Factors affecting rehabilitation and use of upper limb after stroke: Views from healthcare professionals and stroke survivors

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Abstract

OBJECTIVES: Training of the upper limb is limited in stroke rehabilitation, and about 50% of stroke survivors do not regain useful function in their upper limb. This study explored what factors affect rehabilitation and use of upper limb after stroke from a stroke survivor and healthcare professional perspective to better understand low engagement in UL rehabilitation in the chronic stages of stroke.

METHOD: Eight chronic stroke survivors and 21 healthcare professionals took part in semi-structured interviews or in one of three focus groups, respectively.

RESULTS: Thematic analysis revealed three main themes: Availability of resources, Healthcare professional-patient relationship and Psychosocial Factors. Availability of resources and Healthcare professional-patient relationship indicated that due to resource pressures and a lack of communication and education, positive upper limb rehabilitation behaviours (e.g., engaging and integrating the upper limb in daily activity) were not always established in the early stages post-stroke. Psychosocial factors illustrated the cognitive and psychological barriers to sustained engagement with upper limb rehabilitation.

CONCLUSION: The findings indicate that stroke survivors and healthcare professionals have very similar understandings of barriers to UL activity, and positive upper limb rehabilitation behaviours are not always established early in recovery post-stroke. Increased resources and healthcare professional-patient relationships seem key factors to establishing positive perceptions of upper limb rehabilitation. Addressing psychosocial issues and resource limitations may help sustain engagement with upper limb rehabilitation.

Keywords: Chronic Stroke: Upper Limb: Rehabilitation: Behaviour: Perceptions: Qualitative

1. Introduction

Stroke is a leading cause of disability worldwide, leaving survivors with a wide range of problems, including upper limb (UL) and lower limb dysfunction, and cognitive and visual impairments (1, 2). These consequences of stroke lead survivors to require assistance with everyday living and significantly impact on quality of life (1-3).

Recovery of motor function is important post-stroke, with 40% of stroke survivors indicating physical dysfunction is the most difficult aspect to manage (3). Despite the pattern of motor recovery (i.e., the degree and time course of recovery) being similar in the upper and lower limbs (4, 5), statistics indicate that more stroke survivors are able to walk again, compared to those that will regain functional use of their hand (6-8). In line with this, research has consistently shown that levels of UL activity in stroke survivors are very low (8-10). For example, Rand and Eng (10) found that 1-year post-stroke UL activity was similar to that at discharge, and significantly below a control group of older adults.

In addition, Lang et al. (9) found less functional activity was being undertaken in healthcare professional led UL rehabilitation sessions (51%) compared to lower limb rehabilitation sessions (84%). A focus on lower limb rehabilitative exercise and mobility post-stroke has been reported by stroke patients previously (11, 12). Thus, both stroke survivors and healthcare professionals seem less engaged with the UL when it comes to rehabilitation.

A number of qualitative studies have addressed barriers to physical activity (for rehabilitative purposes) with the UL post-stroke (13-15). Factors such as stroke participants' motivation, physical inability to move their arm without assistance and fatigue have been identified as issues that need to be addressed in order to increase uptake of UL activity for rehabilitation purposes (14, 16). However, studies tend to focus on stroke survivor's perspectives and their current barriers to UL use (i.e., what a chronic stroke patient is experiencing now).

The aim of the current report was to better understand low engagement in UL activity in the chronic stages of stroke (i.e., at least six months post-stroke) from a multi-perspective by exploring chronic stroke survivors' and healthcare professionals' experiences of UL rehabilitation (i.e., engagement in UL activity) post-stroke from early to later stages of stroke.

2. Method

2.1. Design and Recruitment

This study is a secondary analysis of a dataset based on a wider study investigating electrical stimulation as a home rehabilitation device for chronic stroke survivors. Participants' experience of UL stroke rehabilitation was explored within this context. A phenomenological qualitative approach underpinned the study as we were interested in describing and understanding the experiences of our participants. Following ethical approval from the Faculty of Health Sciences Ethics Committee (id 5879), data were collected using semi-structured interviews and focus groups. Data was collected from chronic stroke participants and healthcare professionals to allow for triangulation of data from different perspectives of stroke rehabilitation.

