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RESEARCH ARTICLE

One size does not fit all – Stroke survivor's views on group self-management interventions

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ABSTRACT

Introduction: Stroke is the main cause of complex disability in the UK. Many stroke survivors feel abandoned when rehabilitation ends and more than half are left with long-term unmet needs. There is now emerging interest in whether group self-management programs (SMP) specifically for stroke survivors could help. However, more work is required to understand the acceptability of group SMPs to stroke survivors and the factors of concern that could impact efficacy.
Purpose: The purpose of this study is to explore stroke survivor's views on (1) possible benefits of a group SMP, (2) possible challenges of a group SMP, and (3) when/where to implement a SMP in an individual's stroke journey.
Method: Fourteen stroke survivors took part in semi-structured interviews, which were analyzed using an inductive thematic approach.
Results: Three main themes were identified in the data: (1) a space to share support, (2) it is not a one size fits all problem, and (3) how is it all going to happen?
Conclusion: A varied group of stroke survivors can provide valuable insight and ideas about how group SMP's should be constructed. To the best of our knowledge, this is the first patient engagement study that explores group SMPs for stroke. In future work, researchers may find it helpful to consider the findings from this study to inform the design of group SMPs.

➤ IMPLICATIONS FOR REHABILITATION

- There is interest in whether unmet needs after stroke could be addressed through a group self-management program (SMP).
- Stroke survivors can provide valuable insight and ideas about how group SMPs should be constructed.
- Group SMPs should carefully consider: how to create a safe space in which stroke survivors feel comfortable, the impact of the facilitators, tailoring the group to the individual, the presence of carers, and the emotional impact of a group SMP.

Introduction

Stroke can be life threatening but improvements in the quality and effectiveness of acute care mean more people are surviving [1]. As a result, the long-term consequences are now more apparent and stroke is still the largest cause of complex disability in the UK [2]. Residual symptoms post-stroke may include impairments in motor ability, speech, concentration, emotional functioning, and an increase in fatigue levels [3]. Social aspects of an individual's life can also change. Family and friends can become carers [6–8] and 56% of stroke survivor's feel social connections treat them differently [7]. Social isolation can impact quality of life and lead to poorer functional outcomes post-stroke [8,9]. These impacts mean the perception of stroke is changing from an acute event to that of a chronic condition. However, the care models used to manage stroke have not yet anticipated this shift in understanding and many services remain firmly in line with "acute medical ideologies" [10,11].

The full impact of stroke once an individual is discharged home is evidenced in a number of studies. Satink et al. [12] found stroke survivors recall discharge home as an uncertain and ambiguous time lacking in continuity, with some reporting they are unsure where to start in terms of recovery. A survey in Ireland found half of the stroke survivors with memory deficit, a third with speech impairment, and a quarter with physical impairment felt they needed more support from services [3]. In England, 59% of stroke survivors reported unmet clinical needs, and 52% had experienced a loss or reduction in work [13]. It is, therefore, unsurprising that many stroke survivors report feeling isolated in the community and abandoned [14,15]. This highlights the necessity for stroke services to be more accessible and responsive to fluctuating long-term needs.

The National Clinical Guidelines for Stroke (UK) suggest a reduction in unmet needs may be possible by providing access to self-management (SM) support [16]. Many SM programs (SMPs) are based on building the "confidence in individuals to manage the medical and emotional aspects of their condition in order to maintain or create new life roles" [17]. SM is encouraged by providing people with knowledge and skills they can apply to their own lives [18] such as problem solving, information giving, planning, goal setting, and decision making [19].

A review of 550 studies suggests that SM interventions can have an impact on quality of life, self-efficacy, self-care, and clinical outcomes for a variety of chronic conditions [20]. Similar impacts have been found specifically for stroke by three recent systematic reviews [17,19,21]. First, Parke et al. [21] reviewed 13 studies and found high quality evidence for a reduction in dependency and death, improvement in activities of daily living and evidence that the SMPs can facilitate reintegration in the community. Second, Lennon et al. [19] reviewed 15 studies and found significant improvements in favor of SM, including confidence in recovery, stroke specific quality of life, and measures of disability. Finally, Warner et al. [17] reviewed nine studies, four were based on one-to-one interventions, and five on group interventions. Results showed that group SMPs incorporated a greater number of techniques specific to SM than the one to one programs (five versus three). All three reviews report improvements in outcomes that could reduce the unmet needs reported by stroke survivors [13].

