Supporting Family Carers after Stroke and the Impact of Post-Stroke Apathy

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Thesis Portfolio Abstract

Background: Stroke is the leading cause of death and disability worldwide. Survivors frequently rely on family, but stroke carers show increased rates of anxiety and depression. One in three stroke survivors experiences apathy. This is under-researched in stroke but is associated with detrimental effects on carer mental health and well-being in other populations.

Aims: This thesis aimed to investigate the types and effectiveness of interventions provided to informal stroke carers. Additionally, it examined informal stroke carers' experiences of motivational changes after stroke. Finally, it sought to test the criterion validity of the Dimensional Apathy Scale-Informant-rated version (DAS-I) with informal stroke carers.

Method: A systematic review investigated randomised control trials of informal stroke carer interventions for carer burden, quality of life, depression and/or anxiety. An empirical study identified informal carers' supporting stroke survivors with at least one subtype of apathy, using unidimensional and multidimensional apathy scales. Informal stroke carers' experiences of post-stroke apathy were explored using semi-structured interviews. The psychometric properties and validity of the DAS-I were compared to a frequently used unidimensional apathy scale.

Results: The systematic review identified four common characteristics of interventions associated with improved stroke carers' mental health and well-being: increased contact time, longer duration, remote delivery, and skills-based problem-solving content. In the empirical paper, three overarching themes were identified: Emotional Expression and Reflection, Impact on Life, and Things that Helped. Stroke carers reported practical support was the most needed but least available intervention, whereas emotional support was accessible from peers and faith groups. The DAS-I was found to have good internal consistency but poor convergent validity.

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Conclusions: This thesis portfolio highlights a disconnect between the characteristics of existing interventions for supporting stroke carer mental health and well-being and the forms of support accessed or sought by carers of stroke survivors with apathy.

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Chapter One: Introduction to Thesis Portfolio

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Stroke

Stroke is described as a cerebrovascular accident (Murphy & Werring, 2020), in which blood flow to parts of the brain is disrupted, known as an ischemic stroke, or a bleed in the brain, referred to as a haemorrhagic stroke. Stroke requires immediate medical attention (NHS, 2024) and can result in life-altering consequences (Wassenius et al., 2020).

There are currently 1.3 million people living with stroke in the UK, with an average of 100,000 people surviving stroke each year (NICE, 2023). While stroke can occur at any age, the majority of strokes occur after 45 years old (Patel et al. 2017). In the ageing population of the UK, the incidence of stroke is likely to increase each year, with assumptions of up to 2.7 million people living with stroke in the UK within the next 20 years (Patel et al. 2017).

Stroke can impact cognitive, psychological, and physical abilities and alter the relationships survivors have with their families (Gillespie & Campbell, 2011). The psychological aftermath of stroke, particularly depression and anxiety, impacts approximately one in three survivors (Liu et al., 2023). This prevalence has led to the development of various interventions aimed at alleviating these psychological issues, each demonstrating varying degrees of effectiveness (Lavu et al., 2022).

The Impact of Stroke on Family Carers

Family members often take on the role of informal carers after a stroke (Greenwood & Mackenzie, 2010). Recommendations for research on stroke rehabilitation identified ten priorities, with some of these priorities highlighting understanding the psychological difficulties experienced by stroke survivors and their families to improve carer support and carer experience of the stroke pathway (Hill et al., 2022). Acknowledging the challenges associated with caregiving has been explored in a group of dementia carers; they highlighted positive aspects of caregiving such as altruism and self-improvement, which have been seen to reduce carer burden, symptoms of depression and anxiety (Quinn & Toms, 2018).

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However, they recognised that the research typically focused on the negative aspects of caregiving.

The burden of informal care for stroke survivors presents profound challenges for stroke carers and has been well recognised in the research (Lou et al., 2016). Research such as that by Camak (2015) underscores these difficulties. For instance, a meta-analysis highlighted depression impacts approximately 40% of stroke carers (Loh et al., 2016), a rate twice that of the general population (Huang et al., 2023). Stroke carers also grapple with heightened anxiety levels. It is reported that anxiety impacts 30-45% of stroke carers (Zhao et al., 2021). Social engagement among stroke carers diminished significantly (Pesantes et al., 2017), further amplifying their isolation and stress. Inadequate training and comprehension in various stroke-related aspects (King et al., 2013) likely exacerbate carer strain (Byun et al., 2016). These difficulties are further compounded by the family member's lack of recognition of their caregiving role, reducing the likelihood of support-seeking (Knowles et al., 2015). A previous systematic review highlighting the unmet needs of stroke carers indicated difficulties experienced by carers in managing emotional and personality changes in the stroke survivor, access to services and certainty about the future (Denham et al., 2019). They highlighted these difficulties as being more ambiguous and difficult to recognise the further into the caring journey.

Informal carers in other populations, such as carers of people with dementia, report heightened experiences of guilt, loneliness, and frustration when caring for individuals with apathy presentations (Chang et al., 2021). This is similar to the challenges faced by those caring for stroke survivors, who often encounter significant emotional stress, including anxiety, depression, frustration, and guilt (Okoye et al., 2019), with differences in the stroke survivor's mood being particularly stressful (Haley et al., 2009). Informal stroke carers

express challenges associated with caring, yet despite challenging times, they demonstrate resilience and strongly desire support throughout the caring journey (Wang et al., 2023).

Apathy

Apathy has been defined as a reduction in self-initiated or goal-directed behaviours (Heron et al., 2017). It is recognised by a reduction in motivation, emotional expression, and indifference (Radakovic et al., 2016). It is understood to have a detrimental impact on cognitive and functional abilities, reducing quality of life (Agboji et al., 2024) and adversely affecting rehabilitative outcomes (Hama et al., 2011; Kennedy et al., 2015). While apathy is widely acknowledged in neurodegenerative conditions like dementia, its understanding is still limited in both clinical and general contexts (Tay et al., 2021). Given its widespread occurrence in different neurodegenerative diseases, there have been proposals to classify apathy as a standalone diagnosis rather than a symptom (Wong et al., 2020).

Apathy can often arise where patients have reduced insight, or a component of apathy itself may be a lack of concern for their own condition. This means that the consequences of apathy might be more personally significant for those around the survivor. In cases of traumatic brain injury and dementia, carers find apathy highly distressing, and it predicts carer burden (Stanton & Carson, 2015). Alongside carer burden, the impact of apathy on various populations reveals that informal carers face heightened risks of burnout (Wong et al., 2020; Vatter et al., 2020). Burnout is defined by psychosocial difficulties that arise because of work-related and interpersonal stressors, characterised by reduced fulfilment, depersonalisation, and emotional exhaustion (De Souza Alves et al., 2018). Stroke survivors' emotional needs often go unmet (Chen et al., 2019), further affecting stroke carers and leading to increased isolation (Cookson & Casey, 2013).

Stroke and Apathy

Post-stroke apathy is often misdiagnosed because its symptoms overlap with those of depression (Mortby et al., 2021), such as anhedonia and reduced activity (Post & Warden, 2018), although one can have apathy with or without depression. This may also be due to misinterpretations of symptoms as an understandable consequence of stroke, which can lead clinicians and carers to normalise motivational decline, overlooking apathy as a distinct neuropsychiatric syndrome with clinical relevance. As Tay et al. (2021) note, apathy is commonly conflated with depression or fatigue, yet it presents unique behavioural and emotional features that warrant separate recognition and targeted intervention. Failure to differentiate apathy from other post-stroke sequelae may delay appropriate support and contribute to poorer functional outcomes for both the stroke survivor and carer. Research indicates that between 20-44% of stroke survivors have at least one subtype of apathy: executive apathy, initiation apathy, or emotional apathy (Caeiro et al., 2013; Mikami et al., 2013; Myhre et al., 2020; Van Dalen et al., 2013). Executive apathy is an impairment in planning, setting and management of goals; initiation apathy is an impairment in self-generated behaviour, and emotional apathy is an impairment in emotional processing (Radakovic et al., 2020). The development of apathy in other populations can be associated with damage in specific areas of the brain. However, stroke research suggests that apathy's development may not be solely linked to focal brain lesions and may be more widespread across the brain (Tay et al., 2021).

Apathy after stroke is often linked to more severe disabilities and long-term cognitive deficits, negatively impacting quality of life, functional recovery, daily activity maintenance, general health (Van Dalen et al., 2013), and the persistence of disabilities (Van Reekum et al., 2005). As evidenced in other populations, apathy also significantly affects carers, increasing their burden and stress (Wong et al., 2020; Vatter et al., 2020). The overlap of apathy

symptoms with depression complicates apathy diagnosis (Mortby et al., 2022), while the high prevalence of apathy subtypes in stroke survivors (Myhre et al., 2020; Caeiro et al., 2013; Van Dalen et al., 2013) adds to stroke carers' challenges. The experience of caring for someone with post-stroke apathy is not well understood, highlighting the need for further research in this area (Tay et al., 2021). Tay et al. (2021) further highlighted the lack of non-pharmacological interventions in post-stroke apathy for both the survivor and stroke carers. A deeper understanding of stroke carers' experiences could inform the development of better support systems and targeted interventions, ultimately enhancing the well-being and effectiveness of stroke carers.

Interventions for Stroke Carers

Interventions have been developed to support stroke carers, usually through meeting individual needs, using information provision and workbooks (Hall et al., 2019). Previous research has primarily focused on how stroke severity and physical impairments impact stroke carers (Greenwood et al., 2008) while recognising the imperative role of stroke carers in the long-term rehabilitative process (Okoye et al., 2019). Spousal stroke carers often felt underprepared to enter into a caring role, suggesting more stroke information was needed before discharge to help develop their ability to cope with their changing situation (Quinn et al., 2013). Interventions are often delivered to the carer, with the primary intention of supporting the stroke survivor (Aziz et al., 2016). Considering the wide range of adjustments required when caring for family members, difficulties experienced by stroke carers are important in their own right, expressing difficulties with invisible changes being more detrimental than observed limitations to carers of those who experienced an acquired brain injury (Holloway & Tasker, 2019). Kokorelias et al. (2020) identified a common theme across stroke research, that caring is a full-time job, requiring the carer to restructure all aspects of their lives, often with limited support. Bom et al. (2018) systematically reviewed

the causal relationship between caregiving and negative health outcomes experienced by carers. They found a direct relationship between the caregiving role and negative health outcomes, with informal carers more likely to experience negative physical and mental health. In addition to these difficulties, previous research on other populations, such as those with traumatic brain injuries, has shown that there is typically an underrepresentation of men and individuals from diverse groups in the research (Whiffin et al., 2021). This underrepresentation highlights the need for exploring the specific difficulties faced by these groups, alongside the importance of recognising the difficulties faced by informal carers generally, which should be considered in policy and intervention development.

Aim and Structure of the Thesis Portfolio

The work described in this thesis portfolio focuses on the support and experiences of informal stroke carers. A systematic review is presented in Chapter Two. This investigated the interventions available for informal stroke carers and their effectiveness for the psychosocial difficulties experienced by stroke carers. An empirical study is presented in Chapter Four. This used a qualitative methodology to explore stroke carers' experiences of post-stroke apathy. It also investigated the validity of the Dimensional Apathy Scale-informant-rated version (Radakovic & Abrahams, 2014) in informal stroke carers. The portfolio includes a bridging chapter to outline how the systematic review informed the research question of the empirical paper and an extended methodology chapter to explain further methodological details of the empirical study. Lastly, a critical evaluation and discussion chapter appraises the work presented and considers the findings within the wider context of previous theory and research before outlining implications for interventions and future research and drawing on conclusions.

Both the systematic review and the empirical paper were prepared for submission to the Journal *Disability & Rehabilitation* (Appendix A).

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Chapter Two: Systematic Review

Prepared for submission to the Journal of Disability and Rehabilitation

Author Guidelines are available in Appendix A

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The Effectiveness of Interventions to Support Informal Stroke Carers: A Systematic Review

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Abstract

Purpose: Stroke affects one in four adults in the UK, with over a third relying on informal carers. The burden of care has detrimental effects on the mental and physical health of carers, which can impact the rehabilitative process. Despite this, interventions have focused on the physical demands of caregiving, prioritising the stroke survivor. This review aimed to identify effective psychosocial interventions that reduce burden, strain, depression, or anxiety in informal stroke carers.

Methods: A systematic review of the literature was conducted using MEDLINE, EMBASE, PsycINFO, the Cochrane Library, and PubMed, with final searches on the 8th May 2025. Randomised controlled trials (RCTs) published in English from 1980 onwards, including participants aged 18 years or older, were eligible. Risk of bias was assessed using the CASP tool for RCTs. Results were reported using narrative synthesis.

Results: Seven studies were rated as having good methodological quality, fourteen moderate, and three weak. Fourteen studies reported significant findings. Interventions varied widely, with characteristics in effective interventions including skills-based problem-solving content, telephone delivery, longer duration, and increased contact time.

Conclusions: Providing distant support over extended durations may improve the psychological well-being of informal stroke carers. Tentative conclusions are presented, and further research is required.

***Keywords**:* stroke, carer, strain, burden, depression, anxiety, interventions, psychosocial

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Introduction

Stroke, the leading cause of death and disability globally, has nearly doubled in incidence over the past three decades (World Stroke Organization (WSO), 2022). It affects one in four adults globally (WSO, 2022) and one in six adults in the UK (Evans, 2018), showing relatively equal prevalence across men and women (National Institute for Health and Care Excellence (NICE), 2023). Defined as an interruption to cerebral blood flow resulting in cell damage and tissue death, a stroke often leads to long-term disabilities (NHS, 2022). While most strokes are ischemic, a minority involve bleeding into areas of the brain, known as a haemorrhagic stroke. These disabilities encompass not only physical and cognitive impairments but also emotional changes, significantly impacting mood management for survivors (Stroke Association, 2023a). The psychological repercussions of stroke are well documented, with significant research attention directed towards depression and anxiety among stroke survivors, which affect approximately one in three individuals following stroke (Chun et al., 2022). These findings have spurred the creation of interventions to mitigate these issues, each yielding varying levels of effectiveness (Lavu et al., 2022).

Informal carers support individuals across a wide range of clinical populations, yet their role is often under-recognised in long-term care provision. According to Carers UK, half of all carers (51%) took over a year to identify their role, and over a third (36%) took more than three years. This delay is often due to the perception that caring is simply part of being a good partner, parent, or friend, rather than a distinct role with its own identity and support needs. Considering the above-mentioned enduring effects of stroke, over a third of survivors rely on informal stroke carers for support (Aziz et al., 2016). Informal carers provide physical, emotional, social, and/or psychological support in an unpaid capacity to a relative or friend (Stroke Association, 2023b). It is estimated that the cost of informal care to stroke survivors in the UK amounts to £15.8 billion annually (Patel et al., 2020). Extensive research

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has explored the burden of informal care, shedding light on the challenges faced by both stroke survivors and stroke carers (Camak, 2015). Studies have highlighted that around 35% of informal stroke carers experience depression, which is twice the rate observed in the general population (Huang et al., 2023). Alongside depression, increased anxiety levels in this cohort affect both their physical and mental health (Hu et al., 2018).Time spent caring for the stroke survivor limits opportunities for carers to engage in social activities, such as seeing friends, impacting stroke carers' stress levels (Pesantes et al., 2017). Furthermore, a lack of training for stroke carers and a poor understanding of all aspects of stroke (King et al., 2013) are likely to increase perceived carer strain (Byun et al., 2016). In contrast, psychoeducation interventions in other populations have been efficacious in reducing burden by enhancing preparedness both practically and emotionally (Theißen et al., 2024).

Psychological distress and strain among informal stroke carers can impede the stroke survivor's rehabilitation process (Aziz et al., 2016). Stein and Reynolds (2020) proposed that carer strain is associated with an increase in the intensity of the rehabilitative process and poorer functional outcomes for the stroke survivor, especially following left hemisphere stroke. Consequently, these circumstances could potentially serve as predictors of carer depression (Stein & Reynolds, 2020). Despite considerable research, most interventions for carers have historically prioritised reducing the physical demands of caregiving, primarily with the stroke survivor in mind, rather than addressing the carers' own psychological and emotional needs (Hill et al., 2022). Systematic reviews have underscored the importance of psychological interventions for stroke carers. For example, Panzeri et al. (2019) reviewed a wide range of interventions(RCT, clinical trials, uncontrolled trials and pre-post test design) delivered either to carers alone, to stroke survivors, or to dyads, finding reductions in depression, particularly when psychology professionals delivered interventions, though most included studies were nurse-led and focused on skills-building. Similarly, Minshall et al.

(2019), in a systematic review incorporating interventions targeting stroke survivors, carers, and dyadic or family-based formats, also reported improvements in depressive symptoms. However, the review found no significant effects on carer burden, strain, or quality of life. More recently, Mack and Hildebrand (2023) examined interventions within the scope of occupational therapy practice, providing valuable insights but limiting conclusions to a specific professional framework. They further recommended that future research should explore how the frequency, duration, and location of interventions shape their effectiveness.

Previous systematic reviews have not focused on stroke carer-specific interventions in isolation. Given the substantial psychological burden and strain (Olai et al., 2015; Simon et al., 2009) and unique challenges faced by informal stroke carers (Camak, 2015), there is a need to evaluate the effectiveness of interventions targeted specifically at this group. This systematic review aims to meet this need by synthesising evidence, including only interventions for informal stroke carers, thereby providing clearer direction for clinical practice and future research. This aligns with recent recommendations emphasising the need for targeted research to identify which interventions are offered and effective for those impacted by stroke (Hill et al., 2022).

Objectives

Our main objective was to systematically review research on support interventions for informal stroke carers to identify:

1) What are the most commonly investigated support interventions for informal stroke carers?

2) What types of support interventions demonstrate greatest efficacy in reducing carer strain or improving quality of life?

Method

The systematic review was registered on the International Register of Prospective Systematic Reviews (PROSPERO; CRD4202449957)(Farrell et al., 2024) and followed

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guidance for Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA; Page et al., 2021).

Search and Selection

Five electronic bibliographic databases (MEDLINE, EMBASE, PsycINFO, the Cochrane Library and PubMed) were searched from inception to February 2024 using a predetermined search string adapted for each database. Medical subject headings (MeSH) were applied to the relevant databases. This is an example of the search terms used:

- (MH "Stroke, Lacunar") OR ‘transient ischemic attack’ OR ‘TIA’ OR ‘cerebral infarction’ OR ‘ischemic attack’ OR ‘infarct*’
- AND
- (MH "Caregivers") OR ‘informal care’ OR ‘informal caregiver’ OR ‘family care’ OR ‘family caregiver’
- AND

  (MH "Psychosocial Intervention") OR ‘interventions’ OR ‘strategies’ OR ‘best practices’ OR ‘treatment’ OR ‘therapy’ OR ‘program’ OR ‘management’ OR ‘support’
- AND

  (MH "Randomized Controlled Trials as Topic") OR ‘randomised control trial’ OR ‘RCT’

Eligibility Criteria

Studies were included if they were randomised controlled trials (RCTs) of psychological or psychosocial interventions for informal stroke carers, defined as adults aged 18 or over, providing care and support in an unpaid capacity to adult stroke survivors aged 18 or over. Relevant interventions included, but were not limited to: Educational Programs: interventions providing information and education to stroke carers about stroke, and available

resources; Psychosocial Support: programs offering emotional and psychological support to stroke carers', including counselling, support groups, and mental health interventions; Training and Skill-Building: interventions focusing on enhancing practical skills related to caregiving, such as administering medications, managing daily activities, and providing physical care; or Technology-Based Interventions: programs utilising technology (e.g., apps, online platforms) to support stroke carers, providing information, communication, or monitoring tools. Studies were included if they used measures of carer strain or quality of life (primary outcome measures) or measures of anxiety or depression (secondary outcome measures), irrespective of prior validation status. This decision allowed for the inclusion of both validated and emerging tools conceptually aligned with the review's objectives, ensuring a comprehensive synthesis across randomised controlled trials targeting carer outcomes. Studies that utilised only dyadic interventions were also excluded. Limitations placed on studies were: published in English, after 1980, with participants over 18 years old. The restriction to research after 1980 reflects a lack of outcome measures prior to this point. The search was restricted to peer-reviewed journals only.

Study Selection

Identified studies were imported into a reference manager (RAYYAN), and duplicates were removed. Titles and abstracts were screened against eligibility criteria by one reviewer, and those not relevant were removed. Full texts of the remaining articles were obtained and screened against the inclusion criteria. A sub-section of research papers (25%) was randomly assigned to a second researcher for screening against the inclusion and exclusion criteria at full-text stage. There were no disagreements between the researchers about the eligibility of the studies. Information about the intervention, number of participants, primary and secondary outcome measures and results was extracted.

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Assessment of Bias

Two researchers independently reviewed each study using the Critical Skills Appraisal Program checklist for RCTs (CASP, 2023). The checklists were originally developed in 1993 to highlight the best research evidence in the absence of good-quality systematic reviews. The checklist consists of 13 items with options of 'Yes', 'No', or 'Can't tell', relating to the random allocation of participants, the methodological quality, results, and applicability of the evidence. As this was an international review, two questions relating to the application of intervention to the local area were removed, as they were not relevant to the broader scope of this analysis. Therefore, the appraisal was rated out of 11. 'Yes' responses were given a score of 1 and totalled to obtain a general indication of quality. A score of 9-11 was considered good quality, a score of 6-8 was considered moderate, and a score of 5 or below was considered weak (supplementary information 1). Although not originally designed to be scored, the scoring system developed by Butler et al. (2016) was adapted to extend the range to 11, allowing for broader assessment of methodological quality.

Data Synthesis

A narrative synthesis was conducted as recommended by Ryan (2013) for reviews including a range of different interventions. Following Cochrane guidance for narrative synthesis (Ryan, 2013), an overview of included studies was tabulated (Table 1). Included studies were grouped by intervention type and then their efficacy considered taking their quality rating into account.

Results

The electronic search yielded 7,197 records. Prior to screening, duplicates were identified and removed, resulting in the removal of 463 duplicate studies. After reviewing the titles and abstracts of 6,734 remaining studies, the full texts of 85 studies were reviewed for eligibility. A total of 24 articles met the eligibility criteria to be included in the review. During screening, 25% of studies were screened independently by a second rater. Raters had 100% overlap of studies identified for inclusion and exclusion. Details of the process of article selection are included in Figure 1.

