Title: A different way of life: a qualitative study on the experiences of family caregivers of stroke survivors living at home

Abstract

Background: There are approximately 1.3 million stroke survivors in the United Kingdom and the majority rely on family caregivers for support. However, these family caregivers’ needs are not routinely assessed by most services.

Aim: To explore the experiences of stroke family caregivers following implementation of the Care Act 2014.

Methods: 16 semi-structured, digitally recorded face-to-face qualitative interviews were conducted with a purposive sample of stroke family caregivers in North-West England. Thematic analysis was undertaken.

Findings: Two themes were identified: the effects of caregiving and unmet needs. Despite changes to legislation, family caregivers of stroke survivors continue to experience challenges such as financial problems, information needs, lack of respite and emotional support when providing care.

Conclusion: Existing approaches to identifying and supporting caregiver needs are insufficient. Proactive approaches are required to facilitate their needs to be identified and addressed on a regular basis.

Key words: Stroke, family caregivers, Care Act 2014, qualitative research, semi-structured interviews
**Key points**

1. Stroke family caregivers continue to experience challenges when providing care and have unmet needs such as information needs, financial problems, lack of respite and emotional support, despite changes to legislation.

2. Gaps in assessing and supporting the needs of family caregivers of stroke survivors are evident including assessment delays.

3. Alternative proactive approaches are required to identify and support the needs of stroke family caregivers on a regular basis.

4. Further research focusing on interventions to support stroke family caregivers is warranted.

**CPD Reflective questions**

1. What organisations or services are available in your local area to support family caregivers of stroke survivors?

2. What type of respite support services are available in your area?

3. What changes can you make to your practice as a result of reading this article?

**Background**

In the United Kingdom (UK), there are 1.3 million stroke survivors (Stroke Association 2022). Stroke is the fourth leading cause of death and the largest cause of adult disability with two thirds of survivors leaving hospital with a disability (RCP 2017). To continue living independently at home they require care which in many cases is permanent and usually
provided by family caregivers and friends (ISWP 2016). The sudden onset of stroke plus its unpredictable recovery makes it difficult for family caregivers to adjust in their caregiving role (Lincoln et al. 2011). Numerous systematic reviews have focused on a range of negative experiences and outcomes encountered by family caregivers of stroke survivors such as: information needs, lack of emotional support, caregiver burden, financial problems and feeling not prepared for their role (McKevitt et al. 2004; Greenwood et al. 2008, 2009; Kokorelias et al. 2020; Zawawi et al. 2020; Denham et al. 2022). Nonetheless, evidence also suggests some positive outcomes such as strengthened relationships and fulfilment through the caregiving role (Mackenzie and Greenwood 2012).

International stroke guidelines recognise the significant role that family caregivers play and recommend that their needs are assessed and supported (Cameron et al. 2016; ISWP 2016; SFA 2017). However, there is minimal guidance on how the assessments should be conducted. Changes to legislation in the UK (Care Act 2014), resulted in new rights for all family caregivers providing them with the same legal rights and entitlements as those they care for (UK Parliament 2014). The Act places a legal duty on local authorities to assess any family caregiver who requests an assessment or appears to need additional support, regardless of how much care they provide. Nevertheless, the support given to family caregivers is not usually standardised and carers’ assessments are not universally undertaken. National economic restraints have resulted in service cutbacks with limited resources to undertake these lengthy assessments (Carers UK 2017). The number of carers’ assessments have steadily declined in England from nearly 450,000 per year in 2009/10 to just above 350,000 per year in 2017/2018 (Fernandez et al. 2021) and can be expected to have fallen further due to the Covid-19 pandemic.
Despite a plethora of literature exploring the challenges experienced by family caregivers of stroke survivors, relatively few studies have been conducted in the UK since implementation of the Care Act 2014 (Kokorelias et al. 2020; Denham et al. 2022). This study aimed to explore the experiences of stroke family caregivers of factors contributing to burden during caring post the Care Act.