The different delivery mechanisms used, such as one to one SM support and group-based SMPs, may play a role in increasing access to SM services and enable different forms of support. One aspect of a group delivery is peer support, which can provide a platform for sharing experiences, reciprocal gain (being helped and helping others) and reinforcement of SM techniques. Stroke survivors themselves describe peer support as having great value: it can act as a catalyst for action, offer shared decision making, and be a great source of knowledge as peers in the same position, "actually know what they are talking about" [22]. There is relatively little published work on the group delivery of stroke SMPs but they may improve well-being [23], health distress [24], feelings of loneliness [25], medication compliance [26], and cognitive symptom management [27]. Therefore, a group SMP could offer a targeted approach to reduce unmet needs in the stroke population and increase the number of stroke survivors who would have access to such a service.

It is clear that there is a need to reduce unmet needs in the stroke population and that group SM may provide a viable mechanism through which to do this. However, it is important that new developments in stroke rehabilitation: (1) reflect the needs of those who use the service, as SMPs may profess to be patient centered, but can often be professionally led [28] and (2) studies are carried out in line with the Medical Research Council (MRC) guidelines [29] which suggest the design of any complex intervention should be tested for acceptability among its target population. Both these considerations could be achieved through Public and Patient Engagement (PPE) work. One group SM study focusing specifically on stroke does ask participants for their views but this was carried out after members had participated in a group SMP which may have influenced findings [30]. To the best of our knowledge, there has been no research exploring stroke survivors' views on the group delivery of SMPs prior to attendance.

The aims of this research were to explore stroke survivor's insights on (1) possible benefits of a group SMP, (2) possible challenges of a group SMP, and (3) when/where to implement a group SMP in an individual's stroke journey.

Method

Semi-structured interviews enabled researchers to gain an insight into what stroke survivors thought of a group SMP and how it could be delivered. Inductive thematic analysis was used which is recommended for preliminary health service research, and when key themes reflecting variations in the data need to be identified [31,32]. Recruitment, interviews, and data analysis were carried out concurrently over 6 months. This allowed data saturation (defined as when all members of the research team agreed no new categories were emerging from the data) to be considered contributing to rigor [33].

The work was informed by the National Institute for Health Research guidelines which encourage patient and public engagement in health and social care research [33], and the Medical Research guidelines for the development of complex interventions [29]. A favorable ethical opinion was given for this study from the NRES Queen Square committee (13/LO/1412).

Recruitment

The researchers had an initial aim of interviewing at least 12 participants as this is suggested for applied research with narrow questions [34]. Participants were recruited from the Sobell Stroke Database at Queen Square. The database contains contact information for individuals who have previously expressed an interested in research. Researchers can access the database if they work in the Sobell department and have ethical approval for the proposed work. Individuals were initially added to this database through NHS services, the Stroke Research Network, or other research studies conducted within the Sobell Department.

Stroke survivors were approached consecutively about taking part in the study using their preferred method of contact. The majority stated they preferred telephone so where a preference was not listed telephone was used. All potential participants were assured taking part was completely voluntary and would not affect their standard of care within the NHS. Reasons that stroke survivors declined to take part in the study were documented and allowed the researchers to see if any patterns of decline were emerging. It also provided a clear context for the sample which reduces the likelihood of making unsupported statements about overall findings.

The inclusion criteria were designed to ensure as wide a sample as possible. Stroke survivors were included if they had: (1) one or more stroke(s), (2) were able to verbally complete an interview (this included people with aphasia who could understand a two-step command and express thoughts and ideas), and (3) received their care in a UK stroke care pathway.

Interviews

All the semi-structured interviews [35] were conducted by EC who is a PhD student working within the context of stroke self-management and has previous experience in a neurological rehabilitation service including stroke. Interviews were conducted in a university research department in a room with minimal distraction. A university room was chosen as it offered a non-clinical environment and emphasized that the interviews had no impact on clinical care. However, the chosen location meant that participants would need be able to travel to the venue for the interviews. Prior to each interview the room was set up in the same way (chairs facing each other and a low round table in the middle and the curtains open). Each interview was recorded using

a dictaphone. Participants had the option to bring a friend or family member with them.

