Title: What are the perceptions and experiences of falls amongst people with stroke who live in the community?

Running Head: Perceptions of falls in stroke

Abstract:

Purpose: To explore the perceptions and experiences of people with stroke living in the community with regard to the perceived causes, impact and solutions to minimise falls.

Method: A qualitative research approach underpinned by a constructivist paradigm utilising a phenomenological methodology. 12 people with stroke participated in focus groups; the data was analysed using thematic analysis.

Results: Three themes and one foundation theme were identified.
1. Trips and Triggers: falls were perceived to be linked to external triggers, one of which was walking aids.
2. Blame and Burden: self-blame and worry about being a burden may be associated with underreporting of falls.
3. Restrict and Reduce: people with stroke restrict activity and reduce participation to manage falls.
The underpinning theme of self-efficacy highlights the apparent diminished falls self-efficacy, and the perception amongst the participants that falls are inevitable.

Conclusions:
This study highlights the perceived negative consequences of falls amongst people with stroke, and the potential contribution of falls to the reduced levels of physical activity often seen following a stroke. Our findings emphasise the need to address falls and balance related self-efficacy alongside strategies to promote safe mobility. A paradigm shift may be needed to highlight potentially modifiable intrinsic risk factors and emphasise the relevance and value of proactive fall prevention to people with stroke.

Keywords:
Accidental falls; stroke; perceptions; qualitative; participation; self-efficacy.

Implications for rehabilitation

- People with stroke may not report falls or may minimise their significance, using alternative terms such as trips and stumbles. Rehabilitation staff need to approach falls in a way that emphasises the positive value of reporting and addressing falls management proactively.
- People with stroke may focus on extrinsic rather than intrinsic factors, so it is important to identify and highlight potentially modifiable intrinsic falls risks during assessment and treatment.
- Falls are associated with the use of mobility aids, and people frequently report using multiple aids obtained from a range of sources. Our study findings suggest that assessment and education about the appropriate use of mobility aids should be integral to stroke-specific falls interventions.
- Falls are often associated with activity reduction and avoidance, which could contribute to reduced participation and increased secondary issues. Approaches to encourage physical activity after stroke need to include recognition of falls risk and methods to optimise safe mobility.
- The relationship between self-efficacy and people's attitudes and responses to falling is an important consideration. It is likely that that self-efficacy strategies could positively contribute to the effectiveness of stroke falls management interventions.

Introduction

Stroke features in the top 10 most prevalent long-term health conditions in England [1] and is the third largest cause of enduring disability in the world [2,3]. People with stroke are nearly twice as likely to fall as their age and gender matched counterparts [4] and their risk of hip fracture is doubled [5]. Falls after stroke can lead to a cycle of injury, distress, fear of falling, deconditioning and increased costs of care [6], and qualitative studies have highlighted the significant impact of falls on independence, activity and participation levels, both early [7] and later [8] after a stroke. Thus, post-stroke falls present a significant concern, both for the individual and wider society.

In order to minimise the negative consequences of falls post-stroke, researchers have investigated the implementation of falls interventions, but systematic reviews are inconclusive as to their effectiveness [9,10]. Research with older people suggests that two hours of challenging balance training per week for six months is considered the optimum

intensity to reduce falls [11]. This level of engagement has been highlighted as a challenge for people with stroke, requiring a high degree of commitment and self-motivation [12]. Researchers who have applied pre-existing treatment programmes that have proved effective for older people to the stroke population have had limited success [13,14]. This could be because stroke-specific factors which are unaddressed by generic programmes are contributing to falls risk [15], or, alternatively issues around programme design and approach may be significant. Within the community-dwelling stroke population, balance self-efficacy is diminished [16], and poor balance self-efficacy is linked with high falls risk and dissatisfaction in community integration [17]. A recent systematic review found that physical activity was effective in enhancing self-efficacy after stroke, with those participants undertaking more intensive, strengthening, balance and functional exercise making greater improvements [18]. This evidence implies that any intervention designed to reduce falls post-stroke needs to account for the complex stroke specific impairments and will need to ensure intensity and duration of engagement is sufficient to bring about meaningful change.

Understanding the challenges faced by people with stroke, and the methods they use to cope with falls in the community, is essential to ensure an intervention provides optimum long-term support and assistance. Despite the prevalence and significance of falls, review findings offer some evidence that people with stroke may not perceive adopting falls prevention strategies as either desirable, or achievable [19]. Similarly, research with older people suggests that they are reluctant to engage with ‘falls prevention’ exercise classes [20] as they do not perceive the relevance [21]. However, ‘lifestyle physical activity’ programmes are viewed more positively [22], and generic exercise within a supportive community environment has been viewed positively by stroke survivors [23].

