



PEARL

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

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Published in:

Disability and Rehabilitation

DOI:

[10.1080/09638288.2018.1510047](https://doi.org/10.1080/09638288.2018.1510047)

Publication date:

2018

Link:

[Link to publication in PEARL](#)

Citation for published version (APA):

Munford, D., & Gunn, H. (2018). What are the perceptions and experiences of falls amongst people with stroke who live in the community? *Disability and Rehabilitation*, 0(0). Advance online publication. <https://doi.org/10.1080/09638288.2018.1510047>

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

3

4 **Running Head: Perceptions of falls in stroke**

5 **Abstract:**

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

8

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

12

13 **Results:** Three themes and one foundation theme were identified.

14 1. Trips and Triggers: falls were perceived to be linked to external triggers, one of which was
15 walking aids.

16 2. Blame and Burden: self-blame and worry about being a burden may be associated with
17 underreporting of falls.

18 3. Restrict and Reduce: people with stroke restrict activity and reduce participation to
19 manage falls.

20 The underpinning theme of self-efficacy highlights the apparent diminished falls self-efficacy,
21 and the perception amongst the participants that falls are inevitable.

22

23 **Conclusions:**

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

30

31

32 **Keywords:**

33 Accidental falls; stroke; perceptions; qualitative; participation; self-efficacy.

34

1 **Implications for rehabilitation**

2

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

21

22 **Introduction**

23

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

32

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

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

15
16 Understanding the challenges faced by people with stroke, and the methods they use
17 to cope with falls in the community, is essential to ensure an intervention provides optimum
18 long-term support and assistance. Despite the prevalence and significance of falls, review
19 findings offer some evidence that people with stroke may not perceive adopting falls
20 prevention strategies as either desirable, or achievable [19]. Similarly, research with older
21 people suggests that they are reluctant to engage with 'falls prevention' exercise classes [20]
22 as they do not perceive the relevance [21]. However, 'lifestyle physical activity' programmes
23 are viewed more positively [22], and generic exercise within a supportive community
24 environment has been viewed positively by stroke survivors [23].

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

32

33 **Methods**

34

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

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

11

12 **Participants**

13

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

23 *Table 1 about here*

24

25 **Data collection**

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

33 *Table 2 about here*

34 **Data analysis**

35

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

8
9 *Figure 1 about here*

10 11 **Study quality**

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

21 22 23 **Results**

24 Nineteen people with stroke expressed an interest, however, seven were excluded
25 after screening, leaving a final sample of 12 individuals (see table 3). Most participants were
26 male and had their stroke over 10 years ago, with the time since stroke ranging from four to
27 17 years. A greater number of the participants were recruited from community stroke
28 groups; all had a history of falls and there were broadly equal numbers of people with right
29 and left sided hemiplegia. Participants had a range of levels of mobility; the majority used a
30 mobility aid of some kind, mostly walking sticks. Only one participant known as *Jackie had a
31 carer with her. *(All participant names have been replaced with a pseudonym to ensure
32 confidentiality but also to maintain an element of personality to each participant).

33
34
35 *Table 3 about here.*

36

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

4 *Insert figure 2 about here*

5

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

8

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

12

13 *"I see, so, how many falls have you had since your stroke? Approximately...five to*
14 *ten? Ten to twenty?"* *Researcher*

15 *"Something like that. Just tripping... y'know what I mean, catchin' the edge of the*
16 *curb"* *Terry*

17 *"Have they caused you to land on the floor?"* *Researcher*

18 *"Aye, a couple of them, yeah"* *Terry*

19

20

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

24 [referring to the supervisor at the gym] *"...somebody who will keep an eye on me*
25 *and he knows that when I'm on the treadmill... I have the odd stumble on that even,*
26 *yeah"* *Peter*

27 *"Yeah I can't do that without holding on..."* *Doug*

28 *"...Nor me..."* *Peter*

29 *"...because if I get cocky and try and have a drink and.... Ooof! I'm off"*

30 *Doug*

31

32 *Insert table 4 about here*

33 Extrinsic factors such as walking aids were frequently perceived to contribute to falls, and
34 were viewed negatively by many participants, perhaps as they highlighted their disability.

35 Several reported using multiple types of walking aid, sourced from various locations.

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

38

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

43 *Christine*

44

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

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

3

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

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

9

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

11

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

14 *"Do your family worry about you falling?"* Researcher

15 *"Oh yes, my sons do, they say 'Take more care dad, take more care'. I say 'I do my*
16 *best'. He is always there for me.* Terry

17

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

23

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

30

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

35

36 *"So you don't.... I wouldn't tell her if I fell"* Doug
37 [clarifies] *"You wouldn't tell your wife if you fell?"* Researcher

38 *"Well not my arm one because she would say 'what the hell have you done!' ...This*
39 *big bruise... I had to explain that one but not otherwise- she would try and stop me*
40 *going out"* Doug

41

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

43 Participants reported adopting a range of strategies in an attempt to manage their falls.

44 Several people with stroke chose to restrict their activity as one strategy.

45

1 "Stay still" Jackie

2
3 "Drive instead of walk" Elizabeth

4
5 Interestingly, as with the impact of falling, the attitudes of family and external individuals
6 appeared to reinforce the use of activity restriction as a method of reducing falls risk.