Two researchers (E. C. and K. B.) developed the main research questions. Guidelines for developing interview schedules in health research informed the design of the topic guide [31]. The topics themselves were informed by the research questions as well as relevant, previous research. For example, Satink's [36] work drew attention to the time that stroke survivors felt ready for self-management support. As a result, a question surrounding when to implement a group SMP was included in the interview guide. The transcript was piloted in a practice interview and discussed by E. C. and K. B. Some questions were removed after the pilot as they were off topic and did not facilitate full exploration of the research questions.

At the start of the interview, participants were read a paragraph about what self-management means as the term is somewhat ambiguous. They were also given the opportunity to ask questions about this meaning. The Interviews were carried out in two parts. The first part explored participant experiences of SM in their own stroke journey which gave insight into the third aim of the study (when/where to implement a SMP in the stroke pathway/stroke survivor's recovery). The second part of the interview explored the idea of group SMPs and the barriers and gains associated with them. This gave insight into the first and second study aims (possible benefits of a group SMP and possible challenges of a group SMP). An example of the types of questions asked is found in Box 1.

Box 1. Example of questions used in the interview guide.

- How do you think it would have made a difference to your current life if you had experienced self-management support, if at all?
- How would self-management make a difference to your life if you were practicing it now?
- What do you think about the idea of group self-management programs? What would the barriers/benefits be?

Data analysis

Data were interpreted using inductive thematic analysis with codes drawn directly from the data. Codes were phrases or words which were then grouped to develop categories and themes. In the first instance the raw data were interpreted as, codes (e.g., learning from others and new ideas from peers) were combined

to create collections of codes (e.g., collective problem solving). These collections were then combined to produce sub-themes (e.g., peer support), which were again combined to produce the main themes of the study (e.g., a space to share support).

In keeping with guidance on qualitative research [32], themes were formed iteratively which meant data analysis and interviews were done simultaneously. The process involved exploring which themes were identified across the data set as it grew and re-reading interview transcripts to find illustrative examples and adjusting themes to reflect the new data gathered. This process continued until no new themes were identified.

To minimize researcher's preconceptions influencing data analysis, and to offer a broader understanding of the data, three researchers coded data for two interviews (E. C., F. J., and K. B.). Each researcher then wrote a summary of their interpretations and these were discussed as a group, including codes and their descriptive groupings. No substantial differences in interpretation were found and all the remaining interviews were coded separately by two of the researchers (E. C. with either F. J. or K. B.) in keeping with published recommendations [32]. Data management was performed using Nvivo 10 (SPSS Inc., Chicago, IL).

Results

Fourteen participants were interviewed (see Table 1). The interviews lasted from 12 to 54 min, with a mean average of 30 min. The mean age of participants was 58 (with a range of 47–78). The mean time since stroke was 30 months and ranged from 4 months to 174 months. Eight of the interviewees were female, and six were male. Similarly, in the UK, three out of five strokes are in women [37]. Eleven of the interviewees were white British, one was Chinese and one was white Irish. In the UK, people of black and south Asian origin are at a higher risk of stroke compared to white people [38]. The limited ethnic diversity of this research should be considered in terms of transferability of the data. Four of the interviewees were unemployed, three were retired, three were employed (one of the three was self-employed), which is similar to the national statistics which show 69% of stroke survivors were unable to return to work [38]. One participant (8) had mild expressive aphasia. Residuals symptoms reported included: Aphasia, motor impairment, motor weakness, fatigue, low mood, and poor balance. No one else was present at participant interviews 1–12 apart from EC and the participant. Participant 13 brought her husband to the interview, as did participant 14. Five stroke survivors who were approached declined to take part in the study, three as they were too unwell, two as they were too busy.

The research was conducted with the aims to explore (1) possible benefits of a group SMP, (2) possible challenges of a group

Table 1. Participant demographics.

