Fall-related experiences of stroke survivors: a meta-ethnography.

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Implications for Rehabilitation

- Health care professionals should recognise that cognitive and emotional adjustment may be required for stroke survivors to accept strategies for overcoming falls-risk, including dependence on carers and assistive devices.

- Several factors in addition to physical interventions may be needed to minimise falls-risk while increasing activity participation.

- These factors could include increasing public awareness about the effects of stroke and falls-risk, and ensuring access to psychological services for stroke survivors.

- Rehabilitation professionals should reflect on whether they perceive there to be an appropriate level of fear of falling post stroke.

- They should understand that stroke survivors might not conceptualise falls-risk in this way.

ABSTRACT

Purpose: Health professionals view falls after stroke as common adverse events with both physical and psychological consequences. Stroke survivors' experiences are less well understood. The aim of this systematic review was to explore the perception of falls-risk within the stroke recovery experience from the perspective of people with stroke.

Methods: A systematic literature search was conducted. Papers that used qualitative methods to explore the experiences of individuals with stroke around falls, falls-risk and fear of falling were included. Two reviewers independently assessed the methodological quality of papers. Meta-ethnography was conducted. Concepts from each study were translated into each other to form theories that were combined through a "lines-of-argument" synthesis.

Results: Four themes emerged from the six included qualitative studies: (i) Fall circumstances (ii) perception of fall consequences (iii) barriers to community participation (iv) coping strategies. The synthesis revealed that stroke survivors' perceived consequences of falls exist on a continuum. Cognitive and emotional adjustment may be required in the successful adoption of coping strategies to overcome fall-related barriers to participation.

Conclusions: Stroke survivors' fall-related experiences appear to exist within the context of activity and community participation. Further research is warranted due to the small number of substantive studies available for synthesis.

INTRODUCTION

Recently discharged stroke survivors fall at almost twice the rate of their healthy peers in the first year [1]. It is estimated that almost half of stroke survivors fall, half of these repeatedly, mostly in the first two months after being discharged home [2]. Falls are considered by healthcare professionals to be an adverse event during the process of recovery due to their physical and psychological consequences [3]. Fractures and serious injuries from falls are estimated to occur in 5% of stroke survivors [4,5]. Fallers also demonstrate higher levels of anxiety, depressed mood and fear [6,7]. Much quantitative research has focused on the identification of modifiable risk factors for falls among this population, and the ability to predict fall events in stroke survivors returning home from hospital or rehabilitation [8,9]. Stroke survivors' own experiences of falls-risk and fall events are less well understood [10].

Some qualitative studies that explore recovery experiences of community-dwelling stroke survivors have briefly referred to the risk and fear of falling. Associations have been drawn between fear and activity restriction [11,12]. In contrast, falls have also been described as a result of trying new things [13]. Carers have expressed concern about stroke survivors being injured or being unable to rise from the floor [2,14]. Discrepancies in understanding of risk between some stroke survivors and their spouses have also been noted [15]. The importance of self-identity and self-efficacy is frequently discussed in qualitative research exploring the experience of living with stroke [16-19]. For this reason it is necessary to explore the meaning that stroke survivors attach to falls. It is also important to explore how they experience potential falls-risk, fear of falling and others' concerns about falling during their recovery process.

Systematic reviews of qualitative studies complement the research evidence needed in decision-making and facilitate the understanding and explanation of phenomena [20]. Meta-synthesis of qualitative work is needed to realise the full contribution of these studies [21]. The aim of this systematic review is to explore the perception of falls-risk within the stroke recovery experience from the perspective of people with stroke, through the process of meta-synthesis.

METHODS

Study design

A synthesis of qualitative studies that explored falls events, falls-risk or fear of falling from the perspective of stroke survivors was conducted. The methodological approach used was based on meta-ethnography, originally developed by Noblit and Hare [22]. Meta-ethnography is inductive and interpretive [21], and has emerged as a leading method for synthesising qualitative healthcare research in stroke and other fields in recent years [23-25].

Noblit and Hare originally described several phases to their process but did not describe sampling and critical appraisal [22]. Based on seminal and more recent published examples of the process [21,23-26], the present meta-ethnography comprised three steps: (i) identifying relevant papers for inclusion, (ii) critical appraisal and data extraction, and (iii) analysis and synthesis of findings.

Identifying relevant papers for inclusion

While some methodologists suggest sampling qualitative studies theoretically until data saturation is reached, others advocate first identifying all relevant studies [23]. A systematic and comprehensive literature search was therefore conducted in May 2015. It included the following search engines from inception: MEDLINE, EMBASE, CINAHL, PsycINFO, Scopus, Web of Science, and the Cochrane Library. Keywords and MeSH terms were used to combine the topics of stroke, falls/ postural balance, and qualitative research. Due to poor indexing several relevant free-text terms were used to search for qualitative research [23]. Table 1 shows the full MEDLINE string used for each search component. Reference lists and citing articles were hand-searched. Only English language articles were included. This is in keeping with recently published meta-ethnographies [26].

Insert table 1 around here

To determine initial suitability for inclusion, two screening questions were applied to each article [24,27]

 i. Does the paper report findings of qualitative research involving both widely accepted qualitative methods of data collection and analysis, where findings are supported by raw data?

 ii. Is the focus of the research paper, either its original aims or findings, relevant to the synthesis topic?

