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# A systematic review of qualitative studies on adjusting after stroke: lessons for the study of resilience

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## Abstract

*Purpose:* To synthesize qualitative studies on adjusting after stroke, from stroke survivors' and carers' perspectives, and to outline their potential contribution to an understanding of resilience. *Methods:* A systematic review of qualitative studies in peer reviewed journals from 1990 to 2011 was undertaken. Findings from selected studies were summarized and synthesized and then considered alongside studies of resilience. *Results:* Forty studies were identified as suitable. These suggested that the impact of stroke was felt on many dimensions of experience, and that the boundaries between these were permeable. Nor was stroke as an adverse "event" temporally bounded. Adjustment was often marked by setbacks and new challenges over time. Participants identified personal characteristics as key, but also employed practical and mental strategies in their efforts to adjust. Relationships and structural factors also influenced adjustment after stroke. *Conclusions:* The impacts of stroke and the processes of adjusting to it unfold over time. This presents a new challenge for resilience research. Processes of adjustment, like resilience, draw on personal, inter-personal and structural resources. But the reviewed studies point to the importance of an emic perspective on adversity, social support, and what constitutes a "good" outcome when researching resilience, and to a greater focus on embodiment.

## Keywords

Adjustment, recovery, resilience, stroke

## Implications for Rehabilitation

- Stroke is a sudden onset condition which for around a third of people has long-term consequences.
- Stroke can cause a variety of physical and cognitive impairments, some of which may not

be obvious to an outsider.

- As well as physical functioning, stroke can have a profound effect on survivors' sense of self and on their relationships.
- Stroke survivors' accounts suggest that relationships (including relationships with health care professionals) and structural factors (such as access to health services, employment possibilities and welfare systems) mediate efforts to adjust after stroke.
- While there is considerable overlap between notions of adjustment and resilience, the experiences of stroke survivors suggest further issues that need to be addressed in order to gain a more comprehensive understanding of resilience.

## Introduction

Resilience has been at the heart of a growing number of studies of health over the past decades. The term emerged in psychological studies of childhood development seeking to understand how some children living in or subject to adverse conditions nevertheless managed to appear relatively unscathed in terms of outcomes such as "normal development", "problem behavior" or psychiatric illness [1,2]. The concept has since been applied in other disciplines and to other populations, including older people [3–9], adults with disabilities [10–13] and people with terminal illnesses [14]<sup>1</sup>. Resilience research has sought to understand 1) how people achieve normal or better than expected outcomes despite exposure to ongoing risk, or living with an ongoing limitation or (2) successful adjustment following an adverse event, such as ill-health or loss. Resilience (or lack of resilience, often referred to in the resilience literature as "vulnerability") is what goes on in the black box between these start and endpoints. Research has focussed on trying to identify the factors or ingredients that lie behind "positive outcomes". Resilience studies in the health field tend to measure outcomes in terms of quality of life, subjective wellbeing and mental health, although a growing number of researchers within the field are critical of the normative tendencies in defining such outcomes [15, 16]. One might argue that these stand as proxy measures of successful adjustment. The concept of resilience is therefore potentially useful for understanding the experiences of those living with a disability or long-term condition, such as stroke.

Stroke is a prevalent [17], expensive [18], acute-onset health condition, with long term physical, psychological and social consequences for around one-third of survivors [19]. This article synthesizes studies of stroke survivors' experiences of adjusting to stroke, and considers how this body of research might help to inform an understanding of the salutogenic, or health-focussed notion of "resilience". In the area of stroke, a growing body of research is concerned to investigate the impact of stroke from the perspective of survivors but this has been framed in terms of coping, adjustment or recovery, rather

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<sup>1</sup> For a concise overview of the history of resilience research, see Richardson [84]. For an overview of contemporary resilience research across disciplines, see Luthar and Brown [85] or Windle [78].

than resilience. These terms are seldom tightly defined in stroke studies, and are often used interchangeably. But individually and collectively they have much in common with the idea of resilience. From our existing knowledge of the literature on life after stroke and resilience studies it was clear that there was potential overlap between them. But a search for peer-reviewed journal articles dealing with both stroke and resilience unearthed only one article [20]. Furthermore, the resilience literature in general contains relatively little work on resilience from the perspective of those whom researchers judge to be resilient (or not): a perspective best captured by qualitative research methods. Systematic reviews of life after stroke exist [21–27], and largely address the impact, experiences, challenges and consequences of stroke from the perspective of stroke survivors and carers. However, none to date have examined adjustment to inform the discussion on resilience post-stroke. We therefore conducted a systematic review of qualitative studies on stroke survivors' experiences and perceptions of adjustment after stroke. Our aim here was to explore whether findings on adjustment after stroke might inform current understanding of resilience.

## Methodological approach

### Inclusion and exclusion criteria

We included studies that examined adjustment or recovery or resilience after stroke, as such terms are contiguous and may be used interchangeably in qualitative studies of stroke. In order to capture the experiences and perceptions of stroke survivors themselves, we included qualitative studies, which use stroke survivors' accounts. We included studies of all stroke types, but not Transient Ischemic Attacks (TIAs), written in English in peer reviewed journals from 1990 to 2011. We chose this starting point as it was in the 1990s that research into chronic conditions, including stroke, began to foreground the efforts people made to mobilize resources and maximize favorable outcomes [28,29]. It was also the decade that resilience started to emerge in thinking about disability [11,30]. We excluded studies that were not restricted to stroke. We also excluded studies of specific clinical procedures or systems, evaluation studies, and studies restricted to specific symptoms (such as swallowing), since we felt their remit was not sufficiently wide to capture people's accounts of adjustment after stroke. We were interested in adjustment or recovery after the initial impact of stroke, so we excluded studies which focussed only on the first six months after stroke. As our review was carried out to inform an ongoing study of resilience in older stroke survivors, we aimed to focus on studies that included participants aged 60 or over. We also only included studies where participants were living in the community and for reasons of cultural relevance we excluded studies outside Anglophone and European countries. In addition, we excluded studies which solely focused on health care professionals' or on carers' perspectives (though some studies with stroke survivors included carers' views).

## Search strategy

Two authors (SS and CR) carried out the systematic search for studies. CINAHL, Social Science Citation Index (SSCI), Medline, ASSIA and Psychinfo electronic databases were searched from 1990 until 2011. The search strategy used MeSH and free text terminology combining the terms Stroke AND Qualitative AND (Adjust\* OR Recover\* OR Resilien\*) NOT evaluation. This generated 694 papers, and following the removal of duplicates, left 621 papers. During an initial screen of titles and abstracts non-relevant studies that did not meet the inclusion criteria were excluded. The majority of these focussed on functional recovery only. Full text articles were obtained for 43 studies that likely met the inclusion criteria. Reference lists of retrieved papers were also hand searched which generated an additional eight potentially relevant studies. All retrieved papers ( $N = 51$ ) were then read and assessed by SS and CR to see if they met the inclusion criteria. Any disagreements were resolved by discussion. At this stage eight papers were further eliminated as they did not meet the inclusion criteria.

## Quality appraisal

Having carried out the search, the same two authors (SS and CR) used Dixon-Woods et al.'s prompts for appraising the quality of qualitative studies, based on criteria related to the credibility of a study and its contribution [31] (see Box 1). Disagreements on quality scores were resolved by discussion.

### **Box 1. Criteria used to assess quality of included studies (following Dixon-Woods et al. [31]).**

- Are the research questions clear?
- Are the research questions suited to qualitative inquiry?
- Are the following clearly described?
  - sampling
  - data collection
  - analysis
- Are the following appropriate to the research question?
  - sampling
  - data collection
  - analysis
- Are the claims made supported by sufficient evidence?
- Are the data, interpretations, and conclusions clearly integrated?
- Does the paper make a useful contribution?

We rejected three articles that we considered “fatally flawed” in terms of quality for failing at least one of Dixon-Wood et al.'s six prompts on credibility and which also had additional weaknesses that undermined the usefulness of their contribution. The remaining articles varied somewhat in quality, but were all judged to have something to offer in terms of our

research question. This left 40 studies to be included in the review. The trail of our search process is shown in Figure 1.

## Findings

Having selected the studies to include, four authors (SS, CR, AT, CM) were involved in summarizing findings from the studies, working to a template to capture key data where this was given: details of sample (time since stroke, age, class, ethnicity, location, any other important detail); aims of the study; recruitment pool; topic covered in interviews; methods; findings. Themes and sub- themes were built up from this matrix. Interpretations were discussed, cross-checked against the papers, and cross-validated during the writing up process.

The studies included captured the experiences of adjusting after stroke for community dwelling stroke survivors in Europe and Anglophone countries. Although only 10 of the reviewed studies were restricted to those aged 60+, the remaining three quarters dealt with a wide age range, from 18 to 105 years. They focused on stroke survivors representing a broad range of time since stroke (i.e. 6 weeks to 29 years post-stroke). Six studies included the perspective of carers in addition to that of stroke survivors. Overall, it was common for studies to have excluded potential participants whose cognitive or communicative capacity was not judged suitable for participation, although two studies took people with aphasia following stroke as their target group. Further details on the included studies are given in Table 1.

## Themes emerging from existing studies on the experiences of adjustment after stroke

To highlight the fit between the stroke and resilience literatures we set out our findings from the systematic review on adjustment after stroke in a way that mirrors the logic of much resilience research, namely, the impact of an acute adverse event and adjustment to it. Stroke survivors' expectations and understandings of recovery were found to mediate adjustment to some degree, and the psychosocial elements of recovery are also viewed as contiguous with "successful" adjustment. For this reason we first outline the studies' findings on the impact of stroke as an event, and then consider expectations and experiences of recovery, before exploring reports of longer-term adjustment after the event. In presenting our findings we use italics in quotations to distinguish the words spoken by participants from those of a paper's authors.

### The impact of stroke

To understand the processes of adjustment after stroke we first need to outline the dimensions of stroke impact, as depicted in our reviewed studies. Stroke could have an

impact on many areas of life [29,32–38]. For many participants physical impairments were reported to limit survivors' activities of daily living (ADLs) [29,32,35,38–49]. Stroke could also affect a person's communication skills [29,40,45,47,50], which was reported to have a profound effect on self-confidence [45,50], and could make it difficult to sustain friendships [47]. The physical, communicative or cognitive sequelae of stroke could limit survivors' participation in work [37,38,50–53] or other valued activities [34,49,54,55] that they regarded as "an integral part of [their] pre-stroke identity" [55, pp. 325–6]. Some stroke survivors had "hidden" difficulties: finding themselves easily tired, short tempered or lacking in concentration or memory [40,41,44,46–48,50,56].

The ways in which stroke affected people's sense of identity is a common theme in studies of life after stroke [29,34,35,41,46,48,52,54,55,57–59]. Participants' sense of self as expressed through their body was evident in a number of studies [34,35,44,48]. One study noted

a distinct relationship between the experience of the lived body – the ability of "doing", and the concept of self – the experience of "being". [44, p. 9]

Particularly in the first year the body could be experienced as unreliable [35,41], unpleasant or embarrassing [41] and people might refer to their body or ill-functioning parts of their body as objects [35]. Some stroke survivors referred to their lack of energy following stroke as making them feel lazy [44,48] or old [44], while others regarded their appearance after stroke as being of an older person [46].

Changes in the balance of in/dependence in social relationships following stroke were also reported as problematic [29,32–34,41,44–46,48,49,51,55,60,61], with reduced independence sometimes reported as a loss of control [42,48,49,62]. Participants also expressed unease about becoming a burden on others [34,45,49,52,57]. Social re-positioning may not involve, and is certainly not limited to, becoming *dependent*. Four studies [34,41,60,61] reported stroke survivors' frustration at no longer being able to carry out caring activities for *others*, or sadness at no longer being needed. As Dowswell et al. [34] argue, the enforced changes in social positioning involve physical, emotional and social dimensions of being. Not only family relationships but other social positions were put at risk, such as one's position as a valuable member of the workforce [37,44,51,55] or being otherwise productive [61]. Friendships, often regarded by stroke survivors and carers as an important source of support, could either be strengthened or damaged as a consequence of stroke [33,41,45,47,50,63].

Given this breadth of potential impact it is perhaps unsurprising that a number of studies [38,43,44,46,48,52,59,60,62] make the point that stroke causes profound disruption to the lives of stroke survivors. However, a number of other studies claim that, while the impact may be considerable, for many people living in the context of poverty, aging and/or pre-

existing morbidities [34,46,52,59,61,64–67] the occurrence of stroke might appear less as devastating, and more as a “normal crisis” [66], or part of the “biographical flow” [64]. Precisely because of the difficulties of isolating the consequences of stroke some of the more recent reviewed studies excluded people with intervening medical conditions [54], serious illnesses or disorders [41,43,60], or pre-existing disability [35]. Conversely, an assumption that stroke is experienced differently by older people because they have experienced or continue to experience other difficulties, is more or less implicit in that several of the reviewed studies were restricted to older stroke survivors (aged 60+) [36,41,52,55,63,68]. In terms of impact it was also the case that stroke and its consequences moved in and out of salience in different environmental and social contexts [35,47,50,54,62].

## Recovery and adjustment

In the experiences of stroke survivors in the studies “recovery” and “adjustment” were interwoven, and this is reflected in the movement between the terms in the reviewed papers. “Recovery” in the papers consisted of three elements: recovery of function; finding practical ways of dealing with impairment (practical adjustment); and psychosocial recovery despite impairment. We embrace the last two of these in our use of the term *adjustment*. But, as we shall show, all three elements were iteratively interwoven in participants’ experience.

