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"I don't believe in leading a life of my own, I lead his life": A qualitative investigation of difficulties experienced by informal caregivers of stroke survivors experiencing depressive and anxious symptoms

Running Head: I DON'T BELIEVE IN LEADING A LIFE OF MY OWN

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Abstract

Objectives: Health and social care services are increasingly reliant on informal caregivers to provide long-term support to stroke survivors. However, caregiving is associated with elevated levels of depression and anxiety in the caregiver that may also negatively impact stroke survivor recovery. This qualitative study aims to understand the specific difficulties experienced by caregivers experiencing elevated symptoms of anxiety and depression.

Methods: Nineteen semi-structured interviews were conducted with caregivers experiencing elevated levels of depression and anxiety, with a thematic analysis approach adopted for analysis.

Results: Analysis revealed three main themes: Difficulties adapting to the caring role; Uncertainty and Lack of support.

Conclusions: Caregivers experienced significant difficulties adapting to changes and losses associated with becoming a caregiver, such as giving up roles and goals of importance and value. Such difficulties persisted into the long-term and were coupled with feelings of hopelessness and worry. Difficulties were further exacerbated by social isolation, lack of information and poor long-term health and social care support.

Clinical implications: A greater understanding of difficulties experienced by depressed and anxious caregivers may inform the development of psychological support targeting difficulties unique to the caring role. Improving caregiver mental health may also result in health benefits for stroke survivors themselves.

Introduction

Despite decreases in stroke incidence and mortality (Feigin et al., 2014), stroke remains a leading cause of disability worldwide (Feigin et al., 2014; Murray et al., 2013). Decreases in mortality rates are resulting in increased home discharge (Dobkin, 2005) and subsequent rise in stroke survivors returning to the community (Reed, Wood, Harrington, & Paterson, 2012). However, the significant impact of stroke on the person physically, cognitively and emotionally remains (Creutzfeldt, Holloway, & Walker, 2012; Schulz & Sherwood, 2008). As such, stroke survivors commonly suffer limits in functional recovery (Cumming, Marshall, & Lazar, 2013; Luengo-Fernandez et al., 2013) and significant difficulties performing activities of daily living (Mayo et al., 2002). Subsequently, continued support is often required (Kelly-Hayes, 2003), commonly provided by informal caregivers, such as family members, within the home (Sumathipala et al., 2012, Jaracz et al., 2015).

The provision of informal care to stroke survivors within the community can be challenging (Jaracz et al., 2015), and can be associated with significant emotional consequences including sleep difficulties (Rittman, Hinojosa, & Findley, 2009); loss of relationships with family and friends (Rochette et al., 2007); withdrawal from social activities (Mausbach et al., 2011) and poor quality of life (Godwin, Ostwald, Cron, & Wasserman, 2013). Further, caregivers may experience poor physical health (Carretero, Garcés, Ródenas, & Sanjosé, 2009; Legg et al., 2013) and reduced energy (Parag et al., 2008). Given the range of emotional and physical consequences faced by caregivers, typically referred to as caregiver burden (Rigby, Gubitz, & Phillips, 2009), it is unsurprising there is a higher prevalence of mental health difficulties such as depression and anxiety experienced by caregivers of

stroke survivors than the general population (Balhara, Verma, Sharma, & Mathur, 2012; Visser-Meily et al., 2008]. Indeed, 50% of caregivers of stroke survivors experience elevated symptoms of depression (Visser-Meily et al., 2008) and anxiety (Greenwood & Mackenzie, 2010a). Further, research suggests poor caregiver mental health is negatively associated with both quality of care provision and survivor recovery (Perrin et al., 2008).

Despite the high prevalence of depression and anxiety, research identifying factors related to elevated levels of caregiver burden and psychological distress yield inconsistent results (Rigby et al., 2009). Whilst qualitative studies exist examining the experience of carers of stroke survivors (see Lou, Carstensen, Jørgensen, & Nielsen, 2016), studies rarely explicitly examine the specific difficulties and challenges experienced (Greenwood et al., 2009a). Further, qualitative research examining the experience of stroke caregiving has failed to focus on the psychological distress or burden experienced by caregivers (Greenwood & MacKenzie, 2010b). Indeed, to the best of our knowledge, there have been no qualitative studies specifically examining difficulties experienced by carers of stroke survivors with elevated levels of depression and anxiety. Given the paucity of current research there is a need to develop a greater understanding of the specific difficulties experienced by caregivers of stroke survivors with elevated symptoms of depression and anxiety.