Given the likelihood that an effective falls prevention programme for stroke will require long-term commitment and significant engagement from participants, it is essential to develop an appreciation of how falls are experienced and viewed, and the factors likely to impact on the success of such a programme are fully explored. This study therefore aimed to gain an in-depth understanding of the perceptions and experiences of falls from the perspective of adult people with stroke living in the community, with regard to the perceived causes, impact and solutions to minimise falls.

Methods

The qualitative paradigm underpinning this study was social constructivism, utilising a phenomenological methodology [24]. An assumption of the constructivist worldview is that individuals actively seek meaning and understanding of the world they live in and their

experiences within it [25]. The use of a phenomenological methodology was selected to achieve the aim of the study by exploring the 'lived experiences' of individuals [26], whilst focus groups were the chosen method of enquiry to capitalise on the opportunity for social interactions amongst the participants to support them to explore their experiences and to collectively develop meaning [27]. The pragmatic decision was made to run three focus groups, aiming to balance the goal of achieving a comprehensive exploration of the phenomenon with the need to undertake a study which was manageable in a constrained time period [28]. All participants gave written informed consent and the study was approved by Plymouth University Faculty of Health and Human Sciences ethics committee (Reference: HS14/15-153).

Participants

A convenience sample of community-dwelling adults with stroke was recruited via awareness raising visits to local support groups, and advertisements distributed through private therapy practices and a stroke support website. People who expressed an interest in participating were provided with the study information sheet, reply slip and consent form: Those replying were screened by telephone call to ensure they met the inclusion criteria (see table 1), and eligible participants were organised into three focus groups depending upon their availability, aiming for a range of three to five participants per group [29]. Having experienced a fall (defined as 'an unexpected event in which the participant comes to rest on the ground, floor or lower level') [30] was **not** part of the inclusion criteria.

Table 1 about here

Data collection

The focus groups were held in a quiet meeting room on university premises, chosen for its accessible location and familiarity to participants. During the focus groups, the primary researcher referenced an interview schedule (table 2) which had been piloted prior to data collection. The meetings were audio-recorded, and a second researcher was present to observe, take field notes and provide a non-attributable record of proceedings whilst the primary researcher was part of the group discussions. In line with guidance, each focus group ran for approximately 60-90 minutes, being allowed to come to a natural close [31].

Table 2 about here

Data analysis

Data were analysed using the systematic, flexible six-phase process of thematic analysis as described by Braun and Clarke (Figure 1) [32]. Recordings were transcribed verbatim by the primary researcher and the transcripts entered into QSR Nvivo v10 [33] to enable efficient data management. Initial codes were developed which linked to the study objectives; these were then grouped and developed into themes in discussion with the second researcher. An inductive approach was used to ensure the themes were data driven rather than matched with a pre-existing framework.

Figure 1 about here

Study quality

In addition to the participants' cultural and historical experiences influencing the discussion, social constructivists recognise that the researcher's own personal experience may influence the interpretation of the data and the inductive generation of meaning [34]. In this study the primary researcher kept a reflexive diary [26], and regular discussions between the researchers were undertaken to explore their assumptions and the potential impact of these on the research. To maximise credibility, one participant from each of the three focus groups was invited to member check the accuracy of the draft main themes [34]. Two of the three participants confirmed that the summary was an accurate representation of the focus group they attended; there was no reply from the third person.

Results

Nineteen people with stroke expressed an interest, however, seven were excluded after screening, leaving a final sample of 12 individuals (see table 3). Most participants were male and had their stroke over 10 years ago, with the time since stroke ranging from four to 17 years. A greater number of the participants were recruited from community stroke groups; all had a history of falls and there were broadly equal numbers of people with right and left sided hemiplegia. Participants had a range of levels of mobility; the majority used a mobility aid of some kind, mostly walking sticks. Only one participant known as *Jackie had a carer with her. *(All participant names have been replaced with a pseudonym to ensure confidentiality but also to maintain an element of personality to each participant).

Table 3 about here.

Three themes were identified which capture the essence of the data and reflect the objectives of the study. These themes are underpinned by one foundation theme of self-efficacy.

Insert figure 2 about here

1. *Trips and Triggers: The nature of impairments and how they contribute to the perceived causes of falls*

Despite all participants reporting multiple falls (according to the accepted definition [30]) during screening, many of the discussions referenced alternative descriptions of falls, such as trips and stumbles.

> *"I see, so, how many falls have you had since your stroke? Approximately…five to ten? Ten to twenty?"* *Researcher*
> *"Something like that. Just tripping… y'know what I mean, catchin' the edge of the curb"* *Terry*
> *"Have they caused you to land on the floor?"* *Researcher*
> *"Aye, a couple of them, yeah"* *Terry*

Participants reported a variety of perceived causes for their trips and falls (see table 4). They also identified that falls often occurred when they were distracted or had lost focus on the task they were carrying out.