Many stroke survivors’ initial expectations of recovery were to return to their pre-stroke self [32,39,41,43,49,56,60]. Participants’ attitude to change in general (whether they accepted change as part of life) was reported to influence their views on recovery [54,59,67]. The experience of recovery from and adjustment to stroke is largely portrayed as non-linear, ebbing and flowing over time, presenting successes and setbacks [32,33,35,36,40,41,43, 49,50,52,56,60,62]. While some studies talk of phases of recovery [41,43,49] these are presented as distinguishable by their focal points (broadly shock, hard physical work, mental adjustment and moving forward) rather than outcomes. Yet the literature also points to an over-arching pattern of greater acceptance of stroke sequelae, and accompanying changes to recovery expectations as time unfolds [34–36,41,43,49,55,57].

Various dimensions of time appear in the process of recovery. As well as initial expectations that things should be “as before”, one study [59] points to “turning points” on the recovery journey, and another [50] to the importance of timing (or juncture). Stroke survivors talked of the need to take things more slowly whilst also keeping busy [29,41], and of the requirement to plan ahead for activities that they could previously do spontaneously [41,69]. There were conflicting accounts of the relationship between recovery and either forward- or backward-facing thinking. A number of studies note that “harking back” was associated with inhibited adjustment [34,39,48,50,52,56,61,67,69]. However, one longitudinal study of survivors with early depressive symptoms [44] argues that for their sample those who tended to refer back to their pre-stroke selves were galvanized to work towards recovery, while those who were stuck in the chaos of the present seemed unable to focus on a future. In their sample those who looked back and propelled themselves forward were also those



who felt they had a lot to live for, while those stuck in the present were older, more isolated and found less reason to strive. Other studies indicate that looking forward could provide hope of more favorable possibilities [39,40,66], though the future could also provoke feelings of uncertainty [34,37,41,48,51,52,54].

## Adjustment after stroke

Participants in the studies attributed their ability to adjust to a number of factors: personal characteristics, their own deliberative adjustment practices and social support. A number of structural factors were also reported as helping or making adjustment more difficult.

### Personal characteristics

Personal characteristics were widely reported as significant in adjusting to stroke [34,46,50,53,54]. Determination [29,32,38,40,44,52,54,60,63,70], perseverance [32,40], a positive outlook [40,42,43,45,52,54,63,71], hope [39,42,49,54,63], inner strength [39,42] have all been used to describe these key characteristics. Participants in some studies [40,52,71] highlight the importance of drawing on their own sense of humor. Ch'ng et al. [71] portray humor not merely as an innate quality, but as a viable "cognitive strategy" like relaxation or distraction, suggesting it was something that could be conjured up. Other papers do not give any insight into the work involved in mustering and maintaining a positive outlook. Furthermore, whilst uplifting characteristics were noted in a majority of articles, it was not indicated whether or how a gloomy or depressive propensity in life before stroke could impact upon adjusting after stroke.

### Adjustment practices

A vast number of articles make reference to stroke survivors' concerted efforts to adjust by various means after stroke. We distinguish between "practical strategies" (what people do on a practical, mundane level to limit the impact of stroke) and "mental strategies" (suggestive of a thoughtful or psychological approach), though we acknowledge there is some overlap between the two, particularly with respect to engaging in "meaningful" activities [29]. Conceptualizing adjustment practices in terms of this duality has parallels with Folkman and Lazarus' [72] "problem-focussed" and "emotion-focussed" coping.

*Practical strategies.* Practical strategies included: adapting one's activities [41,54,55,61] including taking things more slowly [29,43]; making home modifications [38]; relearning what had once come naturally [29,32,60]; planning [69]; exercising [29]; distractions [69,71]; keeping busy [29,50,63]; goal setting [39,63]; taking risks in an attempt to achieve a goal [29,40]; and making adjustments to keep up self-image [29,47,54,66].

A number of studies highlight the importance of engaging in meaningful activity as a key part of adjusting [34,41,49,50,54, 55,57,59,61]. This might mean making practical adjustments to continue with activities or roles enjoyed prior to the stroke [41,44,55]. A number of studies suggest that the efforts made to re-gain previous levels of physicality and functioning and to resume past activities are motivated by the desire to continue and sustain intrinsic notions of self [29,32,38,43,44,54,60,62].

*Mental strategies.* Mental strategies were also employed in adjusting after stroke. We consider these under the terms “cognitive adjustment” and “meaning-making”. We also consider “acceptance” as portrayed in the stroke studies.

A number of articles highlight the extent to which stroke survivors engage in what we call “cognitive adjustment” in response to stroke – essentially changing the way one *viewed* things, as distinct from the way one *did* things (our “practical strategies”). Three dimensions of cognitive adjustment in response to stroke are discernible in the studies. Stroke was seen to engender processes of redefining, reconsidering and re-evaluating: (1) core ideas of self [36,41]; (2) norms and values [52,58,60–62,69]; and (3) reality [57,64,66].

Two studies of older female stroke survivors remark on changes in participants’ self-understanding largely associated with bodily frailty [36,41]. They talk of “reconstruction” [41] and “transformation” [36]. Eilertsen et al. found that in one phase of recovery:

Previous ideas about whom they had hoped to become needed to be redefined. [... .] What they had thought was transient now seemed permanent. [41, p. 2010]

And Hilton comments:

Each woman embarked on an intellectual journey to reconstruct herself into who she would become. [36, p. 23]

In some studies, participants were seen to re-evaluate gendered norms and values previously key to their lives. In two of the all-female studies [41,60], some women who had previously regarded themselves as central to the needs of others, reported a degree of acceptance, over time, of help from others in what they regarded as *their* domestic role or in some instances giving up the role of “housewife” more or less entirely. Lobeck et al. [52] show that for two male participants, stroke had altered the way they viewed their relationships and the world around them. Whilst this had negative implications, positive changes were also noted. “Mr C” for example stated:

*I mean there’s things that I thought I’d never see myself doing as, as you think you gain that man role in life. I’m now changing beds with the wife and these sorts of things, er, which I’d say has brought us closer together [52, p. 1030]*

Another means of cognitive adjustment was redefining reality. Erikson et al. describes

how stroke survivors' interactions with others shaped their entry in to their "new world after stroke" [57, p. 835]. Particularly participants with children noted being almost re-socialized into family life, guided by family members' reaction to their behavior and ways of being. One stroke surviving father felt his children experienced him "as another [different] person" [57,p. 835]. Yet parents in the study also found that others' altered ways of being became automatic, and so contributed to a new reality.

Adjustment involved actively making, re-establishing or confirming meaning in the world [29,54,59,64]. This included theistic belief systems [39,63,65], a less defined sense of spirituality [63], or an existentialist understanding of life [40,54,71].

Meaning was also made and remade through narratives [32,36,39,49,54,64–66]. Becker [32] writes of an individualized "health biography" wherein highly personal and particular memories and meanings of illness experiences, feelings, pain and discomfort are woven together. Narrative was seen to be central to sharing profound experiences [39,64,66]. Comparisons between pre-stroke and the present featured heavily [34,39,44,48,50,52,58,61,67,69]. Participants also compared themselves in relation to other, worse-off stroke survivors [34,39,52,66], or to various other imagined alternatives (what *could* have happened) [40,41,61,69].

Several studies [40,55,58,69,71] note a degree of "acceptance" amongst participants over time, and suggest this is associated with better mental health and quality of life. However, we note that there is a fine line between acceptance and resignation, which might be experienced less positively. Authors of a study of hope after stroke [63] suggest that a loss of hope led to acceptance. A participant in another study said,

*I take it a day at a time now. If I wake up in the morning, very good luck to me. If I don't, I couldn't care less. [34, p. 513]*

This comment might be interpreted as acceptance, resignation or even despair. It is a challenge for researchers to escape a moral interpretation of participants' responses. One study, exploring "living successfully" with aphasia [40] found that determination and acceptance were both associated with success.

## Relationships

Some of the studies [40,55,71] emphasize the fact that social support came in different guises (practical, emotional, moral), and that individuals may provide any but not necessarily all of these. On a practical level, family members might provide help in accessing resources on behalf of the stroke survivor [45,50,58,71]. Equally important was a sense of belonging that family connectedness provided [39,57,63].

But while a stroke could make relationships with some family members closer, others might

become more distant [45,58]. Family and friends could be seen as preventing stroke survivors from doing things for themselves [51,70] and therefore hampering progress. Pound et al. found that in most cases a family member took up the role of main carer for their participants which, the authors note “necessitated a certain amount of *rearranging* in order to achieve a new balance” [Original emphasis 29: 122]. It is not always clear how such rearranging is established, or to what extent structural constraints influence decisions made.

Friendships were also noted as being an important resource. Friends helped to influence hope and foster recovery [63] or played a supportive and rehabilitative role [46]. If participants had to move home following stroke then losing touch with friends was felt as a loss [34,40,47]. But the loss of friendships is common after stroke. A study investigating the reasons behind this highlighted the difficulties and weaknesses in friendship [47]. In this and another study [62] stroke presented a catalyst for change, with stroke survivors purposely choosing to lose touch with friends who were perceived to undermine them.

Some participants reported specific benefits from joining groups specifically for stroke survivors [40,46,50,60,63,71]. A few studies [39,54,63,71] noted that people of faith identified this as an important factor, though this was not investigated in depth.

### Structural issues

The structural facilitators and hindrances in adjustment after stroke have received much less attention than the micro-level issues of individual characteristics, strategies and personal relationships, both in the reviewed studies and elsewhere [23, cf. 73]. But structural issues reported include the built environment, health care delivery and structure, information, public awareness, employment and welfare practices and policies.

Environmental difficulties were experienced in everyday scenarios, such as the lack of wheelchair accessibility or suitable transport curtailing mobility [38,47,53], or the physical difficulties faced while trying to access otherwise routine healthcare services.

Individual medical staff or rehabilitation therapists and programmes often had a big impact on stroke survivors, both positive and negative [37,42,49,53,63,69]. Unless stroke patients could pay for private care and exercise choice over the health care professionals (HCPs) who treated them, they had little influence over which HCPs they were allocated to (bar refusing treatment). To this extent the relationships with HCPs became a structural issue. On a wider scale, patients in a UK study felt that rehabilitation services stopped at an early stage of recovery, and put this down to

budgetary limits [53].

Information was regarded as a valuable resource, which participants in some studies [53,69,71] found wanting.<sup>2</sup> Another issue was widespread public ignorance surrounding issues of stroke [38,40,46,50,53], particularly “hidden” sequelae:

*you look normal so they think you're all right. They can't make allowances at all ... it's outside their normal experience [53, p. 42].*

In some cases survivors noted their shame as a result of their own moral judgment on sickness and disability prior to stroke [34,52]. Such feeling is perceived to be shared on a grander societal scale. Ignorance of employers and colleagues about the consequences of stroke and of the ways in which these could be minimized could present a barrier to work [53]. Participants also found a lack of awareness in relation to age and stroke, with younger stroke survivors reporting that this was reflected in poor service provision for their age group.

Given the importance of “identity-defining activities or roles” [55] noted earlier, and the fact that stroke has a long-term financial impact,<sup>3</sup> returning to work is a highly salient issue, and was seen as an emotional and functional milestone in recovery [51]. Paid work has been found to facilitate successful adjustment after stroke by: keeping respondents busy; engaging them in physical, mental and social activity; supporting their identity as a worker or contributor; and boosting their income [37]. Volunteering provided many of these benefits too [37,50,53]. However, the following factors influenced experiences of employment after stroke: employers’ willingness to adapt to stroke survivors’ situation [37,51,53]; the legislative infrastructure on sick leave and pay and on disability discrimination; employers’ familiarity with or willing to implement such legislation [53]; and discriminatory reactions amongst colleagues and prospective employers [51]. In addition, uncertainty about whether a return to work would be sustainable, given the consequences of stroke, made some participants reluctant to sign off income support benefits, which had often been difficult to access [51,53]. Some of the participants in Lock et al.’s UK study [53] returned to work for fewer hours or in a role below their abilities so as to sustain their eligibility for benefits, rather than risk losing them altogether. Others, in Hartke et al. [51], reduced their work commitments to minimize stress and in the hope of avoiding another stroke – a decision often prompted by other people.

## Discussion

How can these studies of adjusting after stroke add to or challenge current understandings of

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<sup>2</sup> This is supported by findings from a UK survey showing that over half of respondents said they wanted more information about their stroke (cause, prevention, recurrence) than they were given [86]

<sup>3</sup> 18% of participants in the above survey reported a loss in income, and 31% an increase in expenses up to 5 years post-stroke [86].

resilience? To better observe the “fit” between qualitative findings on adjustment after stroke and current understandings of resilience we attempted to enforce a division between the impact of stroke as an acute adverse event, and then the longer-term adjustment after the event. Resilience studies tend to divide along these lines in their scope of enquiry, examining *either* “bouncing back” from an event *or* living in a situation of ongoing risk. This temporal distinction is somewhat problematic for several reasons. Stroke presents those it touches with *both* of these problems. Although not emerging as a major theme in the reviewed papers it appeared that people experienced uncertainty about recurrence, which we suggest may cast a shadow over progress to adjustment or recovery. So in practice, we argue that stroke was more often experienced by people after stroke as a sudden and disturbing event, and that its impact could be ongoing, sometimes moving in and out of salience in different contexts. Dealing within and across timeframes is not necessarily incompatible with the concept of resilience, and the study of acute-onset long-term conditions affords an interesting opportunity for a fresh resilience perspective.

It is clear that the studies of adjustment after stroke support the argument made in resilience studies that resilience operates on three levels – individual, interpersonal and (in principle at least, though this is often neglected in empirical studies) structural, and that these levels interact. On the individual level, reviews of the development of resilience theory have argued that there has been a broadening out from a focus on resilience as a personality trait to include the social processes of resilience [3,16,74]. What is interesting about the stroke studies reviewed here is that stroke survivors themselves confer great (though not sole) importance to personal characteristics in adjusting after stroke. The mental strategy of making downward comparisons, which was found to be important in adjusting after stroke, is not something noted in the resilience literature.

