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ORIGINAL ARTICLE

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Stroke survivors' views on their priorities for upper-limb recovery and the availability of therapy services after stroke: a longitudinal, phenomenological study

Judy Purton[a,b], Julius Sim[a,c] and Susan M. Hunter[a]

[a]School of Allied Health Professions, Keele University, Keele, UK; [b]School of Science, Technology and Health, York St John University, York, UK; [c]School of Medicine, Keele University, Keele, UK

ABSTRACT

Purpose: Forty percent of stroke survivors have a persistent lack of function in the upper limb, causing significant disability. Most personal-care tasks and meaningful activities require bi-manual function of both upper limbs. However, lower-limb mobility is often viewed as the priority in stroke services. Perspectives of stroke survivors on priorities for upper-limb recovery and therapy have not been investigated in detail. Therefore, this study aimed to explore their views.

Materials and methods: Thirteen stroke survivors each engaged in up to four semi-structured interviews over 18 months. A phenomenological approach guided the research.

Results: Three themes were identified. *Priorities change on coming home:* recovery of walking is a priority early after stroke but upper-limb recovery becomes equally important over time, particularly once living at home. *Limited therapy services:* therapy has a short duration, prioritizes lower-limb mobility, and is short-lived in the community; people feel abandoned by services. *Active partners in recovery*: stroke survivors want intermittent access to review and advice so they can be active partners with therapists to manage their upper-limb recovery.

Conclusion: Therapy services should recognize stroke survivors' changing priorities and work with them as active partners in upper-limb recovery. Intermittent access to review and advice should be included in service design.

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Stroke survivors' priorities; upper-limb recovery; rehabilitation; therapy services; physical therapy

➤ IMPLICATIONS FOR REHABILITATION

- Stroke survivors' priorities may change over time from recovery of walking toward upper-limb recovery.
- Post-stroke services can be perceived as insufficient to meet the needs of stroke survivors who want to participate actively in rehabilitation of their upper limb.
- Stroke survivors may prefer services that are more flexible to provide regular review of their progress, access to guidance and support to self-manage their recovery.

Introduction

Rehabilitation of the upper limb after stroke can be challenging for stroke survivors as well as for therapists due to the complex motor and sensory mechanisms of the arm and hand. The majority of tasks and activities that people perform with the upper limbs require complex differentiated movements of the fingers and thumb in order to grasp, manipulate, explore, and gesture [1]. The hand is richly endowed with sensory cutaneous receptors that are essential in motor function to sustain an appropriate level of force to manipulate objects accurately in tasks and activities [2]. Therefore, functional recovery of the hand and arm after stroke is recognized as being much less frequently attained than that of the lower limb due to these complex physiological and sensorimotor processes [3,4]. Regaining good recovery can be a more difficult and lengthier process than regaining lower-limb function, where walking can be achieved with more gross motor function [5]. The lower limb can be considered functional if a person can walk independently, albeit with the assistance of a walking aid because of impairments in strength, and with limitations in walking endurance [6]. However, a functional upper limb requires much finer sensorimotor function and dexterity in the hand.

Approximately 40% of stroke survivors are left with a more-or-less non-functional hand [7]. This can leave them with significant limitations, as the hands are essential for independence in nearly all personal-care tasks, meaningful activities and life roles in which people engage [8]. Typically, most tasks and activities that people perform require the cooperation of both hands working together, i.e., to be bi-manual, or "two-handed" [9,10]. Furthermore, the upper limbs are also important for independence in mobility and balance. The fluidity, efficiency and speed of walking depend, to some extent, on the motion of the trunk and arms, and reaching, grasping, and touching can be a component of righting reactions in maintaining balance [10,11].

CONTACT Judy Purton j.purton@keele.ac.uk School of Allied Health Professions, Keele University, Keele, ST5 5BG Staffordshire, UK

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Recovery of walking is often prioritized in acute stroke rehabilitation alongside a focus on mobility and transfers to facilitate discharge [3,4,11]. This can continue in the community, where services can be infrequent and short-lived, and the emphasis of therapy often remains on improving mobility [12–16]. However, having a meaningful life after stroke may require more than just the ability to walk [8]. A degree of "two-handedness" may be vital in enabling a person to regain some ability to carry out meaningful tasks [10,11,16]. In 2005, Barker and Brauer [17] explained how stroke survivors felt upper-limb recovery was often a neglected issue and poorly understood by health professionals. Similarly, Connell et al. [3] and Doyle et al. [4] found that sensory loss in the upper limb was often not fully acknowledged or included in rehabilitation, and the impact of upper-limb dysfunction on the individual stroke survivor has been reported [8,16].

However, stroke survivors' priorities for recovery and rehabilitation, and whether these will change over time, have not been investigated in detail. Furthermore, the experience of people with stroke can be a source of valuable knowledge that can inform service delivery [18,19]. Therefore, the aim of this study was to explore with stroke survivors their experiences of recovery of the upper limb after stroke and to understand their priorities for recovery, and the way in which these may change over an 18-month period after stroke. In the process, we draw comparisons with attitudes regarding lower-limb function. This work was undertaken as part of a larger longitudinal phenomenological study investigating the wider topic of upper-limb dysfunction after stroke, from which other findings have previously been published [8].

