

The experience of recurrent fallers in the first year after stroke

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The experience of recurrent fallers in the first year after stroke

Purpose: Understanding the experiences of fallers after stroke could inform falls-prevention interventions, which have not yet shown effectiveness in this population. The aim of this study was to explore the experience of recurrent fallers post stroke in relation to recovery and living with falls. **Methods:** Participants who had more than one fall in the first year after stroke were identified from a prospective cohort study. The methods of Grounded Theory informed data collection and analysis. Semi-structured interviews were conducted, audio-recorded and transcribed. Coding was conducted and categories were developed inductively. **Results:** Nine stroke survivors aged 53–85 were interviewed 18–22 months post-discharge. Participants had experienced between 2 and 9 falls and one participant suffered a fracture. Three inter-linked categories were identified: i) Judging the importance of falls by exploring cause and consequence, ii) getting back up, and iii) being careful. **Conclusions:** Stroke survivors' assessment of their own falls-risk and their individual priorities contribute to their decisions around activity participation. 'Being careful' could be described as a form of self-managing falls-risk. The inclusion of self-management principles, peer-educators and education to rise from the floor in falls-management programmes warrants investigation. Not all falls were considered equally important by participants. This could be considered when defining falls-related outcomes.

Keywords: stroke, qualitative research, fear of falling, accidental falls, Grounded Theory

Introduction

Falls are a common adverse event during stroke recovery [1]. Adults with stroke fall at almost twice the rate of their peers in the first year after discharge and approximately 5% experience fractures or serious injuries [1,2]. Falls-risk assessment is recommended to facilitate post-stroke falls-prevention [3]. Quantitative research aiming to predict post-stroke falls has been unsuccessful to date and some researchers suggest that all individuals with residual stroke deficits should be considered at increased risk of falling [4,5]. Interventions that have been shown to reduce falls in older community-dwelling adults have shown minimal effectiveness at reducing post-stroke falls [6]. Understanding the experience of fallers with stroke could help to inform the development and testing of new interventions.

Limited qualitative research has explored the topic of falls among stroke survivors, with a recent systematic review identifying only six studies [7]. This review suggested that fear of falling and other barriers to community participation could be overcome through caregiver support and assistive devices, but that stroke survivors may struggle to accept increased dependence [7]. Most qualitative research in this area selected participants who expressed concern about falls or mobility [8-10]. For this reason, individuals who may have experienced falls but did not consider them to be important may have been excluded. Participant selection based on the occurrence of actual fall events could help to explore the spectrum of post-stroke fall experiences. The aim of this study was to explore the experiences of stroke survivors who have fallen more than once in the first year post-discharge in relation to recovery and living with falls.

Methods

Theoretical perspective

Grounded Theory, as described by Corbin and Strauss, informed the methods of data collection and analysis within this study [11]. The overall research aim was to inform clinical decision-making around post-stroke falls by providing a voice to stroke survivors. The qualitative analysis was therefore conducted from a position empathic to participants' accounts rather than clinicians' or family members' perspectives [12].

Sampling

Stroke survivors with recurrent falls were identified from a longitudinal cohort study. In the cohort study consecutive patients with acute stroke, with sufficient cognitive (MMSE >18) and communicative ability to provide informed consent, and with a planned discharge home were recruited between December 2013 and June 2014. Prior to discharge home and six-months later, they completed physical assessments of gait and balance and questionnaires related to mood and fear of falling. Fall diaries were kept for 12 months. In the cohort study 128 participants were recruited, 110 were followed for one year and 28 (25%) fell more than once. Ethical approval was sought from three of the original 5 sites to conduct in-depth interviews and for this reason 20 recurrent fallers were eligible for recruitment to this qualitative study. Six participants were purposefully sampled to ensure a mix across the following domains: sex, age group and functional ability. Subsequently, six further participants were theoretically sampled in order to develop emerging code categories [11]. Thus 12 individuals were contacted by telephone between September and November 2015. One declined and two became unavailable prior to interview.

Data collection

Nine participants were interviewed once, eight in their own homes and one in a meeting room in the first author's third level institution by their own choice.