As well as these “levels”, the resilience literature uses the term “domain” to describe an area of functioning that might be affected by an acute event, such as stroke, and in which resilience might become evident at varying levels [6,14,75–78]. Consequently reference is made to physical resilience, psycho-logical resilience, social, spiritual, financial, environmental or mobility resilience and so on. It has been argued that resilience should be studied within different domains, in part because resilience or vulnerability can occur in one but not all domains. Variability in adjustment between areas of experience is also evident in the reported stories of stroke survivors. But these stroke studies also illustrate the inter-connection and permeability between different domains. The studies highlight the entanglement of stroke sequelae: the ways in which physical or cognitive impairments can be exacerbated by a lack of public understanding, and are tightly bound up with psychological markers such as self-image or self-confidence, and with social relationships. It has been argued that physicality and embodiment are relatively neglected in resilience studies [79]. Our review demonstrates that these issues have *particular* consequences, which should be considered in studies of resilience.

The finding that adjustment after stroke is variable over time and context has its parallel in the resilience literature, where resilience is seen to be dynamic and variable over time [2,15,16,77].

While time is often tacitly assumed to play a part in resilience, with limited exceptions [cf. 15,56] the resilience literature has paid little attention to the detail of temporal experience. Masten, writing about the “ordinary magic” of resilience, states that the “new frontier” of resilience research lies in

investigating how the individual as a complex living system interacts effectively and ineffectively over time with the systems in which it is embedded. [80, pp. 234–5]

The reviewed stroke studies point to many temporal nuances in the recovery and adjustment process. These findings suggest that understandings of resilience would be improved by a more explicit focus on temporal experience.

Those studies that embrace the notion that stroke is not a stand-alone or unique acute event [34,46,52,59,61,64–67] highlight the dangers of pre-defining or pre-supposing adversity. This synthesis also exposes factors that make assumptions about “good outcomes” problematic. First, we have argued that “acceptance” lies somewhere on a continuum between despair, resignation and adjustment, and that there is a wide scope for researcher (or reader) interpretation, which may include a moral judgment on “successful” adjustment. Second, there is the importance of meaning in people’s experiences of adjustment. This has particular relevance for quantitative resilience studies, which often read off “adversity” from statistically identified risk factors and which use “flat” and normative outcome measures.<sup>4</sup> On the other hand, some qualitative studies of resilience have argued the importance of narrative reconstruction as a resilience practice [4,10,14] and that the interview process is helpful in this respect [81].

Like the studies of adjustment after stroke, studies of resilience have found that “social support” in the form of family, friends and peers were found to be an important resource [3–5,9–11,14,30]. But the reviewed studies also provide a cautionary tale that social networks are not necessarily experienced as supportive. Furthermore, not *all* significant others will be able to provide the different kinds of support that participants found helpful – practical, emotional and moral. They also show that limitations on stroke survivors’ ability to *provide* support, or otherwise make a useful contribution through work or other activities, can be a source of anxiety and regret. Furthermore, overall and specific changes in the balance of dependence can be experienced as problematic by survivors and by carers. Given the interconnections between survivors and those close to them it could be argued that resilience in a stroke survivor is contingent on the resilience of the carer, as researchers of “family resilience” in cases of childhood cancer and heart disease have noted [82,83].

Structural issues have not been adequately dealt with in resilience research [76]. Findings from studies of adjustment after stroke illustrate structural factors in the realms of: mobility, access, information, public awareness, HCPs, employers, employment legislation, and benefit systems. However, in stroke research, as in resilience research, there is an “ongoing under-theorisation of the role that wider contextual and ‘structural’ factors play” [76, p. 147].

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<sup>4</sup> It must be said that these assumptions have also been challenged by certain resiliency theorists [15,16]

The review suggests a number of lines of enquiry for the future. The studies reviewed here mainly excluded the experiences of people with cognitive or communication problems, and those living in institutionalized care settings, which in part limits the generalizability of our findings to the general stroke population. Further research with these groups is warranted. Time since stroke appears as an important factor in explaining stroke survivors' experiences. But greater attention to the role of time more generally, using a temporal sensibility, might prove an interesting dimension to the study of life after stroke. Further attention to the role of structural factors is also warranted since this appears to be less well studied. In the UK context at least, current reductions in social care budgets, changes to disability benefit systems, and healthcare re-structuring suggest an urgent need for an understanding of the structural barriers to adjustment for people who have survived a stroke.

We have also learnt some useful lessons on how resilience theory might help us to better understand the experiences of adjusting after stroke, which we summarize briefly here. Resilience studies have argued that troubles in one domain of life can spill over into other domains, while resilience in one domain will not necessarily transfer to another domain [6,15,75– 77]. This understanding of resilience might help us to reconcile conflicting evidence on the role that past experience plays in adjusting after stroke. While past experience of adversity *might* help one to adjust, we should not assume that this will be the case, nor that resilience can be gained from experience. Perhaps the greatest contribution from studies of resilience is that they offer a way of theorizing processes and practices of adjustment. We have found recent work that is either explicitly [15,16] or implicitly [76] reflective of an “ecological systems theory” of resilience the most useful for understanding stroke. This emphasises the nested layers of context surrounding the individual (from families to policies and the built environment), and the mutually shaping relationship between the individual and their context. The interpretation or meaning-making of resources and available alternatives is a mediating factor in the resilience-promoting process. Such a theoretical perspective offers us a better grasp of the efforts and actions of stroke survivors in understanding adjustment after stroke, particularly the activity involved in mustering what might be regarded as innate (“passive”) personality traits. According to studies from this perspective it is not just the existence of resources that matters, but the ability to negotiate access to them [3–6,11,12,14,16,76,78], and to convert resources into personally meaningful positive outcomes [6,15,16,76].

## Declaration of interest

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Figure 1 Identifying review studies

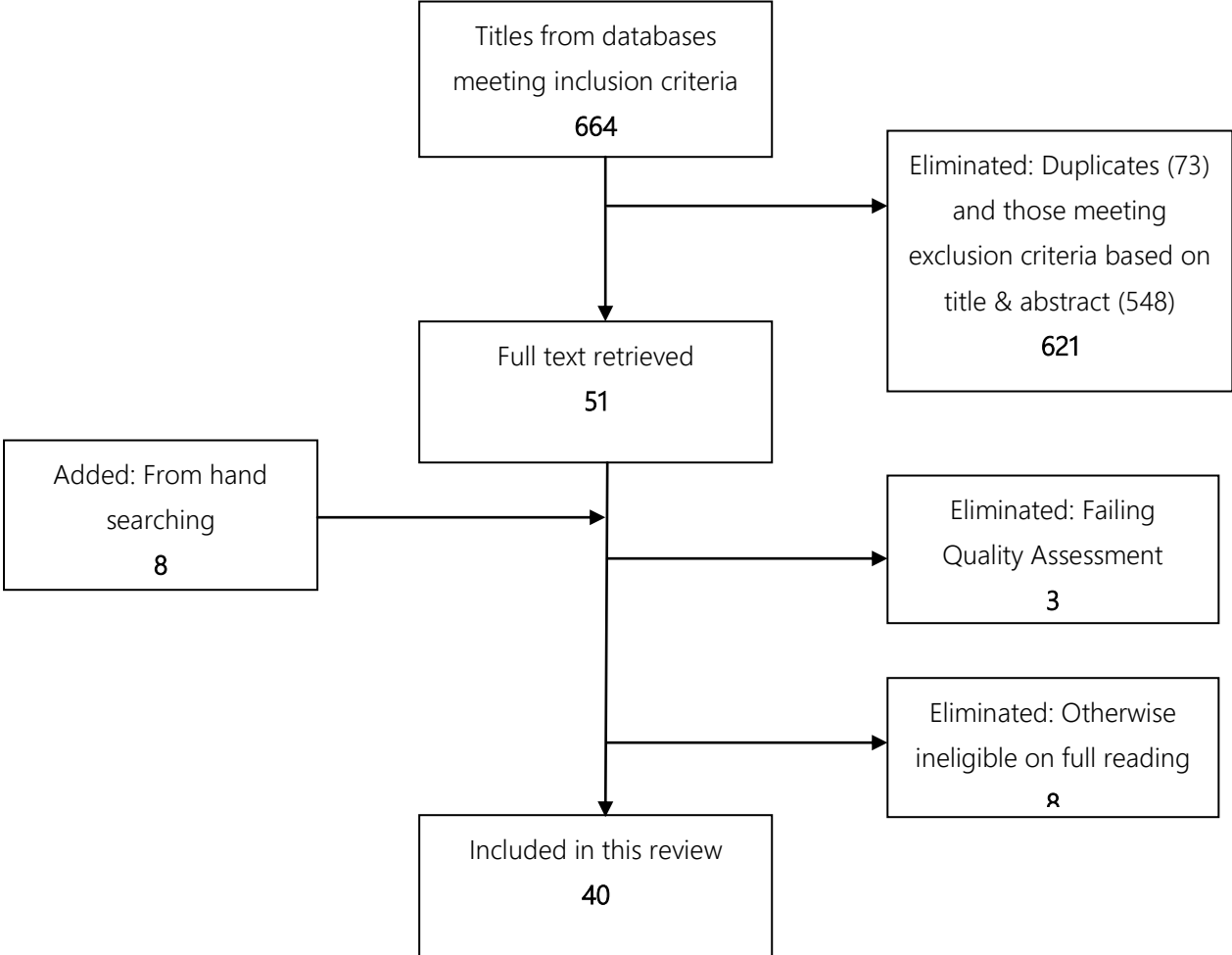


Table 1: Literature on experiences and perceptions of adjusting after stroke for community-dwelling stroke survivors [40]

Key: <sup>1</sup>TSS = time since stroke    <sup>2</sup>SS = stroke survivor    <sup>3</sup>AE=Astheno Emotional syndrome (mental fatigability, concentration and memory, irritability etc.)    <sup>4</sup>ADL = Activities of daily living  
 HCP= Health care professional    SEG=Socio-economic group    HHT=Household type

No.	Author (Year)	Sample Number x description – TSS <sup>1</sup> ; age; class; ethnic <sup>y</sup> ; other detail (location)	Aims	Topics	Methods	Findings	Implications for our study		
1.	Bays (2001)  CR	9 x SSs; TS( <i>most recent</i> )S mean of 29.89 months; mean age 68.22 yrs.; 6f 3m <sup>4</sup> ; 8 C <sup>5</sup> , 1 AA <sup>6</sup> ; living arrangements given; all participants members of church; range of impairments; (US)  Local support group as study pop. Inc/ exc criteria provided.	Investigating the meaning of hope for older SSs for purpose of illuminating previously unknown area AND improve nursing.	Patterns of hope manifested in older adults after a stroke? ( <i>Descriptors of hope: what is hope?</i> ) Factors associated with those patterns? ( <i>Describing what/ how/ when of hope</i> )	Rogers' 'homeodynamics' theory employed as frame. Pilot study amongst 3 SSs, larger study inc 9. Semi-structured interviews.	<table border="1"> <tr> <td data-bbox="1167 496 1420 1102"> <u>Themes related to hope</u> <ul style="list-style-type: none"> <li>• Positive anticipation</li> <li>• Active participation</li> <li>• A forward moving process</li> <li>• Inner sense/ strength</li> <li>• Faith in God</li> <li>• Continuing to hope</li> <li>• Relative comparison</li> <li>• Hope as sustaining life</li> <li>• Realistic possibilities</li> <li>• Connectedness</li> <li>• Hope to return to previous abilities</li> <li>• Mobility</li> </ul> </td> <td data-bbox="1420 496 1675 1102"> <u>Factors in hope-related patterns</u> <ul style="list-style-type: none"> <li>• Family connectedness</li> <li>• Spiritual connectedness</li> <li>• Goal achievement_</li> </ul>   <u>Implications for nursing</u> <ul style="list-style-type: none"> <li>• Importance of nursing in fostering hope</li> <li>• Importance of narrative</li> </ul> </td> </tr> </table>	<u>Themes related to hope</u> <ul style="list-style-type: none"> <li>• Positive anticipation</li> <li>• Active participation</li> <li>• A forward moving process</li> <li>• Inner sense/ strength</li> <li>• Faith in God</li> <li>• Continuing to hope</li> <li>• Relative comparison</li> <li>• Hope as sustaining life</li> <li>• Realistic possibilities</li> <li>• Connectedness</li> <li>• Hope to return to previous abilities</li> <li>• Mobility</li> </ul>	<u>Factors in hope-related patterns</u> <ul style="list-style-type: none"> <li>• Family connectedness</li> <li>• Spiritual connectedness</li> <li>• Goal achievement_</li> </ul> <u>Implications for nursing</u> <ul style="list-style-type: none"> <li>• Importance of nursing in fostering hope</li> <li>• Importance of narrative</li> </ul>	<ul style="list-style-type: none"> <li>• Whilst the study notes themes other than faith in God, to what extent does the fact that all participants were church members impact on the way that hope was conceptualised amongst this particular group (<i>a point also noted by the authors</i>).</li> <li>• Inner strength and 'looking out'.</li> <li>• Place of narrative.</li> <li>• (*See Cross &amp; Schneider 2010)</li> </ul>
<u>Themes related to hope</u> <ul style="list-style-type: none"> <li>• Positive anticipation</li> <li>• Active participation</li> <li>• A forward moving process</li> <li>• Inner sense/ strength</li> <li>• Faith in God</li> <li>• Continuing to hope</li> <li>• Relative comparison</li> <li>• Hope as sustaining life</li> <li>• Realistic possibilities</li> <li>• Connectedness</li> <li>• Hope to return to previous abilities</li> <li>• Mobility</li> </ul>	<u>Factors in hope-related patterns</u> <ul style="list-style-type: none"> <li>• Family connectedness</li> <li>• Spiritual connectedness</li> <li>• Goal achievement_</li> </ul> <u>Implications for nursing</u> <ul style="list-style-type: none"> <li>• Importance of nursing in fostering hope</li> <li>• Importance of narrative</li> </ul>								
2.	Becker (1993)  SS	100 x SSs; age 50-105 (62% in 70s and 80s); TSS 0–4 mths and followed up for 1 year; 62f, 38m; 64 white, 30 Af-Am, 6 other. (US)	Examination of life-course disruption caused by stroke and strategies used to create continuity.	Stroke onset; rehab; feelings about disability, recovery, loss, disruption; views of services; social support; the future.	Paper based on 2 studies between 1988 and 1991. 3 x ints each over 1 year. Study 1 (64 respondents) began in hospital. 2 <sup>nd</sup> study (36	<ul style="list-style-type: none"> <li>• Stroke seen as a profound disruption.</li> <li>• Stroke affected independence in ADLs, mobility, choice of activities, ability to leave home alone, ability to be home alone.</li> <li>• Clinical-lay mis-match re. recovery. SSs sought complete return to pre-stroke.</li> <li>• Initial shock of physical deformity and impairment. Then facing up to limitations in their daily lives at home.</li> <li>• Seeking for continuity w/ old self required</li> </ul>	<ul style="list-style-type: none"> <li>• Recovery over time.</li> <li>• <i>Article doesn't address 'What lay behind the ability to create continuity?', so gap in the lit.</i></li> <li>• Respondents draw on 'perseverance' (though not clear if this is their word). Authors talk about strategies. So, trait and agency. <i>No discussion of structure in this paper.</i></li> <li>• What meaningful activities have respondents managed to sustain? How?</li> </ul>		

