Submitted in partial fulfillment of the Lancaster University, Doctorate in Clinical Psychology

Doctoral Thesis

A case study of a spousal caregiver's experiences during the Covid 19 pandemic for a partner who has had a stroke: identifying implications for psychological support.

May 2023

Ruth Hirst

Doctorate in Clinical Psychology

All correspondence should be sent to:

Ruth Hirst

Division of Health Research, Lancaster University

Health Innovation One

Sir John Fisher Drive

Lancaster University

Lancaster

LA1 4AT

r.kitchen@lancaster.ac.uk

Total Word Counts

Section	Main Text	Appendices, references, tables and figures	Total
Thesis abstract	199	-	199
Literature review	7994	11735	19729
Research paper	7988	11462	19450
Critical appraisal	3721	2212	5933
Ethics section	4186	8325	12511
Total	24088	33734	57822

Thesis Abstract

This thesis is comprised of four chapters: a systematic literature review, empirical research paper, critical appraisal and ethics section.

The literature review explored ethnic minority familial caregivers' experiences of caring for a relative who has had a stroke. The meta ethnographic analysis revealed 4 overarching systemic themes; Self, Family, Culture and Spirituality and Formal Health and Social care systems. Faith and spirituality and dissatisfaction with formal services emerged strongly across the eleven papers.

The empirical paper was a single case study design across two time points to explore the experiences of a spousal caregiver of stroke during the Covid pandemic. An IPA analysis was carried out and three overarching themes emerged: Stopping vs changing, Control and entrapment and Hope and growth. The case study demonstrated how confronting post-stroke difficulties, rather that trying to avoid them, can facilitate the necessary processing to achieve posttraumatic growth and hope for the future.

The critical appraisal seeks to explore and reflect upon the research process with discussion reflecting upon reaching the 'hard to reach', socially sensitive research and methodological considerations of single case study design.

The final section contains the ethics application paperwork supporting the empirical paper; relevant documents are appended.

Declaration

This thesis was undertaken for the Doctorate in Clinical Psychology at Lancaster University, within the Division of Health Research. The work presented herein is the author’s own, except where other’s work is referenced. The work has not been submitted for the award of a degree elsewhere. The author has no competing interests to report.

Name: Ruth Hirst

Date: May 2023

Acknowledgements

I would like to express my thanks to all those people who, in big and small ways, have supported me to complete this work.

‘Sasha’, I owe you a debt of gratitude for taking time out from your very busy life to bravely share your story and take part in my research. I wish you and your family the very best for the future.

To Nargis, the lady with a sparkly cape and jet powered boots who stepped in and saved the day. Thank you for helping me up and guiding me to the finish line, I really couldn’t have done this without you.

To the wonderful ‘Lancs Nobility’ who possess hearts of gold and beautiful souls; I feel blessed to have met you and had you by my side. (PS: ‘Yarnsy’ is back in business!)

To my course mates for keeping the love and sharing the IT tips and fun times; especially to Sara, Rosie and Caela, Sam, Mikey and, the lovely Shazbomb.

To Debs and Vic, Jools, Nic, Kate and Jose; your patience has been a feat of endurance and very much appreciated; I promise never to mention the ‘T’ word again.

To my beautiful wife to be, who has already fulfilled my greatest wish to love and be loved; I can’t wait to spend the rest of our lives together. Thank you so much for believing in me and standing by my side; it’s finally done, let the good times roll!

Lastly, I’d like to dedicate this work to those who didn’t get to see me cross the finish line; to Sheelagh, Cora, Rita and Wendy, but especially to my lovely Pops, my beautiful boy Paddy and my Dad.

Semper diligi; always to be cherished.

.

Contents

Chapter 1 : Systematic Literature Review

The homogeneity of the heterogeneous: A systematic review of the experiences of ethnic minority familial caregivers of stroke

Ruth Hirst

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

All correspondence should be sent to:

Ruth Hirst

Doctorate in Clinical Psychology
Faculty of Health and Medicine
Health Innovation One
Sir John Fisher Drive
Lancaster University
Lancaster
LA1 4AT
r.kitchen@lancaster.ac.uk

Abstract

Purpose

To systematically synthesize qualitative research into the experiences of ethnic minority family caregivers caring for a relative following a stroke

Methods

Seven databases were searched for peer reviewed papers, published up to and including 2022. The papers were reviewed in accordance with the PRISMA 2020 criteria, quality assured using the Critical Appraisal Skills Programme (CASP) checklist for qualitative research and screened against inclusion and exclusion criteria. The review comprised of 11 papers.

Results

Themes identified were Self: Meaning making, Emotional stresses and coping, Practicalities of caregiving; Family: Spousal obligation, Familial piety; Culture and Spirituality: Faith and spirituality, Cultural norms and narratives; Formal Health and Social Care systems: Discharge – the transition home, Meeting needs – provision and adaptation, Rights vs reticence, Information and communication.

Conclusion

Ethnic minority family caregivers shared similar frustrations found in ethnic majority research populations, however nuanced differences were apparent. Cultural competence is an expectation within care frameworks but, appears to lack specific, operationalised guidance on what this entails. More research and greater cultural reference is needed to inform policy, practice and service design.

Introduction

One in four people experience a stroke event, 53% of these die as a result; stroke is the second leading cause of deaths globally and the third leading cause of deaths and disability combined [2]. There are two main types of stroke; ischaemic and haemorrhagic [2]. Ischaemic strokes are caused by blockages or obstructions cutting off blood supply to the brain, haemorrhagic strokes are caused by a ruptured vessel causing bleeding in or around the brain [3]. Disruptions to neuronal blood flow damage brain tissue and can cause temporary or permanent loss of associated function [4], leading to acquired disabilities. By 2035 the number of UK stroke survivors is projected to increase by 32% [5]

Ethnic disparities

Whilst 86% of global stroke mortality occurs within lower and lower-middle income countries [6], stroke incidence in higher income nations is projected to rise with aging populations [5,7]. Research into stroke incidence [8,9] has consistently revealed disparities between ethnicities [10,11]; for example, British ethnic minorities experience strokes approximately five years earlier and generate two to fourfold greater risks of adverse outcomes despite access to free health care [12]. In the US, Native American Indian and black American have higher stroke incidence than white Americans [10] and, although overall stroke-related deaths have fallen, deaths amongst Hispanic Americans have increased over the past decade [10]. Similar ethnic disparities in stroke incidence have been found amongst Māori and Pacific communities within New Zealand [13]; in Canada, First Nation, Meti and Inuit indigenous communities experience disproportionately higher stroke risk [14].

Multiculturalism

The Cambridge Dictionary defines an ethnic minority group as

“a group of people with a shared culture, tradition, language, history, etc. living in a country where most people are from a different ethnic group" [15]. Migration creates multiculturalism; colonialism displaced indigenous cultures across continents [16]. Global trade has since fuelled labour market migration and, inequality, political instability and conflict fuel economic migration and people seeking asylum [17]. Multicultural societies are unremarkable; many migrant populations are well-established in their country of residence having never lived in their country of origin, yet maintain distinctive diasporic cultural identities based on shared history, race and faith [18].

Stroke risk, culture and systems

The INTERSTROKE study (2016) gathered stroke data across 32 countries and found the following risk factors can account for 90.7% of population attributable risks; high blood pressure, inactivity, unhealthy diet, smoking, diabetes, high alcohol consumption, obesity, cardiac disease and psychosocial factors [19]. This suggests ethnic disparities are likely rooted in lifestyle, socioeconomic circumstances and/or cultural influences over genetics; heritability was estimated at 30-40% but mediated by the above factors [20].

Whilst pure nativist and empiricist explanations cannot account for INTERSTOKE findings, behavioural genetics and, more recently, epigenetics seek to understand how genetics and environment interact to generate aetiological disparities [21-26]. Bronfenbrenner's Bioecological model offers a holistic, widely applicable, qualitative framework to analyse variability within and between populations, thereby offering a means of understanding how and why heritability differences in stroke may (or may not) be actualised within ethnic minority populations. Although some systems are vaguely defined, so difficult to test empirically, the model has yielded tangible outcomes through identifiable actions that translate into public policy [27-31].

Bioecological systems theory stipulates that we develop through complex reciprocal interactions within and between the people, objects and symbols in our systemic environments [1]. Brofenbrenner’s Bioecological systems model (figure 1) suggests culture is positioned within a macrosystem, interacts with our indirect and immediate environments and can be influenced by changes over time (chronosystem). However, culture is not necessarily experienced uniformly across settings, and more recent research argues culture is situated within an individual’s microsystem that shapes, and is shaped by, everyday activities, daily routines and practices within family, social and institutional settings [32]. These interactions make up the individual’s mesosystem.

[Insert figure 1]

The microsystem of a stroke survivor is critical to timely help-seeking, treatment, rehabilitation, and recovery. Although acute care provision is largely carried out by professionals within health services, much of the post-stroke rehabilitative care falls to informal carers; usually family and friends of the care recipient (CR) [33]. The disproportionality of ethnic minorities within stroke statistics generates disproportionate numbers of ethnic minority familial caregivers (EMFCs). For example, in the UK approximately 65% of stroke survivors leave hospital with a disability [34]; henceforth families often assume the primary role in coordinating and providing care. The impact of this care burden has been found to significantly impact upon their physical, emotional, economic and social wellbeing [35].

Culturally competent care “means being alert and responsive to beliefs or conventions that might be determined by cultural heritage” [36]. Although in health literature since the 1990’s, the International Organisation for Migration (IOM)’s 2002 publication, “Unequal Treatment”, initiated a drive to address health inequalities through person-centred, individualized and equitable care provision [37]. Embedded within equality legislation, this is now explicit within healthcare frameworks [38], therefore culturally sensitive practice should be well established, and experienced homogeneously, regardless of ethnicity. However, the disproportionate incidence and mortality rates warrant further investigation as, with aging populations and rising stroke rates, EMFC wellbeing could become a health concern across developed countries.

Aims

Whilst research to date shares experiences of specific ethnic minority groups within different countries, searches indicate that themes of experience *across* EMFCs have yet to be systematically synthesised. Diversity will always exist, both within and between different ethnic groups, however any consistent themes identified across EMFCs' identities could form a useful reference point for culturally sensitive and responsive practice/interventions. This review aims to synthesise current research to bring understanding to the experiences of being an EMFC who is caring for a relative following a stroke event.

Materials and methods

This systematic literature review was conducted with reference to the guidance on the PRISMA 2020 Checklist [39]. The design sought to include all papers fitting the inclusion criteria and synthesise information pertinent to the research aims.

Design

The review was conducted using an inductive approach that sought to gain insight into potential contributory factors to ethnic disparities in stroke events, incidence and outcomes and, consequently, to EMFC experiences. Noblit and Hare's seven phase meta-ethnographic method was used [40]. They outline an interpretative, iterative process of translating findings of each publication into the others [41]. This was relevant to understand experiences of eligible EMFC participants across countries and contexts. It is well-utilised within health sciences [42,43], and regarded as a rigorous method of analysing qualitative papers by drawing from findings, themes, constructs and interpretations that can advance understanding and inform policy and practice [41,44].

Search Strategy

As scoping searches, including PROSPERO, revealed a paucity of research, the date range of publications was up-to-and-including 2022; seven electronic databases were searched (CINAHL, PsychINFO, SocIndex, SCOPUS, Web of Science, Medline and EMBASE) using five key concepts as outlined in Table 1. Online thesauruses were used to generate terms, including American spellings and terms where they differed,.

[Insert table 1]

The search was extended to increase sensitivity and broaden the scope using database tools such as ‘MeSH terms’, ‘thesaurus’, ‘subject headings’ or ‘subject terms’ according to the electronic database in use. A total of 1741 papers were returned.

The literature search was carried out by the lead author with guidance from a university library subject specialist, who conducted sensitivity tests on the search terms to further verify their selection. Citations were then transferred into an EndNote library and duplicates were removed using Endnote’s duplicate identification tool.

Eligibility

Inclusion criteria for studies were as follows:

i. Original peer-reviewed studies, reported in English, published up to and including 2022 and available in full text.
ii. Participants identified as being from an ethnic minority within their country of residence.
iii. Content related specifically to those of familial caregivers (if it was possible to separate datasets, papers where both stroke survivors' and caregivers' experiences were reported were included).
iv. Caregiving was elicited by a stroke event and stroke-related care was the focus of the paper.
v. The study was conducted in a country providing access to a Universal Healthcare system or an otherwise widely accessed private healthcare system.

Papers were excluded if they reported experiences of paid or professional caregivers, had no English translation available or were not conducted in a country with widely accessible public or private healthcare in place. Review articles, meeting or training notes, study protocols, editorials and conference papers were also excluded as it was felt they would lack sufficient detail for systematic qualitative review [45,46].

[insert figure 2]

Study Selection and Review Process

The review was conducted as follows (figure 2):

Screening Titles

After duplicates were removed, 1044 records remained for possible inclusion. The record's titles were screened; those that were not peer-reviewed journals were excluded alongside any remaining ineligible records (for example, the focus was on vascular dementia).

Reading abstracts.

After screening the remaining 432 journals by reading abstracts and applying the inclusion/exclusion criteria, 38 studies remained, three of which were identified by handsearching reference lists. Full papers were reviewed if it was unclear from abstracts whether papers were reporting experiences of a specific ethnicity residing in their home country or those of an ethnic minority following migration and, if unclear whether caregiver experiences could be extricated from those of stroke survivors. All 38 papers were thus sought for retrieval; one paper was unretrievable.

Full-text reading

Following full-text reading, data from each article was recorded on a spreadsheet to summarise key information; the title, publication date, author(s), country of origin, aim(s), research design, sample, data collection, outcomes. Reasons for inclusion/exclusion decisions were recorded to facilitate an audit trail and co-researcher discussion. After a final check against inclusion/exclusion criteria, 11 papers remained for quality assurance. Two papers authored by L. L. Pierce [47,48] and two papers authored by N. Greenwood [49,50] analysed data from the same group of participants. It was decided to include all four in the review as the data analyses foci were sufficiently distinct between papers. Pierce & Wilkinson, [48] examined generic African American of secondary EMFC experiences, Pierce [47] focused on the role of spirituality amongst both primary and secondary EMFCs. Greenwood et al [49] focused on generic experiences across 5 ethnic groups within the UK, Pound & Greenwood [50] focused specifically on experiences of paid home care.

Quality Assessment of papers

The papers were quality assured against the Qualitative Studies Checklist published by The Critical Appraisal Skills Programme (CASP) [51] (table 2). This tool is commonly used to apply rigour to qualitative health research syntheses and is endorsed by the Cochrane

Qualitative and Implementation Methods Group [52]. 10 of the studies were rated as good quality. Corbett et al's paper [53] regarding whanau carers, was judged as weaker. Participant data is purposefully scant to obtain consent from community elders and preserve this small community's anonymity; explanation of the data analysis process is also omitted. Māori cultural experiences are rarely captured, so the paper was retained to support the sample's breadth of representation whilst maintaining awareness of quality concerns.

[insert table 2]

Results

Characteristics of the included studies

[insert table 3]

Countries of Research Origin

The 11 studies shared the broad common aim of investigating experiences of familial caregivers of specific ethnic minority group(s) residing outside of their cultural country of origin. The studies were carried out in America (n=5), UK (n=4), Canada (n=1) and New Zealand (n=1).

Sample

The ethnic groups included were Black African (n=5), Black Caribbean (n=3), Latinx (n=1), Hispanic Mexican (n=1), Māori (n=1), Asian-Indian (n=3), Asian-Pakistani (n=2), White British (n=3) and Chinese (n=1); three studies reported on multiple ethnic groups [49,50,54].

Two papers used exclusively female participants [55,56] 9 papers represented both genders; all papers[2] except for Yeung et al's [57] study, had more female participants than males. Familial relationships represented were predominantly spousal, however adult children or children-by-marriage were also well represented, outnumbering spouses in two papers [48,57] with no spousal caregivers in one paper [47]. Small numbers of sisters, grandchildren and other familial relations were also represented. The age of the participants ranged from 24 to 91[1] years at the time of the respective research, with more participants being 60+ years across the samples². The papers were published between 1999 and 2019, with most papers being published from 2014 onwards (n=8).

Studies covered caregivers who had held this role from between one month to 24 years following the stroke event², only two papers interviewed caregivers within the first six months of the stroke incident [54,57].

Data Collection and Analysis Methods

Sampling strategies used were purposive (n=8), convenience sampling (n=2) and theoretical (n=1). The data collection methods were predominantly semi-structured interviews and/or focus groups and discussion; but also included observation-participation in two papers [47,48]. Studies used a range of qualitative analysis methods; the predominant method was Thematic Analysis, four employed framework analyses [47,48,54,57] and one used grounded theory [55].

Although three of the studies included collated experiences of CRs and/or professionals too [56,57,59], only findings reporting EMFC experiences are included within this synthesis.

Synthesis of Data

---

[1] As demographic details were not specified in Corbett’s paper [32], figures exclude this paper

This literature review sought to identify common themes across EMFC experiences, and further extrapolate any shared or culture specific nuances within those themes where they were found.

[insert table 4]

The analysis found that the themes fell within four major categories, three fell within Bronfenbrenner's [1] (1994) Bioecological microsystem and one within the macrosystem structure, although the mesosystem of connections and interactions within the microsystem was also indicated. The intersecting systems result in an interdependency and overlap between themes (figure 3 and table 5)

[Insert figure 3]
[Insert table 5]

Self: Meaning Making

Meaning-making following a stroke can be helpful in processing its impact and reorientating life moving forwards for both EMFCs [60,61] and CRs [62-65] irrespective of culture or gender. Coming to terms with the stroke-event, its actual and potential outcomes, and adjusting to the new normal sometimes evoked a re-evaluation of life itself.

> I believe we have been given a second chance. The major thing for me is really that my husband is here with me. I don't want to be miserable [54,p.436].

Others described a spiritual growth, not only based within the fragility of each other's lives, but after an experience where "it's like the whole family has had a stroke" [47,p.13], the family unit became closer, bound by love and duty to each other and their CR. Close family units were particularly beneficial to spousal EMFCs, who benefitted from the support and respite offered by family and paid caregivers, to retain a life of their own and an identity that was more than that of ‘Caregiver’.

> [My life goal is] to find balance where you can have a healthy life without losing who you are, and taking care of them at the same time [56,p.365]

Meaning-making was often supported by faith; caregiving was perceived as an expression of loving God as well as the CR. Functions recovered by the CR were perceived as rewards from God, and faith made uncertainty tolerable for EMFCs as, ultimately, “God takes care of things in the end” [47,48,54,58].

Care giving was consistently described as an expression of love for the CR, with Whanau EMFCs having their own term for this; ‘aroha’ [53]. Whilst frustrations and difficulties were expressed, only one paper reported a loveless caregiving situation; this was the result of an abusive pre-stroke relationship. However, the adult children of the primary EMFC enacted love-based caregiving for her as she cared for their father; dutiful caregiving for their father as an act of love and loyalty towards their mother [47].

In some cultures, narratives around caregiving as an expression of ‘duty and obligation’ were prominent, especially amongst participants with Eastern ethnic identities such as Indian, Pakistani and Chinese [49,50,54]. However, it could be argued that the comparative distinctiveness of ‘duty and obligation’ of minority caregiving narratives, might equally be explained as a reflection of cultural norms of piety [66]; thus shaping participants’ narrative vocabulary.

> If one is weak, you have to look after the other one. To do with duty and love. [49,p.4]

Self: Emotional stresses and coping

Irrespective of ethnicity and gender, the level of emotional stress and perceived coping was impacted by the nature of the CRs difficulties. Stroke-induced reductions in quality of life were compounded by outcomes of the stroke. Cognitive and behavioural difficulties particularly elicited fear, frustration and distress [54-56,59], due to uncertainty surrounding recovery trajectories, fear of subsequent strokes and difficult CR outbursts.

> I'm mentally stressed out thinking what if her memory gets worse and she might get Alzheimer [54,p.433].

> At times I am afraid of him…he yells at me and becomes verbally abusive. I cry a lot when I am alone…I feel alone most of the time [55,p.45].

Coping with emotional stresses involved drawing upon personal reserves and seizing opportunities to resume activities outside of caregiving such as paid work, pursuing hobbies and engaging with wider family for emotional support, purpose and fun [53-56,59]

EMFCs' coping was undermined by self-criticism around retrospective perceptions of responsibility for the stroke-event, and how they responded to it [57,59]; stroke prevention campaigns were reportedly streamed via media channels rarely accessed by EMFCs and may offer some explanation for this [57]. Guilt was also expressed around the use of respite carers to cope with CR's needs [56] and residential care was widely rejected. Care quality was questioned and many believed that care should rest with spouses and/or family regardless of the emotional cost.

> I think we grew up a different way[…] you always take care of them, more than put them in a home, that would be the last resort. [58,p.163]

> I didn’t trust them with my dad. As soon as he was able to come out I said I would take over the care, which was horrendous, because I was working full time [50,p.1993]

However, high quality home care boosted EMFCs’ resilience, offering physical and psychological respite; “Because as long as he comes here I don’t have to worry about Augustus until I’m ready to give him his breakfast.” [50,p.1993]. Equally, poor home care became a stressor when deemed ill-attuned or disrespectful of CRs’ needs or, was unreliable [50,54]; poor timekeeping was commonly cited as an easily resolved issue.

> Not knowing when the care workers might be coming means I can’t sleep properly as I know I have to open the door early [54,p.432]

Faith supported coping in many papers; whether through physical presence of members of the faith community, or spiritually through prayer and reading religious texts. A belief in God offered containment, direction and tolerance of caregiving challenges that sustained internal strength [47-49,54,55,58,59].

> I get the knowledge, the wisdom and everything come from above so I just, put it in action and just know what it is [58,p.163].

Self: Practicalities of caregiving

Stroke-care is complex and broad-ranging, from physical exercises, communication support to intimate care. EMFC’s reported physical fatigue, sleep deprivation and struggles to attend to their own fundamental needs [53-57], some had their own physical health issues and female EMFCs especially reported difficulties with manual handling and lifting.

> “My sister is here to help at the moment, I don’t know how I’ll cope when I am alone, especially if she does toilet in her clothes and I need to give her a bath” [54,p.432].

Role changes presented particular challenges; spousal EMFCs especially struggled with tasks previously carried out by their spouse, “can’t find nobody to even change a light bulb”[59,p.8], increased income responsibilities alongside intergenerational caregiving roles [47,54-56,59].

> I have my full-time job as a restaurant manager; on days for doctors’ appointments, I go with her, and it changes your life. [56,p.365]

Participation was made difficult because of respite and accessibility challenges. Maori whanau EMFCs reported struggling to partake in cultural observances such as ceremonies for deceased community members owing to rigid home care service packages; “I can’t go up and you know, farewell that one and put him to rest" [53,p.261]

Family unit: Spousal obligation

Across all cultures, spouses accepted the assuming of primary caregiving responsibilities. Whilst many papers used a narrative of spousal ‘duty and obligation’, this often materialised through unremitting empathy and was a key motivator, regardless of the personal sacrifices. CR outbursts and/or lack of gratitude could induce fleeting hurt and frustrations, but only one EMFC reported unwavering resentment towards a CR which reflected abusive behaviour pre-stroke [47,p.13].

Māori spouses reported remaining at their CR’s side from between 4 weeks and 2 ½ months during hospitalisation [53], Latino spouses reported being glad to “serve their husband” and taking pride in “being needed” [55] and British Asian Indian and Pakistani spouses talked of caregiving as an expression of partnership [49]. Spouses conveyed a pride in their caregiving, feeling their intricate knowledge of their spouse meant only they truly understood how to meet the CR’s needs [58].

> No burden after 52 years of marriage. She (wife) has served me well all my life and now I am paying my debt [54,p.435]

Family unit: Filial piety and familism

Filial piety is a highly regarded value within some traditional Asian cultures and shapes caregiving, older age support and living arrangements in some East Asian cultures [66]. This review demonstrated that principles of filial piety were not restricted to East Asian cultures, ‘familism’ was reported across Latino, Hispanic and Maori cultures fuelling collectivist approaches to care. Familial narratives conveyed restructuring of lives to tend to CR needs; for example, Māori EMFCs organised themselves to ensure that whanau (family) remained at the bedside of the CR around the clock during the acute stroke phase [53]. Similar unity was reported amongst African American and Latino American communities [47,48,55] and was often attributed to cultural dynamics:

> “We’re Muslims, so we do look after our elderly anyway at the end of the day [49,p.4)

Conversely, whilst valuing support from adult children, some parents did not expect it; involvement was mediated by practicalities like geographical proximity, childrearing and occupational responsibilities; “I have a daughter that can help me, but she works full time…I do not like to impose on her” [55,p.45]. For others, cultural norms seemed to dilute between 1st and 2nd generations in families, causing disappointment when family didn’t offer the anticipated response.

> It’s your mother. And in Jamaica, no matter where we are […] if there’s a problem, we jump on the bus and we come home. And we all ... look after mum. [58,p.163]

The position of dual heritage nationality exposed potential conflicts of identity and fit, in terms of which nation had the dominant influence over value set and behavioural norms. Diversity within cultures was as great, if not moreso, as that between cultures.

Culture and spirituality: Faith and Spirituality

Caregiving was often reported as an expression of faith and, for some spouses, encompassed an expression of commitment to their faith and the sacred union of marriage [47-49,55]. Prayer became a coping mechanism, empowering EMFCs in the belief that "God does not give you more than you can handle." [48,p.348]. At times, faith seemed to tip into the realms of fatalism; a passive acceptance of the inevitable, keeping fears at bay [47,48,58].

Culture could motivate care standards that sustained family pride [49,50,54,55]. One example revealed fears of judgement from community members 'at home':

> I used to feel embarrassed for mum when we had to bring her home (from day centre) when her clothes were soiled. We have some women, who go to the same Centre. They see all this and they go and gossip to people in India, it's quite embarrassing. [54,p.433-434]

The importance of faith for EMFCs' resilience meant services failing to acknowledge cultural observances resulted in strained relationships [50,53].

Culture and spirituality: Cultural norms and narratives

Some cultures reported gender differences in EMFC responsibility allocation. Arabit [55] described 'marianismo', cultural inflections placing men as central to Latino homelife; wives earned family respect through devotion to the care of her husband and children. Similarly, African-American samples suggested males were not equally responsible for care amongst secondary EMFCs; females were obliged in caregiving, only in their absence would males contribute [47]. Gendered-care was also important in paid homecare provision with cross-gendered provision reportedly rejected, thereby increasing EMFC's burden to spare the CR's dignity and respect norms [54].

It was argued that culturally sensitive care provision facilitated humanity in the care experience of EMFCs [50]. This went beyond language and religion, to understanding the relevance of cultural activities and differences in communication styles. For example, participants of African ethnic descent discussed their tendency not to ask questions [59] or to talk loudly [49], whilst Asian Indian participants expressed cultural reticence to talk about issues such as continence [49].

> So there are differences between the black and the white culture…Because what I feel is respect, might not be respect for you.[49,p.5]

Cultural differences also existed around belief in western medical approaches. African-American participants shared they would rather "take home remedies in the first place instead of going to the doc (doctor)" [59,p.8]. Chinese-Canadian participants expressed dissatisafaction with the lack of traditional Chinese treatments available within healthcare environments [57].

> We got acupuncture and drank herbal teas. But it is very expensive. If he got acupuncture right after he was discharged, he would have recovered better. [57,p.528]

Similarly, the lack of cultural representation in hospital food was regarded as detrimental to the CRs' physical wellbeing, and added to EMFCs's burden during acute stroke-care as they brought food from home [54,57].

Formal health and social care systems: Discharge – the transition home

Problems with hospital discharge planning was named within seven of the 11 papers. A lack of coordination between acute and community services led to caregivers experiencing a sense of abandonment "The panic sets in when you leave. It's like a bereavement" [49,p.3].

EMFCs noted a lack of information regarding engaging community support services and, even after negotiating the complex bureaucracy, often found services inconsistent, unreliable, and too time-limited to meet CRs’ rehabilitation needs [49,50,53,54,57,59]. This was particularly problematic in the context of the lack of preparedness EMFCs felt for their new roles. Uniquely, Māori EMFC’s literally lived at the hospital for the duration of their CR’s acute care, observing and supporting nursing staff; this proved helpful. “The stay in hospital paid off because I knew how to transfer bed to bed, or wheelchair whatever; and shower him” [53,p.260]. However, overall EMFC’s did not feel suitably skilled post-discharge.

> “At the rehab centre they taught me what I could do to help her do the exercises at home. Of course, it’s not so simple. It’s hard for me to learn it from only the few broad instructions they gave me.” [57,p.527]

Formal health and social care systems: Meeting needs – provision and adaptation

EMFCs expressed frustrations with perceived imbalanced power dynamics and bureaucratic processes to access service support. Some EMFCs expressed suspicions of a hidden agenda to encourage them to quit and felt complaining might elicit slower or restricted support offers [58], others were censored by linguistic challenges; “I can’t fight in English language. So it’s difficult for me” [50,p.1991].

Multigenerational households are more prevalent across cultures, but especially so in ethnic minority households [67], EMFCs felt this was often disregarded by services. Papers reported EMFCs holding occupational, stroke care and multi-generational care responsibilities for immediate and extended family. Where services downplayed EMFCs’ competing demands, perceptions of deficient support and diminished respect increased [49,50,54,55]. Rigidly standardised packages saw provision dictated by providers yet service issues of punctuality, absence and turnover were absorbed by EMFCs, reducing their freedoms and reinforcing power imbalances [50].

Standards of care varied; when humane, high quality and underpinned by respect, services were life-giving, however some EMFC's felt cultural adapations were needed such as same-sex carers for personal care, and flexibility around religious observances such as wudu and prayers [49,50,54,58]. Lack of multi-lingual professionals also created difficulties for CRs which subsequently impacted EMFC's, such as having no speech services for an aphasic CR or exacerbating mood difficulties [50,57,58].

> "(Care worker) rang me 15 times because she couldn't understand what mum was saying ... she can't make herself understood so that frustrates her even more then she lashes out and gets really aggressive." [50,p.1993].

It is noteworthy that culturally-specific support packages received mixed receptions, with some welcoming it and others feeling 'othered' [58].

> I address certain things to you, and all you can send me back is an information pack ... Of Black Afro-Caribbean. This is very insulting, in other words they're saying to me, listen, I can't help you, go to your own people. [58,p.162]

Broaching cultural difference requires professional sensitivity, however offering differentiated provision gives EMFCs choice and dignity. For example, UK EMFCs can request direct care payments to source their own paid care [50].

Formal health and social care systems: Rights vs reticence

The need for EMFC's to battle, advocate and persist came through strongly in all papers. The community care 'system' was widely portrayed as a complex, bureaucratic adversary, that withheld and reluctantly dispensed support only after a fight. EMFCs described being passed between services without securing the support they needed, or were entitled to, with a number of papers referencing having to learn to "speak social care language" in order to secure services [49,50,54-56,58,59]. Torregosa [56] reported on an EMFC community support group evolving into a collective action group "to reach out to the state representative" and address the lack of local stroke services.

Conversely, other EMFCs felt reticent to request support. Without signposting towards practical, social and financial support available, many questioned their entitlement despite national service frameworks stipulating professionals should be proactive with guidance [54]. "Some carers made references to feeling disbelieved and worrying that services and others viewed them as 'scroungers' or as someone taking advantage of welfare benefits" [50, p.1993] this was exacerbated by experiences of gatekeeping and elusivity with services [50]. EMFCs found assessment experiences impersonal, inflexible and shaming [49,50,54]; "he was an object ... to them, the people there they was just another person" [58,p.162] and in the UK, the effort sometimes outweighed the reward of the support allocated [49,54]. American EMFCs reported facing stark choices caused by lack of rehabilitation cover within health insurance.

> "If you can afford to work for it, but if not, that means for 6 weeks of the year you get a little better, but the rest of the year you either stay the same or decline" [56,p.365]

Within the papers were culturally-specific inflections regarding confidence to assert rights in a second language, a felt sense of age and race discrimination around seeking support for speech and language support for a CR [57,58] and the support-seeking process reminiscent of struggles and barriers faced when initially migrating to the country.

> "I say to myself, 'Do they think I might be trying to take something from the government?' It's my home I should do this'. That battle in your mind. [50,p.1993]

Formal health and social care systems: Information and Communication

Despite 'competent communication' being explicit within many official care frameworks [38] issues were common; medical professionals reportedly felt rushed and communication failings "one of the biggest hindrances" to care provision [59].

> "Social care has its own language, which if you don't use, if you don't say you don't, they cannot understand you." [50,p.1991]

Specialist terminology can be a barrier for native speakers however, amongst ethnic minorities it can present an additional, unique layer of challenge if CRs and their EMFCs are not communicating in their preferred language.

EMFCs reported a common plea for information about stroke (including risk factors, symptoms, mode of action, potential difficulties and recovery trajectories) and eligibility for formal respite and financial support. Cultural discrepancies in pre-existing stroke knowledge impacted many participants within the papers, and impeded preventative, acute and rehabiliative measures. EMFCs expressed frustrations with the lack of accessible and translated information from public health campaigns [57] to experiences of support with negotiating layers of bureaucracy to secure formal care.

> "a lot of people can't read or write English and so they find the paper work ... awful, […] there's no support there for people that can't do the paper work [50,p.1991]

In the UK more culturally responsive 'direct payment' support options may be available if EMFCs are able to navigate the system, however even confident communicators reported despondency [49,50,54,58].

Low ethnic minority representation amongst healthcare professionals could impede perceptions of, and/or actual, EMFCs' provision. Research suggests cultural representation across services can improve atunement to cultural nuances and increase satisfaction [68-73] For example Yeung [57] and Strudwick & Morris [58] reported a lack of Speech and Language therapy for ethnic minorities. Specifically, Yeung [57] recounted significant challenges for EMFCs when CRs had English as an additional language. Recovering one's native and domestic language arguably presents greater strain for ethnic minority aphasic CRs; they could benefit from greater ethnic and linguistic diversity amongst professionals.

Some papers discussed a preference for paid carers who shared the language and culture of their CR; cultural references were valued in communication and rapport with CRs.

> One of the carers that comes, he's from Caribbean and he, he also love dominoes. […] he'll sit with him, maybe just for fifteen minutes and play dominoes with him... And he's happy, you'll hear him laughing, you know, bantering together, yeah he loves that. [50,p.1994]

Discussion

This literature review synthesises experiences of EMFCs caring for a relative following a stroke. It depicts complex influences within and between EMFCs' systemic environments; their self (meaning-making, emotional stresses and coping and caregiving practicalities), familial (spousal obligation and familial piety), cultural and/or spiritual (faith and spirituality, cultural norms and narratives) and their formal health and social care system (discharge, provision and adaptions, rights, information and communication). Findings reveal intersecting caregiver and cultural minority statuses across societies and thus, across the systems within Bronfenbrenner's model [1,32].

Findings corroborate issues commonly reported across stroke caregiver populations including the physical and emotional toll of caregiving [49,74-77], alongside the motivations, duty and potential rewards [49,78,79]. Common service issues included dissatisfaction with acute-care discharge and caregivers' information and skills training alongside difficulties securing community-based rehabilitative support [80-87]. However, several distinct themes were revealed relating to EMFC mesosystemic interactions between caregiving and language, faith and cultural norms, and structural macrosystemic intersections with socioeconomic factors, cultural representation and healthcare delivery.

Language

Speaking English (or French in parts of Canada) as an additional language, poses distinct challenges for EMFCs encountering specialist health terminology within stroke health campaigns and service encounters. Language barriers contribute to miscommunication, dissatisfaction with provision and potential safety risks [88] which concurs with review findings indicating deficits in knowledge around recognising and responding to strokes, and preventative lifestyle changes [56,57,59].

Whilst many health settings offer interpreter services, research suggests provision is not always readily available at the point of contact [88,89]. Health policies in many countries stipulate printed and online health information be available in different languages [90-92], however navigating social and community care bureaucracy caused the greatest distress amongst participants within this review. It requires 'health literacy' regarding what may be an unfamiliar healthcare system and, an understanding of entitlements and procedures to obtain support [50]. Research suggests insufficient 'health literacy' is common across migrant populations and health conditions [93] but improving it addresses another issue highlighted in papers, it increases confidence to seek and accept help [76,77,85].

The most concerning language issue was faced by aphasic CRs with an additional language; they experienced an absence of support with speech and language recovery [57,58]. 35% of Canadians and 23% of Americans are bilingual; globally, it is estimated more than 50% of people are fluent in at least two languages [94] so could have multiple phoneme inventories[2] to recover after stroke [95]. This review may have revealed an essential gap in rehabilitation provision that adds to communication difficulties and/or losses for CRs and, amongst EMFCs, creates potential for vicarious moral injury and greater care burden.

Faith & Spirituality

Faith and spirituality (FaS) was an important theme within this review. Research suggests ethnic minorities may be encouraged towards religious identity as a result of "ascribed identities, economic and social exclusion[…] from mainstream society" [96,p.191]. (The religion/ethnicity/migration debate goes beyond the scope of this review, but is well researched [96-101].) Within this review, faith is understood to represent individuals' beliefs, practices and rituals often, though not always, organized through the lens of a religion; spirituality comprises a personalized experience or expression of what individuals regard as sacred [102,p.105-106]. FaS frequently appeared as a protective factor within meaning-making and coping amongst EMFCs. This concurs with studies on cancer and Alzheimers EMFCs whereby strong religious beliefs correlated with reduced anxiety and depression [103]; indeed, research across health conditions and disabilities has found associations between FaS, positive coping and adjustment to caregiving [103,104].

---

[2] Distinctive speech sounds unique to a language

The review revealed several papers resonant with 'fatalismo' [47,48,55,58]. Latino cultures refers to 'fatalismo' as a belief that all life events are predetermined and controlled by God [105]. One could anticipate decreased investment in human caregiving efforts resulting from invested beliefs in an external locus of control; 'it's out of my hands'. The opposite was evident amongst papers reviewed. Pierce [47] and Strudwick and Morris [58] proffer a potential explanation for faith's mediatory effect on caregiver burden; 'it is God's plan therefore I can endure' [105-109]. Another explanation may be an increased sense of mortality, for loved ones and self, following a stroke; research highlights inverse correlations between faith and death anxiety [110-113].

The importance of faith led to feelings of isolation, dismissal and frustration [49,50,54, 57,58] when service provision did not accommodate spiritual ceremonies, observances or rituals [53]. Other research concurs with shortcomings in the cultural competence [4] of frontline care staff. For example, home care staff were observed developing culture-avoidance strategies [114], relying upon rigid cultural perceptions to shape their approach rather than employing person-centred care, and demonstrating significant difficulties working with cultural difference despite good intentions [115]. Furthermore, research exploring professionals' perceptions around 'cultural competence' suggested it was 'very important', rated their own awareness and competence highly, yet also reported receiving little to no training around it [116]. Whilst multiple potential reasons exist, the need is for consistent translation of policy into practice.

Cultural norms

Culture encompasses rituals such as the 'Hui', a collective approach to resolving community issues amongst Māori's [53], values like modesty within Islamic culture [117] and beliefs in the healing powers of balanced diets within Chinese culture [57] and alternative

---

[4] awareness of, and response to, beliefs or conventions influenced by culture [36]

medicines within African cultures [59]. Accommodating and respecting these norms is fundamental to cultural competence and requires services to flex provision, offer gendered-care, serve culturally diverse foods and respect alternative treatment approaches alongside conventional medicine [53,57,59,117]. The papers indicate variability in provision across EMFCs, suggesting a service design and training issue across services.

Spousal obligation, such as upholding family pride and respectability, is a cultural inflection, or perhaps a narrative [47-49,53-56,58], however spouses across cultures commonly assume the greatest care burden. More distinctive were the collective responses from nuclear and extended family in caregiving, which may serve as a protective factor in wellbeing. Research suggests that many stroke caregivers experience declining social support and solitude as initial responses to the CR's stroke event passes [118,119]. Familial networks preserve connectedness, sustain resilience, and enable sharing of emotional burdens. [82,120,121]. The degree of familism and filial piety varied as much within ethnic groups as between, suggesting collective approaches, whilst more likely, are not guaranteed; professionals will need to enquire during assessment.

Consider of intergenerational households is also valuable. Official statistics suggest approximately 3% of the UK population are in the 'Sandwich Generation', caring for children and parents [122,123], and facing higher rates of financial struggles, mental health difficulties and lower life satisfaction than the general population [122]. After adjusting for demographic and economic variables, significantly more US ethnic minority families live in extended family households [124]. Asian and African Americans are more likely to have older relatives or parents living with them, Latino families are more likely to live with siblings, or same-generation relatives [124]. UK census data indicates a similar pattern within Asian and black ethnic groups of multi-generational households in Britain [125]. As stroke incidence increases with age, ethnic minorities adults are increasingly vulnerable to higher care burden, especially females.

Strudwick & Morris [58], exposed the heterogeneity of cultural expressions that can emerge within ethnic minority groups. Migration naturally results in some acculturation, whilst gaining legal citizenship requires demonstrable effort to prove it [126], however diaspora (dispersal) populations are often forced to relocate through war or natural disaster [127]. Research suggests that diaspora populations often maintain a stronger connection to their country of origin and a collective cultural memory, this impacts sense of heritage and identity reorientation; especially true amongst asylum seekers [128], this may explain the differences in acculturation between generations apparent in Strudwick & Morris' paper [58]. Indigenous people became ethnic minorities following colonial occupation of their native lands [129]. Whilst contact and participation may be high between groups, for indigenous populations like New Zealand's Māori, acculturation does not necessarily follow [130]. In some cases, pan-traditionalism, a drive towards positively sustaining traditional cultural values and practices, may ensue [131]. Central to culturally competent care is awareness and understanding, belonging to a group of difference does not imply sameness across its membership [132]; person-centred care prevails.