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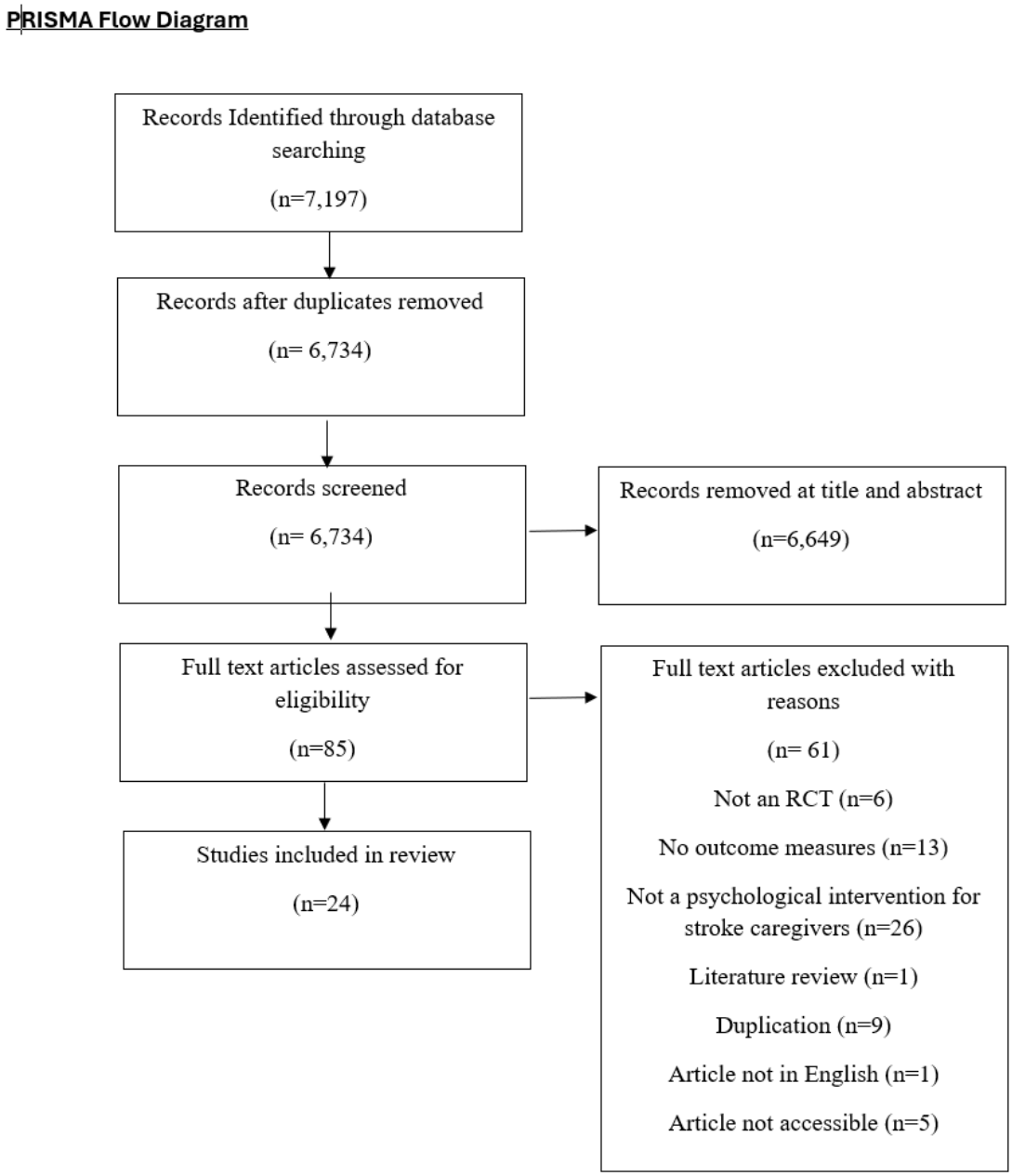
Figure 1

Flow Diagram Demonstrating the Process of Article Selection



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Included Studies

Twenty-four studies were included in the review. A summary of the study details is provided in Table 1.

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Table 1

Correlations Among and Descriptive Statistics for Key Study Variables

Study Identification	**N** **Total (T)** **Intervention (I)** **Control (C)** **Sham (S)**	**Intervention (I)** **Control (C)** **Sham (S)**	**Interventionist**	**Method of delivery**	**Outcome measure**	**Effect size**	**CASP rating /11**
Avci & (2023)	(T) 63 (I) 33 (C) 30	I= TEMpEST (Transitional Care Model Stroke Turkey). C= usual care (UC) + information and support	Researcher, Nurse	Face-to-face, telephone, web-based	MBE-GF Emotional exhaustion Depersonalisation Personal accomplishment	 **0.048** **0.035** **1.39**	**8- moderate**
Bakas et al. (2009)	(T) 254 (I) 123 (C) 131	I= Telephone Assessment and Skills Building Kit (TASK II) C= information, support and referral group	Nurse	Telephone	PHQ-9	**0.24**	**10- good**
Batool et al. (2022)	(T) 66- 3 arms (I) (I) (I)	Group A: virtual reality therapy using Kinect (XBOX360)	Psychologist	Face-to-face	CSI AC-QoL	**Unable to report- missing information**	**7- moderate**

	Allocation not specified	Group B: Psychotherapy using Cognitive Behavioural therapy Group C: CBT and VR training					
Bierhals et al. (2023)	(T) 48 (I) 24 (C) 24	I= Educational intervention (SHARE) C- UC	Nurse	Face-to-face (home visits)	WHOQoL-Bref	**0.45**	**11- good**
Cameron et al. (2014)	(T) 31- 3 arm (I) 10- self-directed (SD) (I) 11 person directed (SSP) (C) 10- Standard care (SC)	I= The timing it right stroke family support program (TIRSFSP) C= standard care (SC)	Unknown	Face-to-face, telephone	CES-D (SSP vs SC) (SSP vs SD) SD vs SC)	 **0.047** **0.43** **-0.37**	**8- Moderate**
Cheng et al. (2018)	64 (T) 32 (I) 32 (C)	I= Psychoeducation programme + Treatment as usual (TAU) C= TAU	Nurse	Face-to-face, telephone	CSI CES-D 10	**-0.48** **-0.42**	**10-good**
Draper et al. (2009)	(T) 39 (I) 19 (C) 20	I= Education, psychological support and skill training C= wait list	Speech pathologist, Social worker	Face-to-face (group sessions)	RSS measuring Carer Burden	**Unable to report due to missing data**	**7- moderate**

Forster et al. (2013)	465 (T) 225 (I) 239 (C)	I= London Stroke Carers Training Course (LSCTC) C= TAU	Unknown	Face-to-face, telephone	CBS HADS-D HADS-A EQ-5D	**0.048** **-0.093** **-0.092** **0.023**	**9- good**
Franzén-Dahlin et al. (2008)	(T) (I) 46 (C) 45	I= support and education group C= TAU	Nurse	Face-to-face (group sessions)	CPRS-S-A	**0.308**	**6- moderate**
Fu et al. (2020)	(T) 68 (I) 34 (C) 34	I= Benefit finding intervention program C= health education information	Researcher, Psychologist, Nurse, Doctor	Face-to-face (home visits)	ZBI AC-QoL Caring Benefit Caring Stress Caring Choice Support for Caring Money Matter	**-0.902** **3.584** **2.343** **1.199** **2.541** **1.475** **2.439**	**10-good**
Grant et al. (2002)	(T)74 dyads (I) (C) (S)	I= social problem-solving therapy C= usual discharge care S= usual discharge + the same number of weekly/biweekly telephone calls	Nurse, Researcher	Telephone	CBS CES-D	**Unable to report due to missing data**	**8- moderate**

	Allocation to groups not specified						
Hekmatpou et al. (2019)	(T) 100 (I) 50 (C) 50	I= Patient care education on burden of care and quality of life C=TAU	Nurse researcher	Face-to-face, telephone	SF-36 Economic subscale	**0.14** **2.514**	**7-moderate**
LeLaurin et al. (2020)	(T) 53 (I) 13 (I) 13 (I) 13 (C) 14	I=RESCUE intervention C=SC	Nurse	Web-based, telephone	CES-D (8-week) CES-D (Attention) ZBI (8-week) ZBI (Attention)	**0.252** **0.217** **0.451** **0.278**	**7-moderate**
Lindley et al. (2017)	(T) 1250 (I) 623 (C) 627	I= Attend Trial- Family-led rehabilitation C=TAU	Rehabilitation professional	Face-to-face (home visits)	CBS HADS total HADS-A HADS-D	**0.0724** **0.0259** **0.0248** **0.024**	**10-good**
Mei et al. (2017)	(T) 83- 3 arm (I) 25- Dyad intervention (G1) (I) 22- carers only (G2) (C) 28 waitlist (G3)	I= Modified reminiscence therapy C=wait list	Psychologist	Face-to-face (home visits)	CBI Chinese version	**-1.509**	**7-moderate**

Mohammadi et al. (2023)	(T)79 (I) 39 (C) 40	I= Teleintervention C= TAU	Researcher	WhatsApp	SF 36	**-0.614**	**7-moderate**
Patchwood et al. (2021)	414 (T) 208 (I) 206 (C)	I= Organising support for carers of stroke survivors (OSCARSS) C= TAU	Unknown	Face-to-face	FACQ measuring strain HADS-A HADS-D	**0.034** **-0.01** **0.095**	**9-good**
Perrin et al. (2010)	T= 61 Numbers allocated to I and C are not stated.	I = Transition Assistance Program (TAP) C = TAU	Unknown	Face-to-face, videophone	CES-D 10	**Unable to report due to missing data**	**4-weak**
Pfeiffer et al. (2014)	(T) 122 (I) 60 (C) 62	I= Telephone based problem-solving C= Information-only group	Clinical Psychologist	Telephone-based	CES-D	**-0.289**	**10-good**
Shyu et al. (2010)	158 (T) 72 (I) 86 (C)	I= carer-oriented intervention programme C= TAU	Nurse	Face-to-face (home visits)	SF-36 Bodily Pain	 **-0.044** **0.144**	**8-moderate**

					General Health Perceptions		
					Vitality (Energy/Fatigue)	**0.031**	
					Social Functioning	**-0.246**	
					Role Limitations (Emotional)	**-0.152**	
					General Mental Health	**-0.192**	
					Physical Functioning	**-0.222**	
					Role Limitations (Physical)	**-0.222**	
Smith et al. (2012)	(T)38 (I) 19 (C) 19	I= Web-based intervention C= wait list	Nurse	Web-based	CES-D	**0.41**	**9-good**
Walker et al. (2020)	35 (T) 18 (I) 17 (C)	I= Biopsychosocial intervention for stroke carers (BISC) C= UC	Research psychologist	Face-to-face	CBS	**0.145**	**6-moderate**
					HADS	**0.175**	
					HADS-D	**0.293**	
					HADS-A	**-0.024**	
					EQ-5D	**0.152**	

Wang et al. (2021)	(T) 110 (I) 55 (C) 55	I=Education and muscle relaxation programme (EMR) C= TAU	Researcher	Face-to-face, self-directed	ZCBS HADS-A HADS-D	**0.505** **0.530** **0.432**	**9-good**
Yilmaz et al. (2019)	(T) 44 (I) 23 (C) 21	I= progressive muscle relaxation C= no intervention	Nurse	Recording-based	ZCBS BDS	**0.118** **-0.532**	**9-good**

Abbreviations: AC-QoL Adult Carer Quality of Life, BDS Becks Depression Scale, CBS Caregiver Burden Scale, CES-D 10 Centre for Epidemiologic Studies- Depression scale 10-item version, CES-D Centre for Epidemiologic Studies- Depression scale, CPRS-S-A Comprehensive Psychopathological Rating Scale -Self-Affective

CSI- Caregiver Strain Index, EQ-5D European Quality of Life- 5 Dimensions, FACQ Family Appraisal of Caregiving Questionnaire, HADS Hospital Anxiety and Depression Scale, HADS-A Hospital Anxiety and Depression Scale- Anxiety, HADS-D Hospital Anxiety and Depression Scale- Depression, MBI-GF- Maslach burnout inventory- general form, PHQ-9 Patient Health Questionnaire -9, RSS Relative Stress Scale, SF-36 Short Form- 36, WHOQol-Bref World Health Organisation Quality of Life- Brief

ZBI Zarit Burden Inventory, ZCBS Zarit Caregiver Burden Scale

Best interpretation of the CASP score in the context of limitations due to missing data/failure to report.

Study Characteristics

The review included a total of 24 studies conducted across various locations. Five studies were undertaken in the United States (Bakas et al., 2009; Grant et al., 2002; LeLaurin et al; 2020; Perrin et al., 2010; Smith et al., 2012), three studies were undertaken in the United Kingdom (Forster et al., 2013; Patchwood et al., 2021; Walker et al., 2020), three studies conducted in China (Fu et al., 2020; Mei et al., 2017; Wang et al., 2021), two in Iran (Hekmatpou et al., 2019; Mohammadi et al., 2023) and two in Turkey (Avci & Gözüm, 2023; Yilmaz et al., 2019). Additionally, a single study was completed in each of the following locations: India (Lindley et al., 2017), Pakistan (Batool et al., 2022), Canada (Cameron et al., 2014), Taiwan (Shyu et al., 2010), Hong Kong (Cheng et al., 2018), Brazil (Bierhals et al., 2023), Australia (Draper 2009), Germany (Pfeiffer et al., 2014) and Sweden (Franzén-Dahlin et al., 2008). This distribution provides a wide geographical range, supporting a broad perspective across international research settings.

Participants

It was not possible to calculate the number of participants included in this review due to some included studies failing to report sample sizes and allocation to groups. It was not possible to calculate the total number of participants included in this review due to a number of included studies failing to report precise sample sizes and allocation to groups (Batool et al., 2022; Grant et al., 2002; Perrin et al., 2010). Despite this, based on available data, at least 3,719 participants were included in the reported numbers.

Informal stroke carer participants were predominantly recruited from rehabilitation centres and hospitals, alongside veterans' groups, community groups, third sector charities and via self-selection web-based studies. Eleven of the twenty-four selected studies specifically looked at family carers (Shyu et al., 2010; Cheng et al., 2018; Wang et al., 2021;

Beirhals et al., 2023; Bakas et al., 2009; Grant et al., 2002; Mohammadi et al; 2023; Hakmatpou et al., 2019; Lindley et al., 2017; Franzen-Dahlin et al., 2008; Mei et al., 2017), two specifically focusing on spouses (Franzen-Dahlin et al., 2008; Mei et al., 2017), the latter focussing on 60-75 years old spouses. Of the remaining thirteen studies, the carer's relationship was not specified, although one study focused on 20-40-year-old carers (Batool et al., 2022).

Study findings

Thirteen of the 24 studies (Avci & Gözüm, 2012; Bakas et al., 2015; Batool et al., 2022; Bierhals et al., 2013; Cheng et al., 2018; Fu et al., 2020; Grant et al., 2002; Hekmatpou et al., 2019; Mei et al., 2017; Mohammadi et al., 2023; Pfeiffer et al., 2014; ; Wang et al., 2021; Yilmaz et al., 2019) reported significant benefits of interventions on carer burden and quality of life, or anxiety and/or depression. One study showed greater improvements in the control group (Walker et al., 2020).

Interventions varied across included studies but shared similar core elements. All of the studies involved an educational component, with information shared by professionals to carers. Twenty-one of the twenty-four studies considered individual needs, one study had a main aim to improve care for the stroke survivor (Lindley et al., 2017), therefore focused on the stroke survivors' needs, two studies utilised group delivery (Draper et al., 2009; Franzen-Dahlin et al., 2008), and one other study was a text-based delivery of education and information (Mohammadi et al., 2023).

There were notable differences across the studies, in the professionals delivering the intervention, how interventions were delivered, the length of each session, the overall duration and frequency of delivery and the outcomes being measured. Within the interventions yielding significant outcomes, no particular trend in intervention type was

observed. Skills development and problem-solving were among the most delivered interventions (Forster et al., 2013; Hekmatpou et al., 2019; Lindley et al., 2017; Bakas et al., 2015; Pfeiffer et al., 2014; Grant et al., 2002; Perrin et al., 2010; LeLaurin et al., 2020) despite only half of them yielding results of significance (Hekmatpou et al., 2019; Bakas et al., 2015; Pfeiffer et al., 2014; Grant et al., 2002).

Interventions were delivered by a range of professionals such as nurses, psychologists, physiotherapists, social workers, frontline staff, rehabilitation staff and researchers. Nurses were the most common interventionists, participating in intervention delivery in 11 of the 24 studies (Avci & Gözüm, 2023; Bakas et al., 2009; Bierhals et al., 2023; Cheng et al., 2018; Franzen-Dahlin et al., 2008; Fu et al., 2020; Grant et al., 2002; Hekmatpou et al., 2019; LeLaurin et al., 2020; Shyu et al., 2010; Smith et al., 2012).

A trend was noted in how interventions were delivered. Eight of the fourteen studies with significant results used a remote delivery method (such as telephone, web-based, or pre-recorded formats) for most of the intervention (Cheng et al., 2018; Bakas et al., 2015; Avci & Gözüm, 2023; Pfeiffer et al., 2014; Smith et al., 2012; Yilmaz et al., 2019; Grant et al., 2002; Hekmatpou et al., 2019). In contrast, non-significant studies mostly used face-to-face methods for delivering interventions (Shyu et al., 2010; Forster et al., 2013; Walker et al., 2020; Patchwood et al., 2021; Draper et al., 2009; Franzén-Dahlin et al., 2008; LeLaurin et al., 2020; Lindley et al., 2017).

Differences in the duration of the study were also observed, with eight of the fourteen significant studies being eight weeks plus (Cheng et al., 2018; Wang et al., 2021; Bakas et al., 2015; Pfeiffer et al., 2014; Mei et al., 2017; Yilmaz et al., 2019; Grant et al., 2002; Fu et al., 2020). Compared to studies that did not find significant benefits of carer interventions, the

majority were less than eight weeks in duration (Shyu et al., 2010; Patchwood et al., 2021; Draper et al 2009; Cameron et al., 2014; Perrin et al., 2010; Franzén-Dahlin et al., 2008).

Similarly, the length of contact time was greater in studies that found significant benefits of carer interventions, with five of the 14 studies reporting at least nine contact hours (Walker et al., 2020; Wang et al., 2021; Pfeiffer et al., 2014; Grant et al., 2002; Batool et al., 2022), compared to only one of the 10 studies that found no significant benefits of carer interventions, reporting a maximum of eight hours contact time (Draper et al., 2009). There was a general lack of reporting on session duration across all included studies.

Studies finding significant benefits of carer interventions typically focused on reducing carer burden (Avci & Gözüm, 2023; Mei et al., 2017) or symptoms of depression (Bakas et al., 2015; Pfeiffer et al., 2014; Smith et al., 2012) or a combination of these outcomes (Cheng et al., 2018; Walker et al., 2020; Wang et al., 2021; Yilmaz et al., 2019; Grant et al., 2002), with fewer focused on improving carer quality of life (Beirhals et al., 2023; Hekmatpou et al., 2019).

Studies that involved skills-building

One study rated good quality, assessed the impact of skills development on carer burden and psychological well-being. Forster et al. (2013) tested the London Stroke Carers Training Course (LSCTC), a competency-based skills development programme to improve burden and quality of life (CBS; EQ-5D) and psychological distress (HADS) compared to usual care. There were no significant findings post-intervention or at six and twelve-month follow-ups.

A second study rated good quality assessed the impact of skills development on carer burden (CBS), anxiety and depression (HADS). Lindley et al. (2017) applied an intervention to develop skills of family members providing care to stroke survivors in place of

rehabilitative care, compared to treatment as usual. The main aim of the intervention was to improve outcomes for the stroke survivor by enhancing the quality of care provided by family members where rehabilitation is not available, with secondary aims of reducing carer burden, anxiety and depression. The study found no significant difference between the intervention and control groups.

Studies that involved Skills Building and Problem Solving

One study rated good quality, assessed the impact of skills building and problem solving on carer depression (PHQ-9). Bakas et al. (2015) compared a Telephone Assessment and Skills Building Kit (TASK II) intervention to an information support and referral (ISR) control group. The intervention aimed to address carer concerns across five areas of need. The intervention took place over eight weeks. The study reported significant benefits for depression in the TASK-II group compared to the ISR group (mean difference [SE]=−2.6 [1.1]; P=0.013.

A second study rated good quality, assessed the impact of a problem-solving intervention on carer depression (CESD). Pfeiffer et al. (2014) tested the effect of a problem-solving intervention (PSI) compared to an information-only control group, on carer depression. The intervention comprised six interlinking components of problem-solving: (a) problem definition and facts, (b) optimism and orientation, (c) goal setting, (d) generation of alternatives, (e) decision making, and (f) solution implementation and verification. The outcomes were measured at baseline, three months, six months and 12 months. The study reported a significant reduction in symptoms of depression across all time points for individuals in the PSI, compared to the information-only group.

A third study rated moderate quality assessed a problem-solving intervention on carer burden (CBS) and depression (CESD). Grant et al. (2002) compared a Social Problem-Solving Partnership (SPSP) intervention to reduce carer burden and symptoms of depression

to usual care and a sham group of usual care and the same number of contacts. Participants in the intervention group had lower depression levels compared to both the sham and control groups.

A fourth study with a weak quality rating assessed a Transition Assistance Program (TAP) to improve symptoms of depression (CESD-10). Perrin et al. (2010) compared the impact of an intervention consisting of skills development, problem-solving and support, to treatment as usual, on depression in carers of veteran stroke survivors. There were no significant differences between the intervention and control groups.

A fifth study rated moderate quality, assessed a skills development and problem-solving intervention to reduce symptoms of depression (CESD) and carer burden (Zarit Caregiver Burden). Lelaurin et al. (2020) conducted a four-arm intervention comparing an intervention delivered over four weeks and eight weeks, an attention control condition and standard care. There were no significant differences between the four groups.

Studies that involved Individualised Support

One study rated moderate quality, assessed a carer-oriented individualised support intervention to improve health related quality of life (HRQoL). Shyu et al. (2010) implemented a carer-led intervention to enhance preparedness for caregiving compared to treatment as usual. There were no significant differences between the groups across any of the 12-month follow-ups.

A second study rated good quality assessed a carer-led intervention of individualised support to reduce carer strain (FACQ) and symptoms of anxiety and depression (HADS). Patchwood et al. (2021) compared the impact of an intervention using an assessment tool to identify, prioritise and address specific needs, to usual care. There were no significant differences post-intervention, or at the three and six-month follow-ups.

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A third study rated moderate quality assessed a tailored support intervention on symptoms of depression (CESD). Cameron et al. (2014) compared the effect of the Timing It Right Stroke Family Support Programme (TIRSFS) to usual care on symptoms of depression. The intervention is tailored to meet information, emotional, and support needs at varying stages of their stroke recovery journey. The study found no significant difference between the intervention and control groups.