> [referring to the supervisor at the gym] *"…somebody who will keep an eye on me and he knows that when I'm on the treadmill… I have the odd stumble on that even, yeah"* Peter
> *"Yeah I can't do that without holding on…"* Doug
> *"…Nor me…"* Peter
> *"…because if I get cocky and try and have a drink and…. Ooof! …. I'm off"* Doug

Insert table 4 about here

Extrinsic factors such as walking aids were frequently perceived to contribute to falls, and were viewed negatively by many participants, perhaps as they highlighted their disability. Several reported using multiple types of walking aid, sourced from various locations.

> *"…I mean, I need my stick to keep my balance - I don't need my stick because I'm a cripple or anything, I just need it to keep my balance"* Mike

> *"I went to the toilet in the middle of the night and I had one of those well, I suppose it is a zimmer frame… normally I went with my stick but on this occasion I thought 'it's here, I will use it', and on the way back there was just a little tiny bump coming from the landing to my door and the wheel got caught and I went over…* Christine

> *"I went to a thing for people who have had survived a stroke… and says 'I think I'm going to have to get one of these 3 wheeler things' and the lady that was a carer said*

'I've got one of those in my garage, my mother had it, she passed on a few years ago and it is in perfect condition'… so she just gave it to me" Jackie

Whilst participants highlighted a range of intrinsic factors contributing to their inability to avoid falling, the majority appeared to focus any falls prevention activities on the modification of extrinsic risk factors.

"See, I have moved everything in my house so I don't trip over it... but I still trip over things" Jackie

2. *Blame and Burden: The impact of falls as experienced by people with stroke.*

People with stroke described risk of falls as a source of concern for both themselves and family members.

"Do your family worry about you falling?" Researcher
"Oh yes, my sons do, they say 'Take more care dad, take more care'. I say 'I do my best'. He is always there for me. Terry

The external impact of falls appeared to be a significant concern amongst participants, who particularly emphasised the potential negative effect of their falls on other people; this appeared to continue throughout the post-stroke journey. However, in some circumstances, participants appeared to downplay or avoid reporting falls, apparently to minimise negative consequences to themselves, such as externally imposed activity limitations.

"I had falls in [hospital] *a number of times. I fell out of bed… it's bad because it is triple paperwork (laughs)….. When I was getting a little bit fitter and I would fall out of bed I would manage to get back in before they* [the nurses] *got to me and they would see a foot or hand coming out from under the screens (laughs) and I would get a wagging finger at me…."* Peter (10 years post stroke)

"Yeah… it worries her [participant's wife] *a bit…. she isn't strong enough to get me on my feet so she will ask somebody, but it worries her and it worries her when we go on holiday. I only go because I know she enjoys her holidays, but I always feel that I am holding her back"* Mike

"So you don't…. I wouldn't tell her if I fell" Doug
[clarifies] *"You wouldn't tell your wife if you fell?"* Researcher
"Well not my arm one because she would say 'what the hell have you done!' …This big bruise… I had to explain that one but not otherwise- she would try and stop me going out" Doug

3. *Restrict and reduce: Peoples' solutions to minimising and managing falls.*

Participants reported adopting a range of strategies in an attempt to manage their falls. Several people with stroke chose to restrict their activity as one strategy.

"Stay still" Jackie

"Drive instead of walk" Elizabeth

Interestingly, as with the impact of falling, the attitudes of family and external individuals appeared to reinforce the use of activity restriction as a method of reducing falls risk.

> *"The trouble is, everybody is looking at you… making sure that you don't do this, or you can't do that, and I'm not allowed to do this… and I'm getting bored because I just want to get on with it…*" Doug

In addition to restricting activity levels, participants suggested behavioural changes such as slowing down, being more careful, being sensible, planning their route, taking rests, only doing one thing at a time and weighing the risk involved with each activity as strategies to manage falls. Practical strategies included asking for help, purchasing a call alarm, adapting the home, using mobility aids and orthotics. Participants appeared to be used to problem-solving, and seemed to value identifying solutions:

> *"I got out of the bath one day and tripped over. I got wedged between the toilet and the radiator and I thought 'What the hell do I do now?' So… I had a shower put in and handrails, they call it a wet room … that is brilliant, now I can look after myself"* *Fred*

Foundation theme of self-efficacy

During analysis, self-efficacy (or participants' personal perceptions and beliefs about their ability to avoid falls during daily activities) appeared to be a recurring theme associated with participants' attitudes to falling and their choices of falls-management strategies. Participants described how falling led to feelings of inadequacy and embarrassment, particularly if falls had happened outside. If a member of the public did see them, participants worried what they would think, and that they would not provide any assistance.

> *"… What do you do after you have fallen?...* Researcher
> *…I think 'What an idiot!' and 'Why did I do it?'"* Terry
>
> *"You have got to realise, it embarrasses you this [the falls], you think 'What the hell has happened to me! I was only taking three steps'…"* Fred
>
> *"It's a pride thing- in town… I fell on my arse and I thought 'this isn't right' and then people walked by…* Ian
> *…They probably thought you were drunk…* Jackie's carer
> *…Yeah! They didn't help me; they said 'He's* [drunk]*'"* Ian

Diminished self-efficacy was particularly apparent when participants discussed blaming themselves for their falls and their belief that falls were an inevitable part of daily life after stroke.