Structural considerations

Consideration of macrosystemic influences within these findings is important. For example, government changes in New Zealand has seen health reforms specifically addressing Maori and Pacific nations' health disparities [133]. Whilst no subsequent research has evaluated the impact of reforms upon Maori EMFCs for stroke, it highlights wider systemic dynamics surrounding EMFC experiences; political agendas shape budgets and service commissioning.

Economic deprivation was noted to intersect with Hispanic EMFCs in Torregosa's research [56]. Participants reported minimal cultural adaptations and that professionals were afraid to enter their neighbourhood. This contributed to a lack of local services and, consequently, greater EMFC care burden. Torregosa [56] also reported an EMFC having to stop CR rehabilitation support after 6 weeks due to the prominent role of health insurance within US healthcare; thereby generating emotional turmoil and greater care burden [56].

Stroke incidence and mortality is higher in socioeconomically deprived areas [133,134]; ethnic minority citizens are disproportionately represented within low socioeconomic groups [135]. The recent rise in first time strokes occuring in middle age (40 – 69 years) [34] impacts both CRs' and EMFCs' incomes [136], thereby creating socioeconomic struggles. Relationships between stroke, deprivation, disability and ethnicity are clear, however there is hope. The introduction of high quality primary care in areas of socioeconomic deprivation, can create disproportionately *positive* health outcomes [137], suggesting that action *across* bioecological systems may most impactfully address EMFCs' experiences.

Strengths and Limitations

The span of the systematic searches was maximized by consulting numerous databases and handsearching, quality was then assured using the CASP tool. The broad timescale and geographical area of papers therefore reflects the paucity of research.

By investigating countries with modern healthcare systems, findings may potentially be less applicable in less developed countries. Findings may also be biased by the unequal representation of countries within the sample; for example, where US EMFCs rely heavily on health insurance, the UK, Canada and New Zealand offer greater access to free healthcare.

Other developed nations, like Australia or within mainland Europe, are not represented because no papers could be found.

Two sample groups were represented twice within the review thereby limiting the number of separate participant groups to 9. However, as discussed earlier, the analyses discussed in the papers were regarded as sufficiently distinct in focus to warrant inclusion.

Quantitative research contributions to this research area may generate epistemological concerns around potential positivism, which may have been countered using a mixed-methods approach, thereby producing a more comprehensive response to the review's aims. Whilst methodologically more complex, a greater breadth of papers may have improved sample-size and extended the span of countries, cultures and health care systems represented [138]. However, qualitative research was ultimately selected to enable experiential nuances to be captured.

Experiences of minority groups are influenced by political, legal and social environments; health and social care services evolve within these constructs. It could be argued that the papers represent a specific time and place and are subject to subsequent change. This is true of all research. In synthesising findings to date, the review seeks to offer professionals a baseline framework from which to understand and evaluate culturally sensitive and responsive EMFC practices within their stroke service context.

Conclusions

This review synthesises existing qualitative research into experiences of ethnic minority family caregivers caring for a relative after a stroke. Universal and culturally nuanced influences and experiences are highlighted along with accounts of formal service provision encountered. Health and social care services are criticised for falling short of expectations to accommodate the needs of ethnic minority EMFCs. This is perhaps unsurprising because, although many care frameworks stipulate culturally competent care, the evidence base required to inform and operationalise this practice is negligible.

Implications for Research

The paucity of published research into ethnic minority familial caregiving for stroke indicates an impetus for further research. The positive impacts of faith identified in the review supports further exploration into how it can be used to bolster resilience, coping and stroke health. Additionally, greater understanding of functional mechanisms within faith and religiosity would be helpful to ascertain to explore whether these mechanisms could be replicated in other settings or through other means to maximise benefits for caregivers across health conditions.

Recommendations for Clinical Practice

EMFCs, especially those without fluent language or who are recently settled, would benefit from public health efforts to build health literacy around stroke and navigation of the health and social care systems. Targeting media, mediums and institutions readily accessed by ethnic minorities would help to achieve this.

The variation in cultural competence amongst services and professionals should be addressed through high quality training structured by key agreed learning objectives to enable quality assurance and measurement of impact upon service users and professionals' practice. Frameworks are already in existence to support spirituality and religiosity training within clinical practice, centralised collation and sharing of relevant materials could support consistency between services and regions.

Service design and development should also support culturally competent care. Review of home care practice and approaches is warranted, alongside investigating means of achieving greater flexibility in care packages to meet the needs of EMFCs such as the delegating procurement decisions to families, offering choice and facilitating bespoke community support.

It is recommended that exploration of informal care contexts constitutes standard practice upon stroke service admission. Helpful aspects to explore may include household living arrangements, familial support networks, general health of EMFCs, additional care responsibilities, any faith or culturally based needs and how services can best accommodate these.

Whilst cultural narratives exist, avoiding assumptions is paramount. Respectfully curious interactions communicating empathy, regard and care are most effective in building trust and rapport; alongside sufficient flexibility to adequately address differences in needs.

Table 1. Search terms

Key Concept	**Terms**
Stroke	**(**Stroke* OR cva* OR "cerebral vascular event*" OR cve OR "transient ischaemic attack*" OR tia OR " transient ischemic attack*" OR "mini-stroke*" OR ((cereb* OR intracereb* OR subarachnoid) N3 (hemorrhage* OR haemorrhage* OR accident* OR infarction*)) OR "encephalorrhagi*" OR "hematencephalo*" OR "ischemic stroke*" OR "brain attack*" OR thrombotic OR emboli* OR thrombos* OR ictus OR apoplexy)
	AND
Qualitative studies	**(**interview* OR "focus group*" OR "case stud*" OR "grounded theory" OR narrative* OR thematic OR ethnog* OR qualitative* OR phenomenolog* OR experienc* OR explor* OR "open question*" OR examin* OR discourse* OR "content analys*" OR "dialogue*" OR "conversation analysis" OR "Case-Oriented Understanding")
	AND
Family	**(**Child* or son* or daughter* or sibling* or brother* or sister* or wife or wives or husband* or spous* or marri* or "significant other*" or partner* or famil* or parent* or father* or dad* or mother* or mum* or mom* or "next of kin" or relative* OR household* OR house-hold*)
	AND
Carer / Informal Caregiver	**(**caregiv* or "informal caregiv*" OR carer* OR "care giv*" or caring)
	AND
Ethnic minority	**(**Immigrant* OR migrant* OR cultur* OR multicultur* OR intercultur* OR minorit* OR ethnic* OR multiethnic* OR racial* OR race* OR refugee* or "non western*" or emigrat* or immigrat*)

Table 2. CASP Quality appraisal

Paper	Clear aims	Qualitative methodology appropriate	Appropriate Research design	Appropriate recruitment strategy	Appropriate data collection	Relationship between researcher/participants considered	Ethical issues considered	Rigorous data analysis	Clear statement of findings	Value of findings
Arabit [55]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Corbett et al. [53]	Y	Y	Y	Y	Y/CT[5]	Y	Y	CT[6]	Y	Y
Greenwood et al. [49]	Y	Y	Y	Y	Y	CT[3]	Y	Y	Y	Y
Katbamna et al. [54]	Y	Y	Y	Y	Y	CT[3]	Y	Y	Y	Y
Magwood et al. [59]	Y	Y	Y	Y	Y	CT[3]	Y	Y	Y	Y
Pierce [47]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Pierce & Wilkinson [48]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Pound & Greenwood[50]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Strudwick & Morris [58]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Torregosa et al. [56]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Yeung et al. [57]	Y	Y	Y	Y	Y	CT[7]	Y	Y	Y	Y

Y - Yes
N – No
CT – Cannot tell

---

[5] Participant details and demographics are omitted for anonymity purposes, areas of data collection are unclear because of this.

[6] Data analysis process details are omitted from paper.

[7] Not explicitly discussed or implied

Table 3. Study characteristics of the papers included in the analysis

Paper	Country and ethnicity/ies	Recruitment	Sample details	Aim	Data Collection	Data Analysis
Arabit [55]	USA Latino	Theoretical sampling	5 Latino female spousal carers Aged 57-85 years 2-9 years caring	To generate a theory explaining the process of caregiving coping strategies from the perspective of Latino women spouses of stroke survivors	Semi-structured interviews	Grounded theory
Corbett et al. [53]	New Zealand Maori	Purposive sampling	7 whanau (families) Each consisting of the spouse & children of CVA affected member, a kaumatua and kuia (respected male and female Maori elders). Additional interviews with 3 lead carers identified through the focus groups. (Selection and demographics not explained)	Understand the experiences of whanau carers of a family member disabled by the effects of a stroke and the accessibility and availability of services during hospitalisation and following discharge	Focus groups and key informant interviews	Thematic analysis
Greenwood et al. [49]	UK Asian Indian Asian Pakistani Black African Black Caribbean White British	Convenience sampling	41 familial carers of which 29 were female and 28 were spouses. Asian Indian participants numbered 17, Asian Pakistani – 4, White British - 10, Black African - 5 and Black Caribbean - 5	To explore experiences of carers of stroke survivors aged 45+ from 5 ethnic groups in accessing and receiving social care services after hospital discharge	7 focus groups - 5 with shared ethnic background, 2 with mixed	Thematic analysis

Katbamna et al. [54]	UK British Asian Indian White British	Purposive sampling	18 carers 7 Asian Indian Carers and 12 White British Carers. Of these 12 were female spouses, 4 male spouse and 2 daughters.	To explore factors contributing to stress in White and British Indian carers of stroke survivors and the strategies they used to overcome the difficulties of providing care	Semi-structured interview at 1 month and 3-6 month post stroke event.	Thematic inductive framework analysis
Magwood et al. [59]	USA African American	Purposive sampling	African American persons with stroke (n=20) and their family members or caregivers (n=19) and health care providers (n=10)	To qualitatively explore post stroke recovery across the care continuum from the perspective of African American adults with stroke, adult caregivers with stroke and helath care professionals with expertise in stroke.	Focus groups with persons family caregivers or stroke survivors. Interviews with health care providers. Reported on as separate groups.	Thematic analysis
Pierce [47]	USA African American	Purposive sampling	8 primary caregivers (key informants - 2 husbands, 3 wives and 3 daughters) and 16 secondary caregivers (9 daughters, 2 sons, 1 daughter-in-law, 2 sisters & 1 friend). 4 males, 20 females.	To examine how spirituality aspects of caring affect caregivers' well-being and African-American families' functioning	3 semi-structured interviews per primary caregiver structured and guided by The Framework of Systemic Organisation (Friedemann, 1995) 4x Observation-participation sessions of 4-6 hours	Thematic analysis

Pierce & Wilkinson [48]	USA African American	Purposive sampling	Secondary Urban Familial Caregivers (supporting the primary caregiver but not their main caregiver) 2 males (sons) and 14 females (9 duaghters, 1 granddaughter, 1 daughter-in-law, 2 sisters and 1 family friend) Ages 22-65 years. Length of caregiving 12months to 11 years.	An ethnographic study to examine the specific cultural influences on the capacity to care for stroke survivors amongst Secondary Urban Family Caregivers from the African-American community. Specifically 1.What are the components for cultural maintenance for African-American secondary UFCs and the family? 2. What are the components of cultural transformation for these secondary UFCs and family?	One 1 hour semi-structured interview with 2 researchers, 1 of whom took field notes and observations to accompany the audiotape transcriptions.	Framework analysis
Pound & Greenwood[50]	UK Asian Indian Asian Pakistani Black African Black Caribbean White British	Purposive sampling	Caregivers - White British 12, Asian Indian 19, Asian Pakistani 2, Black Caribbean 9, Black African 8. 18 males, 32 females; 30 spouses. 15 adult children, 2 parents, 2 daughter in laws and 1 sibling. Ages 45-91 years	To explore the experiences of carers whose relative was receiving social care in their own home and the value of a theory of humanising care to understand and explain these experiences	Secondary analysis of Semi-structured interviews (carried out by the authors in the initial study)	Thematic analysis
Strudwick & Morris [58]	UK African-Caribbean	Convenience Sampling	9 African-Caribbean stroke carers, 8 female, 1 male. 6 spouses/partners, 2 daughters & 1 niece	To explore the experience of African-Caribbean informal stroke carers in the UK	Semi-structured interviews	Thematic analysis

Torregosa et al. [56]	USA Hispanic / Mexican-American	Purposive sampling	8 female Caregivers, 7 of Mexican-Hispanic, 1 non-Hispanic white. Age range 30-68 years, 6 = wife or child, 1 mother, 1 sister	Examine the experiences of post-stroke recovery on survivors and caregivers from an underserved Hispanic community. Analysed distinctly	Semi-structured interviews and focus group of the caregivers (same for survivors, reported separately)	Thematic analysis
Yeung et al. [57]	Canada Chinese-Canadian	Purposive sampling	(5 stroke survivors) 13 caregivers, first language Cantonese. 6 female, 7 male. 4 spouses, 8 adult child caregivers and 1 caregiver friend. Average residency in Canada - 20 years. Ages 24 - 68 years, (mean age = 60). Length of caregiving 2 - 16 months	To explore the experiences and needs of Chinese stroke survivors and their family caregivers, using the 'Timing it Right Framework' upon reintegration into community living following a stroke event.	Semi-structured interviews, either in-person or via telephone. Caregivers and survivors interviewed separately	Framework analysis

Table 4. Summary of the main findings of the studies included

Paper	Main findings
Arabit [55]	Theme 1: Caregiving as a stressor 1-1 Physical stress; 1-2 Emotional stress Theme 2: Caregiving as a spousal obligation Theme 3: Coping 3-1 Socialisation 3-2 Personal leisure 3-3 Religiosity
Corbett et al. [53]	Theme 1: The whanau experience of stroke 1.1 Experience leading up to, and the event of CVA 1.2 Experience of hospitalisation of the whanau member affected by CVA 1.3 Experience of being at home, from the immediacy of post discharge from hospital through to the present day (Whanau, Services, Information, Spirituality)
Greenwood et al. [49]	1. Gap between hospital discharge and home 2. Carers as persistent advocates—knowing the system and fighting for support 3. Balancing the effort in accessing services with their needs and poor or unsuitable services 4. Carers as the best person to care 5. Cultural aspects of caring: ethnicity, culture, religion and language
Katbamna et al. [54]	1. In-patient care and formal support 2. Discharge home and formal support 3. Competent to care 4. Long-term outcome 5. Dynamics of caregiving 6. Anxiety linked to financial pressures 7. Coping strategies and resilience 8. Managing uncertainty

Magwood et al. [59]	Theme 1: Barriers 1.1 Lack of support and resources 1.2 Lack of knowledge about stroke 1.3 Culture/faith Theme 2: Facilitators 2.1 Emotional support/patience; 2.2 Resources/support; 2.3 Knowledge/information
Pierce [47]	1. Caring is a filial ethereal value 2. Self-contemplation 3. Motivation for a philosophical introspection 4. Filial piety 5. Living in the moment and hoping for the future 6. Purpose 7. Motivation that came from approval by care recipients 8. Christian Piety
Pierce & Wilkinson [48]	Caring as experience • Caring actions – Physical work; Sacrifice; Taught & shared; Structured; Communication; Accommodation; Mutuality; Learned • Caring family functions – Adaptation in families; Adaptation in Caregivers' enforcement of old values; Adaptation in caregivers' watchfulness; Differences in filial function Meaning of Caring • Caring expressions- Living in the moment and hoping for the future; Evasion of conflicts; Filial piety; Fairness; Motivation: Love and a sense of duty between caregivers, care recipient and their families; Motivation: approval of the care recipient; Christian piety; Purpose; Filial ethereal value; Self-development; Emotional burden; Motivation: Philosophical introspection; Self-contemplation.
Pound & Greenwood[50]	1. Communication and bureaucracy 2. Time and timing 3. Communication and rapport building 4. Trust and safety

	5. Humanity and the human dimensions of care
Strudwick & Morris [58]	Cultural nuances 1. Understanding of individual needs 2. Battle 3. Independence from services 4. Faith in God 5. Family ties 6. Avoiding institutionalized care
Torregosa et al. [56]	Overarching Theme: Finding meaning Subtheme 1: Emotional struggles: Conflicting emotions; Constant worry; Subtheme 2: Readjustment: Overprotectiveness; Multitasking; Network support; Taking political action; Regaining self Subtheme 3: Deterrent: Guilt
Yeung et al. [57]	Theme 1: Information and training needs of stroke survivors and caregivers change over time Theme 2: Chinese resources are needed across care environments

Table 5 Synthesis of themes with original study themes (Themes: Self and Family)

Paper	Self: Meaning Making	Self: Emotional stresses and coping	Self: Practicalities of caregiving	Family: Spousal obligation	Family: Familial piety
Arabit [55]	Theme 1: Caregiving as a stressor Subtheme 1-2 Emotional stress	Subtheme 2-1 Emotional stress Theme 3: coping	Subtheme 1-1 Physical stressor	Theme 2: Spousal obligation	Marianismo /machismo Family as sacred
Corbett et al. [53]		Experience of being at home, from the immediacy of post discharge from hospital through to the present day	Experience of hospitalisation of the whanau member affected by CVA Experience of being at home, from the immediacy of post discharge from hospital through to the present day	Experience leading up to, and the event of CVA Experience of hospitalisation of the whanau member affected by CVA	Experience leading up to, and the event of CVA Experience of hospitalisation of the whanau member affected by CVA
Greenwood et al. [49]				Carers as the best person to care	Carers as the best person to care
Katbamna et al. [54]	Coping strategies and resilience	In-patient care and formal support Dynamics of caregiving Anxiety linked to financial pressures Coping strategies and resilience	Competent to care Anxiety linked to financial pressures	Dynamics of caregiving Coping strategies and resilience	
Magwood et al. [59]		Facilitators: Emotional support/patience			

Paper	Self: Meaning Making	Self: Emotional stresses and coping	Self: Practicalities of caregiving	Family: Spousal obligation	Family: Familial piety
Pierce [47]	Caring Is Self-Contemplation Caring Is Motivation for a Philosophical Introspection Caring Is Living in the Moment and Hoping for the Future Caring Is Purpose	Caring Is a Filial Ethereal Value Caring Is Motivation for a Philosophical Introspection Caring Is Living in the Moment and Hoping for the Future Caring Is Motivated by Approval From Care Recipients Caring Is Christian Piety		Caring Is Motivated by Approval From Care Recipients	Caring Is Filial Piety
Pierce & Wilkinson [48]	Caring expressions- Living in the moment and hoping for the future; Christian piety; Purpose; Filial ethereal value; Self-development; Philosophical introspection; Self-contemplation.	Caring Actions: Taught and shared Caring expressions- Living in the moment and hoping for the future; Christian piety; Purpose; Filial ethereal value; Self-development; Emotional burden; Motivation	Caring Actions: Physical work; Taught & shared; Structured, Communication; Learned Caring Expressions - Emotional burden; Motivation	Caring Actions: Learned; Mutuality	Caring Actions: Sacrifice; Accommodation Caring family functions – Adaptation in Caregivers' enforcement of old values; Adaptation in caregivers' watchfulness; Differences in filial function Caring Expressions - Evasion of conflicts; Filial piety; Fairness; Motivation: Love and a sense of duty between caregivers, care recipient and their families; Motivation: approval of

the care recipient;
Christian piety; Purpose

Paper	Self: Meaning Making	Self: Emotional stresses and coping	Self: Practicalities of caregiving	Family: Spousal obligation	Family: Familial piety
Pound & Greenwood [50]		Communication and bureaucracy The impacts of time and timing communication and rapport building Trust and safety			
Strudwick & Morris [58]		Faith in God		Independence from services	Avoiding institutionalized care Family ties
Torregosa et al. [56]		Emotional struggles: Conflicting emotions; Constant worry Readjustment: Overprotectiveness; Network support Deterrent: Guilt	Readjustment: Multitasking	Deterrent: Guilt	Deterrent: Guilt
Yeung et al. [57]		Theme 1. Information and training needs of stroke survivors and caregivers change over time Theme 2. Chinese resources are needed across care environments	Theme 2. Chinese resources are needed across care environments		

Table 5 – Synthesis themes with original study (Themes: Culture and spirituality and Health & social care systems)

Paper	Culture & Spirituality: Faith and spirituality	Culture & Spirituality: Cultural norms and narratives	Health & social care systems: Discharge	Health & social care systems: Meeting needs – adaptation & provision	Health & social care systems: Rights vs reticence	Health & social care systems: Information and communication
Arabit [55]	Theme 3: Coping Subtheme 3-3 Religiosity	Theme 2: Caregiving as a spousal obligation		Subtheme 1-2 Emotional stress		
Corbett et al. [53]		Experience of hospitalisation of the whanau member affected by CVA Experience of being at home, from the immediacy of post discharge from hospital through to the present day	Experience of being at home, from the immediacy of post discharge from hospital through to the present day	Experience of being at home, from the immediacy of post discharge from hospital through to the present day		Experience leading up to, and the event of CVA
Greenwood et al. [49]	Balancing the effort in accessing services with their needs and poor or unsuitable services Cultural aspects of caring: ethnicity, culture, religion and language	Carers as persistent advocates—knowing the system and fighting for support Balancing the effort in accessing services with their needs and poor or unsuitable services Cultural aspects of caring: ethnicity, culture, religion and language	Gap between hospital discharge and home	Balancing the effort in accessing services with their needs and poor or unsuitable services Carers as the best person to care Cultural aspects of caring: ethnicity, culture, religion and language	Carers as persistent advocates—knowing the system and fighting for support Balancing the effort in accessing services with their needs and poor or unsuitable services	Gap between hospital discharge and home Balancing the effort in accessing services with their needs and poor or unsuitable services Cultural aspects of caring: ethnicity, culture, religion and language

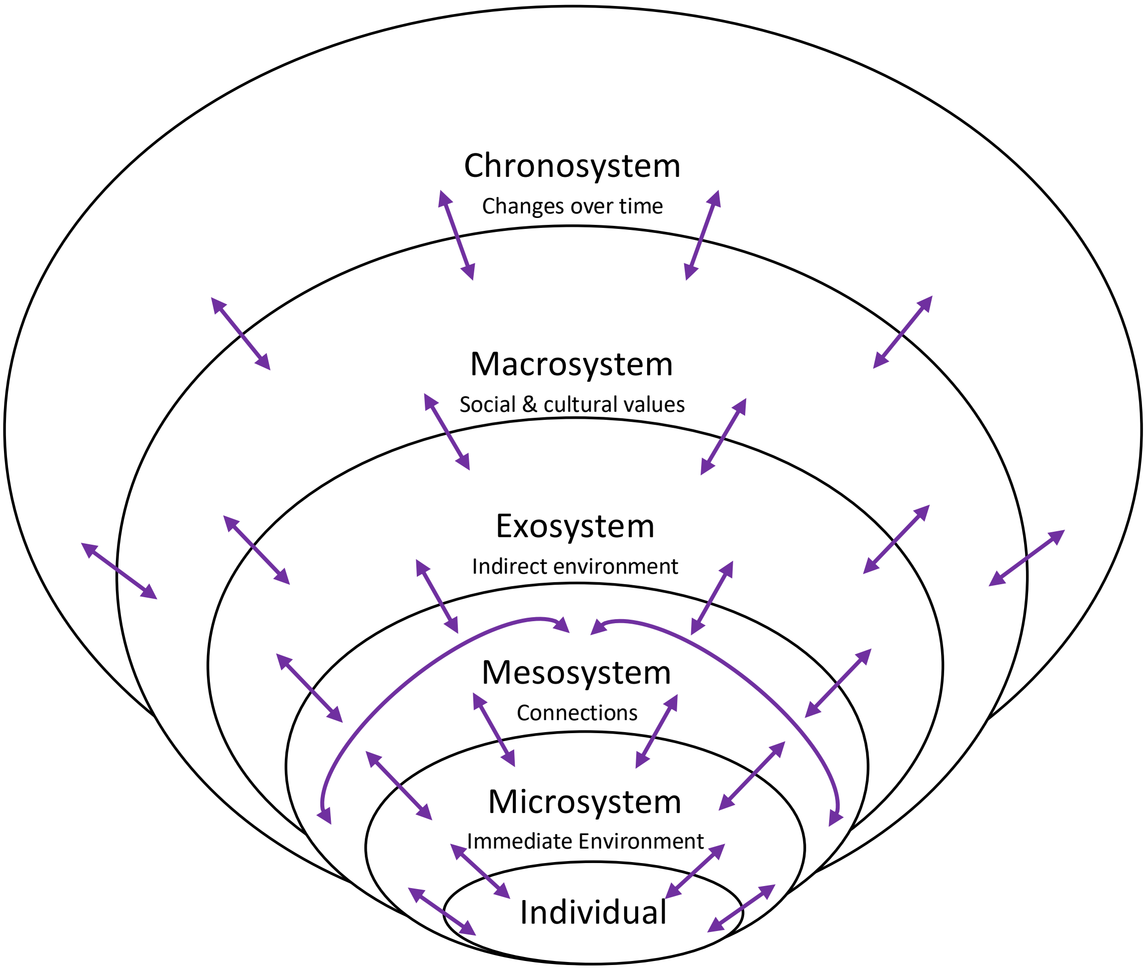
Paper	Culture & Spirituality: Faith and spirituality	Culture & Spirituality: Cultural norms and narratives	Health & social care systems: Discharge	Health & social care systems: Meeting needs – adaptation & provision	Health & social care systems: Rights vs reticence	Health & social care systems: Information and communication
Katbamna et al. [54]	Coping strategies and resilience	Discharge home and formal support Competent to care Long-term outcome Dynamics of caregiving Coping strategies and resilience	In-patient care and formal support Discharge home and formal support	Discharge home and formal support Competent to care	Anxiety linked to financial pressures	In-patient care and formal support Discharge home and formal support Anxiety linked to financial pressures
Magwood et al. [59]	Barriers: Culture/faith	Barriers: Culture/faith	Barriers: Lack of support Facilitators: Resources/support	Barriers – lack of knowledge about stroke Facilitators: Resources/support Facilitators: knowledge/ information		Barriers – lack of knowledge about stroke Facilitators: knowledge/ information

Pierce [47]	Caring Is a Filial Ethereal Value Caring Is Self-Contemplation Caring Is Motivation for a Philosophical Introspection Caring Is Filial Piety Caring Is Living in the Moment and Hoping for the Future Caring Is Purpose Caring Is Christian Piety	Caring Is a Filial Ethereal Value Caring Is Self-Contemplation Caring Is Filial Piety				
Pierce & Wilkinson [48]	Caring expressions- Living in the moment and hoping for the future; Evasion of conflicts; Filial piety; Fairness; Motivation: Love and a sense of duty between caregivers, care recipient and their families; Motivation: approval of the care recipient; Christian piety; Purpose; Filial ethereal value; Self-	Caring Actions: Taught & shared; Learned; Mutuality Caring family functions – Adaptation in families; Adaptation in Caregivers' enforcement of old values				Caring Actions: Learned

development; Philosophical introspection; Self-contemplation.

Paper	Culture & Spirituality: Faith and spirituality	Culture & Spirituality: Cultural norms and narratives	Health & social care systems: Discharge	Health & social care systems: Meeting needs – adaptation & provision	Health & social care systems: Rights vs reticence	Health & social care systems: Information and communication
Torregosa et al. [56]				Emotional Struggles: Constant worry Readjustment: Network support	Readjustment: Taking political action	Emotional Struggles: Constant worry
Yeung et al. [57]	Theme 2. Chinese resources are needed across care environments	Theme 2. Chinese resources are needed across care environments		Theme 1. Information and training needs of stroke survivors and caregivers change over time Theme 2. Chinese resources are needed cross care environments		Theme 1. Information and training needs of stroke survivors and caregivers change over time Theme 2. Chinese resources are needed across care environments

Figure 1 – Bronfenbrenner's Bioecological Systems Model of development



System	Examples
Microsystem	People in your everyday life e.g. family, friends, colleagues, health services, place of worship
Mesosystem	Interactions between people in your life
Exosystem	Neighbourhood, workplace, media, social media
Macrosystem	Socioeconomic status, ethnicity, culture, geographic location
Chronosystem	Changes over the life span; normal and unexpected

Figure 2: .PRISMA 2020 flow diagram for identifying and selection of the studies included in review [39]

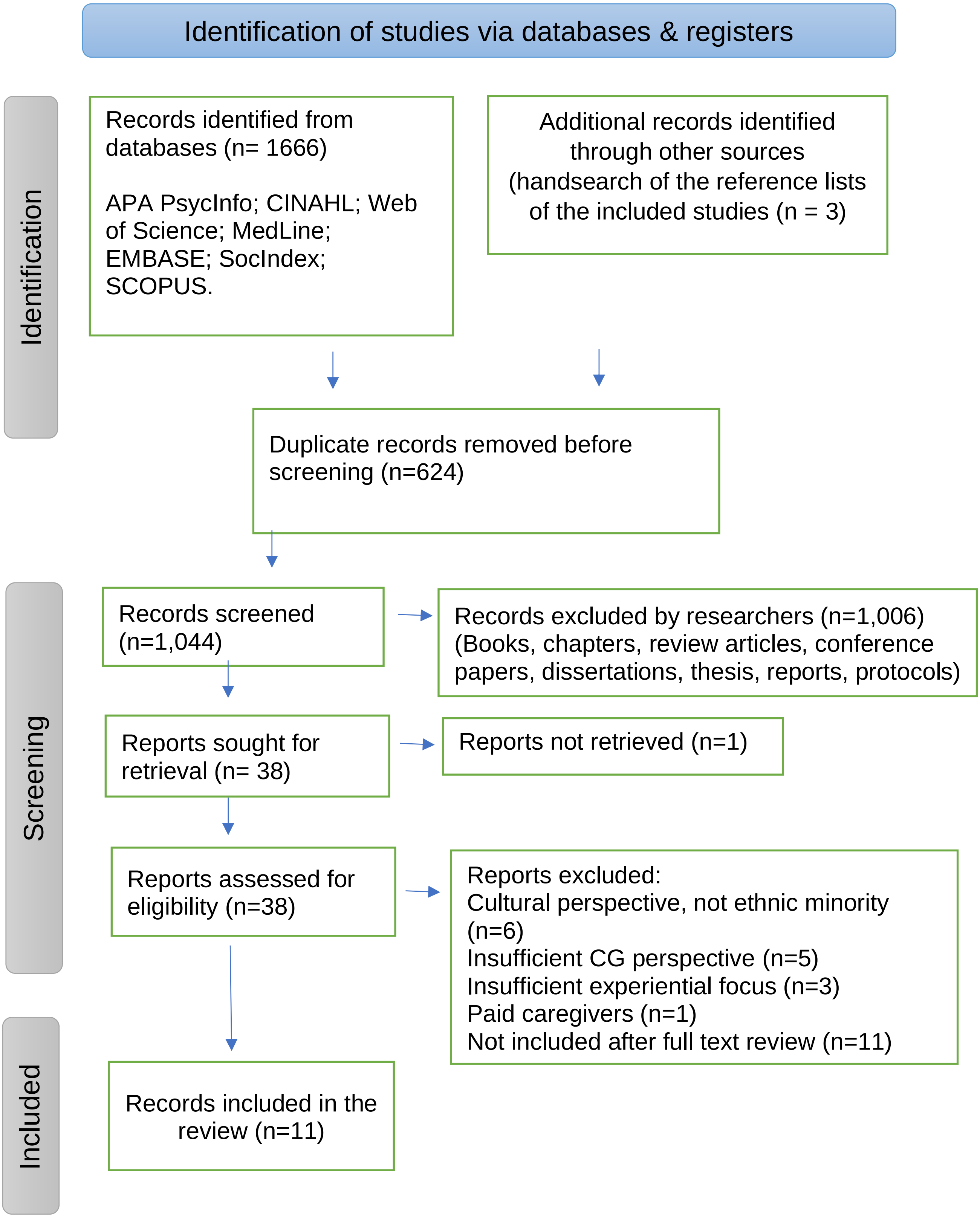
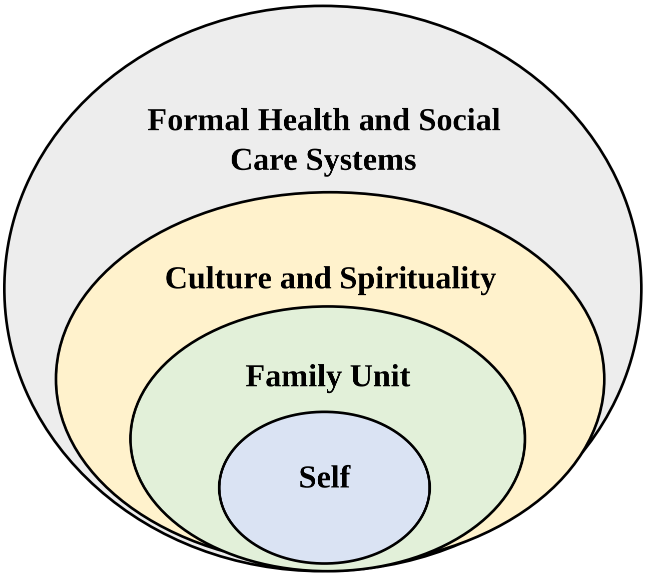


Figure 3 Meta-synthesis systemic category & themes

Category	Theme
Self	Meaning making Emotional stresses and coping Practicalities of caregiving
Family unit	Spousal obligation Familial piety
Culture and spirituality	Faith and spirituality Cultural norms and narratives
Formal health and social care systems	Discharge – the transition home Meeting needs – provision and adaptation Rights vs reticence Information and communication



References

1. Bronfenbrenner, U., & Ceci, S. J. (1994). Nature-nurture reconceptualized in developmental perspective: A bioecological model. *Psychological Review, 101*(4), 568.
2. World Stroke Organization. (2022) *Global stroke fact sheet 2022.* https://www.world-stroke.org/assets/downloads/WSO_Global_Stroke_Fact_Sheet.pdf
3. NHS. (2019). *Recovery: Stroke*. https://www.nhs.uk/conditions/stroke/recovery/
4. Monteiro, M., Fonseca, A., Freitas, A., Pinho E Melo, T., Francisco, A., Ferro, J., & Oliveira, A. (2018). Using machine learning to improve the prediction of functional outcome in ischemic stroke recipients. *IEEE/ACM Transactions on Computational Biology and Bioinformatics, 15*(6), 1953-1959.
5. Stevens, E., Emmett, E., Wang, Y., McKevitt, C., & Wolfe, C. (2017). *The burden of stroke in Europe: The challenge for policy makers.* Stroke Alliance for Europe. https://www.stroke.org.uk/sites/default/files/the_burden_of_stroke_in_europe_-_challenges_for_policy_makers.pdf
6. Feigin VL, Brainin M, Norrving B, Martins S, Sacco RL, Hacke W, Fisher M, Pandian J, Lindsay P. World Stroke Organization (WSO): Global stroke fact sheet 2022. *International Journal of Stroke. 2022 Jan;17*(1):18-29. doi: 10.1177/17474930211065917. Erratum in: *International Journal of Stroke. 2022 Apr;17*(4):478. PMID: 34986727.
7. Centers for Disease Control and Prevention. (2022, April 5). *Stroke facts. Centers for Disease Control and Prevention.* https://www.cdc.gov/stroke/facts.htm
8. Meschia, J. F., Merrill, P., Soliman, E. Z., Howard, V. J., Barrett, K. M., Zakai, N. A., Kleindorfer, D., Safford, M., & Howard, G. (2010). Racial disparities in awareness and treatment of atrial fibrillation: the REasons for Geographic And Racial Differences in Stroke (REGARDS) study. *Stroke, 41*(4), 581-587.

9. Smith, M. A., Risser, J. M., Lisabeth, L. D., Moyé, L. A., & Morgenstern, L. B. (2003). Access to care, acculturation, and risk factors for stroke in Mexican Americans: The Brain Attack Surveillance in Corpus Christi (BASIC) project. *Stroke, 34*(11), 2671-2675.
10. Tsao, C.W., Aday, A.W., Almarzooq, Z.I., Alonso, A., Beaton, A.Z., Bittencourt, M.S., Boehme, A.K., Buxton, A.E., Carson, A.P., Commodore-Mensah, Y., Elkind, M.S.V., Evenson, K.R., Eze-Nliam, C., Ferguson, J.F., Generoso, G., Ho, J.E., Kalani, R., Khan, S.S., Kissela, B.M., Knutson, K.L., Levine, D.A., Lewis, T.T., Liu, J., Loop, M.S., Ma, J., Mussolino, M.E., Navaneethan, S.D., Perak, A.M., Poudel, R., Rezk-Hanna, M., Roth, G.A., Schroeder, E.B., Shah, S.H., Thacker, E.L., Vanwagner, L.B., Virani, S.S., Voecks, J.H., Wang, N.-Y., Yaffe, K., Martin, S.S., 2022. *Heart disease and stroke statistics—2022 update: A report from the American Heart Association.* Circulation 145. doi:10.1161/cir.0000000000001052
11. Stroke Association (2021, June) *Are you at risk of stroke?* https://www.stroke.org.uk/what-is-stroke/are-you-at-risk-of-stroke
12. Fluck, D., Fry, C. H., Gulli, G., Affley, B., Robin, J., Kakar, P., Sharma, P., & Han, T. S. (2023). Adverse stroke outcomes amongst UK ethnic minorities: a multi-centre registry-based cohort study of acute stroke. *Neurological Sciences, 1-10.*
13. Barker-Collo, S., Krishnamurthi, R., Theadom, A., Jones, K., Starkey, N., & Feigin, V. (2019). Incidence of stroke and traumatic brain injury in New Zealand: contrasting the BIONIC and ARCOS-IV studies. *The New Zealand Medical Journal (Online), 132*(1502), 40-54.
14. Heart and Stroke (2022, June 1). *Stroke month 2022: Key messages and background for media.* https://www.heartandstroke.ca/-/media/pdf-files/what-we-do/news/stroke-month-2022-backgrounder-for-media.pdf?rev=a88365a3f5a94dae9ebc8e8f4d0fc310
15. Cambridge University Press. (2022). Ethnic minority. In Cambridge.org dictionary.

Retrieved October 31, 2022, from https://dictionary.cambridge.org/dictionary/english/ethnic-minority

16. Doumanis, N. (2005). History writ large. *Australian Journal of Politics & History, 51*(1), 114-124.
17. Pakulski, J., & Markowski, S. (2014). Globalisation, immigration and multiculturalism–the European and Australian experiences. *Journal of Sociology, 50*(1), 3-9.
18. Brah, A. (2005). *Cartographies of diaspora: Contesting identities*. Routledge.
19. O'Donnell, M. J., Chin, S. L., Rangarajan, S., Xavier, D., Liu, L., Zhang, H., Pais, P., Agapay, S., Lopez-Jaramillo, P., Damasceno, A., Langhorne, P., McQueen, M.J., Rosengren, A., Dehghan, M., Hankey, G.J., Dans, A.L., Elsayed, A., Avezum, A., Mondo, C., Diener, H., Ryglewicz, D., Czlonkowska, A., Pogosova, N., Weimar, C., Iqbal, R., Diaz, R., Yusoff, K., Yusufali, A., Oguz, A., Wang, X., Penaherrera, E., Lanas, F., Ogah, O.S., Ogunniyi, A., Iversen, H.k., Malaga, G., Rumboldt, Z., Oveisgharan, S., Hussain, F.A., Magazi, D., Nilanont, Y., Ferguson J., Pare, G., & Yusuf, S. (2016). Global and regional effects of potentially modifiable risk factors associated with acute stroke in 32 countries (INTERSTROKE): a case-control study. *The Lancet, 388*(10046), 761-775.
20. Dichgans, M., Pulit, S. L., & Rosand, J. (2019). Stroke genetics: discovery, biology, and clinical applications. *The Lancet Neurology, 18*(6), 587-599.
21. Anastasi, A. (1958). Heredity, environment, and the question "how?" *Psychological Review, 65*(4), 197–208. https://doi.org/10.1037/h0044895
22. Plomin, R., & Bergeman, C. S. (1991). The nature of nurture: Genetic influence on “environmental” measures. B*ehavioral and Brain Sciences, 14*(3), 373-386.
23. Bouchard, T. J. (1994). Genes, environment, and personality. *Science, 264*(5166), 1700-1701

24. Johnston, T. D., & Edwards, L. (2002). Genes, interactions, and the development of behavior. *Psychological Review, 109,* 26–34.
25. Baltes, P. B., Reuter-Lorenz, P. A., & Rösler, F. (Eds.). (2006). *Lifespan development and the brain: The perspective of biocultural co-constructivism.* Cambridge University Press.
26. Gottlieb, G. (2007). Probabilistic epigenesis. *Developmental Science, 10,* 1–11.
27. Bronfenbrenner, U., & Ceci, S. J. (1994). Nature-nurture reconceptualized in developmental perspective: *American Psychologist, 43,* 713-720.
28. Bailey, M.J., Sun, S., & Timpe, B. (2021). Prep school for poor kids: The long-run impacts of Head Start on human capital and economic self-sufficiency. *American Economic Review. 111* (12), 3963–4001
29. De Haan, M. & Leuvin, E. (2019). Head Start and the distribution of long-term education and labor market outcomes. *Journal of Labor Economics, 38* (3), 727–765.
30. Eriksson, M., Ghazinour, M. & Hammarström, A. (2018) Different uses of Bronfenbrenner's ecological theory in public mental health research: What is their value for guiding public mental health policy and practice? *Social Theory and Health 16,* 414–433.
31. Paat, Y. F. (2013). Working with immigrant children and their families: An application of Bronfenbrenner's ecological systems theory. *Journal of Human Behavior in the Social Environment, 23*(8), 954-966.
32. Vélez-Agosto, N. M., Soto-Crespo, J. G., Vizcarrondo-Oppenheimer, M., Vega-Molina, S., & García Coll, C. (2017). Bronfenbrenner's bioecological theory revision: Moving culture from the macro into the micro. *Perspectives on Psychological Science, 12*(5), 900-910.
33. Yeandle S, B. L. (2015). *Valuing carers 2015 - the rising value of carers' support.* Carers UK. https://www.carersuk.org/for-professionals/policy/policy-library/valuing-carers-2015

34. Public Health England & Brine S (2018, February 1). *New figures show larger proportion of strokes in the middle aged.* Gov.UK. https://www.gov.uk/government/news/new-figures-show-larger-proportion-of-strokes-in-the-middle-aged https://www.gov.uk/government/news/new-figures-show-larger-proportion-of-strokes-in-the-middle-aged
35. Suksatan, W., Collins, C. J., Koontalay, A., & Posai, V. (2022). Burdens among familial caregivers of stroke survivors: a literature review. *Working with Older People, 26*(1), 37-43.
36. Care Quality Commission, (May 12, 2022). *Culturally appropriate care*. https://www.cqc.org.uk/guidance-providers/adult-social-care/culturally-appropriate-care
37. Beach, M. C., Saha, S., & Cooper, L. A. (2006). *The role and relationship of cultural competence and patient-centeredness in health care quality (Vol. 36).* New York, NY: Commonwealth Fund.
38. Baillie, Lesley (2017). An exploration of the 6Cs as a set of values for nursing practice. *British Journal of Nursing, 26*(10) pp. 558–563
39. Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J.M., Akl, E.A., Brennan. S.E., Chou, R., Glanville, J., Grimshaw, J.M., Hrobjartsson, A., Lalu, M.M., Li, T., Loder, E.W., Mayo-Wilson, E., McDonald, S., McGuinness, L.A., & Moher, D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *Systematic Reviews, 10*(1), 1-11.
40. Noblit, G. W., & Hare, R. D. (1988). *Meta-ethnography: Synthesizing qualitative studies (Vol. 11).* Sage.
41. France, E. F., Cunningham, M., Ring, N., Uny, I., Duncan, E. A., Jepson, R. G., Maxwell, M., Roberts, R.J., Turley, R.L., Booth, A., Britten, N., Flemming, K., Gallagher, I., Garside, R., Hannes, K., Lewin, S., Noblit, G.W., Pope, C., Thomas, J., Vanstone, M.,

Higginbottom, G.M.A., & Noyes, J. (2019). Improving reporting of meta-ethnography: the eMERGe reporting guidance. *BMC Medical Research Methodology, 19*, 1-13.