Studies that involved Muscle Relaxation

One study rated good quality, assessed the effect of an education and muscle relaxation intervention on carer burden (ZCBS) and symptoms of anxiety and depression (HADS). Wang et al. (2021) compared an intervention consisting of health education and guided and self-practice muscle relaxation to treatment as usual over 12 months. The study reported significant differences across all outcomes, with a reduction in anxiety and depression at months six and 12. There was also a significant reduction in carer burden at months six and 12 compared to the control group.

A second study rated good quality assessed a progressive muscle relaxation intervention on carer burden (ZCBS) and symptoms of depression (BDS). Yilmaz et al. (2019) tested the impact of a progressive muscle relaxation intervention across 8 weeks, compared to no intervention, on burden and depression. There were significant reductions in depression and carer burden in the intervention group.

Studies that involved Education

One study rated good quality, assessed an educational intervention on the quality of life of carers (WHOQOL-Brief). Bierhals et al. (2013) compared an educational intervention to improve carers' stroke knowledge and skills to usual care. Outcome measures were completed at baseline, one-month and one-year follow-ups. There were some significant

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findings, with quality of life scores found to be significantly lower in the control group than in the intervention group.

A second study rated moderate quality assessed a mixed delivery of face-to-face and web-based education intervention on carer burnout (MBE-GF). Avci and Gözüm (2012) utilised an educational intervention, the Transitional Care Model Stroke Turkey (TEMPeST), to deliver information about stroke and caregiving compared to a usual care plus information support group. The study showed significant findings of higher levels of burnout in the control group compared to the intervention group.

A third study rated moderate quality assessed an educational intervention on carer quality of life (SF-36). Mohammadi et al. (2023) compared a teleintervention to deliver stroke education to informal carers and treatment as usual. Quality of life was significantly higher in the intervention group compared to the control group, but this difference did not reach statistical significance.

Studies that involved Psychoeducation and Behaviour Regulation

One study rated good quality assessed a psychoeducation-based problem-solving intervention measuring carer strain (CSI) and depression (CESD-10). Cheng et al. (2018) compared a strengths-based psychoeducation intervention focusing on problem-solving abilities, competence, symptoms of depression, burden and resources, physical injury and stroke survivor potential placement, to treatment as usual. The outcomes were measured at baseline, one month and three months post-intervention. There were significant findings, with a reduction in carer burden at three-month follow-up. There were no significant group differences in depression.

Studies that involved Cognitive Behaviour Therapy and Virtual Reality

One study rated moderate quality, assessed a Cognitive Behaviour Therapy (CBT) and Virtual Reality (VR) intervention on carer strain (CSI) and quality of life (AC-QOL).

Batool et al. (2022) tested an intervention to reduce carer strain and improve quality of life. The three-arm intervention compared VR, CBT and VR+CBT across six months. The study reported significant findings across all groups. There was a significant improvement in quality of life and reduction in carer strain, with the greatest improvement being in the VR+CBT group.

Studies that involved Modified Reminiscence Therapy

One study rated moderate quality assessed modified reminiscence therapy on carer burden (CBI). Mei et al. (2017) compared a modified reminiscence therapy intervention delivered across eight weeks, to a waitlist. There were significant findings with a reduction in carer burden compared to the control across all time points.

Studies that involved Biopsychosocial Intervention

One study rated moderate quality assessed the impact of a biopsychosocial intervention on carer depression and anxiety (HADs), quality of life (EQ-5D) and burden (CBS). Walker et al. (2020) implemented the Biopsychosocial Intervention for Stroke Carers (BISC). The intervention compared integrated education on the biological, psychological, and social impacts of stroke with strategies and techniques aimed at helping individuals adjust to stroke and caregiving, to usual care. The study reported significant findings, with those in the control group showing better outcomes than the intervention group.

Studies that involved Education, Psychological Support and Skills-Building

One study rated moderate quality assessed the impact of education, skills-building and support intervention on carer burden (RSS). Draper et al. (2009) compared an intervention providing skills-building, support and education to carers of aphasic stroke survivors to a waitlist. The study showed no significant difference in burden levels between intervention and control groups.

Studies that involved Education and Skills-building

One study rated moderate quality, assessed an education and skills-building intervention on quality of life. Hekmatpou et al. (2019) compared the effectiveness of a skills-building intervention delivered face-to-face with telephone follow-ups, to treatment as usual, on carer burden assessed using the SF-36. The mean scores of quality of life and its sub-scales increased in the intervention group compared with the control group, except for physical function and pain which did not differ significantly.

A second study rated good quality, assessed a web-based education and skills-building intervention on symptoms of depression (CESD). Smith et al. (2012) compared the web-based intervention with female-only carers, to a waitlist. The intervention included five elements aimed at equipping carers with the knowledge, resources, and skills necessary to alleviate their distress and offer the best possible emotional support to stroke survivors. The study found no significant differences in symptoms of depression when comparing intervention and control groups, with large and medium effect sizes at time points two and three respectively.

Studies that involved Education and Peer Support

One study rated moderate quality, assessed an education and peer support intervention on symptoms of depression (CPRS-S-A). Franzén-Dahlin et al. (2008) utilised a group intervention delivered to spouses of stroke survivors compared to treatment as usual. The group intervention covered discussion topics such as stroke symptoms and occurrence, risk factors, treatment, prevention, personality changes, and social aspects. The study reported no significant differences between intervention and control groups.

Studies that involved Benefit Finding

One study rated good quality, assessed a benefit-finding intervention on carer burden (ZCBS) and quality of life (AC-QOL). Fu et al. (2020) compared an intervention consisting of health information and a benefit-finding diary, to a health information-only group. The

study reported a statistically significant reduction in burden levels and increased quality of life in the intervention group compared to the control group.

Primary Outcomes

The included studies examined various aspects of caregiving using different outcome measures to assess primary and secondary outcomes (supplementary information 2).

Primary outcomes, carer burden, strain, burnout, and quality of life were measured using various scales. Carer burden, reflecting the physical, emotional, social, and financial strain of caregiving, was assessed via CBS (k = 6), ZCBS (k = 4), and FACQ (k = 1). Carer strain, referring to the subjective stress of caregiving duties, was measured using CSI (k = 2) and RSS (k = 1). Burnout, involving emotional exhaustion and reduced accomplishment, was evaluated via MBI-GF (k = 1). Quality of life, capturing carers' overall well-being, was assessed using AC-QoL (k = 2), SF-36 (k = 2), EQ-5D (k = 2), HRQoL (k = 1), and WHOQOL-Brief (k = 1).

Secondary Outcome

Secondary outcomes focused on psychological symptoms like depression and anxiety, which are commonly associated with high caregiving burden. Depression, characterised by persistent low mood and impaired functioning, was measured via CESD, CESD-10 (k = 7), PHQ-9 (k = 1), BDI (k = 1), and CPRS-S-A (k = 1). Anxiety, defined by excessive worry and physiological arousal, was frequently assessed alongside depression using HADS (k = 5).

Quality Appraisal

11 of the 24 trials scored between nine and 11 on the CASP tool. 12 scored between six and eight, and one study scored >five (supplementary information 3).

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Discussion

This systematic review aimed to identify the most commonly investigated types of stroke carer interventions and determine which show greatest efficacy in reducing carer strain or improving quality of life.

14 of the 24 included studies reported interventions with significant outcomes for stroke carers. 13 studies reported improvements in quality of life and/or a reduction in depression, anxiety, or carer burden, and one study found adverse effects. Two studies of moderate quality showed that modified reminiscence therapy and education-based interventions significantly reduce carer burden. Another two studies of moderate to good quality found that individualised education intervention and a practical training intervention significantly improved quality of life, and three studies rated good quality reported significant reductions in carer depression utilising a skills-based and resilience-building intervention, a problem-solving intervention and a web-based education and skills-building intervention. Three studies reported significant findings for burden and depression; two good-quality rated studies showed beneficial effects on burden and depression utilising a muscle relaxation intervention and a psychoeducation-based intervention, while one weak-quality study applying a biopsychosocial intervention indicated adverse effects for participants in the intervention group. Two studies of moderate to good quality found that a benefit-finding intervention and CBT and VR training intervention significantly improved burden and quality of life, and one study of good quality improved burden, depression, and anxiety through an educational and muscle relaxation intervention.

Psychological difficulties affecting the lives of those impacted by stroke have been widely recognised, with research recommendations to determine what factors and interventions best support psychological difficulties as a top priority for the James Lind Alliance (Hill et al., 2022). A key contribution of this review lies in its comparative analysis

of intervention design and delivery. Despite considerable heterogeneity in intervention types, professionals involved, and outcome measures, certain trends emerged. Interventions that demonstrated significant improvements in carer outcomes were more likely to be of longer duration, involve higher contact hours, and incorporate remote delivery methods such as telephone, web-based platforms, or asynchronous content (e.g., recordings or app-based tools). This may be attributed to the reduced need for carers to allocate additional time and resources to attend in-person sessions or clinics, thereby alleviating the pressures often associated with logistical planning and travel. Consistent with previous reviews, internet-based interventions have shown promising improvements in burden and depression among informal carers of other populations (Sherifali et al., 2018). These findings suggest that accessibility and sustained engagement may play a crucial role in intervention effectiveness; an insight with direct implications for scalable, cost-effective service delivery, especially in resource-limited settings.

These results are consistent with Mack and Hildebrand (2023), who reviewed interventions within the scope of occupational therapy and similarly highlighted the importance of intervention duration and delivery format. They observed that brief, in-person interventions delivered only prior to discharge rarely produced significant benefits, whereas interventions extending into the post-discharge period or spanning both pre- and post-discharge yielded better outcomes. The present review builds on these findings by incorporating interventions delivered by multiple professions and broader psychosocial approaches beyond the scope of occupational therapy, demonstrating that sustained, flexible, and accessible interventions can effectively support informal carers of stroke survivors.

While most interventions included an educational component, not all were tailored to individual carer needs, and only a minority explicitly addressed carer identity (e.g., spouses,

younger carers). however, factors such as age, cultural differences and individual preference should be considered in intervention development and delivery (Lindeman et al., 2020; Yu et al., 2023). The lack of demographic specificity in many studies points to a significant gap in the literature: few interventions are designed with age, relationship dynamics, or cultural context in mind. This is particularly important given the evolving demographic of carers, which increasingly includes younger adults and working-age carers.

Strengths, Limitations and Methodological Issues of Included Studies

The limited number of studies highlights the scarcity of research in this field. A particular challenge is that many studies included both patients and stroke carers as participants, making it difficult to separate or interpret the results (Cheng et al., 2018; Fu et al., 2020; Lindley et al., 2017; Mei et al., 2017; Perrin et al., 2010; Pfieffer et al., 2014; Shyu et al., 2010; Smith et al., 2012). Several papers considered for this review were excluded due to the combined nature of the intervention, analysis, and reporting of results, further reducing the sample size.

Issues in reporting quality impacted review findings. The intervention components lacked clarity and explanation in some included studies, making it difficult to draw firm conclusions on the impact of the intervention content. Three of the included studies failed to report the number of participants in the experimental and control groups (Batool et al., 2022; Grant et al., 2002; Perrin et al., 2010). None of the included studies reported any descriptions of co-interventions such as anxiolytics or antidepressant medication, which could be a potentially confounding variable.

The well-recognised problem of inadequate reporting led to the creation of the CONSORT (Consolidated Standards of Reporting Trials) statement in 1996, with its latest revision in 2010 (Moher et al., 2010). The CONSORT guidance aims to provide clear and robust reporting criteria to enable clarity to the readers. Notably, approximately two-thirds of

the studies were published after the 2010 revision, suggesting that awareness, adherence, or enforcement of these standards remains inconsistent.

Overall, reporting errors, such as failure to report sample size and gaps in the reports, such as intention to treat and intervention information, make it difficult to make a clear judgement on the risk of bias. These flaws in the reporting of randomised control trials can lead to the underestimation or overestimation of the quality of the intervention.

Strengths, Limitations and Methodological Issues of this Review

This review addresses a gap in the literature by synthesising research on the efficacy of interventions for stroke carers for improving quality of life and carer burden as primary outcomes and depression and anxiety as secondary outcomes. Others have focused on the impact of providing care to a stroke survivor (Jammal et al., 2024). However, this review has several limitations. The review excluded non-English publications and unpublished studies, which could increase the potential for bias, meaning findings may not be generalisable. Excluding unpublished literature adds to publication bias (Ekmeki, 2017), whereby the tendency to publish positive findings and neglect the negative outcomes is tolerated, further perpetuating the 'file drawer problem' (Rosenthal, 1979).

While there is no single gold standard tool for critical appraisal, study-specific appraisal tools are advised (Haile, 2021). Assessing the methodological quality of the included studies was completed utilising the CASP checklist, as this has been endorsed by the Cochrane Qualitative and Implementation Group (Noyes et al., 2017) and utilised in previous systematic reviews for stroke-related RCTs (Yin et al., 2022). The tool itself has been criticised, however. Due to the lack of clarity and guidance on its application (Long et al., 2020), it was decided to measure the quality of studies by totalling the number of criteria met. Given the lack of clarity of the CASP application, it is acknowledged that this may not accurately represent biases in each study.

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The search terms used might not have captured all relevant studies. Despite employing a systematic methodology, some studies may have been overlooked. Since informal carers often do not identify as such, they might not have been identified through the search strategy. Although this study searched five databases, it is acknowledged that a broader search could have been conducted.

Implications for Practice and Research

Trends in the studies reporting significant benefits of carer interventions indicate that increased contact time and interventions over a long duration improved burden, quality of life, depression and/or anxiety. However, there are additional cost implications for services regarding training and implementation of long-term interventions. Guets et al. (2019) systematically reviewed the cost-effectiveness of interventions for informal carers across different populations. They found that reporting of costs was inconsistent across studies, and often neglected the cost of informal care to both the state and the carer, but highlighted the astronomical savings to governments as a result of informal care. Recent research indicated the annual cost of informal care to stroke survivors to be £15.8 billion in the UK (Patel & Patel, 2020). There was also a trend towards telephone contact as an efficacious delivery method. This may be more cost-effective and potentially easier to implement than a face-to-face intervention, but there is limited evidence in this area, which requires future research.

Significant studies with the most efficacious outcomes for stroke carers indicate that a range of interventions may improve burden, strain, depression, and anxiety. Skills-based problem-solving was the most frequently studied intervention, applied across outcome measures related to carer burden, quality of life, and depression. Interestingly, skills-based problem-solving interventions were common regardless of the results. Further research is necessary to reduce the risk of bias and confounding variables and to support the implementation of significant interventions to enhance the current pool of research.

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Future studies need to provide clear reports of the interventions offered. Despite the development of the CONSORT statement and guidance for complex interventions, the included studies consistently failed to include this information. Expanding on the CONSORT guidance, Hoffman et al. (2014) developed the Template for Intervention Description and Replication (TIDieR) checklist and guide. The purpose of the checklist and guide is to provide authors with sufficient detail and clarity of interventions, to enable replication and application of interventions in practice, which will also allow for quality appraisal.

Declaration of interest

The author reports no conflict of interest. This research was supported by the University of East Anglia as fulfilment of the Doctoral Programme in Clinical Psychology

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Chapter Three: Bridging Chapter

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Bridging Chapter

The overarching aim of this thesis portfolio is to explore effective support interventions for informal carers of stroke survivors and their experiences of caring for someone with motivational changes after a stroke.

The systematic review aimed to synthesise research on the types of interventions provided for informal stroke carers and their effectiveness. It examined RCTs of interventions to reduce the psychosocial difficulties of informal stroke carers. Effective interventions available to informal stroke carers had four common characteristics: skills-based problem-solving content, remote delivery, across a longer duration (eight weeks plus) and increased contact time. Interventions with these characteristics were more likely to improve the psychosocial well-being of informal stroke carers. The outcome measures used in studies included in the review focused on carer burden or strain, quality of life, depression, and anxiety. Despite the high prevalence of post-stroke apathy and the impact on the rehabilitative process, there were no studies of interventions to support stroke carers with post-stroke apathy.

Much of the literature in the studies in the systematic review did not include measures for post-stroke apathy or provide stroke carers support for people looking after those with forms of post-stroke apathy. Consequently, the empirical study reported in the next chapter investigated the criterion validity of a carer-rated version of the Dimensional Apathy Scale. In addition, we explored the experiences of stroke carers of survivors meeting the criteria for at least one subtype of apathy.

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Chapter Four: Empirical Study

Prepared for submission to the Journal of Disability and Rehabilitation

Author Guidelines are available in Appendix A

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Supporting Informal Carers with Motivational Changes after Stroke

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Abstract

Purpose: We explored the experiences of caring for someone with post-stroke apathy and the validity of the informant-rated Dimensional Apathy Scale (DAS-I) with stroke carers.

Method: Fifty-one informal stroke carers completed a screening questionnaire to validate the DAS-I against the carer-rated Apathy Evaluation Scale (AES-C). Twelve participants from minority backgrounds were interviewed about their experience of caring for someone with post-stroke apathy, then analysed using Reflexive Thematic Analysis (RTA).

Results: A weak negative correlation was found between the DAS-I and the AES-C (-.324, p=.02). The internal consistency of the DAS-I was acceptable overall ($\alpha = 0.74$) and for initiation and executive subscales ($\alpha = 0.79$, $\alpha = 0.74$, respectively), but poor for the emotional subscale ($\alpha = 0.44$). Qualitative analysis revealed three overarching themes: Emotional Expression and Reflection, Impact on life, and Things that help. These themes showcased the positive changes for stroke carers and the perceived negative impact of emotional expression, mitigated by religion. Early practical support was lacking, whereas emotional support was readily available through faith centres.

Conclusions: Clinical services should integrate culturally sensitive strategies that account for faith and generational influences. Future research should focus on these elements to develop comprehensive support systems that improve carer well-being.

Keywords: post-stroke apathy, stroke, informal carers, apathy, Reflexive Thematic Analysis.

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Introduction

Stroke is the leading cause of disability and death in the UK, with 100,000 people suffering from a stroke each year (Stroke Association, 2023). The impact of stroke varies from mild to severe and can result in wide-ranging changes in physical, emotional, cognitive, and social abilities (Oliva-Moreno et al., 2017). There are currently 1.3 million stroke survivors in the UK, with over a third dependent on family or friends to provide informal care (Stroke Association, 2016). It is estimated that the cost of informal care to stroke survivors in the UK amounts to £15.8 billion annually (Patel et al., 2020), with government agendas often promoting informal care models (Metzelthin et al., 2017).

Extensive research has explored the burden of informal care, shedding light on the challenges faced by stroke survivors and stroke carers (Camak, 2015). As many as 50% of stroke carers experience symptoms of depression or anxiety (Greenwood & McKenzie, 2010; Visser-Meily et al., 2008). Their physical, social, and emotional well-being influences stroke survivor outcomes significantly (Pucciarelli et al. 2017). The unexpected introduction to a new role often leaves stroke carers seeking support for the more practical elements of caring, such as caregiving skills to aid rehabilitation (Zawawi et al., 2020). Stroke carers report that they would benefit from early intervention, yet recruiting carers to research interventions early after stroke can be challenging (Walker et al., 2020). Moreover, when practical and skills-based interventions have been investigated, evidence supporting their effectiveness has been limited (Cheng et al., 2014).

Among the challenges faced by stroke carers, psychological changes after stroke, such as depression and anxiety, have been rated the most stressful (Haley et al., 2009). In other clinical populations, caring for someone with apathy has also been found to be associated with increased experiences of guilt, loneliness, and frustration for carers (Chang et al., 2021). Post-stroke apathy, defined as an overall reduction in goal-directed behaviour after stroke

(Tay et al., 2021), is often misdiagnosed due to symptom overlap with post-stroke depression (Mortby et al., 2022) but is nevertheless known to be a common consequence of stroke affecting approximately one-third of stroke survivors (Caeiro et al., 2013; Van Dalen et al., 2013). Different subtypes of apathy in stroke survivors (Myhre et al., 2022) have been identified utilising the Dimensional Apathy Scale (DAS)(Radakovic & Abraham, 2014).). The DAS distinguishes three subtypes of apathy: 'executive apathy', a diminished motivation for tasks involving planning, organisation, or sustained attention; 'initiation apathy', characterised by a reduced drive to generate independent thoughts or engage in purposeful actions; and 'emotional apathy', a state of emotional indifference or neutrality. In a validation study of the self-rated DAS, Myhre et al. (2022) found that at least 43% of stroke survivors experienced more than one type of apathy.

Post-stroke apathy affects engagement in rehabilitation, leading to decreased participation in daily tasks and increased vascular disease, disability, and mortality (Tay et al., 2021). Apathy remains poorly understood among individuals with neurocognitive disorders and their carers, with Burgon et al. (2023) emphasising that while environmental factors can foster motivation and engagement, these are often facilitated by carers themselves. However, carers frequently misinterpret apathy, which can lead to withdrawal as a maladaptive response to the psychological strain and burden of care (Burgon et al., 2023). This raises a paradox, how can carers be expected to foster motivation within the care environment when apathy itself is poorly recognised and conceptualised. Evidence from other clinical populations suggests that apathy contributes to elevated risks of carer burden and burnout among informal carers (Mason et al., 2024; Penteado et al., 2021; Vatter et al., 2020;Wong et al., 2020). In dementia, apathy has been associated with adverse physical outcomes in patients and increased carer burden (Kılıçaslan et al., 2025), and it has emerged as an independent risk factor for carer burden in the context of amyotrophic lateral sclerosis

(ALS) (Gong et al., 2024), prompting calls for routine screening at diagnosis (Kılıçaslan et al., 2025). However, little is known about the impact of apathy on the experience of caring for someone after a stroke in general and whether this also affects carer burden and burnout. Research on the experience of caring for someone with post-stroke apathy might indicate if there is a need to develop interventions to support stroke carers with this.

In addition, the experience of caring is not uniform. It is important to understand how sociocultural factors such as ethnicity and religion might shape how carers interpret post-stroke apathy, experience their carer roles and engage with services. This is important to consider when developing interventions to support stroke carers. It is well known that stroke prevalence differs across communities, with increased stroke risk among Black and Asian communities (Emmet et al., 2025). Moreover, Buie et al. (2020) highlighted lower recovery rates after stroke and a higher prevalence of comorbid conditions in Black females.

Religious and spiritual beliefs may shape carers' experiences of apathy, though their impact remains complex and not fully understood. Hebert et al. (2006) found mixed associations between religious beliefs and informal carers' perceived burden, while Kes and Yildirim (2020) reported that positive religious beliefs can mitigate caregiver strain, suggesting a potential protective role. Carers UK (2023) found that 56% of UK-based unpaid carers in a sample of over 7,500 respondents identified as Christian, with 30% reporting that their faith improved their health and wellbeing, further indicating that religious engagement can influence how caregiving roles and responsibilities are perceived. Similarly, Ambrosca et al. (2024) found that positive spiritual strategies, such as framing caregiving as 'part of God's plan,' were linked to greater resilience, improved mental health, and enhanced quality of life for informal carers. Conversely, Gong et al. (2024) identified apathy as a distinct risk factor for increased carer burden in ALS carers. Taken together, these findings tentatively suggest that spirituality may provide carers with resources to cope with apathy. However, the

evidence remains insufficient to determine whether religious or spiritual engagement consistently alleviates or inadvertently reinforces positive or negative carer experiences.