Papers were considered for inclusion only if they explored fall-related experiences after stroke from the perspective of individuals with stroke. Studies that focused only on the perspectives of the caregiver, family, or healthcare professional were excluded. Two authors

(MW, FH) independently read potential qualitative studies to determine the relevance to the synthesis topic and disagreements were resolved by consensus.

Critical appraisal and data extraction

There is some disagreement in the literature about whether quality assessment of studies should be conducted within meta-ethnography [23,28]. Some structured approaches to critical appraisal place an emphasis on the procedural aspects of research practice, while other positions place a higher value on theoretical perspective [28]. Quality assessment does have the advantage of highlighting gaps in reporting and providing a deeper understanding of texts [23]. Studies were therefore not excluded based on methodological quality [21,23,28].

The methodological quality of included papers was assessed by two researchers (MW and RG or FH) using criteria based on ten questions derived by the Critical Appraisal Skills Programme [29], which has frequently been used in meta-ethnography studies [23-25]. Each criterion was recorded as "Yes", "No" or "Unclear" along with reasons for this judgement [24]. The CASP checklist also provides a number of prompts for each question [29]. These were used to identify more specific points of quality that are presented narratively. Results of the appraisal were discussed and consensus reached.

In addition, the following information was extracted from each article to provide context for the interpretations of each study: characteristics of participants; format and setting for data collection; theoretical perspective; and the methodology employed [21,24].

Analysis and meta-synthesis

The analysis moved through four primary phases; reading the studies, determining how the studies are related, translating studies into one another, and synthesising translations [21-23].

i) Reading the studies

Each study was read and re-read in full [23]. The original key metaphors and concepts relating to the topic of interest within each of the papers were extracted [21,22]. Quotes from individual participants, described as "first-order constructs", do not reflect the totality of participant experience [21,23]. Therefore data for extraction was the verbatim "second-order interpretations", which are explanations provided by authors of included studies [21,22,25].

ii) Determining how the studies are related

Within meta-ethnography there are three types of synthesis distinguished by the relationship of the papers to each other: concepts may be directly comparable as reciprocal translations; they may conflict as refutational translations; or together the papers may represent lines of argument that infers something about a broader picture [21,22,24]. To determine the relationship of studies a table was constructed to juxtapose relevant details of the study setting and research design and their key concepts, using the process described by Britten and colleagues [21].

iii) Translating studies into one another

Studies were translated into one another using reciprocal translation [22]. Second-order

constructs were grouped into themes. A search was undertaken for the presence or absence of the main themes in each paper [23-25]. Starting with the earliest paper, second-order constructs within themes were compared and translated from one study to another to develop explanatory theories. These theories have been described as "third-order constructs" [21,24].

Discussion of contradictory relationships among findings is important for preserving the uniqueness of individual studies [27]. The process of "refutational synthesis" as described by Noblit and Hare was not applicable as no studies stood in opposition to one another. A specific search was undertaken to characterise contradictions between the reports [22,27].

iv) Synthesising translations

The third-order constructs provided the foundation for lines-of-argument synthesis. This involved the process of building a higher order interpretation grounded in the findings of the separate studies [22,25]. Overarching models and mind-maps linking translations and interpretations were developed and discussed within the research team, and a lines-of-argument synthesis was produced [23].

RESULTS

Identifying relevant published papers

The initial search string yielded 1,635 unique articles, of which 1,527 were excluded based on title and abstract. Full texts of 108 remaining articles were retrieved and 102 were subsequently excluded. Figure 1 describes the flow of studies in the review including reasons for exclusion. As only six relevant articles were identified, theoretical sampling was

not conducted. All six articles were included in the final review [10,30-34].

Insert figure 1 around here

Descriptive characteristics of included studies

The details of studies are presented in table 2. Four studies primarily focus on falls, or fear of falling post stroke [10,32-34]. The two remaining studies provided insights about falls-risk within the context of a home-health intervention [31], and assistive device use [30]. Studies included between six and 42 participants. Three of the six studies included only male participants [10,31,32]. All but one study [30] were conducted in the United States. Two of the studies appear to report findings from the same group of stroke survivors [10,32]. Two other studies selected participants from the same cohort, and data was collected seven years apart. The level of participant overlap between these studies in unclear [33,34].

Insert table 2 around here

All studies analysed data from transcripts of in-depth interviews. These interviews were conducted either at a single time-point [30,31,34], or longitudinally [10,31,32]. Three studies conducted secondary data analysis; they selected transcripts from larger studies using keyword searches to identify participants who discussed fall-related experiences [10,32,33]. In five of the studies spousal caregivers were included in the interview process [10,31-34]. The extent to which this data is analysed separately is explicit in only one study, where "stroke survivor" and "caregiver" sub themes are presented [33].

The theoretical perspective is discussed and justified in only one study [30]. A second study briefly reports using phenomenology [34]. Two studies report using "mixed" methodologies [31,34], while three other studies refer to "quantitative" data that was collected from participants as part of a larger study [10,32,33].

Quality appraisal of included studies

The quality of studies was fair overall. A summary of the appraisal findings is presented in table 3. All studies highlighted the importance of the topic. They all provided clear details about the methods of data collection, an in-depth description of analysis, and had explicit findings supported by participant quotes. All studies received ethical approval, while four described obtaining informed consent [10,30,31,34]. Implications for practice and research were discussed well, with only one study failing to provide insights in this area [34]. There were however some gaps in reporting, primarily around reflecting on the influence of their own positions and potential ethical considerations.