42. Dixon-Woods M, Booth A, Sutton AJ. Synthesizing qualitative research: a review of published reports. *Qualitative Research 2007;7*(3):375–422. doi: 10.1177/1468794107078517
43. Hannes K, Macaitis K. A move to more systematic and transparent approaches in qualitative evidence synthesis: update on a review of published papers. *Qualitative Research 2012;12*(4):402–442. doi: 10.1177/1468794111432992.
44. Campbell R, Pound P, Morgan M, Daker-White G, Britten N, Pill R, Yardley, L., Pope, C., & Donovan, J. Evaluating meta-ethnography: systematic analysis and synthesis of qualitative research. *Health Technology Assessment. 2011;15*(43):1–164. doi: 10.3310/hta15430.
45. Hackenbroich, S., Kranke, P., Meybohm, P., & Weibel, S. (2022). Include or not to include conference abstracts in systematic reviews? Lessons learned from a large Cochrane network meta-analysis including 585 trials. *Systematic Reviews, 11*(1), 1-10.
46. Xiao, Y., & Watson, M. (2019). Guidance on conducting a systematic literature review. *Journal of Planning Education and Research, 39*(1), 93-112.
47. Pierce, L. L. (2001). Caring and expressions of spirituality by urban caregivers of people with stroke in African American families. *Qualitative Health Research, 11*(3), 339-352.
48. Pierce, L. L., & Wilkinson, L. (1999). Caring and cultural maintenance and transformation for secondary urban family caregivers of persons with stroke. *Journal of Cultural Diversity, 6*(1), 5.
49. Greenwood, N., Holley, J., Ellmers, T., Mein, G., & Cloud, G. (2016). Qualitative focus group study investigating experiences of accessing and engaging with social care services: perspectives of carers from diverse ethnic groups caring for stroke

survivors. *BMJ Open, 6*(1), e009498.

50. Pound, C., & Greenwood, N. (2016). The human dimensions of post-stroke homecare: Experiences of older carers from diverse ethnic groups. *Disability and Rehabilitation, 38*(20), 1987-1999.
51. Critical Appraisal Skills Programme (2022). *CASP Qualitative Studies Checklist*. [online] Accessed July 15th, 2022, from https://casp-uk.net/casp-tools-checklists/
52. Long, H. A., French, D. P., & Brooks, J. M. (2020). Optimising the value of the critical appraisal skills programme (CASP) tool for quality appraisal in qualitative evidence synthesis. *Research Methods in Medicine & Health Sciences, 1*(1), 31-42.
53. Corbett, A., Francis, K., & Chapman, Y. (2006). The experience of whanau caring for members disabled from the effects of a cerebro-vascular accident. *Contemporary Nurse, 22*(2), 255-263.
54. Katbamna, S., Manning, L., Mistri, A., Johnson, M., & Robinson, T. (2017). Balancing satisfaction and stress: carer burden among white and British Asian Indian carers of stroke survivors. *Ethnicity & Health, 22*(4), 425-441.
55. Arabit, L. (2008). Coping strategies of Latino women caring for a spouse recovering from a stroke: A grounded theory. *Journal of Theory Construction & Testing, 12*(2), 42.
56. Torregosa, M. B., Sada, R., & Perez, I. (2018). Dealing with stroke: Perspectives from stroke survivors and stroke caregivers from an underserved Hispanic community. *Nursing & Health Sciences, 20*(3), 361-369.
57. Yeung, E. H., Szeto, A., Richardson, D., Lai, S. H., Lim, E., & Cameron, J. I. (2015). The experiences and needs of Chinese-Canadian stroke survivors and family caregivers as they re-integrate into the community. *Health & Social Care in the Community, 23*(5), 523-531.
58. Strudwick, A., & Morris, R. (2010). A qualitative study exploring the experiences of

African-Caribbean informal stroke carers in the UK. *Clinical Rehabilitation, 24*(2), 159-167.

59. Magwood, G. S., Ellis, C., Nichols, M., Burns, S. P., Jenkins, C., Woodbury, M., & Adams, R. (2019). Barriers and facilitators of stroke recovery: perspectives from African Americans with stroke, caregivers and healthcare professionals. *Journal of Stroke and Cerebrovascular Diseases, 28*(9), 2506-2516.
60. Gibbs, L. A. L., Anderson, M. I., Simpson, G. K., & Jones, K. F. (2020). Spirituality and resilience among family caregivers of survivors of stroke: a scoping review. *NeuroRehabilitation, 46*(1), 41-52.
61. Zhang, J., & Lee, D. T. (2017). Meaning in stroke family caregiving: A literature review. *Geriatric Nursing, 38*(1), 48-56.
62. Bronken, B. A., Kirkevold, M., Martinsen, R., Wyller, T. B., & Kvigne, K. (2012). Psychosocial well-being in persons with aphasia participating in a nursing intervention after stroke. *Nursing Research and Practice*, 2012.
63. Faircloth, C. A., Boylstein, C., Rittman, M., & Gubrium, J. F. (2005). Constructing the stroke: sudden-onset narratives of stroke survivors. *Qualitative Health Research, 15*(7), 928-941.
64. Sarre, S., Redlich, C., Tinker, A., Sadler, E., Bhalla, A., & McKevitt, C. (2014). A systematic review of qualitative studies on adjusting after stroke: lessons for the study of resilience. *Disability and Rehabilitation, 36*(9), 716-726.
65. Kitzmüller, G., Mangset, M., Evju, A. S., Angel, S., Aadal, L., Martinsen, R., Bronken, B.A., Kvigne, K., Bragstad, L.K., Hjelle, E.G., Sveen, U., & Kirkevold, M. (2019). Finding the way forward: the lived experience of people with stroke after participation in a complex psychosocial intervention. *Qualitative Health Research, 29*(12), 1711-1724.
66. Spielman, B. (2012). Elderly, social attitudes toward. In R. Chadwick (Ed.), *Encyclopedia*

of applied ethics (second edition) (pp 56-62). Elsevier Inc. https://doi.org/10.1016/B978-0-12-373932-2.00304-5

67. Cohn, D., Menasce Horowitz, J., Minkin, R., Fry, R. & Hurst, K. (2022, March 24). *Demographics of Multigenerational Households.* Pew Research Center. Retrieved October 21, 2022, from https://www.pewresearch.org/social-trends/2022/03/24/the-demographics-of-multigenerational-households/
68. Stanford, F. C. (2020). The importance of diversity and inclusion in the healthcare workforce. *Journal of the National Medical Association, 112*(3), 247-249.
69. George, S., Duran, N., & Norris, K. (2014). A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. *American Journal of Public Health, 104*(2), e16-e31.
70. Farooqi, A., Jutlla, K., Raghavan, R., Wilson, A., Uddin, M. S., Akroyd, C., Patel, N., Campbell-Morris, P.P., & Farooqi, A. T. (2022). Developing a toolkit for increasing the participation of black, Asian and minority ethnic communities in health and social care research. *BMC Medical Research Methodology, 22,* 1-16.
71. Nelson, A. (2002). Unequal treatment: confronting racial and ethnic disparities in health care. *Journal of the National Medical Association, 94*(8), 666.
72. Takeshita, J., Wang, S., Loren, A. W., Mitra, N., Shults, J., Shin, D. B., & Sawinski, D. L. (2020). Association of racial/ethnic and gender concordance between patients and physicians with patient experience ratings. *JAMA Network Open*, *3*(11), e2024583-e2024583.
73. Schoenthaler, A., & Ravenell, J. (2020). Understanding the patient experience through the lenses of racial/ethnic and gender patient-physician concordance. *JAMA Network Open, 3*(11), e2025349-e2025349.
74. Green, T. L., & King, K. M. (2007). The trajectory of minor stroke recovery for men and

their female spousal caregivers: Literature review. *Journal of Advanced Nursing, 58*(6), 517–531.

75. Lutz, B. J., Young, M. E., Cox, K. J., Martz, C., & Creasy, K. R. (2011). The crisis of stroke: Experiences of recipients and their family caregivers. *Topics in Stroke Rehabilitation, 18*(6), 786–797
76. Morris, R. E. G., Payne, O., & Lambert, A. (2007). Patient, carer and staff experience of a hospital-based stroke service. *International Journal for Quality in Health Care, 19*(2), 105-112.
77. O'Connell, B., & Baker, L. (2004). Managing as carers of stroke survivors: strategies from the field. *International Journal of Nursing Practice, 10*(3), 121-126.
78. Subgranon, R., & Lund, D. A. (2000). Maintaining caregiving at home: a culturally sensitive grounded theory of providing care in Thailand. *Journal of Transcultural Nursing, 11*(3), 166-173.
79. Eaves, Y. D. (2006). Caregiving in rural African American families for older adult stroke survivors. *Journal of Neuroscience Nursing, 38*(4), 270-281.
80. Bakas, T., Austin, J. K., Okonkwo, K. F., Lewis, R. R., & Chadwick, L. (2002). Needs, concerns, strategies, and advice of stroke caregivers the first 6 months after discharge. *Journal of Neuroscience Nursing, 34*(5), 242.
81. McCarthy, M. J., & Bauer, E. (2015). In sickness and in health: Couples coping with stroke across the life Span. *Health & Social Work, 40*(3), e92e–100
82. Pringle, J., Drummond, J.S., & McLafferty, E. (2013) Revisioning, reconnecting and revisiting: the psychosocial transition of returning home from hospital following a stroke, *Disability and Rehabilitation, 35*(23), 1991-1999, DOI: 10.3109/09638288.2013.770081
83. Sit, J. W., Wong, T. K., Clinton, M., Li, L. S., & Fong, Y. M. (2004). Stroke care in the home: the impact of social support on the general health of family caregivers. *Journal of*

Clinical Nursing, 13(7), 816-824

84. Visser-Meily, J. M. A., Post, M. W. M., Schepers, V. P. M., Ketelaar, M., van Heugten, C. M., & Lindeman, E. (2005). Spouses' satisfaction with caregiver support in stroke rehabilitation. *Scandinavian Journal of Caring Sciences, 19*(4), 310–316.
85. McKevitt, C., Redfern, J., Mold, F., & Wolfe, C. (2004). Qualitative studies of stroke: a systematic review. *Stroke, 35*(6), 1499-1505.
86. Simon, C., & Kumar, S. (2002). Stroke patients' carers' views of formal community support. *British Journal of Community Nursing, 7*(3), 158-163.
87. Lilley, S. A., Lincoln, N. B., & Francis, V. M. (2003). A qualitative study of stroke patients' and carers' perceptions of the stroke family support organizer service. *Clinical Rehabilitation, 17*(5), 540-547.
88. Shrestha-Ranjit, J., Payne, D., Koziol-McLain, J., Crezee, I., & Manias, E. (2020). Availability, accessibility, acceptability, and quality of interpreting services to refugee women in New Zealand. *Qualitative Health Research, 30*(11), 1697-1709.
89. Jaeger, F. N., Pellaud, N., Laville, B., & Klauser, P. (2019). Barriers to and solutions for addressing insufficient professional interpreter use in primary healthcare. *BMC Health Services Research, 19*, 1-11.
90. Al Shamsi, H., Almutairi, A. G., Al Mashrafi, S., & Al Kalbani, T. (2020). Implications of language barriers for healthcare: a systematic review. *Oman Medical Journal, 35*(2), e122.
91. NHS England (2018) *Guidance for Commissioners: Interpreting and translation services in Primary Care.* Accessed September 10, 2022, from https://www.england.nhs.uk/wp-content/uploads/2018/09/guidance-for-commissioners-interpreting-and-translation-services-in-primary-care.pdf
92. NHS England (2022, March 31) *NHS England and NHS Improvement: Equality*

objectives and information as at 31 March 2022. Accessed March 12, 2023 from https://www.england.nhs.uk/wp-content/uploads/2022/05/B1587-nhsei-equality-objectives-and-information-31-march-2022.pdf

93. Brandenberger, J., Tylleskär, T., Sontag, K., Peterhans, B., & Ritz, N. (2019). A systematic literature review of reported challenges in health care delivery to migrants and refugees in high-income countries-the 3C model. *BMC Public Health, 19*(1), 1-11.
94. Grosjean, F. (2021). *Life as a bilingual: Knowing and using two or more languages.* Cambridge University Press.
95. Samantha, J. (2022, September 25). *The phonological challenges of learning English as a second language.* In Sasha Calhoun, Paola Escudero, Marija Tabain & Paul Warren (Eds.) Proceedings of the 19th International Congress of Phonetic Sciences, Melbourne, Australia 2019. Canberra, Australia: Australasian Speech Science and Technology Association Inc. https://www.icphs2019.org/the-phonological-challenges-of-learning-english-as-a-second-language
96. Smith, G. (2004). Faith in community and communities of faith? Government rhetoric and religious identity in urban Britain. *Journal of Contemporary Religion, 19*(2), 185-204.
97. Dashefsky, A. (1972). And the search goes on: The meaning of religio-ethnic identity and identification. *Sociological Analysis, 33*(4), 239-245.
98. Clayton, J. (2009). Thinking spatially: towards an everyday understanding of inter-ethnic relations. *Social & Cultural Geography, 10*(4), 481-498.
99. Abramson, H. J. (1979). Migrants and cultural diversity: On ethnicity and religion in society. *Social Compass*, *26*(1), 5-29.
100. Anwar, M. (1980). Religious identity in plural societies: the case of Britain. *Institute of Muslim Minority Affairs. Journal, 2*(2), 110-121.

101. Knott, K. (2022). *Religion and identity, and the study of ethnic minority religions in Britain.* Australian Association for the Study of Religions Book Series, 9-9.

102. Newman, L. L. (2004). Faith, spirituality, and religion: A model for understanding the differences. *College Student Affairs Journal, 23*(2), 102-110.

103. Rabins, P. V., Fitting, M. D., Eastham, J., & Zabora, J. (1990). Emotional adaptation over time in caregivers for chronically ill elderly people. *Age and Ageing, 19*(3), 185-190.

104. Weaver, A. J., & Flannelly, K. J. (2004). The role of religion/spirituality for cancer patients and their caregivers. *Southern Medical Journal, 97*(12), 1210-1214.

105. Picot, S. J., Debanne, S. M., Namazi, K. H., & Wykle, M. L. (1997). Religiosity and perceived rewards of black and white caregivers. *The Gerontologist, 37*(1), 89-101.

106. Moreira, T., Hernandez, D. C., Scott, C. W., Murillo, R., Vaughan, E. M., & Johnston, C. A. (2018). Susto, coraje, y fatalismo: Cultural-bound beliefs and the treatment of diabetes among socioeconomically disadvantaged Hispanics. *American Journal of Lifestyle Medicine, 12*(1), 30-33.

107. Shurgot, G. S. R., & Knight, B. G. (2004). Preliminary study investigating acculturation, cultural values, and psychological distress in Latino caregivers of dementia patients. *Journal of Mental Health and Aging.*

108. Maria Bermúdez, J., Kirkpatrick, D. R., Hecker, L., & Torres-Robles, C. (2010). Describing Latinos families and their help-seeking attitudes: Challenging the family therapy literature. *Contemporary Family Therapy, 32*, 155-172.

109. Herrera, A. P., Lee, J. W., Nanyonjo, R. D., Laufman, L. E., & Torres-Vigil, I. (2009). Religious coping and caregiver well-being in Mexican-American families. *Aging and Mental Health, 13*(1), 84-91.

110. Upenieks, L. (2021). Uncertainty in faith, fear of death? Transitions in religious doubt and death anxiety in later life. *OMEGA-Journal of Death and Dying,*

00302228211029475.

111. Ardelt, M., & Koenig, C. S. (2006). The role of religion for hospice patients and relatively healthy older adults. *Research on Aging, 28*(2), 184-215.

112. Koenig, H. G. (2012). Religion, spirituality, and health: The research and clinical implications. *International Scholarly Research Notices*, 2012.

113. Mohammadzadeh, A., & Najafi, M. (2020). The comparison of death anxiety, obsession, and depression between Muslim population with positive and negative religious coping. *Journal of Religion and Health, 59*, 1055-1064.

114. DiCicco-Bloom, B., & Cohen, D. (2003). Home care nurses: A study of the occurrence of culturally competent care. *Journal of Transcultural Nursing, 14*(1), 25-31.

115. Nielsen, L. S., Angus, J. E., Howell, D., Husain, A., & Gastaldo, D. (2015). Patient-centered care or cultural competence: negotiating palliative care at home for Chinese Canadian immigrants. *American Journal of Hospice and Palliative Medicine, 32*(4), 372-379.

116. Beaulieu, L., Addington, J., & Almeida, D. (2019). Behavior analysts' training and practices regarding cultural diversity: The case for culturally competent care. *Behavior Analysis in Practice, 12*, 557-575.

117. Attum, B., Hafiz, S., Malik, A., & Shamoon, Z. (2018). Cultural competence in the care of Muslim patients and their families. StatPearls Publishing. https://europepmc.org/article/nbk/nbk499933

118. López-Espuela, F., González-Gil, T., Amarilla-Donoso, J., Cordovilla-Guardia, S., Portilla-Cuenca, J. C., & Casado-Naranjo, I. (2018). Critical points in the experience of spouse caregivers of recipients who have suffered a stroke A phenomenological interpretive study. *PLoS ONE, 13*(4).

119. Visser-Meilly, A., Post, M., van de Port, I., van Heugten, C., & van den Bos, T.

(2008). Psychosocial functioning of spouses in the chronic phase after stroke: Improvement or deterioration between 1 and 3 years after stroke? *Recipient Education and Counseling, 73*(1), 153–158.

120. Adriaansen, J. J. E., van Leeuwen, C. M. C., Visser-Meily, J. M. A., van den Bos, G. A. M., & Post, M. W. M. (2011). Course of social support and relationships between social support and life satisfaction in spouses of recipients with stroke in the chronic phase. *Recipient Education and Counseling, 85*(2)

121. Luerbe-Puerto, K., Leandro, M.-E., & Baumann, M. (2012). Experiences of caregiving, satisfaction of life, and social repercussions among family caregivers, two years post-stroke. *Social Work in Health Care, 51*(8), 725–742

122. Office for National Statistics. (2020, August 28). *Ethnicity facts and figures: Families and households.* Gov.uk. https://www.ethnicity-facts-figures.service.gov.uk/uk-population-by-ethnicity/demographics/families-and-households/latest

123. Hoyt, J. (2022, June 15). *The sandwich generation.* SeniorLiving.Org. https://www.seniorliving.org/caregiving/sandwich-generation/

124. Kamo, Y. (2000). Racial and ethnic differences in extended family households. *Sociological Perspectives, 43*(2), 211-229.

125. Office for National Statistics. (2019, January 14). *More than one in four sandwich carers report symptoms of mental ill-health.* https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandwellbeing/articles/morethanoneinfoursandwichcarersreportsymptomsofmentalillhealth/2019-01-14

126. Monforte, P., Bassel, L., & Khan, K. (2019). Deserving citizenship? Exploring migrants' experiences of the ‘citizenship test’ process in the United Kingdom. *The British Journal of Sociology, 70*(1), 24-43.

127. Migration Data Portal (n.d.) *Migration & development: Diasporas*. Retrieved April 12, 2023 https://www.migrationdataportal.org/themes/diasporas

128. Berry, J. W. (2008). Globalisation and acculturation. *International Journal of Intercultural Relations, 32*(4), 328-336.

129. Department of Economic and Social Affairs (DESA). (2018). *Promoting inclusion through social protection: Report on the world social situation 2018.* New York: United Nations. pp 97-108. https://doi.org/10.18356/14642ccc-en

130. Stonefish, T., & Kwantes, C. T. (2017). Values and acculturation: A Native Canadian exploration. *International Journal of Intercultural Relations, 61*, 63-76.

131. Ziaian, T., Puvimanasinghe, T., Miller, E., De Anstiss, H., Esterman, A., & Dollard, M. (2021). Identity and belonging: Refugee youth and their parents' perception of being Australian. *Australian Psychologist, 56*(2), 123-136.

132. Olson, H. A. (2011). Sameness and difference. *Library Resources & Technical Services, 45*(3), 115-122.

133. Hauora, N. P., Gibson, D., Leach, D. T., & Coast, E. (2005) Implementing the primary health care strategy: A Māori health provider perspective. *Social Policy Journal of New Zealand: 25*

134. Akyea, R. K., Vinogradova, Y., Qureshi, N., Patel, R. S., Kontopantelis, E., Ntaios, G., Asselbergs, F.W., Kai, J., & Weng, S. F. (2021). Sex, age, and socioeconomic differences in nonfatal stroke incidence and subsequent major adverse outcomes. *Stroke, 52*(2), 396-405.

135. Wang, S., Zhai, H., Wei, L., Shen, B., & Wang, J. (2020). Socioeconomic status predicts the risk of stroke death: a systematic review and meta-analysis. *Preventive Medicine Reports, 19*, 101124.

136. American Psychological Association. (2017). *Ethnic and racial minorities &*

socioeconomic status. Accessed April 29, 2023 from https://www.apa.org/pi/ses/resources/publications/minorities

137. Disability Rights UK (2023, January 4) *Resolution Foundation find 44% income gap for Disabled people.* https://www.disabilityrightsuk.org/news/resolution-foundation-find-44-income-gap-disabled-people#:~:text=Disabled%20people%20now%20account%20for,per%20cent%20a%20decade%20ago.

138. Shorten, A., & Smith, J. (2017). Mixed methods research: expanding the evidence base. *Evidence-based Nursing, 20*(3), 74-75.

Appendix 1-A: Publication information

Instructions for authors

Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read and follow them as closely as possible, as doing so will ensure your paper matches the journal's requirements.

AUTHOR SERVICES
Supporting Taylor & Francis authors

For general guidance on every stage of the publication process, please visit our Author Services website.

EDITING SERVICES
Supporting Taylor & Francis authors

For editing support, including translation and language polishing, explore our Editing Services website

This title utilises format-free submission. Authors may submit their paper in any scholarly format or layout. References can be in any style or format, so long as a scholarly citation format is applied. For more detail see the format-free submission section below.

Contents

About the journal

Disability and Rehabilitation is an international, peer reviewed journal, publishing high-quality, original research. Please see the journal's Aims & Scope for information about its focus and peer-review policy.

From 2018, this journal will be online only, and will no longer provide print copies.

Please note that this journal only publishes manuscripts in English.

Disability and Rehabilitation accepts the following types of article: Research Articles, Reviews, Letters to the Editor, Case Reports, and Editorials. Systematic Reviews including meta-syntheses of qualitative research should be submitted as Reviews. All other types of Reviews will normally be considered as Perspectives in Rehabilitation.

Special Issues and specific sections on contemporary themes of interest to the Journal's readership are published. Please contact the Editor for more information.

Open Access

You have the option to publish open access in this journal via our Open Select publishing program. Publishing open access means that your article will be free to access online immediately on publication, increasing the visibility, readership and impact of your research. Articles published Open Select with Taylor & Francis typically receive 45% more citations* and over 6 times as many downloads** compared to those that are not published Open Select.

Your research funder or your institution may require you to publish your article open access. Visit our Author Services website to find out more about open access policies and how you can comply with these.

You will be asked to pay an article publishing charge (APC) to make your article open access and this cost can often be covered by your institution or funder. Use our APC finder to view the APC for this journal.

Please visit our Author Services website if you would like more information about our Open Select Program.

*Citations for articles published online 2018-2022. Data obtained on 23rd August 2023, from Digital Science's Dimensions platform, available at https://app.dimensions.ai **Usage in 2020-2022 for articles published online 2018-2022

Peer review

Taylor & Francis is committed to peer-review integrity and upholding the highest standards of review. For submissions to *Disability and Rehabilitation* authors are given the option to remain anonymous during the peer-review process. Authors will be able to indicate whether their paper is 'Anonymous' or 'Not Anonymous' during submission, and should pay particular attention to the below:

- Authors who wish to remain anonymous should prepare a complete text with information identifying the author(s) removed. Authors should upload their files using the 'double anonymous peer review' article types during submission. A separate title page should be included providing the full affiliations of all authors. Any acknowledgements and the Declaration of Interest statement must be included but should be worded mindful that these sections will be made available to referees.
- Authors who wish to be identified should include the name(s) and affiliation(s) of author(s) on the first page of the manuscript. Authors should upload their files using the 'authors made known to the reviewers' article types during submission.

Once your paper has been assessed for suitability by the editor, it will be peer-reviewed by independent, double anonymous expert referees. If you have shared an earlier version of your Author's Original Manuscript on a preprint server, please be aware that anonymity cannot be guaranteed. Further information on our preprints policy and citation requirements can be found on our Preprints Author Services page. Find out more about what to expect during peer review and read our guidance on publishing ethics.

Preparing your paper

All authors submitting to medicine, biomedicine, health sciences, allied and public health journals should conform to the Uniform Requirements for Manuscripts Submitted to Biomedical Journals, prepared by the International Committee of Medical Journal Editors (ICMJE).

We also refer authors to the community standards explicit in the American Psychological Association's (APA) Ethical Principles of Psychologists and Code of Conduct.

We encourage authors to be aware of standardised reporting guidelines below when preparing their manuscripts:

- Case reports - CARE
- Diagnostic accuracy - STARD
- Observational studies - STROBE
- Randomized controlled trial - CONSORT
- Systematic reviews, meta-analyses - PRISMA

Whilst the use of such guidelines is supported, due to the multi-disciplinary nature of the Journal, it is not compulsory.

Your paper should be compiled in the following order: title page; abstract; keywords; main text, introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s); figures; figure captions (as a list).

In the main text, an introductory section should state the purpose of the paper and give a brief account of previous work. New techniques and modifications should be described concisely but in sufficient detail to permit their evaluation. Standard methods should simply be referenced. Experimental results should be presented in the most appropriate form, with sufficient explanation to assist their interpretation; their discussion should form a distinct section.

Tables and figures should be referred to in text as follows: figure 1, table 1, i.e. lower case. The place at which a table or figure is to be inserted in the printed text should be indicated clearly on a manuscript. Each table and/or figure must have a title that explains its purpose without reference to the text.

The title page should include the full names and affiliations of all authors involved in the preparation of the manuscript. The corresponding author should be clearly designated, with full contact information provided for this person.

t

Please include a word count for your paper. There is no word limit for papers submitted to this journal, but succinct and well-constructed papers are preferred.

Format-Free Submission

Authors may submit their paper in any scholarly format or layout. Manuscripts may be supplied as single or multiple files. These can be Word, rich text format (rtf), open document format (odt), PDF, or LaTeX files. Figures and tables can be placed within the text or submitted as separate documents. Figures should be of sufficient resolution to enable refereeing.

- There are no strict formatting requirements, but all manuscripts must contain the essential elements needed to evaluate a manuscript: abstract, author affiliation, figures, tables, funder information, references. Further details may be requested upon acceptance.
- References can be in any style or format, so long as a scholarly citation format is applied. For manuscripts submitted in LaTeX format a .bib reference file must be included. Author name(s), journal or book title, article or chapter title, year of publication, volume and issue (where appropriate) and page numbers are essential. All

bibliographic entries must contain a corresponding in-text citation. The addition of DOI (Digital Object Identifier) numbers is recommended but not essential.

- The journal reference style will be applied to the paper post-acceptance by Taylor & Francis.
- Spelling can be US or UK English so long as usage is consistent.

Note that, regardless of the file format of the original submission, an editable version of the article must be supplied at the revision stage.

Alt Text

This journal is now including Alt Text (alternative text), a short piece of text that can be attached to your figure to convey to readers the nature or contents of the image. It is typically used by systems such as pronouncing screen readers to make the object accessible to people that cannot read or see the object, due to a visual impairment or print disability. Alt text will also be displayed in place of an image, if said image file cannot be loaded. Alt Text can also provide better image context/descriptions to search engine crawlers, helping them to index an image properly. To include Alt Text in your article, please follow our Guidelines.

Taylor & Francis Editing Services

To help you improve your manuscript and prepare it for submission, Taylor & Francis provides a range of editing services. Choose from options such as English Language Editing, which will ensure that your article is free of spelling and grammar errors, Translation, and Artwork Preparation. For more information, including pricing, visit this website.

Checklist: what to include

1. **Author details**. Please ensure everyone meeting the International Committee of Medical Journal Editors (ICJME) requirements for authorship is included as an author of your paper. Please ensure all listed authors meet the Taylor & Francis authorship criteria. All authors of a manuscript should include their full name and affiliation on the cover page of the manuscript. Where available, please also include ORCiDs and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. Read more on authorship.
2. A structured **abstract** of no more than 200 words. A structured abstract should cover (in the following order): the *purpose* of the article, its *materials and methods* (the design and methodological procedures used), the *results* and conclusions (including their relevance to the study of disability and rehabilitation). Read tips on writing your abstract.
3. You can opt to include a **video abstract** with your article. Find out how these can help your work reach a wider audience, and what to think about when filming.
4. 5-8 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.
5. A feature of this journal is a boxed insert on **Implications for Rehabilitation**. This should include between two to four main bullet points drawing out the implications for rehabilitation for your paper. This should be uploaded as a separate document. Below are examples:
   Example 1: Leprosy
   - Leprosy is a disabling disease which not only impacts physically but restricts quality of life often through stigmatisation.
   - Reconstructive surgery is a technique available to this group.
   - In a relatively small sample this study shows participation and social functioning improved after surgery.

   Example 2: Multiple Sclerosis

   - Exercise is an effective means of improving health and well-being experienced by people with multiple sclerosis (MS).
   - People with MS have complex reasons for choosing to exercise or not.

  - Individual structured programmes are most likely to be successful in encouraging exercise in this cohort.

6. **Acknowledgement**. Please supply all details required by your funding and grant-awarding bodies as follows: *For single agency grants*: This work was supported by the under Grant . *For multiple agency grants*: This work was supported by the under Grant ; under Grant ; and under Grant .
7. **Declaration of Interest**. This is to acknowledge any financial or non-financial interest that has arisen from the direct applications of your research. If there are no relevant competing interests to declare please state this within the article, for example: *The authors report there are no competing interests to declare.* Further guidance on what is a conflict of interest and how to disclose it.
8. **Data availability statement.** If there is a data set associated with the paper, please provide information about where the data supporting the results or analyses presented in the paper can be found. Where applicable, this should include the hyperlink, DOI or other persistent identifier associated with the data set(s). Templates are also available to support authors.
9. **Data deposition.** If you choose to share or make the data underlying the study open, please deposit your data in a recognized data repository prior to or at the time of submission. You will be asked to provide the DOI, pre-reserved DOI, or other persistent identifier for the data set.
10. **Supplemental online material.** Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about supplemental material and how to submit it with your article.
11. **Figures.** Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour). Figures should be saved as TIFF, PostScript or EPS files.
12. **Tables.** Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.
13. **Equations**. If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about mathematical symbols and equations.
14. **Units.** Please use SI units (non-italicized).

Using third-party material in your paper

You must obtain the necessary permission to reuse third-party material in your article. The use of short extracts of text and some other types of material is usually permitted, on a limited basis, for the purposes of criticism and review without securing formal permission. If you wish to include any material in your paper for which you do not hold copyright, and which is not covered by this informal agreement, you will need to obtain written permission from the copyright owner prior to submission. More information on requesting permission to reproduce work(s) under copyright.

Declaration of Interest Statement

Please include a declaration of interest statement, using the subheading "Declaration of interest." If you have no interests to declare, please state this (suggested wording: *The authors report no conflicts of interest*). For all NIH/Wellcome-funded papers, the grant number(s) must be included in the disclosure of interest statement. Read more on declaring conflicts of interest.

Clinical Trials Registry

In order to be published in Disability and Rehabilitation , all clinical trials must have been registered in a public repository, ideally at the beginning of the research process (prior to participant recruitment). Trial registration numbers should be included in the abstract, with full details in the methods section. Clinical trials should be registered prospectively – i.e. before participant recruitment. The clinical trial registry should be publicly accessible (at no charge), open to all prospective registrants, and managed by a not-for-profit organization. For a list of registries that meet these requirements, please visit the WHO International Clinical Trials Registry Platform (ICTRP). The registration of all clinical trials facilitates the sharing of information among clinicians, researchers, and patients, enhances public confidence in research, and is in accordance with the ICMJE guidelines.

Complying with ethics of experimentation

Please ensure that all research reported in submitted papers has been conducted in an ethical and responsible manner, and is in full compliance with all relevant codes of experimentation and legislation. All papers which report *in vivo* experiments or clinical trials on humans or animals must include a written statement in the Methods section. This should explain that all work was conducted with the formal approval of the local human subject or animal care committees (institutional and national), and that clinical trials have been registered as legislation requires. Authors who do not have formal ethics review committees should include a statement that their study follows the principles of the Declaration of Helsinki.

Please ensure that all research reported in submitted papers has been conducted in an ethical and responsible manner, and is in full compliance with all relevant codes of experimentation and legislation. All original research papers involving humans, animals, plants, biological material, protected or non-public datasets, collections or sites, must include a written statement in the Methods section, confirming ethical approval has been obtained from the appropriate local ethics committee or Institutional Review Board and that where relevant, informed consent has been obtained. For animal studies, approval must have been obtained from the local or institutional animal use and care committee. All research studies on humans (individuals, samples, or data) must have been performed in accordance with the principles stated in the Declaration of Helsinki. In settings where ethics approval for non-interventional studies (e.g. surveys) is not required, authors must include a statement to explain this. In settings where there are no ethics committees in place to provide ethical approval, authors are advised to contact the Editor to discuss further. Detailed guidance on ethics considerations and mandatory declarations can be found in our Editorial Policies section on Research Ethics.

All authors are required to follow the ICMJE requirements and Taylor & Francis Editorial Policies on privacy and informed consent from patients and study participants. Authors must include a statement to confirm that any patient, service user, or participant (or that person’s parent or legal guardian) in any type of qualitative or quantitative research, has given informed consent to participate in the research. For submissions where patients or participants can be potentially identified (e.g. a clinical case report detailing their medical history, identifiable images or media content, etc), authors must include a statement to confirm that they have obtained written informed consent to publish the details from the affected individual (or their parents/guardians if the participant in not an adult or unable to give informed consent; or next of kin if the participant is deceased). The process of obtaining consent to publish should include sharing the article with the individual (or whoever is consenting on their behalf), so that they are fully aware of the content of the article before it is published. Authors should familiarise themselves with our policy on participant/patient privacy and informed consent. They may also use the Consent to Publish Form, which can be downloaded from the same Author Services page.

Health and safety

Please confirm that all mandatory laboratory health and safety procedures have been complied with in the course of conducting any experimental work reported in your paper. Please ensure your paper contains all appropriate warnings on any hazards that may be involved in carrying out the experiments or procedures you have described, or that may be involved in instructions, materials, or formulae.

Please include all relevant safety precautions; and cite any accepted standard or code of practice. Authors working in animal science may find it useful to consult the International Association of Veterinary Editors’ Consensus Author Guidelines on Animal Ethics and Welfare and Guidelines for the Treatment of Animals in Behavioural Research and Teaching. When a product has not yet been approved by an appropriate regulatory body for the use described in your paper, please specify this, or that the product is still investigational.

Submitting your paper

This journal uses Taylor & Francis' Submission Portal to manage the submission process. The Submission Portal allows you to see your submissions across Taylor & Francis' journal portfolio in one place. To submit your manuscript please click here.

By submitting your paper to *Disability and Rehabilitation* you are agreeing to originality checks during the peer-review and production processes.

The Editor of *Disability and Rehabilitation* will respond to appeals from authors relating to papers which have been rejected. The author(s) should email the Editor outlining their concerns and making a case for why their paper should not have been rejected. The Editor may choose to accept the appeal and secure a further review, or to not uphold the appeal. In case of the latter, the Editor of *Disability and Rehabilitation: Assistive Technology* will be consulted.

On acceptance, we recommend that you keep a copy of your Accepted Manuscript. Find out more about sharing your work.

Data Sharing Policy

This journal applies the Taylor & Francis Basic Data Sharing Policy. Authors are encouraged to share or make open the data supporting the results or analyses presented in their paper where this does not violate the protection of human subjects or other valid privacy or security concerns.

Authors are encouraged to deposit the dataset(s) in a recognized data repository that can mint a persistent digital identifier, preferably a digital object identifier (DOI) and recognizes a long-term preservation plan. If you are uncertain about where to deposit your data, please see this information regarding repositories.

Authors are further encouraged to cite any data sets referenced in the article and provide a Data Availability Statement.

At the point of submission, you will be asked if there is a data set associated with the paper. If you reply yes, you will be asked to provide the DOI, pre-registered DOI, hyperlink, or other persistent identifier associated with the data set(s). If you have selected to provide a pre-registered DOI, please be prepared to share the reviewer URL associated with your data deposit, upon request by reviewers.

Where one or multiple data sets are associated with a manuscript, these are not formally peer reviewed as a part of the journal submission process. It is the author's responsibility to ensure the soundness of data. Any errors in the data rest solely with the producers of the data set(s).

Publication charges

There are no submission fees, publication fees or page charges for this journal.

Color figures will be reproduced in color in your online article free of charge.

Copyright options

Copyright allows you to protect your original material, and stop others from using your work without your permission. Taylor & Francis offers a number of different license and reuse options, including Creative Commons licenses when publishing open access. Read more on publishing agreements.

Complying with funding agencies

We will deposit all National Institutes of Health or Wellcome Trust-funded papers into PubMedCentral on behalf of authors, meeting the requirements of their respective open access (OA) policies. If this applies to you, please tell our production team when you receive your article proofs, so we can do this for you. Check funders' OA policy mandates here. Find out more about sharing your work.

My Authored Works

Appendix 1-B

Additional publication content

Implications for Rehabilitation

- EMFCs would benefit from targeted and accessible health campaigns to build health literacy, stroke knowledge and understanding of how to navigate the health and social care system.
- Professionals would benefit from evidence-based cultural competence training that includes faith and spirituality content.
- Service support is more effective when it is accommodating and respectful of cultural and religious rituals and observances.
- Assessments can be used to explore contextual arrangements including family support, intergenerational care responsibilities, faith and/or cultural needs and how these may be met.
- Whilst cultural narratives exist, overgeneralisations and assumptions should be avoided; there are as many differences in cultural expression within ethnic groups as there are between.

Keywords*:* Stroke; ethnic minority, family caregiver, qualitative, experiences, review

Acknowledgements

The authors would like to acknowledge John Barbrook, Faculty Librarian for Health and Medicine at Lancaster University, for his support in the production of this paper.

Disclosure Statement

No potential conflict of interest was reported by the authors.