Located in phase I of the Medical Research Council (MRC) framework for developing complex interventions (Craig et al., 2008) this study aims to gain an understanding of specific difficulties and challenges faced by caregivers of stroke survivors experiencing elevated symptoms of anxiety and depression. Whilst stroke caregiver specific psychological intervention exist, recent systematic reviews and meta-analyses have found only small effect ($ES = 0.19$) with respect to reducing symptoms of depression (Cheng et al., 2014). Furthermore, existing informal carer psychological interventions have been criticised for not being tailored to the unique difficulties experienced by informal carers (Krevers & Öberg, 2011). Evidence highlights that interventions tailored to the specific difficulties experienced by informal carers are more effective than generic interventions (Bakas et al., 2014). As such, understanding these difficulties experienced may represent a first step to inform the development of a psychological intervention targeting problems experienced by caregivers that is more responsive than existing psychological interventions to address caregiver's specific difficulties and needs (Greenwood & MacKenzie, 2010b).

Methods

Semi-structured interviews were used to examine difficulties experienced by caregivers of stroke survivors, with a thematic analysis approach (Braun & Clarke, 2006) adopted for data-analysis. The study was approved by the University of Exeter Psychology Ethics Committee.

Sampling and participants

Participants were recruited from stroke and caregiver specific organisations, with the majority of participants (n=16) recruited from the South West of England and three participants were recruited from the Greater London area (e.g., The Stroke Association; Different Strokes; Carers UK; Headway and Unite Devon). Organisations supporting the study provided caregivers with invitation packs, alongside brochures and flyers advertising the study in community group newsletters, websites and Facebook groups. The first author (JW) gave presentations to community group members to advertise the study where geographically feasible. A researcher spoke to interested caregivers over the telephone to provide further information about the study and sent an invitation pack (invitation letter, participant information sheet, consent form, participant and family doctor contact information form, and screening and demographics questionnaire) to interested caregivers. Once questionnaires and consent forms were received by the research team, participants were telephoned to inform them of their study eligibility. Participant inclusion criteria were: (a) self-identification as a caregiver of a stroke survivor; (b) aged 16 years or over; (c) scoring between 5-23 on the PHQ-9 (Kroenke, Spitzer, & Williams, 2001) reflecting mild to moderately severe levels of depression severity and/or between 5-21 on the GAD-7 representing mild to severe levels of anxiety (Spitzer, Kroenke, Williams, & Löwe, 2006). Severity cut-offs have been raised from traditionally adopted cut-offs on the PHQ-9 (Kroenke, Spitzer, & Williams, 2001) and in line with other research (Woodford, Farrand, Watkins, Richards, & Llewellyn, 2014) in response to findings that traditional cut-offs may lead to an overestimation of patients being classified as severely depressed (Cameron, Crawford, Lawton, & Reid, 2008). Exclusion criteria were: (a) current suicidal ideation; (b) alcohol misuse (above 31 units of alcohol for men and 22 for women per week); (c) dependency on illegal drugs (use of illegal drugs every day); (d) current or historical psychosis or bipolar disorder; and (e) hearing or reading impairment preventing interview participation. Suicidal ideation was determined by a response to question 9 on the PHQ-9: "Over the last 2 weeks, how often have you been bothered by thoughts that you would be better off dead or of hurting yourself in some way." Participants scoring 2 or 3 on question 9 were excluded from the study and the study team then followed the suicide risk protocol for the study. Specifically, the researcher informed the participant's family doctor of their risk status as determined by the PHQ-9. All participants had previously consented to this protocol.

Thirty-one caregivers expressed interest and were sent an invitation pack. Subsequently, 11 caregivers withdrew interest and one caregiver was not eligible for participation (current suicidal ideation). A total of 19 participants were included within the study and analysis. The majority of

caregivers were female (n=17), White British (n=18) and a partner or spouse of the stroke survivor (n=15). Mean age of caregivers was 57 years (range 21-77, S.D. 15.6) and had been in a caregiving role for a mean of 5 years (range 4 months-22 years, S.D. 5.3). The mean PHQ-9 score was 9 (range 1-20, S.D. 5.0), indicating mild depression and the mean GAD-7 score was 8 (range 2-21, S.D. 4.8), indicating mild anxiety. Selected individual participant characteristics, with pseudonyms and age bandings provided to ensure confidentiality (Table 1).

Data Collection

Data was collected through semi-structured interviews conducted by JW. Dependent on participant preference, interviews were available face-to-face (at a location convenient for the caregiver, including their home) or over the telephone. An interview schedule was developed to gain an understanding of the difficulties, challenges and problems experienced by caregivers. Questions were open-ended and structured around areas relevant to the research question, with subsequent questions open and flexible to participant answers (Britten, 1995). Questions included: (a) "Can you tell me a little about some of the challenges you have faced since [stroke survivor] experienced a stroke?"; (b) "In what ways have the types and nature of difficulties / challenges changed over time?"; (c) "Can you tell me about a recent difficult situation and what was going through your mind at the time?"; (d) "What types of barriers have you experienced in accessing support for your difficulties?" The full interview schedule detailing all questions asked can be found in Appendix A. Participants were interviewed only once, with interviews ranging from 52 minutes to 1 hr and 43 minutes, with a mean duration of 1 hour and 18 minutes.

