understanding the psychosocial aspects for carers is important. However this represents just one component of the experience of caring and further research is required to determine the most effective way to prepare and support carers for both the practical and psychosocial aspects of caring during the early stages of transition to home.

An interesting development in transition to home has been the development of early supported discharge programs. From a healthcare provider perspective, the need to reduce healthcare costs and return people to their own homes sooner has supported the evolution of these programs and other transition care services. However, the development of early supported discharge programs has been largely clinician driven and key indicators of success are outcomes that are important to healthcare providers including length of stay and level of functional independence [7]. It currently remains unclear if this model of service delivery has a positive or negative impact on physical and psychosocial outcomes from the perspectives of the client and the carer during the first month. There is scope for alternate models of service delivery to be explored.

Current Study

Transition to home from stroke rehabilitation has gained increasing focus in the research literature with studies exploring client and carer experiences. However, there has

been limited exploration and comparison of the transition experience from the perspective of the client and carer as a working unit. Early supported discharge programs have been developed but the impact for client and carers requires further exploration and there may be scope to develop alternate models of service delivery to prepare and support the client and carer from more than just psychosocial perspectives. The purpose of this study was to build on existing knowledge and describe the transition experience during the first month from the perspectives of the client with stroke and their carer. The results will inform the development of an alternate model of service delivery for stroke rehabilitation and transition to home.

It is proposed that an alternate model of service delivery represents a complex intervention as defined by Campbell and colleagues [15] and that a program of research is required to understand the issues for transition, test the feasibility of the proposed model of service delivery, evaluate its effectiveness, and implement the intervention. Therefore, the study reported in this paper represents an early observational or modelling phase when we are attempting to understand and define the issues for transition. The next study will involve testing of the feasibility of the proposed model of service delivery.

Method

The research design employed for this study was a descriptive qualitative design with semi-structured questioning around the transition experience. Ethical approval for this study was received from the participating hospital and university ethical review committees. The study was conducted in a 26 bed inpatient rehabilitation unit in a major metropolitan hospital. Stroke rehabilitation services in this geographical area occur within rehabilitation wards which generally have at least 50% of the population with a diagnosis of stroke. Following discharge, clients may be referred to transition care services, community based rehabilitation or rehabilitation day services based within the hospital.

Participants

Participants were recruited during a six month period. Inclusion criteria stated that the participant with stroke should be eligible for discharge to the community after inpatient rehabilitation for a first time stroke, and have adequate communication and cognition to participate in the study interviews. Exclusion criteria included discharge to a residential care facility. Participants with stroke were not required to have an identified carer for inclusion in the study. However, carers were recruited where available and were only required to have the demonstrated ability to participate in the study interviews. The carer was identified by the participant with stroke as the person who they considered would offer support following discharge.

Data collection tools

Clinical characteristics

Baseline demographic data were collected from all participants at recruitment to the study including age, gender and hemisphere affected. The type of stroke was classified according to the Oxfordshire Classification of Stroke [16]. The twelve subtypes of this system were collapsed into four categories: Total Anterior Circulation (TAC), Partial Anterior Circulation (PAC), Lacunar Circulation (LAC), Posterior Circulation (POC). The level of functional independence was recorded at discharge using the Functional Independence Measure (FIM) [17].

Semi-structured interview

The semi-structured interview schedule was developed for this study with the aims of exploring the clients and carers experience of transition to home. Clients and carers were interviewed independently of each other with questioning focussed around the experience of transition home, descriptions of their days, activities and supports, and reflections on their preparation for transition while in rehabilitation.

Procedures

Participants were recruited to the study after the healthcare team identified that the goal was for discharge to the community. Informed written consent was obtained from all participants and all quantitative data were collected as outlined above. A member of the research team (KM) completed the follow-up interviews at one-month following discharge. These were conducted within the participants' homes and the client and carer were interviewed separately. Interviews were recorded using a digital audio recorder and transcribed verbatim.

Data analysis

The demographic data were entered into STATA and summarised. Inductive thematic analysis was completed by two members of the research team. Firstly, both researchers independently read through the transcripts of the participants with stroke to establish patterns, themes and meaning [18]. The researchers met to discuss emerging themes and thematic coding categories were determined. Clean copies of the transcripts were independently coded by the researchers and further refinement of the coding categories occurred. This process was repeated two further times until the coding categories had been reduced from eight to the final three thematic categories. This same process was then repeated with the transcripts of the interviews with the carers. Two rounds of coding and discussion were undertaken to identify five thematic coding categories. One further round of analysis was completed to reduce the thematic categories from five to three and to reach consensus.