Interviews were conducted face-to-face by the first author who is a physiotherapist and was known to participants from the cohort study. Interviews lasted approximately 45 minutes. Interviews were semi-structured. Participants were first asked an open question about recovery since stroke. A question focussing on falls was then asked without implying importance. A topic guide (see Appendix) was used to explore particular elements of the research question including why some falls may be important to participants and the part played by family and healthcare professionals in their experience. Some additional open-ended questions allowed for development of emerging categories during later interviews. Interviews were audio-recorded.

Observational field notes and memos were completed immediately after each interview. A carer was present for only one interview at the stroke survivor's request

Ethical considerations

The study received approval from the hospital Research Ethics Committees. Written informed consent was obtained from participants. All participants agreed to audio-recording prior to each interview and they were informed of their right to review transcripts. Identifying information was removed from transcripts. The interviewer remained cognisant of the potential for emotional distress and offered participants contact details for support organisations if necessary.

Data analysis

Audio-recordings were transcribed verbatim and each was analysed prior to conducting subsequent interviews. Transcripts were analysed line-by-line by the first author to identify tentative concepts. Comments made by the carer who was present for one interview were not included in the data for analysis. Techniques detailed by Corbin and Strauss [11] were used to aid the inductive process. Memos were written to explore emerging concepts. Mind-maps were drawn and separate memos written to explore the relationships between initial concepts. An initial theory was developed by grouping concepts into categories and exploring variation. Throughout the process, the 'constant comparative' method was used within and between participants. Focussed coding of all transcripts was conducted using memos, which were organised with associated quotations in a spreadsheet. The analysis was verified by a second author reviewing and coding a subset of transcripts and regular meetings between three authors where the emergent findings and mind-maps were discussed [13]. Throughout the process the first author completed reflective memos to consciously acknowledge assumptions and pre-conceived ideas that may have arisen out of prior familiarity with participants or professional experience. Effort was made to minimise these influences on the analysis[11]. Data saturation was believed to be achieved when no new major categories emerged and when categories showed sufficient variation across their properties and dimensions for the purposes of this research [11].

Results

Nine participants with a median age of 67 years (range 53–85 years) were interviewed. The median number of months since stroke was 20 (range 18–22). Only one

participant lived alone. Participants had experienced between 2 and 9 falls (median 4), with one participant suffering a hip fracture. Table 1 shows other participant characteristics and assigned pseudonyms.

Insert table 1 here

Three inter-linked categories were identified from the analysis:

- (1) Judging importance of fall by exploring causes and consequences
- (2) Getting back up
- (3) Being careful

The way in which these categories interact is presented in figure 1.

Insert figure 1 about here

Judging importance of fall by exploring causes and consequences

It emerged that not all falls were the same for participants. Some falls stood out in their memories as particularly important and they feared specific types of falls. Participants described falls in terms of their causes and consequences. The level of threat to an individual's sense of self posed by the cause or consequence and the level of perceived control that they had over the cause or consequence appeared to influence the meaning they attached to the fall.

Exploration of cause

All participants explored the cause of their falls to some extent. Causes that challenged sense of self and suggested a lack of control increased the seriousness of the fall for them. Some participants normalised the cause of their fall, allowing them to dismiss it.

For some this involved believing that the fall could “have happened to anybody” (Eric), thus removing the cause from themselves. In contrast, many participants described the concept of ‘fault’. Self-attributing blame could lead to embarrassment after the fall. In another way, the belief that the fall was avoidable seemed to afford them an element of control.

"They were all worried and cagey you know but...me... I was explaining it as being a fool, walking in where there was a slippery floor, you know." (Eric)

Some participants attached importance to their falls because the perceived cause both challenged their sense of self and was beyond their control. Specifically, for many who believed the cause to be related to the stroke effects, the falls were a reminder of incomplete recovery and their vulnerability.

"...my feeling about falling now is that I know it could happen without warning at any given time, which is a completely new phenomenon to me."
(Dennis)

All participants showed concern about an invisible cause of falls, completely outside of their control. Some participants dismissed their fall because there was nothing "strange" about it (David) or they didn't worry that there was anything "wrong" (Amy). The fear of this invisible cause was linked by some to a fear of recurrent stroke.