In various cultural contexts, such as sub-Saharan Africa, some beliefs attribute stroke to divine anger, often prompting carers to seek support from religious rather than medical sources (Nwoha et al., 2022). In African-American urban stroke carers, spirituality served as a vital coping resource and a source of motivation, providing emotional strength, resilience, and a sense of divine purpose (Pierce, 2001). These findings align with Carers UK (2023), who advocate for support services tailored to religious identity. Echoing this, Strudwick and Morris (2010) highlighted that while African-Caribbean informal stroke carers in the UK share many caregiving experiences with other ethnic groups, their roles are uniquely shaped by cultural values, religious faith, and a tendency to rely on family and community rather than formal services. This cultural lens may influence how apathy is perceived, managed, and how carers seek or avoid external support.

As so little is known about the experience of caring for someone with post-stroke apathy and whether this varies by apathy presentation or sociocultural influences, we conducted qualitative research with stroke carers who identified as caring for someone with post-stroke apathy. Given the frequent misdiagnosis of post-stroke apathy, the researchers sought to identify and recruit participants for interviews by administering both the informant-rated Apathy Evaluation Scale (AES) and Dimensional Apathy Scale (DAS), to subsequently validate the DAS as a multidimensional tool capable of distinguishing apathy subtypes relevant to intervention development.

Research Questions

Our research focused on the following questions:

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1) Does the Informant-Rated Dimensional Apathy Scale (DAS-I) have sufficient internal consistency and criterion validity compared to the Carer-Rated Apathy Evaluation Scale (AES-C)?
2) What is the experience of caring for someone with a form of post-stroke apathy?
3) What are the needs of informal stroke carers in relation to caring for someone with a form of post-stroke apathy?
4) Do informal stroke carers identify anything that has helped or might have helped in relation to caring for someone with post-stroke apathy, and does this vary by apathy presentation or sociocultural influences?

Methods

Design

To facilitate the identification of appropriate participants, a bespoke online questionnaire was developed and disseminated via self-selection links on social media platforms (X and Facebook) and through the Different Strokes website (Appendix B). Participation was voluntary, and respondents provided consent via a tick-box selection before completing the survey.

The questionnaire incorporated demographic questions and two informant-rated apathy measures: the Apathy Evaluation Scale Carer version (AES-C), a widely used unidimensional tool, and the Dimensional Apathy Scale Informant version (DAS-I), which captures multidimensional apathy subtypes. The primary function of the questionnaire was to identify informal stroke carers supporting individuals who met criteria for at least one form of apathy.

A critical realist perspective was adopted regarding beliefs about reality and knowledge. This acknowledges the existence of a world that cannot be directly observed and that understanding is shaped by personal perceptions and tangible experiences (Archer et al.,

1998). Reflective thematic analysis (Braun & Clarke, 2019) was applied to semi-structured interviews to explore the nuanced experiences of the impact and needs of unpaid stroke carers supporting someone with post-stroke apathy and their ideas about what might help in this situation.

Participants

Participants were recruited through a self-selection hyperlink shared on social media sites (X and Facebook) and the Different Strokes website. Participation was voluntary, and a consent tick box selection was required before completing the survey. Participants identified as supporting stroke survivors meeting criteria for at least one form of post-stroke apathy were invited to participate in semi-structured interviews with an email providing information about the second stage of the study and seeking consent. The inclusion criteria were that participants must be 18 or above, provide unpaid care to a stroke survivor and be able to speak and read English. The study excluded non-English speakers due to resource limitations in translating materials and interpreting responses accurately.

Ethical Approval

The study was approved by the Faculty of Medicine and Health Sciences Research Ethics Committee at the University of East Anglia (ETH2324-0095). Participants were provided with information sheets and consent forms at the start of each stage of the project, and informed consent was obtained from all participants. All participant information was anonymised using pseudonyms and redacting identifiable information. Participants received a £10 Amazon gift voucher as a token of appreciation. Participants completing the quantitative questionnaire were entered into a raffle to win one of three £20 Amazon vouchers as a token of appreciation. Participants were provided with debrief information and a list of local resources for emotional and well-being support.

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Materials

The online survey assessed eligibility, consent to research, demographic and clinical characteristics (sex, ethnicity, age, relationship to stroke survivors, time since stroke, presence of stroke survivor depression and whether pre or post stroke) and post-stroke apathy using the AES-C (the AES, Marin et al, 1991) and DAS-I (Radakovic & Abrahams, 2014) (Appendix C).

The Dimensional Apathy Scale (DAS) (Radakovic & Abrahams, 2014) is a 24-item measure with three eight-item subscales measuring Executive Apathy, Emotional Apathy and Behavioural/Cognitive initiation Apathy. Each item is rated on a four-point scale, ranging from zero (Almost Always) to three (Hardly ever). It takes approximately five minutes to complete the entire scale. DAS total score ranges from zero to 72. Clinical cut-off scores for apathy and apathy subtypes are Total ≥ 39, Executive subtype ≥14, Emotional subtype ≥15 and Initiation subtype ≥16 (Myhre et al., 2022). The DAS has been used with a range of clinical populations and found to have acceptable internal consistency in Motor Neurone Disease ($\alpha = 0.86$) (Radakovic et al., 2016), Parkinson's disease (Cronbach's $\alpha = 0.84$) (Radakovic et al., 2017), Alzheimer's ($\alpha = 0.85$) (Radakovic & Abraham, 2014), and community stroke survivors ($\alpha = 0.84$) (Myhre et al., 2022).

The informant-rated Apathy Evaluation Scale (AES-I) (Marin et al., 1991) measures apathy in adults, particularly those with brain injury, neurocognitive disorders, and other diverse populations. It comprises 18 items rated on a 4-point Likert scale with a total score ranging from 18 to 72. Higher scores indicate greater apathy, and the clinical cut-off indicating abnormal apathy is ≥ 34 (Andersson et al., 1999). Three items are reverse-scored. The AES is regarded as a valuable, dependable, and valid instrument for quantifying and evaluating the severity of apathy symptoms in adults and differentiating apathy associated with Alzheimer's Disease and stroke (Marin et al., 1991).

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Semi-structured interviews were employed to gather information about experiences and collect clinical information (Magaldi & Berler, 2020). An interview topic guide was used to facilitate a semi-structured approach, enhancing flexibility, but also to steer the research questions towards specific domains of apathy.

Procedure

Purposive sampling was used to recruit informal stroke carers supporting stroke survivors meeting criteria for at least one form of apathy. Participants were recruited through a self-selection hyperlink shared on social media sites (X and Facebook) and the Different Strokes website. Participation was voluntary, and a consent tick box selection was required before completing the survey.

As post-stroke apathy is often undiagnosed or misdiagnosed, a small, nested criterion validation study was used to first identify stroke carers providing unpaid support to stroke survivors with apathy presentations and to characterise these presentations. To this end, informant-rated apathy measures were embedded within the online survey. For this stage of the research, an a priori power analysis using G*Power version 3.1.9.7 (Faul et al., 2007) determined a minimum sample size of N=29 to be necessary to validate the DAS-I against the AES-C with 80% statistical power for detecting a large effect and significance criterion of α=0.5.

If thresholds for at least one form of apathy were met, participants were invited to participate in semi-structured interviews. Interviews were recorded on Microsoft Teams and lasted approximately 50 minutes. Each participant was asked a series of open-ended questions, using a flexible approach to the order of questions. This enabled the interviewer to probe specific details as information unfolded. Interviews were reviewed, transcribed verbatim and anonymised before analysis. Further details on the sample characteristics are presented in the results section and Table 1.

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Reflexive thematic analysis (RTA) was chosen as the qualitative methodology for the study. As outlined by Braun and Clarke (2020), RTA complements a critical realist approach by enabling an in-depth, flexible, and iterative analysis of patterns within the data while recognising the active role of the researcher in meaning-making. RTA allows for a rich, context-sensitive exploration of themes without assuming a fixed or purely objective reality. Reflexive Thematic Analysis prioritises the researcher's interpretation of raw data and does not prescribe a minimum sample size to achieve saturation (Braun & Clarke, 2019; Braun & Clarke, 2020). Saturation refers to the point in the analysis where no new themes emerge, rendering the remaining data collection insignificant (Hennink & Kaiser, 2021). The sample size was guided by analytical depth, theoretical sufficiency, and the richness of participant narratives, rather than assumptions of data redundancy. A sample of 12 informal stroke carers was deemed sufficient based on the principle of information power (Malterud et al., 2016), given the study's narrow aim, to explore carer experiences of post-stroke apathy identified through validated informant-rated tools (AES, DAS-I).

Analysis

The software program IBM SPSS v.29 was used to analyse AES-C (the AES, Marin et al, 1991) and DAS-I scores. Missing data were identified and replaced using a multiple imputation method (Ranganathan & Hunsberger, 2024). Scores were checked for normality before utilising non-parametric tests as appropriate to test internal consistency and associations between measures.

Qualitative interviews were imported to NVivo software (QSR International Pty Ltd, 2020) and analysed following the six steps of Reflexive Thematic Analysis (RTA): familiarisation, coding, generating initial themes, reviewing themes, defining and naming themes, and producing a report (Braun & Clarke, 2020). This flexible method allows

consideration of the researcher's engagement with theory, the data, and their interpretation (Braun & Clark, 2020).

Lincoln and Guba's (1985) credibility framework to ensure the scientific rigour of qualitative research was considered. Following this framework, we aimed to ensure credibility, confirmability, dependability, and transferability throughout the study. The researcher kept a reflective journal to align with the central nature of RTA, offering a form of quality control while acknowledging the researcher's influence (Braun et al., 2022).

As the primary researcher of this study from an insider/outsider perspective, I recognise the influence that my personal and professional experience brings to the interpretation. I have previous professional experience as a paid carer for people who have experienced a stroke. I recognise that my experiences may also introduce biases. For instance, my familiarity with certain struggles might lead me to emphasise themes related to the impact of stroke. In contrast, I have no personal or lived experience as an informal carer or familial experience of stroke. This outsider perspective allows me to remain curious about informal stroke carers'' experiences. Throughout the research process, I have engaged in reflexive journaling and sought feedback from colleagues who do not share my background. This has helped me to maintain a critical perspective and ensure that the voices of the participants are represented authentically.

Furthermore, I am aware that my position and social privilege, being a heterosexual white female, potentially viewed in a position of power, might influence how participants respond to my questions. To address this, I have strived to create a comfortable and open environment during interviews, encouraging participants to share their stories freely and without judgment. I have also been transparent about my background when appropriate to build rapport and trust with participants.

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Results

Fifty-one stroke carers responded to the initial online survey. Sample characteristics are provided in Table 1. A Shapiro-Wilk test showed a significant departure from normality in the data from the DAS-I ($W(51)=0.92$, $p=0.003$) and the AES-C ($W(51)=0.95$, $p=0.03$) so non-parametric tests were used to analyse these measures.

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Table 1

Sample Characteristics

	N (%)	
Gender		
Male	28	(54.9%)
Female	23	(45.1%)
Age range		
18-25	4	(7.8%)
26-35	24	(47.1%)
36-45	14	(27.5%)
46-55	4	(7.8%)
56-65	3	(5.9%)
76-85	2	(2%)
Ethnicity		
English/Welsh/Scottish/Northern Irish/British	19	(37.3%)
Black British or Caribbean background	15	(29.4%)
Other Multiple Ethnic background	8	(15.7%)
Other White background	3	(5.9%)
Multiple Ethnicity: White and Black African	3	(5.9%)
African	2	(3.9%)
Indian	1	(2%)
Depression diagnosis (stroke survivor)	39	(76.5%)

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Internal Consistency

Overall, the DAS-I showed acceptable reliable internal consistency (α = 0.74). Internal consistency was acceptable for the Initiation Apathy (α = 0.79) and Executive Apathy subscales (α = 0.74), but not the Emotional Apathy subscale (α = 0.44) in informal stroke carers.

Convergent and Criterion Validity

An unexpected, albeit weak, negative correlation was found between the total scores of the DAS-I and AES-C ($r_s(49)$=-.324, p=.02), implying that the two measures differed in their assessment of apathy.

The DAS-I total score correlated significantly with all subscales: Emotional Apathy $r_s(49) = 0.41$, $p = .003$, Executive Apathy $r_s(49) = 0.68$, $p < .001$, and Initiation Apathy $r_s(49) = 0.86$, $p < .001$. A significant positive intercorrelation was found between Executive Apathy and Initiation Apathy $r_s(49) = 0.42$, p =.002. Emotional Apathy did not intercorrelate with Executive Apathy $r_s(49)$ =-.20, p =.160, or Initiation Apathy $r_s(49)$= .20, p =.160.

The AES-C total score had a negative significant correlation with one of the DAS-I subscales: Emotional Apathy $r_s(49) = -0.42$, p =.002, but did not correlate significantly with the subscale for Executive Apathy $r_s(49) = -0.27$, $p < .051$, or the subscale for Initiation Apathy $r_s(49) = -0.97$, p .496.

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Interviews

Forty-six stroke carers rated the stroke survivor above the clinical cut-off on at least one subtype of apathy and consented to further contact. Sixteen stroke carers responded and scheduled interviews, but four did not attend the scheduled interview time. Interviews were completed with 12 stroke carers (36.4% of those invited). Nine interviewees were male, seven were adult children, three were spouses, one was a niece, and one was a grandchild of the stroke survivor. Two stroke carers had also employed part-time support, but the remaining ten were sole primary stroke carers. All twelve rated the stroke survivor above the clinical cut-off for apathy on the AES-C, and four rated the stroke survivor above the clinical cut-off for at least one apathy subtype on the DAS-I (see Table 2).

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Table 2

Sample Characteristics

Participant number	Gender	Ethnicity	Apathy Scale	DAS-I Apathy Subtype	Age group (years)	Relationship to Stroke Survivor
1	Female	African	AES & DAS	Executive & initiation	26-35	Neice
2	Male	Any other Black, Black British or Caribbean background	AES & DAS	Emotional & Initiation	26-35	Granddaughter
3	Male	White and Black African	AES & DAS	Emotional	56-65	Husband
4	Male	Any other Black, Black British or Caribbean background	DAS	Executive, Initiation & Emotional	18-25	Son
5	Male	Any other Black, Black British or Caribbean background	AES & DAS	Emotional	26-35	Son
6	Female	Any other Black, Black British or Caribbean background	AES		26-35	Daughter
7	Male	White and Black African	AES		26-35	Son
8	Female	Any other Black, Black British or Caribbean background	AES		26-35	Wife
9	Male	Mixed: multiple ethnic backgrounds	AES		26-35	Son
10	Male	Mixed: multiple ethnic backgrounds	AES & DAS		26-35	Son
11	Male	Any other Black, Black British or Caribbean background	AES		36-45	Husband
12	Male	Mixed multiple ethnic backgrounds	AES & DAS	Initiation	26-35	Son

Themes

Three themes reflecting the carers' experience were identified from the interviews:

1. Emotional expression and reflection
    a. *Subtheme- Expressing Difficult Emotions*
    b. *Subtheme- Lack of Reciprocity*
    c. *Subtheme- Religious Influence on Emotional Expression*
2. Impact on life
3. Things that help

Theme 1: Emotional expression and reflection

This theme captured the complex ways in which the emotional changes of the stroke survivor were experienced and understood by stroke carers. Stroke carers discussed the open expression of positive emotions, while negative emotions were only expressed in private. It recognises the reciprocal role of emotions and the influence of religious and spiritual beliefs on expressed and observed emotions. Reflecting on experiences, stroke carers' providing care reflected on the care they received by the survivor as a child as influential in providing care now, 'The fact that eh he is my parent, he brought me up' [Participant 7]. Stroke carers recognised the changes in the stroke survivor, attempting to make sense of the situation and how to respond.

One carer tried to understand why the stroke survivor showed fewer emotions and how this affected their relationship.

> I don't know if she's thinking that she's protecting me, but I.. I feel like.. I feel like she doesn't really take into consideration that I, I'm trying to be helpful and I see that she, like, she lacks the interest of my, my attention and my care… I feel like I'm being pushed away [Participant 11]

Another carer spoke about the toll of the emotional load and struggled to understand why this impacted how they felt.

> It really affects me in the fact that they want to carry all the emotions. I'm the one to bear all the emotions. That does not concern him… It makes me feel somehow strange and somehow I don't know, somehow neglected. I don't know why [Participant 10]

Subtheme: Expressing Difficult Emotions

Almost every carer [Participants 1,2,3,4,5,6,8,9,10,11,12] described a sense of responsibility to remain happy or neutral in front of the stroke survivor and only express negative emotions in private. At times, this resulted in internal conflict for the stroke carers, questioning their own sense of self.

> There are times where I get to cry. I try to let out my emotions, but I try to cry in private and then it's like, ah who am I? [Participant 1]

When discussing a lack of emotional expression of the stroke survivor, there seemed to be a responsibility for stroke carers to uphold a positive façade as they recognised the effect on the stroke survivor.

> When I'm down I I can't, I can't just afford to show it because there was a time where, you know, she wasn't happy, and I showed it. I was like reflecting emotions also. And it got worse. It got worse, and she really, she was so down [Participant 2].

While acknowledging the impact on their own mental health, ‘I don't wanna use the word depressing but it can really get bad at times [Participant 1]’, stroke carers were still reluctant to show their emotions openly. The accumulation of moderating emotional expression in front of the stroke survivor often required thoughtful and planned action to feel a sense of emotional release, highlighting the importance of being able to express emotions and to feel heard.

> Oh, it affects my mood. Let me say 90% because this is a person you are with daily. And before initially I never had to fake anything…Sometimes I end up going out, just cry and scream out because that's the only way that I can express myself. [Participant 6]

Subtheme - Lack of Reciprocity

Two stroke carers [Participant 8, 12] described the difficulty of caring for someone with significant disability from the stroke, 'he's like, he can't move, he can't talk. He's just there' [Participant 8], and how these changes impact their own motivation.

> I consider them as a really great changes because you know you can imagine like talking to someone who is just staring at space, you know, not even looking at you or anything. It's traumatising. [Participant 8]

When stroke carers sought emotional support from peers, it was often met with rationalisation or minimising the difficulties of the stroke survivor. These experiences reinforced the stroke carers' assumptions of needing to remain positive despite the challenges they faced. This increased the level of burden on stroke carers to understand the emotions of others whilst continuing to experience their own in private, resulting in a depressive cycle.

> I tried to express myself and how I feel...they tell me it's normal and I should try, I should practise a mindful activities [Participant 11]

During interviews, participants struggled to describe any negative emotions, they continued to express positivity about their situation even without the stroke survivor being present at the time.

Subtheme - Religious Influence on Emotional Expression

Most stroke carers [Participants 1,2,3,4,5,7,8,10,11] explained that the influence of religious or spiritual beliefs meant they should not express negativity or that God would not have given them this challenge if they couldn't manage it.

I believe that God gives us challenges that we can overcome [Participant 3]

Stroke carers' beliefs align with religious rite, the concept of sacrifice. They expressed making sacrifices or putting certain aspects of life on hold to provide care.

Presently I am ready to sacrifice anything. And I have sacrificed something and I have no regrets doing that. I feel fulfilled. [Participant 2]

There was a sense of the carer's expressions minimising the gravity of their new role, experiences and expression of negative emotions.

We believe in Christianity we believe that whatever you speak.. whatever you you get so, encourage or try to, you know, on speaking positively. [Participant 11]

In contrast, expressing positive emotions can be protective of mental health difficulties in carers of faith.

‘the most helpful thing that I found is you know finding my new self.

This particular self is is one that I'm very proud of. I am being able to put everything down to care for someone else’ [Participant 2]

‘It has actually give me a reason to actually improved my personal self’ [Participant 4]

Some of the stroke carers [Participants 10, 11, 12] referred to a specific scripture that suggests suffering and struggles are rewarded exponentially. They spoke about challenges in life being a test of faith and having to remain devoted to God, and this would be considered on judgment day.

I believe that what I'm doing will be used on Judgement Day and what I do, I know God knows what I'm doing and I know I will be blessed in so many ways... God will give me those blessings, triple. [Participant 12]

Theme 2: Impact on Life

The stroke carers described a sense of significant uncontrollable changes since the stroke, such as unwanted career changes, reduced social interactions and limited personal time. Half of the stroke carers [Participant 3, 5, 8, 9, 10, 12] changed careers to work remotely since the stroke, others stopped working completely [Participants 2, 4, 6] so they could prioritise the needs of the stroke survivor. Those who continued to work outside the home [Participant 8, 11] paid for support in their absence.

There was a consensus among the stroke carers that they were no longer a priority in their own lives, 'In a day, 90% is him and 10% is only me, so all my time is about person I'm caring for '[Participant 6]. Some participants grieved the life they felt they should be living, whilst others ruminated on the stroke.

> I just feel like I'm living someone else's life. I feel like I am not um, living my life the way I wanted. [Participant 1]

> You feel sad, like the fact that you don't have any authority over that situation. Like you can't change anything about it. [Participant 8]

The stroke carers discussed general day-to-day routines. Most of them discussed having to plan the day and tasks that needed completing as the stroke survivor was 'not bothered to do it' [Participant 7]. Some stroke carers felt the stroke survivor could plan their activities, yet there was concern if this could be followed through or if they would be simply less effective at carrying out plans.

> Most of the time I plan the day and at times we're planning together…I think he would be able to do it, but I guess not as effective as would have done. [Participant 5]

Stroke carers discussed the survivor having difficulties planning and initiating tasks. Some stroke carers [Participants 5, 6, 7, 9, 11] expressed this could be attributed to poor memory, but also observed their own concerns of task completion might contribute to this, 'I

think he would be able to do it, but I guess not as effective as we would have done together. Or if I did it on my own' [Participant 5]. Others mentioned [Participant 3, 10] that the stroke survivor would not carry out the plans as they lacked motivation, even though the stroke survivor could create the plans.

> I'm the one who does all the planning. I think he's not able to plan those things. I'm the one who knows. He knows some of the things has to be done, but he really doesn't. It's like not concerned about it' [Participant 10]

Despite the intensity of the caring role, even when the carer was away from the stroke survivor, the stroke survivor remained a priority for the stroke carers.

> You go to work, but all the time, your mind's at home and are trying also to come up with ways to ensure that even the children don't get that sense of depression or because of their the situation that their their mother is in' [Participant 11].