Three studies provided information about individuals who chose not to take part [10,30,33]. The setting for data collection was mentioned in four studies [10,30,32,34], but justified in only one [30]. One study discussed data saturation [34]. Only one study acknowledged the impact of their pre-existing "assumptions, background and earlier experiences" on the study design [30]. Two further studies showed evidence of reflection that the analysis process could be influenced by researchers' clinical experience, knowledge of literature, and previous relationship with participants [32,33]. Although all studies appeared to fulfil mandatory ethical requirements, none showed evidence of considering potential distress or offering support to participants.

Insert table 3 around here

Analysis and synthesis of findings

Four themes have emerged from the synthesis: "fall circumstances", "perception of consequences of falls", "barriers to community participation", and "coping strategies". Three interlinked subthemes emerged under the theme of "coping strategies": "reliance on caregiver", "external devices" and "emotional and cognitive adjustment". Three explanatory theories (third-order interpretations) have emerged from the process of reciprocal translation and of the identification of refutations across studies. Table 4 presents summaries of second-order constructs from included studies, across identified themes, in order to explain the theory development-process.

Insert table 4 around here

Circumstances of falls

The circumstances surrounding actual falls are described in five of the six studies [10,31-34]. The activity being carried out before the fall, and injuries sustained are described [31,33,34]. Schmid and Rittman specifically describe falls that occurred at the time of stroke as traumatic events that may subsequently lead to fear of falling [10,32].

> *"Falling at the time of a stroke is a common experience and may be a harbinger of the development of FoF* (fear of falling)*" [10]*

Perception of consequences of falls

The potential consequences of falls, and how stroke survivors perceive these consequences, are described in each study. Pettersson and colleagues discuss how stroke survivors fear "hurting themselves"[30]. Schmid and Rittman deal with fear of falling in depth in their two papers [10,32]. Fear is discussed in relation to past traumatic events, as an everyday concern, and is associated with potential future injury and loss of function [10]. Some stroke survivors fear being left on the floor for long periods [32]. Lutz and colleagues also describe how stroke survivors who fell while alone would have to wait to be helped up. In contrast, they describe their participants accepting this risk [31].

> "*Despite this, veterans reported that falling at home was a risk they would continue to take in order to keep working on recovering functions lost related to stroke*" [31]

Two further papers describe evidence of fear of falling among participants, but they also describe some individuals as having a "lack of insight" into fall consequences [33,34]. Da Silva and colleagues explicitly acknowledge that they, as researchers, have attributed value to a certain awareness of falls.

> "*...we categorized their awareness of these issues as a positive aspect of adjustment, since it displays some level of insight into their situation and limitations.*"[34]

This value attribution is more implicit but evident in two other papers [10,33]. Kelley and colleagues express concern when they witness an absence of fear of falling.

> "*...some of the SS* (stroke survivors) *comments did not seem to reflect the potential seriousness of falling*" [33]

Schmid and Rittman describe fear of falling among stroke survivors as existing on a continuum from "a healthy sense of fear" to "pervasive fear of falling" [10]. It is not clear whether the "healthy" designation is expressed by stroke survivors, or stems from researcher interpretation.

> *"A continuum of FoF in this poststroke population appears to exist. It ranges from a healthy sense of fear to an overwhelming, all encompassing, everyday, obtrusive fear that is reflected in a "constant awareness" of falls risks and reported changes in activity and participation."*

Taking these studies together, authors of the included studies appear to value an awareness of consequences if it does not lead to activity restriction. It is not clear if fear of falling is conceptualised by stroke survivors themselves in this way.

Barriers to community participation

Barriers to community participation were described in all studies. The awareness of fall consequences appears to exist on a continuum with pervasive fear of falling being a psychological barrier to community participation [10]. This and other fall-related psychological, environmental, physical or social barriers could result in stroke survivors becoming "isolated" and experiencing a restriction of their lived worlds [30,32].

> *"Several reported their inability to fully access the community in order to participate in previous social roles or activities"* [34]

All studies describe stroke survivors' experience of their changed physical body post stroke. "Physical dysfunction" needed to be "compensated for" [30]; the recovery of "functions lost" was important [31]; stroke survivors described "difficulty" on their feet. In addition, episodes of dizziness and loss of balance were noted to occur unexpectedly [10,33]. These impairments were described to affect participation.

> *"Participants discussed physical bodily changes;.....and the ensuing negative impact of decreased mobility, activity, and participation" [32]*

Two studies described stroke survivors perceiving environmental barriers including the weather, uneven surfaces and obstacles [30,34]. They also described a "lack of community awareness", where stroke survivors experienced being "jostled" or bumped into while in public places [30,34].

Stroke survivors' perception of how they were viewed by others in public was described in three studies as a potential barrier to participation [30,32,34]. A sense of "stigma" was described relating to the use of assistive devices [30], decreased mobility and falling [34].