Appendix 1-C: CINAHL search example

S9	S7 AND S8	**Search modes -** Find all my search terms	View Results (128) View Details Edit
S8	s3 AND S4	**Search modes -** Find all my search terms	View Results (2,497) View Details Edit
S7	S5 AND S6	**Search modes -** Find all my search terms	View Results (71,613) View Details Edit
S6	((MH "Family+") OR (MH "Nuclear Family+") OR (MH "Parents+") OR (MH "Mothers+") OR (MH "Spouses")) OR TI (Child* or son* or daughter* or sibling* or brother* or sister* or wife or wives or husband* or spous* or marri* or “significant other*” or partner* or famil* or parent* or father* or dad* or mother* or mum* or “next of kin” OR relative* OR household* OR house-hold*) OR AB (Child* or son* or daughter* or sibling* or brother* or sister* or wife or wives or husband* or spous* or marri* or “significant other*” or partner* or famil* or parent* or father* or dad* or mother* or mum* OR “next of kin” OR relative* OR household* OR house-hold*) Show Less	**Search modes -** Find all my search terms	View Results (1,285,398) View Details Edit

S5	((MH "Caring+") OR (MH "Uncompensated Care") OR (MH "Caregiver Attitudes") OR (MH "Caregiver Support") OR (MH "Caregivers")) OR TI (caregiv* or "informal caregiv*" OR carer* OR "care giv*" OR caring) OR AB (caregiv* or "informal caregiv*" OR carer* OR "care giv*" OR caring)	**Search modes** - Find all my search terms	View Results (138,070) View Details Edit
S4	((MH "Minority Groups") OR (MH "Minority Stress") OR (MH "Immigrants") OR (MH "Refugees+")) OR TI (Immigrant* or migrant* or cultur* or multicultur* or intercultur* or minorit* or ethnic* or multiethnic* or racial* or race* or refugee* or "non western*" or emigrat* or immigrat*) OR AB (Immigrant* or migrant* or cultur* or multicultur* or intercultur* or minorit* or ethnic* or multiethnic* or racial* or race* or refugee* or "non western*" or emigrat* or immigrat*)	**Search modes** - Find all my search terms	View Results (328,993) View Details Edit
S3	S1 AND S2	**Search modes** - Find all my search terms	View Results (42,993) View Details Edit
S2	(MH "Qualitative Studies+") OR TI (interview* OR "focus group*" OR "case stud*" OR "grounded theory" OR narrative* OR thematic OR ethnog* OR qualitative* OR phenomenolog* OR experienc* OR explor* OR "open question*" OR examin* OR discourse* OR "content analys*" OR "dialogue*" OR "conversation analysis" OR "Case-Oriented Understanding") OR AB (interview* OR "focus group*" OR "case stud*" OR "grounded theory" OR narrative* OR thematic OR ethnog* OR qualitative* OR phenomenolog* OR experienc* OR explor* OR "open question*" OR examin* OR discourse* OR "content analys*" OR "dialogue*" OR "conversation analysis" OR "Case-Oriented Understanding") Show Less	**Search modes** - Find all my search terms	View Results (1,595,388) View Details Edit

S1 ((MH "Stroke+") OR (MH "Ischemic Stroke+") OR (MH "Hemorrhagic Stroke") OR (MH "Stroke Units") OR (MH "Stroke Patients") OR (MH "Embolic Stroke") OR (MH "Stroke, Lacunar")) OR TI (stroke or cva or "cerebral vascular event*" or cve or "transient ischaemic attack*" or tia or “ transient ischemic attack*” OR “mini-stroke” OR ((cereb* OR intracereb* OR subarachnoid) N3 (hemorrhage* OR haemorrhage* OR accident* OR infarction*)) OR “encephalorrhagi*” or “hematencephalo*” OR “ischemic stroke” or “brain attack” or thrombotic or emboli* or thrombos* or ictus or apoplexy) OR AB (stroke or cva or "cerebral vascular event*" or cve or "transient ischaemic attack*" or tia or “ transient ischemic attack*” OR “mini-stroke” OR ((cereb* OR intracereb* OR subarachnoid) N3 (hemorrhage* OR haemorrhage* OR accident* OR infarction*)) OR “encephalorrhagi*” or “hematencephalo*” OR “ischemic stroke” or “brain attack” or thrombotic or emboli* or thrombos* or ictus or apoplexy) Show Less

Chapter 2 : Research Paper

Case study of a spousal caregiver's experiences during the Covid 19 pandemic for a partner who has had a stroke: identifying implications for psychological support.

Ruth Hirst

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

All correspondence should be sent to:

Ruth Hirst

Doctorate in Clinical Psychology
Faculty of Health and Medicine
Health Innovation One
Sir John Fisher Drive
Lancaster University
Lancaster
LA1 4AT
r.kitchen@lancaster.ac.uk

Abstract

Purpose

To understand experiences of a spousal caregiver of stroke during the Covid 19 pandemic.

Methods

Two semi-structured interviews explored a spousal caregiver's experiences across the pandemic. The first interview was shortly after England's lockdowns ceased, the second, 14 months later. Results were analysed using Interpretative Phenomenological Analysis (IPA).

Results

Overarching and superordinate themes identified were The pain of reality: "Life just changed vs Everything just stopped"; "Everything is gone" - loss and isolation; Control and entrapment: "I'm trying to keep us going here!" - systemic impact; "We're not the greatest unit" – marital discord; Hope and growth - "He's incredible! That bit that really hasn't been affected by his stroke"; "I've got it in writing!" - subjugation towards empowerment.

Conclusion

The pandemic restrictions on movement triggered a period of cognitive processing within the caregiver, confronting the painful reality of stroke impacts upon her life and family unit. This ultimately appeared to facilitate posttraumatic growth. Caregivers would benefit from psychotherapeutic support, training and couples therapy to adapt to post-stroke changes. The importance of sustaining care-recipients' rehabilitative support during a pandemic was also highlighted.

Introduction

Covid 19 Pandemic

The first recorded outbreaks of coronavirus (Covid-19) occurred in December 2019 in Wuhan, China [1]. Spreading quickly across the world, it was declared a pandemic by the World Health Organisation on March 11th, 2020 [2]. Covid-19 is a highly contagious form of SARS, Severe Acute Respiratory Syndrome; the initial strain of the virus attacked lower respiratory airways resulting in a distinctive, severe form of pneumonia [3]. To date, over 628.5 million confirmed cases and over 6.5 million deaths occurred globally [4], however mortality was complicated by ceilings of care, age, pre-morbid conditions and a lack of physical and human resources at the peak of the outbreak [5].

Initial efforts to contain the spread of the virus involved severe restrictions on gatherings and movement of citizens. Social distancing measures were enforced that banned public transportation, closed workplaces deemed ‘non-essential’ and imposed physical distances of 2 metres between humans not residing in the same household [6]. Many countries imposed ‘lockdowns’ prohibiting people from leaving their homes unless purchasing essential foodstuffs, serving medical needs or because they were classed as ‘essential workers’; the UK also permitted citizens one daily form of exercise outdoors per day [7].

Pandemic caregivers

The UK, along with many other countries, saw marked inequities in Covid-19 death tolls. Elevated mortality rates were observed amongst elder citizens, ethnic minorities and people with comorbid conditions such as cardiovascular disease, respiratory disease, cancers and autoimmune conditions [8]. Groups considered ‘clinically vulnerable’ were urged to take extra precautions to shield from Covid-19 [9]. Stroke-experienced citizens were regarded as clinically vulnerable which had significant implications for informal carers [10]. Secondary caregivers, unless already resident, were unable to enter care-recipients' homes, primary caregivers were advised to observe extra shielding measures to protect care-recipients; thereby magnifying and lengthening caregivers' isolation by proxy [11,12].

Whilst lockdowns proved effective in stemming the spread of coronavirus, widespread fiscal and psychological costs were reported [13]. Evidence indicates trained frontline care professionals experienced mental health difficulties, long- and short-term, arising from pandemic experiences [14] revealing a need to explore *untrained*, informal caregivers' experiences and potential impacts upon *their* psychological, economic and/or social wellbeing etc.

Informal caregivers

The UK's health and social care systems rely upon informal caregivers to fill gaps in provision. Stroke caregiving can be complex and there is no acclimatisation to caregiving; unlike degenerative conditions such as dementia or Parkinson's disease, stroke strikes suddenly and 'turns lives upside down' [15]. The outcomes of stroke are wide-ranging, dependent upon the location and extent of acquired brain injuries [16]. Where strokes are survived, they can cause permanent physical disability, cognitive and speech impairments, temperament changes, and psychological difficulties; all requiring different knowledge and skillsets which can overwhelm the untrained caregiver [17].

The cost of UK stroke care is estimated to reach £75billion by 2035, 62% of this figure comprises care provision from unpaid, informal carers [18,p.12]; usually family members. However, costs for informal caregivers can be substantial; studies indicate potential detriments to physical, financial, social and occupational health, spousal relationship quality and psychological wellbeing [19,20].

Stress Vulnerability

The World Health Organisation stated the pandemic was ‘generating stress throughout the [global] population’ [21]; with additional stressors around care-recipients’ clinical vulnerabilities, alongside being potential transmission sources, caregivers’ lockdown stress and anxiety may have been elevated [22].

The Stress Vulnerability model [23] proffers a lens through which to reflect upon the potential impact of a pandemic on caregivers. Stress acts upon an individual’s physical and psychological systems and can relate to life events, (a pandemic), or ambient stressors (lockdown restrictions, caregiver health etc) [23-27]. ‘Vulnerability’ refers to the individual’s ability to withstand stressors and relates to innate physiological characteristics such as genetic inheritance and acquired vulnerability, such as an accumulation of traumatic life events [23-27]. All stroke caregivers experienced a loved one’s stroke-event, however some may have additional vulnerabilities (and/or protective factors) acquired through other events or innate physiology. The model’s focus on generic vulnerability risks negating the nature of the actual harms; a stroke and a pandemic [28]. Similarly, at a purely dichotomous level of interaction, it oversimplifies the role of individual differences and levels of resilience [29]. It is important to consider societal contexts intersecting pandemic experiences [28]; for example, a caregiver furloughed from low-paid work, living in overcrowded conditions may encounter more stress and/or vulnerability. However, the model’s widescale use and applicability within caregiving and health research makes it useful for this context [29-33].

Vulnerability-Stress-Adaptation Model of relationships

Spousal relationships can undergo significant changes post-stroke which can impact relationship quality [34-36]. Where many theories investigating marital stability focus on interpersonal factors [37-40], this negates fundamental relationship influences such as attachment style, personality traits [41,42] and stressful life events [43,44]. Studies have found experiences of stressors can be mediated by adaptations rooted in physiology, social influences, cognition, personality and/or other relationships [45-48]. The strength of applying the Vulnerability-Stress-Adaptation Model [49] to caregiver / spousal distress lies in how the framework accounts for these enduring vulnerabilities and stressors, it also proposes adaptive processes that may account for individual differences in marital dynamics and stability. Karney and Bradbury [49] posit that these factors are both independent and entangled; it is the interactions between them that constitutes the stability and quality of the relationship (figure 1). Where many models have predominantly relied upon white, middle-class samples, a US study found this model also applied to ethnically diverse, low income newlyweds [50]. Considering the additional stressors of the pandemic and vulnerabilities of stroke caregiving, accessible adaptive coping strategies could hold significant influence over the relational stability underpinning caregivers' roles.

[Insert figure 1]

Research suggests protective factors against caregiver strain include social contact, leisure activities, respite and occupational engagement [51-53]; components significantly curtailed by shielding. Face-to-face support group gatherings were prohibited, respite carers were a transmission risk, accessing psychologically resilient familial support became harder, consequently, caregivers' capacity to sustain self-care and connectedness diminished [54]. However, post-stroke coping research suggests that if mutual support and interdependence is maintained within the caregiver-care recipient relationship, stress can reduce [55]. Indeed, national disaster and posttraumatic growth research has found relationships can strengthen through adversity [24,56-58]. Research into prior SARS (Hong Kong) and Ebola (Uganda) epidemics and into war and conflict (Iraq) suggests this is facilitated amongst survivors [58-

60] and caregivers [60] through positive attitudes and appraisals around efficacy and potential impact, receptiveness to change and adaptation [58-60].

Literature searches reveal a lack of research into spousal caregivers' experiences of caring for their stroke-affected partner during national crises yet, with 1.3 million stroke survivors in the UK [61], they comprise a sizeable group amongst informal caregivers. Evidence-based guidance can support professionals in devising preventative responses, to identify potential longer-term risks to stroke survivors and their spousal carers, and understand concomitant demands on services.

Aims

This qualitative, single case study aims to explore in-depth how a spousal caregiver experienced caregiving during the Covid-19 pandemic to understand situations encountered, how services may lessen the impact of any difficulties in the event of a future pandemic and to ascertain potential longer-term consequences of pandemics on a spousal caregiver of stroke.

Materials and methods

Ethics

Ethical approval was granted for this study by the Faculty of Health and Medicine Ethics Committee (FHMREC) at the University of Lancaster. The participant provided verbal informed consent prior to each interview.

Research Design

This case study adopted an exploratory single case qualitative design whereby data was generated via two semi-structured interviews; shortly after lockdowns ended and 14 months later. Semi-structured interviews were chosen to enable the participant to introduce and expand upon their experiences within the guiding structure of an interview schedule. Interviews were video recorded, transcribed and then analysed using interpretative phenomenological analysis (IPA).

The case study design was selected as the pandemic was a novel, naturally occurring phenomenon that could not be separated from its context [62]; this research sought to learn something new rather than prove or disprove existing findings [63]. Case studies facilitate a depth of insight that reveal contextual, idiographic nuances often missed by larger scale studies [64] and, by adopting a longitudinal approach, it could reveal *how* and *why* the pandemic impacted the spousal caregiver (SCG henceforth) [65], alongside impact longevity.

IPA aims to facilitate in-depth analysis of personal lived experiences, rather than being guided by pre-existing theory [66]. It's explicit commitment to the idiographic makes it particularly suited to analysing a case study alongside its phenomenological roots which focus upon the individual's experience and meaning-making from their perspective [67]. Described as adept at analysing "complex, ambiguous and emotionally-laden" [68], it was felt particularly appropriate to the participant's novel context. It also operates a double hermeneutic approach, thereby accounting for the researcher's interpretation of the participant's sense-making of their own experience [69]. The unique time, place and circumstances within this case study, may limit the scope of directly transferable findings however, individual accounts are performative [70] and can inform systems and policy when approaching future health epidemics.

Quality Assurance

To sustain quality and rigour in the analysis, the researcher sought to engage with experiential and existential aspects of the participant's account and, convey the narrative by carefully selecting quotations to develop depth and reveal any interconnectivity between themes and subthemes [71]. Close attention was also paid to convergences and divergences both within and between the interviews by analysing the data collected in three distinct stages.

Recruitment

A broad range of potential recruitment sources were engaged to reflect the closure of NHS recruitment routes during the data collection time. Independent carer support groups and the Stroke Association's research department were contacted, and the advertisement was posted on social media platforms Twitter and Facebook. The advertisement directed potential participants to a Qualtrix online survey which began with a statement of participant information. Following this, a series of open and multi-choice questions were posed to gather demographic information, contact details and to screen volunteers against inclusion and exclusion criteria.

Participant

[insert table 1]

Data Collection

Inclusion and exclusion criteria were selected to ensure research aims could be met by the research [72]. The participant needed to be the primary caregiver, in an established relationship with the stroke-affected care-recipient (SACR henceforth), English-speaking and cohabiting during the pandemic in England. The SACR's stroke needed to have happened prior to the pandemic and not be comorbid with other conditions such as Alzheimers or Parkinsons which could elicit care needs unrelated to the stroke. The researcher contacted the participant by email, with pdf versions of the information sheet and a consent form appended, to arrange an online interview in accordance with the participant's stated preference.

Interview domains within the schedule were informed by a review of literature on familial caregiving and discussion with a Consultant Neuropsychologist working in stroke care. It encompassed pre, during and post lockdown caring responsibilities, occupational, social and family life, mental health and aspects of support and coping.

Electronic versions of the participant information and consent form were emailed before the online interviews, and each interview commenced by gaining explicit informed consent. The researcher read out the consent form for the participant to give verbal affirmation. She was then given the opportunity to ask questions and reminded of her rights regarding withdrawing her data. At the end of the initial interview, July 2021, the participant agreed to a follow up interview; this was conducted 14 months later in September 2022 following the same process. The interviews lasted 120 minutes and 100 minutes respectively, all data was password protected and stored on a secure network.

Data Analysis

Interviews were video recorded and transcribed verbatim by the researcher after each interview. Interviews were replayed, and transcriptions reread, multiple times to become familiarised with the content. Immersion in the transcript was structured into distinct stages, recorded on separate spreadsheets, to support the iterative nature of IPA analysis; initial coding annotations to focus attention on content of value to the research question [73], then data sorted into clusters of notations on similar issues. Issues were colour coded to support filtering and commentary written to provide an audit trail for coding decisions.

Each cluster of notes were taken in turn to construct an extended narrative that explained and interpreted the nature of the theme, after which the theme was assigned an informative title and assigned illustrative quotations from the transcript to evidence the narrative [73].

The analysis was carried out in three stages; both interviews were analysed independently and separately immediately after data gathering, enabling analysis to offer insights into how the participant was making sense of their experience, at that timepoint and in that context. Subsequently a third analysis was conducted combining both transcripts, with particular attention paid to convergence and divergence between scripts, to construct themes emerging across the full timeline; thus. reflecting the iterative process of interpreting the participant's sense-making over time. Each stage was reinforced via discussion with two external researchers to facilitate critical thinking and synthesis.

Researcher positioning

The researcher is a middle-aged, white female with historical experience of being a young carer for family members during adolescence.

Reflexivity and epistemological stance

IPA guidelines encourage a smaller sample of participants [73]; the researcher chose to apply IPA to a single case study because it was considered most appropriate means of responding to the research aims. The researcher sought to understand the phenomena of caregiving during the pandemic across timepoints. The shared novelty of experiencing a pandemic also gave impetus to attend to the double hermeneutics. IPA offered an established, systematic approach to achieve this and to interpret the idiographic experience of the participant [74].

Taking the epistemological stance of critical realism, the researcher was alert for interactions between the participant's previous life experiences, living situation, culture etc, and her sense-making of the pandemic lockdown [75]. With multiple dynamics present, there would be no definitive, objective reality; her reality was conditional to the interaction between these dynamics [76,77]. The idiographic approach can offer insights which may, when collated with other research, facilitate a ‘general structure statement [that departs] from the specifics of individual experiences to communicate the most general meaning of the phenomenon” [78,pp52], i.e. SCGs’ experiences of the pandemic.

The researcher’s personal reflexivity was maintained through a reflective journal and supervision; enabling critical reflexive questioning of self and from others, to construct the realities of an ‘other’ during the analysis [79].

Results

Context

This case study sought to understand the experiences of a SCG caring for a SACR during the Covid 19 pandemic. Sasha and Enzo (pseudonyms) met after relocating to England from different countries in mainland Europe for work; they married following a short courtship.

They were 10 years married with two young sons when Enzo had a haemorrhagic stroke, aged 40, at his local gym, two years prior to the Covid-19 pandemic. Enzo’s primary post-stroke difficulties were physical; after discharge, supported by workplace adjustments, he returned to working full time in a desk-based position. However, Enzo’s poor balance, laboured mobility, loss of dexterity in his right hand and peripheral vision loss meant Sasha assumed all household and familial responsibilities, alongside working part time and caregiving for Enzo. At the time of the first interview, two months after coronavirus-related legal restrictions were lifted in England, Sasha had been a SCG for two and a half years, had experienced three national lockdowns and an additional two and a half weeks of location-specific lockdown restrictions [80,81].

Themes

Three overarching themes were identified, incorporating six superordinate themes.

[insert table 2]

Theme 1: The Pain of Reality

The enforced hiatus of lockdown emerged as a significant focus of Sasha's commentary. Although an experienced SCG of 2 years, when lockdown commenced the usual distractions of daily living disappeared. Sasha appeared to find herself confronted with a painful reality.

"Life just changed vs Everything just stopped"

The experience of normal life stopping during lockdown, appeared to contrast with the upheaval of the changes induced by the stroke; this theme of stopping and changing was apparent across the interviews.

> And then one day, out of the blue he just had a stroke at the gym […]. Yeah, life just changed.[…] then with Covid happening everything just stopped.[…] (i1)

> Sasha perceived the extent of changes in Enzo since the stroke event to lockdown.

> We had this super healthy guy; muscly, super healthy, cycling to work, gym five days a week[…] He's gone from being like a 40 year old, full of life person to...an 80 year old. (i1)

An unusual change in Enzo's eating habits during lockdown appeared to create concern for his health.

> His cholesterol is high […] but he's not improving his diet (i1).

> He became obsessed with food. Like obsessed! He was really into burgers […] then it was Italian food[…] it was so strange. (i2)

Over the course of the study, Sasha's concerns evolved as she noted his diet-induced weight gain was reversing previous functional gains.

> …made him gain a lot of weight. Uh, which obviously makes life harder for him, you know, climbing in to take a shower[…] picking something up from the floor. All these things become more difficult for him and he can't walk as well…it's frustrating (i2)

Lockdown meant that Sasha had to stop some of the activities that seemed to assist with caregiving by offering an escape.

> I would do like a trip a month where I would stay overnight and it would be like my 'Me time', time to 'just be'… it was so lovely. And then everything just stopped and we were all stuck under one roof. (i1)

She was also furloughed from work, something Sasha seemed to perceive as another escape.

> It's been hard not to have that little time to get away and also to be around people […] That's the thing that I really enjoy about my job. (i1)

Lockdown meant services were closed and Enzo was unable to access rehabilitation appointments. For Sasha this represented a barrier to the "many things that he was doing, trying to get better.[…] So it was a huge set back" (i1). Sasha also missed witnessing signs of functional improvements during rehabilitation sessions; something that seemed a source of hope and joy.

> I used to go with him [to rehab sessions] […] And it was just so nice to see how, you know, how he changed.[…] I didn't know he was capable of doing all these things. […] I was like 'oh my goodness', like 'this is good!'(i1)

Conversely Sasha perceived an end to Enzo's motivation for rehabilitation during lockdown, as he opted against exercising from home. "Our neighbours gave us their exercise bike. Never been used. Still in the garage. […] There's zero motivation for anything. Nothing at all.(i1)" Sasha conveyed a frustration in Enzo's reluctance to reengage in rehabilitation when services reopened.

> That is the crazy thing, but he doesn't, he doesn't seem interested in improving his health. (i1)

> If he could get some motivation back, that would be huge. Yeah. just to see that, you know, that drive in him (i2)

For Sasha, Enzo's lack of motivation appeared to be a lasting, yet unwelcome, change that stood in the way of the potential for change that she *would* welcome.

"Everything is just gone" – loss and isolation

Loss appeared in numerous forms across the interviews, seemingly starting with the loss of freedoms entailed by lockdown.

> I couldn't go to the gym. I couldn't, uh, go away for work. I couldn't, you know, everything was so restricted. […] Yeah, it was a bit like prison to be honest (i1)

Beyond lockdown, loss appeared through an expressed sense of imprisonment by circumstances of aging, caregiving and the physical environment,

> I'm getting close to 50 as well. I'm like 'My God, is this just gonna be my life?! I'm always gonna be looking after him and stuck in this flat? (i2)

Sasha's difficulties during lockdown seemed to trigger thoughts of loss through bereavement.

> It's just uh, even more of a reminder of my mom (voice breaking) not being here anymore. If I'd had her, um, it would have been different […] Yeah, she was my rock (i1).

Support from other family and friends appeared more accessible pre-lockdown, despite living abroad "I can definitely call them whenever and they always listen and support" (i1). However Sasha expressed difficulties calling them during lockdown through a perceived lack of privacy.

> "Because he was always here, I didn't feel like we could speak, even though he doesn't understand [language]" (i1).

She also appeared less able to access Enzo, sensing him withdrawing. "When his day was finished, he just shut down (voice cracking) and, very quiet[…] Strange times" (i1). This appeared to worsen over the course of the study. "He has his headphones on, iPad. It's on 24/7 […] I'm talking to him and he doesn't hear it, hear me. He just shuts everything out basically." (i2)

Sasha recalled the impact of her isolation on her mental health as lockdown took its toll. "I had days where I didn't even want to be around any more.[…] Everything was just like climbing a mountain.(i1) At the end of the study, Sasha believed her mental health had continued to be "a little bit rubbish"(i2).

Theme 2: Control and entrapment

A theme of entrapment emerged with lockdown evoking a sense of feeling trapped.

> There was no place to go really. The children have the YouTube on and games or the homeschooling and he (Enzo) was in [the bedroom] working, and so I just felt a bit trapped. (i1)

Whilst recounting circumstances and marital dynamics specific to Sasha's relationships, the interplay of external entrapment through lockdown, and the ensuing impact on escape and avoidance coping strategies, appeared to expose and amplify existing vulnerabilities within the family unit. In Sasha's case, a theme of control emerged within their relational dynamics.

"I'm trying to keep us going here!" - systemic impact

Sasha appeared to tussle with maintaining a calm environment for the family considering Enzo's stroke-related mood difficulties and disinhibition.

> …even with his Dad, he gets so, he gets so angry with him. Just like he can be with me and the kids.(i1)
>
> He has mood swings. Sometimes I just feel like, "Oh my God, I hate you". You know, like, he can be really like 'Argh!!'. (i2)

Efforts to maintain calm and control appeared to have evoked a growing split within the unit "it's me and the kids and then it's him; we're sort of divided" (i1). She reflected upon her attempts to reduce triggers to protect her children from his anger as potentially contributing to this; "I overcompensate. I hide things and I, you know, end up saying like 'kids let's not mention this to..' and they're like 'Ok. Ok'.(i1)

They also appeared to try to protect her from Enzo's outbursts "if he says anything to me negative in front of the kids, they're right up there defending me. And sometimes, if he gets very angry, they shield around me like (hugs arms across her body)"(i1)

Although Sasha noted an improvement in Enzo's outbursts post-lockdown "he doesn't shout at them much anymore...or he hasn't for a long time."(i2), it appeared to have a cost. Enzo left them alone "he's sort of in his own little bubble". However, Sasha noted the children then distanced themselves from Enzo "and, they don't know whether he's here or not most of the time.(i2) "If I wasn't there to tell him things about school and friends and he just wouldn't know anything."(i2) Moreover, the difficulties in her husband and sons' relationship had become problematic for Sasha's relationship with Enzo; "that's what sort of killed the romantic side, […] I can't relate at all on how you can be so disengaged from your children."(i2)

Conversely, Sasha noted her relationship with their children grew stronger, yet appeared concerned she may have become dependent on them. "I adore my boys.[…] I just really enjoy being in their company. But […] sometimes I feel I need them more than they, they need me. (tearful)"(i2)

'We're not the greatest unit' – marital discord

A sense of entrapment came through within the marital relationship, beginning with Sasha feeling unable to exercise over lockdown.

> I was out for 2 hours and I came back and I'm like 'oh I walked over down the river and la la la' and then he said, "well, that's something I can never do". […] That made it hard for me to then go out and do something 'cause I didn't want him to feel upset. (i1)

Sasha revealed "I really need to exercise in order to keep my mind intact"(i1) and confessed to exercising covertly. "I have the weights in the bedroom, so I had to sneak them out while he was working, so he wouldn't see me" (i1). A change in her job post lockdown meant “I don't exercise as much as I used to, uh, because of work. I really struggle to find the time” (i2).

Sasha changed her job “so I can drop the kids off, then I go to work and then I finish in time so I can go and pick the kids up. So it, it has made our lives easier”(i2). However, this also entailed a change in the balance of responsibility post-stroke, which Sasha appeared to feel went unappreciated.

> My workload has become a lot more. […] The only thing he does is go to work, I do everything else. But to him, that’s, that’s nothing because I didn’t have a stroke. (i1)

The imbalance in paid work also created an imbalance in financial control and disposable income. “I’m not earning enough money because I only work 50%, then I get a bit frustrated because I think that he could like, make my life a little bit easier, like you know. 'Buy me something sometimes'.(i2) It also appeared restrict Sasha’s freedom to be with [European] family, whereas she seemed to perceive his financial situation as comparatively freeing.

> I wanted to go to [home] over the autumn break and it's like, Oh my God, it's so expensive, I just can't do it. […] I'm always stuck here. When he's got a day off, he's out meeting friends, doing things. You know, he doesn't ask me if I have any plans, he just does what he wants to do. (i2)

Sasha discussed the lack of intimacy in her marriage post-stroke.

> We share a bed, but[…] we never kiss any more, like kiss ‘goodbye’, kiss ‘hello’, you know anything like that. When we tried to improve that, it’s always paired with ‘that’ (intercourse)…that sort of stops it. […] Even holding hands is hard, because when he’s walking it takes so much effort […] it’s hard for him to hold somebody’s hand. (i1)

Sasha presented as upset when she explained that she no longer wanted to be intimate with Enzo, but that a part of her would like to want to be intimate with somebody.

> (tearful) I don’t have that attraction towards him anymore. A friend of mine said that ‘maybe you don’t need to stay with him […] I do love him, we’re very good friends[…] But sometimes yeah, sometimes I do feel like it would be nice to, to fall in love again and… (cries) I guess I feel guilty. (i1)

With sharing a bed being the only remaining form of intimacy Sasha identified in her marriage, it was notable that this temporarily became unavailable during lockdown. Enzo initiated this through a refusal to wash.

> He wouldn’t shower any more, he stank. Yuck! It was awful. […] I felt bad like, ‘you stink, you need to..’ He was like ‘yeah, yeah I will’. But it could be like a week and he wouldn’t even take a shower. And it was so awful I couldn’t even sleep next to him.

Although showers and bedsharing resumed when he returned to his workplace, Sasha shared another reticence that she experienced within her relationship. “It gets quite a bit like, well ‘you have nothing to complain about’ because nothing can be as bad as what he’s going through. […]I feel like I can’t, I can’t complain.”(i1) Guilt appeared to both censor and entrap her as she reflected, “I could move away, and then I will feel guilt because I would know that he's on his own and he can't really take care of himself […]. So I can never get away from....'this'” (i2).

Theme 3: Hope and growth

Although there were challenges, lockdown also appeared to cast hope over her relationship with Enzo and initiate helpful growth within Sasha that had a positive impact on her life.

"He's incredible!... That bit that really hasn't been affected by his stroke"

Sasha began the first interview describing her early relationship with Enzo and conveyed an admiration as she recalled meeting him at work.

> "he would just switch language, like he would speak [foreign language] to one and [foreign language] to another. You know, he would just switch like that. And he was so knowledgeable about everything, that's his thing. He knows so much." (i1)

Although they had since changed jobs, lockdown appeared to offer her the opportunity to witness this side of Enzo again.

> I would overhear his conversations with his customers, and it was nice when they had the team meetings […] I really enjoyed that and I enjoyed hearing him. He's, he is incredible when it comes to work, he is incredible! (i1)

Sasha animation as she spoke conveyed admiration; she felt "so proud"(i1). It resonated with the joy expressed earlier as she talked of his functional gains in rehabilitation, however this appeared to symbolise a part of him that had never been lost, just obscured from view.

> It has been really, really nice to see that, that bit that really hasn't been affected by his stroke. I guess that's the only normal thing we have in a way.[…] You know, that's, that's him! (i1)

In those moments the strengths he *had* retained seemed to reveal ‘him’; pre-stroke Enzo. Sasha’s account of another work-related achievement appeared to concur with this and continue that connection with hope.

> So that's [Enzo]! When he sees something, and he really believes in it, he's like ‘I'll sort it out, we'll sort it!’ So we have little golden moments in all the hard times as well, and that's what keeps us going. (i2)

“I’ve got it in writing!” - subjugation towards empowerment

Woven within previous themes was evidence of Sasha’s subjugation such as covertly exercising, suppressing her intimacy needs and reducing her disposable income to pick up additional workload at home. Sasha’s first interview also revealed that, pre-lockdown, she subjugated her need to share her feelings with a local friendship group to protect Enzo’s reputation.

> I don’t want them to, sort of, think that [Enzo] is not a nice person. […] I’m more comfortable speaking to [European contacts]. They don’t judge the same way ‘cause they know him quite well. Friends I have here, they don’t know him so I don’t have huge support (i1)

Post-lockdown a new resolve to recognise and value her own needs seemed to emerge. A significant enabler and catalyst seemed to be a group of School Mums she met post-lockdown.

> I can't keep things in, I can't suffer in silence, I just can't. I used to be like that and then I had a friend who was very open. I thought, 'Oh my God, how could she share so many things?!' Like I was so jealous. […] Somehow it rubbed off and now I'm quite open with how I'm feeling (i2)

This radical change, appeared to bring Sasha belonging, validation and a valuable support network.

> I get so much help through that, just by sharing how I'm feeling and then 'has this happened to anyone else?' and they're like. 'Oh yeah!'. And then it's like, 'Oh my gosh, it's not just me!' (i2)

Sasha also seemed more assertive about her needs with Enzo at home; an example of this was securing his agreement to buy a new kitchen.

> I had begged him, like, can we not get new kitchen? Can we not get new kitchen? And he says, 'No, No. That costs money'. But because I'm the one that has to do everything, I have to clean up everywhere, I have to take care of everyone, then I'm like 'the least you can do for me is to get me a new kitchen'. Like 'show me that you, that you appreciate what I'm doing' […] But um I am getting a new kitchen! Yeah, I am! I have it in writing! (chuckles) (i2)

Perhaps most significant was Sasha making serious enquiries into relocating [to Europe]; this entailed assertive discussions with Enzo.

> I really looked into moving to [Europe] […] you have to find a place to live and you know, I have to get a job. Where do I start?! And when you have kids as well, schools and where to live. I was really set on going and, and I said to [Enzo], 'I will go without you. I, you know, I'm going!'[…] And then, then it...then I calmed down (chuckles) (i2)

This conversation represents a momentous contrast to the Sasha secretly working out during lockdown to avoid offending Enzo.

Discussion

This study has illuminated the considerable psychological and occupational burden spousal caregiving for stroke entails, and how the additional stressors of the Covid-19 pandemic may have exacerbated these. The themes emerging included a painful reality, control and entrapment and hope and growth. The analysis will be expanded upon and will outline the key findings with relevance to current evidence base, and recommendations from the study.

Painful reality - Change

The onset of the pandemic resembled stroke onset; sudden, unexpected and often outside the control of those most directly impacted. Perhaps unsurprisingly, lockdown measures were also linked to adjustment difficulties, especially amongst those with parenting responsibilities, like Sasha, and mental health vulnerabilities [82,83].

Sudden, unknown changes, such as stroke events, commonly evoke a fight or flight response and deployment of coping mechanisms [84]. Sasha seemed to have developed avoidant coping mechanisms (e.g. working and weekends away) or expending arousal levels through exercise, whereas Enzo appeared energized to recover functional losses through rehabilitation and occupational resumption. Lockdown-induced distress may therefore have been exacerbated from habitual coping mechanisms being curbed.

Stroke caregivers research identifies effective coping methods to include social contact, occupational engagement, leisure activities and accessing respite [51-53,85], however these were directly impeded by lockdown and distancing measures. Sasha described challenges exercising and utilising her online social support network and being furloughed; for Enzo his access to rehabilitation services ceased. Distress can manifest in increased perceptions of burden [86], which would be more keenly felt by SCGs alongside emotional responses such as anger, anxiety and low mood [85] (evident in both Sasha and Enzo). This can offer insight into the reports of elevated mental health difficulties amongst pandemic caregivers' as compared to non-caregivers [87,88].

Family support

Results highlighted Sasha's avoidant post-stroke coping strategies, alongside shielding her children from the realities of the stroke-event and post-stroke changes, and how this may have contributed to familial stress vulnerability. Research suggests the impact of change on family units depends upon interactions between familial resources to cope with the change, and their perceived ability to cope with the challenge posed [89]. Potential problems can occur in the event of 'pileup'; when new stressors (such as a pandemic) occur without previous stressors having been worked through to a point of coping [90]. Stroke events can generate many stressors; traumatic experiences around the event, co-morbid conditions, acquired disabilities, changes in finances, familial roles etc. [16,19,91], thus if psychological and practical adjustments are not secure, this vulnerability to 'pileup' may partially account for difficulties reported by SCG's during lockdown [87,88].

When facing crisis, Boss' [92] Family Stress Theory suggests families are pushed towards change, reorientating towards the previous status quo, a better, or a worse state of functioning compared with their pre-crisis situation [92]. This impetus for change was apparent in Sasha's second interview through actions such as developing her local social support and exploring relocation nearer to extended family and leaving Enzo. This highlights a need for standard service provision to include psychological support to re-establish family stability post-stroke; proactive support to process stroke-events and outcomes and readjust could reorientate a family and enhance future resilience.

Loss and Isolation

Sasha communicated a strong sense of loss regarding post-stroke Enzo. Lockdown appeared to focus attention on his functional losses (exercise habits), physical attributes (weight gain) and their lack of intimacy, fuelling rumination *across* loss experiences including her Mother's death. Research into familial carers of cancer patients found that highly stressful events can trigger a 'magnifying glass' being cast over past experiences which can shape experiences and perceptions of the present [93]. Indeed, research by Williams [94] conceptualised social isolation, itself, as a loss in terms of interactions, income, structure which resulted in losses in meaning, self-worth and motivation; this may have facilitated a cognitive priming for loss schema [95-98].

Covid research findings suggest that ongoing exposure to the media drawing attention to negative aspects of lockdown, had the potential to undermine perceptions of coping self-efficacy amongst trauma experienced persons [99]; research would regard Sasha as trauma experienced and susceptible to this dynamic [91,100-103]. Whereas psychological distress amongst professional caregivers is mediated through training and professional support [103]; informal caregivers are often cited as lacking such input in 'normal' circumstances let alone during a pandemic [104]. Collegiate support and interprofessional working supported resilience during Covid [105-108], however 1 in 5 care recipients were unable to access formal support, resulting in unmet care needs causing greater anxiety than mortality rates [109], the lack of respite for caregivers responding to this, heighted *their* anxiety. Pandemic stress was found to be interactional, with caregiver stress predicting symptoms in care recipients and vice versa, however their usual support system was diminished by social distancing [110]. Particularly stress-triggering behaviours stroke caregivers encountered included disputing topics, impatience, over sensitivity or dependency, mood changes and frequent complaining [111]. However, cumulative fatigue and lack of respite for those with high-needs care recipients, such as complex stroke and dementia, are reported to have suffered the most extensive care burden and distress [112].

Spousal relationships

Whilst the impact of Covid on relationship breakdowns is inconclusive [113-116], the pandemic impacted upon levels of relationship satisfaction for many couples [117-121], with pre-Covid relationship quality and marital communication mediating stress levels [122-124]. Sasha’s account suggests her marriage endured considerable stress, describing a ‘prison’ of managing home-schooling and noise, subjugating her need for space, social contact and exercise to maintain familial functioning for a seemingly uncompromising spouse.

SCG experiential differences may be accounted for by the Vulnerability Stress Adaptation Model [49] which suggests that the impact of pandemic-related stressors like social isolation, bereavements or economic difficulties, could be shaped by enduring vulnerabilities and/or adaptive processes within the relationship [125]. Findings suggest that enduring vulnerabilities may make relationships more susceptible to pandemic stressors, related to attachment insecurity, emotional health and regulation difficulties and previous trauma/adversity history [125]. Research focused upon caregivers of cancer found that childhood trauma and relationship history were the two domains most pertinent to the impact of caregiving upon marital stability and quality [126].

Research into caregiving adaptive processes that supported relationships during Covid included affection, support, and shared positive activities [126]. Cancer caregiver research found that love/closeness, communication, intimacy and a shared future were adaptive in spousal caregiver relationships [93]. Many of these adaptive processes appeared diminished within Sasha and Enzo’s post-stroke relationship. The cumulative effect of both Covid and generic caring responsibilities may account for individual differences encountered, however, specific research into vulnerability and adaptive domains within stroke caregiving that may better elucidate pandemic experiences, could not be found.

Although the Vulnerability-Stress-Adaptation model is helpful in conceptualising the dynamics contributing to marital discord, stroke-specific outcomes may introduce other dynamics within and/or acting upon the model's structures. For example, stroke can impact communication, fatigue levels and mood stability as well as mobility and speech clarity [16]; this could introduce novel or nuanced processes and dynamics that warrant attention.

Growth

Calhoun and Tedeschi coined the term 'posttraumatic growth' (PTG) as something that arises from seismic psychological challenges that, whilst not always life threatening, are enough to challenge or disrupt someone's internal assumptive world [127]. Sasha's expressions of 'is this gonna be my life now?!' in interview 1 suggest conscious deliberations concerning the impact of Enzo's stroke on her circumstances. PTG involves acceptance that a return to 'normal' is not possible, which leads to positive cognitive and emotional shifts and can inspire behavioural changes [128-130]. Stroke-events can entail the permanent shifts in 'normality' [131-133] that was arguably paralleled by the pandemic [134-136], thereby generating the seismic challenges and a dual impetus for cognitive processing.

Painful experiences can incite an instinct to escape and avoid; a strategy found more prevalent amongst females [137] and something Sasha relied upon post-stroke. Restrictions on movement during the pandemic impeded her weekend escapes, occupational distractions and efforts to avoid familial conflict; however, as these coping strategies prevent acceptance and resolution of difficult realities, this may have been helpful in reducing stagnation and/or potential longer-term anxiety or depressive symptoms [138].

Sasha’s account indicated considerable distress levels, including suicidal ideations, as she processed her new reality. Research concurs that PTG can often be experienced alongside post-traumatic stress (PTS) symptoms, with research indicating that moderate PTS most likely to lead to the highest rates of PTG [139-142]. Research into frontline pandemic nurses in NYC suggested that over 75% experienced PTG particularly relating to perceptions of being strong, improved relationships with others and appreciating life; those reporting the greatest PTG scored highly for PTS in the initial month of the pandemic [143]. As a sole carer, Sasha had no access to collegiate relationships, restricted access to her online support network and her primary adult relationship became a stressor which could account for her elevated distress during this process.

Findings suggest that PTS symptoms can compel the depth of cogitation and reflexion to process the traumatic memories that is necessary to facilitate growth [144-146]; escape and avoidance are ineffective long-term. Indeed, Sasha’s second interview conveyed shifts in acceptance, determination and assertion around her needs, however her mental health remained ‘a little bit rubbish’. Adaptation to changes incurred through stroke and/or crises appear to require an investment in confronting and learning to accept the new normal, however the complexities of this process for someone who faces both situations reveals a clear role for both preventative and recuperative professional psychological support.