This has impacted several areas of their lives, with most of the stroke carers changing careers to work remotely, enabling them to care for their loved ones. 'I think if I was not working from home, it would be a little bit difficult to support, to give some support' [Participant 9]. However, this has also had a detrimental impact on their support system and opportunities to socialise.

> It feels so much isolated because, since growing up, I grew up with a lot good social group, so I nowadays I have limited time to engage with social activities or hobbies. [Participant 10]

> My life has really changed, and now I'm mostly an in person guy who stays just at home and takes care of my mother. [Participant 12]

Theme 3: Things that Help

Time since stroke and level of disability differed amongst stroke carers; however, there were similarities in their coping strategies used in the moment. Over half found support

in their faith or religious practices and often utilised prayer to reduce their burden [Participants 2,3,8,9,10,11,12]. One participant reported having become even more religious since the stroke, while another expressed hope for a full recovery.

> I have been religious but, even after the stroke, I became more and more religious [Participant 12]

> I thank God that we are..we are both on the…are are trying to ensure that everything will come back to normal, hoping that everything will be normal [Participant 11]

The most common form of support that the stroke carers found helpful was family or support groups. The stroke carers mentioned how they found comfort in those who had similar experiences and who could offer suggestions and practical support.

> I joined caregiver support group, which helps me share my experience and maybe, listen to other caregivers experience and maybe, help one another go through this difficult situations [Participant 10]

Stroke carers found comfort in engaging with others who could relate to their circumstances, some stroke carers took comfort that they were not alone in their experiences.

> The group I joined online shared resources and all it has been quite helpful. I got to know I'm not in this alone. We have people with worst cases. We have people who, who are so aggressive, and this is just normal stuffs [Participant 1]

Other stroke carers used downward social comparison, contrasting themselves with those they perceived to be worse off, making them feel better momentarily about their situation, ‘So when we hear an experience of someone who say, wow, even I'm much better because people go through worse [Participant 6]. While the group experience for another stroke carer seemed to motivate and energise them ‘You get to talk to other people and you see other people who are even worse than what you are going through and you get the energy [Participant 8]

Reflecting on their experiences, stroke carers highlighted that support is usually only offered for the stroke survivor and how this was in the initial stages after stroke. They found this stage difficult as they were adjusting to life-changing circumstances, where the primary aim for them was to learn the practical aspects of caring.

> I just had to adjust to the new condition and I started, you know, looking for ye know information about caring for someone with stroke [Participant 2]

During the early stages, stroke carers felt the most helpful intervention would have been support around the practical aspects, with some suggesting a practical guidebook as a form of support for those in similar circumstances [Participant 1,12]. They reflected on searching for this information, often using YouTube and social media platforms for answers.

> I have to, you know, look up it online, you know, to be able to have that kind of effective uh care for the person, yeah [Participant 4]
>
> I also you know did a lot of research online. Mostly I would say the 80% of the information I got was online [Participant 2]

Despite the challenges presented, some stroke carers often referred to how they have found caring to be rewarding and feel grateful they can provide care to their loved ones. One stroke carer expressed how the challenges improved their ability to have empathy for the stroke survivor.

> You happen to, you know, overcome challenges together so that it uh strengthens uh the bond. And, you know, it fosters empathy. And you know, you've been able to, you know, appreciate the small things. [Participant 4]

Discussion

This is the first study to qualitatively explore informal stroke carers' experiences of supporting someone with post-stroke apathy, a condition which affects motivation, engagement in rehabilitation and recovery (Tay et al., 2021). While apathy has been associated as a single high indicator of carer burden in other populations, such as dementia and ALS (Gong et al., 2024; Kilicaslan et al., 2025), its impact in a stroke population is underexplored. The current findings offer a nuanced account of stroke carers' experiences of post-stroke apathy and its impact on their daily lives. Three overarching themes were identified: (1) Emotional Expression and Reflection, (2) Impact on Life and (3) Things that helped.

The first theme suggested that the stroke carers of people with post-stroke apathy experienced a negative impact of their role on mood and lack of emotional reciprocity within the dyad, but restricted themselves to displaying only positive emotions to the stroke survivors they supported, influenced in this by religious beliefs. Aspects of this theme are congruent with Chang et al.'s (2021) finding of feelings of frustration in carers supporting others with an apathy presentation, in addition to increased stress, depression and reduced quality of life (George et al., 2020). However, while previous research suggested that psychological difficulties after a stroke are the most stressful problems faced by stroke carers (Haley et al., 2009), the current participants described using the challenges of caring for someone with post-stroke apathy as a way to improve themselves. This reflects similar findings by Pierce (2001), which highlighted African-America urban stroke carers were motivated by stroke survivors responses and drew heavily on spirituality as a coping mechanism. Notably, Pierce (2001) also observed in the absence of appreciation from the stroke survivor, other family members often rallied around the stroke carer, reinforcing their role and offering support. The participants in the study described the influence of their

religious beliefs on staying positive and the anticipation of being rewarded for their caring role in the afterlife. Suppressing negative emotions could, however, have an adverse impact on well-being, with physical and mental health affected by reduced emotional expression (Patel & Patel, 2019). For example, religious teachings promoting the idea of enduring suffering silently or finding strength through faith may lead stroke carers to prioritise the well-being of those they care for over their own emotional needs.

The second theme, Impact on life, echoes previous research on the increased isolation that can be experienced by informal carers (Cookson & Casey, 2013; Hill et al., 2021). Interviewees reported feeling socially isolated due to the demanding nature of caregiving responsibilities, which limits their ability to participate in social activities and maintain relationships (Chang et al., 2021). This isolation can be compounded by a career change to remote working, which, while providing flexibility, reduces opportunities for face-to-face social interaction. Many stroke carers described that working remotely was crucial to balancing work and caregiving responsibilities. Without this flexibility, they may be unable to manage both roles effectively, leading to increased stress and potential negative impacts on their mental health Chang et al., 2021). Interviewees had adapted their careers to remote working to ensure they could provide care while maintaining financial stability. Caregiving in itself, let alone while working, can leave minimal time for personal activities that support emotional and psychological well-being (Zhang & Bennett, 2024; George et al., 2020).

Unlike the gradual progression of neurodegenerative conditions such as dementia and ALS, the sudden onset of stroke requires families and carers to adapt rapidly to new, debilitating situations. While apathy is often under-researched and misdiagnosed post-stroke (Tay et al., 2021), the insidious progression of conditions like ALS and dementia allows for a more gradual and recognisable emergence of apathy, making changes in motivation and engagement more observable over time. Despite the slow progression, apathy is recognised as

one of the most distressing symptoms for dementia carers (Yayha, 2018) and significantly influences carer burden in ALS carers (Gong et al., 2024). Stroke carers in the current study reported that the time-consuming nature of planning and managing daily tasks severely impacts their lives. The lack of free time for personal hobbies and relaxation can significantly affect carers' mental health (Pesantes et al., 2017). In a large-scale review comparing care provided at home and in institutions, it was reported that the absence of time for carers' self-care and leisure can lead to burnout, anxiety, and depression (Metzelthin et al., 2017), emphasising the need for support systems that offer stroke carers' respite and opportunities for personal enrichment.

The third theme, Things that Help, highlights participants' perspectives on managing their caregiving role for individuals with post-stroke apathy. Drawing from their experiences, they discussed coping strategies and support recommendations. The study identified barriers such as a lack of practical information, which aligns with prior research on apathy-related conditions (Agboji et al., 2024). While practical caregiving information was valued, it alone may not significantly reduce carer burden or improve quality of life (Farrell et al., 2025), suggesting a need for holistic interventions addressing emotional support, coping strategies, and respite opportunities (Walker et al., 2020; Calderón-Larrañaga et al., 2021). Faith emerged as a vital coping mechanism for those in the empirical study, aligning with previous research highlighting that positive religious beliefs can reduce levels of carer burden (Kes & Yildirim, 2020). Engaging in religious practices, such as prayer, meditation, or attending religious services, offered stroke carers comfort and peace. Stroke carers within the empirical study also engaged in downward social comparison, suggesting that this helps them cope with challenges by recognising that, despite their difficulties, others may be facing even more severe issues, a coping strategy similarly observed among older, healthy populations (Beaumont & Kenealy, 2004).

These findings also align with broader concerns around the intersection of faith, culture, and help-seeking behaviours in caregiving, encompassing both protective and potentially limiting effects. As reported by Carers UK (2023), carers with religious beliefs often turned to faith organisations or places of worship for emotional and spiritual support. Religion can provide carers with emotional and spiritual support, helping to buffer against strain, foster resilience, and enhance wellbeing (Carers UK, 2023), suggesting that religious beliefs can shape perceptions of caring roles and responsibilities. Positive spiritual strategies, such as viewing caregiving as 'part of God's plan,' have also been linked to better mental health and quality of life (Ambrosca et al., 2024), while other studies demonstrate that faith can mitigate carer burden (Kes & Yildirim, 2020). However, there was a notable reluctance among these carers to engage with professional services, particularly those addressing mental health, due to cultural differences and perceived stigma. This hesitancy has tangible implications. A recent review by Emmet et al. (2025) found that delays in hospital presentation among Black Caribbean stroke patients often resulted in more severe outcomes. Such delays may partly reflect tensions between culturally rooted belief systems of stroke as a medical emergency, a dynamic also observed by Lachkhem et al. (2018), who linked delayed hospital access to increased disability and mortality. Thus, religion and faith beliefs can both support carers' coping and wellbeing while sometimes limiting engagement with formal services. These insights underscore the importance of culturally responsive healthcare pathways that acknowledge and integrate carers' spiritual beliefs, reducing barriers to timely intervention. This consideration includes the role of non-traditional stroke services and other potential protective or preventive aspects they could contribute to.

A secondary aim of this study was to test the criterion validity of the informant-rated DAS-I with informal stroke carers. With an adequate sample size, the scale and the Executive and Initiation Apathy subscales showed adequate internal consistency, though the Emotional

Apathy subscale should be used with caution in this population, as our findings indicated inadequate internal consistency, similar to the findings of Myhre et al. (2022). Unexpectedly, a small, weak negative correlation was found between this scale and the more commonly used AES. Although the relationship is weak, it is unlikely to be a chance occurrence, and it will be important to consider its implications. The ability of the DAS-I to characterise specific forms of apathy would provide a more sensitive measure than the AES-C, able to detect specific behavioural changes and guide interventions for survivors and stroke carers more effectively. The implications for criterion validity should be carefully evaluated; however, this warrants further research to replicate the nature of the relationship and consider any potential confounds with larger samples.

This study offers key insights for clinicians across stroke rehabilitation and community care services. Apathy, often misdiagnosed as depression (Tay et al., 2021), should be recognised as a distinct neuropsychiatric syndrome. It's under recognition delays appropriate intervention, affecting recovery outcomes. For carers, apathy erodes relational reciprocity, increasing emotional strain, leading to burden (Mason et al., 2024). Clinicians should proactively screen for apathy using validated tools (e.g. AES) and assess carer well-being alongside patient recovery. Routine conversations should aim to assess the emotional consequences of the caregiving relationship and culturally shaped coping mechanisms, such as faith and downward social comparison. Further, clinicians should consider barriers to formal service engagement, especially among carers from ethnically and religiously diverse communities. These findings support a shift toward more holistic, culturally responsive stroke care that integrates carer support as a core component of clinical practice.

Strengths and Limitations

In terms of credibility and confirmability (Lincoln & Guba, 1985), the position of the researcher in the interpretation of cultural integrity and rigour must be considered. The stroke

carers interviewed were from cultural-minority backgrounds living in the UK. The cultural background and ethnicity of the researcher who conducted and interpreted the interviews differed from the national culture (White, Irish) and that of the interviewees, who were of Black or multiple ethnic backgrounds. As highlighted by Pelzang and Hutchinson (2018), maintaining cultural integrity in countries where the national culture strongly influences how organisations work is difficult, for example, the predominant medical model in stroke care in the Western world. The transferability of this study's findings is supported by the provision of rich, detailed descriptions of the context, participants, and methods (Lincoln & Guba, 1986). These descriptions of stroke carers' experiences enable others to assess the extent to which the findings may apply to their own settings or caregiving populations. While the purposive, self-selected sampling strategy may have led to an overrepresentation of passionate or opinionated stroke carers, the findings remain valuable for understanding the nuanced experiences of this group. By offering comprehensive contextual details, the study facilitates informed judgments about how its insights might resonate with or transfer to other caregiving contexts.

Future Research

The current study offers a valuable springboard for future research on the cross-cultural impact of caring for someone with post-stroke apathy. The current study focused on the experiences of informal stroke carers of stroke survivors with forms of post-stroke apathy, but the consideration of generational and cross-cultural influences was not extensively addressed. Additionally, comparing stroke carers from different cultural backgrounds could highlight unique challenges and coping strategies influenced by cultural norms and values. Further, faith and religious beliefs may affect help-seeking behaviours among stroke carers, so it would be beneficial to explore how these beliefs shape how stroke carers seek support and assistance. Concepts such as sacrifice, suffering, and altruism hold different meanings

across religious traditions, potentially shaping how carers perceive their roles and respond to emotional strain. The current study identified faith as a significant factor that provided support and posed a barrier to emotional expression in the context of caring for a stroke survivor with post-stroke apathy. Investigating how religious beliefs influence help-seeking behaviours in this context could offer insights into developing culturally sensitive support systems that respect and incorporate stroke carers' spiritual needs. Future research should aim to disentangle these spiritual dimensions to inform culturally sensitive support interventions. Other considerations for future research could examine how faith-based support strategies, such as prayer, meditation, and participation in religious communities, contribute to stroke carers' overall well-being. Lastly, future studies should consider developing interventions that address both the practical and emotional needs of stroke carers, supporting stroke survivors with forms of post-stroke apathy. By incorporating cultural, generational, and religious perspectives, researchers can design more effective and holistic support programs that cater to the diverse needs of stroke carers in this context.

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Chapter Five: Extended Methodology

Extended Methodology

This chapter provides further detail in relation to the methodology of the empirical paper. The ontology and epistemology and handling of missing data relating to the informant-rated Dimensional Apathy Scale (DAS-I) are presented.

Ontology and Epistemology

Researchers must establish their ontological and epistemological stance early in their work, as philosophical approaches play a significant role in shaping the research process, including the methodology and interpretation of results (Saliya, 2023). Ontology pertains to the nature of reality and what exists; it deals with questions about what is real and the nature of being (Al-Ababneh, 2020). Epistemology, on the other hand, concerns the theory of knowledge and how we come to know and understand the world (Sol & Heng, 2022).

Ontology and epistemology exist along continua, representing diverse perspectives on the nature of reality and knowledge. At one end of the ontological continuum is realism, which posits that reality exists independently of our perceptions (Pessu, 2019). At the other end is relativism, which views reality as socially constructed and subjective. On the epistemological continuum, objectivism holds that knowledge can be discovered through empirical observation, while subjectivism suggests that knowledge is constructed through social interactions and individual experiences (Al-Ababneh, 2020).

The positivist paradigm focuses on the belief in a single, tangible, measurable reality and that our knowledge is based on what we observe (Wells & Giacco, 2024). In contrast, the interpretive paradigm views reality as socially constructed and subjective, emphasising the understanding of human behaviour through individual experiences and social interaction (Wells & Giacco, 2024). Critical realism fits between these paradigms, acknowledging an independent reality but also recognising that our understanding of it is mediated by social and cognitive processes (Lewani, 2020).

Critical realists delve into three distinct layers of reality: the empirical, the actual, and the real, as articulated by Stutchbury (2021). The empirical level investigates experiences and perceptions, while the actual level examines real-world objects and events. The real level delves deeper into underlying meanings and understanding. In this study, we adopted a critical realist perspective to explore the experiences of informal stroke carers regarding the motivational changes in stroke survivors. We recognise that the researcher's knowledge and experiences influence their assumptions and that these inferences are interpreted within the broader context of others' experiences.

To the researcher's knowledge, the study presented in Chapter Four is the first to investigate informal stroke carers' experiences of caring for someone with post-stroke apathy. The critical realist approach adopted acknowledges a distinction between experiences (stroke carers' subjective perceptions), events (actual changes in motivation), and causal mechanisms (underlying factors influencing these changes) (Fryer, 2021), allowing for an exploration of both the stroke carers' lived realities and the broader social, psychological, and structural influences shaping these experiences.

Missing Data

In the initial screening of the data collected from our quantitative questionnaire in the empirical study, it became evident that a portion of the responses were missing. This missing data presents a significant challenge as it can potentially skew the results and impact the overall validity and reliability of our findings. Understanding the reasons behind this missing data, how it influences our analysis and how to handle it is essential for drawing accurate and meaningful conclusions. Missing data refers to the data that was intended to be collected to answer a research question (Pham et al., 2024). Historically, missing data were often removed from datasets, sometimes rendering some remaining information obsolete. However, modern statistical packages offer methods to estimate reliable values for missing data. To

handle missing data appropriately, however, it is crucial to determine whether it is missing completely at random, missing at random, or missing not at random (Sterne et al., 2009).

Sterne et al. (2009) define these types of missingness as follows:

- Missing completely at random occurs when the absence of data is unrelated to both the participant and the researcher, happening purely by chance.
- Missing at random happens when participants choose not to answer certain questions, making the missingness related to the observed data but not the unobserved data.
- Missing not at random arises when a participant cannot respond because a particular option is not available to them, making the missingness related to the unobserved data.

A significant consequence of missing data is the risk of bias in the interpretation of results. The proper handling of missing data is essential to ensure the validity and reliability of research findings.

The study presented in Chapter Four was found to include ‘missing not at random’ data. This was due to the omission of question ten of the Dimensional Apathy Scale in the online survey administered to the first seven participants (13.7% of the sample), equating to 0.57% of the overall dataset. The error was detected and rectified from participant eight onwards.

Identifying the type of missing data enables us to apply appropriate handling methods. Following multiple imputation methods proposed by Rubin (1987), the first step is to recognise the type of missing data. The second step is replacing missing values by making educated guesses about the relationships between the known data, the missing data, and any other relevant parameters, considering additional data or external information about the likely distribution of preferences for the omitted option. Following these steps, we employed the Markov Chain Monte Carlo (MCMC) technique to produce accurate values based on the

responses in the sample (Van Ravenzwaaij et al., 2016). This approach allowed us to generate multiple plausible values for the missing data within the statistical software package SPSS, resulting in the creation of several complete datasets. Each of these datasets incorporated different possible values for the omitted option, effectively filling in the gaps with various potential scenarios (Carpenter et al., 2023). Lastly, each imputed dataset was analysed individually, and the results were then combined to produce more robust and reliable statistical inferences. This method effectively accounted for the uncertainty associated with the missing data, ensuring the final analysis was comprehensive and accurate.

Chapter Six: Discussion and Critical Evaluation

Discussion and Critical Evaluation

This chapter provides a summary of the systematic review and empirical study presented in this thesis. It considers how these contribute to our understanding of the needs and most frequently offered interventions for informal stroke carers of stroke survivors, with a focus on apathy presentations. It critically reviews both papers, considers implications for clinical practice, and offers recommendations for future research.

Systematic Review

The systematic review aimed to identify the types and efficacy of psychosocial interventions offered to informal stroke carers to improve burden, strain, quality of life, depression, or anxiety. Twenty-four studies met the eligibility criteria and were included in the review. The narrative synthesis highlighted four characteristics of carer interventions that showed significant improvements in carer burden, strain, depression, or anxiety. First, interventions to support skills development and problem-solving were the most frequently delivered type of intervention (Bakas et al., 2015; Forster et al., 2013; Grant et al., 2002; Hekmatpou et al., 2019; LeLaurin et al., 2020; Lindley et al., 2017; Perrin et al., 2010; Pfeiffer et al., 2014), but only half yielded significant benefits for stroke carers (Bakas et al., 2015; Grant et al., 2002; Hekmatpou et al., 2019; Pfeiffer et al., 2014). Second, interventions showing significant benefits for stroke carers tended to use remote delivery methods: eight of fourteen studies with significant results used remote methods (e.g., telephone, web-based) (Avci & Gizem, 2023; Bakas et al., 2015; Cheng et al., 2018; Grant et al., 2002; Hekmatpou et al., 2019; Pfeiffer et al., 2014; Smith et al., 2012; Yilmaz et al., 2019). In contrast, studies that failed to yield significant benefits for stroke carers predominantly used face-to-face methods (Draper et al., 2009; Forster et al., 2013; Franzén-Dahlin et al., 2008; LeLaurin et al., 2020; Lindley et al., 2017; Patchwood et al., 2021; Shyu et al., 2010; Walker et al., 2020). Third, interventions showing significant benefits for stroke carers' tended to last over eight

weeks (Bakas et al., 2015; Cheng et al., 2018; Fu et al., 2020; Grant et al., 2002; Mei et al., 2017; Pfeiffer et al., 2014; Wang et al., 2021; Yilmaz et al., 2019), while most interventions that failed to yield significant benefits for stroke carers lasted under eight weeks (Cameron et al., 2014; Draper et al., 2009; Franzén-Dahlin et al., 2008; Patchwood et al., 2021; Perrin et al., 2010; Shyu et al., 2010). Finally, studies reporting significant benefits for stroke carers had greater contact time, with five reporting at least nine contact hours (Batool et al., 2022; Grant et al., 2002; Pfeiffer et al., 2014; Walker et al., 2020; Wang et al., 2021), compared to only one non-significant study reporting a maximum of eight hours (Draper et al., 2009). This suggests that stroke carer interventions that feature remote delivery, longer duration (over eight weeks), and longer contact time are associated with a greater likelihood of significant benefits for stroke carers, while interventions focusing on problem-solving or skills development are not reliably associated with significant carer benefits.

The review indicated that interventions typically focused on reducing carer burden (Avci & Gözüm, 2023; Mei et al., 2017) or symptoms of depression (Bakas et al., 2015; Pfeiffer et al., 2014; Smith et al., 2012), or both (Cheng et al., 2018; Grant et al., 2002; Walker et al., 2020; Wang et al., 2021; Yilmaz et al., 2019), with fewer improving carer quality of life (Beirhals et al., 2023; Hekmatpou et al., 2019). Seventeen outcome measures were applied across the included studies to measure burden, strain, quality of life, depression, or anxiety. The variety of measurement tools used could lead to inconsistencies (Deeken et al., 2003), complicating comparisons and synthesis of results. This lack of standardisation affects the generalisability and applicability of findings, highlighting the need for consistent and validated measures in future research for more reliable and comparable outcomes.

Empirical Study

The empirical study presented in this thesis explored informal stroke carers' experience of caring for someone with a form of post-stroke apathy. Two informant-rated

apathy measures were used to identify stroke carers meeting criteria for caring for a stroke survivor presenting with at least one subtype of apathy. Qualitative data collected through semi-structured interviews with stroke carers were analysed using reflexive thematic analysis (Braun & Clarke, 2020) and a nested validation study investigated the criterion validity of the informant-rated Dimensional Apathy Scale (DAS-I) against the gold-standard unidimensional carer-rated measure of apathy (AES-C).