Methods

The methodological approach that guided this study was phenomenology, as our aim was to gain an understanding of participants' experiences and priorities. As a philosophical perspective, phenomenology is concerned to express and understand the social world as it is lived in and experienced by individuals, rather than in terms of an "objective" perspective on the world [20]. By extension, phenomenology as a methodology "involves a return to experience in order to obtain comprehensive descriptions that provide the basis for a reflective structural analysis that portrays the essences of the experience" [21, p.13].

Accordingly, by conducting a longitudinal study and creating data with people who have experienced a particular phenomenon—in this instance, recovery of upper-limb function after stroke and priorities in its therapy—an account can be assembled of the essence of that experience over time from the first-person perspective [22], and in the context in which that experience occurs [23]. Our study was centered in the hermeneutic approach to phenomenology, as our aim was to come to an interpretive understanding of the meanings participants ascribed to their experience rather than providing a descriptive account of this experience. Hermeneutics presupposes the researchers' prior knowledge and understanding and asserts that it is not possible fully to bracket this knowledge and understanding.

The first and third authors are physiotherapists with experience in stroke rehabilitation and the second author is a methodologist. The first author, who collected the data, did not fully set aside her prior knowledge and experience as this was deemed essential when analyzing and interpreting participants' accounts; instead, she adopted a reflexive attitude to at least partially prevent her previous understanding from coloring participants' perspectives [24].

A semi-structured interview design, based on an interview guide of non-standardized, open-ended questions, was used so that participants could engage with the researcher on a one-to-one basis to express their experiences, thoughts and feelings [24,25]. The interview guide was developed through an exploratory focus group with members of a Stroke Association support group. A focus group in the preliminary phase of a study is a useful means of developing items in an interview guide, particularly where little is known about a phenomenon [26–28], as in the case of this study where people's priorities for upper-limb recovery and therapy have not been fully explored. Permission to approach the support group members was sought from the Regional Coordinator of the Stroke Association and ethical approval was gained from York St John University Ethics Committee.

Participants were interviewed up to four times over an 18-month period, at 2, 6, 12, and 18 months post-stroke, to capture any changes in their experiences over time. The interviews were conducted by the first author, who was careful to adopt an attitude of "maximum openness to what appears" [29,p.138], avoiding closed questions, and having pauses and periods of silence in the interview to give participants time to reflect, and to respond to further probing questions. Thus, the interviewer could follow and respond to participants' experiences rather than draw upon her knowledge and perspective as a clinician. Although similar questions were asked of all participants at the first interview at two months post-stroke, at subsequent interviews the interview guide was adapted—in terms of its content and format—in relation to perceptions, feelings, and experiences that participants had previously recounted [29–31]. The initial interview guide consisted of questions that explored participants' priorities, hope and expectations for recovery in their upper limb, and their experiences and perceptions of the availability, duration, and focus of therapy for their upper limb after stroke.

Sample

Sixteen adults were recruited over a 17-month period from a stroke rehabilitation unit. Participants were sampled purposefully as to provide insights into recovery of the upper limb and priorities for therapy [31]. Inclusion criteria were: adults (18 years old or over) who had experienced a stroke within the previous two months; impairment of function in the upper limb causing limitation in spontaneous use in functional everyday tasks; and ability to engage in conversation and report their experiences. Exclusion criteria were significant dysphasia or cognitive problems, and previous conditions affecting the upper limb, such as arthritis.

The sample size was deemed large enough to ensure sufficient breadth, i.e., participants who would reflect the range of experiences relevant to the topic, and small enough to allow in-depth data analysis [32].

A local collaborator, who was a health professional working in the stroke rehabilitation unit, identified potential participants in whom upper-limb dysfunction was not expected to resolve with minimal longer term impact, giving them a letter containing information explaining the purpose of the study and their involvement. After one week, during which participants had time to read the information, or have it read to them, the researcher visited them individually either on the stroke rehabilitation unit or, for those who had been discharged by this point, in their homes. The purpose of this visit was to provide any further clarification and to obtain written consent from individuals willing to participate in the study (such consent was obtained from all participants).

This study was approved by an NHS Research Ethics Committee (reference number 10/H1304/38).

Data collection

Although participants were recruited within the two-month period post-stroke, the first interviews only took place at two months post-stroke. This ensured that upper-limb impairment was clearly established and was not likely to resolve quickly with minimal impact in the longer term. Subsequent interviews were at 6, 12, and 18 months post-stroke. The majority of interviews took place in participants' homes where they could feel more relaxed and in control and, therefore, more willing and ready to share their experiences and feelings. However, five participants were still in the stroke rehabilitation unit at the first interview and so a private room on the unit provided a familiar, comfortable and safe environment for them to talk freely without being overheard. The interviews were audio-recorded and the researcher recorded written field notes during the interviews. Immediately after each interview, initial impressions and key issues to remember were noted. These field notes were then used together with the transcript in the initial data analysis.

The age, sex, paretic arm, and hand dominance of each participant were collected, in addition to stroke severity on admission to hospital, in the form of the National Institutes of Health Stroke Scale (NIHSS) [33]. This provided some context for the experiences of each participant and was preferable to carrying out tests of impairment or functions of the upper limb before the first interview, as these could have influenced the direction of the interview and made the relationship between participants and the researcher seem more clinical. Our concern was that the interviews should follow participants' perceptions and experiences and not be focused on just function and impairment, which may not have been meaningful to them.