> *"Is there anything that can be done to reduce your falls?...* Researcher
> *…No I don't think so no, they are going to happen on aren't they?...*

Terry

…You will continue to fall, it's just accidental. It's your fault if you stuck your toe on uneven flagstone because you should be looking for it. No, there's nothing that can cure you. Nothing to sort of, prevent you from falling. Everybody falls."

Mike

Discussion

Participants in this study reported relatively negative attitudes to falling and appeared to view falls as an inevitable consequence of having a stroke. There was a general tendency to minimise the focus on falls. In discussions, participants frequently referred to 'trips' and 'stumbles', which would satisfy the accepted definition of a fall [30]. Differences in perspective and meaning of the term 'fall' have been identified previously across cultures, languages and between older people and health professionals [35]. One reason could be that people associate falls with ageing or disability [36], whereas it may be perceived that trips could occur at any time of life. Older people have suggested that the phrase 'falls prevention' implies vulnerability, therefore the term should be avoided in favour of more positive promotion of strength and balance in order to increase uptake to rehabilitation [21, 37]. This is relevant, as the term 'fall' appeared uncomfortable for people with stroke in this study to identify with. In the future, different terminology and the impact of this on attitudes towards falls prevention amongst people with stroke could be explored.

Under-reporting of falls was widespread amongst our participants, which primarily appeared to be due to not wanting to worry family and friends. Studies of older people highlight similar concerns, with reporting falls being perceived to be associated with loss of independence and control [37]. Importantly, participants used vivid descriptions of their experiences of falling whilst in hospital, despite the length of time since their original stroke (e.g. Peter, who described "wagging fingers" from health professionals when he was in hospital following his stroke 10 years previously). In studies of older people, reasons for not reporting falls to healthcare professionals included the perception that they were not a medical problem, were not serious enough to be reported and people not wanting to be a burden on health services [38]. Our study suggests that following a stroke, people may perceive additional reasons to avoid reporting their falls, emphasising that clinicians need to strongly promote the positive benefits of taking a proactive response to falls to encourage people to report them. This may require work to change attitudes to falls amongst people with stroke, carers and healthcare professionals, for example as suggested by Buetow et al in their recent paper relating to falls in Parkinson's disease [39].

In agreement with other studies [40,41], despite demonstrating an awareness of intrinsic risk factors, our participants primarily focussed on extrinsic triggers as the main causes and potentially modifiable contributors to falls. It has been proposed that this may be because extrinsic factors are perceived as more controllable than intrinsic changes [42], however, it may also add evidence to the suggestion that peoples' response to falling is influenced by their struggle to acknowledge internal limitations associated with their stroke [19]. Given that addressing modifiable intrinsic factors is likely to be a central tenet of falls interventions, supporting people to recognise and prioritise these is essential. This is particularly important given the likelihood that interventions will require considerable investment of time, energy and commitment by participants.

The role of mobility aids in preventing or contributing to falls is an important consideration. Despite negative attitudes towards them and frequently citing them as a contributing factor to falls, our participants often reported using multiple walking aids. Whilst walking aids are recommended to improve mobility after stroke [43], it is recognised that they may increase risk of falls [44]. The use of multiple aids amongst people with stroke is common [45], and it is possible that this may further contribute to risk, as has been highlighted amongst people with Multiple Sclerosis [46]. In addition, many participants reported obtaining aids from 'non-traditional' sources. The sharing of old mobility aids that may not be safe or suitable may reduce their effectiveness [47] and is likely to further increase falls risk. Our study findings suggest that assessment and education about the appropriate use of mobility aids should be integral to stroke-specific falls interventions.

Avoidance related behaviours and activity reduction were common responses to falls in this study. Whilst reducing activity and restricting participation may avoid falls in the short-term, there are significant long-term consequences with this approach. Individuals who have had a stroke are less physically active than their age matched counterparts [48], and the implications of restricting activity are dramatic, both for healthcare use and costs [49] and for the individuals' health, function and quality of life [50]. A tendency to restrict activity may negatively impact people's willingness to engage with the exercise-based activities which are likely to be an essential component of a stroke-specific falls intervention, as well as preventing secondary complications associated with sedentary behaviour. The phenomenon of carers encouraging activity reduction to reduce falls is supported in the literature [9], however, this may lead to an additional cycle of secondary deconditioning, increasing dependence and reduced community participation. The presumption that falls equate to restriction of activity appears to be one reason why older people can feel hostile to the concept of falls prevention [51]. Therefore, supporting the individual who has had a stroke

and their carers and family members to collaboratively develop empowering and enabling strategies to falls management [1] rather than simply restricting activity will be essential.