**Methods**

A qualitative approach was adopted to allow the exploration of participants’ behaviour, feelings and experiences of important issues or phenomena (Holloway and Galvin 2017).

**Ethics**

Ethical approval was obtained from the University’s Faculty Research Ethics Committee (FOHSC 119). All standard ethical procedures including advertising the study, participant information sheets, consent and data storage were followed.

**Participants and recruitment**

Purposive sampling was utilised to recruit family caregivers attending support groups run by a national stroke charity in the North-West of England using flyers distributed via the support groups advertising the study. Additionally, community-based stroke coordinators assisted recruitment by informing caregivers about the study during home visits. Family caregivers (defined as any family member who was active in supporting a stroke survivor in any way) had to be residing at the same address with the stroke survivor, aged over 18 years and English speaking.
Data collection

Face-to-face, digitally recorded semi-structured interviews were undertaken between February and April 2016 lasting between 35 and 55 minutes. An interview guide was developed from existing literature and refined by eight family caregivers of stroke survivors and staff working within stroke services as part of patient and public involvement in research (NIHR 2014). Questions included: demographic information, the caregiving role, support and assessments received (Table 1). Additionally, participants were asked to describe the abilities of the individual they were supporting based on information from the Modified Rankin Scale (a scale commonly used to assess the degree of disability in stroke survivors) (Van Swieten et al. 1988). In total, 16 participants were recruited and interviewed at a suitable location of their choice (Table 2).

Table 1: Interview guide

<table>
<thead>
<tr>
<th>1. Demographics</th>
<th>i.e. gender, age, relationship with stroke survivor, employment, ethnicity</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Current caring role</td>
<td></td>
</tr>
<tr>
<td>a) How long have you looked after name? (when did they have the stroke?, how did the stroke affect them?, MRS descriptors used to establish the level of disability)</td>
<td></td>
</tr>
<tr>
<td>b) Can you describe some of the things that you do for name?</td>
<td></td>
</tr>
<tr>
<td>c) Have there been any occasions when you have found caring to be challenging?</td>
<td></td>
</tr>
<tr>
<td>d) What helps you to cope with the challenges?</td>
<td></td>
</tr>
<tr>
<td>3. Support and assessment</td>
<td></td>
</tr>
<tr>
<td>a) What support or help have you received whilst caring for name?</td>
<td></td>
</tr>
<tr>
<td>b) Is there any help or support you feel you might have benefited from but did not receive?</td>
<td></td>
</tr>
<tr>
<td>c) Have you had any assessments since you started caring for name? (carers’ assessment, other assessments, did assessments result in any additional support?)</td>
<td></td>
</tr>
<tr>
<td>d) What are your thoughts on regular assessments of stroke carers’ needs?</td>
<td></td>
</tr>
<tr>
<td>e) How would you feel being asked about your needs on a regular basis?</td>
<td></td>
</tr>
</tbody>
</table>
Table 2: Demographic information of participants