Results

There were 15 participants recruited to the study, ten clients with stroke and five carers. However, this paper reports only the data collected from the five clients with stroke and their identified carers ($n=5$). All clients were discharged to home to live with others and

their baseline and discharge demographic details are outlined in Table 1. There were predominantly female clients ($n = 4$) who were an average age of 65.4 years (range 36 -79). The average length of stay in rehabilitation was 49.6 days (range 23-93). The results for the clients are presented first, followed by the carers.

The Client Experience

Analysis of the interviews with clients identified three major themes relating to the client experience of transition home after stroke rehabilitation. There was a chronology to the themes with clients talking about their preparation for home '*Rehabilitation was okay*', their personal experience of being home '*It's a struggle*', and descriptions of the supports received when they were at home '*Supports and assistance*'. Pseudonyms have been used below to identify the participants with quoted responses.

Client theme one: Rehabilitation was okay.

In this first theme, the clients' spoke of their experiences in the hospital based rehabilitation program. They spoke of the therapy that they participated in during their hospital stay and the aspects of therapy and rehabilitation which they thought prepared them for the transition home. Clients also spoke about the difficulties with the hospital environment including the regimented nature of their days and the sense that it was difficult for individual needs to be met within this environment.

With respect to therapy, particular importance was placed on the physical exercise that occurred within the rehabilitation gym. The clients reported that "*the exercise, going down to the gym was a high priority because that did help me to get better*" (Patricia). It was also considered important to have the opportunity to practice functional activities with the support of the hospital staff both in the hospital and their own environments. All clients spoke about the value of having opportunities "*to be able to [visit my home and go out into the*

community] before I actually had to do it myself, that was good” (Mary). Counterbalancing this view was the perception that perhaps more could have been done to prepare for transition to home. Anne in particular felt strongly that more could have been done to test out her abilities before returning to home “because[they are just] saying I can come home and do 90 percent of what I used to be able to, but they haven’t actually assessed that I can do it.”

It was reported that one difficulty with the hospital environment was the unfamiliar social situations and routines. A reliance on nursing staff to supervise or assist them to toilet, shower, or leave the room reduced the level of control that clients felt they had over themselves and their days. Anne found that these factors had a negative impact on her hospital experience and reported that she “*wouldn’t say that I enjoyed my time there. It was okay*”. Time outside of therapy was “*boring*” and that there was a lot of time spent “*waiting for things*” to happen such as for the meals to be delivered or for visitors to come. Patricia suggested that activities such as “*line dancing*” or “*singing groups*” would help to fill these spaces. Many reported that the routine nature of the hospital environment with respect to when meals were served or what time people could shower did not readily recognise individual needs for daily routines or control. Individual requests were not readily considered and Robert identified how on one occasion “*...there was a bit of controversy [when] some people didn’t like [my wife] telling them what I could do.*”

Client theme two: It’s a struggle.

The period immediately after coming home was a time when all clients were faced with the many changes to themselves and their daily life. For many, this was overwhelming and daily life was much more difficult than they had anticipated. Clients spoke of changes to engagement in daily activities including community access and daily routines, and the emotional impact of these changes.

There were challenges and difficulties with completing simple personal and domestic activities within the home. Anne spoke of the frustration of experiencing difficulties with activities that she felt she should have been able to do including personal care activities that had been routinely completed by the nursing staff and other household tasks.

“Just actually being able to stand there and actually do [the dishes], until they’re all done. I just can’t, can’t do that. I struggle in the shower with wash[ing] my hair and stuff, but the nurses were doing that at the hospital.”

Clients reported that as a result of the changes in their engagement in activities there was a corresponding need to change their expectations regarding what they could achieve within each day. Mary spoke of the amount of assistance that she had previously provided to her daughter and family:

“I used to tidy up the house, I used to sweep this part of the house, tidy up, washing of dishes... I used to prepare the meals for them. Everyday, I used to do the meals for them for dinner”.