Strengths and Limitations

Single case study design enables in-depth exploration of complex phenomena, such as a pandemic. This can support development of service provision and health care interventions and identify areas for further research. It is both a flexible and rigorous research method for exploring contextual conditions of the phenomena and accessing a participant’s reality within this context so that their actions, thoughts and feelings can be understood. The research process was supported through reflective journals and supervision to preserve an inductive approach. The data was also analysed and coded in three stages at separate timepoints. Each interview was analysed separately, directly after taking place; a third analysis, incorporating both interviews, was then completed to elucidate the themes across the timescale.

This research gathered data as the pandemic unfolded, thus provides more 'live' reflections upon experiences and detailed insights into challenges faced. Its longitudinal approach enables differentiation between temporary and potentially long-lasting effects. Presenting one individual's experiences means findings cannot be easily generalized, however humans are not universal. Whilst precise relational dynamics within this case may not be directly transferable to other stroke caregiving couples, the broader challenges around intimacy, communication and mood disinhibition are apparent across established stroke research [36,147,148].

Recommendations for further research

Research into biopsychosocial models of adaptation amongst the brain injured is limited [149]; initial searches suggest the Vulnerability-Stress-Adaptation model has not yet been applied specifically to stroke. Understanding how the wide-ranging potential stroke-outcomes e.g. communication, motor and/or cognitive impairments, may complicate or interact with relational dynamics, or otherwise respond to adaptive processes, warrants further investigation to bolster SCG-SACR relationship quality and stability.

This case study illustrates a gap and impetus for SCG psychological support. Stroke can entail trauma and significant adjustments for the wider family, especially the SCG. This study reveals potential benefits and growth from psychological processing and reflection, whilst also revealing prospective strains and risks of doing this in isolation. Research into psychological interventions targeting SCGs at different points post-stroke could ascertain impactful approaches, timepoints and identify specific needs and/or benefits of SCG support. A similar approach to investigate couples and family therapeutic support could ensure resources are deployed to maximum benefit.

Recommendations for services

This study reveals key roles for services in providing psychological support for SCGs targeting loss, adjustment, low mood and anxiety. It is recommended that this is a standard offer for all SCGs to access. Similarly, therapeutic support targeting relationships may be helpful in reorientating couples following, often significant, stroke-induced changes; this should include relational and sexual intimacy support.

This study highlights the role of rehabilitation services in sustaining the motivation of care-recipients, which can enhance their family's quality of life. In the event of another pandemic, some service provision should be maintained; online delivery methods could be developed to achieve this.

SCGs could benefit from understanding the needs, behaviours, rehabilitation, and recovery trajectories of their stroke-affected spouse. Stroke professionals access ongoing training to develop their skills; unpaid carers could also achieve this cost-effectively via a centralised online training resource bank.

The recruitment process for this study suggested support groups for stroke carers are not well advertised and, due to being time-poor, SCGs are not always able to research or attend them. A centrally collated directory of rehabilitation and support networks for face-to-face and online access may be helpful for SCGs.

In the event of future national emergency, careful consideration should be given to finding ways of sustaining caregivers' access to practical, emotional and social support. Technological advances have opened up new opportunities to offer this remotely, however care needs to be taken to ensure provision can be accessed by all regardless of education, income and housing circumstances.

Conclusion

This case study gives an individual SCG's account of their experiences during the global Covid-19 pandemic. It demonstrates how pervasive the impact of stroke and caregiving is across all facets of life and the baseline stress vulnerability accumulated through everyday living. The pandemic cast a spotlight over post-stroke challenges that had been previously downplayed in day-to-day life evoking a difficult and distressing phase of processing the changes, losses, and systemic impact on the SCG's life. However, this process facilitated posttraumatic growth, offering future hope and empowerment. The essential role of rehabilitation for SACRs and the need for psychological support, stroke-specific information and training amongst SCGs, and their marital and family units, were identified.

References

1. Ciotti, M., Ciccozzi, M., Terrinoni, A., Jiang, W. C., Wang, C. B., & Bernardini, S. (2020). The COVID-19 pandemic. *Critical Reviews in Clinical Laboratory Sciences*, *57*(6), 365-388.
2. Cucinotta, D., & Vanelli, M. (2020). WHO declares COVID-19 a pandemic. *Acta Bio Medica: Atenei Parmensis, 91*(1), 157.
3. Volpicelli, G., & Gargani, L. (2020). Sonographic signs and patterns of COVID-19 pneumonia. *The Ultrasound Journal*, *12*(1), 1-3.
4. World Health Organisation. (2022, November 4). *WHO Coronavirus (Covid 19) Dashboard.* Retrieved November 6th, 2022. https://covid19.who.int/
5. Vincent, J. L., & Taccone, F. S. (2020). Understanding pathways to death in patients with COVID-19. *The Lancet Respiratory Medicine*, *8*(5), 430-432.
6. Douglas, M., Katikireddi, S. V., Taulbut, M., McKee, M., & McCartney, G. (2020). Mitigating the wider health effects of covid-19 pandemic response. *BMJ, 369.*
7. Greig, F. (2020, April 9). *Coronavirus exercise rules explained: everything you can and can't do to keep fit outside during the UK lockdown. iNews*. https://inews.co.uk/inews-lifestyle/wellbeing/exercise-coronavirus-outside-uk-rules-coronavirus-lockdown-explained-416681
8. Williamson, E. J., Walker, A. J., Bhaskaran, K., Bacon, S., Bates, C., Morton, C. E., Curtis, H.J., Mehrkar, A., Evans, D., Ingelsby, P., Cockburn, J., McDonald, H.I., MacKenna, B., Tomlinson, L., Douglas, I.J., Rentsch, C.T., Mathur, R., Wong, A.Y.S., Grieve, R., Harrison, D., Forbes, H., Schultze, A., Croker, R., Parry, J., Hester, F., Harper, S., Perera, R., Evans, S.J.W., Smeeth, L., & Goldacre, B. (2020). Factors

associated with COVID-19-related death using OpenSAFELY. *Nature*, *584*(7821), 430-436.

9. Ioannidis, J. P. (2021). Precision shielding for COVID-19: metrics of assessment and feasibility of deployment. *BMJ Global Health*, *6*(1), e004614.
10. Stroke Association. (2022, December 7) *Information on coronavirus for stroke survivors*. [Factsheet]. https://www.stroke.org.uk/finding-support/information-coronavirus-stroke-survivors#:~:text=of%20Covid%2D19-,Stroke%20survivors%20and%20Covid%2D19,regular%20handwashing%2C%20and%20good%20ventilation.
11. Berg-Weger, M., & Morley, J. E. (2020). Loneliness and social isolation in older adults during the COVID-19 pandemic: Implications for gerontological social work. *The Journal of Nutrition, Health & Aging*, *24*(5), 456-458.
12. Hanna, K., Giebel, C., Tetlow, H., Ward, K., Shenton, J., Cannon, J., Komuravelli, A., Gaughan, A., Eley, R., Rogers, C., Rajagopal, M., Limbert, S., Callaghan, S., Whittington, R., Butchard, S., Shaw, L. & Gabbay, M. (2022). Emotional and mental wellbeing following COVID-19 public health measures on people living with dementia and carers. *Journal of Geriatric Psychiatry and Neurology, 35*(3), 344-352.
13. Atalan, A. (2020). Is the lockdown important to prevent the COVID-19 pandemic? Effects on psychology, environment and economy-perspective. *Annals of Medicine and Surgery*, *56*, 38-42.
14. Stuijfzand, S., Deforges, C., Sandoz, V., Sajin, C. T., Jaques, C., Elmers, J., & Horsch, A. (2020). Psychological impact of an epidemic/pandemic on the mental health of healthcare professionals: a rapid review. *BMC Public Health*, *20*(1), 1-18.
15. López-Espuela, F., González-Gil, T., Amarilla-Donoso, J., Cordovilla-Guardia, S., Portilla-Cuenca, J. C., & Casado-Naranjo, I. (2018). Critical points in the experience of

spouse caregivers of patients who have suffered a stroke. A phenomenological interpretive study. *PloS One*, *13*(4), e0195190.

16. NHS (2019). *Recovery: Stroke*. https://www.nhs.uk/conditions/stroke/recovery/
17. Lutz, B. J., Ellen Young, M., Cox, K. J., Martz, C., & Rae Creasy, K. (2011). The crisis of stroke: experiences of patients and their family caregivers. *Topics in stroke rehabilitation*, *18*(6), 786-797.
18. Stroke Association. (2017). *Current, future and avoidable costs of stroke in the UK* [PDF file]. https://www.stroke.org.uk/sites/default/files/current_future_avoidable_costs_of_strokesummary-report.pdf https://www.stroke.org.uk/sites/default/files/economic_impact_of_stroke_report_final_feb_2020_0.pdf
19. Greenwood, N., Mackenzie, A., Cloud, G., & Wilson, N. (2009). Informal primary carers of stroke survivors living at home–challenges, satisfactions and coping: A systematic review of qualitative studies. *Disability and Rehabilitation, 31*(5), 337-351
20. Kokorelias, K. M., Lu, F. K., Santos, J. R., Xu, Y., Leung, R., & Cameron, J. I. (2020). “Caregiving is a full-time job” impacting stroke caregivers' health and well-being: A qualitative meta-synthesis. *Health & Social Care in the Community, 28*(2), 325-340.
21. World Health Organization (2020, March 18). *Mental health and psychosocial considerations during the COVID-19 outbreak.* https://www.who.int/publications-detail/WHO-2019-nCoV-MentalHealth-2020.1
22. Alberta Critical Incident Provincial Network [ACIPN] (2020, April 7) *Coping with stress of COVID-19 for public safety personnel* [video]. YouTube. https://www.youtube.com/watch?time_continue=2868&v=IStpr3lsMG8&feature=emb_title

23. Zubin, J., & Spring, B. (1977). Vulnerability: a new view of schizophrenia. *Journal of Abnormal Psychology*, *86*(2), 103.
24. Brennan, G. (2005). Stress vulnerability model and serious mental illness. In C. Gamble and G. Brennan (Eds.) *Working with serious mental illness: a manual for clinical practice*. (pp. 29-39) Elsevier Health Sciences.
25. Simionescu, M., Pellegrini, A., & Bordea, E. N. (2021, May). The effects of covid-19 pandemic on stress vulnerability of nursing students according to labour market status. In *Healthcare 9*(6) pp. 633. MDPI.
26. Corrigan, P. W., & Nieweglowski, K. (2020). Peer-based education regarding the COVID-19 pandemic. *Journal of Psychosocial Rehabilitation and Mental Health*, *7*, 115-117.
27. Stuller, K. A., Jarrett, B., & DeVries, A. C. (2012). Stress and social isolation increase vulnerability to stroke. *Experimental neurology*, *233*(1), 33-39.
28. Demke, E. (2022). The Vulnerability-Stress-Model—Holding up the construct of the faulty individual in the light of challenges to the medical model of mental distress. *Frontiers in Sociology, 67*.
29. Quaedflieg, C.W.E.M., & Smeets, T. (2012). Stress vulnerability models. In *Encyclopedia of behavioral medicine* (pp. 1897-1900). Springer. DOI:10.1007/978-1-4419-1005-9_65
30. Kung, W. W. (2004). Causal attributions of schizophrenia by Chinese American caregivers. *Journal of Ethnic & Cultural Diversity in Social Work*, *13*(1), 37-57.
31. Nolan, M., & Petrakis, M. (2019). Delivering family psychoeducation at the mental health acute inpatient service: A practitioner narrative. *Journal of psychiatric and mental health nursing*, *26*(3-4), 101-107.
32. Baumgardt, J., & Weinmann, S. (2022). Using crisis theory in dealing with severe mental

illness: A step toward normalization?. *Frontiers in Sociology*, *7*, 805604.

33. Mazzarino-Willett, A., & Leveston, A. (2017). EOL clinician at work, EOL caregiver at home: Help is on the way! The dual-role caregiver vulnerability paradigm (TH367). *Journal of Pain and Symptom Management*, *53*(2), 343-344.
34. Gosman-Hedström, G., & Dahlin-Ivanoff, S. (2012). 'Mastering an unpredictable everyday life after stroke'–older women's experiences of caring and living with their partners. *Scandinavian Journal of Caring Sciences*, *26*(3), 587-597.
35. Kitzmüller, G., & Ervik, B. (2015). Female spouses' perceptions of the sexual relationship with stroke-affected partners. *Sexuality and Disability*, *33*, 499-512.
36. Schmitz, M. A., & Finkelstein, M. (2010). Perspectives on poststroke sexual issues and rehabilitation needs. *Topics in Stroke Rehabilitation*, *17*(3), 204-213.
37. Gottman, J. M., & Levenson, R. W. (1986). Assessing the role of emotion in marriage. *Behavioral Assessment 8. pp31-48*
38. Rusbult, C. E., Verette, J., Whitney, G. A., Slovik, L. F., & Lipkus, I. (1991). Accommodation processes in close relationships: Theory and preliminary empirical evidence. *Journal of Personality and Social Psychology*, *60*(1), 53.
39. Cutrona, C. E., Russell, D. W., & Gardner, K. A. (2005). The Relationship Enhancement Model of Social Support. In T. A. Revenson, K. Kayser, & G. Bodenmann (Eds.), *Couples coping with stress: Emerging perspectives on dyadic coping* (pp. 73–95). American Psychological Association. https://doi.org/10.1037/11031-004ort.
40. Jacobson, N. S., & Margolin, G. (2019). *Marital therapy strategies based on social learning & behavior exchange principles*. Routledge.
41. Bowlby, J., & Bowlby, R. (2012). *The making and breaking of affectional bonds*. Routledge.
42. Kelly, E. L., & Conley, J. J. (1987). Personality and compatibility: a prospective analysis

of marital stability and marital satisfaction. *Journal of Personality and Social Psychology, 52*(1), 27.

43. Conger, R.D., Elder Jr, G.H., Lorenz, F.O., Conger, K.J., Simons, R.L., Whitbeck, L.B., Huck, S., & Melby, J.N. (1990). Linking economic hardship to marital quality and instability. *Journal of Marriage and the Family*, 643-656.
44. Bodenmann, G., Meuwly, N., Germann, J., Nussbeck, F. W., Heinrichs, M., & Bradbury, T. N. (2015). Effects of stress on the social support provided by men and women in intimate relationships. *Psychological Science*, *26*(10), 1584-1594.
45. Contrada, R. J. (2011). Stress, adaptation, and health. In R. Contrada & A. Baum (Eds.), *The handbook of stress science: Biology, psychology, and health*, (pp. 1-9). Springer Publishing Company.
46. Story, L. B., Karney, B. R., Lawrence, E., & Bradbury, T. N. (2004). Interpersonal mediators in the intergenerational transmission of marital dysfunction. *Journal of Family Psychology*, *18*(3), 519.
47. McNulty, J. K., Meltzer, A. L., Neff, L. A., & Karney, B. R. (2021). How both partners' individual differences, stress, and behavior predict change in relationship satisfaction: Extending the VSA model. *Proceedings of the National Academy of Sciences*, *118*(27), e2101402118.
48. Fisher, T. D., & McNulty, J. K. (2008). Neuroticism and marital satisfaction: the mediating role played by the sexual relationship. *Journal of Family Psychology*, *22*(1), 112.
49. Karney, B. R., & Bradbury, T. N. (1995). The longitudinal course of marital quality and stability: A review of theory, methods, and research. *Psychological Bulletin*, *118*(1), 3.
50. Ross, J. M., Nguyen, T. P., Karney, B. R., & Bradbury, T. N. (2022). Three tests of the Vulnerability-Stress-Adaptation model: Independent prediction, mediation, and

generalizability. *Frontiers in Psychology*, *13*, 921485.

51. Adriaansen, J. J. E., van Leeuwen, C. M. C., Visser-Meily, J. M. A., van den Bos, G. A. M., & Post, M. W. M. (2011). Course of social support and relationships between social support and life satisfaction in spouses of recipients with stroke in the chronic phase. *Recipient Education and Counseling, 85*(2)
52. Luerbe-Puerto, K., Leandro, M.-E., & Baumann, M. (2012). Experiences of caregiving, satisfaction of life, and social repercussions among family caregivers, two years post-stroke. *Social Work in Health Care, 51*(8), 725–742
53. Pringle, J., Drummond, J.S., & McLafferty, E. (2013) Revisioning, reconnecting and revisiting: the psychosocial transition of returning home from hospital following a stroke, *Disability and Rehabilitation, 35(*23), 1991-1999, DOI: 10.3109/09638288.2013.770081
54. White, R. G., & Van Der Boor, C. (2020). Impact of the COVID-19 pandemic and initial period of lockdown on the mental health and well-being of adults in the UK. *BJPsych Open*, *6*(5).
55. Godwin, K. M., Swank, P. R., Vaeth, P., & Ostwald, S. K. (2013). The longitudinal and dyadic effects of mutuality on perceived stress for stroke survivors and their spousal caregivers. *Aging & Mental Health, 17(4),* 423–431.
56. Schaefer, J. A., & Moos, R. H. (1998). The context for posttraumatic growth: Life crises, individual and social resources, and coping. In R.G. Tedeschi, C.L. Park & L.G. Calhoun (Eds.) *Posttraumatic Growth: Positive Changes in the Aftermath of Crisis (pp99*-126). Routledge.
57. Riffle, O. M., Lewis, P. R., & Tedeschi, R. G. (2020). Posttraumatic growth after disasters. In S.E. Schulenberg (Ed.), *Positive psychological approaches to disaster: Meaning, resilience, and posttraumatic growth* (pp.155-167). Springer Cham. https://doi.org/10.1007/978-3-030-32007-2

58. Cheng, S. K., Chong, G. H., Chang, S. S., Wong, C. W., Wong, C. S., Wong, M. T., & Wong, K. C. (2006). Adjustment to severe acute respiratory syndrome (SARS): Roles of appraisal and post-traumatic growth. *Psychology and Health, 21*(3), 301-317.
59. Matua, G. A., & Van der Wal, D. M. (2015). Living under the constant threat of Ebola: a phenomenological study of survivors and family caregivers during an Ebola outbreak. *Journal of Nursing Research*, *23*(3), 217-224.
60. Mahdi, H. K., Prihadi, K., & Hashim, S. (2014). Posttraumatic growth and resilience after a prolonged war: A study in Baghdad, Iraq. *International Journal of Evaluation and Research in Education*, *3*(3), 197-204.
61. Stroke Association (n.d.) *Stroke statistics.* [Data set]. https://www.stroke.org.uk/what-is-stroke/stroke-statistics#:~:text=Stroke%20strikes%20every%20five%20minutes,stroke%20survivors%20in%20the%20UK
62. Baxter, P., & Jack, S. (2008). Qualitative case study methodology: Study design and implementation for novice researchers. *The Qualitative Report*, *13*(4), 544-559.
63. Eysenck, H. J. (1976). Introduction. In. HJ Eysenck. (Ed.) *Case Studies in Behaviour Therapy.* London: Routledge & Kegan Paul.
64. Flyvbjerg, B. (2006). Five misunderstandings about case-study research. *Qualitative Inquiry*, *12*(2), 219-245.
65. Yin, R. K. (2009). *Case study research: Design and methods (Vol. 5)*. Sage.
66. Smith, J. A., Flowers P., & Larkin M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. London: Sage.
67. Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and health*, *11*(2), 261-271.

68. Smith, J. A., & Osborn, M. (2015). Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain. *British Journal of Pain*, *9*(1), 41-42.
69. Smith, J. A., Flowers, P., & Larkin, M. (2022). *Interpretative phenomenological analysis. Second edition.* SAGE Publications.
70. Caddick N. (2021) Life, embodiment, and (post-)war stories: studying narrative in critical military studies. *Critical Military Studies*, *7(*2), 155-172. DOI: 10.1080/23337486.2018.1554942
71. Nizza, I. E., Farr, J., & Smith, J. A. (2021). Achieving excellence in interpretative phenomenological analysis (IPA): Four markers of high quality. *Qualitative Research in Psychology*, *18*(3), 369-386.
72. Pietkiewicz, I., & Smith, J. A. (2014). A practical guide to using interpretative phenomenological analysis in qualitative research psychology. *Czasopismo Psychologiczne Psychological Journal, 20*(1). https://doi.org/10.14691/cppj.20.1.7
73. Murray, C. D., & Wilde, D. J. (2020). Thinking about, doing and writing up research using interpretative phenomenological analysis. In C. Walshe &S. Brearley (Eds.), *Handbook of theory and methods in applied health research: Questions, methods and choices* (pp. 140-166).Edward Elgar Publishing.
74. Smith, J. A. (2011). Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review*, *5*(1), 9-27.
75. Archer, M., Sharp, R., Stones, R., & Woodiwiss, T. (1999). Critical realism and research methodology. *Alethia, 2*(1), 12-16. DOI: 10.1558/aleth.v2i1.12
76. Bhaskar, R. (1998). Philosophy and scientific realism. In M. Archer, R. Bhaskar, A. Collier, T. Lawson, & A. Norrie (Eds.), *Critical realism: Essential readings* (pp. 16–47). London: Routledge.

77. JFletcher, A. J. (2017). Applying critical realism in qualitative research: methodology meets method. *International Journal of Social Research Methodology*, *20*(2), 181-194. DOI: 10.1080/13645579.2016.1144401
78. Garza, G. (2011). Thematic collation: An illustrative analysis of the experience of regret. *Qualitative Research in Psychology, 8,* 40–65. doi:10.1080/14780880903490839
79. Cunliffe, A. (2004). On becoming a critically reflexive practitioner. *Journal of Management Education, 28*(4), 407–426
80. Institute for Government (December 9, 2022). *Timeline of UK coronavirus lockdowns and restrictions* https://www.instituteforgovernment.org.uk/data-visualisation/timeline-coronavirus-lockdowns
81. Johnson, H. (August 25, 2022). *UK Covid lockdown dates 2021: when did coronavirus pandemic start- date lockdowns and restrictions began 2020*. NationalWorld. https://www.nationalworld.com/health/uk-covid-lockdown-dates-2021-when-did-coronavirus-pandemic-start-lockdowns-2020-3621505
82. Fineberg, N.A., Pellegrini, L., Wellsted, D., Hall, N., Corazza, O., Giorgetti, V., Cicconcelli, D., Theofanous, E., Sireau, N., Adam, D., Chamberlain, S.R., & Laws, K. R. (2021). Facing the “new normal”: how adjusting to the easing of COVID-19 lockdown restrictions exposes mental health inequalities. *Journal of Psychiatric Research*, *141*, 276-286.
83. Giannotti, M., Mazzoni, N., Bentenuto, A., Venuti, P., & de Falco, S. (2022). Family adjustment to COVID-19 lockdown in Italy: Parental stress, coparenting, and child externalizing behavior. *Family Process, 61*(2), 745-763.
84. Wadsworth, M. E. (2015). Development of maladaptive coping: A functional adaptation to chronic, uncontrollable stress. *Child Development Perspectives*, *9*(2), 96-100.
85. Quinn, K., Murray, C., & Malone, C. (2014). Spousal experiences of coping with and

adapting to caregiving for a partner who has a stroke: a meta-synthesis of qualitative research. *Disability and Rehabilitation*, *36*(3), 185-198.

86. Chwalisz, K. (1992). Perceived stress and caregiver burden after brain injury: A theoretical integration. *Rehabilitation Psychology*, *37*(3), 189.
87. Cohen, S. A., Nash, C. C., & Greaney, M. L. (2021). Informal caregiving during the COVID-19 pandemic in the US: background, challenges, and opportunities. *American Journal of Health Promotion*, *35*(7), 1032-1036.
88. Czeisler, M. É., Drane, A., Winnay, S. S., Capodilupo, E. R., Czeisler, C. A., Rajaratnam, S. M., & Howard, M. E. (2021). Mental health, substance use, and suicidal ideation among unpaid caregivers of adults in the United States during the COVID-19 pandemic: Relationships to age, race/ethnicity, employment, and caregiver intensity. *Journal of Affective Disorders*, *295*, 1259-1268.
89. McKenry, P., & Price, S. (2005). Families coping with change. In P.C. McKenry & S.J. Price (Eds.), *Families and change: Coping with stressful events and transitions* (pp. 1-24). Sage.
90. Malia, J. A. (2006). Basic concepts and models of family stress. *Stress, Tauma, and Crisis*, *9*(3-4), 141-160.
91. Bruggimann, L., Annoni, J. M., Staub, F., Von Steinbüchel, N., Van der Linden, M., & Bogousslavsky, J. (2006). Chronic posttraumatic stress symptoms after nonsevere stroke. *Neurology*, *66*(4), 513-516.
92. Boss, P., Bryant, C. M., & Mancini, J. A. (2016). *Family stress management: A contextual approach*. Sage Publications.
93. Clabburn, O. (2023). A qualitative exploration on the impact of cancer to adult relationships: Applying the Vulnerability Stress Adaptation model within couples therapy. *Journal of Couple & Relationship Therapy*, *22*(1), 86-104.

94. Williams, S. N., Armitage, C. J., Tampe, T., & Dienes, K. (2020). Public perceptions and experiences of social distancing and social isolation during the COVID-19 pandemic: A UK-based focus group study. *BMJ Open*, *10*(7), e039334.

95. Ford, B. Q., & Troy, A. S. (2019). Reappraisal reconsidered: A closer look at the costs of an acclaimed emotion-regulation strategy. *Current Directions in Psychological Science*, *28*(2), 195-203.

96. Cohen Ben Simon, O., Ron, L., & Daches, S. (2022). Successful implementation of cognitive reappraisal: effects of habit and situational factors. *Cognition and Emotion*, *36*(8), 1605-1612.

97. Wang, Y. X., & Yin, B. (2023). A new understanding of the cognitive reappraisal technique: an extension based on the schema theory. *Frontiers in Behavioral Neuroscience*, *17*, 1174585.

98. Legra, M. J. H., Verhey, F. R. J., & Van Alphen, S. P. J. (2017). A first step toward integrating schema theory in geriatric psychiatry: a Delphi study. *International Psychogeriatrics*, *29*(7), 1069-1076.

99. Lockett, M., Pyszczynski, T., & Koole, S. L. (2022). Pandemic reminders as psychological threat: thinking about COVID-19 lowers coping self-Efficacy among trauma-exposed adults. *Cognition and Emotion*, *36*(1), 23-30.

100. Merriman, C., Norman, P., & Barton, J. (2007). Psychological correlates of PTSD symptoms following stroke. *Psychology, Health and Medicine*, *12*(5), 592-602.

101. Sembi, S., Tarrier, N., O'Neill, P., Burns, A., & Faragher, B. (1998). Does post-traumatic stress disorder occur after stroke: a preliminary study. *International Journal of Geriatric Psychiatry*, *13*(5), 315-322.

102. Pross, C. (2006). Burnout, vicarious traumatization and its prevention. *Torture*, *16*(1), 1-9.

103. Finklestein, M., Stein, E., Greene, T., Bronstein, I., & Solomon, Z. (2015). Posttraumatic stress disorder and vicarious trauma in mental health professionals. *Health & Social Work*, *40*(2), e25-e31.

104. Liu, C. H., Chen, Y. J., Chen, J. S., Fan, C. W., Hsieh, M. T., Lin, C. Y., & Pakpour, A. H. (2022). Burdens on caregivers of patients with stroke during a pandemic: relationships with support satisfaction, psychological distress, and fear of COVID-19. *BMC Geriatrics*, *22*(1), 958.

105. Takizawa, P. A., Honan, L., Brissette, D., Wu, B. J., & Wilkins, K. M. (2021). Teamwork in the time of COVID-19. *FASEB BioAdvances*, *3*(3), 175.

106. Rehder, K. J., Adair, K. C., Eckert, E., Lang, R. W., Frankel, A. S., Proulx, J., & Sexton, J. B. (2023). Teamwork before and during COVID-19: The good, the same, and the ugly…. *Journal of Patient Safety*, *19*(1), 36-41.

107. Bailey, S., & West, M. (2020). *Learning from staff experiences of Covid-19: let the light come streaming in.* The King’s Fund. www.kingsfund. org. uk/blog/2020/06/learning-staffexperiences-covid-19

108. Slater, B. (2020). *Lessons from implementation-after the crisis, what then?* National Institute for Health Research (NIHR) Applied Research Collaboration Yorshire and Humber. https://sites.google.com/nihr.ac.uk/arc-yh/news-events-and-media/blogs/blog-9-beverley-slater (accessed 10 December, 2023)

109. Bergmann, M., & Wagner, M. (2021). The impact of COVID-19 on informal caregiving and care receiving across Europe during the first phase of the pandemic. *Frontiers in Public Health*, *9*, 673874.

110. Robertson, E. L., Piscitello, J., Schmidt, E., Mallar, C., Davidson, B., & Natale, R. (2021). Longitudinal transactional relationships between caregiver and child mental health during the COVID-19 global pandemic. *Child and Adolescent Psychiatry and*

Mental Health, *15*(1), 1-14.

111. Garcia-Rudolph, A., Sauri, J., Garcia-Molina, A., Cegarra, B., Opisso, E., Tormos, J. M., Frey, D., Madai, V.I., & Bernabeu, M. (2022). The impact of coronavirus disease 2019 on emotional and behavioral stress of informal family caregivers of individuals with stroke or traumatic brain injury at chronic phase living in a Mediterranean setting. *Brain and Behavior*, *12*(1), e2440.

112. Budnick, A., Hering, C., Eggert, S., Teubner, C., Suhr, R., Kuhlmey, A., & Gellert, P. (2021). Informal caregivers during the COVID-19 pandemic perceive additional burden: findings from an ad-hoc survey in Germany. *BMC Health Services Research*, *21*, 1-11.

113. Office for National Statistics (2022, November 2) *Divorces in England and Wales: 2021.* https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/divorce/bulletins/divorcesinenglandandwales/2021#:~:text=Today's%20data%20show%20there%20was,its%20impact%20on%20divorce%20applications.

114. McKay, S. (2020). *Has lockdown strengthened marriages? [pdf]* Marriage Foundation. https://marriagefoundation.org.uk/wp-content/uploads/2020/11/MF-paper-Marriages-in-lockdown-FINAL.pdf

115. Komura, M., & Ogawa, H. (2022). COVID-19, marriage, and divorce in Japan. *Review of Economics of the Household*, *20*(3), 831-853.

116. Fallesen, P. (2021). Decline in rate of divorce and separation filings in Denmark in 2020 compared with previous years. *Socius*, *7*, 23780231211009991.

117. Schmid, L., Wörn, J., Hank, K., Sawatzki, B., & Walper, S. (2021). Changes in employment and relationship satisfaction in times of the COVID-19 pandemic: Evidence from the german family panel. *European Societies*, *23*(sup1), S743-S758.

118. Overall, N. C., Chang, V. T., Cross, E. J., Low, R. S., & Henderson, A. M. (2021). Sexist attitudes predict family-based aggression during a COVID-19 lockdown. *Journal of Family Psychology*, *35*(8), 1043.

119. Overall, N. C., Chang, V. T., Pietromonaco, P. R., Low, R. S., & Henderson, A. M. (2022). Partners' attachment insecurity and stress predict poorer relationship functioning during COVID-19 quarantines. *Social Psychological and Personality Science*, *13*(1), 285-298.

120. McRae, C. S., Overall, N. C., Henderson, A. M., Low, R. S., & Chang, V. T. (2021). Parents' distress and poor parenting during a COVID-19 lockdown: The buffering effects of partner support and cooperative coparenting. *Developmental Psychology*, *57*(10), 1623.

121. Waddell, N., Overall, N. C., Chang, V. T., & Hammond, M. D. (2021). Gendered division of labor during a nationwide COVID-19 lockdown: Implications for relationship problems and satisfaction. *Journal of Social and Personal Relationships*, *38*(6), 1759-1781.

122. Martin, L. N., Giff, S. T., Ribeiro, S., Fyffe, S., & Renshaw, K. D. (2022). Changes in relationship quality in the COVID-19 pandemic: Associations with pandemic stressors and couple communication. *The American Journal of Family Therapy*, 1-17.

123. Balzarini, R. N., Muise, A., Zoppolat, G., Di Bartolomeo, A., Rodrigues, D. L., Alonso-Ferres, M., Urganci, B., Debrot, A., Pichayayothin, N.B., Dharma, C., Chi, P., Karremans, J.C., Schoebi, D., & Slatcher, R. B. (2023). Love in the time of COVID: Perceived partner responsiveness buffers people from lower relationship quality associated with COVID-related stressors. *Social Psychological and Personality Science*, *14*(3), 342-355.

124. Pieh, C., O´ Rourke, T., Budimir, S., & Probst, T. (2020). Relationship quality and

mental health during COVID-19 lockdown. *Plos One*, *15*(9), e0238906.

125. Pietromonaco, P. R., & Overall, N. C. (2022). Implications of social isolation, separation, and loss during the COVID-19 pandemic for couples' relationships. *Current Opinion in Psychology*, *43*, 189-194.

126. Pietromonaco, P. R., & Overall, N. C. (2021). Applying relationship science to evaluate how the COVID-19 pandemic may impact couples' relationships. *American Psychologist*, *76*(3), 438.

127. Tedeschi, R. G., Shakespeare-Finch, J., Taku, K., & Calhoun, L. G. (2018). *Posttraumatic growth: Theory, research, and applications*. Routledge.

128. Calhoun, L. G., Cann, A., Tedeschi, R. G., & McMillan, J. (2000). A correlational test of the relationship between posttraumatic growth, religion, and cognitive processing. *Journal of Traumatic Stress: Official Publication of The International Society for Traumatic Stress Studies*, *13*(3), 521-527.

129. Park, C. L., Aldwin, C. M., Fenster, J. R., & Snyder, L. B. (2008). Pathways to posttraumatic growth versus posttraumatic stress: Coping and emotional reactions following the September 11, 2001, terrorist attacks. *American Journal of Orthopsychiatry*, *78*(3), 300-312.

130. Shakespeare-Finch, J., & Barrington, A. J. (2012). Behavioural changes add validity to the construct of posttraumatic growth. *Journal of Traumatic Stress*, *25*(4), 433-439.

131. Moura, A., Magalhães, P., Pais, S.C., & Alves, E. (2023). Adaptation processes of survivors and informal caregivers after stroke: A scoping review through the lens of educational sciences. *American Journal of Health Education, 1(*12).

132. Lobo, E.H., Frølich, A., Abdelrazek, M., Rasmussen, L.J., Grundy, J., Livingston, P.M., Islam, S.M.S., & Kensing, F. (2023). Information, involvement, self-care and support—The needs of caregivers of people with stroke: A grounded theory

approach. *Plos One, 18*(1), e0281198.

133. Wang, L., Liu, J., Wu, L., Zhang, J., & Fang, H. (2023). Caregiving experiences of stroke caregivers: A systematic review and meta-synthesis of qualitative studies. *Medicine*, *102*(13).

134. Jamaludin, S., Azmir, N.A., Ayob, A.F.M., & Zainal, N. (2020). COVID-19 exit strategy: Transitioning towards a new normal. *Annals of Medicine and Surgery*, *59*, 165-170.

135. Corpuz, J.C.G. (2021). Adapting to the culture of 'new normal': an emerging response to COVID-19. *Journal of Public Health*, *43*(2), e344-e345.

136. Emanuel, E.J., Osterholm, M., & Gounder, C.R. (2022). A national strategy for the "new normal" of life with COVID. *JAMA*, *327*(3), 211-212.

137. Panayiotou, G., Karekla, M., & Leonidou, C. (2017). Coping through avoidance may explain gender disparities in anxiety. *Journal of Contextual Behavioral Science*, *6*(2), 215-220.

138. Holahan, C. J., Moos, R. H., Holahan, C. K., Brennan, P. L., & Schutte, K. K. (2005). Stress generation, avoidance coping, and depressive symptoms: a 10-year model. *Journal of Consulting and Clinical Psychology*, *73*(4), 658.

139. Greenberg, J., Tsai, J., Southwick, S. M., & Pietrzak, R. H. (2021). Can military trauma promote psychological growth in combat veterans? Results from the national health and resilience in veterans study. *Journal of Affective Disorders*, *282*, 732-739.

140. Pietrzak, R. H., Tsai, J., & Southwick, S. M. (2021). Association of symptoms of posttraumatic stress disorder with posttraumatic psychological growth among US veterans during the COVID-19 pandemic. *JAMA Network Open*, *4*(4), e214972-e214972.

141. Xu, W., Jiang, H., Zhou, Y., Zhou, L., & Fu, H. (2019). Intrusive rumination, deliberate rumination, and posttraumatic growth among adolescents after a tornado: the

role of social support. *The Journal of Nervous and Mental Disease*, *207*(3), 152-156.

142. Yang, S. K., & Ha, Y. (2019). Predicting posttraumatic growth among firefighters: The role of deliberate rumination and problem-focused coping. *International Journal of Environmental Research and Public Health*, *16*(20), 3879.

143. Feingold, J. H., Hurtado, A., Feder, A., Peccoralo, L., Southwick, S. M., Ripp, J., & Pietrzak, R. H. (2022). Posttraumatic growth among health care workers on the frontlines of the COVID-19 pandemic. *Journal of Affective Disorders*, *296,* 35-40.

144. Tsai, J., El-Gabalawy, R., Sledge, W. H., Southwick, S. M., & Pietrzak, R. H. (2015). Post-traumatic growth among veterans in the USA: Results from the National Health and Resilience in Veterans study. *Psychological Medicine*, *45*(1), 165-179.

145. Wu, X., Kaminga, A. C., Dai, W., Deng, J., Wang, Z., Pan, X., & Liu, A. (2019). The prevalence of moderate-to-high posttraumatic growth: A systematic review and meta-analysis. *Journal of Affective Disorders*, *243*, 408-415.

146. Tsai, J., Mota, N. P., Southwick, S. M., & Pietrzak, R. H. (2016). What doesn’t kill you makes you stronger: A national study of US military veterans. *Journal of Affective Disorders*, *189*, 269-271.

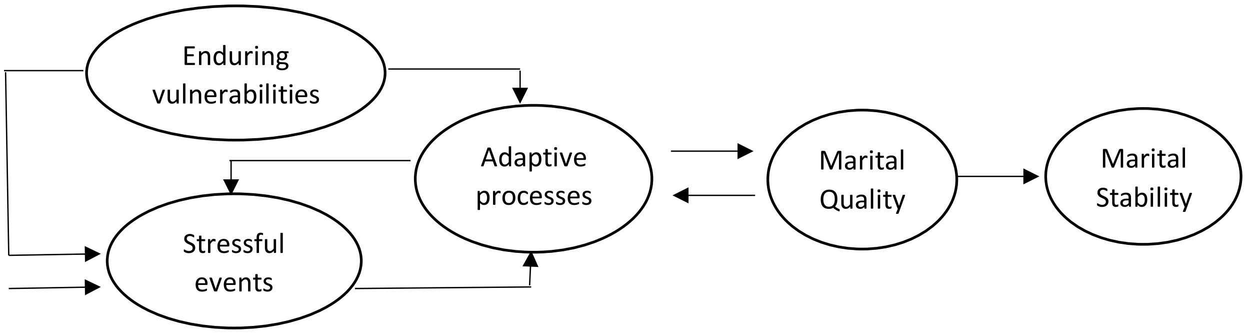
147. McCarthy, M.J., Lyons, K.S., Schellinger, J., Stapleton, K., & Bakas, T. (2020). Interpersonal relationship challenges among stroke survivors and family caregivers. *Social Work in Health Care, 59*(2), 91-107.

148. Ferro, J.M., & Santos, A.C. (2020). Emotions after stroke: A narrative update. *International Journal of Stroke, 15*(3), 256-267.

149. Martelli, M., Zasler, N., & MacMillan, P. (1999). Biopsychosocial models and brain injury: a vulnerability, stress and coping model of adaptation following brain injury. *Rehabilitation Psychology, 26*(3), 8-10.

FIGURES

Figure 1 – The Vulnerability-Stress-Adaptation Model: Karney and Bradbury, 1995



Tables

Table 1 Participant demographics (omitting identifying features)

Demographic	Response
Age	47
Gender Identity	Female
Ethnic Identity	White European
Relationship to SACR	Married (10 years)
Location during pandemic	South East England
Employment status	Part time employee

Table 2 Case study themes

Overarching themes	Superordinate themes
The pain of reality	“Life just changed vs Everything just stopped” “Everything is just gone” - loss and isolation
Control and entrapment	“I'm trying to keep us going here!” - systemic impact “We're not the greatest unit” – marital discord
Hope and growth	“He’s incredible!... That bit that really hasn’t been affected by his stroke” “I’ve got it in writing!” - subjugation towards empowerment

Appendix 2-A

Guidelines for publication

Instructions for authors

Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read and follow them as closely as possible, as doing so will ensure your paper matches the journal's requirements.

AUTHORSERVICES
Supporting Taylor & Francis authors

For general guidance on every stage of the publication process, please visit our Author Services website.

EDITINGSERVICES
Supporting Taylor & Francis authors

For editing support, including translation and language polishing, explore our Editing Services website

This title utilises format-free submission. Authors may submit their paper in any scholarly format or layout. References can be in any style or format, so long as a scholarly citation format is applied. For more detail see the format-free submission section below.

Contents

About the journal

Disability and Rehabilitation is an international, peer reviewed journal, publishing high-quality, original research. Please see the journal's Aims & Scope for information about its focus and peer-review policy.

From 2018, this journal will be online only, and will no longer provide print copies.

Please note that this journal only publishes manuscripts in English.

Disability and Rehabilitation accepts the following types of article: Research Articles, Reviews, Letters to the Editor, Case Reports, and Editorials. Systematic Reviews including meta-syntheses of qualitative research should be submitted as Reviews. All other types of Reviews will normally be considered as Perspectives in Rehabilitation.

Special Issues and specific sections on contemporary themes of interest to the Journal's readership are published. Please contact the Editor for more information.