<table>
<thead>
<tr>
<th>Participant</th>
<th>Sex</th>
<th>Age in years</th>
<th>Relationship to stroke survivor</th>
<th>Employment</th>
<th>Stroke survivor MRS*</th>
<th>Duration of caring in years and months</th>
<th>Carers’ Assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>M</td>
<td>66-75</td>
<td>Husband</td>
<td>Retired</td>
<td>3</td>
<td>2 years, 2 months</td>
<td>No</td>
</tr>
<tr>
<td>P2</td>
<td>F</td>
<td>36-45</td>
<td>Partner</td>
<td>Unemployed</td>
<td>4</td>
<td>7 months</td>
<td>Awaiting</td>
</tr>
<tr>
<td>P3</td>
<td>M</td>
<td>66-75</td>
<td>Husband</td>
<td>Retired</td>
<td>4</td>
<td>4 months</td>
<td>Yes</td>
</tr>
<tr>
<td>P4</td>
<td>M</td>
<td>76 plus</td>
<td>Partner</td>
<td>Unemployed</td>
<td>2</td>
<td>9 months</td>
<td>Yes</td>
</tr>
<tr>
<td>P5</td>
<td>M</td>
<td>56-65</td>
<td>Husband</td>
<td>Employed</td>
<td>2</td>
<td>1 year, 10 months</td>
<td>No</td>
</tr>
<tr>
<td>P6</td>
<td>F</td>
<td>66-75</td>
<td>Wife</td>
<td>Retired</td>
<td>3</td>
<td>1 year</td>
<td>No</td>
</tr>
<tr>
<td>P7</td>
<td>F</td>
<td>76 plus</td>
<td>Wife</td>
<td>Retired</td>
<td>3</td>
<td>9 months</td>
<td>Uncertain</td>
</tr>
<tr>
<td>P8</td>
<td>F</td>
<td>76 plus</td>
<td>Wife</td>
<td>Retired</td>
<td>2</td>
<td>10 years</td>
<td>Uncertain</td>
</tr>
<tr>
<td>P9</td>
<td>F</td>
<td>66-75</td>
<td>Wife</td>
<td>Retired</td>
<td>4</td>
<td>4 months</td>
<td>Awaiting</td>
</tr>
<tr>
<td>P10</td>
<td>F</td>
<td>56-65</td>
<td>Wife</td>
<td>Unemployed</td>
<td>3</td>
<td>1 year, 6 months</td>
<td>Uncertain</td>
</tr>
<tr>
<td>P11</td>
<td>F</td>
<td>66-75</td>
<td>Wife</td>
<td>Retired</td>
<td>3</td>
<td>10 months</td>
<td>No</td>
</tr>
<tr>
<td>P12</td>
<td>F</td>
<td>66-75</td>
<td>Wife</td>
<td>Retired</td>
<td>4</td>
<td>6 years</td>
<td>Yes</td>
</tr>
<tr>
<td>P13</td>
<td>M</td>
<td>56-65</td>
<td>Husband</td>
<td>Unemployed</td>
<td>4</td>
<td>11 years, 3 months</td>
<td>Yes</td>
</tr>
<tr>
<td>P14</td>
<td>F</td>
<td>66-75</td>
<td>Wife</td>
<td>Retired</td>
<td>3</td>
<td>11 months</td>
<td>Uncertain</td>
</tr>
<tr>
<td>P15</td>
<td>F</td>
<td>66-75</td>
<td>Wife</td>
<td>Retired</td>
<td>4</td>
<td>9 years</td>
<td>No</td>
</tr>
<tr>
<td>P16</td>
<td>F</td>
<td>56-65</td>
<td>Wife</td>
<td>Employed</td>
<td>2</td>
<td>4 years</td>
<td>No</td>
</tr>
</tbody>
</table>

*Modified Rankin Scale (range 0-6) a higher reading indicates greater disability
Data analysis

Interviews were transcribed verbatim and anonymised by replacing all identifiable information with pseudonyms. Qualitative data analysis software, NVivo version 11® assisted with organising the data. Six phases of thematic analysis (Braun and Clarke 2006) were followed. Two members of the team (JT, BJ) independently reviewed half of the transcripts to establish agreement with the preliminary themes. The themes were later discussed with the wider team to enhance rigour (Silverman 2017). Two main themes identified were: effects of caregiving and unmet needs (Table 3). Unique numerical identifiers denoting participant number, relationship to the stroke survivor and age were adopted to maintain confidentiality and exemplars of quotes provided to substantiate findings.