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Analysis

Audio recordings of interviews were transcribed verbatim by the first author, with NVIVO10 (QSR International, 2012) software used to assist with data analysis. Data analysis commenced after the first interview was conducted with an iterative approach to analysis undertaken. A thematic analysis approach was adopted following established guidelines (Braun & Clarke, 2006), with initial codes and themes developed by the first author. Transcripts were read multiple times, enabling meanings and patterns to be identified within the data. Subsequently, initial codes were identified across the data set, with codes subsequently collated into initial themes to provide meaningful themes and

subthemes across the dataset. Themes and subthemes were refined until themes represented the data set as a whole (Braun & Clarke, 2006). To establish rigor, triangulation through dialog was adopted. Initial themes and subthemes were discussed with a second researcher during fortnightly research meetings over a 6 month period to reach consensus, bring and further refine theme development (Lietz, Langer, & Furman, 2006). Full consensus between the two researchers was reached in all cases. Additionally, disconfirming cases were actively sought to increase trustworthiness (Patton, 1999). To improve transparency of analysis, verbatim extracts of data are presented within the results, alongside descriptions of each theme (Elliot, Fischer, & Rennie, 1999).

Results

Three major themes emerged - "Difficulties adapting to the caregiving role", "Uncertainty about the future" and "Lack of support." Furthermore, a number of subthemes were derived (Table 2).

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Theme 1: Difficulties adapting to the caregiving role.

Substantial difficulties were reported relating to adapting to the caregiving role and consequences of this challenging life transition. Five subthemes were generated concerning problems caregivers experienced when attempting to adapt to the role of caregiver.

Subtheme 1: Having to give up other roles and life goals of value and importance.

Caregivers described giving up roles and activities of importance and value, in particular those related to work, plans for retirement and education:

It is hard, I'm not going to say it isn't because I mean I've always worked, right up to the day he had his stroke and suddenly I haven't got that anymore, so I haven't got a life outside of caring. (Maude)

Additionally, caregivers felt unable to engage in previously valued activities, such as socialising with friends, hobbies, taking vacations, visiting restaurants, going on walks or sporting interests. As such, caregivers reported feelings of boredom, social isolation, lack of independence and thoughts of there being very little life outside of the caregiving role:

I don't like this life ... I suppose, it's getting by, it's not really living, it's not a life, it's not a life I would have ever, we came here to do all the lovely things that [county name] has to offer, and it's like having your nose rubbed in it. (Celina).

A number of reasons were identified by carers for giving up previous goals and activities, including financial restrictions, lack of time, the physical consequences of stroke, motivational difficulties experienced by the stroke survivor and anxiety concerning leaving the stroke survivor without supervision. Consequently they felt trapped and unable to change the situation, leading to some carers reporting feelings of resentment, for example, "You start resenting, resentment's a good one, everything that you've given up and everything that you're doing" (Aida).

Subtheme 2: Changes in relationships. Significant difficulties regarding changes to caregivers' relationships with the stroke survivor, as well as wider family and friends, were reported. Post-stroke communication difficulties contributed to these changes, leading to a lack of understanding of one another, resulting in difficult emotions such as frustration and anger. Mood difficulties and personality changes in the stroke survivor also led to caregivers feeling a sense of loss in relation to the person the stroke survivor once was:

The person I married has gone, he's not the same person that I married, that person has gone. So you're mourning for the person that you've lost, and you've now got another person, you've come home with a completely different person and so I find that quite difficult. (Alana)

Additionally, assuming the role of carer resulted in changes to the dynamics of their existing relationship with the stroke survivor. Both spousal and adult child carers equated their new relationship to that of parenthood, also leading to feelings of guilt and shame:

I've had to sort of take over as the adult to look after two children that, they behave like children ... you lose the people they were, which is an awful thing to say. I do think that's a terrible thing to say but it's the only way I can describe the way I feel about them now. That makes me feel guilty as well. (Karina)

Subtheme 3: "A prisoner in your own home." A loss of freedom and independence was a further difficulty identified by participants, with caregivers no longer able to do activities spontaneously, leading to feelings of boredom and a sense of having no life outside caring. The caregiving role was described as "twenty-four-seven" and "a prison sentence", leading to caregivers feeling trapped: "It feels like I'm a prisoner in my own home. You feel as if you're a prisoner and you can never get up in the morning and say 'I think I'll just go here' or 'I'll just go there'" (Alana).