For stroke survivors, letters of invitation were sent out to volunteers on the Faculty of Health Sciences Volunteer Database. Purposeful and self-selecting sampling by age and gender was used to ensure range and diversity in participant experiences. For healthcare professionals who were involved in the delivery of stroke rehabilitation invitation letters were handed out at team meetings at rehabilitation facilities in Dorset and Hampshire. Purposeful and self-selecting sampling by the stages at which the healthcare professionals were involved in stroke rehabilitation and type of healthcare professional was used to ensure range and diversity in participant experiences. All stroke participants or healthcare professionals that expressed an interest in the study and met inclusion criteria were recruited. Inclusion criteria are shown in table 1.

[table 1 about here]

Eight chronic stroke survivors and 21 healthcare professionals were recruited. Some stroke participants had taken part in previous research studies run by the authors, and some healthcare professionals were ex-colleagues of EH. As such, there was an existing rapport between some participants and the primary interviewer, EH. To reduce biased responses, a question guide was used, KM sat in on one focus group and it was emphasized that there were no right or wrong answers.

EH was a PhD student exploring home rehabilitation for the UL. EH and AMH are physiotherapists with experience in stroke, KM has a background in psychology and CF has a background in control engineering. All authors have knowledge of UL dysfunction as a result from stroke, have investigated healthcare technologies for UL stroke rehabilitation and were not naïve to the issues surrounding UL rehabilitation for stroke.

2.2. Data collection

Qualitative data were generated using semi-structured interviews and focus groups during July and August 2013. Semi-structured interviews allowed for a comprehensive exploration of stroke survivor experiences and perspectives (17). Interviews were conducted by EH, individually with a stroke survivor or with their carer present, at the participant’s home. The interviewer (EH) used an interview guide to facilitate discussion in the interviews.

Healthcare professionals were interviewed in three focus groups consisting of 6-8 healthcare professionals and one or two researchers (EH and KM). Focus groups allowed for exploration of the topic through group discussion, and a mixed group of healthcare professionals was sought to generate group interaction and facilitate insight regarding stroke rehabilitation (18). A separate interview guide (from the stroke participant interviews) was used to facilitate discussion within the focus groups (see table 2).

[table 2 about here]

Informed written consent was taken at the beginning of a session. Interviews/focus groups lasted about 1 hour, were audio-recorded and externally transcribed verbatim. The guides were developed by EH and reviewed by AMH (an experienced researcher in stroke). KM checked the transcript of the focus group that she attended and clips from each transcript against the audio recordings to ensure accuracy.

2.3. Data Analysis

The transcripts were analysed using thematic analysis, and followed the steps set out by Braun and Clarke (17). Step 1 involved familiarisation with the data. Step 2 involves generating codes. Step 3 involves extracting initial themes from the codes. Step 4 involves reviewing the initial themes. Step 5 involves defining and naming the themes. To become familiar with the data, one author (KM) read and re-read the data. Once KM was familiar with the data, statements were coded line-by-line. Initial codes were words or phrases that encompassed the meaning of the statement (e.g., “discharge”, “go home”). These initial codes were then consolidated, and grouped into collections of codes. From this KM identified common themes. Two researchers (KM and AMH) then met to review the initial themes. Through an iterative process, themes and interpretations were refined (see figure 1 for an example of theme formation). The coding process was inductive as no prior themes or framework was considered and the themes were data driven; however, the data were explored from an assumption of low participation in UL rehabilitation, in chronic stroke. The authors were also mindful of their preconceptions about barriers to UL rehabilitation, especially in relation to healthcare technologies. The COREQ Guidelines (19) for reporting qualitative data were used as a quality check.

3. Results

Characteristics of the two participant groups (stroke survivors and healthcare professionals) are described in tables 3 and 4. Three main themes, with subthemes, were extracted from the data: 1. Availability of resources; 2. Healthcare professional-Patient relationship and 3. Psychosocial Factors (see figure 1).

[tables 3 and 4 about here]

3.1. Availability of resources

This theme reflected the practical side of why UL rehabilitation may not take priority for people who have had a stroke; namely a lack of key resources. There were two subthemes: *Health service resources and Environmental Factors*. At the core of this theme was that all participants felt that with more time and access to resources stroke patients would receive more UL rehabilitation in the acute stages of stroke and that this could be followed through from acute to chronic stages of stroke.