"I just think there's something wrong inside that I'm not...There must be something wrong. And do I have it investigated or do I just take a chance and carry on you know?" (Alice)

Perception of consequences

The participants also spoke about consequences to convey their perceived seriousness

of different falls. Consequences that threatened participants' pride or independence emerged as important. If participants believed that they had control over the consequence, this threat could be alleviated. The concern about emotional consequences was described to be worse than the fear of injury for some participants. Being left on the floor was described as potentially traumatic, while some feared the embarrassment of falls in public.

"I'm afraid of looking like an idiot more than... I don't even think of the hurting myself" (Amy)

Being in control of the fall consequences seemed to temper the seriousness. Several participants described their ability to get up independently or call for help easily after a fall was important.

"And I think a lot of that too is to do with living on one's own. I'd be afraid that if I fell I'd be there. When now well I have... wear the alarm thing and all the rest. I feel safer with that." (Alice)

One participant explained how he has learned to fall "properly", in a more controlled fashion, thus reducing his fear of injury (Dennis). In contrast, two other participants describe experiencing "bad" falls in which they could see themselves falling in "slow-motion" but were not able to "control it" (Emma).

"I could literally see myself in the air heading for the floor. And I could...I said it before I hit the floor 'this is going to hurt'." (Douglas)

Getting Back Up

Several participants described picking themselves up literally after falls and

metaphorically after the stroke, falls and other set-backs. The metaphorical and literal meanings were often intertwined in participants' narratives.

Regaining equilibrium

All participants described having experienced change due to ageing, the stroke, falls and other set-backs. They described decreased levels of energy, confidence and independence. Many tried to achieve a balance between striving to return to their former state and accepting a certain level of change.

"...see I think I've got to 80% back to where I was and I feel comfortable and I don't know what's needed to get to 90%, to 100%. What does it need physically for me to do? Can't spend all my day...what do you call it...eh...exercising you know what I mean?" (Andrew)

Participants found a new balance, in part, by comparing themselves to others with stroke. This facilitated a normalisation of the stroke effects. As one participant described about attending a stroke support group:

"....when I went there I just felt normal and I didn't feel like I was surrounded by people who were looking out for signs of disability" (Amy)

Picking oneself up after being knocked back

Participants encountered challenges in moving on from their stroke. Falls and other symptoms could cause set-backs in recovery.

"...all the hard work I've put in, and here it is. It's still causing me problems. So that really knocked me back." (Amy)

Participants described strategies for picking themselves up and dealing with these set-

backs including having goals, planning and being determined.

"That's how you learn I suppose, you know is...and rebuild. And you can do that through goals, and little targets and little achievements" (Andrew)

Just as participants moved on from set-backs, the physical act of rising from the floor marked the end of the fall experience for several of the fallers.

"I don't think about it too much I just recover my balance or my position or get back up and move on." (Dennis)

Several participants described the physical challenge of getting themselves up off the floor. This difficulty had developed since the stroke, with age or due to other comorbidities. These participants described needing to lean on something with their upper body to get up. Some modified activities to plan rising from the ground.

"If I go out, I bring out a chair, an old chair from the garage. You know, a chair like that, and I'd have no problem getting back up" (Damien)

Reaching for the helping hand

Participants described the type of support they needed to pick themselves up, both literally after a fall and metaphorically after the stroke or set-back. In both circumstances help that was respectful of their sense of identity and their desire for independence seemed preferable. All participants showed gratitude to professionals that cared for them in hospital but they could also be seen as overprotective.

"The physios. They're over cautious, they don't want anything to happen while you're here. That kind of carry on, like and if they'd just said carry on and do your thing I'd have been better off" (Eric)

Similarly, some participants, while grateful for family support, described reacting negatively to perceived overprotectiveness. They described how communication was crucial to get the support they needed from families while minimising conflict or hurt.

The balance thing...that was a problem. I suppose as I got a bit better the things that annoyed me was people's, my family and friends...they never seemed to leave me alone, there was always someone there. But that was their way of protecting I suppose (Emma) Parallels can be drawn between participants' response to support and to being physically helped up from the ground after falling. Some recognised their need for physical help and did not perceive it as a threat to their sense of self.