> *"Some participants were fearful that they would fall while out in the community and addressed the embarrassment of a public fall" [32]*

Coping strategies

Coping strategies for dealing with falls and falls-risk emerged as an important theme within the synthesis. Three specific strategies were described in detail. Stroke survivors increased their reliance on caregivers and used assistive devices in order to overcome barriers to participation. Emotional and cognitive adjustment emerged as a strategy in itself, but it also

appeared necessary for the success of other strategies. While Schmid and Rittman describe activity and participation limitation as "a strategy to prevent falls", it is not described in any study as a desirable coping strategy, rather a consequence of fear [10,32].

Reliance on caregiver

Five studies describe stroke survivors' increased reliance on caregivers [30-34]. Spousal caregivers are described as "the best device", and reliance on them an essential "strategy" to prevent falls and facilitate independence [30,32]. Stroke survivors valued the encouragement and support provided by spouses and families [33,34].

It is evident throughout these studies that there can be disparities between stroke survivors' and caregivers perception of falls-risk. Caregivers were described to "help too much" and encourage activity limitation to prevent falls [30,32]. Some stroke survivors and caregivers were described as having different levels of confidence in the stroke survivor's safety during specific activities [34]. Conflict was described around the need to balance the wishes of both parties [33]. As spouses were frequently involved in interviews it is somewhat unclear to what extent this finding arises out of researcher interpretation [31-34].

> *"Both CGs* (caregivers*) and SSs* (stroke survivors) *reported how conflicts arose related to the SSs wanting more independence and less supervision" [33].*

Stroke survivors' perception of risk to their caregivers is described in four studies [30,31,33,34]. They express concern about both the risk of physical harm and emotional load associated with caregiving [30,31,33,34]. This perception appears to be conceptualised

differently across three studies from an "anxiety" [30], to a "realization" [33], to a "positive" aspect of adjustment [34].

External devices

While the use of assistive devices and the adaption of the environment to prevent falls are mentioned in five studies [30-34], these strategies are most thoroughly explored by Pettersson and colleagues [30]. Two studies refer only briefly to the need for walking aids [31,33]. Others describe stroke survivors feeling a "sense of security" and increased confidence by using walkers, canes and home modifications [30,32,34].

> *"They reported feeling safer and more confident when having their equipment for external support." [34]*

Pettersson and colleagues express that while assistive devices are valued, they can also challenge stroke survivors' sense of self. They can be a symbol of disability, "demeaning and unpleasant" [30].

> *"... while the devices are a prerequisite for well-being, independence and the performance of daily activities and are highly esteemed, they also give rise to negative feelings." [30]*

Emotional and cognitive adjustment

Emotional and cognitive adjustment emerged as important to overcoming fear, barriers to participation, and the challenges of increased dependence. It was expressed as "acceptance of condition and situation" [34], "patience and perseverance" [33], becoming "accustomed" [30], and "managing falls and fear of falling in everyday life" [32]. Cognitive strategies

including "mental practice, planning ahead" and carefully analysing new situations were also described [31,34]. Kelley and colleagues highlight the importance of this adjustment through their overarching theme [33].

".... the need to "keep stepping no matter what" the obstacles are that occur along the path to continued recovery from the stroke" [33]

Lines-of-argument synthesis

The six identified studies have varying focuses, but when taken together they tell us more about the whole picture [22]. Schmid and Rittman deal largely with fear of falling and resulting activity restriction [10,32]. Two studies describe actual falls, injuries and fall-circumstances, but they also explore strategies including perseverance and adjustment [33,34]. Lutz and colleagues provide an insight into how stroke survivors assess falls-risk [31]. Pettersson and colleagues explore community access and emotional adjustment in relation to assistive devices [30].

Figure 2 provides a visual representation of how the third-order interpretations presented in table 4 interact. The awareness of fall consequences exists on a continuum with pervasive fear of falling being a psychological barrier to community participation. This and other barriers can result in stroke survivors experiencing restriction of their lived worlds. Physical, social and environmental barriers can be overcome through the support of caregivers and the use of assistive devices. Emotional and cognitive adjustment can be required to accept strategies and to adapt to increased dependence. This adaption is also particularly linked to overcoming the psychological barriers to community participation; fear of falling, self-consciousness and other threats to sense of self.

DISCUSSION

This meta-ethnography provides both a summary of how stroke survivors experience the concepts of falls and falls-risk, and how qualitative researchers have interpreted these experiences to date. The methodology has allowed for insights that are more than "the sum of parts" [24]. Within this synthesis falls and the perceived consequences of falls exist within the context of activity and community participation. Barriers to participation, and coping strategies used to overcome these barriers, are complex and interrelated.

It has emerged from this synthesis that stroke survivors' perception of fall consequences exists on a continuum from limited awareness to pervasive fear. It became evident that some researchers attached a value to a certain awareness of falls-risk [10,33,34]. In contrast, Lutz and colleagues simply report that falling was a risk participants were willing to take [31]. This mismatch of falls-risk perception is evident in other syntheses of qualitative studies focussing on falls in older adults [35,36]. McInness and colleagues suggest that while healthcare professionals may focus on physical risk, older people may be more concerned with perceived threats to their identity as able and independent [35]. Child and colleagues describe "hierarchies of expertise" whereby healthcare professionals may assume that older people lack the competency to identify their own falls-risk [36]. Other work has demonstrated that older people place a higher emphasis on maintaining independence as opposed to falls-reduction when choosing to participate in an exercise-based falls-prevention programme [37]. Multifactorial falls-prevention interventions post stroke have

not yet been shown to be effective [38]. Professionals' focus on "risk" may have implications for the uptake of these interventions [36]. It must also be noted that objective "falls-risk" post stroke remains an ill-defined concept as much quantitative research has found that falls are difficult events to predict [9]. Further qualitative research could focus on how stroke survivors conceptualise the consequences of falls, and how they self-assess risk, in order to inform the development of self-management interventions.