Subtheme 4: Assuming new roles and responsibilities. Caregivers reported feeling overwhelmed by new roles and responsibilities associated with caring and assuming roles previously undertaken by the stroke survivor. Such tasks included housework, gardening, Do-it-Yourself (e.g., general household maintenance and repair) and finance management, as well as caring specific tasks. Caregivers felt they were being pulled in multiple directions and as if they were failing to do a good enough job:

I feel I'm pulled in so many different directions that I don't do any of them well. And I don't always feel like that, but then it does, it does come sometimes out of the blue and I just feel that I'm doing everything very badly and I just can't cope. (Matilda).

Caregivers reported finding taking sole responsibility for decision making as difficult and shouldering such responsibility was something they did not want:

Everything seemed to be just on my shoulders and there are times when I don't want it. I don't want to have this responsibility, it wasn't mine, I don't want it, take it back you know. Please somebody, please come and take it away. (Aida)

Subtheme 5: Lack of balance. Balancing the caregiving role with other activities was difficult, with caregivers generally reporting little time for activities outside the caregiving role and little time for a break:

I get tired obviously and you never get time for yourself to sit and relax. I mean, I don't necessarily want to go out, I just want a couple of hours with nothing to do, but you have to run the whole house. (Leanne)

This lack of balance in the caring role was reported as overwhelming and contributing factor to caregivers' low mood or depression and feelings of sadness: "I think, I don't know really, it's just, just daily. It's just always there in front of you. I don't ever feel, I never feel happy, I can't remember what feeling happy is" (Celina).

Lack of breaks from the caring role led to difficulties with exhaustion, fatigue and boredom. However, breaking from the caring routine was considered difficult, with fear of forgetting important elements of the caring routine, such as administering medication. As such, some caregivers reported feeling the routine was essential for them to successfully manage the caring role and also important for the stroke survivor: "If I go out of the routine I'd never cope with it. You know like his medication ... And I've got to be in that routine" (Maude). However, being tied to the caring role, with little opportunity for a break also fed into caregivers feeling overstretched with no time or energy to do any activities for themselves.

Theme 2: Uncertainty

This theme is concerned with feelings of uncertainty reported about the future health of the stroke survivor, the future in general, and lack of knowledge and information concerning the caring role.

Subtheme 1: No light at the end of the tunnel. Uncertainty concerning the future was associated with caregivers reporting low levels of hope for the future, mainly related to the health of the stroke survivor and their future caring role. Caregivers referred to the chronic nature of stroke, seeing no end to the caring role, coupled with concern about how they would manage longer term: "I suppose the way I look at it at the moment is it's a long dark tunnel and there's no light at the end of the tunnel at all" (Alana). Health professionals' ambiguous long-term prognosis for the stroke survivor further exacerbated difficult feelings of hopelessness. Additionally, uncertainty around caregivers' own health in the future was frequently reported, with some caregivers concerned about what would happen to the stroke survivor if they became sick or died themselves.

Subtheme 2: Worry about the stroke survivors. Uncertainty concerning the health of the stroke survivor and their ability to perform certain activities fed into feelings of worry and anxiety in caregivers. They reported feeling uncertain about leaving the stroke survivor alone, through fear of the stroke survivor falling or suffering another stroke, transient ischaemic attack (TIA) or post-stroke secondary health complication. Anxiety and worry led to caregivers reporting overwhelming feelings of responsibility and protectiveness for the stroke survivor, resulting in behaviors such as constant monitoring. In some cases past experiences contributed to feelings of anxiety and worry, for

example, the stroke survivor had been left alone and they had fallen or experienced a seizure: “It’s just the anxiety that something will happen to him while I’m not there. So I don’t believe in leading a life of my own, I lead his life” (Maryanne). Furthermore, uncertainty was reported regarding managing physical setbacks, such as if the stroke survivor experienced a fall or seizure. As such, some caregivers felt unable to cope with the stroke survivor outside the home, leading to carers feeling incapable of leaving their home, resulting in further social isolation.

Subtheme 3: Lack of information. Lack of information contributed to the uncertainty caregivers felt in the caring role. Lack of information regarding the physical and emotional impact of assuming a caring role led to caregivers feeling ill equipped and unprepared. Assumptions were made by health professionals the carer would adopt the role of caregiver, without providing information concerning how to care for someone with a stroke or what to expect in the caregiving role:

Everybody is different and the level of care is different but I think it would be nice if somebody had taken the time to sit down and say “You do realize that your life is going to change dramatically?” I mean, I am bright enough to know that my life was going to change, but I don't think I ever realized quite how much it was going to change. (Bettie).