The relationship between self-efficacy and people's attitudes and responses to falling is an important consideration. Following stroke, low self-efficacy is a known risk factor for recurrent falls and deteriorating quality of life [52], whilst higher self-efficacy is linked with greater functional independence and reduced incidence of falls [53]. In our study, participants consistently expressed negative perceptions of falls, and an external locus of control in their response to falling was a recurrent theme which is highly suggestive of poor self-efficacy. It is likely that such nihilistic attitudes amongst our participants would significantly affect their enthusiasm to engage with falls management interventions, as well as the likelihood of them achieving the greatest benefit from a programme. However, the positive responses from participants when they reported successfully solving problems to reduce falls risk is encouraging. A systematic review has indicated that stroke specific self-management programmes may be effective in improving confidence and self-efficacy [54]. The included interventions were not falls-specific, and the review was unable to indicate optimal content, theory or outcomes due to the variety of programmes being offered, however it is encouraging, and suggests that self-efficacy strategies could positively contribute to the effectiveness of stroke falls management interventions.

A strength of this study is that its primary aim was to gain and in-depth understanding of the perceptions and experiences of falls amongst people with stroke. However, there are a number of limitations. Firstly, all participants involved in this study were considered cognitively unaffected by their stroke, had sufficient communication skills to interact in a focus group and none were housebound or wheelchair dependant. Therefore, this study represents the perceptions and experiences of a relatively narrow group of participants. Specifically engaging subgroups of the community stroke population could be one potential method of expanding this study in future, as would utilising alternative methods (such as one-to-one interviews), which would enable those who would struggle to engage fully in a group setting to participate.

Secondly, although we aimed to recruit people from across the spectrum, it is possible that our recruitment strategy (specifically, publicising the study primarily through long-term community support groups rather than in more acute settings) led to some bias, as the average time since stroke amongst our participants was 13 years. This reduces the transferability of our findings; for example, falls amongst people just going home after a stroke are likely to be associated with different mechanisms to those who have had their

stroke a long time ago. Falls risk factors are also likely to differ, and it is also probable that perceptions and attitudes change significantly over time. Therefore, our findings should be interpreted with caution, and further work to explore the experiences of people whose stroke was more recent is important. Additionally, whilst we aimed to maximise diversity within each focus group, logistical considerations meant that this was not entirely achieved. Due to the necessity to share transport, the first focus group included three male friends who were all ambulant with left sided weakness. It could be argued that pre-existing relationships may have had a polluting or inhibiting effect on the discussion due to pre-established norms and hierarchies [55]. However, by exploring the perceptions of people who were in some cases, already acquainted, the researcher was able to examine issues and decisions made by individuals in a naturally occurring group. Therefore, perhaps the level of honesty and opinions shared were enhanced by pre-existing relationships in this group.

Finally, carers were not invited to take part in this study, although one carer did spontaneously attend the second focus group to support a participant, and also contributed to the discussions. Exploring the views and perceptions of falls from a carer's perspective is essential, particularly given the importance placed on the impact of falls on others by our participants. Carer involvement, engagement and burden are all significant factors affecting engagement with rehabilitation interventions [56] and this would be particularly significant in a falls programme, which would be likely to require a substantial amount of individual practice.

Conclusions

This study suggests that people with stroke perceive falls as a source of embarrassment and frustration, and to be associated with restriction of activity and participation. It is important that open and honest discussions involving people with stroke, carers and professionals address falls as a manageable issue, and encourage open reporting of falls. Whilst our participants represent a small proportion of the spectrum, the need to promote falls and balance related self-efficacy is a recurring theme which is likely to impact all aspects of falls management for people who have had a stroke. Further research is needed to explore how this may be best achieved, particularly in the context of stroke-specific falls management interventions.

4263 words

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References

[1] Department of Health; Long Term Conditions Compendium of Information 3rd edn. [Internet] [updated 2012, cited 2015 June 05] Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216528/dh_134486.pdf

[2] Ma VY, Chan L, Carruthers KJ. 2014. Incidence, prevalence, costs, and impact on disability of common conditions requiring rehabilitation in the united states: Stroke, spinal cord injury, traumatic brain injury, multiple sclerosis, osteoarthritis, rheumatoid arthritis, limb loss, and back pa. Archives of Physical Medicine and Rehabilitation. p. 986–995.e1.

[3] NICE; Stroke rehabilitation – long-term rehabilitation after stroke [Internet] [updated 2013, cited 2015 June 10] Available from http://www.nice.org.uk/guidance/cg162/resources/guidance-stroke-rehabilitation-pdf

[4] Simpson, LA., Miller, WC., Eng, JJ. Effect of stroke on fall rate, location and predictors: a prospective comparison of older adults with and without stroke PLoS ONE. 2011; 6 (4) e19431.