Fall-related physical, psychological and social barriers to community access can restrict stroke survivors' lived world [30]. This can result in both social isolation and a restriction of the everyday environment. Previous meta-syntheses of qualitative studies post stroke have highlighted the complex interaction of barriers and facilitators to participation [17,18]. Several systematic reviews, both qualitative and quantitative, have described how self-consciousness about physical abilities and appearance can lead to withdrawal from social activity [17,39]. In addition, a grounded theory developed by Barnsley and colleagues suggests emotional disposition, beliefs about recovery and available social support will affect the confidence with which stroke survivors travel outdoors [11]. The aims of falls-prevention interventions are to decrease the incidence of fall events, while increasing confidence and activity participation [40]. This review suggests that several factors in addition to physical interventions may need to be considered to achieve this aim. These could include increasing public awareness about the effects of stroke, educating staff of public services about falls-risk, and ensuring access to psychological services for stroke survivors as recommended in clinical guidelines [41]. Current research suggests poor satisfaction with help available to deal with social and psychological consequences of stroke [42].

Adopting strategies to overcome falls-related barriers to community participation appears, from this synthesis, to require cognitive and emotional adjustment. As described, increased dependence on assistive devices and caregivers, due to physical deficits or falls risk, can challenge stroke survivors' identity. Reconciling these changes is not likely to be an easy process. A previous meta-ethnography suggests that an individual's ability to persevere in their recovery, overcome emotional challenges and accept necessary help and adaptations can facilitate their reintegration into the community in the first year after stroke [18]. Adjustment post-stroke has been previously described as being so important as to be "interwoven" with the concept of recovery within survivors' experience [16]. It has also been identified among fallers in the general population, where "regaining a valued individual and social self from within a falls or fear of falling trajectory" is vital [43]. In their grounded theory Kubina and colleagues highlight the importance of stroke survivors feeling in charge of decisions to accept strategies, and feeling that they make a contribution in their social relationships [19]. These points may be important in facilitating adjustment among stroke survivors.

The findings of this meta-synthesis need to be considered in the context of limitations in the original studies and the assumptions of meta-ethnography as a methodology. Although meta-ethnography is increasingly being applied to healthcare issues, it is still an evolving method [23]. The process applied was based on Noblit and Hare's original description as well as published examples of the methodology [21-25]. The results of this synthesis are based on the assumptions that studies are comparable, that the individual results are not overly limited in scope, and that concepts are transferable across settings [21]. As all studies

were conducted with community-dwelling stroke survivors, and the majority were conducted in the United States, this is likely to be the case.

Although a comprehensive literature search was conducted only six studies were identified, two of which reported on results from the same sample [10,32]. In addition, one study reported "brevity and lack of depth" in the data available for analysis [33]. It is likely that data saturation has not been reached given the small number of substantive studies available [44]. Further qualitative research in this area would therefore be warranted. Three of the studies within this review selected transcripts from larger studies, based on participants' expression of concern about falls, mobility or fear of falling [10,32,33]. For this reason individuals who may have experienced falls but did not attach significance to these experiences may have been excluded. Qualitative research among fallers in the general population has suggested that specific fall events may not be neatly labelled within individuals' experience [43]. They may conceptualise fall events as non-serious "trips", and may not consider them, or express them as important [35]. Future qualitative research, focusing on stroke survivors who are known to have experienced fall events, could help to explore the spectrum of fall experiences.

It is important that qualitative researchers are reflexive and recognise their own influence on the data collection and analysis process [45]. Through the quality appraisal process it emerged that only half of the studies in this review showed evidence of this awareness [30,32,33]. In addition, the level of interpretation applied to the data was not overtly expressed in many of the studies. It was therefore difficult to decipher to what extent the second-order constructs were influenced by authors' background or theoretical position

[45]. This difficulty particularly manifested itself within this synthesis around two issues. Firstly, do stroke survivors conceptualise a certain "healthy" sense of fear of falling [10]? Secondly, do stroke survivors perceive disparities between their own perception of falls-risk and that of their caregivers? As all of the studies except one [30] report interviewing caregivers as well as stroke survivors, it is unclear if these disparities were noted by stroke survivors, carers, or by researchers noting differences between accounts. This difficulty in understanding the original authors' position and approach to the data is on-going within the field of meta-ethnography [23].

The findings of this review may have been influenced by the authors' research and clinical experience and should be interpreted within this context. All authors (MW, RG, FH) are physiotherapists who have worked in acute hospitals with survivors of stroke. All have conducted both quantitative and qualitative research in the areas of stroke recovery and falls-risk. These experiences may have affected the composition of the original search string, decisions around inclusion, quality appraisal and theory development. Rigour and trustworthiness were ensured by following well-recognised guidance [24,29], by carrying out independent assessments before reaching consensus, and by ensuring that findings were grounded in the data [21].