Additionally, caregivers reported receiving little information concerning secondary post-stroke health complications, such as communication difficulties, mood changes, hallucinations and epileptic seizures. As such, caregivers felt ill equipped to manage these difficulties. Uncertainty was exacerbated by receiving little information concerning stroke survivor prognosis, or how to access long-term support. However, there were two disconfirming cases whereby caregivers reported receiving a large amount of written information post-stroke, however, this resulted in carers feeling overwhelmed and not reading the information provided. Additionally, the information provided tended to be generic, making it difficult to identify what information applied to them: “Leaflets are great but they are generalized, and you have so many of them that, in all honesty, you read a few, and then they are gone!” (Aida).

Theme 3: Lack of Support

A lack of support was reported regarding both health and social care (with some disconfirming cases reported below) and social support from family and friends. Two main subthemes were identified:

Subtheme 1: Social isolation. Some caregivers felt socially isolated and at times unsupported by friends and family, which for some worsened over time. Caregivers reported friends and family did not understand the caring role or impact of stroke, leading to caregivers feeling increasingly social isolated. Specific examples, such as friends and family being unable to understand the financial restrictions caregivers faced, or not being able to participate in social activities as they did previously, were reported:

I tend to not get too involved with people because it hurts to hear, I know it sounds horrible, but it hurts to hear how wonderful a time they're all having. And I don't think mine's much good ... sometimes it's very hard to stomach people going on about how they're always going out here there and everywhere. And you know we're lucky if we go out once every two weeks somewhere for a meal. (Celina)

Changes to caregivers' roles, for example no longer being in employment, further exacerbated feelings of social isolation. Feeling confined to the house and having little time outside of the caregiving role also contributed to carers feeling unable to socialize as they would have in the past. Further, whilst support was provided by friends and family during the initial stages post-stroke, over time support lessened, further contributing to feelings of isolation

You've got a lot of backup at the beginning, a lot of family friends, everyone's there and it's like bereavement, it's like anything big that happens. In an emergency everyone's there and they all drift away, the phone calls stop and I think you feel more isolated, you feel like you're on your own. (Aida)

However, some caregivers (Ivy and Harriet) were disconfirming cases, whereby they emphasized the importance of having a good network of family and friends, especially social support facilitated through stroke groups in the community.

Subtheme 2: Health and social care. Difficulties were frequently reported regarding access to long-term health and social care, for both stroke survivors and caregivers themselves. Some caregivers talked about not being offered carer assessments, or even being aware they were available. Additionally, some caregivers were provided with incorrect information concerning social welfare benefits and also felt guilty asking for welfare support. Frustration with health services was also common, especially concerning lack of long-term healthcare provision for stroke survivors.

Caregivers believed if better long-term healthcare had been provided stroke survivors' recovery would have improved, reducing carer burden. Further, lack of long-term healthcare provision often resulted in the caregiver assuming responsibility for motivating the stroke survivor to persist with rehabilitation, leading to further strain, burden and feelings of frustration:

I actually got [stroke survivor] some more physiotherapy to try and help her ... And on the third visit she [physiotherapist] said "right well that's up to you now [stroke survivor] to keep it going" and you just feel so frustrated. I know there is a constraint upon money and constraint on professional's time. But sometimes you think if a bit more time had been spent on [stroke survivor] when she first came out then I think a lot of the problems that we've got now five years on may not have been there. (Simon)

Whilst caregivers reported the person they cared for with a stroke as having excellent acute stroke care, they also highlighted how their needs actually increased over the long-term, especially in cases whereby the stroke survivor's condition was deteriorating. Caregivers found themselves fighting to gain support, which was exhausting and frustrating. Further, a lack of general practitioner recognition concerning the impact of the caring role and subsequent provision of appropriate emotional support was identified by some caregivers.

Although, on the whole, caregivers reported a lack of long-term healthcare, there were some disconfirming cases. Maryanne reported receiving excellent support from their local hospital, receiving continued physiotherapy for the stroke survivor. Bettie reported receiving excellent support from their general practitioner.

Discussion

This is the first study to specifically examine difficulties experienced by caregivers of stroke survivors experiencing elevated symptoms of depression or anxiety, complementing existing research examining the general experience of being a caregiver of a stroke survivor (e.g. Bakas et al., 2002; Bugge, Alexander, & Hagen, 1999; Greenwood, et al., 2009a; Pinguart & Sörensen, 2003a). Findings demonstrate significant difficulties relating to adaptation to changes and losses experienced within the caring role, hopelessness and worry, social isolation, lack of information and poor long-term health and social care support. Of importance, these difficulties led to caregivers reporting a number of significant distressing emotions associated with anxiety and depression, including feelings of guilt, resentment, frustration, anger, shame, failure, sadness and fear.