					<p>respondents) approx 4 months after stroke. Part-obs in hospital forms background.</p>	<p>life re-organization. For the majority this process was still ongoing at end of the study (12-16 mths. post stroke.)</p> <ul style="list-style-type: none"> <li>• Focus on tiny incremental gains.</li> <li>• Respondents attributed achievement of continuities amid overwhelming discontinuity to <b>perseverance</b>.</li> <li>• Strategies of adaptation in effort to <b>close the gap</b> between then and now.</li> <li>• “Some persons with this level of impairment demonstrated an ability to create a sense of continuity; others did not.” (156). <b>Why?</b></li> <li>• “a holistic approach [to continuity] is needed. Such an approach would extend the continuity construct to encompass discontinuity, incorporate interpretive approaches, reflect change as well as stability, include routine daily life as well as broader social and temporal patterns, and analyze subjective links between meanings and objective measures of function, while placing them in their social context.” (158)</li> </ul>	<p>(strategies). But also ....</p> <ul style="list-style-type: none"> <li>• Struggle for a sense of continuity as a sign of meaning-making. “continuity itself is apparently an illusion, but the preservation or restoration of that illusion enables individuals to view their lives as having order and consistency in the midst of change.” (156). <b>So, how do people frame their strategies?</b></li> <li>• [Other studies indicate that successful adjustment draws on finding meanings in <b>dis-continuity</b>, i.e. an enforced slow down or a re-evaluation of what matters in life]</li> </ul>
3	<p>Brown et al (2010)</p> <p>SS</p>	<p>25 x SSs<sup>2</sup> w/ (mild to severe) aphasia; TSS 2+yrs; aged 38-86; range of socio-economic status; range of HHT. (Australia)</p> <p>Recruitment – self-selected from wide net. NOT selected on basis of living successfully with aphasia [LSA].</p>	<p>Explore the meaning of “living successfully w/ aphasia”, i.e. as seen by respondents</p>	<p>General ideas about living successfully w/ aphasia; self-rating (and why); high points; role models; what helps; advice.</p>	<p>Semi structured interviews + taking photos + photo-elicited interviews.</p>	<ul style="list-style-type: none"> <li>• Resp<sup>s</sup> drew on what they had now (i.e. life with their partner) to explain success; and conversely on what they had lost or what they lacked as contributing to a lack of success. ie both sides could identify w/ the notion and position themselves according to it.</li> <li>• LSA was multi-faceted and highly individualised.</li> <li>• Core themes in success were: Doing things as a strategy [i.e. “not just sitting @ home”]; meaningful relationships; striving towards a positive way of life; communication. Also: physicality; external support; living @ home (*See Dowsnell); public ignorance.</li> <li>• Continued acceptance by others &amp; continuity in roles, i.e. <i>contributing</i> to family life.</li> </ul>	<ul style="list-style-type: none"> <li>• “Living successfully” may be a contiguous concept to R. It may be another outcome measure of R. But some of the factors contributing to success were the ability to draw on internal resources.</li> <li>• Doing things as a strategy – what activities or roles have been unaffected / what have you continued via adaptation / new activities or roles?</li> <li>• Why is it important to keep active? (Probe - independence, achievement, sense of purpose, pleasure, mental [or physical] stimulation)</li> <li>• Different kinds of support (not <b>pity</b>) – practical, emotional, moral. ‘Being there’.</li> <li>• Have they met others in the same boat? How? Peer support?</li> <li>• Explore ‘Have a go attitude’.</li> <li>• Need to keep TSS tight.</li> </ul>



						<ul style="list-style-type: none"> <li>• Knowing others in same boat.</li> <li>• Outlook – positive attitude; determination [to change what you can]; accepting what you cannot change (<i>*This combo also found in Young &amp; McNicoll's (1998) study of positive life experiences in people with ALS [locked in syndrome]; getting on w/ life; looking forward; re-framing (i.e. advantages of slowing down; changing priorities); [being grateful for small mercies] (*Also found in user group. As was 'determination'); taking risks [have a go attitude]; adaptive strategies; sense of humour (*Young &amp; McNicoll (1998)).</i></li> <li>• Improvement over time.</li> </ul>	<ul style="list-style-type: none"> <li>• Impact on communication v. important (whether talking, understanding, reading or writing) so need to get at how the interviewee is affected in this way.</li> </ul>
4	Burton (2000)  SS	6 x SSs; TSS 0-12 mths.; 4 f, 2m; aged 52-81. (NW England, UK)	Living w/ stroke	Story of your stroke; updates	Longitudinal. Monthly ints for 1 year post stroke.	<ul style="list-style-type: none"> <li>• Impact of (and recovery from) stroke felt in all aspects of life.</li> <li>• The taken-for granted became challenging / unfamiliar.</li> <li>• Physical or emotional <b>recovery not linear</b>.</li> <li>• The ability to <i>cope</i> w/ physical impairments may be as or more meaningful than physical improvement or adaptation.</li> <li>• All respondents reported that their roles and responsibilities were threatened (vis. work, finance, family, friends).</li> </ul>	<ul style="list-style-type: none"> <li>• Worth asking respondents to describe a good day / event and a bad day / event. What made them so? [taps into meanings and context]</li> <li>• What are the goals of recovery for the indiv SS? Have they changed over time?</li> </ul>
5	Carlsson et al (2009)  SS	18 xSSs w/ mild stroke AND AE <sup>3</sup> (i.e. <i>not</i> coping well); age 30-69 at time of stroke; all living w/ a partner; range of occupations; no other intervening illnesses. (Sweden)	Investigate "coping" after mild stroke. "Coping is ... embedded in complex contexts + is a dynamic process that includes the person + the environment in transaction, in which	Experience of: stroke event, health care & rehab; their view of life and the future.	Semi-structured interviews	<p>[Overall the analysis is arranged thematically and does a rather confusing job of higher-level analysis].</p> <ul style="list-style-type: none"> <li>• Had to cope w/ having had a life-threatening condition and living w/ risk and uncertainty (<i>*Also found in user group</i>), as well as w/ limitations of activities and participation.</li> <li>• 'Self-reliance' [self-efficacy] – making adjustments to keep up self image, like avoiding difficult situations, wishful thinking.</li> <li>• Finding meaning in activities (and adapting to continue activities that gave them meaning).</li> <li>• People attributed coping (or not) to</li> </ul>	<ul style="list-style-type: none"> <li>• The definition of coping that Carlsson draws on (Lazarus 1999) seems to incorporate strategies as well as mental and emotional processes. Pound et al (1999) differentiate coping and strategies. Which is more useful to us?</li> <li>• Do individual traits feature in people's accounts? Is it worth asking directly whether they attribute R to traits?</li> <li>• What's the relationship between faith and fatalism? Does fatalism make you accepting (good?) or morose (bad?)</li> <li>• It might be useful to use a snapshot (can you describe your day yesterday) as part of the interview, alongside a more retrospective, longer time-frame approach.</li> </ul>

			meaning is also an important feature [19].” (p.774)			<p>personality traits – being a worrier, an optimist, stubborn or competitive.</p> <ul style="list-style-type: none"> <li>• Faith important for some</li> </ul>	
6	Ch’Ng et al (2008)  SS	26 x SSs; aged 22 – 79; TSS 6mths – 12 yrs. Recruited from stroke support groups  (Australia)	Explore long-term perspectives on coping w/ recovery from stroke (to inform psychological interventions)	What are the challenges after stroke (short and longer-term); what has helped/ would have respondents to cope?	6 x focus groups	<ul style="list-style-type: none"> <li>• 3 themes of coping: social support, active / behavioural strategies, cognitive strategies.</li> <li>• Social support could be practical or emotional (care, encouragement).</li> <li>• Peer support from SS groups (social gathering, feel understood; situation normalised; practical tips).</li> <li>• Behavioural strategies – info-seeking; participation in rehabilitation [drawing on and engaging w/ external resources], problem-solving strategies (adapting and working a way around a problem) [internal resources], activities [inter-personal resources].</li> <li>• Cognitive strategies – acceptance [coming to terms]; “positive reinterpretation, taking a philosophical approach”; appreciating life, less emphasis on material goods [looking outwards]; humour; faith [looking outwards]; distraction</li> </ul>	<ul style="list-style-type: none"> <li>• A differentiation between behavioural and cognitive strategies may be useful in the analysis.</li> <li>• Internal, interpersonal and external resources.</li> <li>• ‘Looking outwards’ can be faith based or existential.</li> </ul>
7	Clarke (2003)  SS	8 x SSs; TSS 7mths – 9 yrs.; aged 60 - 89; middle class; white; various levels of residual impairment (though not w/ severe cognitive or communication problems); high and low social support (self-defined). (Canada). Fieldwork 2000.	[investigate the factors influencing subjective well-being following stroke [a chronic disabling condition].” (172)		Quant& qual study. Analysis of national survey to explore patterns and correlates of well-being following S. +	<ul style="list-style-type: none"> <li>• Same data as reported more fully in Clarke &amp; Black 2005 (number 8)</li> </ul>	<ul style="list-style-type: none"> <li>•</li> </ul>
8	*Clarke & Black (2005)	8x SS; TSS 7mths – 9 yrs.; aged 60-81	Underlying process by		Semi-structured interviews	<ul style="list-style-type: none"> <li>• “physical and cognitive disability are especially problematic for survivors’ [QoL]</li> </ul>	<ul style="list-style-type: none"> <li>• Discussion of “disability paradox”</li> <li>• What were respondents’ ‘self-defining’</li> </ul>

	SS	[actually 89]; middle class; white; range of phys impairment and of social support (self-defined) (Canada). [Fieldwork 2000]	which subjective QoL = maintained / lost following stroke			<p>if they infringe on or limit an individual's ability to return to activities that are integral to that person's identity." (p.332)</p> <ul style="list-style-type: none"> <li>• Adaptation strategies can minimize the impact of disability.</li> <li>• Services (OT, transport) can help SSs to maintain identity-defining activities / roles.</li> <li>• Social support can be instrumental +/- emotional. Some carers may only be able to provide one aspect.</li> <li>• Worry about impact on others (*See Dowsell).</li> <li>• Dynamic interaction between individual and social factors.</li> <li>• &gt; TSS -&gt; greater acceptance in accounts of SSs</li> </ul>	<p>activities / roles, and how have they been impacted on?</p> <ul style="list-style-type: none"> <li>• Have they managed to adapt their activities in order to keep them up?</li> <li>• Have they had any social / service support that has helped them to keep up self-defining activities / roles?</li> <li>• What instrumental and what emotional support have they had, and from where?</li> <li>• Important to keep the time-frame of TSS tight in the sample.</li> </ul>
9	Cross & Schneider (2010)  SS	<p>10 x SSs; TSS 1–13 yrs.; aged 71-100; range of impairments. (Canada)</p> <p>Recruited from a medical clinic and a convent!</p>	Explore the perceived influence of hope on stroke recovery in women	Circs leading up to stroke; the recovery process; perceived influence of hope on recovery; present life & future hope.	Completed 2 scales (HHI hope scale and the GHS hopelessness scale) as background data. Semi-structured ints.	<ul style="list-style-type: none"> <li>• "Hope is a multidimensional concept that has a subconscious and ongoing impact on stroke recovery. It is a silent motivator that keeps individuals fighting and maintains their spirits." (487)</li> <li>• Hope needed progress to thrive.</li> <li>• Loss of hope -&gt; acceptance [serenity prayer]</li> <li>• Hope influenced by: <ul style="list-style-type: none"> <li><b>'External factors':</b> <ul style="list-style-type: none"> <li>- Support systems (family, friends, therapists, services).</li> <li>- Other SSs.</li> </ul> </li> <li><b>'Internal factors':</b> <ul style="list-style-type: none"> <li>- Determination.</li> <li>- Positive attitude</li> <li>- Spirituality</li> </ul> </li> <li><b>'Personal factors':</b> ("These factors influence an individual's participation in recovery and the pursuit of external resources to aid them in the journey to a successful recovery." (490) <ul style="list-style-type: none"> <li>- Personal progress / incremental improvements.</li> <li>- Goal setting (though not always an explicit coping mechanism)</li> </ul> </li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• <del>[More women get strokes and are left w/ greater disabilities than men. Death rate around twice that of breast cancer.]</del></li> <li>• Recruitment from convent may have led to a conflation between hope and faith?</li> <li>• Recruitment channels and research question may have -&gt; a predominance of hopeful respondents.</li> <li>• Importance of knowledge and of having the internal resources to navigate towards other resources.</li> <li>• Wide range of TSS, so recall and accounting variable.</li> <li>• (* See Bays 2001)</li> </ul>