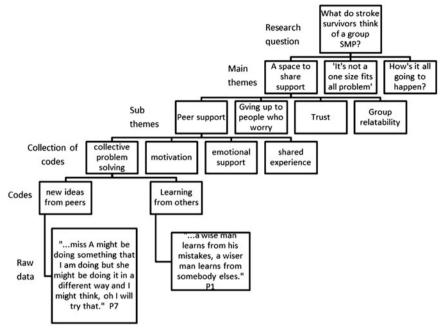| Participant number	Gender	Age	Ethnicity	Employment status	Time since stroke (months)	Living situation
1	M	48	White British	Employed	33	Living alone
2	F	50	White Irish	Employed	57	Living alone
3	M	47	White British	Self-employed	16	Living alone
4	F	73			4	Living with partner
5	M	78	White British	Retired	174	Living with partner
6	M	51	White British	Unemployed	9	Living alone
7	F	50			61	Living with partner
8	F	57	White British	Unemployed	31	Living alone
9	F	66	Chinese	Volunteer	24	Living alone
10	M	53	White British	retired	40	Living with partner
11	F	54	White British	Volunteer and student	4	Living with partner
12	M	51	White British	Unemployed	34	Living with partner and daughter
13	F	76	White British	Unemployed	23	Living with partner and daughter
14	F	69	White British	Retired	26	Living with partner

Figure 1. Example of theme formation.

SMP, and (3) when/where to implement a SMP in an individual's stroke journey. The aims are discussed within the context of the three main themes that were identified in the data. The first theme, "A space to share support" illustrates the challenges and benefits of a shared space that would be created as part of a group SMP. An example of the sub-themes that made up this theme is found in Figure 1. The second theme, 'It's not a one size fits all problem" illustrates the view that a group approach needs to be able to address the heterogeneity of stroke. The third theme, "How's it all going to happen?" was identified in discussions around the logistical aspects of a group SMP, for example transportation and facilitators.

A space to share support

"A space to share support" represents what participants felt about the social aspects inherent to a group SMP, in particular, the challenges and benefits of a shared space. Four sub-themes contributed to this overarching theme as follows: Peer support, giving up to people who worry, group relatability, and trust.

Peer support within a group setting

The value of peer support was referenced by nine participants, and included reflections on the value from both a practical and emotional stance. Many participants described how they had faced new challenges after their stroke and highlighted the potential benefit that could be gained through peers by collectively problem solving:

> I do think [one-to-one] would limit me. You know, cos I think it is good to have other people around (researcher in bold) **Why would it be limiting?** Well because it is just one person and she, there is only her or his ideas, I just think with other people's ideas you get more of an all-round idea you know …. Miss A might be doing something that I am doing but she might be doing it in a different way and I might think, oh I will try that. you just don't know. (Jess)

Participants felt others who had experienced a stroke would have a greater understanding of where they are coming from. Linda explains this may be in part because you are "working towards the same goals". In addition, discussions around this

shared experience may reduce feelings of loneliness as Paul illustrates:

> That is good if you know there are others in the same position as you. Going, going through the same thing as you. So you don't think you are the only one … It's good talking to other stroke survivors because with their experiences you know you are not alone then. Because it is very demoralising once you have had your stroke. (Paul)

Motivation from peers was mentioned by a number of participants. It was spoken about in relation to vicarious experience or learning from others. Seeing others succeed could be particularly motivating:

> Sometimes it is peer pressure. You see someone doing well and you want to get better as well so it spurs you on a bit. (Paul)

Peer support was seen as a positive thing by the majority of participants due to the potential for shared problem solving, increased motivation, and a reduction in loneliness.

The ripple effect – a group just for stroke survivors?

"The ripple effect" depicts the effect stroke can have on family and friends and also the impact family and friends can have on an individual's self-management. Participants described the need for those caring for them, as well as themselves, to understand what is going. A shared understanding was felt to be important as those caring for stroke survivors can then offer a "nudge" in the right direction. This was illustrated by Henry who said:

> I think erm a carer, even if they are just there to nudge support, is important. So I think the carer needs to be involved in the management program so they know what is going on.

Similarly, Liz felt that a group SMP might help her husband better understand how to encourage her to self-manage:

> If my husband is there I would use him … .Like you know [if I ask], "can you do this and can you do that?". Then they would be trained to say, "oh you know, let's see if you can do it yourself" … I know I can do it, as I have done it myself. But you give up to people who worry about you.

Overall, participants felt family and friends were involved with the process of self-management. For this reason, it was felt

important that a stroke survivor could share the group SM sessions with family and friends if they chose to.