The findings highlighted that the experience of caregiving for someone with post-stroke apathy has implications for the emotional expression of the caregiver. Alongside this, stroke carers identified prioritising the stroke survivors' needs over their own, finding this difficult to manage, and that it left limited personal time for themselves, resulting in feelings of loneliness or social isolation. Lastly, stroke carers highlighted positive outcomes and changes in themselves as a result of these experiences, suggesting types of support those in similar positions may find helpful. Stroke carers chose to control their emotional expression in front of the stroke survivor they cared for as they felt responsible for the survivor's mood and believed expressing negative emotions may adversely affect the survivor's mood. Previous studies indicate the interplay of mood moderation in carer-survivor dyads, highlighting the protective factors for both the carer and survivor (Bannon et al., 2021). Participants with religious beliefs talked about how certain teachings motivated them to express their emotions in certain ways, e.g. trying to suppress negative emotions / emotional expression to stay aligned to being outwardly positive. Some stroke carers highlighted that their comments and actions would be considered on Judgement Day and that they would be rewarded for their sacrifices. Others described the lack of reciprocity in their relationships with the stroke survivor to be extremely distressing, with some questioning themselves or if they had done something wrong. On top of this, some with particular faith beliefs felt unable to express these emotional challenges publicly, resulting in times when they might 'scream

and cry' privately. For some reason, religion provides positive meaning from the value of self-sacrifice and the perceived future rewards. Participants also identified time constraints and changes to daily life as impacting their well-being. Key aspects of apathy, such as lack of planning and initiating tasks on the part of the stroke survivor (Levy & Dubois, 2006), were considered time-consuming for stroke carers. Often, time constraints and the needs of stroke survivors took priority over the stroke carers' own needs. The final theme encompassed perceived support. Stroke carers used hindsight to reflect on what they found helpful in their journey and what they feel is lacking to support stroke carers of stroke survivors with changes in motivation. Stroke carers reflected on the benefits of peer support and often used a downward social comparison to feel better about their situation; despite this, however, they suggested that practical support was the type of support most needed early in the stroke journey.

Interpretation of Findings in Relation to Previous Research and Theories

Both the systematic review and the empirical study highlight the emphasis placed on skills-based, problem-solving interventions. The systematic review investigated which interventions best prevent psychological difficulties and improve well-being for people affected by stroke and their families. No single type of carer intervention was found beneficial, though successful carer interventions shared similar characteristics. Participants in the empirical study highlighted the value of general peer support but continued to advocate for practical support interventions with activities of daily living, neglecting to mention any need for emotional support when caring for someone with post-stroke apathy. This appears consistent with previous findings, which suggest better adjustment in carers who adopt a problem-focused perspective compared to emotion-focused perspectives (Pakenham, 2001). However, the systematic review highlights that only half of problem-solving and skills-based interventions for stroke carers are beneficial in improving psychosocial difficulties.

In the study presented in Chapter Four, stroke carers predominantly sought practical support while acknowledging but minimising their emotional needs. This is similar to the findings of Norup et al. (2015), who conducted a global study on support needs for families affected by acquired brain injuries. This highlighted that the most sought-after and provided support was health-based, while emotional support remained the greatest unmet need worldwide. The researchers also stressed the paramount importance of health-based support for family members. In another study with similar findings, Wade et al. (2023) investigated barriers to engagement in an online problem-solving intervention for teens with traumatic brain injury (TBI). They reported patient barriers such as stigma associated with mental health, a reluctance to acknowledge difficulties associated with TBI, and prioritisation of more practical areas such as homework. Barriers for families were that they often prioritised the child's physical care needs over their own. Professional barriers included a reluctance to refer patients to new interventions, potentially explaining the repetition of interventions despite their mixed effectiveness.

The empirical study delves into the theme of emotions, focusing on the lack of reciprocity between stroke survivor and carer, and religion as a factor influencing emotional expression and well-being. Stroke carers discussed feelings of frustration when faced with non-reciprocal emotional expression, a prominent feature of apathy, consistent with previous research in Huntington’s research (Mason et al., 2024). Similarly, findings from Chandola et al. (2007) explored the effects of reciprocity on social relationships, suggesting that non-reciprocal relationships reduce the quality of life and lead to feelings of frustration. The stroke carers often moderated their emotional expression around the stroke survivor as they felt responsible for the stroke survivor's mood. Barrowclough and Hooley's (2003) attributional model, developed in the context of psychosis, suggests that carers’ beliefs about symptom controllability shape emotional responses. This may also be relevant to stroke

caregiving. In particular, if carers perceive symptoms of post-stroke apathy as uncontrollable or biologically driven, they may respond with compassion and patience. However, it is possible that when carers see themselves as responsible for regulating the stroke survivor's emotional state, this may lead to heightened emotional over-involvement through excessive self-monitoring and suppression of negative emotions. Carers' interpretations of post-stroke apathy could influence their emotional reactions, coping strategies, and risk of burden, underscoring the need to explore emotional attributions of apathy in stroke carers.

By exploring individuals' experience of caregiving for someone with an apathy presentation, the empirical study provides insights into how faith and religious beliefs can improve well-being and mood. The stroke carers in the empirical paper spoke about how religious beliefs mitigate their emotional responses and actions for current and future gain. Similar to a report by Carers UK (2023), some carers reported that religion influenced how they view their role as a carer, with some religions promoting an altruistic perspective of putting others' needs before one's own. The stroke carers recognised the positive impact of caring for a loved one and valued their role and increased responsibility. Ambrosca et al. (2024) reviewed the effects of both positive and negative spiritual strategies. They found that positive strategies, such as holding the notion of being 'part of God's plan' as a means of gaining strength, protected against a lower quality of life and poor mental health. Similar results were reflected in the empirical study, which found that stroke carers believed that God would not challenge them if they could not handle it. In contrast, Nwoha et al. (2023) identified faith-based beliefs that may harm carer and stroke survivor well-being. Stroke carers referred to the concept of the spoken word, a belief rooted in many faith traditions, which suggests that what one speaks about can manifest in reality. In Sub-Saharan cultures, spiritual beliefs are intertwined with perceptions of health and illness. Some have interpreted a stroke as a representation of God's anger, which can reduce help-seeking behaviours (Bell-

Gam et al., 2012). Consequently, treatment is often sought in faith centres rather than medical facilities. This cultural approach to stroke treatment highlights the critical role of community and spiritual support in the management of stroke. Marmot (2010) emphasises that asset-based approaches in healthcare suggest that community organisations, in partnership with health and social care services, are well-positioned to collaborate effectively in mobilising resources for wellbeing. By joining forces, they can leverage community resources to enhance health and reduce health inequalities.

A report exploring asset-based approaches to care in the UK by Hopkins and Rippon (2015) suggested that shifting focus from deficits to strengths could significantly enhance individual and community well-being. Asset-based approaches underscore the importance of recognising and leveraging existing strengths, skills, and resources by emphasising what makes people healthy rather than ill. This method fosters stronger community connections and engagement, creating a supportive network that empowers individuals to participate in decision-making. Collaboration with family, friends, and community resources is vital in promoting a holistic approach to health care. The principles outlined in the "Head, Hands, and Heart" report (Hopkins & Rippon, 2015) provide a framework that can be integrated into mainstream health and care strategies, highlighting the transformative potential of an asset-based approach in fostering resilience and empowerment within communities.

Carers UK (2023) found that carers of faith often sought support from a faith organisation or place of worship. They reported a reluctance of carers of faith to seek professional support due to cultural differences and stigma, particularly relating to mental health. A recent review by Emmet et al. (2025) comparing stroke severity among Black and White participants highlighted a troubling delay in hospital presentation among Black Caribbean populations. This delay often resulted in poorer outcomes. In Western cultures, a stroke is typically viewed as a medical emergency requiring immediate hospital intervention.

When belief systems conflict with medical practices, the delay in seeking hospital care is likely to increase the length of hospital stay, disability and mortality (Lachkhem et al., 2018).

In light of the complex emotional and cultural dynamics at play, assessing and addressing apathy in stroke survivors becomes even more critical. The multi-dimensional neurocognitive model of Levy and Dubois (2006) underpins the Dimensional Apathy Scale (DAS; Radakovic & Abrahams, 2014), which assesses three subtypes of apathy: emotional, initiation, and executive apathy. Compared to unidimensional assessments, the DAS provides more comprehensive data, potentially aiding in the formulation and treatment of these issues. Validating the DAS-I in stroke carers would be valuable for both research and clinical practice. Myhre et al. (2020) found the prevalence of post-stroke apathy in a sample of community-based stroke survivors to be between 22- 41%. Apathy places an additional burden on informal stroke carers.' Research has shown that non-pharmacological interventions with stroke survivors and apathy have been effective (Skidmore et al., 2015). Therefore, distinguishing between subtypes of apathy will enhance targeted intervention development and improve the rehabilitative process.

The findings in Chapter Four indicated that stroke carers rated stroke survivors significantly higher on a unidimensional apathy scale than on a multidimensional apathy scale (DAS-I and AES-C). There was a weak negative correlation between the DAS-I and the AES-C, poor internal consistency of the emotional apathy subscale, and a further negative correlation between the emotional subscale and the AES-C. These findings suggest the DAS-I lacks criterion validity in this population. The nature of the correlation between the DAS-I and the AES-C could suggest that the DAS-I is a more sensitive measure in detecting apathy or domains of apathy. Stroke carers reported higher scores across all apathy dimensions, particularly initiation and executive apathy. Previous research examining the self-reported DAS in stroke groups highlighted questionable reliability in the emotional subscale,

recommending additional research from an informant perspective (Myhre et al., 2020). It is important to consider the qualitative aspects of the carer sample, however, including the expressed emotions, cross-cultural differences mentioned above and faith-related factors in mitigating emotional expression. Notably, the Emotional Apathy subscale of the DAS was found to have inadequate internal consistency in the current study, indicating the need for further research about how best to identify emotional apathy in stroke survivors.

Clinical Implications and Future Research

The systematic review identified key characteristics of stroke carer intervention delivery that should be considered during the development and implementation of interventions. It also highlighted that varied measurement approaches led to a lack of clarity regarding psychosocial difficulties, which calls attention to the necessity for more consistent measurement methods. In an older study, unidimensional measurements of burden were criticised for being too simplified (Deekan et al., 2003). Notably, this study recommended two measures of burden to be applied in intervention and research, citing expertise, replication and statistical significance, the Caregivers Reaction Assessment (Given et al., 1992) and the BAKAS Caregiving Outcomes Scale (Bakas & Champion, 1999). However, considering the age of this study, it may be valuable to replicate it while also validating it among informal stroke carers.

Research concerning regional and other differences in post-stroke care has been prioritised to reduce health inequalities in the UK (Hill et al., 2021). The empirical study sheds light on the factors influencing seeking psychological support for the stroke carers, identifying religious and cultural influences in seeking support and stroke care. Further consideration is given to cultural and religious influences on the timing of support-seeking, as delayed stroke intervention often leads to increased disability. This goes beyond regional differences and highlights the need for a cross-cultural lens to be applied to stroke care.

Previous research has highlighted cultural beliefs as influencing seeking medical care at the onset of stroke, as mentioned above, whereby the understanding of stroke among the population is incongruent with the country of residence. According to NICE guidance NG44 (2016), engaging community resources and increasing community involvement can help reduce health inequalities that stem from varying access to resources. This study supports recommendations to include faith centres in stroke care and prevention, advocating for asset-based approaches to stroke care (Hopkin & Rippon, 2015). Furthermore, it emphasises the importance of clinicians understanding faith-based needs, identifying barriers to accessing services and highlighting the potential for prevention within a community setting.

Considering the dyadic influence and the importance placed on carers in the recovery process, understanding and differentiating apathy is crucial. Alongside this, the understanding of the bi-directional influence of the belief system is pivotal in the cross-cultural recognition, treatment and support of stroke survivors and informal stroke carers. Faith and religious beliefs significantly shape stroke carers' perspectives, offering resilience but sometimes hindering professional support-seeking. Cultural differences also affect stroke carers' engagement with healthcare systems, occasionally delaying necessary interventions. These findings underscore the need for a holistic, asset-based approach that incorporates community, faith, and healthcare resources to better support stroke survivors and their stroke carers.

Clinical recognition of apathy is important as this can result in longer-term detrimental effects (Tay et al., 2021). The current study aimed to validate the DAS-I to support early intervention, as those receiving treatment for apathy were 1.84 times less likely to develop an apathy presentation (Tay et al., 2021). Future research could explore factor analysis of the Emotional Apathy subscale with a larger and more diverse sample to improve its reliability.

Strengths and Limitations

A significant strength of the empirical study is its demographic sample. Most participants were male stroke carers, with the whole sample from multiple minority ethnic backgrounds; this population is often underrepresented in research. It was crucial to explore the experiences of a diverse group in the current context, marked by an increasing emphasis on diversity and inclusion. This approach not only aligns with ethical research practices but also addresses social justice issues by ensuring that the experiences of all groups are considered. Different demographic groups may face unique challenges and have distinct experiences. By capturing a range of perspectives, the study can identify specific needs and tailor interventions more effectively. The empirical study highlights the importance of asset-based approaches to healthcare and support, drawing attention to involving faith-based organisations in stroke care.

A key limitation of the systematic review was the reliance on a narrative synthesis of randomised control trials (RCTs), which, unlike meta-analyses, does not provide a quantitative or statistical integration of findings. This may limit the ability to generalise conclusions or identify broader trends across the studies reviewed. Furthermore, the systematic review included papers published only in the English language. Publications may have excluded significant research in other languages, potentially narrowing the diversity of perspectives and findings.

The empirical study faced limitations, including issues with missing data that may have introduced biases or reduced the robustness of the findings. Additionally, the participant sample, primarily from a minority demographic, might represent the strongest and most engaged views within this group. While this offered a valuable depth of insight, it might also limit the scope of perspectives included. However, from a critical realist perspective, the emphasis is on uncovering underlying mechanisms and contextual truths rather than

achieving broad generalisability. As such, the study's findings remain meaningful within the context of the participants' experiences and provide a foundation for further exploration.

Reflexive Process

The empirical paper adopted a detailed and comprehensive approach throughout the research process. The use of semi-structured interviews ensured adherence to the interview topic guide, keeping the information relevant to the research question. This also provided opportunities for flexible responses from participants, room for exploring more nuanced information, and triangulation of responses to research (DeJonckheere & Vaughn, 2019). Reflexive thematic analysis was chosen for its flexibility, which allowed the research process to be both rigorous and adaptive. This approach considers the researcher's engagement with the theory, the data, and their interpretation (Braun & Clark, 2020).

Lincoln and Guba's (1985) framework to evaluate the quality and rigour of qualitative research- credibility, dependability, confirmability, and transferability- was considered throughout the research. Repeatedly revisiting transcripts enhanced credibility (Ahmed, 2024), and dependability was maintained through continual engagement with the data and triangulation with the research (Yahya, 2018). Themes were developed aiming for transferable findings (Yahya, 2018). Engaging with participants and keeping a reflective journal aided the neutrality of the researcher (Braun & Clarke, 2022). The reflective log captured personal, functional, and disciplinary reflexivity, recognising the researcher as an active participant in the study (Wilkinson, 1988). The researcher critically reflected on the analytical process, acknowledging the perspectives and positions contributing to their understanding of the stroke carers' experiences. interpretations. For example, the following considerations related to positionality, which could influence unconscious bias and thinking, were identified at the outset and continuously reflected upon throughout the research process:

- White, female, Irish background may have influenced my views and interpretations of various topics.
- Societal and political power of a monotheistic religion and how the influence of power has changed in the last four decades. I grew up in a religious household but adopted a non-religious stance in adulthood. Having an awareness of religious values, but limited to a particular denomination.
- Systemic influence on the interpretation of gender roles and differences from a caring perspective.
- Societal influence on understanding of shown emotions.

Conclusion

In conclusion, this thesis portfolio suggests that skills-building and problem-solving interventions are sought after by stroke carers, but evidence does not show these to be reliably effective. Participants in the empirical study noted that practical support for caregiving was often lacking early in their journey, which resulted in them turning to resources like YouTube to upskill. Stroke carers in the empirical study sought emotional support from their faith and religious groups, mitigating emotional expression and holding an abstract concept of greater reward in the future. They highlighted drawing on community resources and peer support, consistent with asset-based approaches. Factors associated with asset-based approaches are incorporating stronger community connections and engagement, and creating a network that empowers individuals to participate in decision-making, supporting a problem-solving aspect of interventions. Considering the common characteristics of different intervention types within the systematic review suggests that factors outside the intervention may also play a role in improving psychosocial difficulties for informal stroke carers.

The empirical study addressed a gap in the literature by focusing on the experience of caring for someone with post-stroke apathy. This research involved a diverse sample and highlighted cross-cultural implications of stroke care and support. Future research recommendations include engaging with asset-based approaches to understand what stroke carers find helpful in mitigating psychological distress and improving well-being.

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Appendices

Appendix A: Journal requirements for SR and EP

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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.

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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.

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- Diagnostic accuracy - STARD
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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.

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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 .

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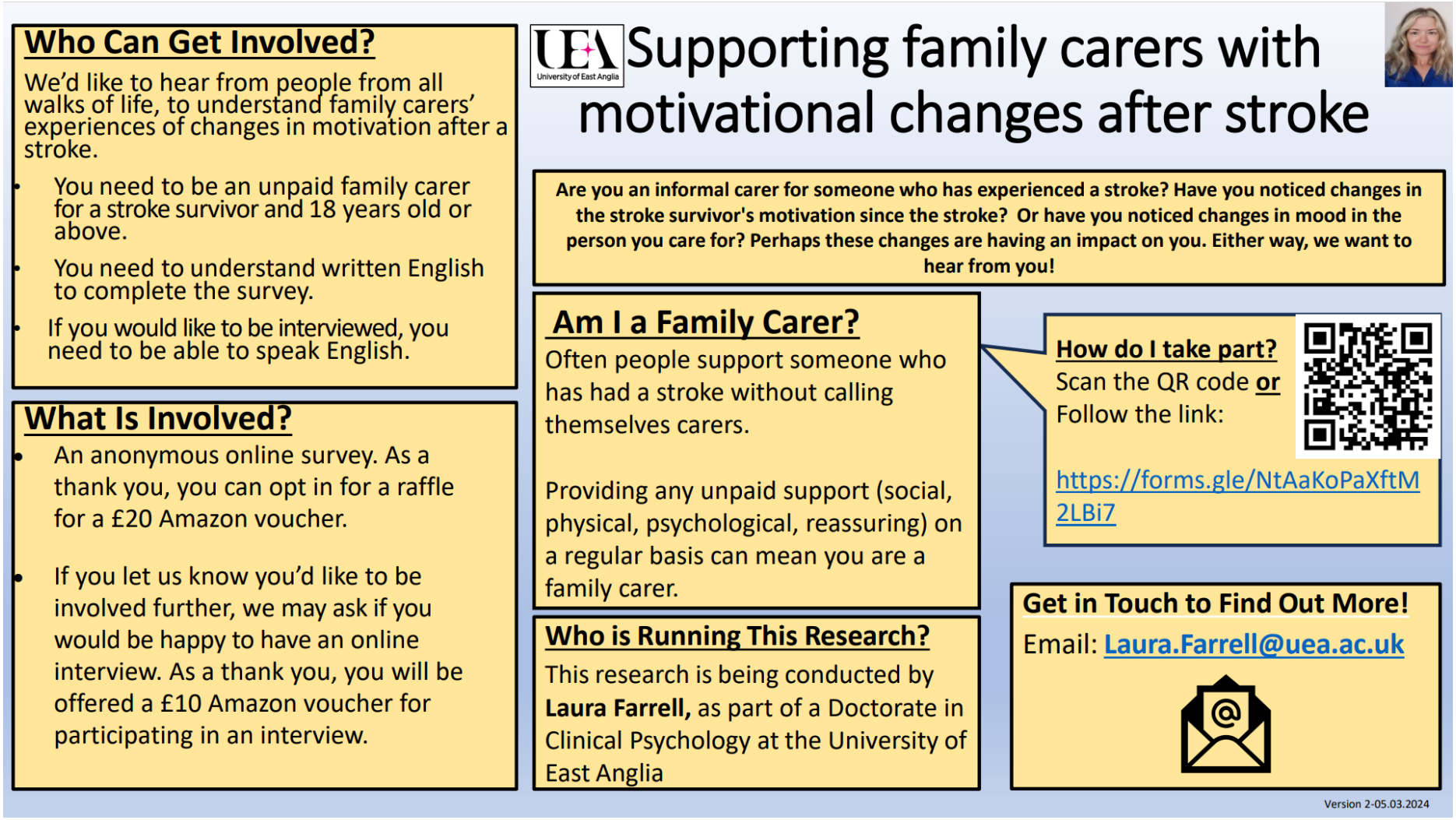
Updated 12-11-2021

Appendix B: Social Media Advert



Appendix C: Dimensional Apathy Scale (Ratko & Abraham, 2014)

DAS **Dimensional Apathy Scale (Informant/Carer)** PN:

Relationship to patient.....