CONCLUSION

Falls and the perceived consequences of falls exist within the context of activity and community participation. Barriers to participation, and coping strategies used to overcome these barriers, are complex and interrelated. Cognitive and emotional adjustment may be required in the successful adoption of coping strategies. Future qualitative research should

focus on how stroke survivors themselves conceptualise the consequences of falls, and how they self-assess risk. Participant selection should also be based on the experience of actual fall events, to explore the experience of both those who attach and do not attach importance to their falls.

Declarations of Interest

The authors report no conflicts of interest.

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Table 1. Full OVID MEDLINE search-string

Stroke	cerebrovascular disorders/ or stroke/ or exp basal ganglia cerebrovascular disease/ or exp brain ischemia/ or exp brain infarction/ or exp intracranial hemorrhages/ or stroke or poststroke or post-stroke or cerebrovasc* or CVA or (brain ADJ5 vasc*) or (cerebral ADJ5 vasc*) or hemiplegia/ or exp paresis/ or hemipleg* or hemipar* or paresis or paretic
Falls/ Balance	accidental falls/ or accidents/ or exp accident prevention/ or accidents, home/ or accident proneness/ or postural balance/ or exp gait disorders, neurologic/ or exp ataxia/ or (fall or falls or faller or fallen or fallers or falling or "fall-related" or "near-fall" or "falls-efficacy" or "fear of falling" or slip or slips or slipped or slipping or trip or trips or tripped or tripping or stumble* or tumble*).af or balance or imbalance or unbalanced or steady or unsteady or steadiness or unsteadiness or "balance confidence" or "balance efficacy" or footing or instable or instability or unstable or wobbl* or ataxia
Qualitative Research	qualitative research/ or interviews as topic/ or focus groups/ or anecdotes as topic/ or narration/ or video recording/ or tape recording/ or personal narratives as topic/ or "life experiences" or "narrative analysis" or "field research" or "field studies" or "field study" or "constant comparison" or "constant comparative" or "grounded research" or "grounded studies" or "grounded study" or phenomenol* or ethnon*or qualitative or multimethod* or triangulat* or saturation or perspective or inductive or "in-depth" or "in depth" or "semi-structured" or transcribed or theme or ecological or transcript or "content analysis" or thematic or verbatim or "open-ended" or (discourse* adj3 analysis) or (lived adj3 experience*) or (data adj1 saturat*) or (purpos* adj3 sampl*) or (grounded adj1 theor*) or (mixed adj model*) or (mixed adj design*) or multiple adj method*)

Table 2. Characteristics of included studies

First Author Year Country	Primary focus of study	Methods	Participants (n, age, presence of spouse)	Data collection	Time since stroke
Pettersson [30] 2006 Sweden	Experiences of using assistive devices one year post-stroke	Hermeneutic-phenomenological method	n=22 (16 male) Mean age 75 years (range 35-86) Presence of spouse not reported	Home interviews	One year post stroke
Schmid [10] 2007 USA	Fear of falling during the first 6 months after stroke	Latent content approach and analysis Transcripts selected from larger study	n=42 (all male) Mean age 66.2 (SD 10.44), Range: 40-93 Spouses interviewed separately	Home interviews at one and 6 months post stroke	One month post stroke at first interview
Lutz [31] 2009 USA	Evaluation of a post-stroke tele-health intervention	Mixed methods: Qualitative component: Constant comparative analysis	n= 9 (all male) Mean age 72 (range 57–85) 6 spouses present	Semi-structured interviews post 14-day tele-health intervention	Mean 15 months Range 5-60 months
Schmid [32] 2009 USA	Perceived consequences of post-stroke falls during the first 6 months after stroke	Latent content approach and analysis Transcripts selected from larger study	n=42 (all male) Mean age 67.5 (SD 11.93) Spouses interviewed separately	Home interviews at one and 6 months post stroke	One month post discharge at first interview
Kelley [33] 2010 USA	Stroke survivors' and spousal caregivers' lived experiences about falling and general mobility	"Generic methods" of qualitative research Transcripts selected from larger study	n=30 Age/ gender not reported All spouses present	Interviews at baseline, 3, 6, 9 and 12 months	Within one year of stroke
Da Silva [34] 2014 USA	Issues expressed related to falling and fear of falling	Mixed methods: Qualitative component: Phenomenology	n=6 (4 male) Mean age 69.5 years (SD not reported) 5 spouses present	Home interviews	7.2 years (range 6-8 years)

Table 3. Methodological quality assessment

First author, year	CASP Questionnaire*									
	1	2	3	4	5	6	7	8	9	10
Pettersson, 2006 [30]	X	X	X	X	X	X	X	X	X	X
Schmid, 2007 [10]	X	X	X	X			X	X	X	X
Lutz, 2009 [31]	X	X	X	X			X		X	X
Schmid, 2009 [32]	X	X	X	X	X			X	X	X
Kelley, 2010 [33]	X	X	X	X	X			X	X	X
Da Silva, 2014 [34]	X	X	X		X		X	X	X	

"X" indicates sufficient evidence reported in text of meeting quality criterion

* CASP Key [29]
1= Was there a clear statement of the aims of the research?
2= Is a qualitative methodology appropriate?
3= Was the research design appropriate to address the aims of research?
4= Was the recruitment strategy appropriate to the aims of the research?
5= Was the data collected in a way that addressed the research issue?
6= Has the relationship between researcher and participants been adequately considered?
7= Have ethical issues been taken into consideration?
8= Was the data analysis sufficiently rigorous?
9= Is there a clear statement of findings?
10= How valuable is the research