She then described how this had now changed so that her daughter left food out for her and an acknowledgement that she found even simple tasks are tiring. *“All I had to do was to warm my food and eat. She did everything when she went, I didn’t have to do anything... I do get tired. I get very tired”.* (Mary)

There was an emotional impact from the changes to daily activities and routines. Clients described how their mood was inextricably linked to their daily experiences, finding that they were *“angrier”* than previously due to the frustration of their changed abilities. Mary reflected that her *“mood is okay sometimes, then sometimes you think oh ... I can’t do all these things.”*

There were also changes to how people engaged in activities outside of the home largely due to limited community access. Visits into the community appeared to be limited

by reduced confidence or mobility, and the need to rely on the assistance of others to drive and assist with walking or wheeling in the community.

“I haven’t got a lot of confidence going out shopping. I’ve got to be with [my husband]. I’ve got to hang onto him because...someone might come and ... bump not really meaning to. My mind’s thinking that I could fall over.” (Patricia).

Client theme three: ‘Supports and assistance at home’

In this theme, the clients spoke of the practical supports and assistance they were receiving now that they were at home. These included community-based services that were coming into the home and the assistance that family and friends were now providing. With respect to community-based services, the clients spoke about receiving follow-up medical appointments, continuing therapy, community services, and home modifications and equipment which were all considered valuable.

“Transition [care team] have been terrific. Very helpful [with the] things that I can get and they’ve given me names of all the people I can ring who can who help me.”

(Catherine)

However, there were some practical issues raised by others who did not know who to contact or the limitations of not having transport to assist with follow-up appointments. In one case the assistance that was expected never arrived.

“There’s another folder that’s got the discharge thing in it that actually lists (I think), lists what services they were going to give.”(Anne)

The assistance received from family and friends was positive and considered integral to the client’s ability to remain at home. Clients perceived that the carers were encouraging and doing their best to assist them to further develop their independence and abilities. The increased involvement of family was viewed positively by many but perhaps most by Catherine who described that she felt “... so much better as a person now, certain things that

I remember now that never happened before I was in hospital. Like, for instance, the support of my husband and my children”.

The Carer Experience

There were three carer themes identified from the interviews which also had a chronology to them. The first spoke of the aspects of rehabilitation which were aimed at preparing the client for home *‘the purpose of rehab’* followed by descriptions of their lives now that the person with stroke was home *‘life is different now’*. Finally, the carers spoke of the importance of *‘looking to the future’*.

Carer Theme One: The purpose of rehab.

There were a number of aspects discussed here which were related to how well or how poorly the client and carer were prepared for the move back to home. The major discussions surrounded preparation from within the rehabilitation ward including the weekend leave and family meetings that occurred in the rehabilitation ward, the therapy and other daily activities.

Weekend leave was a common practice for all clients. The carers described how the client would go home and stay overnight on the weekend before returning to the rehabilitation ward for the week. This was considered an important aspect of the preparation for discharge. William felt that without this preparation, discharge and transition would have been very difficult.

“I mean the first two weekends were a bit rough, because she was basically still in a wheelchair ... I think if she’d been in the hospital for the five months without coming home and then suddenly she was home...by herself, unless she had another nurse or someone here,[it] would be a real drama no matter who it was. So that slower introduction to home works.”

Clear communication between the rehabilitation team, the client, and the carer was emphasised as an important process in planning for discharge. The family conference, which occurred in the weeks early after admission and in the weeks prior to discharge were highlighted as an important time for the client, family and rehabilitation team to openly discuss issues and future plans.

“Within the first week we had the choice of a family conference, which we elected to have. And we got all the family, and they all sat down with all the staff that [sic] were involved with Catherine’s rehabilitation. And they explained what they did and what they’re plans were... that type of planning on behalf of the hospital is very good to give you an idea of what’s going to happen.” (William)

The therapy aspect of rehabilitation was discussed in generally positive terms. Spending time in the rehabilitation gym and observing therapy was important for understanding abilities and progressions. However, the lack of activity on the ward outside of therapy time was highlighted as a possible improvement in services. Carers acknowledged that clients would become bored and that this would impact their mood. Carers spoke of how they felt it was important to allow the client to perform the activities that would be completed at home more regularly. This included the ability to make a cup of tea or coffee for themselves every day, or to be able to make their own bed as they would normally do at home. The limited ability to perform these everyday tasks for Kate seemed at odds with the philosophy of rehabilitation. She stated *“it wasn’t done at the hospital like you would at home you know. And that was the whole point of rehab, as far as we were told, was to prepare her for coming home”*.