						<ul style="list-style-type: none"> <li>- Being active (inc. helping others)</li> <li>- Knowledge</li> <li>• Hope was an often unacknowledged backbone of recovery (492).</li> </ul>	
10	* Dowswell et al (2000)  SS	30 x SSs + 15 caregivers; TSS 13-16 mths.; stratified by stroke severity.  (UK)	To access detailed description of psycho-social difficulties associated w/ stroke; consider the benefits of a qualitative dimension.  What matters to patients and caregivers in the recovery process, and how do they measure recovery?	Impact of stroke; services received; perceptions of the recovery process; obstacles to recovery.	Designed to complement parallel quant study.  Semi-structured interviews. Patients and carers interviewed separately.	<ul style="list-style-type: none"> <li>• Recovery perceived in terms of the degree of congruence between their lives pre- and post-stroke (and occasionally using other SSs as a benchmark).</li> <li>• “Progress was not absolute or measured against external criteria, it was personally defined and took account of previous abilities, activities and roles.” (510)</li> <li>• Patients experienced life holistically, not in terms of physical, emotional, social.</li> <li>• Differences from own and (how they perceived) professional views of recovery.</li> <li>- What is successful adjustment? “I take it a day at a time now. If I wake up in the morning, very good luck to me. If I don’t, I couldn’t care less.” (513).</li> <li>- A patient w/ a Barthel Index score of 20 still said, referring to leisure activities] “Everything I liked has gone” (511)</li> <li>• Enforced changes in social positioning involving physical, emotional &amp; social dimensions of being (“I can’t bake a cake for a birthday”).</li> <li>• Secondary effects – having to move home affects social networks (*Also in Brown et al (2010)).</li> <li>• Worry about impact on others (*Also in Clarke and Black (2005) and user group). “I think I’d be better off not being here. Well, my daughter would be better off with me not being here because I’m ruining her life” (512).</li> <li>• Change in expectations over time – from seeing impact as temporary and malleable to realization this may not be so (difficult to accept). (*See Eilertsen).</li> <li>• Frustration. This is related to fact that pre-stroke self used as yardstick of recovery.</li> </ul>	<ul style="list-style-type: none"> <li>• Need to widen the focus of rehab to include affective and social dimensions of recovery, and to do so over the longer-term. What do they consist of and how are they linked?</li> <li>• Stroke has physical, social and psychological consequences [and so all these dimensions must be considered in a study of recovery].</li> <li>• The paper contains a well-presented rationale for emic qualitative studies on recovery from stroke (p.508-9).</li> <li>• Nice, succinct methods write-up.</li> <li>• Need to take a holistic approach in data collection and analysis.</li> <li>• Do WE take a view on “successful adjustment”?</li> <li>• Difficulty of separating the effects of stroke from those of ageing or other health issues.</li> <li>• Look at shame. [In the user group some people mentioned that being compassionate and patient helped them to adjust].</li> <li>• What has their journey of recovery / adaptation been like? Changes in expectations along the way?</li> </ul>

						<ul style="list-style-type: none"> <li>• Some felt ashamed as a result of their own moral judgement on sickness / disability.</li> <li>• “Adjustment was not merely an adjustment to impairment and disability, it was also an adjustment to an unspecified prognosis.” (514) (<i>*Also in Brown et al (2010)</i>).</li> </ul>	
11	Eilertsen et al (2010)  SS	6 x SSs; TSS 0-24 mths. (longitudinal study); aged 68-83; all women; mild – moderate functional deficits. (Norway)	Illuminate older women’s experiences and the characteristics of the recovery process following a stroke.	Respondents experiences of their body, their self-understanding and the impact of stroke on their daily lives.	Series of 12-24 semi-structured interviews during first 24mths post stroke	<ul style="list-style-type: none"> <li>• 4 distinct phases of recovery distinguishable by changes in focus: (0-2 mths.) concern w/ bodily changes; (2-6 mths.) activities of daily living; (6-12 mths.) self-understanding [re-defining the self]; (12-24 mths.) getting on w/ life. Changes in expectations of recovery over time, starting with ‘this will pass’ (<i>*Also in Dowswell et al (2000)</i>).</li> <li>• [Grateful for small mercies] (<i>*Also in user group</i>).</li> <li>• Labours of love and identity (i.e. baking (<i>*Also in Dowswell et al (2000)</i>): “Woven into the mundane tasks [of everyday living] were values that confirmed the women’s understanding of self: as spouse, mother, grandmother and friend. The reason for the struggle to resume previous activities could thus be understood at different levels. From a practical perspective, it concerned the ability to perform household duties. From an existential perspective, it concerned their engagement in meaningful work that supported and maintained the understanding of the self” (2009)</li> <li>• [Some interesting temporal dimensions: slow but busy w/ appointments, need for planning ahead]</li> <li>• Continuing uncertainty.</li> <li>• Associating stroke sequelae w/ age (p.2010)</li> <li>• Re-evaluating life</li> </ul>	<ul style="list-style-type: none"> <li>• Authors identified 3 major themes in <i>existing</i> lit of SS experiences: bodily changes; changes in everyday life; changes in the understanding of self. Useful hangers?</li> <li>• Changes in expectations of recovery? Re-definitions of the self?</li> <li>• Impact on social roles and identities?</li> </ul> <ul style="list-style-type: none"> <li>• Stroke &amp; ageing</li> <li>• Positive result of stroke</li> </ul>

12	Ekstam et al (2011)  AT	2 couples, couple A: wheelchair user f 77; TSS 5 weeks; married to m 79 carer. Lived in country in Sweden  Couple B : m 80 TSS 10 weeks; Married to f 70 carer. Lived in apartment in city and country cottage in Sweden.  Recruitment from different geriatric clinics in Stockholm. (Sweden)	To describe 2 couples' approaches to changes in everyday life during the first year after a stroke; how they viewed rehabilitation; their own personal training relative to changes in everyday life.	The experiences of everyday life after stroke. Goals, expectations, concerns, worries, experiences in everyday life from an occupational perspective (personal care, IADLs, leisure & other activities regarded as important). Views of rehabilitation, including perception of own & professional's roles	Initial interview in hospital, then in participants' homes. Both working from an interview guide + formal questionnaire. QoL from SF – 36 scale	<ul style="list-style-type: none"> <li>• The couples had different experiences.</li> <li>• In couple A SS adapted well and resumed many of her previous occupations in the home. She experienced more experience and feedback from doing than B. She started to engage in occupations. She seemed to really want to get better.</li> <li>• In couple B ss appeared to be waiting to get better. He did not engage in occupations that he had previously done.</li> <li>• In couple A the carer actively encouraged the ss and actively withdrew from some activities to help</li> <li>• In couple B the carer found it easier to do things for the ss</li> <li>• In couple A the ss went regularly for rehabilitation and practiced at home supported by the carer</li> <li>• In couple B they were not impressed with the rehab team who wanted him to engage in the same activities as before the stroke whereas they wanted his leg and hand restored</li> </ul>	<ul style="list-style-type: none"> <li>• Getting experience and thereby feedback from doing was found to be a key 'driver' in the process</li> <li>• Wanting small steps to normality seems a more realistic approach than waiting to be completely restored quicker</li> <li>• Couple A were able to integrate the training into their everyday lives</li> <li>• It is important to listen to the views of the ss and the carers. One reason why ss A seemed to do better was that the aims of the rehab matched their expectations of B where they did not.</li> <li>• The spouse (carer) is a client too and needs to have their views taken account of.</li> <li>• [No explanation given for the differences. Indicates a gap re. underlying factors. Resilience?]</li> </ul>
13	* Ellis-Hill et al (2000)  SS	8 x Ss + their spouses; TSS 0- 16 mths.; age 56-82 (mean 67); 7 Cau, 1 Af-Car; 5m, 3f; no prev. serious disability. (Southampton, UK)	Explore perceived life & identity changes	Past, present and future life story.	Life narrative approach.  Longitudinal interviews (in hosp, 6mths + 12 mths post-discharge).	<ul style="list-style-type: none"> <li>• Stroke cause of fundamental life change – challenge to the whole of one's being, not just physical impact.</li> <li>• The taken-for granted became challenging / unfamiliar.</li> <li>• Experience of self-body split <ul style="list-style-type: none"> <li>- Body or parts of body as object (0 + 6 mths)</li> <li>- "Perplexing body" (0 + 6 mths)</li> <li>- "Unreliable body" (even at 1 yr.)</li> </ul> </li> <li>• Self-body split relationship was neither fixed nor gradually improving. Rather it was dynamic and situation dependent. [Impairment itself and] self-body split <b>moved in and out of salience.</b></li> </ul>	<ul style="list-style-type: none"> <li>• The <b>importance</b> of the existence of and specificity of physical impairments.</li> <li>• Recovery, and one's views of recovery, are <b>context-dependent.</b></li> <li>• What are the meanings attached to the body?</li> <li>• When do one's stroke sequelae become salient? Does R. reside in navigating away from these situations, or in exposing oneself to them?</li> <li>• The physical and social environment away from home may be challenging and therefore limit going out.</li> </ul>
14	Erikson et al (2010)  SS	9 x SS; 42-61 yrs. old; TSS 3,6,9 & 12 months.; men & women; range of	The meaning of acting w/ others	Experiences in performing daily activities pre- and post-stroke.	Longitudinal	<ul style="list-style-type: none"> <li>• Not recognised as person I am</li> <li>• The burden of being a burden (not only needing to take, but not being able to give are problematic)</li> </ul>	<ul style="list-style-type: none"> <li>• Belonging – how achieved and how does it help?</li> </ul>

		<p>impairments; range of HHT.</p> <p>(Sweden)</p>		Daily life		<ul style="list-style-type: none"> <li>• Inspiration and belonging through acting w/ others</li> <li>• Reality adjustment through acting w/ others</li> </ul>	
15	<p>Faircloth et al (2004a)</p> <p>SS</p>	<p>57 x SS [so far]; 46-88 y.o.; All but 2 male; range of impairments; Puerto Rican Hispanic, African-American, non-Hispanic white; [living w/ a caregiver].</p> <p>(Puerto Rico &amp; US)</p>	<p>Discursive resources used to offset the disrupting connotations of stroke</p>	<p>[Daily life; life pre- and post-stroke; personal management in public settings; embodiment; meaning of life; ethno-cultural understandings; the future.]</p>	<p>In-depth ints; some observations @ home.</p> <p>Longitudinal 1, 6, 12mths post discharge. [Data from 18 &amp; 24 mths. upcoming]</p>	<ul style="list-style-type: none"> <li>• “Biographical flow”.</li> <li>• Factors mitigate against stroke as biographical disruption: <ul style="list-style-type: none"> <li>- Stroke a normal part of ageing.</li> <li>- Stroke as co-morbidity.</li> </ul> </li> <li>- Impact mediated by pre-existing knowledge of stroke.</li> <li>• These mitigating factors operate through SSs drawing on them as narratives to make sense of stroke. Agentic. “The ill ‘are theoreticians of both illness and the body and are not simply passive in the face of illness and medicine’ (Williams 1996: 24), but are actively working towards maintaining a certain level of quality of life.” (256)</li> </ul>	<ul style="list-style-type: none"> <li>• How does stroke sit within the person’s wider context (and how does this affect their framing and / or their resilience?)</li> <li>• Stroke &amp; ageing</li> </ul>
16	<p>Faircloth et al (2004b)</p> <p>SS</p>	<p>111 x SS; average age 67; <b>all male</b>; [range of impairments;] Puerto Rican Hispanic, African-American, non-Hispanic white; living w/ a caregiver.</p> <p>(Puerto Rico &amp; US)</p>	<p>Constructing the future through discursive practices.</p>	<p>Daily life; life pre- and post-stroke; personal management in public settings; embodiment; meaning of life; ethno-cultural understandings; the future.</p>	<p>In-depth ints; some observations @ home.</p> <p>Longitudinal 1, 6, 12, 18 &amp; 24 mths. post - discharge.</p>	<ul style="list-style-type: none"> <li>• 3 narrative anchors / interpretive schemas of illness narratives, embedded in the ordinary and everyday practice: <ul style="list-style-type: none"> <li>- Spirituality and God in constructing the future. [<i>Concise review of the lit.</i>]</li> <li>- Co-morbidities in constructing the future.</li> <li>- Activity &amp; leisure in constructing the future.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• How might we best tap ethno-cultural understandings?</li> <li>• The place of “biographical work” (Gubrium &amp; Holstein 1995) in constructing and interpreting data.</li> </ul>
17	<p>Green &amp; King (2009)</p> <p>SS</p>	<p>26 x male SSs + their wife care-givers; TSS 1-12+ months; SSs aged 39-83; all ‘<b>minor stroke</b>’; all Caucasian; predominantly middle-class.</p> <p>(Canada)</p>	<p>Recovery from minor stroke.</p> <p>Dimensions of impact of minor stroke on male SSs and their care-giving wives.</p>	<p>Ps: Quality of life after the stroke.</p> <p>Cs: Changes in your life post-stroke.</p>	<p>Analysis of 2 open-ended Qs (as part of QoL questionnaire) followed by probes. Telephone interviews.</p> <p>Longitudinal 1, 2, 3, 6, 9 &amp; 12mths. post -</p>	<ul style="list-style-type: none"> <li>• Male identity (physical strength, provider, protector) threatened.</li> <li>• Wives were hyper-vigilant (doing more, encouraging husbands and also buffering husbands from worries).</li> <li>• Over time balance was restored (though not the return to pre-stroke life originally aimed for).</li> </ul> <p>“This new balance was achieved by an appreciation and acceptance of what had transpired in their lives, an acknowledgement of the difficulties</p>	<ul style="list-style-type: none"> <li>• The sequelae may be hidden (i.e. AE). Need impact assessment from SSs perspective (and carers where included).</li> <li>• Recovery happens over time.</li> <li>• Recovery is multi-dimensional.</li> <li>• Reflection and re-evaluation [<b>‘looking in and looking out’</b>]</li> <li>• Care-givers also may re-evaluate their lives and values.</li> <li>• Can affect family relationships in opposite ways.</li> </ul>