Data analysis

Audio recordings of the interviews were transcribed by a local transcription service. A form of framework analysis based on the work of Ritchie and Spencer [34] guided the data analysis. The method was selected so that initial analysis could identify key themes from each participant's interview transcript [20] and then, using a framework, these data were charted, organized, and interpreted so that data could be viewed both within and across all participants at the different data collection points. Framework analysis is a flexible approach that is not aligned with a particular philosophical or theoretical approach [35], but the way in which it allows analysis of data both within and across participants reflects the approach taken in one form of phenomenology (interpretative phenomenological analysis) [36,37]. Table 1 shows the steps taken in the data analysis process.

Transcripts were read several times over, interview recordings listened to again, and field notes consulted (steps 2 and 3), so that the sense of the interview as a whole could be recalled [38]. The next stage of analysis (steps 4 and 5) reduced the data in the transcripts into themes through a process of coding, using the computer package NVivo10, where transcripts were annotated to identify codes, and memos were written to record initial observations, thoughts and impressions about the data [22]. A table of themes was developed from each interview (step 6), which were then organized into charts of superordinate and subordinate themes, with key illustrative extracts from transcripts from each of the four data collection points (step 7).

Nowell et al. [39] refer to key concepts in qualitative research of credibility (an appropriate fit between the participants' views and the researcher's representation of these views) and dependability (creating a traceable and documented account of the research). The researcher who conducted the interviews (first author) engaged in a reflexive process before all interviews and during data analysis. This was recorded in a reflexive log, and any issues that arose were discussed with the other team members, thereby assisting the credibility of the interpretation of the data (step 1). Furthermore, a second researcher (third author) completed independent analysis of a sample of interview transcripts to further ensure credibility. All aspects of the data analysis were discussed regularly by all three authors, to maintain dependability of the findings (steps 8, 9, and 10). All participants were sent a summary of the overall findings so they could comment on whether or not the findings resonated with their experiences and so were a credible representation [40]. We did not receive any such comments.

Results

Sixteen stroke survivors were initially recruited into the study; three participants subsequently withdrew before data collection began due to deteriorating health or personal reasons. In all, 13 people participated in the study, with 11 participants completing the whole study over a period of 18 months. The participants' ages ranged from 62 to 86 years, with 3 of the 13 participants having right-sided paresis, and only one person being left-hand dominant. The NIHSS scores, where a lower score corresponds to a less severe stroke, indicated that all participants were in the moderate-to-severe category of stroke on admission to hospital; see Table 2. Pseudonyms were assigned to all participants to maintain anonymity. Unfortunately, two participants died, at a point before completing all four interviews.

Three themes were identified from the data: *priorities change on coming home; limited therapy services*; and *active partners in recovery*. The sources of quotations supporting each theme can be identified by the participant's pseudonym and a number that indicates the relevant data collection point; e.g., "Alan (6)" indicates a quotation from an interview with Alan at six months post-stroke.

Table 1. Data analysis process, based on the work of Ritchie and Spencer [34].

Step 1	Adopting a phenomenological attitude to be open to all possibilities in the data.
Step 2	Listening to the interview several times, referring to any field notes, to remember the interview as a whole.
Step 3	Reading and re-reading the transcript several times.
Step 4	Annotating the transcript where recurring ideas of interest are identified and coded.
Step 5	Reviewing the coded data within the transcript to identify and label the broader themes and to look for similarities between them.
Step 6	Clustering of similar themes into a table of themes for each interview with every participant.
Step 7	Organizing tables of themes into framework charts to provide overview of data within and across participants
Step 8	Second researcher analysis of a sample of three transcripts from each interview point.
Step 9	Discussion between researchers and review of data analysis and development of tables of themes.
Step 10	Discussion between researchers and review of development of charts.

Table 2. Participant demographics.

Participant	Age	Hemiparetic side	Dominant hand	NIHSS score
Ada[a]	74	Left	Right	5
Barbara	67	Left	Right	2
Alan	62	Left	Right	12
Cath[a]	84	Left	Right	8
Doris	84	Left	Right	2
Eve	65	Left	Right	8
Jenny	76	Right	Right	4
Lily	77	Left	Right	3
Bob	70	Right	Right	6
Meg	80	Left	Right	16
Colin	71	Left	Right	14
Gordon	62	Right	Right	Not available
Harry	86	Left	Left	15

Participants names are pseudonyms. NIHSS: National Institutes of Health Stroke Scale.
[a]Participant died before end of study.

Priorities change on coming home

Two months post-stroke

At two months post-stroke, when asked what was most important to them in terms of recovery, participants' focus was more on the lower limb than on the upper limb; nearly all participants reported that regaining the ability to walk or improving their walking was the priority. This was particularly so for those who were still in hospital at this point and were unable to walk independently. They were very clear and emphatic about this, as these comments indicate:

> Interviewer: *What do you think is your priority for getting better? What's important to you at the moment?*
>
> Meg (2): *Walking, because I'd like to get out of the chair and walk across there* [pointing to the wash basin] *and walk back.*
>
> Interviewer: *So is there anything more important to you than your arm and hand, in terms of getting better?*
>
> Ada (2): *Being able to walk out and go wherever I want.*

Walking is a fundamental part of human activity and was seen by the participants as the key to becoming more independent and having freedom and choice in where and when they could go and, for those still in hospital, crucial to discharge home. Alan and Harry were both happy to ignore their upper limb at this point and concentrate on walking. Alan explained that he felt he could work on his arm later. Harry wanted mobility. He compared his feelings to a broken-down car in a way that expressed his frustration and anger with his lack of function:

> *I'm ignoring them. … It's not working so, I mean a bit like a car, if it won't work you get out and slam the door!* Harry (2)

Interestingly, despite the fact they were ignoring their arms, both men were optimistic of a full recovery in a relatively short period of time. Alan anticipated six months and Harry stated *"I fully expect the arm to work properly soon."*

At two months, while still in hospital, Jenny could begin to see that her priority might soon change:

> Interviewer: *So you feel that your leg and foot are more important than your arm at this stage?*
>
> Jenny (2): *At this stage it is, because I can do things with my left hand. I can eat with it, I can make cups of tea, I can do what I need to do at the moment, but not for long.*

However, the lower limb was not the priority for all participants at two months. In contrast to the other participants, Bob, who was a musician and living at home, considered upper-limb recovery was as important as that of his lower limb, in order to play keyboard and woodwind instruments, and also to drive. Gordon, also living at home, acknowledged that while in hospital he was more concerned with his leg but this had improved considerably, and he now saw his arm and hand as vital to his independence and return to work as a maintenance fitter. It would seem that both participants were at a point in their general post-stroke recovery where regaining their valued and meaningful activities was now a priority and they recognized that two functional upper limbs were vital in order to do this.

Six months post-stroke

By six months post-stroke, all participants had returned to live in their homes, and priorities for recovery had changed for many, with a greater emphasis on upper-limb function. The inability to manage self-care independently and participate in valued activities was now clear to them. Going home from hospital is seen as a crucial point at which people often begin to grasp the extent of their disabilities [41]. It is not surprising, therefore, that this was the experience of these participants, particularly when both upper limbs are involved in nearly all of the tasks and activities that people normally engage in:

> *Get this hand going … definitely. I think it's coming home and trying to do things here and I can't do them … I'd love to, you know, but even to bake a cake, a simple thing, there is no way I could do it.* Ada (6)

Eve could walk around her home with a stick in her unaffected right hand but then was frustrated at being unable to carry any objects in her right hand or use it functionally, stating that *"It's me arm what stops me from doing things"* (Eve, 6).

However, for those who were either unable to walk independently or dissatisfied with their level of mobility, walking continued to be their priority:

> [Partner] *is on about getting married, but I want to be walking properly … 'cause I don't want to be wheeled down the aisle … and everyone* [thinking] *"look I feel sorry for her, looking after him."* Alan (6)
>
> *Walking at the moment … I used to like walking to the shops.* Meg (6)

Harry declared he was still *"not bothered"* about his arm and hand as he saw walking as the key to competence in self-care:

> *I feel if you're walking then the rest of you will improve with it … I need to get to the toilet and shower and shave myself.* Harry (6)

This prioritization of recovery of walking over the upper limb is recognized in other research on stroke [42,43] and is understandable. Using a wheelchair for mobility can make a person seem more dependent as it can be a barrier to moving freely within the home and the external environment, and can necessitate dependence on others for transfers and propulsion. However, Harry's comment belies the fact that if he made it into the bathroom on his own he may not necessarily be able to shower and shave independently without two functioning upper limbs, as Eve's earlier comment illustrates.

At six months post-stroke, participants who had seen some recovery in their upper limb were experiencing a slowing down in the rate of recovery. These comments from Lily were typical and showed that some participants were not prepared for this slowing down:

> *I seemed to make such good progress to begin with, and then it seems to have slowed up … it's been a lot slower than I thought it would be. I expected it would continue, yes, but it's not.* Lily (6)

Many participants were holding onto the advice and experiences of other stroke survivors and hoping that in time more

recovery would come. Gordon admitted that he had initially expected his arm to recover within four months of the stroke but now was looking much further ahead:

> *Her* [his partner's] *uncle had a stroke and took him two and a half years before he got full use of his hand.* Gordon (6)

Twelve months post-stroke

By 12 months, all participants were now concerned about their upper limb, and there was a realization of how vital functional activity in the arm and hand was for personal care and to participate in meaningful activities, and to do so independently:

> Eve (12): *Well if I can only use my arm I'd be able to do a lot more for myself.*
>
> Interviewer: *What sort of things are you thinking about that you'd be able to do for yourself?*
>
> Eve: *Well, I'd be able to dress myself and undress myself properly, and then I'd be able to have a shower… on my own.*

Harry was no longer ignoring his arm. He was still unable to walk at this point, but felt he would be more competent in feeding himself if he had two functioning hands:

> *Well* [wife] *will cut it up for me, and I drop a lot, I feel a bit of an idiot, you know you have to cut your own food up, and a bit like a baby, you're dropping food all over the place.* Harry (12)

Jenny admitted that up to that point she had considered recovery of function in her leg to be more important, so that she could walk to the local shops; however, she now wanted a "normal" hand to enable her to resume her hobby of gardening:

> Interviewer: *What sort of things, having your hand back, more "normal" would enable you to do?*
>
> Jenny (12): *Well, I'd potter in the garden more than I do now.*
>
> Interviewer: *And is that something you would really enjoy?*
>
> Jenny: *Well I've always been a gardener. I don't like having to wait for people to come and do it for me.*

Meg had fallen several times and realized how essential her affected arm was to assist in maintaining her balance, and for function:

> *Sometimes I just wish I could save myself with this hand… It would help if I could walk like I do* [with stick in non-paretic hand] *and I could use my hand for something.* Meg (12)

Eve felt her inability to use her affected arm to hold onto or touch supporting surfaces prevented her from walking outdoors and using public transport as she was fearful of losing her balance and falling: "*Yeah, I'd be able to walk down the street and get on a bus*" Eve (12).