The experience of change and loss has previously been posited to underlie the stroke caregiving experience, impacting carer identity (Greenwood & MacKenzie, 2010b). Changes to existing roles, relationships and responsibilities are commonly reported in the stroke caregiver literature (Greenwood & MacKenzie, 2010b; Quinn, Murray, & Malone, 2014). Further, loss of a previous life and relationship with the stroke survivor are further difficulties supported by wider research (Bäckström & Sundin, 2007, 2009; Coombs, 2007). Some evidence suggests caregivers adjust to changes and losses associated with the caring role and develop coping strategies to manage problems experienced over time, however research findings are inconsistent (Gaugler, 2010). This present study identified caregivers experiencing elevated levels of anxiety or depression experience specific difficulties related to adapting to these changes and losses, with these difficulties persisting into the long term. The majority of caregivers were long-term carers (mean of 5 years) yet were experiencing significant distress as a result of changes associated with the caring role. As such, whilst some caregivers may be able to adapt to the demands of the caring role, some caregivers struggling with elevated levels of depression and anxiety may be experiencing significant difficulties adapting to the caring role. However the direction of the effect here remains unknown.

An associated difficulty concerns restrictions caregivers experience working towards life roles and goals of importance and value. Other qualitative research has identified caregivers experience a reduction in social participation (Bulley, Shiels, Wilkie, & Salisbury, 2010) and loss of spontaneity and freedom (Backstrom & Sundrin, 2009). Further, quantitative research suggests caregivers experiencing restrictions in working towards roles and goals of importance and value experience increased levels of depression (Grigorovich et al., 2016; Hwang et al., 2009; Mausbach et al., 2011; Rochette et al., 2007). Whilst some caregivers are able to re-engage with activities over time, those with higher levels of depression and caring for stroke survivors with greater illness severity are less likely to (Grigorovich et al., 2016). As such, an important finding emerging from this study is caregivers with elevated depressive and anxious symptoms may experience long-term difficulties in re-engaging with goals and roles of importance. Further, caregivers experienced difficulties performing new roles and responsibilities associated with caregiving. Indeed, other research has found caregivers of stroke survivors with depression perceive greater levels of task difficulty concerning caregiving related tasks, finance management and liaising with healthcare professionals than caregivers without depression (McLennon et al., 2014). This finding is also supported by other qualitative research demonstrating caregivers experience difficulties with increased workload and levels of responsibility (Bulley et al., 2010).

Uncertainty is a further common theme found within the caregiver qualitative research (Greenwood, MacKenzie, Wilson, & Cloud, 2009), coupled with poor communication from

healthcare providers and lack of stroke specific information and discharge needs not being met (Creasy et al., 2013; Camak, 2015). However, previous research identifying uncertainty underling the caregiving experience has focused on caregivers of stroke survivors recently discharged up to three-months post-discharge (Greenwood et al., 2009b). Findings have demonstrated caregivers adopt various strategies such as implementing routines (Greenwood et al., 2009b), identifying with positives (Greenwood et al., 2009a; Mackenzie, & Greenwood, 2012) and accepting the situation (Bäckström & Sundin, 2009) to cope with uncertainty. However, this present study identified for some caregivers uncertainty persists into the long-term, possibly indicating caregivers with elevated levels of depression and anxiety may have difficulties utilising more positive coping strategies to manage uncertainties associated with the caring role.

Limitations

First, whilst caregivers were experiencing elevated levels of depression and anxiety confirmation of meeting diagnosis for major depression or a specific anxiety disorder was not conducted. As such, results may not be generalisable to a clinically depressed or anxious caregiver population. However, it is important to note that the PHQ-9 and GAD-7 adopted within this study are measures designed for use within primary care settings to detect depression and anxiety. Second, there was a lack of homogeneity concerning length of time within the caring role. Given significant health transitions (for example falls, subsequent strokes, hospitalisations and diagnoses of other chronic health conditions) may occur during the post-stroke trajectory (Gaugler, 2010) caregiving experiences will differ during these events (Gaugler et al., 2008). No data was collected concerning whether significant health transitions had recently been experienced, that may have impacted on the difficulties of importance and relevance to the carer at the time of the interview. Consequently, the generalisability of findings may be limited. Third, generalisability may be further limited given the sample consisted mainly of English-speaking White British female spousal caregivers engaged with community based organisations. Given resource limitations it was not possible to make specific efforts to recruit ethnically/racially diverse participants, sexual and gender minority participants, nor to include non-English speaking participants. Fourth, given that 50% of caregivers experience symptoms of depression (Visser-Meily et al., 2008) and anxiety (Greenwood & Mackenzie, 2010a) it could be argued that although previous research has not targeted caregivers with known elevated levels of depression or anxiety, it is likely at least some caregivers included within previous qualitative studies were experiencing some level of psychological distress. As such, it is difficult to ascertain to what extent the population recruited within the present study necessarily differs from caregiver populations included within previous studies examining the difficulties experienced by

stroke caregivers more generally. Future research studies should seek to examine difficulties experienced by caregivers in these populations, as these difficulties may differ to the general caregiver population. Further, future research should examine methods of recruitment, such as assertive community outreach approaches, to ensure better reach of minority caregiver populations. Finally, whilst the present study has identified a number of difficulties experienced by a small sample of caregivers experiencing depressive and anxious symptoms, the direction of effect remains unknown and warrants further quantitative research.