Carer Theme Two:- Life is different now

In this theme, the carers reflected on the impact of caring for a person with stroke on their day including descriptions of how their days were busier and how they needed to plan

more to be able to leave the house. Increased medical appointments also kept them busy and these changes had affected their ability to participate fully in their own interests and activities. Of note, the carers all described how life was comparatively better than when they were travelling daily to visit the client when they were in hospital. The day when the client came home was “ ... *such a relief. [Going to the hospital] was twenty minutes driving each way every day, and there was extra washing to do...*” (Jack).

The reality of caring for a person with stroke at home meant that all carers were now doing much more around the home. There was a need for them to plan and organise their days around the increased activities and the increased number of medical and follow-up appointments. Carers described the different strategies that they had adopted to assist with this planning including strategies for shopping. “ ... *if I just wanted to race off to the shop now, that’s a problem. And so you’ve got to plan when you’re next going to the shop and write notes. I got notes in my pocket and that’s something I didn’t do before. So yeah, it does restrict your activities but you just have to work around it*” (William)

Carers generally spoke of how their own interests and hobbies were no longer undertaken or how they were now less prominent because it required extra planning to arrange for people to be with the client when they left the home. The impact of the extra medical appointments on work was also raised by a younger carer who noted that “*there’s a lot more running around, with appointments and things like that...so you know there’s not too much time for me to be able to do many things myself and I’ve had to even cut down some of my hours at work because of that.*” (Alison)

Theme three: Looking to the future

The final theme included all descriptions of looking to the future. Firstly, the carers spoke of their role as therapists and motivator, working for further recovery and hope for the future. Secondly the carers acknowledged the importance of accessing supports and services

which were considered an essential component of sustaining their ability to care into the future.

The carers felt that they had an important role as motivator or informal therapist. This included encouraging and assisting the client to attend to some of their daily activities themselves. Jack stated *“I hang out the washing, or help her with the heavy washing. I know I’m leaving a bit more to her all the time, but that is planned by me to get to see if she can do a little bit more”*. This role of motivator or informal therapist may have been perceived negatively by the client but it was driven by a need to promote further recovery. The carers at times, found themselves struggling with the positive and negative aspects of this new role.

“I find I’ve got to be on her all the time... ‘You have to do it yourself, you have to do this, you have to do that.’ So in some ways I think it can get a bit strained because you feel like you’re on someone’s back, your nagging them all the time, and that’s what I feel, I’m nagging all the time. But I feel it’s necessary, it’s a very necessary part of it because if I don’t she might lose out in some ways.” (Alison)

Access to supports and services were perceived positively and were considered very important due to two factors. Firstly, a fear of what would happen if their own health failed and secondly, uncertainty about what would happen when the outpatient rehabilitation stopped. Jack in particular worried about his own health and the importance of these services in supporting him to support his wife. Jack identified *“I realise I’ve got to look after myself because if I don’t look after myself then Patricia is not going to get looked after too well”*. Carers knew that, despite their hope that recovery would continue and that the days would become easier, there would be a time when outpatient rehabilitation would stop. They were fearful about what would happen for the client and unsure of what alternatives would be available to them. Alison expressed that *“it’s also a constant worry thinking that she’s not going to regain the use of her limbs and not be independent, and with[out] independence also*

comes other issues such as depression and that sort of thing. And I think my main concern is, after rehab, I'd like her to continue to do the exercises to reap the full benefits of what was provided for her in hospital."

Discussion

This purpose of this study was to explore and contrast the transition to home experience of clients with stroke and their carer during discharge and the first month at home. Analysis of transcripts from five clients and their carers identified three themes for each group. The first theme for each group focussed on the time spent in hospital and their preparation for discharge to home. The second theme addressed the time immediately after return to home and the third theme spoke of the supports and services and future plans. There were both similarities and differences in how the clients and carers spoke in all of these themes and this will be explored in more detail in this discussion.