"And if I fell, well I fell and I ultimately got up or was helped up, and that was the end of it." (David)

In contrast, others described strangers rushing to pick them up after a fall, a situation that could be embarrassing. One participant shared how she didn't mind falling if nobody knew and it was her "secret" (Emma).

"...when somebody had to pick you up. And you felt so stupid. And you know...It's not me you know? And I want to be me again." (Emma)

Several participants also described the difficulty that carers had in helping them up.

"And (my wife) had to go and get the neighbour to pick me up. She wouldn't have the strength to pick me up and I couldn't get up myself."
(David)

Being Careful

'Being careful' was a strong theme across all participants' stories and all used the term.

It was described as a method of avoiding falls, while maintaining participation in activities. For all participants 'being careful' manifested itself in planning of movement, involving self-assessment and incorporation of advice from various sources.

Planning movement

All participants described planning the way they moved and interacted with their environment to some extent. This facilitated their participation in activity despite residual effects of their stroke. They described bringing movement under more conscious control.

"I would probably be more careful than I ever was before. I'd think about things now that you'd do automatically and you don't give a thought to."
(Eric)

Evolving self-assessment

Participants made decisions about how and when to plan movement. This involved comparing their abilities to their belief about the activity. Several stroke survivors described under or overestimating their own abilities early after stroke. With exposure to new challenges, participants described becoming more familiar with their bodies and their deficits, leading to more specific strategies for planning movement under particular conditions.

"When I get tired I know I'm at high risk. I walk into something or I'll stumble" (Emma)

Pride also played a role in what participants' final action would be. One participant stated that a desire to be independent led her to carry out activities that she knew

could put her at risk of falling (Alice). Others described the need to be extra careful in public to avoid embarrassment. One faller described how his movement in public differs from how he moves at home:

"...it's slower, more considered and more deliberate. Unless I'm in a real hurry where I kind of forget myself. But I have forgot myself once or twice so I'm slow to do so now." (Dennis)

Incorporating advice

The advice received from various sources could inform stroke survivors' definitions of 'being careful'. This advice was not always strictly followed. Instead, its meaning was interpreted and its usefulness decided upon before participants incorporated it into their lives.

"I would have taken it on board but I would have assessed it and I would have incorporated it into my own strategies if you get me?" (Dennis)

The level to which participants incorporated advice around falls was dependent on several properties: specificity, perceived validity, relevance and acceptability to the individual. Participants described how specific advice, for example in the form of a home exercise programme, could be helpful. Advice from various sources could become more relevant to participants if they experienced its importance.

"In the ward they'd say 'be careful walking on the floor', because I wouldn't be wearing any shoes. I just had stockings on and I never realised until one day I did get out of the bed and nearly went flying and I said to myself 'now I understand why they're saying you have to wear shoes or slippers or something you know'." (Douglas)

Even if participants felt that advice was valid, if it challenged their identity, then they could be reluctant to heed it. One participant described how he felt about advice given by his dance instructor.

"And so she's very good at the organising of the thing or giving me instructions on it, you know, "If you can't do it don't do it, you sit down". But needless to say nobody sits down." (Damien).

Regarding patient–professional communication around falls-risk within the hospital setting, many participants inferred that they were 'at risk' because they found physiotherapy assessments difficult, or because they were provided with walking aids. One participant felt that he was always being warned about falls. In contrast, another participant shared how she would have liked healthcare professionals to speak more openly about risk.

"As part of the programme be something there 'you're at high risk of falling. To prevent falls, you know, look at your shoes, look at your...' The OT like fine, she'll do all of that but the person themselves needs to look at it" (Emma)

Discussion

This study provides an insight into the experiences of nine stroke survivors who experienced recurrent falls after stroke. Participants described working to get back to some form of normality after stroke while being challenged by set-backs. The extent to which a fall resulted in a set-back for these participants was determined by the perceived threat to self of the causes or consequences of the fall and the perceived control that they had over the causes or consequences. Help appeared to be valued if

needed but it was important that help was respectful of their sense of self.