Clinical Implications

Greater consideration is needed in terms of developing interventions to maintain carer wellbeing (Naylor et al., 2016). The identification of difficulties experienced by caregivers of stroke survivors with elevated symptoms of depression and anxiety has a number of clinical implications concerning the provision of psychological support. First, a clear finding supported by other literature (Greenwood & MacKenzie, 2010b) is caregivers may struggle with losses, for example experiences losses related to previously held roles and relationships. Indeed, during the lifespan people experience losses associated with ageing (Baltes, 1991; Baltes & Carstensen, 1996; Baltes & Smith, 2003). The “selection, optimization and compensation” (SOC) framework of successful ageing (Baltes, 1991; 1997) provides a theory concerning how older adults maximize the achievement of desired gains, goals and outcomes, whilst minimising undesirable losses and outcomes (Baltes, Staudinger, & Lindenberger., 1999). Indeed, caregivers of stroke survivors have been found to use SOC strategies to cope in the caring role (Greenwood, Mackenzie, Cloud, & Wilson, 2010). Whilst many of the caregivers in the present study were not older adults, the SOC model has been applied as a more general model of adaptive behaviour throughout the life span and to a variety of life domains. For example, research has suggested SOC strategies are adopted to manage work–family conflict (Baltes & Heydens-Gahir, 2003) and achieve success in career and partner-related goals in young adulthood (Weise, Freund, & Baltes, 2000). Further, the SOC model has been posited as a potential framework to inform stroke rehabilitation interventions (Donnellan & O’Neill, 2014). As such, integration of the SOC framework into a psychological intervention for carers of stroke survivors may be a potential solution and is easily incorporated into psychological approaches such as cognitive behavioral therapy (CBT) (Laidlaw & McAlpine, 2008). Integration of the SOC framework may therefore be helpful to facilitate the use of SOC strategies to support successful adaptation to the caregiving role, despite losses associated with becoming a caregiver of a stroke survivor.

Second, a clear finding within the present study was that restrictions associated with the caring role and subsequent disengagement from activities of value impact the ability of the

caregivers themselves to engage in behaviors that may be associated with improvements in their mood (Hopko, Lejuez, Ruggiero, & Eifert, 2003). Behavioral activation is a well-established (Ekers et al., 2014; Richards et al., 2016) psychological approach focusing on reintroducing activity into peoples' lives, increasing opportunities to engage in positively reinforcing activities (Hopko et al., 2003). Supporting caregivers' use behavioral activation may increase engagement in rewarding activities, thereby improving mood. Indeed, behavioral activation has been demonstrated to improve mood in caregivers of people with dementia (Au et al., 2014; 2015; Lovett & Gallagher, 1998).

Third, caregivers struggle with the responsibility of the caring role, effective decision making and performing new tasks and activities. Problem-solving therapy (D'Zurilla & Goldfried, 1971), commonly used as a therapeutic technique within CBT (Nezu, 2004), may represent a further solution. Problem solving therapy has a well-established evidence base for depression (Cuijpers et al., 2007b; Bell & D'Zurilla, 2009) and facilitation of adaptive and effective problem solving when dealing with difficult situation may reduce levels of depression, as well as worry and anxiety, often reported by carers (Bell & D'Zurilla, 2009). Indeed, problem solving is an integral part of caregiver interventions. For example, problem solving represents a key component of Resources for Enhancing Alzheimer's Caregiver Health (REACH) (Belle et al., 2006; Gitlin et al., 2003) and interventions for caregivers of cancer patients (Blanchard, Toseland, & McCallion, 1996; Toseland, Blanchard, & McCallion, 1995).

As such, the SOC model (Baltes, 1991; 1997), behavioral activation (Hopko et al., 2003) and problem solving therapy (D'Zurilla & Goldfried, 1971) may offer potential frameworks to develop a psychological intervention for caregivers of stroke survivors, better tailored to target specific difficulties experienced (Greenwood & MacKenzie, 2010b). Effective psychological support may not only result in improved mood and quality of life in caregivers but may also lead to an improvement stroke survivor physical and emotional outcomes. It is also important to note caregivers reported a number of significant difficulties arising from the lack of long-term health and social care support received post-stroke. This finding has important implications concerning the need to improve the provision of support throughout the post-stroke care trajectory (Greenwood, Holley, Ellmers, Mein & Cloud, 2016), thus potentially improving both physical and emotional outcomes in both informal caregivers and stroke survivors.