Group relatability – "I might not fit in"

"Group relatability" describes the importance of relating to others in a group SMP. There were some overlaps in the factors participants found relatable but the importance of these factors varied from person to person. Mukesh suggested that a similar age was what he would relate to in a group. He says this because age may alter the challenges you face. For example, younger people he had met were all keen to get to the gym, but he felt older people would not have the energy for this. Thomas agreed with Mukesh that age was significant but also mentioned gender:

> I think really if I was going to sit down with a bunch of men my age I would probably be, you are more likely to be more open and you are going to relate to them more.

Thomas's view on gender was held by the majority; all but one participant stated they feel more comfortable around people of the same gender as them. However, Patricia recalled a group she attended that was all women in which she felt like she "just didn't fit in". Similarly, Jane reflected on a recent group program she had attended for neurological psychological impacts of stroke. She suggests that gender was less important to her than circumstance:

> It is helpful to meet other people in the same circumstances to you and actually I felt more in common with the 2 guys in that.

Helping people feel that they fit in and can relate to others in a group may be linked to creating an environment in which people feel able to share personal information. George emphasizes why this is important when he says he may not be "able *to open up about personal things in front of a group of strangers*".

These results demonstrate that a range of factors can make stroke survivors feel like they could fit in with a SM group. Age and gender were mentioned most often followed by personal circumstances. In addition, this highlights that some participants may not feel comfortable opening up and "being themselves" in a group setting if they do not know the people in it.

"A space to share support" explores peer support, the role of family and friends in SM, and factors that impact whether a stroke survivor would feel they "fitted in". A number of benefits of peer support were highlighted and included collective problem solving. The shared education of best practice with carers was also seen as a positive outcome. Finally, participants emphasized the importance of creating a space they would feel comfortable in.

"It's not a one size fits all problem"

"It's not a one size fits all problem" illustrates the inevitable heterogeneity and variation in long-term needs after stroke that may present in a group SMP. It is made up of three categories: the importance of being individualized, ability to cope emotionally, and when to implement a group SMP.

The importance of being individualized

Eight of the participants discussed the need for a group SMP to be individualized or tailored to the person. Stroke can cause a huge range of residual symptoms and the symptoms themselves may be managed differently by different people.

> It depends on how the stroke has affected you. Every stroke is different so you need to have it tailored to individual need. (Paul)

Linda expands on this, stating that when an intervention is tailored to someone it is more relevant to their personal situation.

For example, she suggests that the program content should be tailored to different levels of cognition:

> I suppose like any group things, if people are different levels. Erm, if you have a clever kid and a stupid kid, that's mean but you know what I mean. If you have too many levels and you teach to many people, then people say, 'it's not relevant to me. (Linda)

Emma talks about the mechanism used to deliver SMP as opposed to the content. She suggests that the delivery mechanism of a group SMP could be tailored to your personality as opposed your post-stroke symptoms.

"If someone is shy then you would do 1–1 [as opposed to a group]"

The importance of having an individualized SMP is clear. Participant's felt they would be less likely to attend if they feel the SMP is not relevant to them. Perception of relevance may be based on residual stroke symptoms, cognition, or personality.

Ability to cope emotionally – "perhaps not everyone can cope"

The ability of each individual to cope with the potential emotional demands of a group SMP was discussed by participants. Some aspects of a group may be emotive for some individual's such as, discussing experiences of stroke and remembering things that are distressing. Five stroke survivors spoke about how they would cope emotionally when hearing and talking about stroke. Thomas reflects on times he has had to hear about stroke, such as in the paper. He says he does not like it as he finds it both "difficult" and "distressing" to hear. Other participants expressed concerns at how they would feel attending a group SMP. For example, Liz mentioned attending a group may scare her as she would have a greater insight into the medical factors surrounding stroke. James said he would not want to put himself in a situation in which he might get stressed as he worries it would aggravate his atrial fibrillation. Margaret, whilst more certain about how she might react emotionally, also sees the experience as challenging:

> "I have found I have got more emotional, I will cry at the drop of a hat, you know, happy times, or sad times. And erm, if I had somebody who was in a group who was reduced to tears I would be too. …. it is not a nice feeling I suppose."

The concern that all these participants share is summarized by Ben, who talks about emotional management in relation to group programs:

> I suppose the danger with rolling it out to everyone, is perhaps not everyone can cope. Because it's not very good news this stuff you are being told.

Discussion around how people may cope with the emotional demands of a group SMP emphasized the need for a space in which people feel able to share they are not always coping. It also highlighted the importance of a skilled facilitator to manage complex group dynamics.