Meg's and Eve's comments emphasize the important role of the upper limb in maintaining balance and preventing falls. Furthermore, if the affected arm had recovered sufficiently to be used as a prop or counterbalance in standing and walking, this could release the non-affected arm for more dexterous, functional tasks, instead of holding a walking aid.

18 Months post-stroke

The focus on regaining more recovery in the upper limb continued at 18 months post-stroke for all participants. For Barbara and Meg, when asked what was important to them, it was clear their upper limb was just as vital as their lower limb. When asked about her priorities for the next six months, Barbara (18) indicated that functional activities involving the upper limb and walking were both priorities:

> *To be able to use them* [hands] *more and walking about—probably be able to do some cooking.* Barbara (18)

Similarly, when asked about the relative priority of her affected arm and affected leg, Meg (18) responded that they were both the same. Harry, however, seemed to have given up hope of walking again, but the ability to write and sign important documents with his affected dominant left hand was an important aspect of upper-limb functional recovery for him. Prior to the stroke, he had been able to touch type with both hands, and his previous domestic responsibilities required him to do this. However, now that he was unable to write or touch type, this responsibility had passed to his wife, which he perceived as a challenge to his role within the home:

> Harry (18): *Yeah, like re-taxing the car… and house insurance and stuff like that. Yeah, she does everything.*
>
> Interviewer: *So how does that feel now then that you can't touch type… you can't write or sign something?*
>
> Harry: *Ah you feel a bit useless.*

These findings from an 18-month period after stroke indicate that, as time passes after stroke, people may become more concerned with the function of their upper limb than they were in the early stages after stroke. They recognize that their arm and hand can be just as vital as their lower limb in regaining a highly valued sense of independence in self-care and participating in valued activities.

Limited therapy services

Two months post-stroke

At two months post-stroke, all participants considered therapy—and physiotherapy in particular—to be essential to their recovery.

> Interviewer: *How do you feel in terms of the help and advice you've been given to get more recovery in your arm and hand?*
>
> Lily (2): *I want more physiotherapy… I mean I've got some things to do here* [at home] *but I don't think they're good enough. I want something more to build up my muscle.*

On the whole, participants were satisfied with the amount of physiotherapy received in hospital. However, there was less satisfaction with how much of the therapy had been directed at recovery of the arm. Colin felt that therapy had been focused on gaining recovery in his lower limb in order to improve his mobility and so facilitate discharge from the hospital setting. His words suggest something of a feeling of abandonment: "*They just get you out of there*" (Colin, 2).

Six months post-stroke

For most participants, dissatisfaction with therapy became apparent only after discharge from hospital, at the point at which therapy was discontinued; and therapy had become very infrequent by six months post-stroke. Ada and Alan described how they felt isolated and abandoned after having only been visited twice by the community physiotherapist:

> *I just feel a bit let down… Well… they've got rid of me… I'm on my own now* [became tearful]. Ada (6)
>
> Alan (6): *I've only had it* [physiotherapy] *about two or three times.*
>
> Interviewer: *and how do you feel about that?*
>
> Alan: *I feel cut off.*

Several participants reported that they had received six weeks of therapy following discharge home, but this was mostly directed

at their lower limb and walking. Meg described how this approach had been justified by the physiotherapist, who had given the impression that it was an "either-or" choice between recovery of the lower or the upper limb, but not both:

> *But then they ask you: "what would you rather have—your hand or your walking?" They seemed to think that, er, get me walking and then concentrate on your hand.* Meg (6)

Unfortunately, having prioritized recovery of mobility over hand function, Meg's physiotherapy was subsequently discontinued before any further attention could be given to recovery in her hand. Bob reported similar experiences, as did Jenny and Eve:

> *OT came weekly and took me for walks to get me going but other than that they didn't do a lot.* Jenny (6)

> Eve (6): *You know I've never had a phone call or anything since the last time they were here, which was months since.*
>
> Interviewer: *Did they leave you with any activities or exercises you could do with your arm?*
>
> Eve: *Just exercises and I do them every day, but they haven't done any good.*

Specific therapy for the upper limb was reported to be lacking; one participant described how the physiotherapist had visited to review progress but did not prescribe any specific exercises for her hand and advised her to *"just use it"* (Lily, 6). Gordon, similarly, reported having *"a flying visit"* from a physiotherapist who gave him an exercise sheet, which he had followed and subsequently made good improvement. However, being unsure of how to progress further, in the absence of any follow-up visit, he devised his own exercises:

> *Well, they have been helpful to start with and then you get to a point… you don't seem to be getting anywhere. So, you have to make your own exercises up.* Gordon (6)

Eve was concerned about doing the correct activities to promote recovery:

> *I try different things, but I don't know if I'm doing right or doing wrong.* Eve (6)

At the conclusion of a six-week period of physiotherapy, two participants were referred to a local gymnasium to continue with regular exercise. Both declined to attend as, in their eyes, this setting did not provide them with the specific help they felt they needed to aid recovery of the arm and hand. Bob, for example, wanted more dexterity in his hand and fingers, as he was a musician:

> *Well, I've seen quite a lot of the machines in the* [gym] *but not a lot of them seem to be to do with fingers… I want to be able to do that sort of thing you know* [moves the fingers of his unaffected hand]. Bob (6)

Twelve months post-stroke

By 12 months post-stroke, therapy had stopped for all participants, apart from Harry, and there was dissatisfaction with this, with many participants feeling unsupported, ignored and abandoned by therapy services. Gordon felt that therapy services should do more, but he thought that "*they just write you off*." Ada and Eve expressed a similar view:

> *It's as if I've been let down. You're out of hospital that's it, you know, do your own thing… it's just as if I've been deserted, that's it.* Ada (12)
>
> *Once you've come out of hospital you're out of their care now and they're not bothered about you then. Yeah, that's it, you look after yourself and that's it.* Eve (12)

Eve's words suggest a degree of resignation to this lack of support.

Harry, who was still receiving some physiotherapy—due mainly to his wife's persistence with the GP—was concerned that his rehabilitation priorities were not being considered, as his treatment was focused on balance and walking, which he considered to be the therapist's goals for him rather than his upper limb:

> *Well you feel you've been left out in the cold. All the time seems to be taken up with what they want to do.* Harry (12)

As Jenny looked back over the 12 months since her stroke, she expressed the view that her experiences of therapy were not what she had anticipated. Her expectations of when upper-limb recovery could occur, and of the duration and timing of therapy for her upper limb, were not met:

> Interviewer: *How has life turned out for you? Is it what you thought it was going to be when you looked ahead in hospital?*
>
> Jenny (12): *No, I just thought I'd go home, I'd learn, I would catch up with my walking 'cause that was coming in the hospital and this* [referring to her hand] *would follow!… I mean silly me, naïve me thought it would come back automatically.*
>
> Interviewer: *What do you think about the fact that therapy stopped when it did? You know that you got it for a little while and then it didn't continue?*
>
> Jenny: *Well at the time I felt ok about it, because my leg was fine you know and I was getting out on my own without having to have somebody with me and it was only after that I thought "Well hey up" …*
>
> Interviewer: *"What about my arm"?*
>
> Jenny: *Yes! But they'd done their time….*

18 Months post-stroke

At 18 months post-stroke, the situation with therapy had changed little for all participants. Eve had been reviewed by a physiotherapist, but no further treatment was given, and there was a sense that therapy was now futile because of long-standing inactivity:

> *Well, nothing happened 'cause I couldn't move my arm so she couldn't do anything with it.* Eve (18)

She went on to explain how she had been given botulinum toxin injections by a hospital doctor to reduce spasticity in her arm. However, this was not coordinated with physiotherapy services, as guidelines suggest that it should, to ensure the full effectiveness of the injections [7]. She reported that the doctor advised her to *"get the carers to try and pull your arm down a bit."*

A prevalent view held by the stroke survivors was one of surprise and disappointment that there was so little therapy available to them. They expressed a desire for more physiotherapy for their upper limb, and a belief that more physiotherapy would improve their rehabilitation outcome. The sentiment expressed by Alan reflected the views of other participants:

> *I reckon a bit more physio on this* [pointing to his hand] *and I'd be able to use it a bit more. I feel gutted, you know, because they came for about three months and they suddenly stopped.* Alan (18)

At this point, as participants looked back on their experiences of therapy, some felt that they could have had more recovery in their upper limb if more treatment had been available and had commenced from the beginning:

> *I'm sure it would have made a difference if I'd had therapy in hospital. They should have done more, should have been more helpful, even though they are busy… I'd have got better quicker.* Gordon (18)

These findings show how limited therapy services reportedly were for these participants, especially in the community after discharge from hospital. It seems that the duration of therapy was

thought to be too short to enable more attention to be directed to the upper limb.

Active partners in recovery

Throughout the 18-month period after stroke, and despite the short-lived nature of the therapy services offered, participants recognized that they themselves had a significant and important role to play in their own recovery. There was a belief that they should follow advice from therapists about exercises and activities, where it had been given, and should try to maintain a positive attitude and remain motivated:

> *If you're not prepared to do as you're told then you won't get anywhere… No need to be negative about things, you've got to try and be positive about things.* Lily (2)

However, in the absence of professional therapist advice as time passed, several participants were devising their own exercises and purchasing commercially available small equipment without knowing how to use it, or whether it was appropriate. Harry, at 12 months post-stroke, had bought a muscle stimulator for his arm and hand; however, the physiotherapist showed little interest in this, continuing to direct attention to the lower limb. When asked how he felt about this, he responded with some frustration: "*I'd like to get my arm and hand going, to be able to do things.*" Meg's husband had bought her a small pedal machine at six months for use with her arms as well as her legs; but, similarly, she reported that the physiotherapists paid little attention to her efforts with this.