Health service resources reflected the pressures and priorities around the provision of rehabilitation in hospital. A major part of this subtheme was the targets around discharge from hospital. Discharge pressures and priorities came from the healthcare service, as well as from patients wanting to return home.

> *It's just purely because of the acute pressures. It's purely because in the last 5 years the NHS has changed so much that the goal of therapy is to get the patient home as*

> *quick as possible. So even two years ago from an OT perspective you would have targeted the arm in stroke a lot more. Our time now is going on to equipment for discharge planning and getting the people that can get out. Focus Group 2*

Both stroke participants and healthcare professionals acknowledged that lower limb activity was the priority in the early days following stroke so that the patients would meet discharge requirements.

> *I do think that they focused more on getting me on my feet and moving around on my feet, because to me, that was something I had to do in order to get -- well, literally walk out of hospital. Not that I was walking home, but you know what I mean. Participant 3*

There was also a sense that regaining lower limb function allowed more practical tasks, such as toileting, to be achieved.

The time pressure felt by healthcare professionals was also discussed in relation to the amount of time that they had available to see each patient. Although healthcare professionals stated that they had 45 minutes with each patient, not all of this time was spent undertaking therapy but administration tasks too. These issues were also echoed by the stroke survivors.

Participants also commented that the UL is viewed as more complicated than the lower limb. Consequently, it was felt that more time and specialist therapy was required to provide effective UL rehabilitation. Healthcare professionals also commented that the therapist working with the patient needed to have a greater degree of skill, and so UL rehabilitation could not always be delegated to care assistants and rehabilitation assistants.

Environmental Factors. The second subtheme to incorporate resource limitations spanned acute to chronic stages of stroke. They included external factors such as on-going therapy costs, availability of assistive technologies and access to support. More intensive UL rehabilitation was received in private settings; however, these were expensive to sustain. Advances in technology have meant that there are more assistive devices available for stroke rehabilitation. However, many healthcare professionals and stroke survivors felt that they could not engage with these technologies in a clinical setting or at home due to time and cost.

> *And the other thing there's a lot of things out there for the arm that aren't in the NHS. It's very difficult for us to get them for our patients because there's a cost involved. […] Focus Group 3*

Some stroke survivors felt constrained because they could not practice UL tasks without help from a carer because of the heaviness of the arm or difficulty in achieving the correct positions.

> *I presume that it's because it's been lack of use overall and probably lack of consistent stretching with the help of somebody who isn't necessarily there all the time. Participant 5*

Healthcare professionals further indicated that, whilst family members and carers of stroke survivors were willing to help, the intensity of the exercise was still not always achieved. However, it was acknowledged that responsibility for rehabilitation should not fall to the family, especially in the acute stages of stroke.

3.2. Healthcare professional – Patient Relationship

This theme encompassed the bond that develops between a healthcare professional and a patient, and how this can affect the rehabilitation process. There were two subthemes within this theme: *Communication between healthcare professionals and patients; and Patient Education.* The rapport between the healthcare professional and patient was a central component to each of these subthemes, and both healthcare professionals and stroke survivors commented on how this rapport could have a major influence on rehabilitation, both in terms of engagement and effort.

Communication between healthcare professionals and patients. This subtheme related to how information was conveyed to patients by the healthcare professionals. Stroke survivors felt some of the healthcare professionals that they saw had very low expectations for their UL recovery. This was seen as negative communication and stroke survivors felt that this often limited their possibilities for receiving UL rehabilitation, as well as impacting on their motivation.

> *Yes because I feel that I went to a -- some sort of meeting was arranged for me with several physiotherapists and my consultant at the meeting and umm at the end of the meeting they said well lots of people manage with just one arm so you'll have to get on and manage with just one arm. Participant 5*

The stroke survivors also indicated that they felt that there was sometimes inconsistency between different healthcare professional providers and in what information the healthcare professionals told the patient compared to the carer/family. This led to confusion over what activities they should or should not be undertaking, and often resulted in no activity.