Furthermore, the fallers in this study managed the potential for falling in their everyday lives by 'being careful'.

Stroke survivors' conceptualisation of risk in relation to falls

This study details how stroke survivors judge their own falls-risk, and how their priorities contribute to their decision-making around activity participation. Other qualitative work among stroke survivors shows a spectrum of priorities, with participants in one study accepting risk in order to prioritise physical recovery [20], and participants of another study avoiding activity to prevent falls [10]. Participants in this study wished to use healthcare professionals' advice about falls-risk to participate safely, but if it did not reflect their priorities it was not incorporated into their daily lives. As reported amongst older adults, it seems important for stroke survivors to have control over whether to accept risk status and falls-prevention strategies [21]. In contrast, although being labelled as 'at risk' may represent a sudden life-change for older adults [18], for participants in this study the stroke itself was a catalyst for change and risk was experienced within this context.

Other qualitative researchers have described some stroke survivors as having a 'lack of insight' into the seriousness of falling when they did not attach importance to particular consequences [8,19]. Participants in this study did not view all falls as posing the same risk, instead considering causes and consequences. They were more likely to dismiss falls perceived to be avoidable. In contrast, they showed concern about invisible causes of falls. This reflects previous work where fear of falling and recurrent stroke 'intertwined' in survivors' experience [9]. As was also identified in research

amongst older adults, participants in this study were concerned about potential loss of independence due to injury, but social embarrassment was as significant due to potential damage to identity [20]. Stroke survivors have previously described the 'stigma' of public falls [10]. As stroke survivors do not view all falls as equal this may need to be considered when defining outcomes for falls-management interventions.

The stroke survivors in this study described judging their ability to avoid falls while carrying out specific activities. This is similar to the construct described as falls self-efficacy [21]. Some participants reported having difficulty judging their abilities early after stroke but this became easier as they became familiar with symptoms. The development of self-efficacy after stroke can be facilitated by experiences of success in tasks, comparisons to other stroke survivors, verbal encouragement and physiological feedback [25]. While participants' narratives in this study referred to several of these self-efficacy sources, some highlighted how professionals did not communicate directly with them about falls-risk. Healthcare professionals may be able to offer an increased sense of control to stroke survivors through education about how to avoid particular causes and consequences of falls.

While participants valued support provided by their families, they also described disparities between their own and their family's assessment of their abilities and falls-risk. This finding is reflected in other qualitative studies after stroke where carers could be perceived as overprotective [8]. In the present study individuals described communicating with their families to get the support they needed while minimising conflict. They valued being facilitated to return to 'normality'. Other qualitative research has highlighted the importance of stroke survivors feeling in charge of decisions to accept help [23]. Professionals should be cognisant of the

potential differences of opinion that may arise between stroke survivors and their families.

Being careful as a form of self-management

Moving on from the stroke and set-backs was highly valued by participants. This is mirrored by the work of Kelley et al [8], whose overarching theme is 'keep stepping no matter what', denoting perseverance towards recovery. The participants in the current study showed that they were willing to accept help and advice when necessary but also valued their ability to help themselves. They described 'being careful' by planning the way they moved to maintain activity participation. Similar strategies among older adults have been described as 'self-management' that can alleviate fear of falling [18]. 'Self-management programmes' aim to enable an individual to cope with the physical, psychosocial and lifestyle changes associated with chronic disease [24]. They have been found to reduce disability and increase confidence after stroke [24]. Research among older adults has also proposed that fostering shared decision-making between patients and professionals could improve engagement in falls-management interventions [25]. Future research could assess whether self-management principles could influence post-stroke falls outcomes.

Participants in this study valued advice they perceived relevant to them. In addition, making comparisons with other stroke survivors could improve their acceptance of their condition. Peer-educators have been included in some post-stroke self-management programmes and some falls-prevention programmes for older adults [26,27]. They have been suggested to contribute to increased engagement from participants and peer-educators have reported believing that they can improve the

acceptance of falls-prevention messages [26,27]. Some participants in this study referred to a right 'frame of mind' being required to use peer-comparisons in a positive way. Further research should investigate the acceptability to stroke survivors of peer-educators being involved in falls-management programmes.