					discharge.	<p>encountered, and by redefining their life direction and values to meet their current reality.” (1197)</p> <ul style="list-style-type: none"> <li>• Care-giver burden – loss of autonomy, time and space to themselves.</li> <li>• Some family groups got closer, some more distant.</li> </ul>	
18	Hartke et al (2011)  SS	<p>12xSSs; TSS 0.5 – 16 yrs (mean 4.5 yrs.; aged 31-67 (mean age 51); 6 Caucasian, 5 Af-Am, 1 Asian; skilled + unskilled in each of: preparing to return, returned for ≤ 6 months, returned for over 6 months. (Chicago, US)</p> <p>Convenience sample from fliers and contacts.</p>	To describe the facilitators and barriers to return to work (RTW) after stroke.	Stroke onset; deficits; treatment; prior wk exp.; thoughts and efforts re. RTW (meaning of wk., ‘successful’ RTW, risks + benefits, facilitators and barriers.	Semi-structured interviews	<ul style="list-style-type: none"> <li>• Benefits trap due to uncertainty of work capability.</li> <li>• Impairments as barriers.</li> <li>• Social + wk networks could encourage or discourage.</li> <li>• The importance of being a valued contributor in the workplace.</li> <li>• Formal resources aimed at RTW were critical.</li> <li>• A number of organizations were implicated (workplace, insurance companies, benefits offices and other local and national agencies).</li> <li>• SSs’ desire to return to work may be mediated by a fear of failure, of stress and consequent future stroke.</li> </ul>	<ul style="list-style-type: none"> <li>• RTW as emotional and functional milestone in recovery.</li> <li>• SS opportunities to <i>contribute</i> (either to family or work).</li> <li>• Structural inhibitors (including benefits system).</li> <li>• Who (family, colleagues, professionals) influenced their RTW (or non-return)? How?</li> <li>• Fear as underlying issue.</li> </ul>
19	Hilton (2002)  SS	<p>5 x SSs; TSS 1+ yrs. (though no detail given); aged 66-80; 4 white, 1 black; all women.</p> <p>(southern US)</p>	Meanings of stroke in elderly women	Life prior to stroke; experiences of living w/ stroke; making sense of stroke; meaning of stroke.	2 x semi-structured ints (in close succession?). Hermeneutic phenomenological approach.	<ul style="list-style-type: none"> <li>• <del>[Gender differences in likelihood of stroke and in type of stroke.]</del></li> <li>• Transformation.</li> <li>• “Each woman embarked on an intellectual journey to reconstruct herself into who she would become.” (23). They <b>actively engaged</b> w/ this process [practically, relationally and cognitively.]</li> <li>• Discovery in the present alongside re-envisioning the future [temporality]</li> <li>• Fluctuations in transformation. Not linear (23). [Though respondents described it “like a journey” (24). This is perhaps more about narrative than time or trajectory.]</li> </ul>	<ul style="list-style-type: none"> <li>• Importance of de-limiting and publishing TSS.</li> <li>• R. as practical, relational and cognitive.</li> <li>• <i>[QA no data on TSS (apart from at least 1 yr.); themes and sub-themes noted but then not expounded on, though interpretation interesting]</i></li> <li>• The place of narrative in interpreting the data. It may tend to make things look more linear.</li> </ul>
20	Jones et al (2008)  AT	<p>10 x SSs; TSS 6 wks to 13 mnths; 4 F, 6 M; age 29 – 75 (mean 61.8); 8 white British, 1 white French, 1</p>	Individual beliefs and personal strategies to support the	Memories of stroke and first few weeks of recovery, what felt enable the	Semi structured /free flowing interviews lasting 60 – 90 minutes	<p>1. Internal influences</p> <ul style="list-style-type: none"> <li>• Personal strength and control over recovery</li> <li>• Generalised optimism/hope</li> </ul>	<ul style="list-style-type: none"> <li>• Need to take account of both internal and external factors</li> <li>• Need for professional to take account of the SS preferences and personal goals</li> </ul>



		black Caribbean; 4 living alone, 6 with partner. (Surrey, UK)  Purposive sampling from registers of an acute hospital stroke unit and an intermediate (community care) team.	period of recovery after stroke. What factors perceived as enablers / challenges to recovery and / or progress.	recovery, anything that hampered recovery.		<ul style="list-style-type: none"> <li>• Influence of dependency – all felt loss of control but sometimes this served as an impetus to make an effort to recover</li> </ul> <p>2. External influences</p> <ul style="list-style-type: none"> <li>• Markers of independence – all described external signs e.g. resumption of activities such as making a drink</li> <li>• Therapeutic interventions - importance of therapists although some felt the relationship was passive and they were not in control. Felt need for honesty about predictions of progress.</li> </ul> <p>3. All participants stressed the importance of both factors</p>	<ul style="list-style-type: none"> <li>• Need to ensure that preferences are taken into account in treatment</li> <li>• Personal control over progress should be considered at all stages of recovery</li> <li>• More innovative ways are needed to actively involve individual in their own rehab is important</li> <li>• Literature section useful e.g. 'The domination of physical measures of recovery, used in stroke research, and their value to the individual, may also be misleading in terms of what constitutes a successful recovery</li> </ul>
21	Kirkevold, M. (2002)  AT	9 x SS (3 with aphasia); TSS 2 – 4 weeks to 12 months; aged 40-83; no info on socio-economic status; (Norway)  Recruitment – consecutive first time stroke survivors recruited from 2 medical centres	To describe the characteristics of the illness trajectory of stroke during the course of the first year.	Patients experience of bodily changes, the biographical impact of the stroke and consequences in the structure and function of daily life.	Repeated semi- structured interviews between 5 and 10 times during the first year (average 7 per person)	<ul style="list-style-type: none"> <li>• A stroke is not necessarily experienced as an abrupt psychosocial crisis by the SS</li> <li>• The adjustment seems to gradually evolve and is prolonged for most of the 1<sup>st</sup> year post stroke</li> <li>• The illness trajectory seems to be divided into 4 phases each with characteristic tasks and focal points</li> <li>• Phase 1 involves surprise and suspense</li> <li>• Phase 2 involves hard physical work</li> <li>• Phase 3 is continued rehab with a focus on psychosocial and practical adjustment</li> <li>• Phase 4 is a semi stable phase – getting on with life</li> <li>• The adjustment process involves hard physical and psychosocial work by the patient</li> <li>• A necessary prerequisite for adjustment was a realistic conception of the illness and its implications which takes time and experience to achieve.</li> </ul>	<ul style="list-style-type: none"> <li>• Rather than thinking of the stroke trajectory consisting of acute, crisis like onset, an improvement (rehab) and a stable post rehab phase, it is more complicated than this and the 4 stages outlined under findings is relevant.</li> <li>• There is a gradual coming to terms with the post stroke position (my words) which all the sample realised that life would never be the same</li> <li>• The sample varied in terms of psychological reaction to the process. Some were optimistic but others were not. No reasons are given which is why our study will be relevant</li> </ul>
22	Koch (2005)  CR	12 x SSS; TSS min. 6 months; 2f, 10m (SS); 11f, 2 m (caregivers); mean age 61; education/ employment details given; <i>mix of RURAL</i> ,	Develop a better understanding of the experiences of right hemisphere	What challenges are encountered by SS in attempting to reintegrate back into their communities?	Open-ended, semi. struc. interviews	<ul style="list-style-type: none"> <li>• Functional limitations resulting from stroke</li> <li>• Employment changes precipitated by stroke</li> <li>• Psychosocial impact of stroke precipitated employment changes on the SS</li> <li>• Reciprocal impact of stroke on the employment on the primary caregiver</li> </ul>	<ul style="list-style-type: none"> <li>• Inter-relatedness of factors/ processes/ outcomes.</li> <li>• <i>*See Lock for similar subject area: returning to work post-stroke.</i></li> <li>• Work as therapy (p 213).</li> </ul>

		<p><i>urban, suburban communities</i> (US).</p> <p>Recruited from local stroke support groups (9 SS &amp; 10 caregivers) AND regional stroke caregiving conference (3 SS &amp; 3 caregivers)</p>	<p>SS as they attempt to integrate back into their community. Return to work as focus.</p>	<p>What resources are identified by SS in helping achieve reintegration?</p>		<p>(*See Rudman 2005)</p> <ul style="list-style-type: none"> <li>• Factors associated with successful reintegration into employment</li> </ul>	
23	<p>Kouwenhoven (2011)</p> <p>CR</p>	<p>9 x SSs; TSS 6, 12 &amp; 18 months; 6f, 3m; aged 30-85 (mean age 62.6); depressed; 'various backgrounds' (<i>table provided</i>); range of impairments (Norway)</p> <p>Recruited from several hospital stroke units.</p>	<p>Describe the lived experience as it develops over time in SS <b>suffering from early depressive symptoms</b> (<i>seen as complex phenomenon: inc. brain injury &amp; psychological reaction</i>).</p>	<p>What is the nature of depression as experienced by SS at 6, 12, 18 months? How do experiences of stroke change over time? What are the impacts of depression on SS everyday life?</p>	<p>Phenom. interview study of 9 SS at 6, 12, 18 months TSS.</p> <p>Use of metaphor to capture essence of viewpoint: 'colour' &amp; 'journey'</p>	<p>SS related stroke to depressive symptoms → experience of loss as crucial.</p> <p><u>3 patterns of experience</u> (<i>related to stroke severity</i>):</p> <ul style="list-style-type: none"> <li>• Finding restored self (<i>less severe stroke/gained much initially lost</i>).</li> <li>• Trapped in a different life in the present (<i>more severe stroke &amp; no rehabilitation help</i>).</li> <li>• Referring back to former selves and fighting to regain self (<i>most significant stroke, younger &amp; more commitments</i>).</li> </ul> <p><u>Particularly vulnerable</u>:</p> <ul style="list-style-type: none"> <li>• Older adults living alone. These may have faced difficulties in accessing resources.</li> <li>• Adults experiencing serious threats to life commitments <i>family, work, children</i>. Though they were spurred to fight.</li> </ul>	<ul style="list-style-type: none"> <li>• Post-stroke depression (PSD) = one of the most prevalent affective symptoms &amp; occurs in at least ¼ SS during 1<sup>st</sup> yr. Impact on resilience?</li> <li>• Different reactions to stroke in relation to severity.</li> <li>• No gender correlations.</li> <li>• The 'process of going on with life' (p 9).</li> <li>• Interesting sense time &amp; perspective – Other studies (*Roman, *Wyller ?) found that those fixated on the past fared poorly. This study suggests that looking back at what you were COULD provide impetus to regain that self (p 10). Another group got stuck in the present – the found things so hard they couldn't look to the future.</li> <li>• Negotiating access to resources.</li> </ul>
24	<p>Kvigne et al (2004)</p> <p>SS</p>	<p>25 x SS; TSS 0-18 mths.; aged 37-78 (15 aged 71-78); low ed levels; moderate – serious impairment immediately after stroke.</p> <p>(Norway)</p>	<p>Explore how female SSs experienced their life and how they managed their altered situation post-stroke.</p>	<p>Everyday life before &amp; after; thoughts and experiences related to suffering from a stroke; experiences w/HCPs, the future.</p>	<p>Longitudinal (3 ints: in hosp, 6 mths + 12 mths. after return home.)</p>	<ul style="list-style-type: none"> <li>• Struggle to maintain valued roles tied to gendered family placement.</li> <li>• Initial feelings of being overwhelmed. Followed by a determination to return to previous levels of functioning, first ADLs in hosp then in daily life at home. Small improvements encouraged them. Need to re-learn what had come naturally was frustrating. (*Also Becker (1993)).</li> <li>• Recovery not linear - may ebb and flow and have setbacks.</li> <li>• SSs could feel over-monitored and needed</li> </ul>	<ul style="list-style-type: none"> <li>• Balance in relationships between giving and receiving care; getting enough or too much care.</li> <li>• Cohort effect re. gendered roles.</li> </ul>