> *[Name] was told, the physio said, "you are not to wheel yourself to the loo". Participant 6 carer*
>
> *That's right, because of the tone. Participant 6*
>
> *The nurses were insisting, she did learn, she did wheel herself to the loo. So you got two conflicting views.. […]. Participant 6 carer*

Patient Education. Both healthcare professionals and participants understood the importance of education in engaging participants in UL rehabilitation. The healthcare professionals indicated that they tried to educate participants about the UL by providing information and exercise sheets. However, they also acknowledged that they found delivering education difficult.

> *And if you educate them about why, that's the approach I find really helps if you explain the pathways and how they can understand if they repeat and do this is going to have an impact, people do seem to take it on board. Focus Group 3*

Healthcare professionals were very aware that their language and actions could affect engagement in UL activity and tried hard to encourage their patients to engage in self-directed UL activity; however, this was not always followed through with hands-on examples.

> *Especially if someone is learning something if they can start it off in their more supported environment with staff there all the time and then be able to take it home then you've got that consistency. Focus Group 1*

3.3. Psychosocial factors

Psychosocial factors related to the cognitive and psychological aspects of stroke that could impact on a person's ability to undertake UL rehabilitation. There were three main subthemes within psychosocial factors: *The Role of Motivation; Co-morbid impairments and The Role of Acceptance.*

The Role of Motivation. This subtheme reflected the facilitators and barriers that underpin a person's willingness and drive to engage in UL rehabilitation. The factors affecting motivation to undertake UL rehabilitation encompassed a breadth of data. It reflected participants' understanding that recovery was not something that was just going to happen, and that it required both physical and mental effort.

It also demonstrated stroke survivor's knowledge about recovery and the importance of using their UL every day. This was discussed within the context of them undertaking more therapy, and in using the UL in more activities of daily living. However, no matter how driven some people were, finding the motivation to engage in UL rehabilitation was difficult: *"I've always been very competitive and motivated and determined, but it's hard just to keep going" (Participant 2).* Furthermore fatigue and mental well-being issues often compounded this.

Stroke survivors also spoke about frustration as another reason for why they tended to shy away from using their more impaired UL. The frustration was such that the stroke survivors expressed that they would rather use their less impaired arm or compensate in another way, rather than struggle and feel the frustration of not being able to use their more impaired arm properly, *"Ease of use I suppose just achieving what you want to achieve that you don't spend hours getting frustrated so you'll just take the easiest route." (Participant 4).*

Although much of the discussion around motivational factors emphasised barriers to motivation, there were also factors that had a positive influence on motivation to engage in UL rehabilitation. For example, continuation with UL activity was more likely if they saw change in their UL function, and that even the smallest of changes, either in their own ability or in someone else could produce significant benefits, *"Oh yes, to see your arm moving as you'd expect it to move, it's absolutely brilliant" (Participant 5)*. This was also echoed by the healthcare professionals. They acknowledged that one reason that they enjoyed working with the lower limb over the UL was because of their desire to see results, and that they felt that they would be more likely to see a result in the lower limb.

> *I think there's an element of you shy away from what you feel you cannot solve and because I haven't got the intensity of resources, I will work on the things I think I can do and change and if I haven't got a solution for somebody's arm, I think subconsciously you shy away from it a little bit unless the patient was going -- this bit. Focus Group 3*

Incorporating meaningful tasks into rehabilitation exercises also had similar benefits, with both participant groups commenting on this.

Co-morbid impairments. In this subtheme, both participant groups indicated that cognitive, visual and sensation impairments that can be experienced following stroke can have a big effect on UL rehabilitation. From the healthcare professional perspective, there was discussion around the importance of being aware of these other impairments, so that the patients were treated in the most appropriate way to help them understand the rehabilitation process. In contrast, for the stroke survivors, many reflected on how easy it was to forget to do UL activity because their awareness of the UL was greatly diminished, be that due to sensation impairments, visual deficits or cognitive impairments, such as visual neglect or concentration.