Table 4. Theory development process

Theme	Pettersson 2007 [30]	Schmid 2007 [10]	Lutz 2009 [31]	Schmid 2009 [32]	Kelley 2010 [33]	Da Silva 2014 [34]	*Explanatory theory (Third-order interpretation)*
Falls circumstances	(Actual falls not described)	A fall at the time of stroke could be a traumatic event that precipitates fear of falling	Falls and near falls usually occurred when beginning a new activity, especially early post-discharge	A fall at the time of stroke could be a traumatic event that precipitates fear of falling	Stroke survivors describe indoor and outdoor falls, some of which result in injuries	Stroke survivors describe injuries such as contusions, fractures, and lacerations from falling	*Stroke survivors' perception of fall consequences exists on a continuum from limited awareness to pervasive fear*
Perception of consequences of falls	Participants' were are afraid of hurting themselves by not using assistive devices	A continuum of fear of falling exists from a healthy sense of fear to an overwhelming fear	Falling at home was a risk that participants were willing to take in order to keep working on recovery	Fear of falling included fear of being hurt, fear of deterioration in function and fear of being left on the floor	Although stroke survivors discussed fear, some of their comments did not reflect the potential seriousness of falling	Stroke survivors' awareness of falling and injuries is a positive aspect of adjustment, since it displays some level of insight	
Barriers to community participation	Participants' lived space became restricted because access depended on disability, devices, the climate, other people, and the design of the surroundings	Participants described the need to curb activities to manage fear and to prevent a fall	(Not described)	Participants became isolated because they were fearful to leave their home	The risk of falling must be managed in the home and community environment	Safety concerns included environmental impact of loss of community access, fear of falling, lack of community awareness, lack of personal safety insight, and vulnerability to crime or injury	*Physical, psychological and social barriers to community access restrict stroke survivors' lived world*

