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Research Article

Development of the Carers' Alert Thermometer for Stroke Family Caregivers (CAT-S): A Multiphase Action Research Study

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An estimated 1.3 million stroke survivors living in the United Kingdom (UK) currently rely on family caregivers for daily support. The needs of stroke family caregivers are, however, not routinely assessed by most clinical services. Early identification of their needs and support is crucial to maintain their well-being and caregiver role. At present, stroke-specific caregiver screening tools are lacking. This mixed method, the multiphase study aimed to develop a Carers' Alert Thermometer for stroke family caregivers (CAT-S) by adapting the CAT, a short screening tool developed in the context of end-of-life care. Underpinned by principles of action research, qualitative and quantitative data were collected sequentially between February 2016 to December 2017 from purposive samples of stroke family caregivers ($n = 76$) and staff working within stroke services ($n = 238$) in the UK. Semistructured interviews were conducted to inform the contents of the CAT-S. Key items for inclusion were identified through a modified Delphi survey and consultation with an expert panel. The CAT-S was then piloted in North West England to test its usability and usefulness in practice to identify the needs of stroke family caregivers. Thematic and content analysis were used to analyse qualitative data. Quantitative data were analysed using descriptive statistics. The CAT-S comprises the key challenges that are experienced by stroke family caregivers. Two additional items not present on the original CAT were identified and included; training needs of family caregivers to provide care and support for caregivers' emotional needs. The CAT-S was found to be useful and acceptable by both staff and stroke family caregivers and resulted in action plans and support being provided. The CAT-S is a supportive tool for achieving person-centred care and prioritising stroke family caregivers requiring comprehensive assessments.

1. Introduction

Stroke is a worldwide cause of neurological disability in adults [1] with over 12 million people annually suffering a stroke [2]. Despite major advances in treatment, most stroke survivors have disabilities preventing them from functioning independently without additional support [3]. Family caregivers play a critical role in maintaining the physical, psychological, and social well-being of stroke survivors [4]. However, the sudden nature of stroke and the abrupt uptake of the caregiving role plus the unpredictable nature of stroke recovery, makes it particularly difficult for family caregivers to adjust to the caregiving role [5]. High

rates of stress-related psychological problems [6, 7], physical ailments [8, 9], and financial hardships [10, 11] have been reported among family caregivers who support stroke survivors.

The vital role played by family caregivers is acknowledged by most stroke guidelines globally, e.g., in the United Kingdom (UK) [12, 13] Australia [14], and Canada [15]. The guidelines recommend that these family caregivers have an assessment of their needs and be referred to appropriate support services with regular reassessment over time as needs change. Nonetheless, minimal guidance is provided about who should carry out the assessments and content. In the United States of America (USA), legislation

exists (The Recognise, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act) [16], that seeks to support all family caregivers generally. Likewise, in the UK, legislation on carers' assessments exists in each of the four nations. In England, historic changes to legislation, The Care Act, [17] provided caregivers with the same legal rights and entitlements as those they care for and placed a legal duty on local authorities to undertake assessments. Despite both the USA and the UK having some level of legislation to support family caregivers which included recommendations for assessment [16, 17], in practice this is not always the case for a plethora of reasons. Economic restraints and complex care systems have contributed to delays of longer than six months to have an assessment being reported plus inconsistencies in how the assessments are carried out [18, 19]. Furthermore, the number of carers' assessments has steadily declined in England from nearly 450,000 per year in 2009/10 to just above 350,000 per year in 2017/2018 [20] and can be expected to have fallen further due to the Covid-19 pandemic. In the context of stroke care, the shortfalls with assessments have huge implications, particularly since the establishment of accelerated rehabilitation models, such as "early supported discharge" (ESD) leading to earlier hospital discharge [12]. Therefore, with an increasing number of stroke survivors requiring the support of family caregivers, it is essential that proactive approaches to assessing their needs and supporting them in the caregiving role are prioritised.

2. Literature Review

A narrative review was undertaken of published studies (1980–2022) of existing tools used to assess the needs and burden of caregiving experienced by stroke family caregivers residing at home. A total of 21 tools from 19 countries located on five continents (North America, South America, Europe, Asia, and Australia) were identified suggesting that the topic is an important global issue in countries with established stroke services. Five out of the 21 tools were developed within the stroke population with the remaining 16 developed within nonstroke populations. Most of the tools underwent psychometric testing indicating the high reliability of the tools [21] making them valid for use in the context of research.