Open Access

You have the option to publish open access in this journal via our Open Select publishing program. Publishing open access means that your article will be free to access online immediately on publication, increasing the visibility, readership and impact of your research. Articles published Open Select with Taylor & Francis typically receive 45% more citations* and over 6 times as many downloads** compared to those that are not published Open Select.

Your research funder or your institution may require you to publish your article open access. Visit our Author Services website to find out more about open access policies and how you can comply with these.

You will be asked to pay an article publishing charge (APC) to make your article open access and this cost can often be covered by your institution or funder. Use our APC finder to view the APC for this journal.

Please visit our Author Services website if you would like more information about our Open Select Program.

*Citations for articles published online 2018-2022. Data obtained on 23rd August 2023, from Digital Science's Dimensions platform, available at https://app.dimensions.ai **Usage in 2020-2022 for articles published online 2018-2022

Peer review

Taylor & Francis is committed to peer-review integrity and upholding the highest standards of review. For submissions to *Disability and Rehabilitation* authors are given the option to remain anonymous during the peer-review process. Authors will be able to indicate whether their paper is 'Anonymous' or 'Not Anonymous' during submission, and should pay particular attention to the below:

- Authors who wish to remain anonymous should prepare a complete text with information identifying the author(s) removed. Authors should upload their files using the 'double anonymous peer review' article types during submission. A separate title page should be included providing the full affiliations of all authors. Any acknowledgements and the Declaration of Interest statement must be included but should be worded mindful that these sections will be made available to referees.
- Authors who wish to be identified should include the name(s) and affiliation(s) of author(s) on the first page of the manuscript. Authors should upload their files using the 'authors made known to the reviewers' article types during submission.

Once your paper has been assessed for suitability by the editor, it will be peer-reviewed by independent, double anonymous expert referees. If you have shared an earlier version of your Author's Original Manuscript on a preprint server, please be aware that anonymity cannot be guaranteed. Further information on our preprints policy and citation requirements can be found on our Preprints Author Services page. Find out more about what to expect during peer review and read our guidance on publishing ethics.

Preparing your paper

All authors submitting to medicine, biomedicine, health sciences, allied and public health journals should conform to the Uniform Requirements for Manuscripts Submitted to Biomedical Journals, prepared by the International Committee of Medical Journal Editors (ICMJE).

We also refer authors to the community standards explicit in the American Psychological Association's (APA) Ethical Principles of Psychologists and Code of Conduct.

We encourage authors to be aware of standardised reporting guidelines below when preparing their manuscripts:

- Case reports - CARE
- Diagnostic accuracy - STARD
- Observational studies - STROBE
- Randomized controlled trial - CONSORT
- Systematic reviews, meta-analyses - PRISMA

Whilst the use of such guidelines is supported, due to the multi-disciplinary nature of the Journal, it is not compulsory.

Your paper should be compiled in the following order: title page; abstract; keywords; main text, introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s); figures; figure captions (as a list).

In the main text, an introductory section should state the purpose of the paper and give a brief account of previous work. New techniques and modifications should be described concisely but in sufficient detail to permit their evaluation. Standard methods should simply be referenced. Experimental results should be presented in the most appropriate form, with sufficient explanation to assist their interpretation; their discussion should form a distinct section.

Tables and figures should be referred to in text as follows: figure 1, table 1, i.e. lower case. The place at which a table or figure is to be inserted in the printed text should be indicated clearly on a manuscript. Each table and/or figure must have a title that explains its purpose without reference to the text.

The title page should include the full names and affiliations of all authors involved in the preparation of the manuscript. The corresponding author should be clearly designated, with full contact information provided for this person.

t

Please include a word count for your paper. There is no word limit for papers submitted to this journal, but succinct and well-constructed papers are preferred.

Format-Free Submission

Authors may submit their paper in any scholarly format or layout. Manuscripts may be supplied as single or multiple files. These can be Word, rich text format (rtf), open document format (odt), PDF, or LaTeX files. Figures and tables can be placed within the text or submitted as separate documents. Figures should be of sufficient resolution to enable refereeing.

- There are no strict formatting requirements, but all manuscripts must contain the essential elements needed to evaluate a manuscript: abstract, author affiliation, figures, tables, funder information, references. Further details may be requested upon acceptance.
- References can be in any style or format, so long as a scholarly citation format is applied. For manuscripts submitted in LaTeX format a .bib reference file must be included. Author name(s), journal or book title, article or chapter title, year of publication, volume and issue (where appropriate) and page numbers are essential. All

bibliographic entries must contain a corresponding in-text citation. The addition of DOI (Digital Object Identifier) numbers is recommended but not essential.

- The journal reference style will be applied to the paper post-acceptance by Taylor & Francis.
- Spelling can be US or UK English so long as usage is consistent.

Note that, regardless of the file format of the original submission, an editable version of the article must be supplied at the revision stage.

Alt Text

This journal is now including Alt Text (alternative text), a short piece of text that can be attached to your figure to convey to readers the nature or contents of the image. It is typically used by systems such as pronouncing screen readers to make the object accessible to people that cannot read or see the object, due to a visual impairment or print disability. Alt text will also be displayed in place of an image, if said image file cannot be loaded. Alt Text can also provide better image context/descriptions to search engine crawlers, helping them to index an image properly. To include Alt Text in your article, please follow our Guidelines.

Taylor & Francis Editing Services

To help you improve your manuscript and prepare it for submission, Taylor & Francis provides a range of editing services. Choose from options such as English Language Editing, which will ensure that your article is free of spelling and grammar errors, Translation, and Artwork Preparation. For more information, including pricing, visit this website.

Checklist: what to include

15. **Author details**. Please ensure everyone meeting the International Committee of Medical Journal Editors (ICJME) requirements for authorship is included as an author of your paper. Please ensure all listed authors meet the Taylor & Francis authorship criteria. All authors of a manuscript should include their full name and affiliation on the cover page of the manuscript. Where available, please also include ORCiDs and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. Read more on authorship.
16. A structured **abstract** of no more than 200 words. A structured abstract should cover (in the following order): the *purpose* of the article, its *materials and methods* (the design and methodological procedures used), the *results* and conclusions (including their relevance to the study of disability and rehabilitation). Read tips on writing your abstract.
17. You can opt to include a **video abstract** with your article. Find out how these can help your work reach a wider audience, and what to think about when filming.
18. 5-8 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.
19. A feature of this journal is a boxed insert on **Implications for Rehabilitation**. This should include between two to four main bullet points drawing out the implications for rehabilitation for your paper. This should be uploaded as a separate document. Below are examples:
    Example 1: Leprosy
    - Leprosy is a disabling disease which not only impacts physically but restricts quality of life often through stigmatisation.
    - Reconstructive surgery is a technique available to this group.
    - In a relatively small sample this study shows participation and social functioning improved after surgery.

    Example 2: Multiple Sclerosis

    - Exercise is an effective means of improving health and well-being experienced by people with multiple sclerosis (MS).
    - People with MS have complex reasons for choosing to exercise or not.

   - Individual structured programmes are most likely to be successful in encouraging exercise in this cohort.

20. **Acknowledgement**. Please supply all details required by your funding and grant-awarding bodies as follows: *For single agency grants*: This work was supported by the under Grant . *For multiple agency grants*: This work was supported by the under Grant ; under Grant ; and under Grant .
21. **Declaration of Interest**. This is to acknowledge any financial or non-financial interest that has arisen from the direct applications of your research. If there are no relevant competing interests to declare please state this within the article, for example: *The authors report there are no competing interests to declare.* Further guidance on what is a conflict of interest and how to disclose it.
22. **Data availability statement.** If there is a data set associated with the paper, please provide information about where the data supporting the results or analyses presented in the paper can be found. Where applicable, this should include the hyperlink, DOI or other persistent identifier associated with the data set(s). Templates are also available to support authors.
23. **Data deposition.** If you choose to share or make the data underlying the study open, please deposit your data in a recognized data repository prior to or at the time of submission. You will be asked to provide the DOI, pre-reserved DOI, or other persistent identifier for the data set.
24. **Supplemental online material.** Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about supplemental material and how to submit it with your article.
25. **Figures.** Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour). Figures should be saved as TIFF, PostScript or EPS files.
26. **Tables.** Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.
27. **Equations**. If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about mathematical symbols and equations.
28. **Units.** Please use SI units (non-italicized).

Using third-party material in your paper

You must obtain the necessary permission to reuse third-party material in your article. The use of short extracts of text and some other types of material is usually permitted, on a limited basis, for the purposes of criticism and review without securing formal permission. If you wish to include any material in your paper for which you do not hold copyright, and which is not covered by this informal agreement, you will need to obtain written permission from the copyright owner prior to submission. More information on requesting permission to reproduce work(s) under copyright.

Declaration of Interest Statement

Please include a declaration of interest statement, using the subheading "Declaration of interest." If you have no interests to declare, please state this (suggested wording: *The authors report no conflicts of interest*). For all NIH/Wellcome-funded papers, the grant number(s) must be included in the disclosure of interest statement. Read more on declaring conflicts of interest.

Clinical Trials Registry

In order to be published in Disability and Rehabilitation , all clinical trials must have been registered in a public repository, ideally at the beginning of the research process (prior to participant recruitment). Trial registration numbers should be included in the abstract, with full details in the methods section. Clinical trials should be registered prospectively – i.e. before participant recruitment. The clinical trial registry should be publicly accessible (at no charge), open to all prospective registrants, and managed by a not-for-profit organization. For a list of registries that meet these requirements, please visit the WHO International Clinical Trials Registry Platform (ICTRP). The registration of all clinical trials facilitates the sharing of information among clinicians, researchers, and patients, enhances public confidence in research, and is in accordance with the ICMJE guidelines.

Complying with ethics of experimentation

Please ensure that all research reported in submitted papers has been conducted in an ethical and responsible manner, and is in full compliance with all relevant codes of experimentation and legislation. All papers which report *in vivo* experiments or clinical trials on humans or animals must include a written statement in the Methods section. This should explain that all work was conducted with the formal approval of the local human subject or animal care committees (institutional and national), and that clinical trials have been registered as legislation requires. Authors who do not have formal ethics review committees should include a statement that their study follows the principles of the Declaration of Helsinki.

Please ensure that all research reported in submitted papers has been conducted in an ethical and responsible manner, and is in full compliance with all relevant codes of experimentation and legislation. All original research papers involving humans, animals, plants, biological material, protected or non-public datasets, collections or sites, must include a written statement in the Methods section, confirming ethical approval has been obtained from the appropriate local ethics committee or Institutional Review Board and that where relevant, informed consent has been obtained. For animal studies, approval must have been obtained from the local or institutional animal use and care committee. All research studies on humans (individuals, samples, or data) must have been performed in accordance with the principles stated in the Declaration of Helsinki. In settings where ethics approval for non-interventional studies (e.g. surveys) is not required, authors must include a statement to explain this. In settings where there are no ethics committees in place to provide ethical approval, authors are advised to contact the Editor to discuss further. Detailed guidance on ethics considerations and mandatory declarations can be found in our Editorial Policies section on Research Ethics.

All authors are required to follow the ICMJE requirements and Taylor & Francis Editorial Policies on privacy and informed consent from patients and study participants. Authors must include a statement to confirm that any patient, service user, or participant (or that person’s parent or legal guardian) in any type of qualitative or quantitative research, has given informed consent to participate in the research. For submissions where patients or participants can be potentially identified (e.g. a clinical case report detailing their medical history, identifiable images or media content, etc), authors must include a statement to confirm that they have obtained written informed consent to publish the details from the affected individual (or their parents/guardians if the participant in not an adult or unable to give informed consent; or next of kin if the participant is deceased). The process of obtaining consent to publish should include sharing the article with the individual (or whoever is consenting on their behalf), so that they are fully aware of the content of the article before it is published. Authors should familiarise themselves with our policy on participant/patient privacy and informed consent. They may also use the Consent to Publish Form, which can be downloaded from the same Author Services page.

Health and safety

Please confirm that all mandatory laboratory health and safety procedures have been complied with in the course of conducting any experimental work reported in your paper. Please ensure your paper contains all appropriate warnings on any hazards that may be involved in carrying out the experiments or procedures you have described, or that may be involved in instructions, materials, or formulae.

Please include all relevant safety precautions; and cite any accepted standard or code of practice. Authors working in animal science may find it useful to consult the International Association of Veterinary Editors’ Consensus Author Guidelines on Animal Ethics and Welfare and Guidelines for the Treatment of Animals in Behavioural Research and Teaching. When a product has not yet been approved by an appropriate regulatory body for the use described in your paper, please specify this, or that the product is still investigational.

Submitting your paper

This journal uses Taylor & Francis' Submission Portal to manage the submission process. The Submission Portal allows you to see your submissions across Taylor & Francis' journal portfolio in one place. To submit your manuscript please click here.

By submitting your paper to *Disability and Rehabilitation* you are agreeing to originality checks during the peer-review and production processes.

The Editor of *Disability and Rehabilitation* will respond to appeals from authors relating to papers which have been rejected. The author(s) should email the Editor outlining their concerns and making a case for why their paper should not have been rejected. The Editor may choose to accept the appeal and secure a further review, or to not uphold the appeal. In case of the latter, the Editor of *Disability and Rehabilitation: Assistive Technology* will be consulted.

On acceptance, we recommend that you keep a copy of your Accepted Manuscript. Find out more about sharing your work.

Data Sharing Policy

This journal applies the Taylor & Francis Basic Data Sharing Policy. Authors are encouraged to share or make open the data supporting the results or analyses presented in their paper where this does not violate the protection of human subjects or other valid privacy or security concerns.

Authors are encouraged to deposit the dataset(s) in a recognized data repository that can mint a persistent digital identifier, preferably a digital object identifier (DOI) and recognizes a long-term preservation plan. If you are uncertain about where to deposit your data, please see this information regarding repositories.

Authors are further encouraged to cite any data sets referenced in the article and provide a Data Availability Statement.

At the point of submission, you will be asked if there is a data set associated with the paper. If you reply yes, you will be asked to provide the DOI, pre-registered DOI, hyperlink, or other persistent identifier associated with the data set(s). If you have selected to provide a pre-registered DOI, please be prepared to share the reviewer URL associated with your data deposit, upon request by reviewers.

Where one or multiple data sets are associated with a manuscript, these are not formally peer reviewed as a part of the journal submission process. It is the author’s responsibility to ensure the soundness of data. Any errors in the data rest solely with the producers of the data set(s).

Publication charges

There are no submission fees, publication fees or page charges for this journal.

Color figures will be reproduced in color in your online article free of charge.

Copyright options

Copyright allows you to protect your original material, and stop others from using your work without your permission. Taylor & Francis offers a number of different license and reuse options, including Creative Commons licenses when publishing open access. Read more on publishing agreements.

Complying with funding agencies

We will deposit all National Institutes of Health or Wellcome Trust-funded papers into PubMedCentral on behalf of authors, meeting the requirements of their respective open access (OA) policies. If this applies to you, please tell our production team when you receive your article proofs, so we can do this for you. Check funders’ OA policy mandates here. Find out more about sharing your work.

My Authored Works

On publication, you will be able to view, download and check your article's metrics (downloads, citations and Altmetric data) via My Authored Works on Taylor & Francis Online. This is where you can access every article you have published with us, as well as your free eprints link, so you can quickly and easily share your work with friends and colleagues.

We are committed to promoting and increasing the visibility of your article. Here are some tips and ideas on how you can work with us to promote your research.

Appendix 2-B

Additional publication content

Implications for Rehabilitation

- Caregivers value stroke-specific information and training to support their understanding
- Psychological support for caregivers is needed to process post-stroke life changes
- Couples and family therapy would be beneficial for reorientating spousal relationships post-stroke
- Access to rehabilitative services can be pivotal to care-recipient motivation, and consequently caregiver quality of life

Keywords: Stroke; caregiver; spouse; pandemic, Covid-19; case study; experiences; stress-vulnerability

Acknowledgements

The authors would like to acknowledge; ‘Sasha’, the participant; and the following psychologists for research input and support; Dr Caroline Malone, Greater Manchester NHS, Dr Michael Larkin, Aston University and the DClinPsy Clinical Tutors, Dr Suzanne Hodge and Dr Craig Murray at Lancaster University.

Disclosure Statement

No potential conflict of interest was reported by the authors.

Appendix 2-C

Interview Schedules

Interview Schedules

Initial Interview

1. Can you tell me a little bit about your relationship with your partner? E.g. how long you've been together, how your relationship developed, what you enjoy most about your relationship.
2. I wonder if you could tell me a little bit about your partner's stroke and what impact this had on their life (have they been able to work since? Has it affected their communication, mobility, physical or mental health?)
3. What sorts of things were you doing to support your partner as their carer before the Covid pandemic started? Has this changed during Covid?
4. During Covid, what sort of support have you had from other people? Formal carers, family and friends etc?
5. How has your social life been impacted by Covid restrictions? How has being a carer impacted upon this?
6. Has your mental health been impacted by Covid restrictions? How has being a carer supported or detracted from this?
7. To what extent have you been able to pursue your normal hobbies, interests and activities during Covid restrictions? How has being a carer impacted upon this?
8. If you were to think about your day to day life as a carer before and during Covid, how is it the same?
9. How is it different?
10. If you could go back in time to life before Covid, and could tell the people that run health and social care services how they should run things. What would you suggest that they do to support someone caring for a partner who's had a stroke during Covid
11. What would help you now as we move forward through the Covid pandemic and beyond?

Follow Up Interview

Introduction - Setting context

'When we last spoke the pandemic was still very much in the news, the country had experienced a series of lockdowns – both national and regional - social distancing and wearing of masks in public was mandatory/ recommended, and there were a series of Covid vaccinations and booster programmes being carried out by age group and medical vulnerabilities across the country.

Now, the pandemic continues on with new, potentially less life-threatening strains and few, if any, restrictions on our way of life.

If it's OK with you, I was hoping to use our time to first of all get an update on your general context; your living and occupational arrangements, your husband's support needs etc, and then move on to look at focusing on how life looks for you now, how it's similar and/or different to life pre Covid and at the height of Covid restrictions. Then I'll ask you about and any lasting reflections you have about being a spousal carer for stroke during a pandemic'

1. How are things since we last spoke?
2. Has anything changed?

Prompts re: aspects of life to reflect upon

- Impact of the stroke on husband – recovery trajectory (e.g. physical or psychological abilities)
- Working life
- Family life
- Caring responsibilities - Life as a Carer – day-to-day
- Support network
- Social life
- Mental health
- Ability to pursue normal hobbies, interests and activities

3. If you could go back in time to life before Covid, and could tell the people that run health and social care services how they should run things. What would you suggest that they do to support spousal carers of partners who've had a stroke – leading up to, during and post pandemic
4. What, if anything, would help you now as we move forward through the Covid pandemic and beyond?

Appendix 2-D

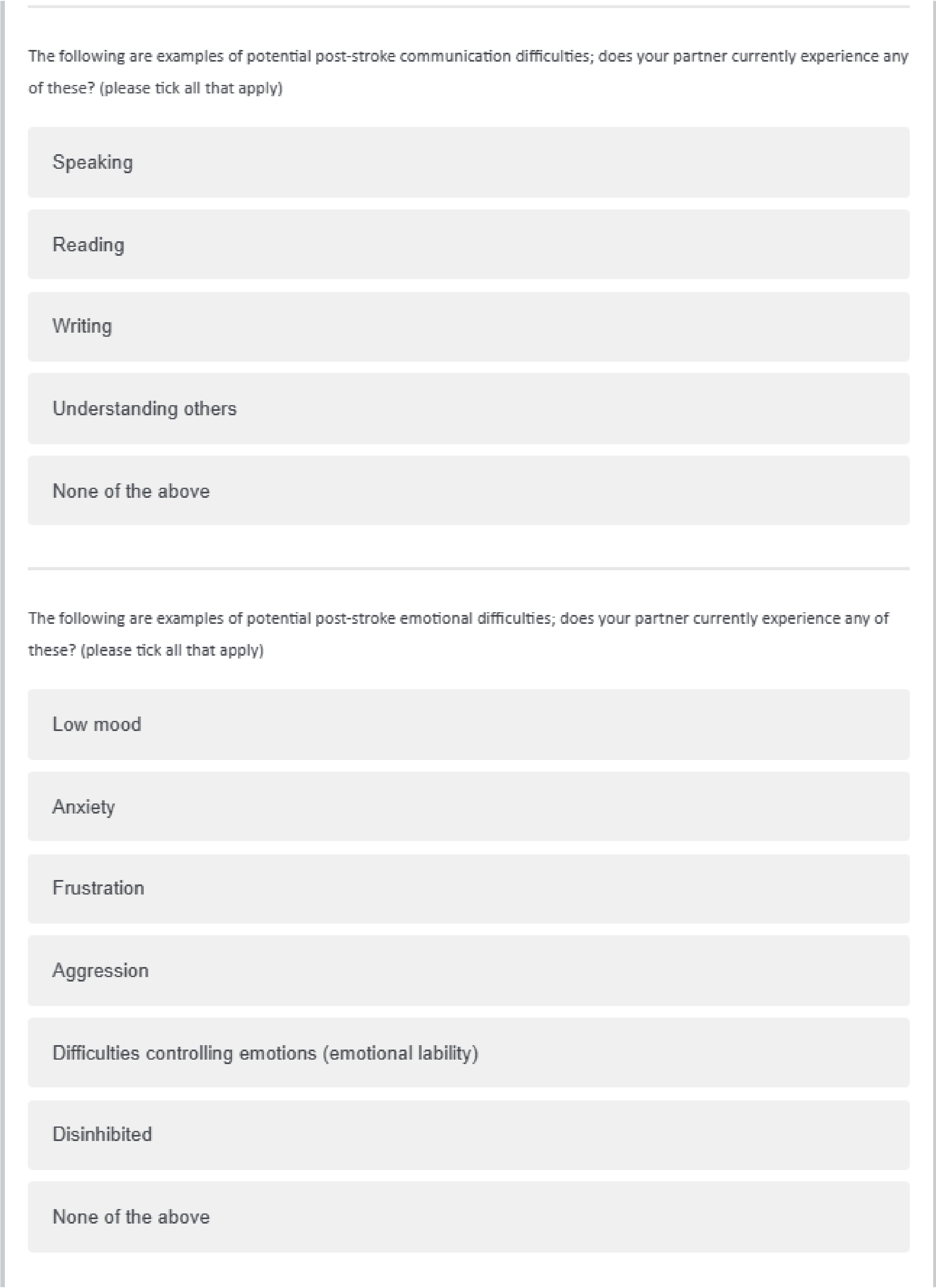
Participant Pre-Screening Questions

QID1	My partner has had one stroke, this occurred prior to January 2020
QID3	My partner and I were living together before and during the Covid 19 pandemic
QID5	My partner requires support from me to manage the outcomes of their stroke (this may range from ensuring they are not left alone in the house to carrying out intimate care)
QID7	My partner and I have been living in England during the pandemic
QID8	I have access to the internet or a telephone and speak English
QID11	Prior to the stroke my partner had a pre-existing condition that required care and support for that diagnosis e.g. Alzheimers, Parkinsons, Multiple Sclerosis, Motor Neuron Disease etc.
QID12	My partner had a transient ischaemic attack, sometimes called a TIA or ‘mini stroke’
QID22	The following are examples of potential post-stroke physical difficulties; does your partner currently experience any of these? (please tick all that apply)
QID23	The following are examples of potential post-stroke communication difficulties; does your partner currently experience any of these? (please tick all that apply)

QID24	The following are examples of potential post-stroke emotional difficulties; does your partner currently experience any of these? (please tick all that apply)
Q13	The following are examples of potential post-stroke cognitive difficulties; does your partner c
QID26	The following are examples of potential post-stroke sexual difficulties; does your partner currently experience any of these? (please tick all that apply)
QID27	If there are any other difficulties that your partner experiences as a result of their stroke that are not covered above, please use the space below to give brief details.
QID28	Please write your age in the box below
QID29	What is your gender identity?
QID31	Which of the following best describes your sexual orientation?
QID30	Please write your ethnic identity in the box below
QID34	How long have you been in a relationship with your current partner?
QID32	Which of the following best describes your marital status?
QID33	Whereabouts in England have you been living during the pandemic?
QID35	Which of the following best describes your employment status?
QID36	To enable me to contact you to arrange an interview, please would write your email address in the box below
QID37	Please indicate below whether you would prefer for your interview to take place over the internet (e.g. Teams or Zoom) or by telephone.

Appendix 2-E

Excerpt from multi-choice pre-interview questions



The following are examples of potential post-stroke communication difficulties; does your partner currently experience any of these? (please tick all that apply)

Speaking

Reading

Writing

Understanding others

None of the above

The following are examples of potential post-stroke emotional difficulties; does your partner currently experience any of these? (please tick all that apply)

Low mood

Anxiety

Frustration

Aggression

Difficulties controlling emotions (emotional lability)

Disinhibited

None of the above

Appendix 2-F

Initial annotations excerpt

Notes	Line / Time	Transcript
	88	R: [Pause} I just wonder if, in terms of, if we look at, specifically around Covid; I wonder how things are similar, how things are different, as a result of Covid?
He was housebound, he didn't leave the house at all He put on weight You stink - he stopped showering, it was so awful I couldn't sleep next to him Some days he didn't even brush his teeth, it was horrible.	89	P: Um with Covid the hardest thing was just, that he was just housebound; he just didn't leave the house at all. He wouldn't shower any more, he stank, euch, it was awful. He wouldn't take a shower, or he wouldn't.. He just literally rolled out of bed, sat in front of the computer, worked, ate and then back to bed. Put on loads of weight, um. Some days he didn't even brush his teeth, it was horrible. And I kept.. And then I felt bad like, 'you stink, you need to..' He was like 'yeah, yeah I will' But it could be like a week and he wouldn't even take a shower. And it was so awful I couldn't even sleep next to him. Um, that was really hard. That has, thank God, since changed.
Pre-Covid he saw a personal trainer, posture physio, soft tissue masseuse Everything just stopped with Covid It was a huge set back	22m 47s	And then, cause before he used to go to, he had a friend who was a personal trainer, he would go to the gym and work out with him; he had a lady he went to see that used to help him with his posture and things like that; and then he went to another friend who's a soft tissue therapist who would go and massage his arm and shoulders… Um so you had all these things that he would do, um and then with Covid, everything just stopped. So it was a huge set back for him, it really was.
	90	R: So it sounds like where, where his physical therapy stopped, and then perhaps that sense of determination to overcome things was blocked?
	24m 13s	
	91	P: Yeah
	92	R: Did he give up a little bit?
Wouldn't go out for a walk or use the exercise bike given to them by neighbours Zero motivation He would just sit in bed or work Went to the	93	P: Oh totally. I said to him, like 'when you finish work, like, let's go for a walk.' You know, like 'when you finish work, go for a walk'. Or even in the morning.. Cause our son, well he wasn't at school then, so, but..that was later on I said that…(tails off, scratching head in thought). But I said 'just go for a walk, just go for a walk around the block.' Or our neighbours, they were moving, and they gave us their exercise bike that was in perfect condition, never been

supermarket on a Sunday to get a few bits		used. Still in the garage. And I said 'cause that you can use' and then.. but there's zero motivation for anything. Nothing at all. He would just sit in bed or work, then, and um.. yeah. Maybe on a Sunday he would go to the supermarket, just to get a few bits, and then, that was the only thing he did.

Appendix 2-G

Initial clustering excerpt

Theme	Potential Basis for Clustering	LINE NO.	Summary Phrase	Comments / Thoughts
Covid Spotlight	Family Dynamics	35	Challenges of home schooling 2 children quietly to enable husband to work from home	
	Family Dynamics	63	Protecting the kids from him	Ref normalising their life (as if the stroke didn't happen)
	Family Dynamics	63	Me and the kids and then him	
	Family Dynamics	67	The kids defend me	
	Family dynamics	109	Husband had more appreciation for what I do	
	Family dynamics	109	The kids were happy to see me	
	Family dynamics	109	The kids had time with their Dad	
	Family dynamics	137	When he finishes work he reverts back into his own world	
	Family dynamics	243	Book explains to them why Dad is angry and doesn't smile	
	Family dynamics	247	It's great he's alive, but our quality of life is not great	
	Family dynamics	255	Difficulty managing school runs when Sasha is working	
	Family dynamics	260	'Our family unit isn't great'	
	Marital relationship	9	We travelled the world together, really good friends, similar values	Exciting, well bonded, similar lifestyle, interests & values
	Marital relationship	51	You have nothing to complain about	She feels guilt, he generates it. Restricts her life to reduce his frustrations
	Marital relationship	51	He has no empathy towards me whatsoever	Imbalance in power and rights?
	Marital relationship	51	He goes to work, I do everything else	Inequity in role sharing. Impacts on his relationship with boys

Marital relationship	51	My struggles are nothing because I didn't have a stroke	Frustrations & guilt. How does this impact on how his children see Dad
Marital relationship	55	I can't complain	
Marital relationship	55	He is ungrateful	
Marital relationship	59	I'm trying to keep us going here	Unfair division of labour. Sasha absorbing the extra work.
Marital relationship	59	I get put down for not being perfect	
Marital relationship	59	We have this great friendship	Friendship as a foundation remains, now a companionate relationship, intimacy & passion is limited/absent
Marital relationship	69	Something changed so dramatically	
Marital relationship	69	He was so horrible	
Marital relationship	75	I'm very sensitive and I pick up on it and feel yuck	Sasha absorbing his frustrations by directing the cause of her discomfort inwards rather than towards Enzo. (i.e. He 'nitpicks' but it hurts because she is ‘too sensitive’)
Marital relationship	75	He's a lovely man really	
Marital relationship	79	No sexual intimacy since the stroke	
Marital relationship	79	Erectile dysfunction gets him down	Subjugation - How is it for her?! Does she want to rekindle sexual?
Marital relationship	79	All the things he used to enjoy have been taken from him	Subjugation - What has been taken from her

			that she previously enjoyed?
Marital relationship	79	Continence difficulties, he weed himself on the train going to meet a friend	Husband in the child role - how does this impact on her feelings towards him as a man, partner, lover?
Marital relationship	81	Sexual attraction has gone	

Appendix 2-H

Example of extended narrative

Theme	Subtheme	Narrative	Line	Quotations
The Covid Searchlight	He's Incredible – unveiling something 'normal'	Enzo's stroke outcomes primarily impacted his emotional and physical mobility. At home, the Enzo that Sasha sees struggles with basic everyday tasks such as chopping vegetables, cleaning his ears, cutting his toenails and wiping the shower down. His difficulties require Sasha to remain alert and offer assistance to prevent injury. Enzo's subsequent frustrations play out in his mood and relational strains are exacerbated. However, his recovery trajectory during inpatient rehabilitation, along with the nature of his job [redacted] enabled Enzo to return to work as soon as he returned home. A supportive manager and occupational adaptations including flexibility around responsibilities, targets and breaks, coupled with Enzo's problem-solving abilities have retained Enzo as the main breadwinner. Engagement in working life was the only activity Enzo maintained during lockdown; potentially the only normality accessible to him and a source of pride and esteem in challenging times. Homeworking, whilst presenting environmental challenges for Sasha to manage, also cast a searchlight of hope and pride on Sasha's world. She described her admiration of his work ethic, knowledge and social skills when they first fell in love at work; lockdown gave Sasha a window into those aspects of her husband once more. She spoke animatedly about his coming to life, how he helped others to overcome [redacted] difficulties, shared expansive knowledge and how highly his team regarded him.	19 47	*he came home [from rehab] and just started working straight away…* [redacted]*, so it has been a little bit challenging for him 'cause he can't use his right arm or hand... They're an amazing company, amazing. They have given him so much support; letting him take lots of breaks, and he doesn't have that target of the amount of things he has to fix, like the others have. And, when Covid happened he started working from home. So he's just been doing phone calls and things… Work wise, everything's been great.* *He doesn't really want help unless he really, really has to; even at work…* [redacted] *which requires a lot of typing, he just started using the dictation thing and he just found, he just finds ways around it. Um, which is really good. It's good for him because, he feels like he can do it, but yeah, they just, it's just things like chopping vegetables and things like that, they're just really hard*

		Her pride and emotions were clear as she once more saw the man that she fell in love with and a light was cast of those things he could do, the strengths he had retained and this enabled her to admire him once more. Whilst Enzo appeared to shut down along with his computer at the end of each working day, those glimpses of action, motivation and ability were energising and hopeful behaviours by unveiling pre-stroke normality.	135	*during lockdown he was just, he was just quiet. And. And just didn't do anything (sniffs). I mean thank God he worked, cause he got to speak to people and he's very, he is a people person. He's very, very outgoing. He will help anyone, and so he really, that he really…he livens up and he really likes that. And then, when his day was finished, he just shut down (voice cracking) and, very quiet* *I mean I would only overhear it because I was here, so I would hear the conversations and things, and it was really nice. (smiles broadly and gesticulates with hands). It was nice hearing his conversations with his customers, and it was nice when they had the team meetings* [redacted] *Such amazing people. You know, I got to hear some of it.. and just help. And how amazing his manager was and things. I, I really enjoyed that and I enjoyed hearing him. He's, he is incredible, like when it comes to work, he is incredible. Really, really, really good. And the things he says, he's very positive. And I'm like (side ways glance, facial expression suggestive of surprise/disbelief and chuckles). Uh, but then he*

				is, in his element, you know? You know, that’s, that’s him
			137	*Like he just knows everything. He knew all the rules and sometimes he would almost be like a manager* [redacted]*, but not. You know, he’s not one of those, like ‘oh I know everything’ No. He’s just like quietly doing his thing, but he’s so brilliant, and it’s the same now. Like with* [redacted]*, he loves* [redacted]*, he knows everything. And the way he interacts with his customers, and he’s like ‘oh have you thought about doing this, this way?!’ Or ‘instead of* [redacted] *you could just* [redacted]*’ or ‘you could do this, la, la, la, la, la’. And they’re like ‘oh my God, that’s fantastic’. And he’s, you know, he’s so. Whatever he’s doing, he’s so into it and very knowledgeable.*
				they have so many talented people and they, they allow each person to have a day to show what they can do, you know where [unintelligible example] or whatever, and it’s just been really, really nice. And to hear how they feed back to [Enzo], um, about whatever he said, or.. he’s very liked. (wiping tears, smiling) Like the other day I

			147	*found his rucksack. Just a little note from his coworkers, how great he is, and I'm like 'you didn't tell me about this'. And he's like 'Oh, no' you know, but uh. Yeah that has been really, really nice to see that, that bit that really hasn't been affected by his stroke I guess. I guess that's the only normal thing we have in a way*

Chapter 3 : Critical Appraisal

Ruth Hirst

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

All correspondence should be sent to:

Ruth Hirst

Doctorate in Clinical Psychology
Faculty of Health and Medicine
Health Innovation One
Sir John Fisher Drive
Lancaster University
Lancaster
LA1 4AT
r.kitchen@lancaster.ac.uk

Introduction

This critical appraisal will commence with a brief summary of the thesis findings followed by an analysis of issues that arose in the process of carrying out this work and the implications of these.

Key results of the thesis

The systematic literature review focused on synthesising the experiences of ethnic minority family caregivers of stroke and captured data from 11 papers. A meta-ethnographic approach was used to synthesise the findings from across the papers [1] and revealed 11 themes. These were organised into 4 overarching systems, representing different structures within Bronfenbrenner's Bioecological Systems Theory [2] Themes that emerged were as follows: *Self*: Meaning-making; Emotional stresses and coping; Practicalities of Caregiving; *Family*: Spousal obligation; Filial piety; *Culture & Spirituality*: Faith and spirituality; Cultural norms and narratives and *Health & social care systems*: Discharge, Meeting needs – adaptation & provision; Rights vs reticence ; Information and communication. The review highlighted convergence and divergence within and between different ethnic minority groups and between ethnic minority and majority experiences, offering areas for exploration with caregivers that can support and inform culturally competent practice. These are discussed within the body of the work.

The research paper was a single case study design investigating a spousal caregiver of stroke and her experiences across two timepoints of the Covid 19 pandemic. The semi-structured interviews were analysed using Interpretative Phenomenological Analysis (IPA) [3].

Three overarching themes incorporating six subthemes were identified. *The pain of reality*: "Life just changed vs Everything just stopped"; "Everything is just gone" - loss and isolation; *Control and entrapment*: "I'm trying to keep us going here!" - systemic impact; "We're not the greatest unit" – marital discord and *Hope and growth*: "He's incredible!... That bit that really hasn't been affected by his stroke"; "I've got it in writing!" - subjugation towards empowerment. The research revealed a turbulent experience of lockdown where the caregiver was confronted with unavoidable realities of post-stroke life and familial relationships. Processing these issues, whilst distressing at times, appeared to facilitate aspects of reorientation, post traumatic growth and hope moving forwards.

Reaching the hard to reach

Reaching the hard to reach was an issue that emerged across both papers. The intersection of ethnic minorities as family caregivers revealed a disappointing, yet not surprising paucity of research to review [4]. Statistical data has highlighted ethnic inequalities in stroke incidence and mortality over a period of time [5-12], so what I initially experienced as scant efforts to explore their familial caregivers experiences seemed dismissive. My research paper quickly illuminated many of the reasons why hard-to-reach populations are named as such, offering first-hand experience of the challenges it entails, but also, the reward it can bring.

Recruiting in a pandemic – Empirical research

The World Health Organisation [13] raised concerns early on in the pandemic regarding the elevated stress experienced by citizens globally [13], this baseline was exacerbated by the additional shielding measures of their care recipient, concerns about contagion, and difficulties in accessing external formal care services amongst family caregivers [14-18]. Key challenges for caregivers included increased care burden and intensity, mental health challenges and lower quality of life, especially amongst female caregivers [14,16]. In non-pandemic times caregivers can be time-poor, especially if stroke outcomes are complex or co-morbid or they have family or occupational responsibilities [19,20], however their capacity for pursuits such as research participation appeared to reduce further.

Recruitment sources in stroke research are often formal health settings such as hospital and community stroke units or support groups; all of the studies included in the literature review used these routes [21-31]. However, the pandemic put NHS recruitment routes out of bounds as research ethics committees were understandably not prioritising trainee research at the time. The Stroke Association (local support groups and centralised research department) were similarly unable to support recruitment for this project citing similar reasons. Other independent, peer-led groups contacted had been disbanded under social distancing measures, and many of the voluntary co-ordinators relayed difficulties they were experiencing when trying to facilitate communication with and between their members; their caregivers had limited access to technology and/or technological skills.

Digital methods of recruitment and research became more prominent during the pandemic; researchers were able to take advantage of reaching a wider geographical span [32] and the accelerated take up of video meeting technologies soared amongst the public facilitated this development [33-35]. Looking to capitalise upon the increase in technological engagement in my research I moved to advertising with keyword hashtags on Twitter, signposting Facebook users to the University Facebook page where my advert was also situated, alongside attempts at initiating a snowball sampling with some stroke-experienced former work colleagues; however, their pandemic homeworking demands prevented this. Facebook stroke caregiver groups were also approached, but most had a strictly no researchers policy as they are set up as virtual psychologically safe spaces where caregivers can freely share honest experiences [36,37]. A predominantly US-based group run by an Occupational Therapist permitted an advertisement in their group but prewarned; “these are busy people, but you can try”.

As seen with the volunteer-led support groups, reliance upon technology has the potential to omit marginalised groups who may lack digital literacy due to age, or low income for example [38]. Strokes disproportionately impact older populations and can restrict finances due to additional heating and laundry costs for example [26]. However recent data suggests that 38% of strokes occur in middle age (40-69 years), and that this is increasing [39]. Barriers to this age group may have entailed some additional pressures such as competing for computers for homeschooling or recreational purposes [40]. If not working from home, the caregivers were potentially also vulnerable to additional financial pressures of job losses and/or furlough [41]; it is reasonable to suggest having mental and/or physical capacity to engage in research was thus likely reduced further still.

A participant was recruited from within the middle-aged bracket; her first interview revealed a fascinating account and compelling candor. When the time came to make important research decisions to complete data collection; the investment of her time, energy and engagement generated an impetus throughout the discussions to honour her contribution to date.

Paucity of research - SLR

Typical stroke caregiver characteristics (older, poorer physical health, lower incomes) intersected with the most commonly underserved sectors of society during the pandemic; notably they are also consistently under-represented in research across disciplines, yet were overrepresented within pandemic mortality rates [42]. With multiple layers of underrepresentation and disadvantage, a rigorous search strategy was needed to find relevant research that had been carried out.

It was clear from the scoping searches carried out, that the search would need to be widely cast and thus the only date limit was that it was listed on electronic databases at that point in time, up to and including 2022. The consideration of how old research is before it is no longer useful is often debated with some not offering any set rule and others citing between three and ten years, [43]. However, these papers were selected because of their relevance to the research aims; the review is then able to synthesise experiences up to and including 2022, creating discussion, signposting potential considerations for services and, moreover, it draws attention to the situation and has the potential to motivate subsequent research in this important area. The presentation of the findings are purposely tentative; the critical realist stance of the research acknowledges the lack of definitive answers; it is the interactions between the systems, experiences, thoughts and behaviours of individuals and the dynamics between them that nuances the phenomenon [44,45].

I sought support from an academic librarian to quality assure the rigour of my search, and support with sensitivity tests. Although 38 papers made it through to full text reading, this was because abstracts were not clear about whether caregiver data was reported distinctly and whether they were investigating different ethnicities in terms of Chinese caregivers in China, or first nation ethnic minorities such as the Māori in New Zealand, or ethnic minorities through migration such as current and former British Commonwealth citizens invited to migrate to the UK. Of these Chinese caregivers in China would be excluded. Once this process was complete, only 11 remained and one was missing information in the paper [25], and they encompassed 9 participant groups.