> Interviewer: *So, most of the attention, most of the effort's been around your walking, has it?*
>
> Meg (6): *Standing up and sitting down that's me exercises … but not much with me hand.*

At each interview, Gordon described how he was working hard on his arm despite the lack of therapy and advice:

> *Well, muscles are painful. I'm trying to build it. I don't know whether I'm building up right things or not.* Gordon (6)

However, not all participants portrayed themselves as so self-motivated from the beginning. Alan appeared to be less proactive at six months post-stroke and was pinning a lot of hope on a forthcoming appointment with the consultant and expecting more help with his arm. The consultant was described as showing no interest in his arm and so, at 12 and 18 months post-stroke, Alan's attitude had changed. His comment of having someone to "*show me exercises to do*" was typical of many participants who expressed a desire for exercise prescription, guidance about upper-limb functional activities that they could practice, and encouragement and confirmation that they were doing the right things to promote more recovery:

> *Well, if somebody gave me instructions I could do them at home.* Lily (12)
>
> *You just need that little bit of pushing behind you, for somebody to say "Yes, you've done that right, yes, it is getting better."* Ada (12)

All participants were realistic and recognized that there were not sufficient resources available to them for continuous long-term therapy, but they did want access to regular review, and advice. Several participants had been prescribed exercises early after their stroke, some of which had been effective and some not, but had received no follow-up to help them move forward:

> *I've accomplished that* [touching her index finger with her thumb], *so what else can I do?* Ada (6)
>
> *I slosh it about in water, which I was told to do in* [hospital]… *just* [want] *somebody to talk to about it now and again.* Jenny (18)

Group therapy was suggested as being a more cost-effective way of providing support and therapy in the longer term, in which stroke survivors themselves could be a good resource and encouragement for one another:

> *I think group therapy would be better. You can see how well other people are doing and they can see how well you are doing, and while you are doing it, have a chat. You have got to be with other people who have had a stroke.* Gordon (6)

Our findings indicate that, in general, these stroke survivors did not want to be passive recipients of therapy but, rather, active in partnership with therapists. They wanted to take responsibility for their upper-limb recovery and work with the therapists to solve the problem of upper-limb dysfunction, and they were ready to put in the effort required so that they could be more independent and more useful in their lives. Unfortunately, participants perceived this positive attitude and desire to take responsibility for their own recovery as being undermined by a lack of services. Comments from Harry sum up very well how participants felt their hope and desire to be more active in their recovery was apparently disregarded by services, and a missed opportunity for people to become less dependent on services in the longer term. As part of this problem, he perceived an issue with how resources are allocated:

> *Well, I mean, there'll be a lot of people like me around and, er… well, they should see it as wasting assets… there aren't enough resources for people in our situation… they're not putting their money in the right place.* Harry (6)

These findings would support the recent interest in the benefits of self-management in long-term conditions such as stroke, both for service users and for more effective use of resources. The participants in this study could potentially have benefited from this to help them drive forward their recovery.

Discussion

It is clear from the findings in this study that the importance of upper-limb recovery to people with stroke can change over time. The participants' priorities at two months post-stroke reflect those reported by other studies, where regaining or improving walking can be seen as the key to being discharged from hospital and, thus, the main priority for stroke survivors [3,42]. In their study of experiences of sensory impairment in the upper limb, Doyle et al. [4] found that people's attention only turned to their upper limb once they had achieved some recovery of walking. There is no doubt that walking achieves a degree of independence in being able to move around the environment without the need for assistance and, therefore, will enable people to live in their homes and community more easily. However, as the full impact of stroke becomes apparent once people have been discharged from hospital and are living in their homes, stroke survivors may experience a change in their focus toward recovery of function in the upper limb at around six months post-stroke [38,44]. When living at home, they are confronted with the reality of the life they had led before their stroke, and the tasks and activities that they want and need to do at home. Conversely, when in hospital they were in an unusual situation where healthcare staff were present and more was done for them, so masking the impact of upper-limb dysfunction on their activities of daily living [41].

The continued prioritization by the participants in our study toward recovery of the upper limb at 12 and 18 months post-

stroke could be due to their trying to regain and rebuild a meaningful life after stroke, as has previously been reported [8,42,45]. This process of re-building a meaningful life is referred to by Ellis-Hill et al. [46] in their Life Threads Model as individuals trying to reconnect to the components, or threads, of their life after stroke that are most important to them, and it appears that the participants in our study found upper-limb dysfunction to be a barrier to this.

Participants' prioritization of recovery in the lower limb over that of the upper limb, at two months post-stroke, matched that of their therapists. The priority of recovering walking ability to facilitate a speedier discharge from hospital is reported in other studies [3,4,14]. Length of stay in hospital is an outcome recorded by the Stroke Sentinel National Audit in the UK [47], where a shorter length of stay on an acute stroke unit is regarded as a positive outcome. This, therefore, could put pressure on therapists to prioritize mobility in order to reduce length of hospital stay.

The infrequency of therapy in the community and the limited attention being paid to the upper limb at such an early stage after stroke, as reported by our participants, do not meet current guidelines and standards. The National Clinical Guidelines for Stroke [7] recommend that treatment for the upper limb should be incorporated into early rehabilitation. Coleman et al. [48] conclude that it is highly plausible that early intervention to prevent learned over-use of the non-affected side can positively influence cortical re-organization within the brain. Borschmann and Hayward [49] and Winter et al. [50] also conclude that there is potential for recovery of movement and function up to two years after stroke. Therefore, neglecting the arm at an early stage could potentially reduce recovery and the effectiveness of any later therapy, if available. Although stroke survivors might consider walking to be more important at this early stage, therapists should be educating and advising them about the need for therapy in relation to longer term outcomes for their arm and hand, in addition to ensuring that such therapy is available.