						<p>“breathing space”.</p> <ul style="list-style-type: none"> <li>• Peer support. A shared world.</li> <li>• Respondents saw recovery as entailing establishing new norms, but keeping continuity of roles within that (383).</li> </ul>	
25	Lobeck et al. (2005)  CM	<p>7 x SSs<sup>2</sup> (7 male); TSS 6-12 months; 64-70 years; all selected on basis of being in process of retirement at time of stroke. (UK)</p> <p>Recruitment through stroke specialist nurses, day hospitals. Men only on grounds of supposed gender differences in retirement experience.</p>	Explore psychological issues arising when stroke occurs during retirement transition.	Stroke, recovery, retirement, family & social support	Semi-structured interview following IPA procedures	<ul style="list-style-type: none"> <li>• Ambivalence about retirement : pleasure and fear</li> <li>• Impact of stroke: <ul style="list-style-type: none"> <li>- Biographical rupture: loss of self</li> <li>- Support seen as crucial to recovery but at a cost to partner especially</li> <li>- Coping strategies include humour; comparisons (downward; peer); determination and motivation.</li> <li>- Taking control (I can do it), i.e. taking mental control over recovery</li> <li>- Healing and adjustment – a long process</li> <li>- Feeling different: change in sense of self</li> <li>- Altered outlook: identity, view of relationships and their place in world</li> <li>- Uncertain future; beginning to find balance of realism and optimism</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Note: study by psychologists</li> <li>• Suggest retirement concerns mapped onto stroke impact and experience</li> <li>• Personal characteristics in environmental context, including cultural notions of gender, work ethic &amp; class</li> <li>• Participants characterised as having active (not passive) coping styles: exercising, making changes, taking initiative</li> <li>• Impact of family &amp; informal support on rehab process</li> </ul>
26	Lock (2005)  CR	<p>37 x SS, 12 x supporters; TSS from 6 weeks to 10 yrs; TSS for 1 = 32 yrs; 13f, 24m; below retirement age; employment details given; range of impairments (UK)</p> <p>Research conducted in conjunction with ‘Different Strokes’ org. 1<sup>st</sup> part of larger study.</p>	To explore SS own perspectives about what helps and hinders paid or vol. work after stroke.	Prepared topic-guides to aid group discussions centred on: employers, adaptations at work, transport, doctors, advice, family/ friends, benefits/ education training. Guide rarely used as such topics arose independently of researchers.	5 focus group discussions	<p>Factors representing barriers to or enablers to work:</p> <ul style="list-style-type: none"> <li>• Rehabilitation process.</li> <li>• Employer agency</li> <li>• Social structural (Insufficient length of care to prepare for work)</li> <li>• Personal</li> </ul> <p><i>Evidence of social oppression via infrastructure, institutional structures and practices, and some individuals’ attitudes.</i></p>	<ul style="list-style-type: none"> <li>• SS were not of similar TSS i.e. period ranged from 6 weeks to 10 years – average of 3.9 yrs. While 1 participant TSS = 32 yrs. Since TSS appears crucial then studies need to happen within a strict timeframe.</li> <li>• <i>*See Koch for similar subject area: returning to work post-stroke.</i></li> <li>• Interesting note that the context in which study took place included a strong bias in favour of employment (New Labour slogans) (p 35).</li> <li>• Does return to work show resilience of SS or the combination of factors that result in employment/ vol work? Can they be untangled?</li> <li>• Does returning to work represent resilience? <i>Is not working also resilient? Does this show more of our political culture than individual ‘coping strategies’?</i></li> </ul>
27	Lynch et al.	9 x SSs <sup>2</sup> (5 male); TSS	Identify	How stroke	Focus group	<ul style="list-style-type: none"> <li>• Social relationships and changes in these:</li> </ul>	<ul style="list-style-type: none"> <li>• Maintenance of healthy social relationships</li> </ul>

	<p>(2008) <i>CM</i></p>	<p>2 -29yrs (mean 11.9 years); mean age 54.7; SES unknown; 8 Af-Am, 1 Caucasian. 6 carers (1 male) mean age 57.2 caring for people with mean age of 65.6 years. (US)</p> <p>Recruitment – self-selected from patient groups &amp; clinics.</p> <p>Note: not patient &amp; carer dyads.</p>	<p>dimensions of QoL in long term stroke to assist development of new stroke HRQOL measure.</p>	<p>affected QOL, especially communication, physical functioning, self esteem.</p>	<p>(1X patients; 1 X carers)</p>	<ul style="list-style-type: none"> <li>- <b>Social support</b></li> <li>- Ps: lack of social support from family &amp; friends</li> <li>- Carers: stroke strengthened support with family &amp; friends</li> <li>- <b>Communication</b></li> <li>- Ps: speech problems more significant than other disabilities, reduced self-esteem/confidence.</li> <li>- Carers: not raised as an issue until prompted.</li> <li>- <b>Independence</b></li> <li>- Ps: ambivalence: appreciated support but uncomfortable being dependent</li> <li>- Carers: frustration that pt did not want or acknowledge need for help</li> <li>- <b>Role changes</b></li> <li>- Ps: rarely discussed</li> <li>- Carers: seen as most significant factor affecting QoL</li> <li>• Individual level themes</li> <li>- <b>Physical functioning</b></li> <li>- Ps: challenges to be overcome through development of personal strategy</li> <li>- Carers: discussed in relation to impact on other (social) aspects of life</li> <li>- <b>Coping strategies</b></li> <li>- Ps: emphasise positive, de-emphasise negative</li> <li>- Carers: rarely discussed</li> </ul>	<p>most salient influence of stroke on QoL.</p> <ul style="list-style-type: none"> <li>• Importance of shift in social roles.</li> <li>• Important differences in pt and carer perspectives</li> <li>• Impact on communication v. important</li> </ul>
28	<p>Murray &amp; Harrison (2004) <i>CR</i></p>	<p>10 x SS; TSS mean of 9 yrs; aged 38-81 (mean age 48.8 yrs); 6f, 4m; marriage status given; range of impairments (UK)</p> <p>Contacted via the National Stroke Network &amp; an e-mail discussion group.</p>	<p>To investigate the meaning &amp; experience of being a SS</p>	<p>SS treated as experts of own experience; qual. approach allows researcher to enter world of participant to gain insight into thoughts/feelings.</p>	<p>Qual. in-depth semi-structured interview with 10 SS; 5 face-to-face, 5 email. (Use of diff interview techniques to allow more to participate)</p>	<ul style="list-style-type: none"> <li>• Disrupted embodiment &amp; the loss of self</li> <li>• Invisibility of emotional difficulties</li> <li>• Gender, romance &amp; sexuality</li> <li>• Social interaction (*See Northcott)</li> </ul>	<ul style="list-style-type: none"> <li>• Question of emailed semi-structured interview – some difficulties discussed on p 810.</li> <li>• QA – p810 – ‘internal coherence’ &amp; ‘presentation of data’ i.e. raw data.</li> <li>• Personality of SS is a factor in developing emotional difficulties post-stroke.</li> <li>• Unseen emotional changes more marked than physical.</li> <li>• ‘Disabled men are more likely than women to maintain their relationships following a</li> </ul>

							<p>disability, with women often being left by their partner' (p 814).</p> <ul style="list-style-type: none"> <li>• Relevant terms used during theoretical discussion: 'negotiate new identities': <i>relates to phenomenological body/self distinctions</i> (p 814); 'self-definitions' <i>relates to Levitin (1975): 'this deviance (disability) is not all of me'</i> (p 815).</li> </ul>
29	Northcott & Hilari (2011)  CR	<p>29 x SSs; TSS between 8 &amp; 15 months; purposive sampling (<i>for which criteria was formulated</i>); age 18-90 (12≤65); 12f, 17m; ½ British <i>further characteristics given</i>; range of impairments, <i>aphasia included</i>; living arrangements; no. of friends (UK)</p> <p>Part of larger QoL study; recruited from 2 acute stroke units; inc/ exc criteria.</p>	<p>Exploring why people lose contact with their friends. Perceptions of friendship loss and change.</p>	<p>What are the perceived causes of f/ship loss after a stroke? What factors help to protect f/ships? How is f/ship loss &amp; change perceived by the individual?</p>	<p>In-depth qual. Interviews; topic guide.</p>	<p><u>Causes</u></p> <ul style="list-style-type: none"> <li>• Loss of shared activities</li> <li>• Reduced energy levels</li> <li>• Poor mobility</li> <li>• Unhelpful responses of others</li> <li>• Environmental barriers</li> <li>• Aphasia</li> <li>• Changing social desires of participants 'Closing in on myself' – includes points above &amp; contextual difficulties of crowds/ noise etc.</li> </ul> <p><u>Protective Factors</u> → Quality of f/ ship/ Distance/ Availability of friend/ Not activity based prior to stroke/ Regular, supportive groups/ Family friends/ Social network established before stroke. (*See Clarke &amp; Black).</p> <p><u>Perceptions of f/ship loss &amp; change</u> → Hurt by rejection/ Sadness for lost friends/ Hope for resumed relationship/ Choosing to 'lose friends' who make one feel undermined</p>	<ul style="list-style-type: none"> <li>• Techniques used to interview those with aphasia.</li> <li>• Vicious cycle of social isolation &amp; depression post-stroke (p 532).</li> <li>• Pre-stroke factors significant in predicting psychological distress 6 months post-stroke (p 532).</li> <li>• Socialising: not necessarily a positive aspect (p 532).</li> <li>• (*See Murray p 813)</li> </ul>
30	Pearl (2011)  CR	<p>10 x SSs for interviews (<i>method 1</i>), TSS 3-12yrs; aged 32-78; 4f, 6m; 10C British; job before stroke given.</p> <p>5x SSs for focus group (<i>method 2</i>); TSS 1-10yrs; aged 42-82; 1f, 4m; 4C British (<i>other 1 not mentioned?</i>); job</p>	<p>Exploring significance of volunteering as community participation for people with aphasia. Understand impact of therapeutic</p>	<p>Explore perceptions, experiences of those vol.; identify effects of vol.; perceptions of what facilitates/ hinders vol.</p>	<p>Semi-struc. interviews; focus group details given.</p>	<p><u>Variables impacting on involvement</u>: TSS/ Skills possessed pre-stroke - now limited/ Fatigue/ Concentration, emotions &amp; memory/ Personality characteristics</p> <p><u>External variables</u>: Context/ reactions of individual people/ timing</p> <ul style="list-style-type: none"> <li>• Effects of participation in vol.: confidence/ feel-good factor/ fulfilling self-expectation/ communication skills/ inspiration/ self-growth.</li> <li>• (Neg effects: tiredness/ ill-suited activities)</li> </ul>	<ul style="list-style-type: none"> <li>• Confidence as significant impact of vol. &amp; maintained existing confidence: <i>virtuous cycle</i>.</li> <li>• Contact with similar others.</li> <li>• Breaking into the cycle: effected by other people's awareness of aphasia; knowledge of vol. activity itself; support from others.</li> <li>• Diagrammatic explanation of how activity begins &amp; is maintained.</li> <li>• Authors note 'the activity is triggered and becomes successful' (p 1818) (See *Roman P 541 for similar descriptors used).</li> </ul>

		before stroke given.  Different severity levels of aphasia: Scale given. (UK)  Recruited through stroke/ aphasia vol. org; inc criteria for each method	activities on personal growth.			<ul style="list-style-type: none"> <li>• Effects on other people: communication skills of others with aphasia/ family &amp; friends/ assistance for people with disabilities.</li> <li>• Effects of vol. on host orgs: Activities or services offered/ support for those with aphasia/ status of org/ practical help/ increased public awareness/ reflection on org effects</li> </ul>	
31	Pound, Gompertz & Ebrahim (1998)  CR	40 x SSs; TSS 10 months; 19f, 21m; 35C, 3B <sup>9</sup> , 2Ca <sup>10</sup> ; aged 40-87 (mean age 71); accommodation, living arrangements & employment given; area of London discussed(UK) NETSOS Stroke Register, part of larger study.	Exploring view that stroke was 'not that bad': ways in which age may mediate illness experience.	Examining usefulness of ( <i>socio.</i> ) theoretical approach for SS. Finding instead prior experience of illness placates devastation expected by authors'.	In-depth semi-struct. Interviews.	<ul style="list-style-type: none"> <li>• Illness experienced differently amongst older people, having prior experience of illness personally &amp; within family.</li> <li>• Crises not unusual, element of familiarity &amp; normality of stroke against background of struggle.</li> <li>• Downplaying severity of illness in order to normalise it.</li> </ul>	<ul style="list-style-type: none"> <li>• Only those of younger age (2 aged 40 and 64) reported stroke as devastating impact on life.</li> <li>• Resilience of stroke in relation to wider, more desperate problems i.e. hunger (p 499) and inadequate housing (p 499-500).</li> <li>• Impact of East Ender myth: stoicism in face of adversity.</li> </ul>
32	Pound, Gompertz & Ebrahim (1999)  SS	40 x SS; TSS 10 mths.; 40-87 yrs. old; range of class; 35/40 were white.  (North Thames RHA)	Explore the practical and social strategies created by SSs (p.121)	The day of the stroke; experiences in hospital; <b>life at home; changes; responses to changes.</b> This paper focuses on <b>latter.</b>	Semi-structured interviews	<ul style="list-style-type: none"> <li>• 'Mobilizing informal social support' [though also accessed services].</li> <li>- Reconfiguring relationships of <i>interdependence.</i></li> <li>- Safety measures in case of recurrence.</li> <li>• 'Creating new ways of doing things'.</li> <li>• Taking things more slowly.</li> <li>• Relearning (walking, talking, vocabulary, reading).</li> <li>• Exercise. (Seen to prevent further deterioration, as well as 'keeping busy').</li> <li>• 'Covering up' (maintaining self-esteem)</li> <li>• Some overlap bet. practical 'strategies' + mental / affective 'coping'</li> </ul>	<ul style="list-style-type: none"> <li>• Pound et al draw on Bury (1991) who differentiates between strategies as what people <i>do</i> and coping as mental processes [implying passivity]. Other papers summarised on this table emphasise an effort to re-frame things and to change one's mental attitude, i.e. <i>coping as cognitive strategies.</i></li> <li>• Negotiating one's way to services and other help.</li> <li>• Social support ≠ the <i>presence</i> of a network of people. It is an <i>experience.</i></li> <li>• Who relies on you (not just vice versa)?</li> <li>• Strategies may be anticipatory or preventative, as well as about meeting immediate needs.</li> <li>• Caution not to conflate stigma and self-image.</li> <li>• What's the relationship bet. strategies and</li> </ul>