Choose the answer on what you have observed the person has been **feeling, behaving or thinking**, based on the rate of occurrence in the last month:
(Circle the statement that applies)

1. S/he needs a bit of encouragement to get things started
   - ◊ Almost always
   - ◊ Often
   - ◊ Occasionally
   - ◊ Hardly Ever

2. S/he contacts his/her friends
   - ◊ Almost always
   - ◊ Often
   - ◊ Occasionally
   - ◊ Hardly Ever

3. S/he expresses his/her emotions
   - ◊ Almost always
   - ◊ Often
   - ◊ Occasionally
   - ◊ Hardly Ever

4. S/he thinks of new things to do during the day
   - ◊ Almost always
   - ◊ Often
   - ◊ Occasionally
   - ◊ Hardly Ever

5. S/he is concerned about how his/her family feel
   - ◊ Almost always
   - ◊ Often
   - ◊ Occasionally
   - ◊ Hardly Ever

6. S/he stares in to space
   - ◊ Almost always
   - ◊ Often
   - ◊ Occasionally
   - ◊ Hardly Ever

7. Before s/he does something s/he thinks about how others would feel about it
   - ◊ Almost always
   - ◊ Often
   - ◊ Occasionally
   - ◊ Hardly Ever

8. S/he plans his/her days activities in advance
   - ◊ Almost always
   - ◊ Often
   - ◊ Occasionally
   - ◊ Hardly Ever

9. When s/he receives bad news s/he feels bad about it
   - ◊ Almost always
   - ◊ Often
   - ◊ Occasionally
   - ◊ Hardly Ever

10. S/he is able to focus on a task until it is finished
    - ◊ Almost always
    - ◊ Often
    - ◊ Occasionally
    - ◊ Hardly Ever

11. S/he lacks motivation
    - ◊ Almost always
    - ◊ Often
    - ◊ Occasionally
    - ◊ Hardly Ever

12. S/he struggles to empathise with other people
    - ◊ Almost always
    - ◊ Often
    - ◊ Occasionally
    - ◊ Hardly Ever

DAS **Dimensional Apathy Scale (Informant/Carer)** PN:

13. S/he sets goals for him/herself
    - ◊ Almost always
    - ◊ Often
    - ◊ Occasionally
    - ◊ Hardly Ever

14. S/he tries new things
    - ◊ Almost always
    - ◊ Often
    - ◊ Occasionally
    - ◊ Hardly Ever

15. S/he is unconcerned about how others feel about his/her behaviour
    - ◊ Almost always
    - ◊ Often
    - ◊ Occasionally
    - ◊ Hardly Ever

16. S/he acts on things s/he has thought about during the day
    - ◊ Almost always
    - ◊ Often
    - ◊ Occasionally
    - ◊ Hardly Ever

17. When doing a demanding task, s/he has difficulty working out what s/he has to do
    - ◊ Almost always
    - ◊ Often
    - ◊ Occasionally
    - ◊ Hardly Ever

18. S/he keeps him/herself busy
    - ◊ Almost always
    - ◊ Often
    - ◊ Occasionally
    - ◊ Hardly Ever

19. S/he gets easily confused when doing several things at once
    - ◊ Almost always
    - ◊ Often
    - ◊ Occasionally
    - ◊ Hardly Ever

20. S/he becomes emotional easily when watching something happy or sad on TV
    - ◊ Almost always
    - ◊ Often
    - ◊ Occasionally
    - ◊ Hardly Ever

21. S/he finds it difficult to keep his/her mind on things
    - ◊ Almost always
    - ◊ Often
    - ◊ Occasionally
    - ◊ Hardly Ever

22. S/he is spontaneous
    - ◊ Almost always
    - ◊ Often
    - ◊ Occasionally
    - ◊ Hardly Ever

23. S/he is easily distracted
    - ◊ Almost always
    - ◊ Often
    - ◊ Occasionally
    - ◊ Hardly Ever

24. S/he is indifferent to what is going on around him/her
    - ◊ Almost always
    - ◊ Often
    - ◊ Occasionally
    - ◊ Hardly Ever

Appendix D: Online Questionnaire

Supporting Family Carers with Motivational Changes after Stroke

My name is
Laura Farrell and I am carrying out research as part of my Doctorate in Clinical Psychology at the University of East Anglia (UEA). The research has two phases: Phase 1) will validate a measure of apathy in a stroke population from the perspective of informal caregivers and Phase 2) will investigate informal caregivers experiences of motivational changes after stroke. We will seek the approval of the UEA Faculty of Medicine and Health Sciences Research Ethics Committee before collecting data.

Purpose of the study

Research shows
that changes in motivation caused by some health conditions (e.g. forms of dementia), affect the relationships and experiences of carers, but we do not know if this also the case for stroke informal caregivers or what information or support stroke informal caregivers might want about motivational changes after stroke. This research will help answer these questions.

What would taking part involve?

Phase 1 of this
study involves completing and submitting the survey below to test if a questionnaire about apathy is suitable for stroke informal caregivers and identify people eligible to take part in Phase 2 of the research. Contact information for support services are included on the final page of the survey in case any of the issues the questionnaires we ask about raise difficult feelings for you. It is important that you
understand that by completing and submitting the questionnaire that you are consenting to participate in phase 1 of this study

Phase 2 of the study involves meeting me to talk about experiences of motivational changes after stroke as a stroke informal caregiver. Those invited to take part who wish to do so, will have a choice of times and dates to choose from for online interviews. I will analyse themes and connections between the experiences of informal caregivers. The findings will then be presented to charitable organisations, written up as a doctoral thesis available online and published in an academic journal.

Are there any benefits to taking part?

Findings of phase 1 could help to validate a measure for identifying apathy in individuals who have experience stroke. Findings of phase 2 could be important for improving knowledge and potentially aid intervention development for informal caregivers of stroke survivors. A small gratuity will be given to participants in phase 2 of this study.

Are there any risks to taking part?

Participation is completely voluntary and you are not obliged to take part. We do not expect taking part to be upsetting but it is possible that answering questions or talking about your loved one who has experienced a stroke could raise difficult emotions, so we will provide information about support services at the end of the questionnaire and interviews.

At the end of the survey, there is a question about whether you would be interested in being recontacted to take part in phase 2 of the research.
If you are interested in taking part in phase 2 of the research, you will be asked about your preferred method of contact, and more information about phase 2 will be provided. Your contact details and preferred method of contact will remain confidential.

Are you 18years or older *

- ◯ Yes
- ◯ No

Do you consent to the use of these answers for research purposes? *

- ◯ No
- ◯ Yes

Are you an informal caregiver of someone who has experienced a stroke *

- ◯ Yes
- ◯ No

Questions about you

What is your relationship to the stroke survivor *

- ◯ Spouse/partner
- ◯ Sibling
- ◯ Child
- ◯ Parent
- ◯ Other: _____

Your gender *

- ○ Male
- ○ Female
- ○ Non-binary
- ○ prefer not to say

What age range do you belong to *

- ○ 18-25 years old
- ○ 26-35 years old
- ○ 36-45 years old
- ○ 46-55 years old
- ○ 56-65 years old
- ○ 66-75 years old
- ○ 76-85 years old
- ○ 86+ years old

Is English your first language? *

- ○ Yes
- ○ No

How long ago was the stroke *

- ◯ 0-6 months
- ◯ 6-12 months
- ◯ 1-3 years
- ◯ 3-5 years
- ◯ 5+ years

Do you live with the stroke survivor? *

- ◯ Yes
- ◯ No

Do you provide any practical support?

- ◯ Yes
- ◯ No

Would you consider yourself an informal care giver?

- ◯ Yes
- ◯ No

Has the stroke survivor been given a diagnosis of depression?

- ◯ Yes
- ◯ No

If yes to diagnosis of depression, when was this?

- ◯ Depression diagnosed before the stroke
- ◯ Depression diagnosed after the stroke

What is your Ethnicity *

Choose

DAS-I

Choose the answer on what you have observed the person has been **feeling, behaving or thinking,** based on the rate of occurrence in the last month: (please select the statement that applies

S/he needs a bit of encouragement to get things started *

- ◯ almost always
- ◯ often
- ◯ occasionally
- ◯ hardly ever

S/he contacts his/her friends *

- ◯ almost always
- ◯ often
- ◯ occasionally
- ◯ hardly ever

S/he expresses his/her emotions *

- ◯ almost always
- ◯ often
- ◯ occasionally
- ◯ hardly ever

S/he thinks of new things to do during the day *

- ◯ almost always
- ◯ often
- ◯ occasionally
- ◯ hardly ever

S/he is concerned about his/her family feel *

- ◯ almost always
- ◯ often
- ◯ occasionally
- ◯ hardly ever

S/he stares into space *

- ◯ almost always
- ◯ often
- ◯ occasionally
- ◯ hardly ever

Before s/he does something s/he thinks about how others would feel about it *

- ◯ almost always
- ◯ often
- ◯ occasionally
- ◯ hardly ever

S/he plans his/her days activities in advance *

- ◯ almost always
- ◯ often
- ◯ occasionally
- ◯ hardly ever

When s/he receives bad news s/he feels bad about it *

- ◯ almost always
- ◯ often
- ◯ occasionally
- ◯ hardly ever

S/he is able to focus on a task until it is finished *

- ◯ almost always
- ◯ often
- ◯ occasionally
- ◯ hardly ever

S/he lacks motivation *

- ○ almost always
- ○ often
- ○ occasionally
- ○ hardly ever

S/he struggles to empathise with other people *

- ○ almost always
- ○ often
- ○ occasionally
- ○ hardly ever

S/he sets goals for him/herself *

- ○ almost always
- ○ often
- ○ occasionally
- ○ hardly ever

S/he tries new things *

- ◯ almost always
- ◯ often
- ◯ occasionally
- ◯ hardly ever

S/he is unconcerned about how others feel about his/her behaviour *

- ◯ almost always
- ◯ often
- ◯ occasionally
- ◯ hardly ever

S/he acts on things s/he has thought about during the day *

- ◯ almost always
- ◯ often
- ◯ occasionally
- ◯ hardly ever

When doing a demanding task, s/he has difficulty working out what s/he has to do *

- ◯ almost always
- ◯ often
- ◯ occasionally
- ◯ hardly ever

S/he keeps him/herself busy *

- ◯ almost always
- ◯ often
- ◯ occasionally
- ◯ hardly ever

S/he gets easily confused when doing several things at one *

- ◯ almost always
- ◯ often
- ◯ occasionally
- ◯ hardly ever

S/he becomes emotional easily when watching happy or sad on TV *

- ◯ almost always
- ◯ often
- ◯ occasionally
- ◯ hardly ever

S/he finds it difficult to keep his/her mind on things *

- ◯ almost always
- ◯ often
- ◯ occasionally
- ◯ hardly ever

S/he is spontaneous *

- ◯ almost always
- ◯ often
- ◯ occasionally
- ◯ hardly ever

S/he is easily distracted *

- ◯ almost always
- ◯ often
- ◯ occasionally
- ◯ hardly ever

S/he is indifferent to what is going on around him/her *

- ◯ almost always
- ◯ often
- ◯ occasionally
- ◯ hardly ever

AES-I

For each statement, please select the answer that best describes the subject's thoughts, feelings and activity in the past 4 weeks

She/He is interested in things *

- ○ Not at all
- ○ Slightly
- ○ Somewhat
- ○ A lot

She/He gets things done during the day *

- ○ Not at all
- ○ Slightly
- ○ Somewhat
- ○ A lot

Getting things started on his/her own is important to him/her *

- ○ Not at all
- ○ Slightly
- ○ Somewhat
- ○ A lot

She/He is interested in having new experiences *

- ○ Not at all
- ○ Slightly
- ○ Somewhat
- ○ A lot

She/He is interested in learning new things *

- ○ Not at all
- ○ Slightly
- ○ Somewhat
- ○ A lot

She/He puts little effort into anything *

- ○ Not at all
- ○ Slightly
- ○ Somewhat
- ○ A lot

She/He approaches life with intensity *

- ◯ Not at all
- ◯ Slightly
- ◯ Somewhat
- ◯ A lot

Seeing a job through to the end is important to him/her *

- ◯ Not at all
- ◯ Slightly
- ◯ Somewhat
- ◯ A lot

She/He spends time doing things that interest him/her *

- ◯ Not at all
- ◯ Slightly
- ◯ Somewhat
- ◯ A lot

Someone has to tell him/her what to do each day *

- Not at all
- Slightly
- Somewhat
- A lot

She/he is less concerned about his/her problems than he/she should be *

- Not at all
- Slightly
- Somewhat
- A lot

She/he has friends *

- Not at all
- Slightly
- Somewhat
- A lot

Getting together with friends is important to him/her *

- ◯ Not at all
- ◯ Slightly
- ◯ Somewhat
- ◯ A lot

When something good happens, she/he gets excited *

- ◯ Not at all
- ◯ Slightly
- ◯ Somewhat
- ◯ A lot

She/he has an accurate understanding of his/her problems *

- ◯ Not at all
- ◯ Slightly
- ◯ Somewhat
- ◯ A lot

Getting things done during the day is important to him/her *

- ◯ Not at all
- ◯ Slightly
- ◯ Somewhat
- ◯ A lot

She/He has initiative *

- ◯ Not at all
- ◯ Slightly
- ◯ Somewhat
- ◯ A lot

She/He has motivation *

- ◯ Not at all
- ◯ Slightly
- ◯ Somewhat
- ◯ A lot

Further participation

As part of this research, there is an option to engage in a more in depth discussion which focuses on your experiences as an informal caregiver. Further participation involves an interview using an online platform such as MS teams. More information will be shared with you if you consent to be re contacted for additional participation.

Do you consent to sharing your contact information with us so we can contact you about possibly taking part in additional discussions about your experiences in phase 2 of this research? *

- ◯ Yes
- ◯ No

Personal contact information

Please provide details of how you would prefer to be contacted. This information will be stored on a password protected file, on a secure drive. Your contact information will only be retained for the duration of the study and only used for the purpose of contacting you for additional participation in phase 2.

Please provide information of how you would prefer to be contacted below, and if there are better times during the day to reach you (email, telephone, internet call etc). By providing details you are consenting to be recontacted for the purpose of the research only. *

Your answer

Appendix E: Qualitative Information Sheet

Study Title: Supporting Family Carers with Motivational Changes After Stroke

My name is Laura Farrell and I am carrying out research as part of my Doctorate in Clinical Psychology at the University of East Anglia (UEA). This phase of the research will investigate informal/family care givers experiences of motivational changes after stroke. We will seek the approval of the UEA Faculty of Medicine and Health Sciences Research Ethics Committee before collecting data.

Purpose of the study

Research shows that changes in motivation caused by some health conditions (e.g. forms of dementia), affect the relationships and experiences of carers, but we do not know if this also the case for stroke carers or what information or support stroke carers might want about motivational changes after stroke. This research will help answer these questions.

What would taking part involve?

This phase of the study involves meeting me to talk about experiences of motivational changes after stroke as a stroke carer. Those invited to take part who wish to do so, can decide a suitable time across a range of dates for interview to take place online. The interview will be guided by questions about your experience as an informal stroke carer. After the interviews have taken place, I will analyse themes and connections between the experiences of informal care givers. This will be anonymised and you will have the opportunity to read through your anonymised transcript. The findings will then be presented to charitable organisations, written up as a doctoral thesis available online and published in an academic journal.

Are there any benefits to taking part?

Findings from interviews could be important for improving knowledge and potentially aid intervention development for informal care givers of stroke survivors.

There will be £10 Amazon voucher for each participant as a form of gratuity for your time.

Are there any risks to taking part?

Participation is completely voluntary and you are not obliged to take part. We do not expect taking part to be upsetting but it is possible that answering questions or talking about caring

for someone after stroke could raise difficult emotions, so we will provide information about support services at the end of the questionnaire and interviews.

If during the interview the topic is too distressing, there is scope for changing discussion or thinking about things in another way or also completely changing topic. There is flexibility in the interview and will be led by how comfortable you feel. Your contact details and preferred method of contact will remain confidential.

Interviews will be confidential, however if you disclose information where I believe there is a risk to your safety or the safety of others, I have a legal duty to pass on relevant information regarding the nature of the risk to the relevant authority. This information would include your name and relevant contact details, along with any need to know information. However, I would discuss this with you first and inform you of the information I was sharing and with whom.

Will my information be kept confidential?

I will use a fake name for you, you will have the opportunity to choose this if you like. Recordings of interviews and consent forms will be stored confidentially and within password protected files. I will transcribe the interviews, removing identifying information such as names, places and names of other people. Once I have transcribed the interviews, the recordings will be deleted. After transcription, other members of the research team will be able to read your transcribed interview. Any signed consent forms will be stored separate from any of the recordings and transcription, and will only be accessible to the researcher and the research supervisor.

It is important that if the interview takes place online, no one else is able to hear you. This will protect your confidentiality and allow you to speak freely.

Are there any other details I need to consider?

You may wish to discuss your participation with the person you are caring for prior to engaging in the study. Whilst we do not need consent from the cared for person as we will be discussing your experiences, it may provide them with an opportunity to ask any questions they have about the study. They cannot be present for the interview.

It is important to be aware that it is expected that interviews will take approximately 1 hour, so there may be a need to arrange alternative care for this duration.

If you decide to take part and then later change your mind, you can withdraw during the interview or any time prior to your information being anonymised. You will also have the opportunity to review your anonymised transcript, once you have received your anonymised transcript you will have 14 days to read this, make changes or withdraw if you wish and your information will be destroyed and not used in the research.

If you decide you do not want to review your transcript you will have 14 days from date of interview to withdraw, after this stage your information will be anonymised and analysis will begin therefor you will no longer be able to withdraw.

If you would like more information about any part of the study, please contact the researcher Laura Farrell at laura.farrell@uea.ac.uk or Research Supervisor Dr Cat Ford at Catherine.Ford@uea.ac.uk

If you would like to make a complaint or have any concerns about this research, please contact Prof. Niall Broomfield at n.broomfield@uea.ac.uk

Appendix F: Qualitative Consent Form

Consent Form

Title of the study: Supporting Family Carers with Motivational Changes after Stroke

Name of Researcher: Laura Farrell

1. **I confirm that I have read and understood the information sheet of the study above. I have had time to consider my decision and have my questions answered** ☐

2. **I understand that participation is voluntary and can withdraw during participation and at the times specified without any reason.** ☐

3. **I understand that if the researcher has any concerns for my safety, or the safety of others they have a legal duty to share this information. I understand that the researcher will attempt to inform me first, but this may not always be possible.** ☐

4. **I understand my personal details will not be published in the paper. I understand they will not be shared with anyone outside of the research team.** ☐

5. **I agree to my interview being audio recorded and my anonymised speech to be quoted in publications.** ☐

By signing this declaration, I am agreeing to take part in the study above.

_____	_____	_____
Name of participant	**Date**	**Signature**
_____	_____	_____
Name of person	**Date**	**Signature**

Appendix G- Interview Topic Guide

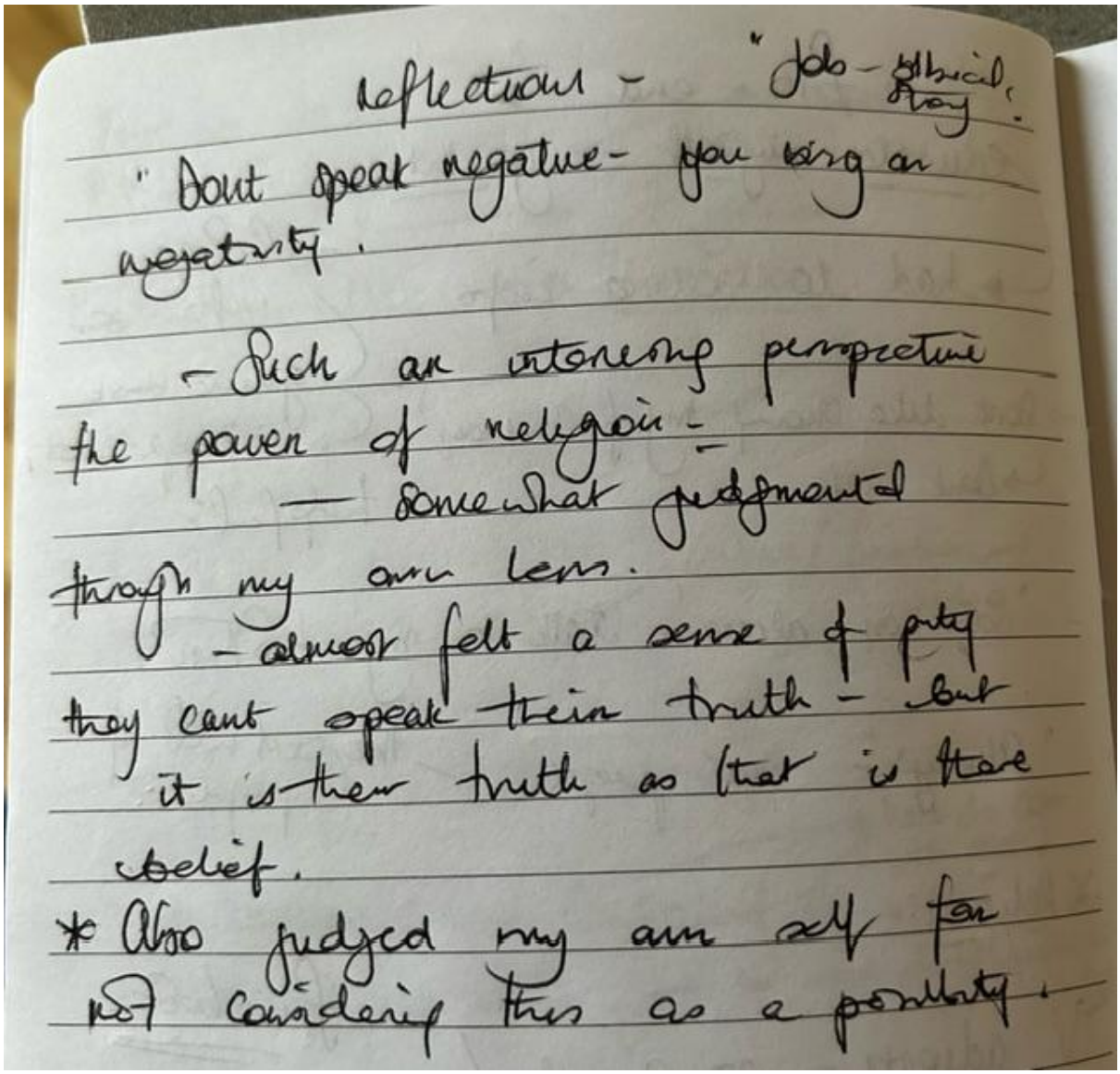
Interview

- Can you tell my about your experience of the person you care for since the stroke?
- What have you noticed in relation to post-stroke apathy?
- What is the impact of changes in motivation after the stroke for you as an informal carer?
- Do you provide any practical support?
- Has anything helped?
- What would you like to know about?

Possible prompts-

- What has day to day life been like?
    - Can you tell me more about changes to your daily routines? (executive and initiation apathy)
    - What is the impact of this?
- Can you tell me about changes in yourself? (Burnout)
    - Is there anything that has surprised you or new things you have learned since the stroke
- How has this affected your relationship? (understanding emotional apathy)
- How have these experiences affected how you cope/manage with life's challenges?
- What do you think have contributed to the challenges mentioned?
    - Who or what have you found the most helpful/unhelpful
- Looking back over the experience, is there anything you would have liked to have known?