When is the right time?

Participants were asked at what time they would have liked a group SMP in their personal stroke journey. Opinion varied but five participants suggested, "the sooner the better". Margaret explains why she would like to have access to a group SMP as soon as possible:

> Because I felt so down and so … traumatised by the stroke that I didn't understand why I had it … so I would have liked someone to have come in and talked to me about it.

However, other participants felt that the time immediately after their stroke could be too soon:

> For the first month of so I don't think I would have taken it In. For the first month everything was too much for me. (Jess)

Ben expressed similar views as Jess:

> You need a bit of time to calm down, to err, get a little bit more empathy to say everybody's different yet we are all the same.

The transition home was mentioned by six participants as the time they would like a group SMP to be on offer. This was a time many felt support was lacking:

> I would say once [I] got home. I think then would have been a good time, the third stage, so after the 6 week of community rehab. Because that's when we feel it all disappeared. It all stopped. (Liz)

This period is perhaps one of the most important for strengthening self-efficacy as individuals are often starting to do more things for themselves:

> It would be best here cos then you've gone from being in a caring environment and then to being in your own home or flat, and I moved cos of this yeah, so, (pauses). I think it would just help people deal with the outside world. (Patricia)

Some participants mentioned ways in which they were already self-managing. Paul had his stroke 40 months before the interview; he felt that it was "too late for him now". He says this is because he created his own support network earlier on his stroke pathway:

> I have got things in place that I do. I have created strategies that I was taught by [group name] and that. Different strategies so I did things to remind me and that. I am also part of different strokes on Facebook and I talk to loads of other stroke survivors that way as well. I have got a network from that.

Although Paul feels it is too late for him to attend a group SMP now, the fact Paul sought out this support through social media suggests that he was seeking this type of support earlier on in his journey. In contrast, others who had their stroke a relatively long time ago said they would still like a group SMP.

As the title of this theme suggests, participants perceived that a "one size fits all approach" wouldn't be appropriate given the individual needs and experiences of each group member. The right time to implement a SMP varies from person to person, highlighting individual preferences, the heterogeneity of stroke and the need for an intervention that can be accessed when an individual feels ready.

How's it all going to happen?

The final theme: "How's it all going to happen?" was identified in discussions about the logistical aspects of a group SMP. The sub themes are (1) course facilitators – who would stroke survivors like to facilitate a group SMP and (2) transport-how will stroke survivors get to a group SMP.

Course facilitators – "what do they know?"

Participants suggested facilitators could come from variety of professional backgrounds and have different experiences. For example, some participants suggested practitioners such as nurses, physiotherapists, and counselors, while others were less enthusiastic about the idea of a health care practitioner, *"what do they know?"* (Ben). The idea of an experienced stroke survivor facilitating a group SMP was seen as a benefit by many participants.

Views on this are summed up by Ben who notes, "they have been me". In contrast, speaking from her own experiences, Jane says:

> Organisationally though for the different stroke things, I do think it would be better if we had somebody non-stroke to help because we do a lot for ourselves but at the same time it is very difficult to organise and remember.

Henry suggests a combination of both Ben and Jane ideas:

> I think you need both a stroke survivor who can bring really … .well. Personal and professional to some extent, a comprehension of what happened. Then a specially trained person could fill in the gaps or put it all in perspective.

The type of group SMP facilitator that would be acceptable to stroke survivors varies. However, as suggested above a combination of facilitators may satisfy all viewpoints.

Travel to the venue – "but I haven't even got on the bus yet"

"Travel to the venue" describes how participant's felt about the practical considerations of getting to a group SMP. Patricia spoke about traveling to a venue as a potential barrier of attendance:

> Erm, where it is, you know, it is purely local factors that would determine if people would go … .how easy it is to get to. Transport of course would be a big problem. It can't obviously provide transport as that would be expensive so it has to use public transport but has to be convenient transport

The importance of convenient transport was explained in two ways. First, Jane says traveling any distance after her stroke was difficult as it was "too tiring". Second, Mukesh highlights the motor difficulties as a result of stroke that make taking public transport particularly difficult.