- Caregivers of stroke survivors experience difficulties persisting into the long-term concerning adapting to the caring role, hopelessness and worry, social isolation, lack of information and poor long-term health and social care support.

- The integration of psychological approaches within a targeted intervention, such as the selection optimization and compensation model, behavioral activation and problem solving therapy, may be beneficial to target specific difficulties experienced by caregivers of stroke survivors.

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Declaration of Interest

The authors declare they have no competing interests.

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Appendix A: Qualitative Interview Topic Guide

Thank-you for agreeing to be interviewed today. The purposes of today's interview are to understand your experience of being a caregiver of a stroke survivor, for example the challenges and difficulties you may have experienced and ways in which you have found helpful and also unhelpful in coping with these difficulties.

The results will be used to develop a psychological treatment for carers of stroke survivors experiencing emotional difficulties such as low mood, depression or anxiety.

The interview will last around 1 hour (possibly a little longer, or a little shorter). I would like you to answer the questions in your own words and in your own time. If at any point in time you change your mind and don't want to continue that's fine, just say stop. Or if there is a question you don't want to answer we can skip the question.

Everything that you tell me in the interview will be confidential.

1. Can you tell me a little about some of the challenges you have faced since [stroke survivor] experienced a stroke?
 - a. From answers here funnel down around the type and nature of the difficulties / challenges
 - b. In what ways have the types and nature of difficulties / challenges changed over time? Ascertain whether the type and nature of difficulties / challenges have changed over time, specifically to ascertain:
 - i. Some of the difficulties faced immediately after [stroke survivor] experienced a stroke
 - ii. Some of the difficulties faced once [stroke survivor] was back home?
 - iii. Some of the difficulties faced a few months after XX was back home?
2. Can tell me about a recent difficult situation and what was going through your mind at the time? (This point try and funnel around thoughts – can do this from the answers elicited above - funnel down).
3. Can you tell me a little bit about how you feel [stroke survivor] is coping? (emotional and practical impact of the stroke)
4. What strategies have you found helpful in the way you have cared for [stroke survivor]?
5. What strategies have you found unhelpful in the way you have cared for [stroke survivor]?
6. What type of support do you feel would have been helpful in your role as being a carer?
 - a. Try and ascertain both emotional and practical support.
7. What types of barriers have you experienced in accessing support for your difficulties?
8. Have you received any support for your emotional difficulties? If so, what type of support have you received for your difficulties?
 - a. How helpful has this support been and why?
 - b. How unhelpful was this support and why?
 - c. What could be changed about this support to make it better?
9. What type of additional information do you think would be helpful when adjusting to becoming a carer of a stroke survivor?

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Tables

Table 1. Details of Sample

Name	Age	Relationship to stroke survivor	Length of time in caregiving role	PHQ-9 Score	GAD-7 Score
Simon	50 - 60	Spouse / Partner	5 years, 2 months	10	9
Fern	20 - 30	Granddaughter	4 months	8	5
Corinne	60 - 70	Spouse / Partner	4 years, 2 months	7	11
Bettie	50 - 60	Spouse / Partner	1 year, 1 month	15	9
Aida	50 - 60	Spouse / Partner	1 year, 3 months	6	3
Maude	60 - 70	Spouse / Partner	10 years	1	7
Leanne	70 - 80	Spouse / Partner	12 years, 6 months	15	16
Ivy	60 - 70	Spouse / Partner	1 year	6	6
Matilda	30 - 40	Other relative	3 years, 1 month	14	7
Karina	50 - 60	Mother	5 years, 2 months	7	6
Alana	60 - 70	Spouse / Partner	1 year, 8 months	20	21
Gerald	70 - 80	Spouse / Partner	22 years, 3 months	8	12
Clarissa	70 - 80	Spouse / Partner	7 years	8	5
Celina	60 - 70	Spouse / Partner	6 years	5	6
Frances	60 - 70	Spouse / Partner	1 year, 1 month	6	2
Maryanne	50 - 60	Spouse / Partner	3 years, 7 months	12	5
Clare	50 - 60	Spouse / Partner	1 year, 3 months	5	7
Amy	20 - 30	Daughter	3 years, 7 months	17	13
Harriett	50 - 60	Spouse / Partner	2 years, 7 months	5	3

Note. Pseudonyms assigned and ages provided in bandings to protect confidentiality

Table 2. Major Themes and Subthemes

Major themes	Subthemes	Disconfirming cases
Difficulties adapting to the caregiving role	Having to give up other roles and life goals of value and importance	
	Changes in relationships	
	“A prisoner in your own home”	
	Assuming new roles and responsibilities	
	Lack of balance	
Uncertainty about the future	No light at the end of the tunnel	
	Worry about the stroke survivor	
	Lack of information	Too much information
Lack of support	Social isolation	Excellent support from friend and family
	Health and social care	Excellent healthcare support

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