The six-week duration of therapy that some participants reported received after discharge from hospital is also not reflective of the guidelines and standards for stroke [7,51]. These recommend that therapy should continue for as long as patients continue to benefit, rather than stopping at an arbitrary point in time that seems driven by the needs of the service rather than those of the stroke survivors. Our participants' experiences reflect a finding of the Post-acute Stroke Commissioning Audit in the UK [52], namely that there is insufficient commissioning of post-acute stroke services nationally; furthermore, the audit noted that there is widespread variation in the rehabilitation services provided in the post-stroke period, with many areas failing to provide comprehensive care. The choice presented at six months by the physiotherapist to one of the participants in this study (Meg), to aim for recovery either in the hand or in walking ability, suggests that rehabilitation priorities may be determined primarily by the limited time available to spend with patients, rather than by a person's potential for more recovery. Again, participants' experiences resonate with the literature, in which the insufficient and short-term nature of therapy provision after stroke has been reported over many years [12–15,17]. This could indicate that some services are not meeting national stroke guidelines, which recommend that people should be given every opportunity to practice activities and engage in repetitive task-specific training for the upper limb [7,53].

Recovery of normal hand function may not be attainable, but even partial recovery of the arm and hand could restore some important functional activity, for example during walking (arm swing for increased gait speed and counterbalance) and for balance (righting reactions involving the arm) [54,55]. These functions of the upper limb could contribute to improvements in mobility and a reduction in the fear of falling, common in people after stroke [56]. Further, partial recovery of the paretic upper limb could enable it to be used as a supporting or stabilizing prop, thus releasing the non-paretic arm and hand from being used to maintain stability and balance so it can be used for more complex and dexterous tasks [55].

All the participants in our study recognized that they had an important role to play in their recovery through staying positive and motivated, and complying with prescribed exercises or activities. These attitudes and attributes are recognized elsewhere in the stroke literature as being important for enhancing recovery potential [41,43]. Participants showed remarkable resilience in persevering to find their own ways of improving arm and hand function but expressed disappointment that appropriate therapy services were not available to support them.

It is interesting that participants were realistic about the finite health care resources available to them, and there was a clear message from them that they did not expect therapy to continue indefinitely. However, they did want continuing access to services for regular review and advice on how to progress recovery further over time. Advice on the trajectory of recovery after stroke would have been beneficial to Lily and George, at six months post-stroke, so that they could have anticipated the slowing down in the rate of recovery to manage their expectations. This highlights how important accurate advice could be to people after stroke. It also supports the findings of other studies [15,41,57] that have reported that stroke survivors want intermittent access to services for review and advice. Furthermore, in their systematic review on the influence of physiotherapist-patient relationships on treatment outcome, Hall et al. [58] suggest that the provision of opportunities for patients to ask questions, receive feedback and have clear instructions for home practice positively correlated with high levels of patient satisfaction.

Self-management programmes for stroke are becoming more prevalent as a means of engaging stroke survivors in taking more responsibility for their condition and a more active role in maintaining good health. A systematic review by Warner et al. [59] reported growing evidence that self-management after stroke can lead to improved functional ability and social participation. Identifying and strengthening stroke survivors' resources, providing tools for self-management, and offering advice on what patients can do for themselves, can heighten a sense of control over their life [60]. The participants in our study could have been ideal candidates to participate in a self-management program that included a focus on the upper limb, since many acknowledged a desire to be active agents in their recovery, an attribute deemed crucial to successful self-management [61]. Developing a therapist-patient partnership based on trust, mutual respect, knowledge exchange, and agreed therapy goals is essential in motivating people to take an active role in their rehabilitation [62,63]. In the longer term, self-management programs may be a more effective and efficient approach to support some stroke survivors to regain more recovery in their upper limb, with services that are patient-led and responsive to patient needs, and that enable and support stroke survivors in setting goals that are meaningful to them.

Limitations

The participants in this study were all recruited from one stroke rehabilitation unit and so the findings could reflect the model of

care adopted locally and could mean that the findings are not generalizable to the wider stroke population and services. The youngest participant was 62 and so the findings may not be transferable to younger stroke survivors. However, the purpose of qualitative research has more to do with the transferability of insights than with straightforward empirical generalization [64,65], and the description of the participants in this study and the details of their experiences within the quotations presented should allow others to decide to what extent the findings are transferable to their patients and local stroke services.

Conclusions

Recovery of mobility was considered by participants to be a priority for their rehabilitation in the first two months post-stroke, but as they are faced with the challenges of self-care and meaningful activities over time, particularly as they return home from hospital, upper-limb recovery may become equally important as walking. Accordingly, by 12 and 18 months, they recognized that upper-limb recovery was as much a priority as walking. . There is a desire and willingness in stroke survivors to be active in facilitating more recovery in their upper limb, but this must be matched with improved access to community-based therapy services for ongoing support and guidance. Development of such services might be financially challenging, but viable models of services that capitalize on people's desire to take responsibility for their recovery, such as appropriate self-management programs, could be a cost-effective way of meeting the rehabilitation needs of people with upper-limb dysfunction after stroke. Further research could explore the views of stroke survivors from younger and older age-groups on self-management programmes for the upper limb and the support required for these to be effective.

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ORCID

Judy Purton http://orcid.org/0000-0002-7900-6274
Julius Sim http://orcid.org/0000-0002-1816-1676
Susan M. Hunter http://orcid.org/0000-0001-8844-6848

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