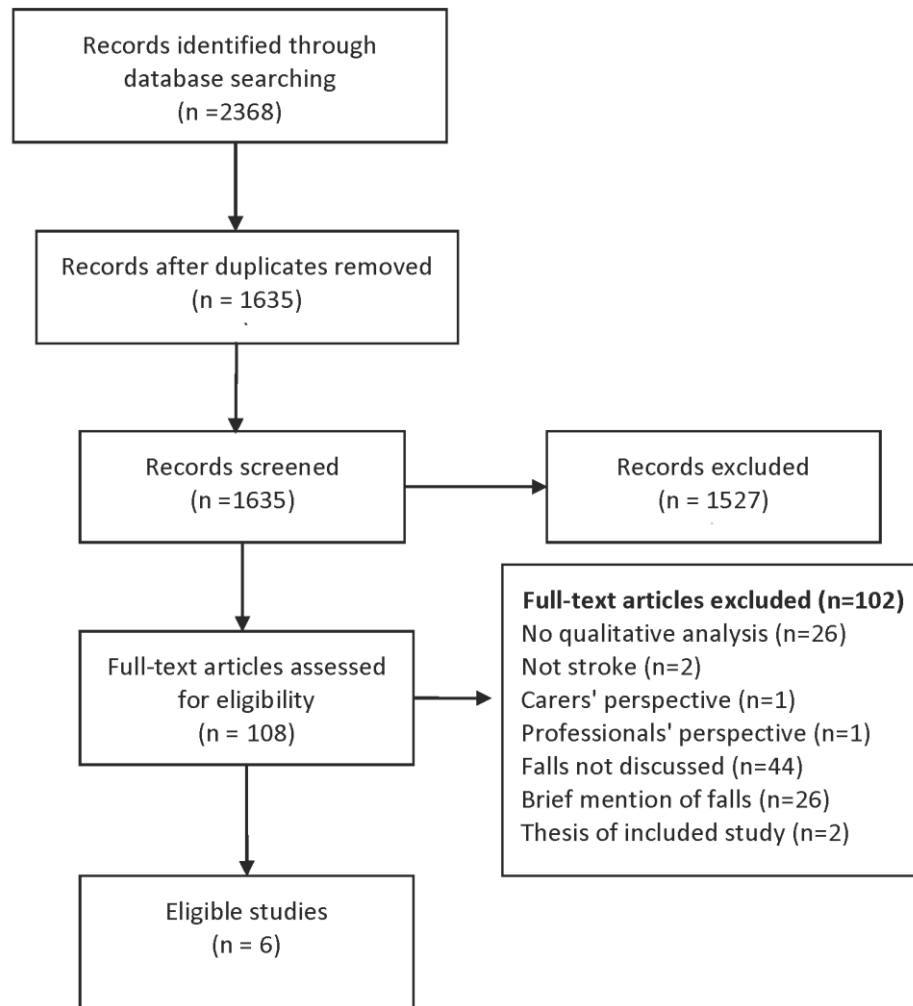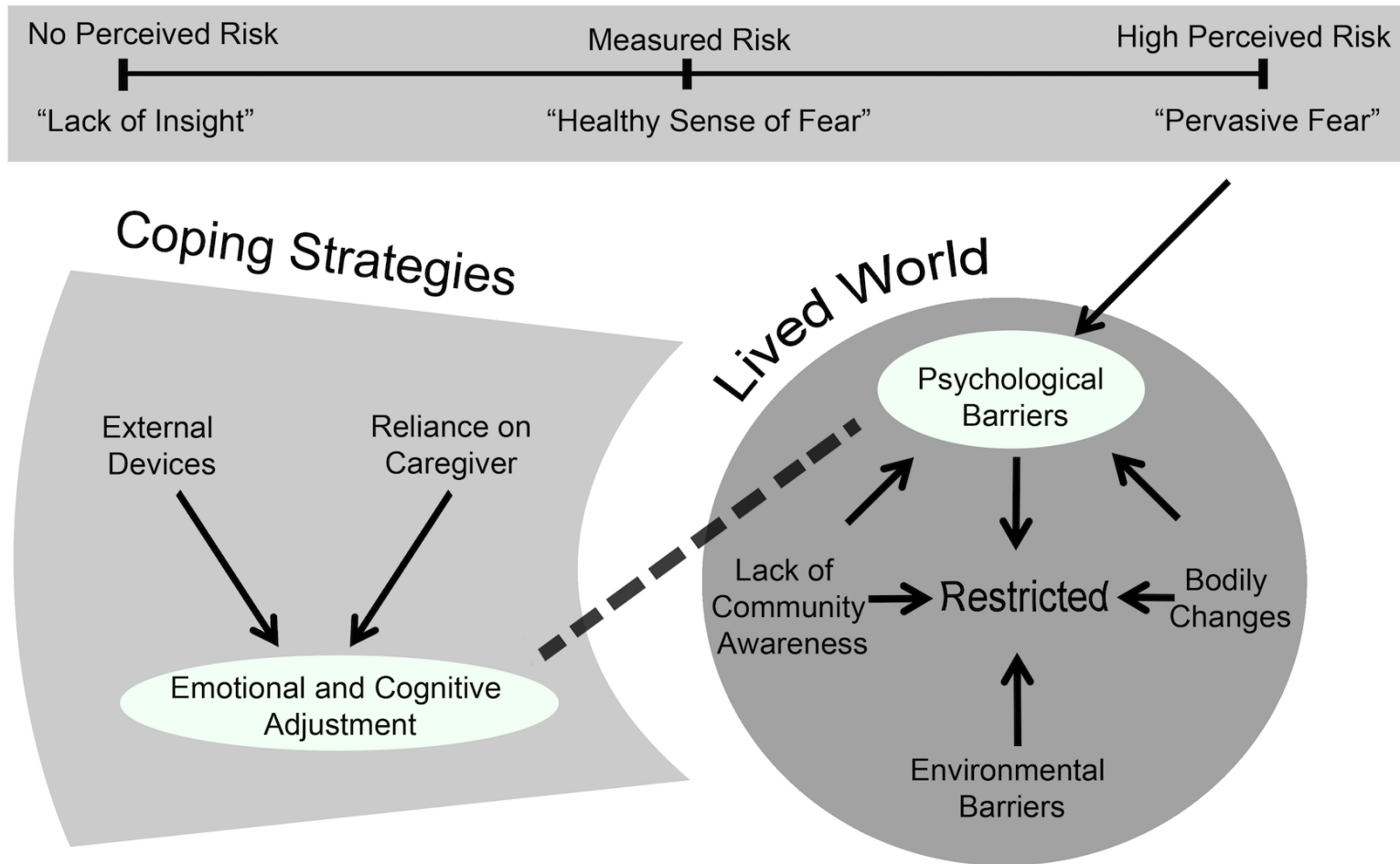| Coping strategies: Reliance on caregiver	Spouses were seen as the best "device", and were relied upon but stroke survivors were anxious lest spouses became overburdened	Participants discussed their need for assistance to maintain their balance to manage fear and to prevent a fall	Veterans who fell were reliant on help to get up. They also acknowledged potential risks to their spouse	Survivors are reliant on caregivers as a strategy to reduce falls but carers sometimes encourage activity limitation to reduce falls	Stroke survivors value spouses' support but also realise the demands placed on their spouses. Conflicts can arise related to balancing independence and supervision	Participants receive support from families but perceive stress on their spouse. (This awareness is placed under category of "positive emotional/ cognitive adjustment")	
Coping strategies: External devices	Assistive devices were seen to facilitate independence and offered a sense of security	(Not described)	(Brief mention of participant using quad cane to facilitate outdoor walking)	Participants were dependant on assistive devices to reduce falls and feel secure in their environment	(Described only by spouses: they fear the stroke survivor falling, if they walk without using the prescribed assistive devices)	Participants modified homes to reduce barriers and reported feeling safer and more confident with equipment for support	*Accepting strategies to overcome falls-related barriers to community participation requires cognitive and emotional adjustment*
Coping strategies: Cognitive and emotional adjustment	While assistive devices were highly esteemed, they also gave rise to negative feelings. Participants became accustomed to the devices over time	(Not described)	Participants developed strategies they believed would minimise their fall risk including careful analysis of new situations	Managing falls and fear of falling in everyday life became an important aspect of poststroke adjustment	Participants described "hurdles" to their recovery that required them to have patience and perseverance, keep trying, and find ways to cope or adapt	The positive sub-theme of emotional and cognitive adjustment included acceptance of condition and situation, determination, self-confidence, strategies, and support	

Figure 1. Flow diagram of studies included in the review

Figure 2. Lines of argument synthesis