> *I think part of the problem, I've got the strength to get it there and I think I probably have got the strength to hold it there, but part of the problem is, as soon as I get it there and I concentrate in getting it there, and I concentrate on, oh, it's there, that's great. And then I look to get the peg, I forget about the left arm and it just goes, because as soon as I'm not looking at it, I forget what I've got to do with it and the concentration goes, which I think is partially my concentration. Participant 3*

> *I know that I should spend all my life -- when I'm watching television or something like that, doing that [using the UL], but unfortunately it doesn't always come to mind and days fly by and when it's doing that, it's [the arm] just sitting there. Participant 5.*

The Role of Acceptance. In contrast to the negative feelings of frustration and anger, there was also talk of acceptance, and this seemed to contribute significantly to UL non-use. Some stroke survivors commented that it had got to a point where they now accepted that function was not going to significantly improve and so they no longer viewed that arm as a functioning limb.

> *I'm happy but I have got my head round the fact that I'm one sided. It's reflected in how I see- my sense of gravity is no longer where it should be because this bit has gone. I suppose part of me has just lost that part of my body. Participant 7*

The fact that stroke survivors can compensate for UL dysfunction with the other limb or by doing the movement in an abnormal way was also acknowledged: "*The people think if they can do something with one hand, they just think ah well I'll just do it with that hand to compensate (Focus Group 2)".* Healthcare professionals further qualified that it was easier to compensate with the UL than the lower limb for everyday tasks. Both participant groups also emphasised that acceptance and learned non-use was more likely to occur if the more impaired UL was the person's non-dominant hand.

4. Discussion

The aim of this study was to examine what factors affect UL use and rehabilitation post-stroke from the perspectives of healthcare professionals and stroke survivors. Three main themes were extracted from the data. These indicated availability of resources, therapist-patient relationship and psychosocial factors were key factors to affect engagement in UL rehabilitation. A key message drawn from the data was that positive UL rehabilitation behaviours are not always established early post-stroke and in turn this contributes to a lack of engagement in UL rehabilitation throughout the stroke recovery. The main themes were all discussed by both participant groups, and the inclusion of healthcare professional perspectives added greater insight to current understanding about low engagement in UL rehabilitation.

The themes of availability of resources and healthcare professional-patient relationship related mainly to the early stages of rehabilitation post-stroke, although for stroke survivors environmental factors also continued into later stages of stroke. It was indicated that, due to resource pressures and a lack of consistent communication and education, appropriate UL rehabilitation behaviours (e.g., engaging in daily UL activity and integrating the UL into everyday tasks) are not established in the early stages post-stroke. The third theme, psychosocial factors, related more to later stages post-stroke and the cognitive and psychological factors that contribute to reduced engagement with UL rehabilitation.

The sense of urgency for being discharged from hospital was a key factor discussed by both participant groups. Current clinical practice favours early supported discharge and indicates that for this to occur, patients are required to transfer and walk (3, 20). In order to achieve this, the focus of rehabilitation is on the lower limb rather than the UL (11, 12). Thus, both of our participant groups seemed to indicate that from early post-stroke, the message that patients receive is that UL rehabilitation is not a priority (compared to the lower limb).

Barker and Brauer (2005; 14) reported that stroke survivors felt that the UL was neglected in the early days post-stroke, and this was despite the known benefits of intensity and repetition of exercise. More recently, Lang et al. (2009; 9) also reported a bias in rehabilitation sessions towards healthcare professionals supporting more functional activity for the lower limb compared to UL. The current data are, therefore, consistent with other reported stroke survivor perspectives and healthcare practice. Incorporating healthcare professional perspectives not only supports themes drawn from purely stroke survivor perspectives but provides further insight into why this may occur. For example, the healthcare professionals in this study expressed an interest in providing therapy in which they, as professionals, would see change. They indicated that it was easier to achieve better results for the lower limb and so were more motivated to work on the lower limb in their therapy sessions. Previously the motivation to see change has only been discussed from the stroke survivor perspective.

In line with Jones et al (21), the current data show that the interactions between a stroke survivor and healthcare professional was very important, especially early post-stroke. However stroke survivors expressed this more in terms of communication and how information was conveyed to and perceived by the stroke survivors, whereas the healthcare professionals framed this relationship in an education context. Linked to patient education was healthcare professional's awareness of a patient's comorbid impairments in the early stages post-stroke, so they could treat (and educate) the patient in the most effective way. By contrast, stroke survivors discussed comorbid impairments in relation to everyday activity in the later stages post-stroke.