[5] Pouwels, S., Lalmohamed, A., Leufkens, B., De Boer, A., Cooper, C., Van Staa, T., De Vries, F. Risk of hip/femur fracture after stroke: a population-based case-control study. Stroke 2009; 40; 3281–3285.

[6] Friedman, SM., Munoz, B., West, SK., Rubin, GS., Fried, LP. Falls and fear of falling: which comes first? A longitudinal prediction model suggests strategies for primary and secondary prevention. J Am Geriatr Soc 2002; 50 (8) 1329–1335.

[7] Schmid AA, Rittman M. 2009. Consequences of post-stroke falls: Activity limitation, increased dependence, and the development of fear of falling. Am J Occup Ther. 63(3):310–6.

[8] Schmid AA, Arnold SE, Jones VA, Ritter MJ, Sapp SA, Van Puymbroeck M. 2015. Fear of falling in people with chronic stroke. Am J Occup Ther. 69(3):1–5.

[9]. Verheyden, GSAF., Weedestyn, V., Pickering, RM., Kunkel, D., Lennon, S., Geurts, ACH., Ashburn, A. Interventions for preventing falls in older people after stroke (Review) [Internet] [updated 2013; cited 2015 January 10] Available from: www.thecochranelibrary.com

[10] Batchelor, F., Hill, K., Mackintosh, S., Said, C. What works in Falls Prevention after stroke? A systematic review and meta-analysis Stroke 2010; 41, 1715.

[11] Sherrington, C., Tiedemann, A., Fairhall, N., Close, JCT., Lord, SR. Exercise to prevent falls in older adults: an updated meta-analysis and best practice recommendations New South Wales public health bulletin 2011; 22 (3-4) 78-83.

[12] Nyman SR, Victor CR. Older people's participation in and engagement with falls prevention interventions in community settings: an augment to the Cochrane systematic review. Age Ageing. 2012; 41(1) 16–23.

[13] Batchelor, FA., Hill, KD., Mackintosh, SF., Said, CM., Whitehead, CH. Effects of a multifactorial falls prevention program for people with stroke returning home after rehabilitation: a randomised controlled trial Archives of Physical Medicine Rehabilitation 2012; 93 1648-1655.

[14] Dean, CM., Rissel, C., Sherrington, C., Sharkey, M., Cumming, RG., Lord, SR., Barker, RN., Kirkham, C., O'Rourke, S. Exercise to enhance mobility and prevent falls after stroke: the community stroke club randomised controlled trial. Neurorehabilitation and Neural Repair 2012; 26 1046-1057.

[15] Weerdestyn, V., Niet, MD., Dujinhoven, HJR., Geurts, ACH. Falls in individuals with stroke' Journal of Rehabilitation Research & Development 2008; 45 (8) 1195-1214.

[16] Salbach, N., Mayo, N., Robichaud-Ekstrand, S., Hanley, J., Richards, C., Wood-Dauphinee, S. Balance self-efficacy and its relevance to physical function and perceived health status after stroke. Archives of Physical Medicine and Rehabilitation 2006; 87 (3) pp. 364- 70.

[17] Pang, MYC., Eng, JJ., Miller, WC. Determinants of satisfaction with community integration in older adults with chronic stroke: role of balance self-efficacy' Physical Therapy 2007; 87 282 – 291.

[18] Tang, A., Tao, A., Soh, M., Tam, C., Tan, H., Thompson, J., Eng, JJ. The effect of interventions on balance self-efficacy in the stroke population: a systematic review and meta-analysis' Clinical Rehabilitation 2015; 29 (12) 1168-1177.

[19] Walsh M, Galvin R, Horgan NF. 2017. Fall-related experiences of stroke survivors: a meta-ethnography. Disability and Rehabilitation. p. 631–40.

[20] Whitehead, C. H., Wundke, R. and Crotty, M. Attitudes to falls and injury prevention: what are the barriers to implementing falls prevention strategies? Clinical rehabilitation, 2006; 20(10) pp. 536–542.

[21] Yardley, L., Bishop, FL., Beyer, N., Hauer, K., Getrudis, I., Kempen, JM., Piot-Ziegler, C., Todd, CJ., Cuttelod, T., Horne, M., Lanta, K., Rossell Holt, A. Older people's views of falls prevention interventions in six European countries The Gerontologist 2006; 46 (5) 650-660.

[22] Clemson L, Fiatarone MA. 2012. Integration of balance and strength training into daily life activity to reduce rate of falls in older people (the LiFE study): randomised parallel trial. BMJ. 4547(August) 1–15.

[23] Reed, M., Harrington, R., Duggan, A., Wood, VA. Meeting stroke survivors' perceived needs: a qualitative study of a community-based exercise and education scheme Clinical Rehabilitation 2010; 24 16-25.

[24] Creswell JW, Poth C. Qualitative inquiry and research design: choosing among five approaches. London: SAGE Publications; 2017.