Table 3: Main themes and subthemes

<table>
<thead>
<tr>
<th>Main theme</th>
<th>Sub-theme</th>
<th>Ideas in relation to the research question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Effects of caregiving</td>
<td><strong>Physical effects</strong></td>
<td>• Tiredness&lt;br&gt;• Physical strain&lt;br&gt;• Increasing workload&lt;br&gt;• Advancing age and pre-existing medical conditions</td>
</tr>
<tr>
<td></td>
<td><strong>Emotional effects</strong></td>
<td>• Family caregivers’ emotions&lt;br&gt;• Patients emotions and behaviour</td>
</tr>
<tr>
<td></td>
<td><strong>Socio-economic effects</strong></td>
<td>• Changes to lifestyle&lt;br&gt;• Relationships with friends&lt;br&gt;• Money issues, employment</td>
</tr>
<tr>
<td>Unmet needs</td>
<td><strong>Lack of respite support</strong></td>
<td>• Time off caring&lt;br&gt;• Barriers to accessing respite care</td>
</tr>
<tr>
<td></td>
<td><strong>Lack of information</strong></td>
<td>• Information on discharge&lt;br&gt;• Information on available support services&lt;br&gt;• Information about stroke&lt;br&gt;• Uncertainty of the future</td>
</tr>
<tr>
<td></td>
<td><strong>Lack of additional support</strong></td>
<td>• Paid caregivers&lt;br&gt;• Listening ear&lt;br&gt;• Equipment</td>
</tr>
</tbody>
</table>
Findings

The effects of caregiving

Physical effects

Most family caregivers stated that they provided assistance with activities of daily living such as mobility and toileting. It was evident that supporting stroke survivors can be physically demanding with some referring to their caregiver role as ‘hard work’. This was the case for most caregivers especially during the early days following hospital discharge as over time, the stroke survivors’ functional abilities appeared to improve.

‘He couldn’t walk unaided, to stand up originally I’d have to put my hand underneath his bottom and lift him up, it was hard work, but now he’s actually walking round with the aid of a stick which is absolutely unbelievable...’ (P10-Wife-56-65).

On the contrary, participants who were supporting individuals who suffered recurrent strokes reported increasing demands.

‘Since the December one things just went bad to worse. I’ve got two carers four times a day but it’s just hard because in between, I’ve got to transfer him onto a perching stool...’ (P9-Wife-66-75).

Increasing workload resulting from routine chores plus additional tasks to support the stroke survivors often led to tiredness. Furthermore, waking up at night to assist with positioning and toileting contributed to fatigue. For most participants their increasing age, poor health and frailty hindered their ability to perform some tasks.

‘Because I am 70 next birthday, I have told him I can’t be doing this on my own, he’s going to have carers in because I do have a bad foot and I’m finding it difficult to walk, I have high blood pressure, I will get carers in to take the strain off me.’ (P15-Wife-66-75).
Emotional effects

Overwhelmingly, participants described the effects relating to managing the emotions and behaviours of the stroke survivors as well as their own feelings. Most family caregivers were involved in offering encouragement and reassurance to the stroke survivors ‘to raise their spirits’ as they adjusted to the devastating effects of the stroke. However, managing the stroke survivor’s emotions and behaviour remained a major and ongoing challenge.

‘The daily aspects of looking after [husband] we’ve got quite comfortable because we’re doing downstairs living, but I think it’s keeping his morale up, I’d say that is the hardest...’ (P12-Wife-66-75).

Participants cited a range of behaviours and emotions exhibited by the stroke survivor they found challenging e.g., mood swings, impatience, depression, verbal abuse, social withdrawal and demanding behaviour. The unpredictability of these behaviours coupled with the lack of insight by the stroke survivor made it difficult for the family caregivers to cope.

‘If I tell him to do things, I’m bossy and get told to get lost. I’ve been told in no uncertain terms that I’m useless, helpless and rubbish...I find that very hard to take in’ (P9-Wife-66-75).

There was a clear emphasis from participants that managing their own feelings and emotions was a major challenge. Feeling upset due to the sudden changes to their lifestyle and the effects of stroke on the survivors were commonly described. Participants also reported feelings of depression and suggested common triggers to be: taking up the caregiving role abruptly, giving up employment and living in fear of a recurrent stroke. Being taken for granted by health and social care professionals was also highlighted. Although others managed to seek emotional support from professionals most were reluctant for fear of being commenced on antidepressants.
‘If you’d talked to somebody who’d had that experience you could say to them, ‘I start to hate myself’, and they say ‘yeah but it’s just a normal human feeling’. Talk to a professional then they’ll be writing your prescription or sending you to the funny farm to be assessed …’ (P5-Husband-56-65).