Eliciting behaviour change can be a difficult challenge, especially if patient factors such as motivation, frustration or depression are apparent (22). This study confirms psychosocial factors were major facilitators and barriers to undertaking UL activity (13, 15, 16, 23). It is becoming clearer that recovery is not limited to a certain time frame, and some stroke survivors are observing motor improvements many years post-stroke (24, 25). Addressing some of the psychosocial barriers to motivation, such as depression, and establishing good UL rehabilitation behaviour in the early stages of stroke may help to increase and maintain engagement in UL rehabilitation throughout post-stroke.

This study was a secondary analysis of data collected for a different purpose. Although the data provided some new insights into factors affecting engagement with UL activity, a more in-depth interview schedule may provide greater depth and understanding on this topic. The use of a purposeful and self-selecting participant sample may have introduced recall bias (participants were at least 5 years post-stroke) and social acceptability bias (due to the existing relationship between interviewer and participants). In addition, participants were not given the opportunity to comment on transcripts or findings, as recommended by COREQ (19). The authors also explored the data from the assumption that there is low participation in UL rehabilitation, in chronic stroke survivors which may have affected interpretations. Nevertheless, this paper provides a solid foundation from which researchers and clinicians can start to understand how behaviours surrounding UL rehabilitation develop and evolve.

In conclusion, through exploring both stroke survivor and healthcare professional perspectives, the study adds to current understanding of low engagement in UL rehabilitation in the chronic stages of stroke. The findings indicate that stroke survivors and healthcare professionals have very similar understandings of barriers to UL activity and highlight little change over the last decade with respect to these issues. Healthcare professional-patient interactions were identified as key factors in establishing positive perceptions of UL rehabilitation. To address this, stroke teams require more time and resources for targeting UL rehabilitation. Establishing positive behaviours towards UL rehabilitation from an early stage post-stroke may facilitate engagement with UL rehabilitation behaviours throughout the recovery process.

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Declaration of Interest. The authors report no declarations of interest.

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Table 1. Inclusion/exclusion criteria for stroke survivors and healthcare professionals.

Stroke survivors	Healthcare professionals
Aged 18 or over and be able to provide written informed consent	Aged 18 or over and be able to provide written informed consent
Sustained a stroke at least 6 months prior and so in chronic stage of stroke recovery	Involved in the provision of stroke rehabilitation (e.g., physiotherapist, occupational therapist, speech therapist)
Experience difficulty in using their upper limb	Provide stroke rehabilitation either in the clinical setting or community environment (including home)
Demonstrates some volitional activity in the wrist and hand (assessed by a EH, a physiotherapist)	Have had experience of providing rehabilitation to stroke survivors for a minimum of two years

Table 2. Topics in the interview and focus group guides

Interview topics for stroke survivors	**Focus group topics for healthcare professionals**
How things have been since their stroke	Why they think arm dysfunction is so significant
What are their main problems with using the arm	What rehabilitation devices they have used with patients and at what stage these are most useful
Reflection on what tasks they find difficult,	What are the main opportunities for using assistive technology with the arm for patients
What arm exercise programmes they have used.	What are the advantages or disadvantages in using assistive technology with the arm
What arm rehabilitation devices they have used.	