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

10
11 In addition to restricting activity levels, participants suggested behavioural changes such as
12 slowing down, being more careful, being sensible, planning their route, taking rests, only
13 doing one thing at a time and weighing the risk involved with each activity as strategies to
14 manage falls. Practical strategies included asking for help, purchasing a call alarm, adapting
15 the home, using mobility aids and orthotics. Participants appeared to be used to problem-
16 solving, and seemed to value identifying solutions:

17 "I got out of the bath one day and tripped over. I got wedged between the toilet and
18 the radiator and I thought 'What the hell do I do now?' So... I had a shower put in and
19 handrails, they call it a wet room ... that is brilliant, now I can look after myself"
20 Fred
21

22 **Foundation theme of self-efficacy**

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

29 "... What do you do after you have fallen?... Researcher
30 ...I think 'What an idiot!' and 'Why did I do it?'" Terry

31
32 "You have got to realise, it embarrasses you this [the falls], you think 'What the hell
33 has happened to me! I was only taking three steps'..." Fred
34

35 "It's a pride thing- in town... I fell on my arse and I thought 'this isn't right' and then
36 people walked by..." Ian

37 ...They probably thought you were drunk... Jackie's carer

38 ...Yeah! They didn't help me; they said 'He's [drunk]'" Ian
39
40

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

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

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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].

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

11

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

23

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

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

3
4 The relationship between self-efficacy and people's attitudes and responses to falling is an
5 important consideration. Following stroke, low self-efficacy is a known risk factor for
6 recurrent falls and deteriorating quality of life [52], whilst higher self-efficacy is linked with
7 greater functional independence and reduced incidence of falls [53]. In our study,
8 participants consistently expressed negative perceptions of falls, and an external locus of
9 control in their response to falling was a recurrent theme which is highly suggestive of poor
10 self-efficacy. It is likely that such nihilistic attitudes amongst our participants would
11 significantly affect their enthusiasm to engage with falls management interventions, as well
12 as the likelihood of them achieving the greatest benefit from a programme. However, the
13 positive responses from participants when they reported successfully solving problems to
14 reduce falls risk is encouraging. A systematic review has indicated that stroke specific self-
15 management programmes may be effective in improving confidence and self-efficacy [54].
16 The included interventions were not falls-specific, and the review was unable to indicate
17 optimal content, theory or outcomes due to the variety of programmes being offered,
18 however it is encouraging, and suggests that self-efficacy strategies could positively
19 contribute to the effectiveness of stroke falls management interventions.

20
21 A strength of this study is that its primary aim was to gain an in-depth understanding of the
22 perceptions and experiences of falls amongst people with stroke. However, there are a
23 number of limitations. Firstly, all participants involved in this study were considered
24 cognitively unaffected by their stroke, had sufficient communication skills to interact in a
25 focus group and none were housebound or wheelchair dependant. Therefore, this study
26 represents the perceptions and experiences of a relatively narrow group of participants.
27 Specifically engaging subgroups of the community stroke population could be one potential
28 method of expanding this study in future, as would utilising alternative methods (such as
29 one-to-one interviews), which would enable those who would struggle to engage fully in a
30 group setting to participate.

31
32 Secondly, although we aimed to recruit people from across the spectrum, it is possible that
33 our recruitment strategy (specifically, publicising the study primarily through long-term
34 community support groups rather than in more acute settings) led to some bias, as the
35 average time since stroke amongst our participants was 13 years. This reduces the
36 transferability of our findings; for example, falls amongst people just going home after a
37 stroke are likely to be associated with different mechanisms to those who have had their

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

13

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

22

23 **Conclusions**

24

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

34

35 4263 words

36

37

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1 **Figure captions**

2 Figure 1: thematic analysis

3

4 Figure 2: themes in the data

5

6 **Tables:**

7

8 **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 |

9

10 Table 1: Inclusion criteria

11

12

13 **Table 2**

14

15

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

1

2 Table 2: Focus group discussion guide

3

4 **Table 3**

5

| *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 |

1

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

5

6 Table 3: Participant demographics

7

1 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. |

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

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4

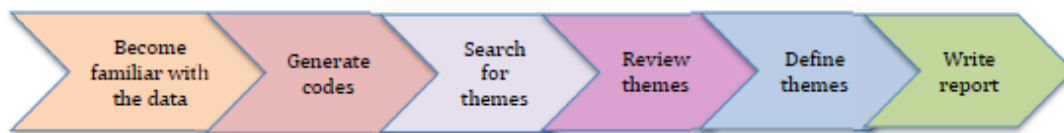
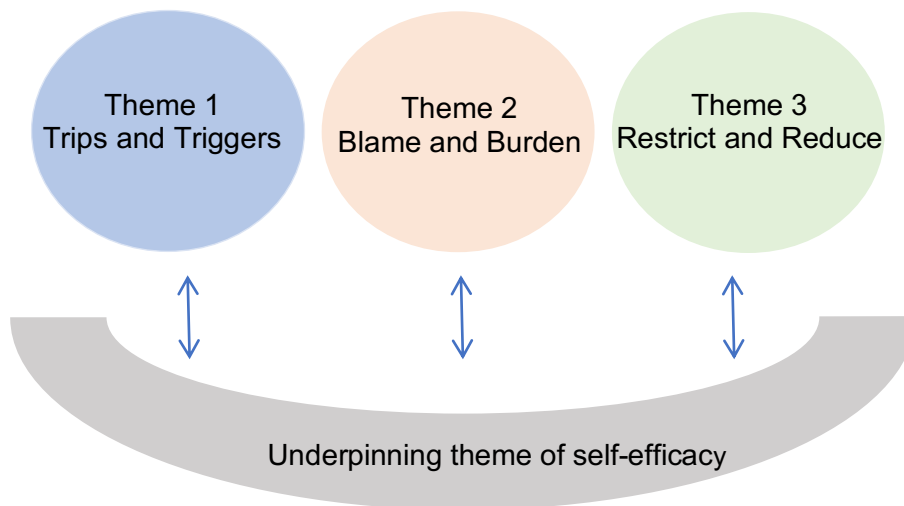


Figure 1: The six phases of thematic analysis adapted from Braun and Clarke [28].

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Figure 2: Themes captured in the data



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