> There is a gym a bus ride away but I haven't even got on the bus yet. I can do a bit of walking but as soon as you go outside the flat, I can walk inside the flat, but as soon as you are outside on uneven pavements, it is a different kettle of fish

This final theme, "How's it all going to happen?" depicts the logistical issues surrounding who could facilitate a group SMP, and the practicalities of how stroke survivors could attend. The skills and experiences needed by a facilitator are complex, but a combination of professional skills and personal stroke experience was important to participants. The importance of holding group SMPs somewhere convenient was conveyed by most participants and if people cannot get to the venue easily they may be less likely to attend.

Discussion

In total 14 stroke survivors were interviewed for this research and three themes were identified from the data: (1) "A space to share support", (2) 'It's not a one size fits all problem", (3) "How's it all going to happen?" In line with other research [14,21,22], the results suggested that a group SMP may have a number of benefits such as peer support, reduced loneliness and shared problem solving. The novel aspect of a group compared to a one-to-one SMP is the addition of peer support. In this study, we found that stroke survivor views of a group SMP were wide-ranging on the relative merits and challenges of group based SMPs. There were also a number of contextual issues such as when best to implement a group SMP in the stroke recovery pathway.

Our findings are in line with other research which shows stroke survivors acknowledge the benefits afforded from peer support [39,40]. In particular, participants thought that through joint problem solving and peer support they may feel less alone. However, we know from previous work that some stroke survivors are reluctant to talk about their stroke in a group SM setting [40]. This fits

with our finding that there is a great significance placed on the trust and relatability between peers, particularly when sharing personal information in a group of strangers. This in turn highlighted the importance of creating a "safe space" for attendees. One way of doing this is with skilled facilitators who can help manage the group dynamic. Similar to other studies, this study found that having a peer with the same chronic condition facilitating was viewed positively by attendees [23,24,27].

An individual's support network can impact their ability to SM [41]. It is, therefore, unsurprising that we found participants wanted family and friends to be able to attend a group SMP with them. Previous research evaluating two different group SMPs (Living With Stroke, and Moving On After Stroke) found participants felt the presence of family members to be beneficial as it helped them understand what it was like to live with a stroke [25]. Having the opportunity to attend with and without their family members, and having this flexibility built into the provision of group SMPs would be an advantage.

A key area of concern expressed by all participants was surrounding the time to implement a group SMP in a stroke survivor's journey. A previous study investigating perceptions of stroke SMPs in the community suggested participants were not ready to manage themselves immediately after post-discharge from hospital [36]. In contrast, our research found some participants saw discharge from hospital as the optimum time for a group SMP. This could be because the ideal time for a group SMP varies from person to person. Delivering a group SMP at the "wrong" time in an individual's stroke care pathway may be emotionally detrimental to individuals if they are unable to cope with the demands of the program. Therefore, future group SMPs may be most effective using self-referral so each individual can access it when they feel it is the right time in their journey.

Guidelines were followed for the analysis of the data [32], as well as for the design on the study to ensure rigor [34,42]. The description of self-management given to participants was central to the interviews, as were any prior beliefs participant's held about self-management. The former was standardized but the latter could be explored in more depth in future research as this may have influenced the responses. We acknowledge that this group of participants may preference towards those that had made a good level of functional recovery as the study design meant only stroke survivors who could travel to the research venue and had no or very mild aphasia could be included. This is worth considering when designing group SMPs as venue accessibility may create an additional exclusion criteria.

The findings of this study contribute to current knowledge about group SMP's as a mechanism for providing support. Group SMP's were found to be an acceptable format to stroke survivors. These findings inform the development of group SMPs. In particular, the consideration of: how to create a safe space in which stroke survivors feel comfortable, the impact of the facilitators, the need for SMPs to be tailored to the individual, the presence of carers, and the emotional impact of a group SMP. Different ways should be employed to ensure that group SMPs are accessible and relevant to individuals with different levels of recovery and disability from stroke. Following the MRC guidelines for complex interventions [29], the next step in the development is to conduct a feasibility study, the design of which will be informed by the views of stroke survivors expressed in this study.

Conclusion

We have found that stroke survivors can provide valuable insight and ideas about how group self-management programs should be

constructed. In particular, the relative merits and challenges involved in creating a space that can increase the reach to more participants and their friends and families. This work will be used to progress to a feasibility study and the findings from this research can be to inform the design of group SMPs relevant and applicable for people post stroke.

Disclosure statement

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