Rehabilitation is described as a process through which clients work to 'get back to normal' by returning to familiar activities and re-establishing their social position [19 -22]. The opportunity to participate in familiar, meaningful activities is considered important for re-establishing identity [23] and facilitates the process of adaptation and recovery after a brain injury [24-26]. The comments from both clients and carers in this study suggest that the inability to engage in meaningful activities and routines within the hospital environment may have prevented adaptation and recovery. Participants suggested that the routines of the rehabilitation unit could be more flexible to allow for individual wishes and that the environment should be developed to provide increased opportunities for practice of activities that are meaningful to the client and important for return to home.

After discharge, the clients and carers both spoke of how their days were now different. The clients focussed on adapting to their slower pace for managing daily activities while the carers reported being much busier and juggling the new caring arrangements with

their own lifestyles. Rittman and colleagues [27] highlighted that developing strategies and routines to manage time such as organising their day around essential activities was an important aspect of recovery. The clients in this study appeared to be starting to develop their new routines while the carers appeared to be struggling with the concept that new routines often meant that personal interests or hobbies were no longer possible. A follow up study by Ekstam and Borrell [28] found that carers described that this struggle or inability to regain their personal interests was continuing up to twelve months after stroke. These results promote the need for ongoing support for the carers is required to ensure that they can develop routines that allow ongoing engagement in personal hobbies or interests.

Finally, the impact of the stroke on relationships was viewed differently by the clients and the carers. Clients were aware of their increased reliance on family members but they were likely to identify positive effects including a perceived improvement in family relationships and frequency of contact. The carers however, spoke more of their changing role and the difficulty reconciling the role of spouse or carer with the roles of motivator and therapist. Palmer and Glass [29] have demonstrated how spouses struggle with the challenges of simultaneously caring, supporting, coaching and assisting the person with stroke. The concept of family-centred care has been raised previously for stroke rehabilitation [28,30] and is evident in this treatment centre in the form of family conferences and the support provided during the hospital period. However, continuation of this support after discharge to assist the carer as they adapt to their new role and altered life circumstance is indicated.

Further studies are required to explore alternate approaches for rehabilitation that provide enhanced opportunities for the client and carer to practice meaningful activities prior to transition home. As noted earlier, the results of this study will guide the development and pilot of an alternate model of service delivery which will involve increased outreach from hospital to the home environment prior to discharge.

There are limitations inherent with a study of this nature. The small participant group and recruitment from one treatment centre limit the ability to generalise the results. In hindsight it would have been helpful to complete a depression and or anxiety scale with the client and a caregiver strain index to assist further with understanding the results. Finally this was not designed as a longitudinal study which allowed a focus on the early time at home but does limit the ability to see how experiences change over time.

Conclusion

The clients and the carers in this study all identified both positive and negative aspects of rehabilitation when considering their preparation for transition. The results suggest a need to develop hospital environments which offer more opportunities for practice of activities that are meaningful and important for return to home. There were differences in how the clients and carers experienced the time at home, highlighting the importance of enhanced family-centred preparation and support for transition. Future studies should be undertaken to trial alternate models of service delivery that include more outreach into the home environment to improve the transition to home experience

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Declaration of Interest

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Table 1: Demographic characteristics

| | Age | Gender (Relationship) | Type of Stroke | Hemisphere affected | Length of Stay (Days) | MMSE | FIM TOTAL |
|----------------|---------|--------------------------|----------------|------------------------|--------------------------|------|-----------|
| Anne | 36 | Female | PAC & POC | Left | 23 | 27 | 119 |
| <i>Kate</i> | 37 | Female (Friend) | | | | | |
| Catherine | 62 | Female | TAC | Right | 93 | 24 | 88 |
| <i>William</i> | 63 | Male (Spouse) | | | | | |
| Patricia | 71 | Female | PAC | Right | 33 | 29 | 114 |
| <i>Jack</i> | 75 | Male (Spouse) | | | | | |
| Mary | 79 | Female | LAC | Right | 62 | 24 | 113 |
| <i>Alison</i> | 51 | Female (Daughter) | | | | | |
| Robert | 79 | Male | PAC | Left | 37 | 29 | 109 |
| <i>June</i> | unknown | Female (Wife) | | | | | |

PAC = Partial anterior circulation stroke

POC = Posterior circulation stroke

TAC = Total anterior circulation stroke

LAC = Lacunar stroke