**Socio-economic effects**

The caregiving role presented negative impacts on family caregivers’ social lives and financial situations. They described living a ‘different sort of life’ as they could no longer engage in hobbies previously enjoyed with the stroke survivor such as walking while others were unable to go on holiday.

‘Well, it were a totally different way of life for us because we went out regular and had holidays all the time but all that’s not there now, it is a different sort of life this than we had before’…” (P14-Wife-66-75).

Isolation was also reported and several discussed challenges with maintaining social relationships.

‘I do go to church and have friends at church and I’m finding it harder now because I’m looking after [husband], but I’m not mixing with people quite as much and I feel isolated…’ (P8-Wife-76 plus).

Taking up the caregiving role led to financial difficulties for most family caregivers. Although the majority were retired, four gave up employment. Increasing expenditures particularly with regards to transportation resulted in many family caregivers reporting financial challenges. A few reported lack of information on how to seek financial support while some described receiving financial assistance such as benefits to make ends meet. Although most participants were appreciative of the financial support received, others seemed dissatisfied with the amount and the length of time they had to wait to receive support.
‘You’ve got to be six months down the line to get it, even attendance allowance you can’t get, and it’s in the first six months that you need it because your expenses go up and your outgoings increase when someone’s ill...’ (P6-Wife-66-75).

Unmet needs

_Lack of respite from caring_

There was a clear sense from participants that occasionally, they needed to have time off caring to rest. Both new and established family caregivers (those who had been providing care for several years) expressed their desire to have a break. Only four participants mentioned having accessed respite support.

‘What would help me was for him to be taken off my hands so that I could have my head to myself and not constantly thinking about his needs... so that I could have a break you know, because it’s constant...’ (P7-Wife-76 plus).

The requirement for respite was varied. Some preferred having a few days, others wished for longer. Leaving the stroke survivor alone even for a few hours was not an option for most family caregivers due to concerns over safety. Barriers such as dissatisfaction with services and reluctance of the stroke survivor were cited by the few participants who attempted to access respite support. Nonetheless, the majority reported the lack of information to access respite services as the main barrier.

‘To tell you the truth I wouldn’t even know how to apply for respite care because no one’s ever mentioned it to us... I wouldn’t even know how to go round it...’ (P13-Husband-56-65).

_Lack of information_

The general lack of information emerged strongly from participants. They reported receiving inadequate information from hospital staff at discharge. Furthermore, the majority were unaware of the carer support services available locally.
‘And you’re a ship without a rudder there’s nothing, and you don’t know about the various pieces that you can get, the various supports that there are…’ (P5-Husband-56-65).

Additionally, uncertainty regarding recovery of the stroke survivors affected their ability to plan for the future. Participants wanted to know from professionals how far their spouse’s abilities would improve or how long they would continue in their caregiving role.

‘You’re constantly saying; ‘well is he going to get better?’ And they constantly say; ‘it takes time, we can’t tell you, every stroke patient is different’… (P10-Wife-56-65).

Lack of support

Most participants remarked on the invaluable support received from friends and family plus health and social care staff which made their role bearable. However, family caregivers experienced difficulties where support was not forthcoming. Most expressed disappointment at the lack of support from family members:

‘His family aren’t helpful, and my family are busy, if people helped more, then maybe things would be better, but they just don’t…’ (P2-Partner-Female-36-45).

Not having a listening ear was another unmet need that was reported. Respondents discussed their desire to have ‘someone’ to talk to, who could listen to them, either face-to-face or over the phone. Although a few appeared to be receiving this support from close friends, the majority weren’t:

‘Whether it’s a listening ear or counselling service could be offered to carers especially in that initial phase when you’re coming to terms with what’s happened, that could be useful’… (P11-Wife-66-75).

Additionally, others described the lack of support from professionals and paid caregivers. Participants who were receiving additional support with personal hygiene tasks from paid
caregivers cited the lack of flexibility and inconsistencies as deterrents for continuing to receiving such support. With regards to equipment provisions, most received their required equipment such as commodes on time. However, others clearly expressed dissatisfaction and reported delays.