Papers ranged from 1999 to 2019 across 4 countries and reported on a range of ethnic minority groups. It was helpful to frame the papers as conveying a shared experience of difference by ethnicity within one's country of residence, therefore "the studies taken together offer a line of argument rather than a reciprocal or refutational translation" [1,p36]. This revealed some important experiences that both converged and diverged across and within ethnic groups.

As discussed in the literature review, it is important to conduct further research in this area; the chronosystem of changes over time and macrosystems within which individuals and health and social care operates continue to evolve [2]. Recent events such as Brexit, the Covid pandemic, immigration reforms and pockets of war and persecution have generated the movement of peoples, greater socioeconomic deprivations within vulnerable groups and cultural tensions [46,47]. However more proactive political actions have also taken place to restructure healthcare systems to increase cultural competence and representation of minority groups in countries such as in New Zealand [48]. It is hoped that this paper will generate interest and engagement in moving this field forwards with further research. Other implications and recommendations are discussed within the main body.

Socially sensitive research - SLR.

The topic of the literature review elicited careful attention to moral and professional responsibilities to conduct it as thoroughly as circumstances would allow. By using the conceptual framework Bioecological System theory [2], the research seeks to draw attention to the intersectionality of variables, structures and systems that interact with the caregivers' experience [49].

The main tension I experienced related to my research position. Whilst experienced in the nuances of difference through sexuality, decolonised narratives are constructed through the perspectives of indigenous research lenses, so that the Eurocentric lens does not conceal or misinterpret the data [50]. Whilst experienced in working in multi-cultural settings, at best I have a solid baseline understanding of spirituality, alternative cultural norms and faiths as a white woman, however I acknowledge my white privilege and the constraints of this. Similarly, my supervisor identifies as an ethnic minority professional, however, whilst she may be able to support with an informed lens on her own ethnic group, this research ideally would have benefited from consultation across a broader range of ethnic groups as themes were revealed to quality assure the process and interpretations. In the absence of this I spent time reading up on the cultures within the research. I found Maori culture, in particular, quite novel and complex and spent considerable time researching history, timeline and some of the ceremonial aspects of the culture.

A risk of conducting research of this nature, especially in looking to synthesise papers, is that the response is reductionist and/or contributes to understating difference within and between ethnic minority groups and overstating those between the majority and minority. Research supervision, reflexive journalling and frank discussions were key to working with this dynamic; it is too important to get it wrong. In light of inequitable representation of ethnic minority professionals within the field of Clinical Psychology, the temptation to avoid tricky topics is not an option if we are going to be able to tackle some of the structural inequalities across society, the profession and most importantly in this context, the familial caregivers of stroke population. It has been a thought-provoking process.

Researcher positioning and the inductive method

I adopted an inductive approach to both the SLR and empirical papers. Seeking meaning from qualitative sources relied upon constant comparison across the literature review papers and a narrative analytical approach within the empirical research [51]. This approach entails an implicit degree of subjectivity however, although the themes are expressed in *my* words, themes were selected to consistently and honestly summarise the psychological meanings represented by the *participants'* words [52]. By using established, evidence-based procedures to add rigour to my research designs, derived themes achieve a degree of objectivity through being empirically grounded within the respective published papers of the SLR and subjective account of my case study participant [52]. Although often preferred by academic journals, a deductive approach was unsuitable to meet my research aims, and the conclusions drawn via the inductive process can offer valid contributions to understanding and may support further research or enquiry [53].

Use of models and frameworks to guide discussion

Sasha's account of the pandemic was highly relationally focused, whereas much of my initial scoping search of publications specifically regarding carers and the pandemic discussed more practical burdens of care. Sasha's situation appeared to offer a novel perspective but was also a case study which, as discussed below, can experience a dismissive reception within academia. By contextualising the findings within a widely accepted, relevant model it validated findings and supported the analytical and evaluative process against the existing empirical evidence-base.

The Vulnerability-Stress-Adaptation model has been widely used to investigate the mechanisms by which relationships can break down over time in the face of stressors [54- 60]. Whilst it doesn't explain *how* these factors beget relational degradation or dissolution, it posits a helpful lens through which to structure empirical enquiry, grounding Sasha's novel experience within a known context, and the mechanisms within it (individual vulnerabilities, stress and communication) have been found to have predictive validity of marital satisfaction [61]. Furthermore, as more published research on the pandemic became available, an evidence base was emerging which largely corroborated Sasha's experience [56-58] which generated greater confidence in adopting this approach.

In the case of the literature review, a clear pattern emerged from the analysis of findings representative of the systemic rings depicted within Bronfenbrenner's Bioecological Systems Theory [62]. Whilst it was felt that the location of cultural experience did not neatly fall within the macrosystem as Bronfenbrenner et al, 1994, suggest [63], the model provided a useful, widely known and applicable framework though which to discuss findings[64,65], and indeed to demonstrate the presence of cultural inflections across and between all ecological systems. As discussed within the main body of the review, this is not the only model that could have been applied, but it was used as a structural tool to consider the findings and discussion, as opposed to a lens that directed the analysis.

Single case study design – Research paper

IPA is a well-known research approach that facilitates a structured process to guide the analysis of a phenomenon [66]. The use of IPA in single case study design is less well known and potentially the decision to opt for a single case study design is one that is also unusual within the context of the Clinical Psychology doctorate research.

Single case studies have been making contributions to the advancement of psychological and neurological issues in psychology for decades. Most psychologists will be familiar with the names Phineas Gage, HM, Kitty Genovese, David Reimer and Genie to name just a few [67]. Although often dismissed as a pilot study to generate hypotheses for larger scale research, the significance of findings and contributions that the above sample of case studies brought is evident. Case studies generate concrete, practical data that are dependent upon the context in which they take place [68].

When pandemic restrictions were lifted and the new normal began to emerge, there was an opportunity to revisit recruitment in order to carry out a more conventional sample size for multi-participant IPA [66]. However, in doing so, even if successful, the data collection timepoints would differ to Sasha's and be more reliant upon retrospective self-report. In light of a growing urge to employ avoidance strategies to prevent the psychological and emotional response of discussing the pandemic [69], it was possible that in trying to recruit more participants to observe conventions, the real potential of this research would be missed – a phenomena over time that could offer insights into the why and how questions [70].

Significant discussion took place in supervision, and also with other experts in the field. It was decided that to step away from the context would weaken the research, a sentiment best captured by Eysenck in 1976. "Sometimes we [have to] look carefully at individual cases—not in the hope of proving anything, but rather in the hope of learning something!" [68,p224]. The unique context of a global pandemic warranted in-depth exploration and Sasha's voice deserved a central position in that.

Ethics were given special attention to ensure that the interviews embraced beneficence. The participant information and informed consent forms were shared at prescreening, via email before each interview and verbally at the start of each interview. We agreed an easy visual signal should a question or topic not feel comfortable to discuss, a raised hand, and potential sources of support [71]. We ended each interview with a debrief on how it felt for her, any questions she had and potential service contacts. I followed up the interviews with a brief email check in to thank her for her time and offer a space if she wanted to reflect. She did not take up this offer. Similarly, in the write up care was taken to anonymise or remove any potential identifying information for any member of the family [71]. By respecting participants, we in turn sustain the reputation of our profession and future participant pool for subsequent research [72].

Aspects of quality assurance are discussed in the main body, however I felt it important to reflect upon the I and the P of IPA. As clinicians, our main interactions with N=1 situations is within a therapeutic setting, this created a tension for me during the analysis phase as I felt pulled towards the story to formulate and interpret, and needed to remind myself to step back and objectively analyse the themes of the phenomenon. Mastering this entailed many false starts but was supported through reflective journaling, ‘good example’ papers recommended by Michael Larkin, who has played a significant part in developing IPA methodology, and the support of an excellent and patient supervisor. Another design feature that helped to manage this tension was carrying out the analysis in 3 separate stages with time in-between; the rich density of the interview meant that it was best approached as distinct parts of the whole before seeking to tackle the phenomena as a whole across the timepoints.

Despite initial concerns that anything short of an RCT or a larger participant sample for IPA, would elicit problems in meeting the thesis criteria, I feel that Sasha brings a genuinely insightful account that demonstrates change over time, the importance of confronting the difficult feelings, and how significant the natural experiment of having nowhere else to look or hide in lockdown was in nourishing buds of significant growth. As a European migrant caregiver of a comparatively young care recipient within stroke populations whilst also working and being a parent, the dynamics, interrelatedness and ultimately, synthesis proved challenging, but I feel a sense of achievement in completing my first case study and feel that I have produced a piece of work that represents a fascinating woman and phenomenon.

I feel that with further investigation into the impact of well-timed therapeutic support for caregivers, at different timepoints post-stroke and in different formats, (face to face, online and/or in group settings), an evidence base could be built to endorse the commissioning of targeted caregiver services within stroke services. The case study format reveals a mode of action behind posttraumatic growth that supports a more proactive involvement of services; whilst we were all in the same storm, the levels of distress Sasha experienced were concerning and her sons were substantial protective factors for her at times. Proactive services could facilitate, structure and support the adjustment and reorientation process much earlier and in a much safer and more dignified way.

I also feel that other, more creative, methodologies including using workshops as a research method, could be employed to support appropriate training design, delivery and content on the practicalities of caregiving, stroke and health literacy. This approach would use the workshop as the vehicle to achieve research aims [73]. This could be appealing to a caregiver group, especially if there is a therapeutic, information or training benefit as part of the workshop research. Online technology and/or face to face methods could be used to achieve the aims, however in offering something that is so often noted as lacking for caregivers, it may open up new impetus for research participation.

A final amendment in the research design to support recruitment would be to have offered the online pre-screening questionnaire as an option, but otherwise conduct this on pen and paper or verbally. Whilst it felt suitable during pandemic times, it could have been a barrier for participants who did not have IT access or were not digitally literate.

Selection of research topics

I spent my previous career working with multi-cultural, socioeconomically deprived, inner-city families and have developed a keen interest in amplifying the voices that are often unheard or dismissed. Stroke felt to be a particularly interesting field of investigation because of the complex and diverse range of outcomes that can result across the body, brain and mind. Considering the prevalence of stroke, and number of family caregivers that are thrust into the role, I felt that research in this area had the potential to have a meaningful impact upon a large population. They appear to be too busy toiling in the background to access the platforms where change can be made.

Prior to commencing my doctoral studies, I worked with the most incredible young people whose stories were essential to informing pathways around barriers in their lives, yet who were assessed and compared against numerical targets, averages and norm deviations. Embracing the new freedoms to set my own parameters, I wanted my research to be about stories and not statistics. I believe that quantitative data has a very important role to play in advancing understanding, however I wanted to go deeper into the how and why questions and get to know the people behind the numbers. My previous qualitative stroke topic became unviable when the pandemic struck; conversely this also offered a unique opportunity to investigate a live and ongoing phenomenon.

References

1. Noblit, G. W., Hare, R. D., & Hare, R. D. (1988). *Meta-ethnography: Synthesizing qualitative studies (Vol. 11)*. Sage.
2. Bronfenbrenner, U., & Ceci, S. J. (1994). Nature-nurture reconceptualized in developmental perspective: A bioecological model. *Psychological Review, 101*(4), 568.
3. Murray, C. D., & Wilde, D. J. (2020). Thinking about, doing and writing up research using interpretative phenomenological analysis. In C. Walshe & S. Brearley (Eds.), Handbook of theory and methods in applied health research: Questions, methods and choices (pp. 140-166).Edward Elgar Publishing.
4. NHS Providers (n.d.) *Same storm, different boats: inequalities in the Covid pandemic*. https://nhsproviders.org/same-storm-different-boats#:~:text=A%20poem%20published%20at%20the,not%20in%20the%20same%20boat%22.
5. Feigin VL, Brainin M, Norrving B, Martins S, Sacco RL, Hacke W, Fisher M, Pandian J, Lindsay P. World Stroke Organization (WSO): Global stroke fact sheet 2022. *International Journal of Stroke. 2022 Jan;17*(1):18-29. doi: 10.1177/17474930211065917. Erratum in: *International Journal of Stroke. 2022 Apr;17*(4):478. PMID: 34986727.
6. Centers for Disease Control and Prevention. (2022, April 5). *Stroke facts.* Centers for Disease Control and Prevention. https://www.cdc.gov/stroke/facts.htm
7. Meschia, J. F., Merrill, P., Soliman, E. Z., Howard, V. J., Barrett, K. M., Zakai, N. A., Kleindorfer, D., Safford, M., & Howard, G. (2010). Racial disparities in awareness and treatment of atrial fibrillation: the REasons for Geographic and Racial Differences in

Stroke (REGARDS) study. *Stroke, 41*(4), 581-587.

8. Smith, M. A., Risser, J. M., Lisabeth, L. D., Moyé, L. A., & Morgenstern, L. B. (2003). Access to care, acculturation, and risk factors for stroke in Mexican Americans: the Brain Attack Surveillance in Corpus Christi (BASIC) project. *Stroke, 34*(11), 2671-2675.
9. Tsao, C.W., Aday, A.W., Almarzooq, Z.I., Alonso, A., Beaton, A.Z., Bittencourt, M.S., Boehme, A.K., Buxton, A.E., Carson, A.P., Commodore-Mensah, Y., Elkind, M.S.V., Evenson, K.R., Eze-Nliam, C., Ferguson, J.F., Generoso, G., Ho, J.E., Kalani, R., Khan, S.S., Kissela, B.M., Knutson, K.L., Levine, D.A., Lewis, T.T., Liu, J., Loop, M.S., Ma, J., Mussolino, M.E., Navaneethan, S.D., Perak, A.M., Poudel, R., Rezk-Hanna, M., Roth, G.A., Schroeder, E.B., Shah, S.H., Thacker, E.L., Vanwagner, L.B., Virani, S.S., Voecks, J.H., Wang, N.-Y., Yaffe, K., Martin, S.S., 2022. *Heart disease and stroke statistics—2022 update: A report from the American Heart Association.* Circulation 145. doi:10.1161/cir.0000000000001052
10. Stroke Association (2021, June) *Are you at risk of stroke?* https://www.stroke.org.uk/what-is-stroke/are-you-at-risk-of-stroke
11. Barker-Collo, S., Krishnamurthi, R., Theadom, A., Jones, K., Starkey, N., & Feigin, V. (2019). Incidence of stroke and traumatic brain injury in New Zealand: contrasting the BIONIC and ARCOS-IV studies. *The New Zealand Medical Journal (Online), 132*(1502), 40-54.
12. Heart and Stroke (2022, June 1). *Stroke month 2022: Key messages and background for media.* https://www.heartandstroke.ca/-/media/pdf-files/what-we-do/news/stroke-month-2022-backgrounder-for-media.pdf?rev=a88365a3f5a94dae9ebc8e8f4d0fc310

13. World Health Organization (2020, March 18). *Mental health and psychosocial considerations during the COVID-19 outbreak.* https://www.who.int/publications-detail/WHO-2019-nCoV-MentalHealth-2020.1
14. Cohen, S. A., Kunicki, Z. J., Drohan, M. M., & Greaney, M. L. (2021). Exploring changes in caregiver burden and caregiving intensity due to COVID-19. *Gerontology and Geriatric Medicine, 7*, 2333721421999279.
15. Otobe, Y., Kimura, Y., Suzuki, M., Koyama, S., Kojima, I., & Yamada, M. (2022). Factors associated with increased caregiver burden of informal caregivers during the COVID-19 pandemic in Japan. *The Journal of Nutrition, Health & Aging, 26*(2), 157-160.
16. Zwar, L., König, H. H., & Hajek, A. (2023). Gender differences in mental health, quality of life, and caregiver burden among informal caregivers during the second wave of the COVID-19 pandemic in Germany: A representative, population-based study. *Gerontology, 69*(2), 149-162.
17. Berg-Weger, M., & Morley, J. E. (2020). Loneliness and social isolation in older adults during the COVID-19 pandemic: Implications for gerontological social work. *The Journal of Nutrition, Health & Aging, 24*(5), 456-458.
18. Hanna, K., Giebel, C., Tetlow, H., Ward, K., Shenton, J., Cannon, J., Komuravelli, A., Gaughan, A., Eley, R., Rogers, C., Rajagopal, M., Limbert, S., Callaghan, S., Whittington, R., Butchard, S., Shaw, L., & Gabbay, M. (2022). Emotional and mental wellbeing following COVID-19 public health measures on people living with dementia and carers. *Journal of Geriatric Psychiatry and Neurology, 35*(3), 344-352.
19. Cohen, S. A., Nash, C. C., & Greaney, M. L. (2021). Informal caregiving during the

COVID-19 pandemic in the US: background, challenges, and opportunities. *American Journal of Health Promotion, 35*(7), 1032-1036.

20. Czeisler, M. É., Drane, A., Winnay, S. S., Capodilupo, E. R., Czeisler, C. A., Rajaratnam, S. M., & Howard, M. E. (2021). Mental health, substance use, and suicidal ideation among unpaid caregivers of adults in the United States during the COVID-19 pandemic: Relationships to age, race/ethnicity, employment, and caregiver intensity. *Journal of Affective isorders, 295*, 1259-1268.
21. Pierce, L. L. (2001). Caring and expressions of spirituality by urban caregivers of people with stroke in African American families. *Qualitative Health Research, 11*(3), 339-352.
22. Pierce, L. L., & Wilkinson, L. (1999). Caring and cultural maintenance and transformation for secondary urban family caregivers of persons with stroke. *Journal of Cultural Diversity, 6*(1), 5.
23. Greenwood, N., Holley, J., Ellmers, T., Mein, G., & Cloud, G. (2016). Qualitative focus group study investigating experiences of accessing and engaging with social care services: perspectives of carers from diverse ethnic groups caring for stroke survivors. *BMJ Open, 6*(1), e009498.
24. Pound, C., & Greenwood, N. (2016). The human dimensions of post-stroke homecare: Experiences of older carers from diverse ethnic groups. *Disability and Rehabilitation, 38*(20), 1987-1999.
25. Corbett, A., Francis, K., & Chapman, Y. (2006). The experience of whanau caring for members disabled from the effects of a cerebro-vascular accident. *Contemporary Nurse*, *22*(2), 255-263.
26. Katbamna, S., Manning, L., Mistri, A., Johnson, M., & Robinson, T. (2017). Balancing

satisfaction and stress: carer burden among White and British Asian Indian carers of stroke survivors. *Ethnicity & Health, 22*(4), 425-441.

27. Arabit, L. (2008). Coping strategies of Latino women caring for a spouse recovering from a stroke: A grounded theory. *Journal of Theory Construction & Testing, 12*(2), 42.
28. Torregosa, M. B., Sada, R., & Perez, I. (2018). Dealing with stroke: Perspectives from stroke survivors and stroke caregivers from an underserved Hispanic community. *Nursing & Health Sciences, 20*(3), 361-369.
29. Yeung, E. H., Szeto, A., Richardson, D., Lai, S. H., Lim, E., & Cameron, J. I. (2015). The experiences and needs of Chinese-Canadian stroke survivors and family caregivers as they re-integrate into the community. *Health & Social Care in the Community, 23*(5), 523-531.
30. Strudwick, A., & Morris, R. (2010). A qualitative study exploring the experiences of African-Caribbean informal stroke carers in the UK. *Clinical Rehabilitation, 24*(2), 159-167.
31. Magwood, G. S., Ellis, C., Nichols, M., Burns, S. P., Jenkins, C., Woodbury, M., & Adams, R. (2019). Barriers and facilitators of stroke recovery: perspectives from African Americans with stroke, caregivers and healthcare professionals. *Journal of Stroke and Cerebrovascular Diseases, 28*(9), 2506-2516.
32. Kara, H., Khoo, S. (2020, October 26). *How the pandemic has transformed research methods and ethics: 3 lessons from 33 rapid responses.* London School of Economics Impact Blog. https://blogs.lse.ac.uk/impactofsocialsciences/2020/10/26/how-the-pandemic-has-transformed-research-methods-and-ethics-3-lessons-from-33-rapid-responses/

33. Evans, B. (2020 June 4). *The Zoom revolution: 10 eye-popping stats from tech's new superstar.* Cloud Wars. https://cloudwars.co/covid-19/zoom-quarter-10-eye-popping-stats-from-techs-new-superstar/

34. Peters, P. (2020 April 29). *Google's Meet teleconferencing service now adding about 3 million users per day.* The Verge. https://www.theverge.com/2020/4/28/21240434/google-meet-three-million-users-per-day-pichai-earnings

35. Thorp-Lancaster D. (2020, April 29). *Microsoft Teams hits 75 million daily active users, up from 44 million in March.* Windows Central. https://www.windowscentral.com/microsoft-teams-hits-75-million-daily-active-users

36. Mikal, J. P., Beckstrand, M. J., Parks, E., Oyenuga, M., Odebunmi, T., Okedele, O., Uchino, B., Horvath, K. (2020). Online social support among breast cancer patients: longitudinal changes to Facebook use following breast cancer diagnosis and transition off therapy. *Journal of Cancer Survivorship, 14*, 322-330.

37. Pan, W., Feng, B., & Li, S. (2019). Online support groups dedicated to specific health problems. *Social Support and Health in the Digital Age, 109*.

38. Mitchell R. (2021, January 21). *How to overcome the challenges of doing research during Covid-19.* Institute of Development Studies. https://www.ids.ac.uk/opinions/how-to-overcome-the-challenges-of-doing-research-during-covid19/

39. Public Health England & Brine S (2018, February 1). *New figures show larger proportion of strokes in the middle aged.* Gov.Uk. https://www.gov.uk/government/news/new-figures-show-larger-proportion-of-strokes-

in-the-middle-aged https://www.gov.uk/governm

40. Heers, M., & Lipps, O. (2022). Overwhelmed by learning in lockdown: Effects of Covid-19-enforced homeschooling on parents' wellbeing. *Social Indicators Research, 164*(1), 323-343.
41. Escudero-Castillo, I., Mato-Díaz, F. J., & Rodriguez-Alvarez, A. (2021). Furloughs, teleworking and other work situations during the COVID-19 lockdown: Impact on mental well-being. *International Journal of Environmental Research and Public Health, 18*(6), 2898.
42. Witham, M. D., Anderson, E., Carroll, C. B., Dark, P. M., Down, K., Hall, A. S., Maher, E.R., Maier, R.H., Mountain, G.A., Nestor, G., O'Brien, J.T., Oliva, L., Wason, J., & Rochester, L. (2020). Ensuring that COVID-19 research is inclusive: guidance from the NIHR INCLUDE project. *BMJ Open, 10*(11), e043634.
43. Hallas, K. (2016, May 10). *Thesis link: Why you should use older references in your thesis.* Auckland University of Technology. https://thesislink.aut.ac.nz/?p=4865#:~:text=For%20example%2C%20if%20you%20notice,%2Dto%2Ddate%20empirical%20studies.
44. Archer, M., Sharp, R., Stones, R., & Woodiwiss, T. (1999). Critical realism and research methodology. *Alethia, 2*(1), 12-16. DOI: 10.1558/aleth.v2i1.12
45. Bhaskar, R. (1998). Philosophy and scientific realism. In M. Archer, R. Bhaskar, A. Collier, T. Lawson, & A. Norrie (Eds.), *Critical realism: Essential readings* (pp. 16–47). London: Routledge.
46. Sobolewska, M., & Ford, R. (2019). British culture wars? Brexit and the future politics of immigration and ethnic diversity. In G. Kelly & N. Pearce (Eds.), *Britain Beyond*

Brexit, The Political Quarterly, Vol 90, Issue S2 pp. 142–154. https://doi.org/10.1111/1467-923X.12646

47. Duszczyk, M., & Kaczmarczyk, P. (2022). War and migration: the recent influx from Ukraine into Poland and possible scenarios for the future. *CMR Spotlight, 4*(39).
48. Hauora, N. P., Gibson, D., Leach, D. T., & Coast, E. (2005) Implementing the primary health care strategy: A Māori health provider perspective. *Social Policy Journal of New Zealand: 25*
49. Chan, C. D., Henesy, R. K., & Erby, A. N. (2019). Toward praxis, promise, and futures of intersectionality in multimethod counseling research. *Counseling Outcome Research and Evaluation, 10*(1), 12-18.
50. Smith, L. T. (2021). *Decolonizing methodologies: Research and indigenous peoples*. Bloomsbury Publishing.
51. Alexandridis, K. T. (2006). *Exploring complex dynamics in multi agent-based intelligent systems: theoretical and experimental approaches using the multi agent-based behavioral economic landscape (MABEL) model* (Publication No. AAI3232142) [Doctoral dissertation, Purdue University]. ProQuest Dissertations Publishing.
52. Ratner, C. (2002, September). Subjectivity and objectivity in qualitative methodology. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research 30(*3).
53. McAbee, S. T., Landis, R. S., & Burke, M. I. (2017). Inductive reasoning: The promise of big data. *Human Resource Management Review*, *27*(2), 277-290.
54. Schiltz, H. K., & Van Hecke, A. V. (2021). Applying the vulnerability stress adaptation model of marriage to couples raising an autistic child: a call for research on adaptive

processes. *Clinical Child and Family Psychology Review*, *24*, 120-140.

55. Langer, A., Lawrence, E., & Barry, R. A. (2008). Using a vulnerability-stress-adaptation framework to predict physical aggression trajectories in newlywed marriage. *Journal of Consulting and Clinical Psychology*, *76*(5), 756.
56. Karantzas, G. C., Toumbourou, J. W., Knox, L., Greenwood, C. C., & Westrupp, E. M. (2023). Predicting the trajectories of parents' relationship well-being during COVID-19 lockdowns and beyond: A vulnerability, stress and adaptation model perspective. *Prevention Science*, 1-17.
57. Pietromonaco, P. R., & Overall, N. C. (2021). Applying relationship science to evaluate how the COVID-19 pandemic may impact couples' relationships. *American Psychologist, 76*, 438–450
58. Pietromonaco, P. R., & Overall, N. C. (2022). Implications of social isolation, separation, and loss during the COVID-19 pandemic for couples' relationships. *Current Opinion in Psychology, 43*, 189–194.
59. Sanchez-Ruiz, P., Maldonado-Bautista, I., & Rutherford, M. (2018). Business stressors, family-business identity, and divorce in family business: A vulnerability-stress-adaptation (VSA) model. *Journal of Family Business Strategy*, *9*(3), 167-179.
60. Clabburn, O. (2023). A qualitative exploration on the impact of cancer to adult relationships: Applying the Vulnerability Stress Adaptation model within couples therapy. *Journal of Couple & Relationship Therapy*, *22*(1), 86-104.
61. Ross, J. M., Nguyen, T. P., Karney, B. R., & Bradbury, T. N. (2022). Three tests of the Vulnerability-Stress-Adaptation Model: Independent prediction, mediation, and generalizability. *Frontiers in Psychology, 13*, 921485.

62. Bronfenbrenner, U., & Ceci, S. J. (1994). Nature-nurture reconceptualized in developmental perspective: A bioecological model. *Psychological Review, 101*(4), 568.
63. Vélez-Agosto, N. M., Soto-Crespo, J. G., Vizcarrondo-Oppenheimer, M., Vega-Molina, S., & García Coll, C. (2017). Bronfenbrenner's bioecological theory revision: Moving culture from the macro into the micro. *Perspectives on Psychological Science, 12*(5), 900-910.
64. Eriksson, M., Ghazinour, M. & Hammarström, A. (2018) Different uses of Bronfenbrenner's ecological theory in public mental health research: What is their value for guiding public mental health policy and practice?. *Social Theory and Health 16,* 414–433.
65. Paat, Y. F. (2013). Working with immigrant children and their families: An application of Bronfenbrenner's ecological systems theory. *Journal of Human Behavior in the Social Environment*, *23*(8), 954-966.
66. Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis.* SAGE Publications
67. Rolls, G. (2019). *Classic case studies in psychology*. Routledge.
68. Flyvbjerg, B. (2006). Five Misunderstandings About Case-Study Research. *Qualitative Inquiry, 12*(2), 219-245. https://doi.org/10.1177/1077800405284363
69. Ytre-Arne, B., & Moe, H. (2021). Doomscrolling, monitoring and avoiding: News use in COVID-19 pandemic lockdown. *Journalism Studies, 22*(13), 1739-1755.
70. Baxter, P., Jack. S (2008). Qualitative case study methodology: Study design and implementation for novice researchers. *The Qualitative Report, 13*(4) 544-559 https://www.nova.edu/ssss/QR/QR13-4/baxter.pdf

71. Barrow, J. M., Brannan, G. D., & Khandhar, P. B. (2022). *Research ethics.* StatPearls [Internet]. StatPearls Publishing FFC. PMID: 29083578. https://europepmc.org/article/NBK/nbk459281
72. Hopner, V., & Liu, J. H. (2021). Relational ethics and epistemology: The case for complementary first principles in psychology. *Theory & Psychology, 31*(2), 179-198.
73. Ørngreen, R., & Levinsen, K. (2017). Workshops as a research methodology. *Electronic Journal of E-Learning, 15*(1), 70-81.

Chapter 4 : Ethics

Ruth Hirst

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

All correspondence should be sent to:

Ruth Hirst

Doctorate in Clinical Psychology

Faculty of Health and Medicine

Health Innovation One

Sir John Fisher Drive

Lancaster University

Lancaster

LA1 4AT

r.kitchen@lancaster.ac.uk

Faculty of Health and Medicine Research Ethics Committee (FHMREC)
Lancaster University

Application for Ethical Approval for Research

for additional advice on completing this form, hover cursor over 'guidance'.

Guidance on completing this form is also available as a word document

Title of Project: A case study on the experience of being a carer in the UK during the Covid 19 pandemic for a partner who has had a stroke: identifying the implications for psychological support.

Name of applicant/researcher: Ruth Hirst

ACP ID number (if applicable)*: **Funding source (if applicable)**

Grant code (if applicable):

***If your project has *not* been costed on ACP, you will also need to complete the Governance Checklist [link].**

Type of study

☐Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. **Complete sections one, *two* and four of this form**

☒Includes *direct* involvement by human subjects. **Complete sections one, *three* and four of this form**

SECTION ONE

1. Appointment/position held by applicant and Division within FHM Trainee Clinical Psychologist

2. Contact information for applicant:

E-mail: r.kitchen@lancaster.ac.uk **Telephone**: [redacted] (please give a number on which you can be contacted at short notice)

Address: Doctorate in Clinical Psychology, Faculty of Health and Medicine, Health Innovation Campus, Lancaster University, Bailrigg, Lancaster, LA1 4YW

3. Names and appointments of all members of the research team (including degree where applicable)

Dr Craig Murray. Senior Lecturer, Lancaster University.
Dr Caroline Malone. Clinical Neuropsychologist, Bolton Royal Hospital.

3. If this is a student project, please indicate what type of project by marking the relevant box/deleting as appropriate: (please note that UG and taught masters projects should complete **FHMREC form UG-tPG**, following the procedures set out on the FHMREC website

PG Diploma ☐ Masters by research ☐ PhD Thesis ☐ PhD Pall. Care ☐

PhD Pub. Health ☐ PhD Org. Health & Well Being ☐ PhD Mental Health ☐ MD ☐

DClinPsy SRP ☐ [if SRP Service Evaluation, please also indicate here: ☐] DClinPsy Thesis ☒

4. Project supervisor(s), if different from applicant:
Dr Craig Murray. Senior Lecturer, Lancaster University.
Dr Caroline Malone. Clinical Neuropsychologist, Bolton Royal Hospital.

5. Appointment held by supervisor(s) and institution(s) where based (if applicable):
Dr Craig Murray. Senior Lecturer, Lancaster University.
Dr Caroline Malone. Clinical Neuropsychologist, Bolton Royal Hospital.

SECTION TWO Complete this section if your project involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants

1. Anticipated project dates (month and year)
Start date: End date:

2. Please state the aims and objectives of the project (no more than 150 words, in lay-person's language):

Data Management

For additional guidance on data management, please go to Research Data Management *webpage, or email the RDM support email:* rdm@lancaster.ac.uk

3. Please describe briefly the data or records to be studied, or the evaluation to be undertaken.

4a. How will any data or records be obtained?

4b. Will you be gathering data from websites, discussion forums and on-line ‘chat-rooms’

4c. If yes, where relevant has permission / agreement been secured from the website moderator?

4d. If you are only using those sites that are open access and do not require registration, have you made your intentions clear to other site users? 4e. If no, please give your reasons

5. What plans are in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

8. Confidentiality and Anonymity

a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications?

b. How will the confidentiality and anonymity of participants who provided the original data be maintained?

9. What are the plans for dissemination of findings from the research?

10. What other ethical considerations (if any), not previously noted on this application, do you think there are in the proposed study? How will these issues be addressed?

SECTION THREE Complete this section if your project includes *direct* involvement by human subjects

Summary of research protocol in lay terms (indicative maximum length 150 words):

The 2020 global Covid-19 pandemic led to national imposition of measures such as self-isolation, quarantine and social distancing that, whilst protecting physical health, have incurred psychosocial costs amongst the general population.

This research aims to explore the psychosocial experiences-of a partner stroke carer during the pandemic. It is hoped that, in developing our understanding of their specific experiences, emerging psychological support needs of this group can be identified which will contribute to follow up professional support planning and advanced preparation in the event of any future pandemics.

The participants will be recruited through support groups and social media. They will be invited to attend a emi-structured interview where their experiences will be explored. Interviews will be digitally recorded and a analysed using Interpretative Phenomenological Analysis (IPA)

2. **Anticipated project dates (month and year only)**

Start date: October 2020 End date January 2022

Data Collection and Management
For additional guidance on data management, please go to Research Data Management *webpage, or email the RDM support email:* rdm@lancaster.ac.uk

3. Please describe the sample of participants to be studied (including maximum & minimum number, age, gender):

The target sample will be partners of people who have experienced an ischaemic or haemorrhagic stroke, who have been living together in England during the 2020 Covid-19 pandemic. The participant will be recruited through the use of social media including Facebook support groups and Twitter and also national carer support organisations as detailed in the recruitment section of the research protocol). Participation is open to all genders, ages, ethnicities and sexual orientations provided they meet the following eligibility criteria.

nclusion Criteria

-Spouse/partner of someone who has had a first-time stroke (to ensure comparable post-stroke adjustment to caregiving)
-English speaking (Trainee is English speaking and the available funding would not enable translation or interpretation of recruitment materials, interviews and analysis of data etc in other languages)
-Able to participate and give informed consent (identified via the demographic questionnaire)
-Stroke event took place before January 2020 (ensuring that the stroke did not take place during the Covid lockdown and that the initial post-stroke adjustment phase has passed so that this does not become a confounding variable within the sample)
-Living together before and during the Covid 19 pandemic
-Recipient requires partner support related to outcomes of the stroke (this may range from ensuring they are not alone in the house to intimate care which will be ascertained within the pre-interview demographic questionnaire)
-Residing in England (to ascertain parity of lockdown and Covid restrictions imposed)
-Access to telephone or online interview medium

Exclusion Criteria

-Prior to the stroke the recipient had a pre-existing condition that required care and support for that diagnosis e.g. Alzheimers, Parkinsons, MS, MND etc. (to enable specific stroke care needs to be extrapolated)
-Recipient had a transient ischaemic attack (mini stroke) as care needs are typically preventative and unlikely to be comparable in nature to the care needs for haemorrhagic or ischaemic strokes

4. How will participants be recruited and from where? Be as specific as possible. Ensure that you provide the *full versions* of all recruitment materials you intend to use with this application (eg adverts, flyers, posters).

The primary recruitment source will be through a Stroke Association Emotional Support group, this is an established group facility located in Liverpool, and the facilitator of this group has expressed an interest, subject to ethics approval. If the desired participant has not been recruited within 2 months of advertising the study, then the researcher and supervisors will seek to expand the range of advertisement sites to include the use of professional Clinical Psychology Twitter accounts such as @LancsDClinPsy and the wider Stroke Association organisation, social media including Facebook support groups and Twitter and websites of other third sector support services such as The Carers Trust and Carers UK.

Anyone expressing an interest will be given a participant information sheet and asked to complete an online prescreening questionnaire which will ensure that the eligibility criteria are met before any interviews are arranged. Anyone expressing an interest in the project will be emailed the participant information sheet and a hyperlink to an online questionnaire created on Qualtrics. Qualtrics is an established software tool designed to gather experiential data through both open and closed question formats. (It is currently in use by the Lancaster DClinPsy programme to securely collect student voice data). The questionnaire will commence with the inclusion and exclusion criteria, as detailed in question 3 above. Where the respondent does not meet eligibility criteria they will be referred to the 'Cease Questions Message' which will ensure that no more data than is necessary to make a decision regarding eligibility, is being collected. Should they be eligible, then demographic data will then be collected to enable participant characteristics and interview preferences to be collected prior to the interview. Full details are outlined in Appendix 4 of the Research Protocol.

What will help them moving forward from the pandemic

6. What plan is in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc.)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

Storage, back up and security

Online interviews will be recorded using the MS Teams meeting recording function. MS Teams is an established video conferencing software tool used in many organisations, including Lancaster University. Within the software there is a 'more options' tab and a drop-down menu with an option to record the meeting; once selected the meeting is recorded until this is deselected at the end of the meeting. Once the meeting has stopped recording, a video is automatically uploaded to MS Stream, a private and secure area within the University platform from where the video will be cut and pasted into my personal OneDrive

account, also on the University platform. All software tools used for this option are located within the University network thereby ensuring security of recording and storage at all times. In the event of alternative online platforms being requested, these will be recorded via Dictaphone.
Telephone calls will be recorded using a Dictaphone.
Interviews will be transcribed on MS Word with participants being given pseudonyms as soon as interviews are complete to ensure participants' confidentiality.
Any paper printouts created by the researcher to assist with data analysis process will be stored in a locked filing cabinet at the researcher's home when not in use. All paper copies will be shredded as soon as the coding process is complete.
All electronic data will be uploaded to Lancaster University's OneDrive as password protected documents and stored there during the data analysis process. The University has the necessary IT network support in place to ensure greater protection of electronic data.
In addition to the researcher, the research supervisor and field supervisors will be given online access to the transcribed interviews via OneDrive in order to share perspectives on the emergence and classification of data themes
After the study is complete, the electronic data will be kept by Lancaster University for 10 years, after which the data will be deleted by the Research Coordinator on the DClinPsy course in accordance with the GDPR and Data Protection Act 2018.

7. Will audio or video recording take place? ☐ no ☒ audio ☒ video
a. Please confirm that portable devices (laptop, USB drive etc) will be encrypted where they are used for identifiable data. If it is not possible to encrypt your portable devices, please comment on the steps you will take to protect the data.

Recordings will be uploaded directly to the secure University storage area as soon as possible after interviews

b What arrangements have been made for audio/video data storage? At what point in the research will tapes/digit
recordings/files be destroyed?

Recordings will be stored until the research has been examined, and potentially published. At this point all recordi
deleted. At the end of the study, anonymised written
e transferred electronically to the DClinPsy Research Coordinator using a secure method supported by the
e stored for 10 years before being deleted by the research co

e following questions *only* if you have not completed a Data Management Plan for an external

How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE

At the end of the study, anonymised written transcripts will be transferred electronically to the DClinPsy

Research Coordinator using a secure method supported by the University. These transcripts will be stored for 10 years before being deleted by the research co-ordinator

8b. Are there any restrictions on sharing your data ?

Access to the data will be permitted to verify data collection has taken place. Data will not be shared with other researchers until the applicant has published the results of the study. Following this, the decisions to share the data will be made by the research team on a case-by-case basis where the purpose is to conduct a secondary analysis of the data for publication.

9. Consent

a. Will you take all necessary steps to obtain the voluntary and informed consent of the prospective participant(s) or, in the case of individual(s) not capable of giving informed consent, the permission of a legally authorised representative in accordance with applicable law? yes

b. Detail the procedure you will use for obtaining consent?

At the start of the interview, the consent form will be reviewed; each point will be read out and will need to attain explicit verbal agreement from the participant prior to the interview questions being asked. The consent form will be recorded as a separate recording from the interview. The participant will be given a pseudonym for confidentiality purposes and both their consent form and interview will be recorded with the pseudonym as the given file name

10. What discomfort (including psychological eg distressing or sensitive topics), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks. State the timescales within which participants may withdraw from the study, noting your reasons.

participants may experience distress in relation to recalling difficult experiences relating to their partner's stroke event, any resulting difficulties their partner experienced and the experience of the Covid pandemic relating to experiences of being a carer and other issues such as the death of friends or relatives to Covid.

Participant levels of distress will be carefully monitored throughout the process to minimise distress. They will be encouraged, as part of the introductory information, to reflect upon their own mental state and inform the researcher should they wish to take a break or stop the interview. It is anticipated that, having the opportunity to share their experiences and difficulties may have validating and cathartic benefits in itself. However, if it is felt that the participant is experiencing distress then the researcher will proactively pause the interview to ask them if they wish to continue, take a break, stop the interview and continue another day, or stop and withdraw from the process. At the end of the interview, the participant's' wellbeing will be ascertained in order that the researcher can signpost them to available sources of support where appropriate (e.g. GP, Samaritans, Carers UK). In addition, the researcher will, as a matter of course, carry out a wellbeing check phonecall the following day where distress during the interview is apparent or indicated by the participant.

days following the interview. This will be explicitly stated within both the participant information sheet and consent process.

11. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling considerations arising from the sensitive or distressing nature of the research/topic; details of the lone worker plan you will follow, and the steps you will take).

I will not be meeting the participant in person, all interviews will be conducted online or over the telephone. I will be providing a University email addresses and mobile phone number (non personal, research mobile phone) to potential study participants for recruitment and interviewing purposes to safeguard myself. I have set up professional Twitter and Facebook accounts, purely for the purposes of this study, which contains no personal information other than my name on it.

Should I require support in managing risk or distress, I will seek it from my field or research supervisor as necessary.

12. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

Whilst it is anticipated that the participants may gain some cathartic benefit from discussing their experiences, there will be no direct benefit from participating. It is hoped that their participation may contribute to an evidence base for supporting carers' psychological needs moving forwards through the pandemic and beyond.

13. Details of any incentives/payments (including out-of-pocket expenses) made to participants:
n/a

14. Confidentiality and Anonymity
a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications? yes
b. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality.

The research will not require names to be used in any public domain, and all transcriptions of video and audio recordings will use pseudonyms, maintaining anonymity. Full confidentiality cannot be promised, as direct quotes may be used, however the participant is explicitly made aware of this in the participant information and consent form

As this is a case study, further steps to protect anonymity will be taken. Their specific location, nationality/place of birth, occupational details and/or other potentially identifying characteristics will be withheld or generalised based on whether it is pertinent to understanding their experience. For example, location is pertinent to understanding lockdown frequency and length and therefore the context of the participant's experience. Location will be referred to by the general region [redacted], occupation [redacted] as opposed to anything that may be suggestive of employer, where [redacted] and thus identify the participant), nationality will refer to the continent [redacted] as opposed to the country of origin etc.

The limits of confidentiality will be explained to the participant at the beginning of the interview and addressed within the consent form. If a disclosure takes place which indicates any safeguarding issues then confidentiality will be revisited and the interview will be terminated. This issue would then be reported to supervisors and relevant safeguarding procedures would be adhered to. Types of disclosures that could result in confidentiality being broken include harm to self or to others.

15. If relevant, describe the involvement of your target participant group in the *design and conduct* of your research.

Unfortunately, in light of the recent Covid restrictions, this has not been possible.

16. What are the plans for dissemination of findings from the research? If you are a student, include here your thesis.

The raw data from this research will be seen by the research team members, comprising of the named researcher and supervisors. In terms of dissemination, this piece of research will contribute to a thesis as part of the Doctorate in Clinical Psychology. In addition, it is hoped that a summary of the project will be submitted to a peer reviewed journal for publication. The participants will also be offered a summary of the findings.

17. What particular ethical considerations, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek guidance from the FHMREC?

The researcher has historical experience of being a familial ‘young carer’ (in the role of daughter and sibling, as opposed to that of a partner) and as such will need to be aware of their own perspectives during the project. This will include remaining impartial and focusing on participant’s responses and experiences. This will be managed through use of supervision and a reflective diary.

SECTION FOUR: signature

Applicant electronic signature: R. Hirst

Date 08.10.2021

Student applicants: please tick to confirm that your supervisor has reviewed your application, and that they are happy for the application to proceed to ethical review ☒

Project Supervisor name (if applicable): Dr Craig Murray

Date application discussed 08.10.2021

Submission Guidance

1. Submit your FHMREC application by email to Becky Case (fhmresearchsupport@lancaster.ac.uk) as two separate documents:
    - i. **FHMREC application form.**
      Before submitting, ensure all guidance comments are hidden by going into 'Review' in the menu above then choosing *show markup>balloons>show all revisions in line.*
    - ii. **Supporting materials.**
      Collate the following materials for your study, if relevant, into a single word document:
        - a. Your full research proposal (background, literature review, methodology/methods, ethical considerations).
        - b. Advertising materials (posters, e-mails)
        - c. Letters/emails of invitation to participate
        - d. Participant information sheets
        - e. Consent forms
        - f. Questionnaires, surveys, demographic sheets
        - g. Interview schedules, interview question guides, focus group scripts
        - h. Debriefing sheets, resource lists

   Please note that you DO NOT need to submit pre-existing measures or handbooks which support your work, but which cannot be amended following ethical review. These should simply be referred to in your application form.

2. Submission deadlines:
    - i. Projects including direct involvement of human subjects **[section 3 of the form was completed]**. The *electronic* version of your application should be submitted to Becky Case **by the committee deadline date.** Committee meeting dates and application submission dates are listed on the FHMREC website. Prior to the FHMREC meeting you may be contacted by the lead reviewer for further clarification of your application. Please ensure you are available to attend the committee meeting (either in person or via telephone) on the day that your application is considered, if required to do so.
    - ii. The following projects will normally be dealt with via chair's action, and may be submitted at any time. **[Section 3 of the form has *not* been completed, and is not required].** Those involving: a. existing documents/data only;
      b. the evaluation of an existing project with no direct contact with human participants; c. service evaluations.

3. **<u>You must submit this application from your Lancaster University email address, and copy your supervisor in to the email in which you submit this application</u>**

Appendix 4-A

RESEARCH PROTOCOL

September 2020

Title: A case study on the experience of being a carer in the UK during the Covid 19 pandemic for a partner who has had a stroke: identifying the implications for psychological support.

Applicant: Ruth Hirst

Research Supervisor: Dr Craig Murray. Senior Lecturer, Lancaster University

Field Supervisor: Dr Caroline Malone. Clinical Neuropsychologist, Bolton Royal Hospital.

Introduction

Stroke affects 1 in 6 people across the globe (World Stroke Organisation, 2019). As mortality rates fall, the burden upon informal care support increases; a large proportion of this care falls to spouses/partners (‘partners’ henceforth) (Haley et al., 2010). It is important to understand the psychosocial impact of caring for a spouse or partner with stroke (‘recipients’ henceforth) in order to sustain the relationship, and the health and quality of life of both partners and recipients.

The demands placed upon partners can be significant in magnitude and complexity; as a result, they can be at risk of becoming patients themselves without appropriate support (Alexander & Wilz,2010; McCarthy & Bauer, 2015; Sit et al., 2004). The initial ‘crisis’ of post-stroke adjustment appears more prevalent in the initial year following the stroke event (Green & King, 2007; Lutz et al., 2011). Kruithof et al. (2016) found that, whilst reduced from 32% within the first 2 months post-stroke, 19.2% of partners reported ongoing difficulties with anxiety after the first year. The World Health Organisation declared Covid-19 a pandemic in March 2020, stating it was ‘generating stress throughout the [global] population’ (World Health Organisation, 2020). Recipients are identified as having a higher risk of complications if they contract Covid-19; comorbidity with other high-risk groups, such as those with heart conditions or diabetes, is also more likely (Stroke Association, 2020). Additional efforts to protect recipients from exposure to Covid-19 could thus exacerbate inherent stress and anxiety amongst partners (Alberta Critical Incident Provincial Network, (ACIPN) 2020).

Governmental responses to Covid-19 in the UK began in February 2020, where frequent handwashing, ‘social distancing’ (including maintaining a distance of 2 metres from people who are not residing with you even if they are family) was advised, along with self-isolation and quarantine of between 7 to 14 days should any symptoms of the virus be displayed (Beadsworth & Walawalkar, 2020). On 23rd March compulsory ‘lockdown’ measures were introduced whereby schools and many business were closed and all citizens were advised to stay at home. People could leave home only for essential reasons such as, buying foodstuffs and medicine, provision of medical care to vulnerable persons and a daily walk unless they were deigned ‘key workers’ (BBC, 2020).

Visser-Meilly et al. (2008) found over half of partners report depressive symptoms within the first three years of the stroke event which contributes to low relationship satisfaction (Kruithof et al., 2016). Described as a life of ‘caregiving and that’s all’ within non-pandemic times (Lopez-Espuela et al., 2018), dissatisfaction could be exacerbated by restrictions imposed by Covid-related quarantine, social distancing and self-isolation.

Alternatively, post-stroke coping research suggests that, if partners are able to identify interdependence within their relationship, perceived stress can reduce (Godwin et al., 2013). Indeed, post traumatic growth has been observed in national crisis situations, which could see strengthened partner-recipient relationships and connections emerging (ACIPN, 2020).

A significant protective factor in partners' mental health is social contact and connection. Support and contact from extended family can counter partners' negative feelings and sense of isolation (Adriaansen et al., 2012; Luerbe-Puerto et al., 2012; Pringle et al., 2013). Stroke can result in leisure loss for partners, something found more acutely with male partners (Forsberg-Warelby et al., 2004). Male partners have also been found to rely more on family for emotional support than female partners as they have less access to this within social circles. (Larson et al, 2008; Pierce et al., 2004). This concurs with disaster response research which suggested familial contact and social engagement are fundamental psychological first aid responses (Schreiber et al., 2006). Engaging in enjoyable activities and ensuring good self-care habits such as maintaining a good sleep routine and eating healthily are also recommended (Schreiber et al., 2006). However, the unique phenomena of life under lockdown creates significant challenges for social connection, accessing resilient support and engaging respite care which, in turn, can reduce capacity for partners' self-care (Gray, 2020).

Literature searches reveal a lack of research into informal carers' experiences during national crises. With a high incidence rate and wide-ranging needs, partners present a significant, potentially vulnerable, group. Evidence-based guidance can support professional in devising preventative crisis responses and in identifying potentially longer term demands on services.

The current project aims at exploring the experiences and perspectives of people who are partner carers of someone who has experienced a stroke. The main research question is: "What are the psychosocial experiences of partners during the Covid 19 pandemic in the UK?" It is hoped that, in exploring this, any emerging needs of this particular community resulting from their experiences of caring during the Covid 19 pandemic may be highlighted. Additionally, it may provide an insight for psychological services' planning, practice and intervention in the face of potential future national crises.

Method

Design

The research will be conducted via semi-structured interviews, with a brief demographic questionnaire being employed as part of the recruitment screening process. One-to-one semi-structured interviews will be used to gather the perspectives of the participant on their experiences of caring for their stroke-affected partner during the Covid 19 pandemic.

A semi-structured interview approach has been chosen to enable the gathering of rich experiential data, whilst bringing structure and standardised elements to the interviews. Interviews will be conducted online via MS Teams for example, or via telephone; the medium selected will be based upon the technology available to, and preferred by, the participant.

Demographic data collected through the pre-screening questionnaire will be analysed via descriptive analysis. Data collected from the interviews will be transcribed verbatim and analysed using Interpretative Phenomenological Analysis as it is a method more commonly used with single participant data due to its emphasis on idiographic analysis.

Participants

The sample will comprise of a single participant who meets the criteria outlined below.

Inclusion Criteria

- Spouse/partner of someone who has had a first-time stroke (to ensure comparable post-stroke adjustment to caregiving)
- English speaking (Trainee is English speaking and the available funding would not enable translation or interpretation of recruitment materials, interviews and analysis of data etc in other languages)
- Able to participate and give informed consent (identified via the demographic questionnaire)
- Stroke event took place before January 2020 (ensuring that the stroke did not take place during the Covid lockdown and that the initial post-stroke adjustment phase has passed so that this does not become a confounding variable within the sample)
- Living together before and during the Covid 19 pandemic
- Recipient requires partner support related to outcomes of the stroke (this may range from ensuring they are not alone in the house to intimate care which will be ascertained within the pre-interview demographic questionnaire)
- Residing in England (to ascertain parity of lockdown and Covid restrictions imposed)
- Access to telephone or online interview medium

Exclusion Criteria

- Prior to the stroke the recipient had a pre-existing condition that required care and support for that diagnosis e.g. Alzheimers, Parkinsons, MS, MND etc. (to enable specific stroke care needs to be extrapolated)
- Recipient had a transient ischaemic attack (mini stroke) as care needs are typically preventative and unlikely to be comparable in nature to the care needs for haemorrhagic or ischaemic strokes

Materials

- Recruitment advert (Appendix 1)
- Participant information sheet (Appendix 2)
- Consent form (Appendix 3)
- Pre-screening demographic questionnaire via Qualtrics (Appendix 4)
- Interview schedule (Appendix 5)

Recruitment

The recruitment plan will entail 4 main approaches to ensure an appropriate participant-is recruited

1. Recruitment advertisement on Facebook stroke and carer-related support groups
2. Recruitment poster with the Stroke Association's Emotional Support Service based in Liverpool and via the leader of the group
3. Recruitment poster on the @LancsDClinPsy Twitter account, and other professional accounts.
4. Recruitment poster on websites of carer support organisations. For example, I will contact Carers UK (www.carersuk.org) and Carers Trust (www.carers.org) via their websites and contact information and ask them to share the recruitment poster on their social media and websites to access another source of potential participants.

I will contact the group administrators of specific Facebook groups set up for the purpose of enabling stroke carers and survivors to discuss issues around caring responsibilities and the challenges associated with having a stroke (e.g. 'Stroke Caregivers Support Group', 'Carers of Stroke Survivors'). My advertisement will be posted on the Lancaster University DClinPsy facebook page Doctorate in Clinical Psychology at Lancaster University |

Facebook . If the group administrators are agreeable, I will ask them to share the advertisement and details of my study to their pages in order for their members to access.

Some Facebook support group pages specifically state that they do not want to be contacted by researchers, I will ensure that I adhere to these rules at all times and will refrain from contacting any such groups. Where such conditions exist they are set out in the Membership details (Public and Private groups have these - see Appendix 6 for example of Group Rules set by Group administrators.)

Facebook is a more commonly used social media platform amongst my target participants and will enable me to reach a higher number of people in order to secure a suitable and willing participant

I will set up a professional Twitter account for the express purposes of the research which will enable people interested in taking part to access more information about the research. The Twitter account will post the inclusion/exclusion criteria, a link to the pre-screening electronic survey, participant information sheet and my university email contact details for people wanting more information or to volunteer their participation.

I will follow up all enquiries by email, from my university account, and send out a copy of the participant information sheet and a link to the pre-screening questionnaire. Participants will be able to indicate their availability for interviews and preferred method for conducting the interview (telephone or online) via the prescreening questionnaire. Where a participant meets the necessary criteria, I will then confirm a date and time for the interview with them and send an online meeting invite out to them as appropriate.

Procedure

Pre-screening:

Volunteers will be asked to complete the pre-screening electronic questionnaire to confirm their details against the inclusion and exclusion criteria. In addition, they will be asked to provide basic demographic information regarding age, gender, ethnicity, sexuality, marital status, region within the UK, length of relationship, employment status and post-stroke disability in their partner.

Anyone expressing an interest in the project will follow a hyperlink which contains the participant information sheet and the online questionnaire created on Qualtrics. Qualtrics is an established software tool designed to gather experiential data through both open and closed question formats. The questionnaire will commence with volunteers being asked to confirm their circumstances against the inclusion and exclusion criteria. Where the respondent does not meet eligibility criteria they will be referred to a 'Cease Questions Message' which will ensure that no more data than is necessary to make a decision regarding eligibility, is being collected. Should they be eligible, then demographic data (including age, gender, ethnicity, sexuality, marital status, region within the UK, length of relationship, employment status and post-stroke disability in their partner) will then be collected. This will provide relevant information about participant characteristics beyond the Covid-19 experience that may impact upon the nature of their experience. Finally, participants' preferences relating to interview medium will be collected to facilitate interview arrangements. Full details are outlined in Appendix 4 of the Research Protocol

Interviews:

All aspects of the interviews will be recorded, either via Teams or a Dictaphone. MS Teams is an established video conferencing software tool used in many organisations. Within the software there is a 'more options' tab and a drop-down menu with an option to record the meeting; once selected the meeting is recorded until this is deselected at the end of the meeting. Once the meeting has stopped recording, a video is automatically uploaded to MS Stream, a private and secure area within the University platform, from where the video will be cut and pasted into my personal OneDrive account, also on the University platform. As all software tools used for this option are located within the University network security of recording and storage is thereby ensured at all times.

At the start of the interview, there will be a review of the consent form; each point will be read out and will need to attain explicit verbal agreement from the participant prior to the interview questions being asked. The consent form will be recorded as a separate recording from the interview. The participant will be given a pseudonym for confidentiality purposes and both their consent form and interview will be recorded with the pseudonym as the given file name. Following the consent recording, the interviewer will ascertain that the participant is happy to continue and will be reminded of their right to withdraw at any time during the interview and/or up to 2 weeks post interview to ensure that they have a cooling off period.

A new recording will be started for the interview. It will commence with some engagement questions to relax the participant and to gain some background information regarding the relationship and stroke incident as per the interview schedule. Following this, the interview will be guided by the interview schedule with follow up/expansion questions being employed as deemed appropriate. The interview will end with an opportunity for the participant to ask questions and to reflect on how they found the process.

Following initial analysis of the transcript, the participant will be invited to take part in a second semistructured interview. The purpose of this will be to strengthen and increase the data gathered in the initial interview.

It is anticipated that the participant may experience some distress when recounting their experiences and that their levels of distress will need careful monitoring throughout the process. They will be encouraged, as part of the introductory information, to reflect upon their own mental state and inform me should they wish to take a break or stop the interview. It is anticipated that~~,~~ having the opportunity to share their experiences and difficulties may have validating and cathartic benefits in itself. However, if it is felt that the participant is experiencing distress then I will proactively pause the interview to ask them if they wish to continue, take a break, stop the interview and continue another day, or stop and withdraw from the process. At the end of the interview, their wellbeing will be ascertained in order that the researcher can signpost them to available sources of support where appropriate (e.g. GP, Samaritans, Carers Trust). In addition, the researcher will, as a matter of course, carry out a wellbeing check phonecall the following day where distress during the interview is apparent or indicated by the participant.

Data analysis

All sound and video files will be stored to Lancaster University's OneDrive account. I will transcribe the interviews verbatim and store them on OneDrive. Data will be analysed using Interpretative Phenomenological Analysis (IPA) following the process laid out by Smith et al (2012), the stages are briefly summarised as follows:

1. Reading and rereading of the transcript to become immersed in the participant's experience
2. Initial noting: recording descriptive, linguistic and conceptual observations and summary notations in the margin of the transcript as it is being read.
3. Developing emergent themes: analysing and organising the summary notations into chunks that capture the participant's words and experiences alongside the researcher's understanding and interpretation
4. Searching for connections across emergent themes: clustering of the summary notations and observational notes into chunks of data within the transcript and considering how they relate.

5. Moving the interpretation to a deeper level: reviewing the individual themes and, through a process of merging, collapsing and relabelling them, creating superordinate themes that represent the data ideographically and meaningfully
6. Produce the report in a concise, coherent and interesting way that captures the experiences told within the data, including relevant participant quotes, and provides a detailed interpretative commentary

During the analysis, I will seek regular consultation with my supervisors to ensure that my analysis is carried out appropriately. I will also keep a reflexive research diary to record the process from my own perspective, in order to be able to identify and reflect upon any potential influence from my own values, experiences and beliefs that may otherwise enter the coding and interpretation of the data generated.

Data Management

All data collected with and about participants, including video and audio interview recordings, transcripts, prescreening data and personal data, will be password protected and stored in Lancaster University's OneDrive area. Interviews will be transcribed on MS Word with the participant and their partner being given pseudonyms as soon as interviews are complete to ensure confidentiality. Any paper printouts created by the researcher to assist with data analysis process will be stored in a locked filing cabinet at the researcher's home when not in use. All paper copies will be shredded as soon as the coding process is complete.

Audio and video recordings will be uploaded directly onto OneDrive from the recording device directly following the interview in a password protected folder. Where there are any technical difficulties with accessing the network, data will be password protected and stored on an encrypted USB stick, stored in a locked filing cabinet, and uploaded to OneDrive as soon as the function becomes available again.

Access to the data will be restricted to the researcher and, for the purposes of providing feedback and guidance, the research and field supervisors. Once the project is complete, audio and video recordings will be deleted. All other confidential and personal electronic data will be kept by Lancaster University for 10 years, after which the data will be deleted by the Research Coordinator on the DClinPsy programme in accordance with the GDPR and Data Protection Act 2018.

Ethical considerations

- *Anonymity:* The identity of the participants taking part in the research will only be known to the researcher who will keep all participant information confidential. On completion of the interview, the participant and their partner will be allocated a pseudonym and, from that moment forwards will only be referred to by their pseudonym. The participants will be made aware of the limits of anonymity of verbatim quotes in qualitative research within the consent to participate process, both verbally and in writing. As this is a case study, further steps to protect anonymity will be taken. Their specific location, nationality/place of birth, occupational details and/or other potentially identifying characteristics will be withheld or generalised based on whether it is pertinent to understanding their experience. For example, location is pertinent to understanding lockdown frequency and length and therefore the context of the participant's experience. Location will be referred to by the general region (South East), occupation (hospitality as opposed to anything that may be suggestive of employer, where few employers in this industry may exist and thus identify the participant) and nationality will refer to the continent (mainland Europe) as opposed to the specific country etc.
- *Confidentiality:* The participants will be made aware of confidentiality of the data and its limits in the participant information sheet and they will be further reminded of this within the introductory script. For the purposes of safeguarding, they will be reminded of the exception to this relating to disclosures indicating potential for serious harm to themselves or others. If this were to occur then, whenever

possible, this will first be discussed with the participant, followed by urgent consultation with the research supervisor and any necessary actions to reduce or remove the source of risk.

- *Containing potential distress:* As discussed within the procedure, participant distress levels will be closely monitored by the researcher and feedback from the participant will be invited both during and after the interview. In the event of participant distress, this will be offering the option to pause, take a break, stop and continue another day or stop and withdraw from the process. In the event that distress has been indicated by the participant or noted by the researcher during the interview, a follow up phonecall will be made the next day. In addition, they will be signposted to sources of support within the participant information sheet and reminded of this within the closing stage of the interview.
- *Right to withdraw:* The participants will be informed of their right to withdraw from the interview at any stage, and to withdraw their data within 2 weeks of the interview taking place. This will be explicitly stated within both the participant information sheet and consent process.
- *Informed consent:* As indicated within the procedure, details of the research will be available via the participant information sheet prior to any participant agreeing to take part in an interview. In addition, a verbal consent form process will take place as a standard pre-cursor of each interview to ensure that the implications of participation are explicitly explained and agreed to prior to any interview discussion taking place.

Approximate Timescales

- Submit application to University ethics: October 2020
- Recruitment Process: November 2020
- Data collection: December 2020 - January 2021
- Data analysis: January 2021 – February 2021
- Research paper writing up: February – March 2021
- Submission of draft report: April 2020
- Deadline for submission of final report: May 2020
- Dissemination to the Field Supervisor’s Stroke Service and Stroke Association where applicable. Copy to be sent to participants: Summer 2021
- Submit for Publication: Summer 2021

References

ACIPN Alberta Critical Incident Provincial Network (2020, April 7) Coping with Stress of COVID-19 for Public Safety Personnel [video]. YouTube. https://www.youtube.com/watch?time_continue=2868&v=IStpr3lsMG8&feature=emb_title

Adriaansen, J. J. E., van Leeuwen, C. M. C., Visser-Meily, J. M. A., van den Bos, G. A. M., & Post, M. W. M. (2011). Course of social support and relationships between social support and life satisfaction in spouses of recipients with stroke in the chronic phase. *Recipient Education and Counseling, 85(2)*

Alexander, T., & Wilz, G. (2010). Family caregivers: Gender differences in adjustment to stroke survivors' mental changes. *Rehabilitation Psychology, 55(2),* 159–169

Appelros, P., Stegmayr, B., & Terént, A. (2009). Sex differences in stroke epidemiology: a systematic review. *Stroke*, *40*(4), 1082-1090.

Barker-Collo, S., Bennett, D. A., Krishnamurthi, R. V., Parmar, P., Feigin, V. L., Naghavi, M., ... & Vos, T. (2015). Sex differences in stroke incidence, prevalence, mortality and disability-adjusted life years: results from the Global Burden of Disease Study 2013. *Neuroepidemiology*, *45*(3), 203-214.

BBC (2020, March 20) *UK pubs and restaurants told to shut in virus fight. https://www.bbc.co.uk/news/uk51981653*

Beadsworth, J & Walawalkar, A. (2020, May 10) *UK coronavirus timeline: from liberty to lockdown.* Each Other. https://eachother.org.uk/uk-coronavirus-timeline-from-liberty-to-lockdown/

Forsberg-Warleby, G., Moller, A., & Blomstrand, C. (2004). Life satisfaction in spouses of recipients with stroke during the first year after stroke. *Journal of rehabilitation medicine*, *36*(1), 4-11.

Godwin, K. M., Swank, P. R., Vaeth, P., & Ostwald, S. K. (2013). The longitudinal and dyadic effects of mutuality on perceived stress for stroke survivors and their spousal caregivers. *Aging & Mental Health, 17(4),* 423–431.

Gray, M. [@artybagger]. (2020, April 18). Hello home carers again. This is the time of night you wish you could sleep. But you're still on duty.[Tweet]. Twitter. *https://twitter.com/ArtyBagger/status/1251308442607910916*

Green, T. L., & King, K. M. (2007). The trajectory of minor stroke recovery for men and their female spousal caregivers: Literature review. *Journal of Advanced Nursing, 58(6)*, 517–531.

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough?: An experiment with data saturation and variability. *Field Methods, 18*, 59–82. doi:10.1177/1525822X05279903

Kruithof, W. J., Post, M. W. M., van Mierlo, M. L., van den Bos, G. A. M., de Man-van Ginkel, J. M., & VisserMeily, J. M. A. (2016). Caregiver burden and emotional problems in partners of stroke patients at two months and one year post-stroke: Determinants and prediction. *Patient Education and Counseling, 99(10)*, 1632–1640

Larson, J., Franzén-Dahlin, Å., Billing, E., von Arbin, M., Murray, V., & Wredling, R. (2008). The impact of gender regarding psychological well-being and general life situation among spouses of stroke recipients during the first year after the recipients' stroke event: A longitudinal study. *International Journal of Nursing Studies, 45(2),* 257–265.

López-Espuela, F., González-Gil, T., Amarilla-Donoso, J., Cordovilla-Guardia, S., Portilla-Cuenca, J. C., & CasadoNaranjo, I. (2018). Critical points in the experience of spouse caregivers of recipients who have suffered a stroke A phenomenological interpretive study. PLoS ONE, 13(4).

Luerbe-Puerto, K., Leandro, M.-E., & Baumann, M. (2012). Experiences of caregiving, satisfaction of life, and social repercussions among family caregivers, two years post-stroke. *Social Work in Health Care, 51(8),* 725–742

Lutz, B. J., Young, M. E., Cox, K. J., Martz, C., & Creasy, K. R. (2011). The crisis of stroke: Experiences of recipients and their family caregivers. Topics in Stroke Rehabilitation, 18(6), 786–797

McCarthy, M. J., & Bauer, E. (2015). In sickness and in health: Couples coping with stroke across the life Span. *Health & Social Work, 40(3),* e92e–100

Pierce, L. L., Steiner, V., & Olson, D. A. (2004). What are male caregivers talking about? *Topics in Stroke Rehabilitation, 11(2),* 77–83.

Pringle, J., Drummond, J.S., & McLafferty, E. (2013) Revisioning, reconnecting and revisiting: the psychosocial transition of returning home from hospital following a stroke, Disability and Rehabilitation, 35:23, 19911999, DOI: 10.3109/09638288.2013.770081

Schreiber, M., Gurwitch, R., & Wong, M. (2006). Listen, Protect, Connect--Model & Teach: Psychological First Aid (PFA) for Students and Teachers. *US Department of Homeland Security*.

Smith JA, Flowers P, Larkin M. Interpretative phenomenological analysis: theory, method and research. London: Sage, 2012

Sit, J. W., Wong, T. K., Clinton, M., Li, L. S., & Fong, Y. M. (2004). Stroke care in the home: the impact of social support on the general health of family caregivers. *Journal of clinical nursing*, *13*(7), 816-824.

Stroke Association, (2020, April 24). *Information on coronavirus for stroke survivors.* Stroke Association. https://www.stroke.org.uk/finding-support/information-coronavirus-stroke-survivors

Visser-Meilly, A., Post, M., van de Port, I., van Heugten, C., & van den Bos, T. (2008). Psychosocial functioning of spouses in the chronic phase after stroke: Improvement or deterioration between 1 and 3 years after stroke? *Recipient Education and Counseling, 73(1)*, 153–158.

Wolters Gregório, G., Visser-Meily, J. M. A., Tan, F. E. S., Post, M. W. M., & van Heugten, C. M. (2011). Changes in the coping styles of spouses and the influence of these changes on their psychosocial functioning the first year after a recipient's stroke. *Journal of Psychosomatic Research, 71(3)*, 188–193.

World Health Organization (2020). *Mental health and psychosocial considerations during the COVID-19 outbreak.* https://www.who.int/publications-detail/WHO-2019-nCoV-MentalHealth-2020.1

Appendix 4-B: Recruitment advert

Did your partner or spouse experience a stroke before January 2020?

Have you been their carer both before and during the Covid pandemic?

If so, I would like to hear from you.

I am a Trainee Clinical Psychologist at Lancaster University and would like to understand more about the specific experiences of partner/spousal carers of stroke during the Covid pandemic. I would like to contribute to building a better understanding of your situation amongst psychological and health services so that effective support can be planned for stroke carers moving forwards. If you would like to take part, the interview will take approximately 1 hour of your time.

For further information, please contact Ruth Hirst via email r.kitchen@lancaster.ac.uk or on Twitter @RuthHirst3

Thank you

Appendix 4-C: Participant information sheet

The experience of being a carer in the UK during the Covid 19 pandemic for a partner who has had a stroke: identifying the implications for psychological support.

Hello, my name is Ruth Hirst and I am conducting this research as a student of the Clinical Psychology doctorate programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?

The purpose of this study is to explore how carers of a partner who has experienced a stroke have experienced the Covid 19 pandemic and how psychological services may best be able to support you in both managing the current situation and moving forwards.

Are there any specific requirements about who takes part?

Yes. In order to ensure that the research can be used as widely as possible, I am looking for people who fit the following criteria:

- This was your partner's first stroke
- The stroke happened before January 2020
- You were living together before and during the Covid 19 pandemic
- Your partner requires support from you related to the outcomes of the stroke (this may range from ensuring they are not left alone in the house to carrying out intimate care)
- You have lived in England during the pandemic
- You have access to the internet or a telephone and speak English.

If any of the following apply to you, then unfortunately you would not be able to take part in the study:

- Prior to the stroke your partner had a pre-existing condition that required care and support for that diagnosis e.g. Alzheimers, Parkinsons, Multiple Sclerosis, Motor Neuron Disease etc.
- Your partner had a transient ischaemic attack, sometimes called a TIA or 'mini stroke'

Do I have to take part?

No. It's completely up to you to decide whether or not you take part. Furthermore, if you decide to take part and then feel that you don't want to continue in the study, you can withdraw at any point leading up to and during the interview. You will also have up to two weeks after the interview to withdraw your participation in this study (after which time your data will have been anonymised and been pooled with other participants' data for analysis.)

What will I be asked to do if I take part?

If you decide you would like to take part in the study, you would be asked to take part in an interview with me; this can be during the day or in the early evening, whichever suits you best. Interviews will be carried out remotely via safe and secure online software such as MS Teams or, if you don't have access to Teams, this can be conducted over Skype or Zoom. If you don't have access to a private computer it can also be carried out over the telephone if you would prefer. During the interview I will ask you about your experiences of being a carer for your partner during the Covid 19 pandemic and how this has impacted on you and your life. I hope to make the interview as relaxed and comfortable for you as possible, and you will not be asked to share anything that you feel uncomfortable to talk about. The interview is likely to take approximately one hour and, to enable me to listen carefully to what you are saying during the interview, I will audio or video record it. After the interview I will transcribe the interview word for word, so that I can take time to study and reflect upon everything that you have told me.

Will my data be Identifiable?

The data you provide in the interview is confidential. All research data will be anonymised (by removing all references to your name) and the data collected for this study will be stored securely on University approved secure cloud storage and only myself and my supervisors (Dr Craig Murray and Dr Caroline Malone) will have access to this data:

- All video and audio recordings will be deleted once the study has been examined ○ Interviews will be transcribed into an anonymised electronic form
- The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected. All files will be destroyed once the study has been assessed
- The electronic copy of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them. All reasonable steps will be taken to protect the anonymity of the participants involved in this project. ○ All your personal data will be confidential and will be kept separately from your interview responses.
- There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at risk of harm, I will have to break confidentiality and speak to a member of staff about this. If possible, I will tell you if I have to do this.

What will happen to the results?

The results will be summarised and reported in a thesis and may be submitted for publication in an academic or professional journal. If any direct quotes are used within this, they will be anonymised.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress during or after participation you are encouraged to let me know. In addition there are sources of support provided at the end of this sheet.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you are happy to participate in this research, please contact the main researcher below by e-mail to receive a link to a pre-screening questionnaire. If you have further questions, please contact the main researcher below or any of the other contacts displayed below. Main researcher: Ruth Hirst: r.kitchen@lancaster.ac.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Dr Craig Murray,
Senior Lecturer in Health Research Doctorate in Clinical Psychology Programme
Faculty of Health and Medicine
Lancaster University
Lancaster
LA1 4YG
c.murray@lancaster.ac.uk

If you wish to speak to someone outside of the Clinical Psychology Doctorate Programme, you may also contact:

Professor Roger Pickup Tel: +44 (0)1524 593746
Associate Dean for Research Email: r.pickup@lancaster.ac.uk
Faculty of Health and Medicine
(Division of Biomedical and Life Sciences)
Lancaster University
Lancaster
LA1 4YG

Thank you for taking the time to read this information sheet.

Resources in the event of distress

As part of the interview, you may choose to talk about things that are difficult for you and cause distress. These feelings may go within a few minutes, hours or days. However, should you continue to feel distressed, either as a result of taking part, or in the future, the following resources may be useful:

- Samaritans Helpline (emotional support): Telephone (freephone) 116 123, Website: www.samaritans.org Email: jo@samaritans.org
- Carers UK: Telephone: 0808 808 7777, Website: www.carersuk.org, Email**:** advice@carersuk.org
- The Carers Trust: Telephone**:** 0300 772 9600, Website: www.carers.org, Email: info@carers.org
- Your GP

Appendix 4-D: Consent Form

The experience of being a carer in the UK during the Covid 19 pandemic for a partner who has had a stroke: identifying the implications for psychological support.

I am asking if you would like to take part in a research project to explore the experiences of being a carer for a partner who has had a stroke during the Covid 19 pandemic.

Before you consent to participating in the study, I ask that you read the participant information sheet and the points below. We will go through each of these points together before the interview begins so that you can indicate your agreement verbally and ask any questions; this will be recorded and used as confirmation of your consent to take part in the study. If you have any questions or queries about the consent process please speak to the researcher, Ruth Hirst email: r.kitchen@lancaster.ac.uk.

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study ☐
2. I confirm that I have had the opportunity to ask any questions and to have them answered. ☐
3. I understand that my interview will be video or audio recorded and then made into an anonymised written transcript. ☐
4. I understand that the video / audio recordings will be kept until the research project has been examined. ☐
5. I understand that my participation is voluntary and that I am free to withdraw within 2 weeks of the interview taking place without giving any reason, without my medical care or legal rights being affected. ☐
6. I understand that my data will have been anonymised and incorporated into themes after 2 weeks of the interview so it will not be possible for it to be withdrawn beyond this point. ☐
7. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published; all reasonable steps will be taken to protect the anonymity of the participants involved in this project. ☐

8. I consent to information and quotations from my interview being used in reports, conferences and training events. ☐
9. I understand that the researcher will discuss data with their supervisor as needed. ☐
10. I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the research will need to share this information with their research supervisor. ☐
11. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished. ☐
12. I consent to take part in the above study. ☐

Appendix 4- E: Pre-screening demographic questionnaire

Pre-Screening Questions: Responses to be gathered via an electronic 'Qualtrix' questionnaire

Introductory information

Thank you very much for coming forwards to share your experiences of caring for your partner during the Covid pandemic. Certain criteria have been set out to ensure that all of the participants share some key characteristics so, before I book an interview with you, it's important for me to gather a little bit of information about your circumstances. This will take about 5 minutes of your time, but ensures that, if you go on to give an interview, I can use your information in my analysis. All information that you give will be kept strictly confidential and treated with the same security and care as that outlined in the participant information sheet.

Inclusion / Exclusion Criteria check

Please indicate True or False to the following statements.

Inclusion Criteria (if True then the questions will progress)

	True	False
My partner has had one stroke which occurred prior to January 2020		
We were living together before and during the Covid 19 pandemic		
My partner requires support from me to manage the outcomes of their stroke (this may range from ensuring they are not left alone in the house to carrying out intimate care)		
We have lived in England during the pandemic		
I have access to the internet or a telephone and speak English.		

Exclusion Criteria (if True then the questions will cease and the respondent will be thanked for their time)

	True	False
Prior to the stroke my partner had a pre-existing condition that required care and support for that diagnosis e.g. Alzheimers, Parkinsons, Multiple Sclerosis, Motor Neuron Disease etc.		
My partner had a transient ischaemic attack, sometimes called a TIA or 'mini stroke'		

Cease Questions Message: Thank you so much for your interest in taking part in this research. Unfortunately, I am looking to recruit participants with key characteristics in common and your circumstances do not match these. Thank you again for your time and interest and I wish you all the very best.

Information about you

The information you've given so far means that you match the key characteristics I am looking for within my research. I have just a few more questions which will help me to understand your personal circumstances more clearly so that any patterns, similarities and differences between you and other participants can be taken into account when I'm analysing the data. This will save us a lot of time during the interview.

Age: *free text entry*

Gender: Male/female/transgender male/transgender female/nonbinary/other *free text entry*

Ethnic Identity: *free text entry*

Sexual orientation: heterosexual, gay, lesbian, bisexual, pansexual, asexual, other

Marital status: Married, cohabiting, divorced, separated, single

Region within the UK: South East, South West, East Midlands, West Midlands, North East, North West

Length of relationship *free text entry*

Employment status: employed full time, employed part time, unemployed

The nature of your partner's post-stroke difficulties Please tick all that apply:

Physical: Pain / swallowing / vision / continence / mobility / balance / seizures / fatigue

Communication: speaking / reading / writing / understanding others

Emotional: low mood / anxiety / frustration / aggression / difficulties controlling emotions (emotional lability) / disinhibited

Cognitive: Memory / attention / concentration / problem solving

Engagement in sexual activity: reduced sex drive / difficulties or discomfort during sex Anything not covered

above: *free text entry*

Closing message and email address request

Thank you so much for the time you have taken to complete these questions. Depending upon the response rate to my advert, I should be in contact with you within the next 2 weeks. Please would you write your email address below to ensure that I am able to contact you and indicate how you would like me to conduct the interview.

Email address: *free text entry*

I would prefer my interview to take place: online / by telephone

If online, I would prefer to use: Teams (most secure platform)/ Skype / Zoom

Appendix 4-F: Sample Interview Schedule

Introductory Question:

Can you tell me a little bit about your relationship with your partner? E.g. how long you've been together, how your relationship developed, what you enjoy most about your relationship.

Interview Questions

I wonder if you could tell me a little bit about your partner's stroke and what impact this had on their life (have they been able to work since? Has it affected their communication, mobility, physical or mental health?)

What sorts of things were you doing to support your partner as their carer before the Covid pandemic started? Has this changed during Covid?

During Covid, what sort of support have you had from other people? Formal carers, family and friends etc?

How has your social life been impacted by Covid restrictions? How has being a carer impacted upon this?

Has your mental health been impacted by Covid restrictions? How has being a carer supported or detracted from this?

To what extent have you been able to pursue your normal hobbies, interests and activities during Covid restrictions? How has being a carer impacted upon this?

If you were to think about your day to day life as a carer before and during Covid, how is it the same?

How is it different?

If you could go back in time to life before Covid, and could tell the people that run health and social care services how they should run things. What would you suggest that they do to support someone caring for a partner who's had a stroke during Covid

What would help you now as we move forward through the Covid pandemic and beyond?

Appendix 6 - Example of 'Group Rules' set out by Facebook Group administrators – taken from the Caregiver Support Group Facebook group.

Appendix 4-G

Faculty of Health and Medicine Research Ethics Committee (FHMREC) Lancaster University
Application for Amendment to Previously Approved Research

1. Name of applicant:

Ruth Hirst

2. E-mail address and phone number of applicant:

r.kitchen@lancaster.ac.uk
[redacted]

3. Title of project:

A case study on the experience of being a carer in the UK during the Covid 19 pandemic for a partner who has had a stroke: identifying the implications for psychological support.

4. FHMREC project reference number:

FHM20028

5. Date of original project approval as indicated on the official approval letter (month/year):

16/12/2020

6. Please outline the requested amendment(s)

Note that where the amendment relates to a change of researcher, and the new researcher is a student, a full application must be made to FHMREC

1. Change from a multiple participant study to a single case study
2. Change from Thematic Analysis to Interpretative Phenomenological Analysis (IPA)
3. Consent to approach the interviewee for a second interview

7. Please explain your reason(s) for requesting the above amendment(s):

1. Ongoing recruitment efforts utilising social media, support group forums and multiple approaches to engage the support of 3rd sector stroke organisation networks, have resulted in one participant coming forward for interview. The applicant's intention to write up the current project as a case study.

2. IPA is a method more commonly used with single-participant data due to its emphasis on idiographic analysis. The demographic and experiential characteristics of the participant are statistically less typical of many spousal carers of stroke-affected partners. As a younger carer, with two young children, living in the context of Covid

lockdown in the UK, which was not their country of birth, the applicant considers IPA to be a more suitable means of systematically analysing their unique meaning making and experiences.

3. The applicant is seeking consent to approach the participant to request a second interview in order to strengthen and increase the data gathered from the first interview.

Guidance:

a) Resubmit your research ethics documents (**the entire version which received final approval, including all participant materials, your application form and research protocol**), with all additions highlighted in yellow, and any deletions simply 'struck through', so that it is possible to see what was there previously.
b) This should be submitted as **a single PDF** to Becky Case There is no need to resubmit the Governance Checklist

Applicant electronic signature:	Date
R. Hirst	05/10/2021

Student applicants: please tick to confirm that you have discussed this amendment application with your supervisor, and that they are happy for the application to proceed to ethical review ☒

Project Supervisor name (if applicable):	Date application discussed
Craig Murray	08/10/2021

You must submit this application from your Lancaster University email address, and copy your supervisor in to the email in which you submit this application