[25] Pope, C., Mays, N. Qualitative methods in health research' in Pope, C., Mays, N. Qualitative Research in Health Care. London: BMJ Publishing Group; 1999.

[26] Cresswell, JW. Research design – qualitative, quantitative and mixed methods approaches 4th edn. International student edition. London: SAGE Publications; 2014.

[27] Kitzinger, J. Focus groups with users and providers of health care in Pope, C., Mays, N. Qualitative Research in Health Care. London: BMJ Publishing Group; 1999.

[28] Pope C, Ziebland S, Mays N. 2000. Qualitative research in health care. Analysing qualitative data. BMJ. 320(7227):114–6.

[29] Morgan, DL. Focus Groups Annual review of Sociology 1996; 22 129-152.

[30] Lamb, S. E., Jørstad-Stein, E. C., Hauer, K., Becker, C. Development of a common outcome data set for fall injury prevention trials: The Prevention of Falls Network Europe consensus Journal of the American Geriatrics Society, 2005; 53, 1618–1622.

[31] Kreuger, RA., Casey, MA. Focus groups: a practical guide for applied research 4th Ed. Thousand Oaks CA: SAGE Publications; 2009.

[32] Braun, V., Clarke, V Successful qualitative research: a practical guide for beginners. London: SAGE Publications; 2013.

[33] QSR International 2012 Nvivo 10 [Internet] [updated 2015; cited 2015 August 10]. Available from https://ict-webtools.plymouth.ac.uk/workathome/QSR/NVivo10.aspx

[34] Cresswell, JW. Research design – qualitative, quantitative and mixed methods approaches 4th edn. International student edition. London: SAGE Publications; 2014.

[35] Ballinger, C., Payne, S. Falling from grace or into experts' hands? Alternative accounts about falling in older people. British Journal of Occupational Therapy 2000; 63, 573–579.

[36] Bunn, F., Dickinson, A., Barnett-Page, E., McInnes, E., Horton, K. A systematic review of older people's perceptions of facilitators and barriers to participation in falls prevention interventions. Ageing and Society 2008; 28 (4) 449-472.

[37] Clark, L., Thoreson, S., Goss, CW., Marquez Zimmer, L., Marosits, M., DiiGuiseppi, C. Understanding fall meaning and context in marketing balance classes to older adults Journal of Applied Gerontology 2013; 32 (1) 96-119.

[38] Dickinson, A., Horton, K., Machen, I., Bunn, F., Cove, J., Jain, D., Maddex, T. The role of health professionals in promoting the uptake of fall prevention intervention: a qualitative study of older peoples views Age and Ageing 2011; 40 724-730.

[39] Buetow SA, Martínez-Martín P, McCormack B. 2017. Falling upward with Parkinson's disease. Nature Partner Journals Parkinson's Disease. 3(1):29.

[40] Schmid, AA., Klar Yaggi, H., Burrus, N., McClain, V., Austin, C., Ferguson, J., Fragoso, C., Sico Jason, J., Miech Edward, J., Matthias Marianne, S., Williams Linda, S., Bravata Dawn, M. Circumstances and consequences of falls among people with chronic stroke. Journal of Rehabilitation Research & Development 2013; 50 (9) 1277–1285.

[41] Nyberg, L., Gustafson, Y. Patient falls in stroke rehabilitation. A challenge to rehabilitation strategies. Stroke 1995; 26 838-42.

[42] Horton, K. Gender and the risk of falling: A sociological approach. Journal of Advanced Nursing 2007; 57 69–76.

[43] Laufer Y. The use of walking aids in the rehabilitation of stroke patients. Rev Clin Gerontol. 2004; 2 137-44.

[44] Tilson, JK., Wu, SS., Cen, SY., Feng, Qiushi., , DR., Behrman, AL., Azen, SP., Duncan, PW. Characterizing and Identifying Risk for Falls in the IEAPS study – a randomized clinical trial of interventions to improve walking post-stroke. Stroke 2012; 43 446-452.

[45] Intercollegiate Stroke Working Party (ISWP) National Clinical Guideline for Stroke, 4th ed. [Internet] [updated 2012; cited 2015 June 07]. Available from https://www.rcplondon.ac.uk/sites/default/files/national-clinical-guidelines-for-stroke-fourth-edition.pdf

[46] Finlayson, ML., Peterson, EW., Asano, M. A cross-sectional study examining multiple mobility device use and fall status among middle-aged and older adults with multiple sclerosis. Disability Rehabilitation Assistive Technology 2014; 9 (1) 12-6.

[47] Elmamoun, M., Mulley, G. Walking sticks and frames for patients with neurological disorders. Practical Neurology 2007; 7 24-31.

[48]. Ivey, FM., Hafer-Macko, CE., Macko, RF. Exercise Rehabilitation After Stroke. NeuroRX 2006; 3 (4) 439-50.