‘We haven’t got a chair for him to sit on and our couch is too low... we’re still waiting for a proper chair for [person’s name] and he’s been home since July’ (P2-Partner-36-45).

Discussion

Findings from this study suggest that despite changes to legislation, family caregivers continue to experience challenges when supporting individuals following a stroke. Physical, emotional and socio-economic effects of caring were reported in the current study consistent with findings from national and international studies (Greenwood et al. 2009; Kokorelias et al. 2020). Additionally, participants in our study discussed unmet needs regarding information, respite and support, findings reported in research by Zawawi et al. (2020) and more recently, Denham et al. (2022).

Overwhelmingly, participants reported negative emotional experiences such as frustration and depression with only a few admitting to having sought support. Others were reluctant to request help due to fear of being started on antidepressants. These findings support existing literature as similar observations were made in a UK survey conducted by the Stroke Association with over 2,000 respondents. Although 79% had experienced anxiety and 59% felt depressed, two-thirds did not seek any support or receive advice (Stroke Association 2013). The fear of being commenced on antidepressants described by participants in the current study may indicate lack of knowledge regarding the treatment options available such as counselling (Thomas et al. 2017). Our findings reinforce the need for information from health
and social care professionals on available treatment options to enable family caregivers to seek appropriate support. The findings also support the need for further research focusing on interventions that would assist family caregivers of stroke survivors in managing their emotions (Cheng et al. 2014).

Lack of respite support was emphasised as an important unmet need in the current study. These assertions highlight the value of respite support among stroke family caregivers and are consistent with previous research within this population (Bastawrous et al. 2015; Torregosa et al. 2018). Provision of respite support reflects the Care Act’s ambitions to support family caregivers to have an independent life alongside caregiving (Marczak et al. 2021). In our study, very few participants accessed respite support. Although various barriers were highlighted by participants, it should be acknowledged that the provision of respite services vary widely across the UK which may potentially prevent family caregivers from accessing respite support. This is an area in need of further research and consideration by local authorities in order to make the ambitions outlined in the Care Act a reality.

As reported, our findings indicate that the needs of stroke family caregivers are still not regularly assessed post the Care Act. Only four out of 16 participants confirmed having completed a formal carers’ assessment. Delays of up to seven months were identified when assessments were undertaken. The lack of carers’ assessment among family caregivers observed in the current study was previously highlighted as a concern by the Care Quality Commission who reported that, nationally, less than half of stroke family caregivers were offered an assessment and received support (CQC 2011). Ignorance regarding carers’ assessments in our study and the general caregiver population could partly explain the low uptake of carers’ assessments. A commissioned report for Carers Trust in 2016, ‘Care Act for
Carers: One Year On’, concluded that further work is warranted to ensure that family caregivers are aware of their rights and that the quality of assessment is of a high standard (Bennett 2016). This study’s findings support the report’s conclusions. Additionally, it can be suggested that alternative, proactive approaches to identifying the needs of stroke family caregivers are required to prioritise those requiring a detailed carers’ assessment. Findings from our research provide an insight into the challenges that family caregivers of stroke survivors continue to experience post the Care Act. However, the findings should be considered in light of some limitations. Participants were recruited from one geographical area in the UK and focusing on older spousal caregivers. Additionally, the exclusion of non-English speaking family caregivers warrants further research with the increasing diversity within the UK.

Conclusion

This study indicates that family caregivers of stroke survivors continue to experience considerable problems despite changes to legislation. Shortfalls in existing approaches to assessment of family caregiver’s needs are apparent. Our findings have been used to inform the development of a screening tool for use with family caregivers of stroke survivors. Since data collection was undertaken, the Covid-19 pandemic has led to reduced services resulting in a reduction of assessments and support being provided (SCIE 2021). The impact of the pandemic coupled with the lack of assessments and support pre-pandemic, can be suggested to have had major impact upon family caregivers and needs urgent attention.
References