The ability to get off the floor was described as both important and difficult by some participants. Their descriptions of relying on their upper bodies reflect quantitative research among older adults [28]. A prospective study of stroke survivors found that a third of fallers experienced a lie of greater than five minutes [29], a circumstance feared by participants in this study. Some participants were also embarrassed by being helped up in public. The inability to rise independently decreased the control they had over potential fall consequences. This study and other qualitative work in stroke have also highlighted the difficulty family members have in providing assistance with rising from the ground [19]. Stroke rehabilitation programmes have increasingly addressed rising from the floor in recent years and the UK stroke guidelines recommend providing this training [3,30]. Its inclusion in post-stroke self-management programmes may therefore be warranted.

Strengths and limitations of the study

This is the first qualitative study after stroke where participants were selected based on prospectively recorded falls, facilitating insights from individuals regardless of the importance they attached to their falls. Quantitative measures and reported fall circumstances also allowed for purposeful sampling. The inductive nature of this research allowed findings to be grounded in participants' experiences. The use of the 'constant comparative' method and multiple researchers lends confidence to the

findings. The use of Grounded Theory methods allowed for the development of theoretical explanations that could be applicable to a wider population of recurrent fallers after stroke [11]. However, it must be noted that the findings may not be representative of non-fallers or those who rarely fall but may still experience falls-related concerns. The authors chose to prioritise the rich data offered by those with multiple fall experiences. The findings of the study may have been influenced by the authors' professional backgrounds as physiotherapists and physicians, and the relationship of the interviewer with participants through the original cohort study. Efforts were made to reduce the effect of these factors on the analysis by the first author completing reflective memos throughout the process. In the first year after stroke, participants were assessed physically on several occasions and asked about falls and fear of falling, potentially increasing their awareness of the topic. As participants were interviewed 18–22 months after discharge this may have affected their recall of events early after stroke. The authors believe however that the insights obtained by recurrent fallers over a long timeframe are valuable in the context of this work. The study has been reported in accordance with COREQ guidelines to ensure transparency [31].

Conclusion

This study details how stroke survivors judge their own falls-risk, and how their priorities contribute to their decision-making around activity participation. It provides an insight into how individuals work to regain equilibrium after stroke while being challenged by falls and other set-backs. Participants described 'being careful' by planning the way they moved to maintain activity participation. Future research could

assess whether including self-management principles, peer-educators and education to rise from the floor in falls-management programmes could influence falls-related outcomes post stroke. Not all falls are viewed as posing the same risk by stroke survivors. This may need to be considered when defining outcomes for falls-management interventions.

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Declaration of interests

The authors report no conflicts of interest

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Appendix

Topic Guide/ Interview Schedule

Preamble

Thank you for agreeing to take part in this follow-up study and for talking with me today. We are really interested in hearing your story. You are the expert about your own experiences. There are no right or wrong answers to the questions I might ask.

Opening question:

How have things have been for you since you've left hospital, in your own words. How has everything gone for you?

Topic 1: The importance of falls

- In the course of the last year you told us just that you had had a few slips or trips or falls. Can you talk me through how they fit in to the whole picture?
- Potential prompts: If participant mentions serious, significant or bad fall ask: "Why does that fall stand out for you in particular?"
- If participant mentions fall that seemed unimportant ask: "Why do you think you are able to dismiss that fall in particular?"

Topic 2: Self-assessment of falls-risk

- Think back to when you were in the hospital. Was the possibility of falling something you thought about at all?
- After you came home from hospital and up to today has the way you've thought about falling changed in any way?
- Potential prompt: If participant mentions being nervous or afraid ask: "What are you worried about specifically?"
- "Does that affect how you go about your day to day activities?"

Topic 3: Perception of how healthcare professionals communicate falls-risk and provide education

- During the time you were in hospital after your stroke, did any doctor, nurse,

physiotherapist or occupational therapist apart from myself, mention anything about falls to you?