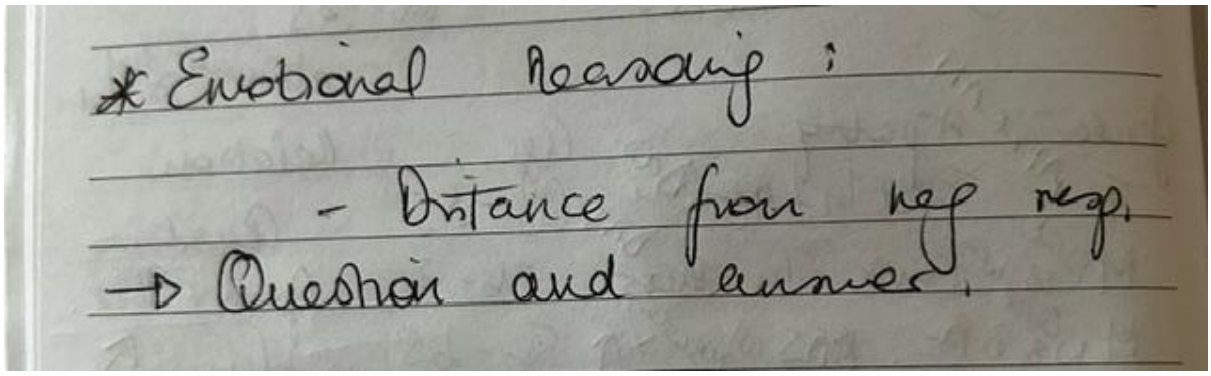
Appendix H- Reflexive Log Excerpts



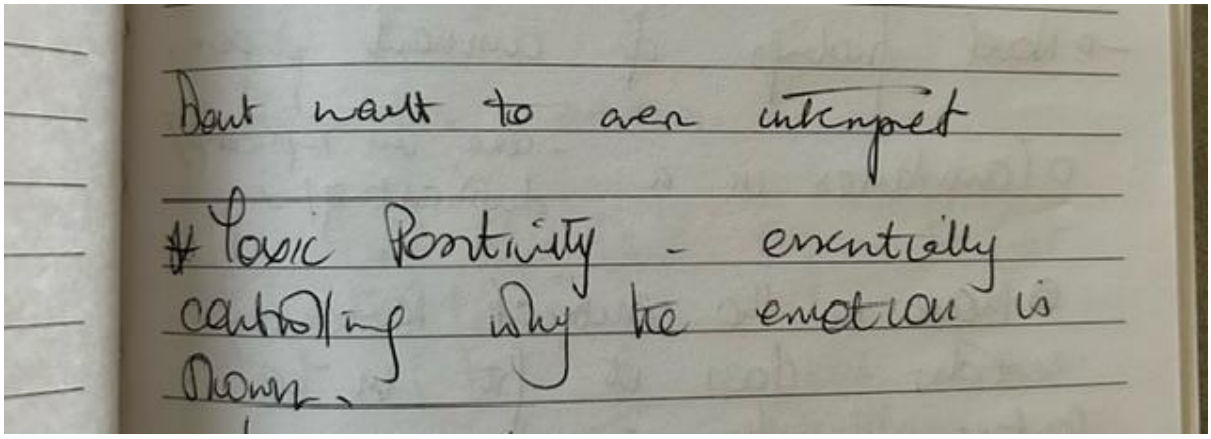
Reflection - "Jobs - Ethical Risks".

"Dont speak negative - you bring on negativity".

- Such an interesting perspective the power of religion -
— somewhat judgmental through my own lens.
- almost felt a sense of pity they cant speak their truth - but it is their truth as that is their belief.
* Also judged my own self for not considering this as a possibility.



* Emotional Reasoning :
- Distance from neg resp.
→ Question and answer.


Don't want to over interpret

Toxic Positivity - essentially controlling why the emotion is there.

Appendix I- Ethical Approval

University of East Anglia
Norwich Research Park
Norwich. NR4 7TJ

Email: ethicsmonitor@uea.ac.uk
Web: www.uea.ac.uk

Study title: Supporting Family Carers with Motivational Changes after Stroke

Application ID: ETH2324-0095

Dear Laura,

Your application was considered on 8th January 2024 by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee).

The decision is: **approved**.

You are therefore able to start your project subject to any other necessary approvals being given.

If your study involves NHS staff and facilities, you will require Health Research Authority (HRA) governance approval before you can start this project (even though you did not require NHS-REC ethics approval). Please consult the HRA webpage about the application required, which is submitted through the IRAS system.

This approval will expire on **31st July 2025**.

Please note that your project is granted ethics approval only for the length of time identified above. Any extension to a project must obtain ethics approval by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) before continuing.

It is a requirement of this ethics approval that you should report any adverse events which occur during your project to the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) as soon as possible. An adverse event is one which was not anticipated in the research design, and which could potentially cause risk or harm to the participants or the researcher, or which reveals potential risks in the treatment under evaluation. For research involving animals, it may be the unintended death of an animal after trapping or carrying out a procedure.

Any amendments to your submitted project in terms of design, sample, data collection, focus etc. should be notified to the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) in advance to ensure ethical compliance. If the amendments are substantial a new application may be required.

Approval by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) should not be taken as evidence that your study is compliant with the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018. If you need guidance on how to make your study UK GDPR compliant, please contact the UEA Data Protection Officer (dataprotection@uea.ac.uk).

Please can you send your report once your project is completed to the FMH S-REC (fmh.ethics@uea.ac.uk).

I would like to wish you every success with your project.

On behalf of the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee)

Yours sincerely,

Dr Paul Linsley

Supplementary information 1

CASP Checklist:

For Randomised Controlled Trials (RCTs)

Reviewer Name:	
Paper Title:	
Author:	
Web Link:	
Appraisal Date:	

During critical appraisal, never make assumptions about what the researchers have done. If it is not possible to tell, use the "Can't tell" response box. If you can't tell, at best it means the researchers have not been explicit or transparent, but at worst it could mean the researchers have not undertaken a particular task or process. Once you've finished the critical appraisal, if there are a large number of "Can't tell" responses, consider whether the findings of the study are trustworthy and interpret the results with caution.

Section A Is the basic study design valid for a randomised controlled trial?	
1. Did the study address a clearly formulated research question?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: *Was the study designed to assess the outcomes of an intervention?* *Is the research question 'formulated' in terms of:* • *Population studied* • *Intervention given* • *Comparator chosen* • *Outcomes measured?*	
2. Was the assignment of participants to interventions randomised?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER:	

• *How was randomisation carried out? Was the method appropriate?* • *Was randomisation sufficient to eliminate systematic bias?* • *Was the allocation sequence concealed from investigators and participants?*	
3. Were all participants who entered the study accounted for at its conclusion?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: • *Were losses to follow-up and exclusions after randomisation accounted for?* • *Were participants analysed in the study groups to which they were randomised (intention-to-treat analysis)?* • *Was the study stopped early? If so, what was the reason?*	
Section B Was the study methodologically sound?	
4. (a) Were the participants 'blind' to intervention they were given?	☐ Yes ☐ No ☐ Can't Tell
(b) Were the investigators 'blind' to the intervention they were giving to participants?	☐ Yes ☐ No ☐ Can't Tell
(c) Were the people assessing/analysing outcome/s 'blinded'?	☐ Yes ☐ No ☐ Can't Tell

5. Were the study groups similar at the start of the randomised controlled trial?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: • *Were the baseline characteristics of each study group (e.g. age, sex, socio-economic group) clearly set out?* • *Were there any differences between the study groups that could affect the outcome/s?*	
6. Apart from the experimental intervention, did each study group receive the same level of care (that is, were they treated equally)?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: • *Was there a clearly defined study protocol?* • *If any additional interventions were given (e.g. tests or treatments), were they similar between the study groups?* • *Were the follow-up intervals the same for each study group?*	
Section C: What are the results?	
7. Were the effects of intervention reported comprehensively?	☐ Yes ☐ No ☐ Can't Tell

CONSIDER: • *Was a power calculation undertaken?* • *What outcomes were measured, and were they clearly specified?* • *How were the results expressed? For binary outcomes, were relative and absolute effects reported?* • *Were the results reported for each outcome in each study group at each follow-up interval?* • *Was there any missing or incomplete data?* • *Was there differential drop-out between the study groups that could affect the results?* • *Were potential sources of bias identified?* • *Which statistical tests were used?* • *Were p values reported?*	
8. Was the precision of the estimate of the intervention or treatment effect reported?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: • *Were confidence intervals (CIs) reported?*	
9. Do the benefits of the experimental intervention outweigh the harms and costs?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: • *What was the size of the intervention or treatment effect?* • *Were harms or unintended effects reported for each study group?* • *Was a cost-effectiveness analysis undertaken? (Cost-effectiveness analysis allows a comparison to be made between different interventions used in the care of the same condition or problem.)*	

APPRAISAL SUMMARY: *List key points from your critical appraisal that need to be considered when assessing the validity of the results and their usefulness in decision-making.*

Positive/Methodologically sound	Negative/Relatively poor methodology	Unknowns

Supplementary information 2

Table of primary and secondary outcome measures

Scale	Description	Reliability	Validity	Reference
Caregiver Burden Scale (CBS)	22-item scale assessing caregiver burden across five domains.	α=0.70-0.87	Good convergent validity.	Elmståhl, S., Malmberg, B., & Annerstedt, L. (1996). Caregiver's burden of patients 3 years after stroke assessed by a novel caregiver burden scale. *Archives of Physical Medicine and Rehabilitation*, *77*(2), 177–182. https://doi.org/10.1016/s0003-9993(96)90164-1
Zarit Caregiver Burden Scale (ZCBS)	Assesses burden experienced by caregivers.	α = 0.89	Validated in diverse population including stoke	Bachner, Y. G., & O'Rourke, N. (2007). Reliability generalization of responses by care providers to the Zarit Burden Interview. *Aging & Mental Health*, *11*(6), 678–685. https://doi.org/10.1080/13607860701529965
Caregiver Strain Index (CSI)	13-item questionnaire assessing strain in informal caregivers.	α = 0.86	Validated in diverse caregiver populations. Including stroke	Robinson, B. C. (1983). Validation of a caregiver strain index. *Journal of Gerontology*, *38*(3), 344–348. https://doi.org/10.1093/geronj/38.3.344
Adult Carer Quality of Life Questionnaire (AC-QoL)	Measures quality of life in adult informal carers.	α =0.91	Validated in informal stroke carers (Portugese version)	Teixeira, F., Moura, A., & Alves, E. (2021). Portuguese validation of the Adult Carer Quality of Life Questionnaire (AC-QoL). *European Journal of Public Health*, *31*(Supplement_3). https://doi.org/10.1093/eurpub/ckab164.728
Short Form-36 Health Survey (SF-36)	36-item survey assessing health-related quality of life.	α =0.70	Validated for physical and mental health measurement.	Anderson, C., Laubscher, S., & Burns, R. (1996). Validation of the Short form 36 (SF-36) Health Survey questionnaire among stroke patients. *Stroke*, *27*(10), 1812–1816. https://doi.org/10.1161/01.str.27.10.1812

European Quality of Life-5 Dimensions (EQ-5D)	Standardised instrument for health outcomes.	α =0.69	Not validated in stroke informal carers	Van Oppen, J. D., Conroy, S. P., Coats, T. J., Mackintosh, N. J., & Valderas, J. M. (2023). Measuring health-related quality of life of older people with frailty receiving acute care: feasibility and psychometric performance of the EuroQol EQ-5D. *BMC Emergency Medicine*, *23*(1). https://doi.org/10.1186/s12873-023-00909-4
Family Appraisal of Caregiving Questionnaire (FACQ)	Assesses caregivers' perceptions and appraisals.	α =0.70-0.85	Construct validity shown in palliative care, but used in stroke studies	Cooper, B., Kinsella, G. J., & Picton, C. (2005). Development and initial validation of a family appraisal of caregiving questionnaire for palliative care. *Psycho-Oncology*, *15*(7), 613–622. https://doi.org/10.1002/pon.1001
WHO Quality of Life (WHOQOL-BREF)	26-item scale across physical, psychological, social, environmental domains.	α= **0.89**, with domain-specific alphas ranging from **0.68 to 0.85**	Cross-culturally validated, utilised in stroke research	Martini, S., Ningrum, D. a. S., Abdul-Mumin, K. H., & Yi-Li, C. (2021). Assessing quality of life and associated factors in post-stroke patients using the world health organization abbreviated generic quality of life questionnaire (WHOQOL-BREF). *Clinical Epidemiology and Global Health*, *13*, 100941. https://doi.org/10.1016/j.cegh.2021.100941
Relative Stress Scale (RSS)	Measures stress in relatives of chronic condition patients.	α= 0.70-0.86	Valid for assessing caregiver stress in other population.	Ulstein, I., Wyller, T. B., & Engedal, K. (2006). The relative stress scale, a useful instrument to identify various aspects of carer burden in dementia? *International Journal of Geriatric Psychiatry*, *22*(1), 61–67. https://doi.org/10.1002/gps.1654
Maslach Burnout Inventory – General Form (MBI-GF)	Assesses burnout in general populations.	α= 0.81-0.88	Uncertain	De Beer, L. T., Van Der Vaart, L., Escaffi-Schwarz, M., De Witte, H., & Schaufeli, W. B. (2024). Maslach Burnout Inventory – General Survey. *European Journal of Psychological Assessment*, *40*(5), 360–375. https://doi.org/10.1027/1015-5759/a000797

Supplementary information 3

CASP Appraisal Questions

Study ID	Did the study address a clearly formulated research question?
Avci (2023)	Yes
Bakas (2009)	Yes
Batool (2022)	Yes
Bierhals (2023)	Yes
Cameron (2014)	Yes
Cheng (2018)	Yes
Draper (2009)	Yes
Forster (2013)	Yes
Franzén-Dahlin (2008)	Yes
Fu (2020)	Yes
Grant (2002)	Yes
Hekmatpou (2019)	Yes
LeLaurin (2020)	Yes
Lindley (2017)	Yes
Mei (2017)	Yes
Mohammadi (2023)	Yes
Patchwood (2021)	Yes
Perrin (2010)	Yes
Pfeiffer (2014)	Yes
Shyu (2010)	Yes
Smith (2012)	Yes
Walker (2020)	Yes
Wang (2021)	Yes
Yilmaz (2019)	Yes

Study ID	Was the assignment of participants to interventions randomised?
Avci (2023)	Yes
Bakas (2009)	Yes
Batool (2022)	Yes
Bierhals (2023)	Yes
Cameron (2014)	Yes
Cheng (2018)	Yes
Draper (2009)	Yes
Forster (2013)	Yes
Franzén-Dahlin (2008)	Yes
Fu (2020)	Yes
Grant (2002)	Yes
Hekmatpou (2019)	Yes
LeLaurin (2020)	Yes
Lindley (2017)	Yes
Mei (2017)	Yes
Mohammadi (2023)	Yes
Patchwood (2021)	Yes
Perrin (2010)	Yes
Pfeiffer (2014)	Yes
Shyu (2010)	Yes
Smith (2012)	Yes
Walker (2020)	Yes
Wang (2021)	Yes
Yilmaz (2019)	Yes

Study ID	Were all participants who entered the study accounted for at its conclusion?
Avci (2023)	Yes
Bakas (2009)	Yes
Batool (2022)	Yes
Bierhals (2023)	Yes
Cameron (2014)	Yes
Cheng (2018)	Yes
Draper (2009)	Yes
Forster (2013)	Yes
Franzén-Dahlin (2008)	Yes
Fu (2020)	Yes
Grant (2002)	Yes
Hekmatpou (2019)	Yes
LeLaurin (2020)	Yes
Lindley (2017)	Yes
Mei (2017)	Yes
Mohammadi (2023)	Yes
Patchwood (2021)	Yes
Perrin (2010)	Can't tell
Pfeiffer (2014)	Yes
Shyu (2010)	Yes
Smith (2012)	Yes
Walker (2020)	Yes
Wang (2021)	Yes
Yilmaz (2019)	Yes

Study ID	Were the participants 'blind' to intervention they were given?
Avci (2023)	No
Bakas (2009)	Yes
Batool (2022)	Yes
Bierhals (2023)	Yes
Cameron (2014)	Yes
Cheng (2018)	Yes
Draper (2009)	Yes
Forster (2013)	Yes
Franzén-Dahlin (2008)	No
Fu (2020)	Yes
Grant (2002)	Yes
Hekmatpou (2019)	Can't tell
LeLaurin (2020)	No
Lindley (2017)	Yes
Mei (2017)	No
Mohammadi (2023)	No
Patchwood (2021)	Yes
Perrin (2010)	No
Pfeiffer (2014)	Yes
Shyu (2010)	Yes
Smith (2012)	Yes
Walker (2020)	No
Wang (2021)	Yes
Yilmaz (2019)	Yes

Study ID	Were the investigators 'blind' to the intervention they were giving to participants?
Avci (2023)	No
Bakas (2009)	Can't tell
Batool (2022)	Yes
Bierhals (2023)	Yes
Cameron (2014)	No
Cheng (2018)	No
Draper (2009)	No
Forster (2013)	No
Franzén-Dahlin (2008)	No
Fu (2020)	Yes
Grant (2002)	Yes
Hekmatpou (2019)	Can't tell
LeLaurin (2020)	No
Lindley (2017)	Yes
Mei (2017)	No
Mohammadi (2023)	No
Patchwood (2021)	Yes
Perrin (2010)	Yes
Pfeiffer (2014)	No
Shyu (2010)	No
Smith (2012)	Yes
Walker (2020)	No
Wang (2021)	No
Yilmaz (2019)	No

Study ID	Were the study groups similar at the start of the randomised controlled trial?
Avci (2023)	Yes
Bakas (2009)	Yes
Batool (2022)	Yes
Bierhals (2023)	Yes
Cameron (2014)	Yes
Cheng (2018)	Yes
Draper (2009)	Yes
Forster (2013)	Yes
Franzén-Dahlin (2008)	Yes
Fu (2020)	Yes
Grant (2002)	Can't tell
Hekmatpou (2019)	No
LeLaurin (2020)	Yes
Lindley (2017)	Yes
Mei (2017)	Yes
Mohammadi (2023)	Yes
Patchwood (2021)	Yes
Perrin (2010)	Can't tell
Pfeiffer (2014)	Yes
Shyu (2010)	Can't tell
Smith (2012)	Yes
Walker (2020)	Yes
Wang (2021)	Yes
Yilmaz (2019)	Yes

Study ID	Apart from the experimental intervention, did each study group receive the same level of care (that is, were they treated equally)?
Avci (2023)	Yes
Bakas (2009)	Yes
Batool (2022)	No
Bierhals (2023)	Yes
Cameron (2014)	Yes
Cheng (2018)	Yes
Draper (2009)	Yes
Forster (2013)	Yes
Franzén-Dahlin (2008)	Yes
Fu (2020)	Yes
Grant (2002)	Yes
Hekmatpou (2019)	Yes
LeLaurin (2020)	Yes
Lindley (2017)	Yes
Mei (2017)	Yes
Mohammadi (2023)	Yes
Patchwood (2021)	No
Perrin (2010)	Yes
Pfeiffer (2014)	Yes
Shyu (2010)	Yes
Smith (2012)	Yes
Walker (2020)	Yes
Wang (2021)	Yes
Yilmaz (2019)	Yes

Study ID	Were the effects of intervention reported comprehensively?
Avci (2023)	Yes
Bakas (2009)	Yes
Batool (2022)	No
Bierhals (2023)	Yes
Cameron (2014)	Yes
Cheng (2018)	Yes
Draper (2009)	Yes
Forster (2013)	Yes
Franzén-Dahlin (2008)	Yes
Fu (2020)	Yes
Grant (2002)	Yes
Hekmatpou (2019)	Yes
LeLaurin (2020)	Yes
Lindley (2017)	Yes
Mei (2017)	Yes
Mohammadi (2023)	Yes
Patchwood (2021)	Yes
Perrin (2010)	Can't tell
Pfeiffer (2014)	Yes
Shyu (2010)	Yes
Smith (2012)	Yes
Walker (2020)	Yes
Wang (2021)	Yes
Yilmaz (2019)	Yes

Study ID	Was the precision of the estimate of the intervention or treatment effect reported?
Avci (2023)	Yes
Bakas (2009)	Yes
Batool (2022)	No
Bierhals (2023)	Yes
Cameron (2014)	No
Cheng (2018)	Yes
Draper (2009)	No
Forster (2013)	Yes
Franzén-Dahlin (2008)	No
Fu (2020)	Yes
Grant (2002)	No
Hekmatpou (2019)	Yes
LeLaurin (2020)	No
Lindley (2017)	Yes
Mei (2017)	No
Mohammadi (2023)	No
Patchwood (2021)	Yes
Perrin (2010)	No
Pfeiffer (2014)	Yes
Shyu (2010)	Yes
Smith (2012)	No
Walker (2020)	No
Wang (2021)	Yes
Yilmaz (2019)	Yes

Study ID	Do the benefits of the experimental intervention outweigh the harms and costs?
Avci (2023)	Can't tell
Bakas (2009)	Yes
Batool (2022)	Can't tell
Bierhals (2023)	Yes
Cameron (2014)	Can't tell
Cheng (2018)	Yes
Draper (2009)	No
Forster (2013)	No
Franzén-Dahlin (2008)	No
Fu (2020)	Yes
Grant (2002)	Can't tell
Hekmatpou (2019)	Yes
LeLaurin (2020)	Can't tell
Lindley (2017)	No
Mei (2017)	Can't tell
Mohammadi (2023)	Yes
Patchwood (2021)	No
Perrin (2010)	Can't tell
Pfeiffer (2014)	Yes
Shyu (2010)	Yes
Smith (2012)	Can't tell
Walker (2020)	No
Wang (2021)	Yes
Yilmaz (2019)	Yes

Study ID	Can the results be applied to your local population/in your context?
Avci (2023)	Yes
Bakas (2009)	Yes
Batool (2022)	Can't tell
Bierhals (2023)	Yes
Cameron (2014)	Can't tell
Cheng (2018)	Yes
Draper (2009)	n
Forster (2013)	Yes
Franzén-Dahlin (2008)	n
Fu (2020)	Yes
Grant (2002)	Yes
Hekmatpou (2019)	Yes
LeLaurin (2020)	Can't tell
Lindley (2017)	n
Mei (2017)	Can't tell
Mohammadi (2023)	Yes
Patchwood (2021)	Yes
Perrin (2010)	No
Pfeiffer (2014)	Yes
Shyu (2010)	Yes
Smith (2012)	Yes
Walker (2020)	Can't tell
Wang (2021)	Yes
Yilmaz (2019)	Yes

Study ID	Would the experimental intervention provide greater value to the people in your care than any of the existing interventions?
Avci (2023)	Can't tell
Bakas (2009)	Yes
Batool (2022)	Can't tell
Bierhals (2023)	Yes
Cameron (2014)	Can't tell
Cheng (2018)	Yes
Draper (2009)	No
Forster (2013)	No
Franzén-Dahlin (2008)	No
Fu (2020)	Yes
Grant (2002)	Yes
Hekmatpou (2019)	Yes
LeLaurin (2020)	Can't tell
Lindley (2017)	No
Mei (2017)	Can't tell
Mohammadi (2023)	Yes
Patchwood (2021)	No
Perrin (2010)	No
Pfeiffer (2014)	Yes
Shyu (2010)	Can't tell
Smith (2012)	Can't tell
Walker (2020)	Can't tell
Wang (2021)	Yes
Yilmaz (2019)	Yes