[49] Gill, TM., Desai, MM., Gahbauer, EA., Holford, TR., Willimas, CS. Restricted activity among community living older persons: incidence, precipitants and healthcare utilisation Annals of Internal Medicine 2001; 135 (5) pp. 313-321.

[50] Department of Health. National Stroke Strategy [Internet] [updated 2007; cited 2015 June 10] Available from: http://clahrc-gm.nihr.ac.uk/cms/wp-content/uploads/DoH-National-Stroke-Strategy-2007.pdf

[51] Yardley, L., Donovan-Hall, M., Francis, K., Todd C. Older people's views of advice about falls prevention: a qualitative study Health Education Research 2005; 21 (4) 508-517.

[52] Pang MYC, Eng JJ Fall-related self-efficacy, not balance and mobility performance is related to accidental falls in chronic stroke survivors with low bone mineral density Osteoporosis Int 2008; 19 7 919-27.

[53] Hellstrom, K., Lindmark, B., Wahlberg, B., Fugl-Meyer, AR. Self-efficacy in relation to impairments and activities of daily living disability in elderly patients with stroke: a prospective investigation Journal of Rehabilitation and Medicine. 2003; 35 202-207.

[54] Lennon, S., McKenna, S., Jones, F. Self-management programmes for people post stroke: a systematic review Clinical Rehabilitation 2013; 27: 10 867-878.

[55] Kitzinger, J., Barbour, RS. Introduction: the challenge and compromise of focus groups in Barbour, RS., Kitzinger, J. Developing focus group research. London: SAGE Publications; 1999.

[56] Lutz, B., Chumbler, N., Lyles, T., Hoffman, N. Testing a home telehealth programme for US veterans recovering from stroke and their family caregivers'. Disability and Rehabilitation 2009; 31 (5) 402 – 409.

Figure captions

Figure 1: thematic analysis

Figure 2: themes in the data

Tables:

Table 1

Inclusion criteria
Diagnosed with a stroke
Live in the community
Able to communicate to be able to participate in a focus group
Cognitively intact
Able to travel to attend focus group

Table 1: Inclusion criteria

Table 2

Introduction and welcome
Experiences of falls
Frequency
Consequences
Response
Perceptions of falls
Causes
Risk factors
Impact of falls
Activities/ Participation
Concerns re: future falls

Changes to reduce risk **Any other comments** **Thanks and close**

Table 2: Focus group discussion guide

Table 3

*Participant pseudonym	Gender	History of falls	Recruitment source	Age *	Time since first stroke *	Hemi Side	Current level of mobility
Included participants:							Total included: 12
A. Terry	M	Y	TSA	78	17	Left	Mobile WS
A. Fred	M	Y	TSA	73	17	Left	Mobile WS
A. Mike	M	Y	TSA	66	13	Left	No aid
B. Ian	M	Y	TSA	56	16	Right	Mobile WS
B. Christine	F	Y	TSA	84	11	Left	Mobile 3WW
B. Jackie	F	Y	TSA	48	4	Right	Transfers with 1 + PWC
B. Dom	M	Y	PP	62	5	Right	Mobile WS
C. Doug	M	Y	TSA	73	14	Left	Mobile WS+S
C. Ness	F	Y	TSA	74	13	Left	Mobile WS
C. Elizabeth	F	Y	TSA	60	4	Right	No aid
C. Peter	M	Y	PP	77	10	Left	Mobile WS+S
C. Sandra	F	Y	TSA	50	13	Right	No aid
Excluded participants (with reasons):							Total excluded: 7

-Diagnosed with a TIA rather than stroke	2
-Unable to communicate verbally to be able to participate in a focus group	1
-Confused	1
-Carer unwell - unable to travel to attend focus group	2
-Too busy	1

*years; M: male; F: female. Y: yes; N; no. TSA: The Stroke Association; PP: private practice. WS: with stick; WS+S: with stick and scooter; WC: wheelchair; 3WW: 3 wheeled walker; PWC: powered wheelchair.

Table 3: Participant demographics

Table 4

Intrinsic	Extrinsic
stroke-specific issues including: balance deficits, muscle weakness, reduced co-ordination, the feeling of legs giving way, fatigue, memory and confidence.	furniture (type and configuration), uneven pavements/ flooring, steps, busy crowds, slopes, in/out of car, noisy environments, walking aids.

Table 4: summary of risk factors for falling identified by participants.

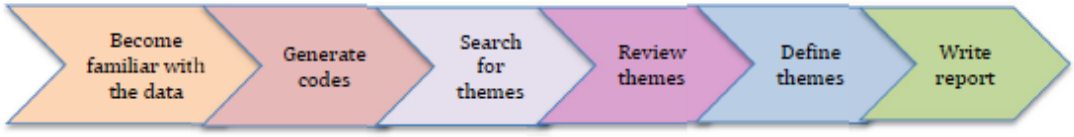

Figure 1: The six phases of thematic analysis adapted from Braun and Clarke [28].

Figure 2: Themes captured in the data