							<p>coping. (How) does this map onto social – individual responses?</p> <ul style="list-style-type: none"> <li>• Is “Illness work” (Strauss &amp; Corbin 1988) a useful concept?</li> </ul>
33	<p>Roman (2006)</p> <p>CR</p>	<p>2 x SSs; TSS 5 &amp; 9 yrs; 2m; Sam-aphasia aged 45, James-aphasia aged 71 (US)</p> <p>Recruited from uni-based recovery program; part of larger study.</p>	<p>Investigate the process of recovery: How does one recover from stroke, what is the process? How is a sense of normality restored? How is one’s sense of self involved?</p>	<p>Cases of ‘Sam’ &amp; ‘James’: the story, the archival records &amp; individual case analysis</p>	<p>2 case studies; interviews; archival materials.</p>	<ul style="list-style-type: none"> <li>• 2 case studies discussed at length, taking into account medical archives to triangulate data.</li> </ul> <p><u>Inter-related aspects, salient to recovery:</u></p> <ol style="list-style-type: none"> <li>1. The continuous/ discontinuous self</li> <li>2. One’s worldview on change (*Wyller, *Kouwenhoven)</li> <li>3. Grief/ Loss – co-occurring mourning &amp; reconstructing. <i>Which prevails?</i> (p 554)</li> </ol> <p><u>Recommendations for healthcare treatments:</u></p> <ul style="list-style-type: none"> <li>• Reframe process as mourning while reconstructing.</li> </ul>	<ul style="list-style-type: none"> <li>• Holistic/ contextual in scope. Taking into account wife of Sam losing her job as highlighting how Sam copes with situations.</li> <li>• ‘Resilience’ noted on p 552: author’s 3 main findings tie in with mental health delivery systems (<i>New Freedom Commission</i>) in that they <i>should</i> focus on building resilience, not just managing symptoms.</li> <li>• Authors note activities that ‘might re-ignite a spark in a stroke victim’ (p 541) (<i>See *Pearl p 1818 for similar descriptors used</i>).</li> <li>• Turning point.</li> </ul>
34	<p>Rudman et al (2005)</p> <p>AT</p>	<p>16 x SSs wheelchair users for at least 1 year (on average had used a wheelchair for just over 5 years); TSS not given; aged 69-86 (mean 76); 12 m, 4f; 12 Caucasian; all relatively well educated and generally with adequate income.</p> <p>15 matched (mainly spouses) carers; aged 45 – 84 (mean 68); 10 Caucasian; all relatively well educated and generally with adequate incomes. (Canada)</p>	<p>The occupational experience of stroke survivors who use wheelchairs and their primary carers.</p>	<p>Very unclear apart from activities lost and new activities started since using a wheelchair.</p>	<p>Semi structured interviews and probes.</p>	<ul style="list-style-type: none"> <li>• Difficult to disentangle the impact of the wheelchair from other factors associated with the stroke</li> <li>• Both SSs and carers described their daily lives filled with restrictions on occupational participation</li> <li>• Limitations in accessibility within the home and outside were limited activities including access to health care</li> <li>• Narrowing of social worlds for both</li> <li>• Most occupations for both were home based, sedentary and related to self care</li> <li>• Above meant that both groups felt changes in personal and social identity</li> <li>• ‘Although much of the findings highlight experiences of occupational restriction, there were particular instances where specific occupations were pursued through determination, creativity and adaptation’ (but no details given)</li> </ul>	<ul style="list-style-type: none"> <li>• The impact of stroke seems to be felt as much by the carers as the SS</li> <li>• Importance of spouse care and the effects it has on the relationship</li> <li>• Modifications for the home can help mitigate the effects of using a wheelchair</li> <li>• Highlights the importance of resilience and what we are studying as this study gives us little clue.</li> </ul>

		Recruitment – self-selected from community agencies and rehabilitation facilities. NOT selected on basis of living successfully with a stroke in a wheelchair.					
35	* Secrest & Thomas (1999)  SS	14 x SSs; TSS 9 mths – 23 yrs. (median 2 yrs.); age 40-93 (median 67); 7m, 7f; all Caucasian; range of disabilities, <b>including some w/ cognitive or speech impairment</b> (US)	SSs experience of QoL following stroke. <b>‘Quality’ as texture rather than grade.</b>	Describe specific instances post-stroke that stand out for you.	Unstructured ints.  Existential phenomenological approach.	<ul style="list-style-type: none"> <li>• People’s lives were experienced against backgrounds of <b>loss</b> and <b>effort</b>.</li> <li>• Against this background were 3 inter-related themes: <ul style="list-style-type: none"> <li>- independence-ability / dependence-disability (what I can / can’t do)</li> <li>- in control (strategies) / out of control (of body, speech, emotions)</li> <li>- connection / disconnection with others</li> </ul> </li> <li>• Informing and informed by all of these themes was <b>“continuity and discontinuity in the experience of the self”</b></li> <li>• Disability moves in and out of salience acc. context (<i>*Also Ellis-Hill (2002)</i>)</li> <li>• Examples of respondents reassessing life</li> </ul>	<ul style="list-style-type: none"> <li>• Examples of good coming from stroke (p.244)</li> </ul>
36	Thompson & Ryan (2009)  CR	16 x SSs; TSS mean 18 months; aged 22-78 yrs (mean 56); 7f, 9m (Northern Ireland)  Stroke nurse spec. register; inc/ exc criteria.	Explore the impact of stroke consequences on spousal relationships from perspective of SS.	Life before stroke; life after stroke; coping strategies adopted.	18 contacted, 16 consented; in-depth interviews; reflexive of authors’ position in research.	<p>Four categories:</p> <ul style="list-style-type: none"> <li>• Dichotomies of pre &amp; post stroke self (prone to anger/ frustration of dependence &amp; burden)</li> <li>• Sexuality, sexual function &amp; desire (altered roles/ physical appearance/ sexual dynamics)</li> <li>• Perceived loss of control (identity &amp; self/ socialising/ fatigue/ lack of ability to plan)</li> <li>• Stroke – a life-changing event (a daily struggle to achieve normality/ lack of visible effects of stroke).</li> </ul>	<ul style="list-style-type: none"> <li>• Authors Banks &amp; Pearson (2004) &amp; Kvigne et al. (2004) are cited in relation to strengthening optimism and achieving self-worth post stroke.</li> <li>• Impact of strained relationship on resilience.</li> <li>• Factors such as age &amp; gender have been shown to contribute to post stroke fatigue (<i>link between fatigue &amp; depression</i>) (p 1809).</li> </ul>
37	White et al (2008a)  SS	12 SSs; TSS 1,3,5 yrs.; 6 m = 6 f; aged 42 – 92; range of demographics and experiences.	Explore the long-term experience of stroke. Identify	Life before stroke; stroke onset; post-stroke lifestyle	Semi-structured interviews	<ul style="list-style-type: none"> <li>• Reduced engagement in activities = role loss. This was associated with feelings of lower self-efficacy + negative emotions.</li> <li>• Could be an iterative relationship between loss of confidence and withdrawal from</li> </ul>	<ul style="list-style-type: none"> <li>• The analysis in this paper needs better unpacking in places. E.g. more forensic analysis of “frustration”, “hope” “resilience”.</li> <li>• OT of some kind may be beneficial over the</li> </ul>



		(Coastal city, NSW, Australia)	influences on occupational engagement			<p>activities. Link between mood and meaningful activity.</p> <ul style="list-style-type: none"> <li>• “I just don’t feel that I am as necessary to [my daughter] as I was before.” (163) i.e. <i>making a contribution</i> is important.</li> </ul> <p>Impact of stroke could be moderated by:</p> <ul style="list-style-type: none"> <li>• Use of strategies to get around everyday hurdles.</li> <li>• Re-evaluation of life and lifestyle.</li> <li>• Grateful for small mercies (comparing self to others or what might have been).</li> <li>• Connecting outward (to God or other people).</li> <li>• Practical &amp; emotional social support.</li> <li>• Some people drew on their experiences of pre-stroke adversities to explain learning to “stand on their own two feet” (165)</li> </ul>	longer term to bolster self-efficacy, social engagement and enhance QoL.						
38	Widar (2004)  CR	43 x SSs; TTS 2 yrs; 20 months duration of pain; age range 33-82. 13f men (mean age 76) 30m (mean age 64); 15=CPSP, 18=nociceptive pain, 10 headache (combinations of pain types i.e. 4 had 2 types); (Sweden)  Hospital register	Describe pain, coping strategies & experienced outcome of coping with long-term pain post-stroke.	Narratives analysed to find how pain is described & understood; strategies employed to cope with pain; experienced outcomes of coping.	2x interviews each – at 24 & 27 months ( <i>with medical exam in between</i> ).	<p><u>Different coping strategies employed:</u></p> <table border="1"> <tr> <td><i>Common to all</i></td> <td> <ul style="list-style-type: none"> <li>• Making pain comprehensible</li> <li>• Planning of activities</li> <li>• Taking medications</li> <li>• Communicating</li> <li>• Distractions</li> </ul> </td> </tr> <tr> <td><i>Central/ nociceptive pain</i></td> <td> <ul style="list-style-type: none"> <li>• Changing body position</li> <li>• Making comparison</li> <li>• Enduring pain</li> </ul> </td> </tr> <tr> <td><i>Tension-type headache</i></td> <td> <ul style="list-style-type: none"> <li>• Rest/relaxation</li> </ul> </td> </tr> </table> <p><u>Experienced Outcomes:</u></p> <ul style="list-style-type: none"> <li>• Neg – perplexity &amp; resignation. Questions/ requests for support by SS cease when healthcare team seen to lack knowledge. Not being understood by others.</li> <li>• Pos – short-term relief. Shown consideration by others.</li> </ul>	<i>Common to all</i>	<ul style="list-style-type: none"> <li>• Making pain comprehensible</li> <li>• Planning of activities</li> <li>• Taking medications</li> <li>• Communicating</li> <li>• Distractions</li> </ul>	<i>Central/ nociceptive pain</i>	<ul style="list-style-type: none"> <li>• Changing body position</li> <li>• Making comparison</li> <li>• Enduring pain</li> </ul>	<i>Tension-type headache</i>	<ul style="list-style-type: none"> <li>• Rest/relaxation</li> </ul>	<ul style="list-style-type: none"> <li>• Efforts to ‘manage’</li> <li>• Women used ‘somewhat more coping strategies than the men’ (p 217).</li> <li>• Experienced outcomes reportedly largely negative, reflecting efforts not successfully accomplished.</li> <li>• Difficulty of verbalising experiences of pain in everyday language (p 223).</li> <li>• Making pain comprehensible = cognitive strategy.</li> </ul>
<i>Common to all</i>	<ul style="list-style-type: none"> <li>• Making pain comprehensible</li> <li>• Planning of activities</li> <li>• Taking medications</li> <li>• Communicating</li> <li>• Distractions</li> </ul>												
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<i>Tension-type headache</i>	<ul style="list-style-type: none"> <li>• Rest/relaxation</li> </ul>												
39	Wood (2010)	10 x SSs; TSS 2 weeks over 1 yr.; aged 31-	Examine process of	Interviews conducted at 2	Semi-struct. interviews of	<ul style="list-style-type: none"> <li>• Participants described transition through/ between stages:</li> </ul>	<ul style="list-style-type: none"> <li>• Terms used: reconcile, transitioning, confidence, motivation, control, strategy,</li> </ul>						

	CR	79; 4f, 6m; 8 C, 1 EI <sup>7</sup> , 1A <sup>8</sup> ; living arrangements given; employment details given; less severe stroke (Canada)  Recruited from rehabilitation facilities: part of larger study; Inc/ exc criteria.	community reintegration over 1 <sup>st</sup> yr post stroke from SSS perspective.	wks, 3, 6 months & 1 yr to establish 4 stages of transitioning back to 'real living' within community.	10; 4 times over 1 yr.	<ol style="list-style-type: none"> <li>1. Gaining physical function</li> <li>2. Establishing independence</li> <li>3. Adjusting expectations</li> <li>4. Get back to real living (<i>engaging in meaningful activities as well as maintaining and developing relationships</i>)</li> </ol> <ul style="list-style-type: none"> <li>• Ultimate challenge for SS: balancing expectations and self-identity with physical capacity to engage in meaningful roles.</li> </ul>	<p>adjust, reappraising, come to terms with, adapt, hope, rebuilding, accommodating, belief in capability, <i>self-efficacy</i> (p 1053 - Bundura).</p> <ul style="list-style-type: none"> <li>• Longitudinal interviews add interesting temporal dimension to idea of 'resilience' as ongoing process in flux, relating to successes &amp; setbacks of physical rehabilitation and personal support networks.</li> <li>• How does 'stage' theory fit w/ flux? Narrative construction by SSSs or by authors?</li> </ul>
40	Wyller (1999)  CR	6 x SSS; TSS 3 yrs.; aged 65-85; 2f, 4m; range of impairments; (Norway)  Study pop. recruited from hosp; Inc/ exc criteria.	Contribute to theoretical account of mechanisms by which QoL is affected by stroke. Study oriented to subjective position in order to broaden/ understand its use.	(i) Explore whether QoL concept is known by SS (ii) describe how stroke influences QoL.	In-depth interviews of 6; reflexive of authors' position in research.	<p><i>Background to study:</i> Low QoL found amongst SSSs. Difficulty of using QoL concept (<i>Sub/Ob arguments etc</i>).</p> <ul style="list-style-type: none"> <li>• QoL – Unfamiliar term/ meaningful concept.</li> <li>• QoL not necessarily affected by severe sequelae post-stroke. Equally, QoL can be dramatically affected by mild stroke.</li> <li>• Significance of personal comparative reference point in time/ world view as static or changing (<i>*Kouwenhoven, *Roman</i>).</li> <li>• Dynamic bet. QoL criteria from objective &amp; subjective viewpoints.</li> <li>• QoL as an evaluative concept.</li> </ul>	<ul style="list-style-type: none"> <li>• This paper evaluates the usefulness of QoL as a tool post-stroke, rather than discussing QoL of SS outright.</li> <li>• Discusses the cultural significance of a concept such as QoL (p159); authors prepared definition if QoL was unknown amongst participants. <i>Possibility of 'resilience' being more well-known &amp; understood amongst particular groups.</i></li> <li>• To what degree will resilience be noted in our study? Unobservable actions? Attitudes? (I.e. resilience has same issues w/ measurement? The lack of correlation between severity of stroke &amp; QoL suggests resilience.</li> </ul>