- Potential prompt: Can you recall what health professional mentioned it to you?
- How did you feel at the time about what you heard?
- Do you think any one thought you might fall at the time? What made you think that?
- What advice would you give to professionals looking after people like yourself coming out from hospital after a stroke, in terms of preparing them for going home?
- Since you came home, did any physiotherapist, doctor, nurse or OT outside of this study say anything or talk to you about falls?

Topic 4: Family response and interaction

- How have your family or the people closest to you responded since you came home after the stroke?
- How did they respond or react to the falls?
- How do you feel about their response?

Closing question

- If you had any advice for someone like yourself, going home from hospital after a stroke, what would that be?
- Potential prompt: "In general first, then in relation to falls"

Thanks and end

Thank you again for talking with me today. Just to remind you no-one else will hear this tape. I will use it for my notes so that I can explain to doctors, nurses, occupational therapists and physiotherapists how people like yourself feel and how we might be able to improve what we do. Is there anything else you'd like to say or add to help me do that?

Table 1. Participants characteristics based on results from original cohort study

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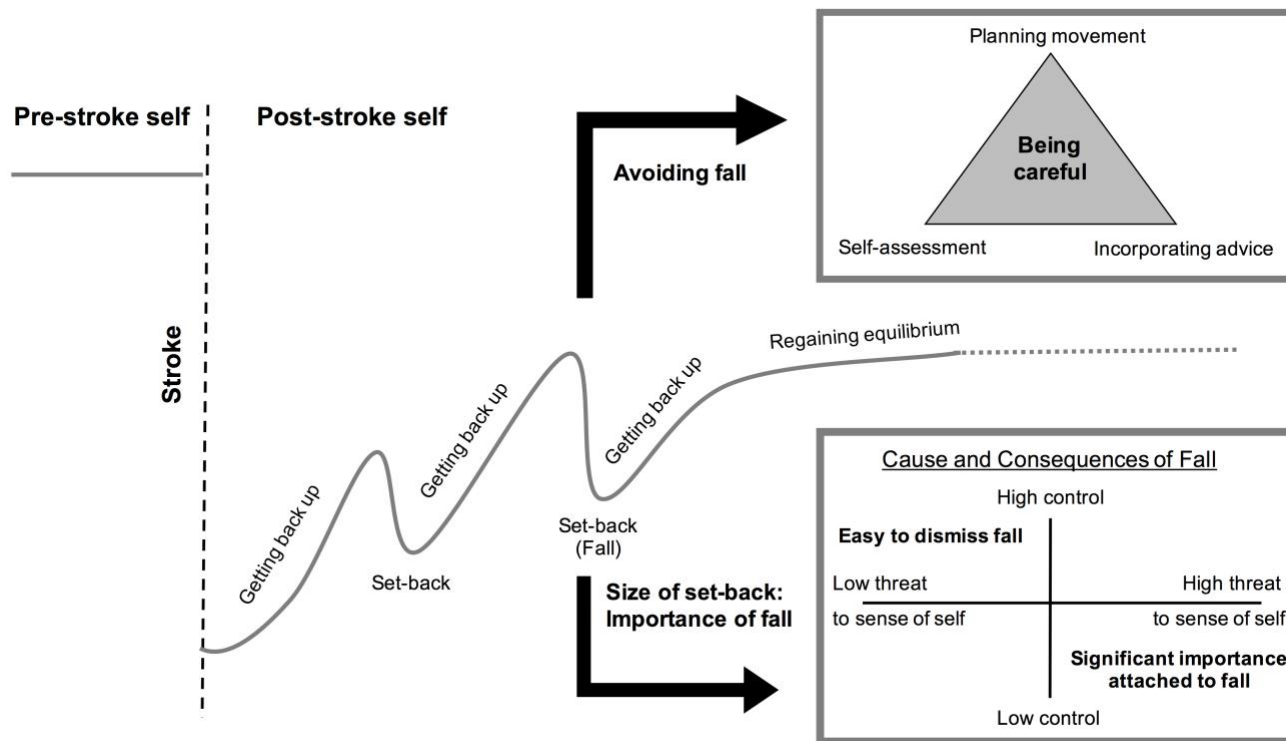


Figure 1. Visual representation of interaction of three categories emerging from analysis