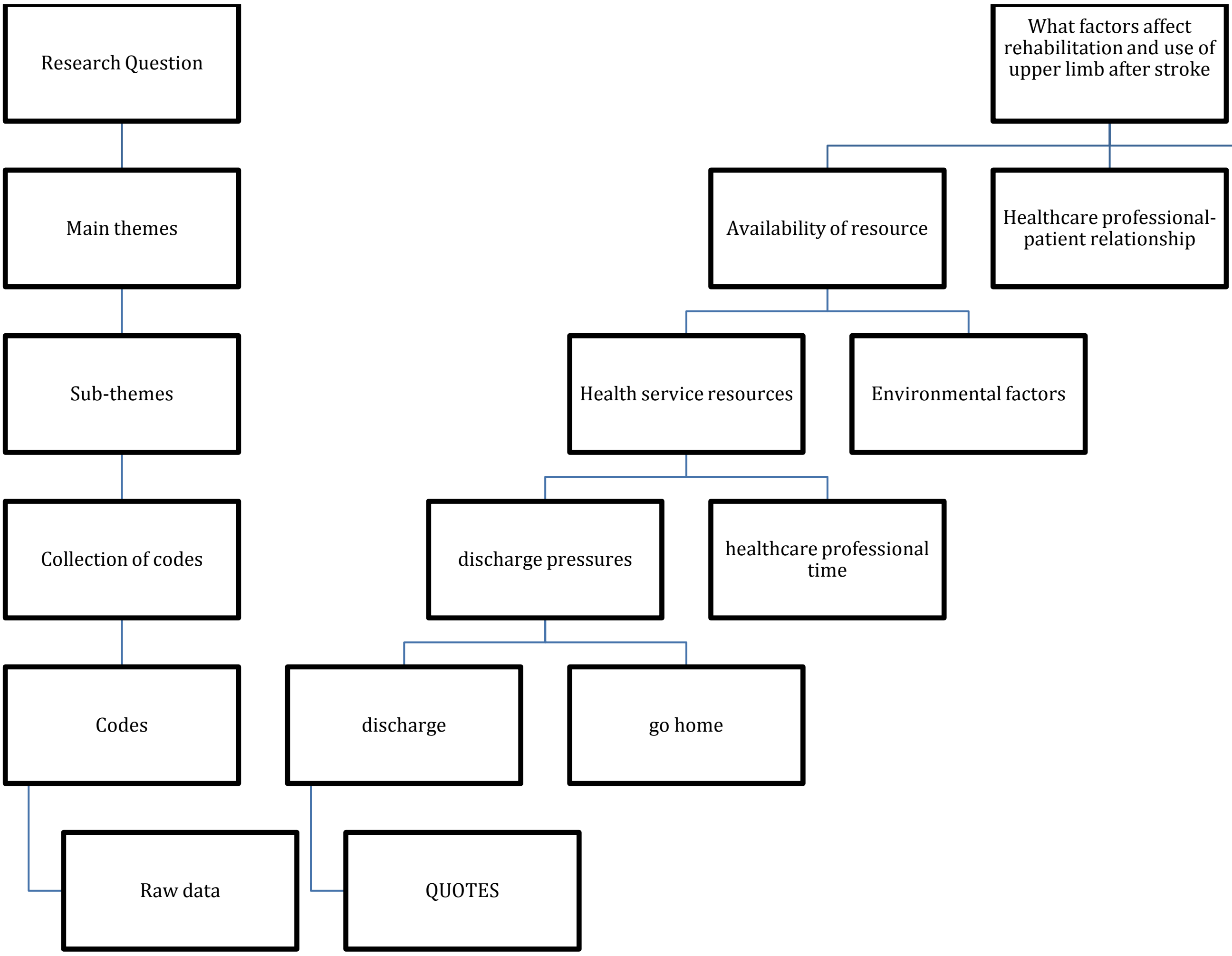
Table 3. Stroke participant characteristics

Group	Stroke survivor
Number of Participants (female:male)	3:5
Age (Average years (SD), range)	57.6 (11.89), 44-78 years
Years post-stroke (Average years (SD), range)	7y 7m 9 (2y 5m), 5 – 11y 3 months
Side of paresis (left:right)	6:2

Table 4. Healthcare professional participant characteristics.

Group	Focus Group 1	Focus Group 2	Focus Group 3
Number of Participants:(female:male)	7:0	8:0	6:0
Profession	5 PT; 2 OT	4 PT; 4 OT	2 PT; 2 OT; 2 RA
Experience in stroke: (Average years (SD), range)	14.71 (4.96), 7-22	11.75 (5.78), (3-19)	13.33 (6.65), (3-23)
Stage of rehabilitation involved in	Chronic (4); subacute and chronic (2); acute and chronic (1)	Acute/sub-acute (8)	Sub-acute and chronic (6)
Private or NHS worker	Private (4); Private and charity (1); NHS and Private (1); Private and social services (1)	NHS (8)	NHS (6)
Where the majority of their rehabilitation take place	Community (6); Out patient clinics and community (1)	Acute Trust (8)	Community (6)

Note. PT = physiotherapist; OT = occupational therapist; RA = rehabilitation assistant



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