Nonetheless, limitations were noted regarding the lack of involvement of family caregivers when developing the tools. The five stroke-specific tools identified were developed in four different countries (China, the USA, Germany, and Sweden). Although the tools could potentially be relevant for use in the UK in the context of research, their clinical relevance may be limited due to different health and social care provisions and cultural systems in the countries where they were developed [22]. Out of the 21 identified tools, only one, the Relatives Stress Scale [23] was developed in the UK with family caregivers of people with dementia. Therefore, it is unlikely to be applicable due to the different disease trajectories of stroke and dementia. Additionally, few studies reported how long it took to administer the tools in practice

and the experiences of staff and family caregivers were not reported. None of the tools offer signposting or suggestions for further action, limiting their potential use by practitioners. Furthermore, there were no tools offering a screening facility that is valuable for crisis situations or where there are delays in waiting for comprehensive assessments. Thus, at the onset of this study, no evidence-based screening tool was identified as suitable for use in practice with stroke family caregivers. Although a stroke carer assessment tool has been developed in the UK, the Carer Support Needs Assessment Tool for Stroke (CSNAT-Stroke) [24] is a lengthy comprehensive assessment tool and not a screening tool.

In view of the ongoing challenges with carer assessments and the current climate of limited resources, added to the impact of the global pandemic, short screening tools for use by a wide range of staff are required to assist in prioritising family caregivers in need of detailed formal assessment [25]. Importantly, the involvement of family caregivers when developing the tool is required to ensure the inclusion of the perspectives of professionals and family caregivers. This paper reports on how the priority areas of need of stroke family caregivers were identified and utilised to adapt the Carers' Alert Thermometer (CAT) [25, 26] developed in the context of palliative care to develop the Carers' Alert Thermometer for Stroke (CAT-S) for use with stroke family caregivers. The original CAT v1.1 (2014) is provided in the supplementary material section (available here). An updated version (2019) is available upon request.

3. Methods

Qualitative and quantitative data were collected from family caregivers of stroke survivors and staff working within stroke services across the UK between February 2016 and December 2017 (further work was delayed with the impact of the global pandemic Covid-19). Data were analysed and integrated sequentially. Action research was adopted due to its participatory and democratic nature allowing active engagement with stakeholders [27, 28]. This was deemed important to facilitate quicker adoption of the CAT-S into clinical practice [29]. The action research process characterised by three interrelated phases namely exploration, intervention, and evaluation was followed [27]. At the beginning of the study, a virtual advisory group (VAG) was set up comprising eight family caregivers and staff working within stroke services which are seen to be vital for action research studies [30]. The input was obtained from this group throughout the duration of the study.

The study comprised five phases. A summary of the aim, data collected, and participants across the five phases are presented in Table 1. Ethical approval was obtained from the University's Research Ethics Committee (FOHSC 119). All standard ethical procedures including advertising the study, participant information sheets, consent, and data storage were followed. Due to the iterative nature of the study, the methods and results for each phase are presented together.

TABLE 1: Overview of the study design and participants.

Phase	Aim	Design and data type	Participants
Consultation exercise (pre-exploratory)	To explore the value of the study	Phone calls, emails, face-to-face meetings (qualitative data)	18 current family caregivers supporting stroke survivors and 11 members of staff. Participants were from two stroke charities in London and a national charity in the North West of England and a stroke unit in London. Total $n = 29$
Phase 1 (exploratory)	To identify factors contributing to burden during caregiving post stroke	Semistructured interviews (qualitative data)	16 stroke family caregivers from a national stroke charity in North West England. Total $n = 16$
	To seek the views of stroke family caregivers about the CAT	Semistructured interviews (qualitative data)	As above
Phase 2 (exploratory)	To gain consensus on the most important factors from phase 1 for inclusion in the CAT-S	A two-round modified Delphi survey (quantitative and qualitative data)	The survey was completed across two rounds from staff and family caregivers of stroke survivors nationally. Total $n = 249$
		Round 1: 43 items across 8 topic topics	Round 1 staff $n = 101$; family caregivers $n = 12 = 113$ (42 physiotherapists, 31 occupational therapists, 14 nurses, 1 speech therapist, and 12 staff from a stroke charity; and 1 staff participant did not provide demographic information)
		Round 2: 33 items across 8 topic topics	Round 2 staff $n = 117$; family caregivers $n = 19 = 136$ (39 physiotherapists, 27 occupational therapists, 28 nurses, 12 speech therapists, 3 staff from a stroke charity, and 1 other. 7 participants (staff) did not provide demographic information)
Phase 3 (exploratory)	To seek an expert panel review of the top 10 items to include in the CAT-S	Consultation and consensus selection (quantitative and qualitative data)	8 members of the VAG and 3 family caregivers who participated in phase 1 (6 family caregivers and 5 staff) total $n = 11$
Phase 4 (intervention)	To pilot the readability and usability of the initial CAT-S	A small pilot study of the initial CAT-S (quantitative and qualitative data)	4 community-based stroke coordinators based at a national stroke charity in the North West of England and 5 family caregivers of stroke survivors total $n = 9$
Phase 5 (evaluation)	To explore the experiences of stroke family caregivers and community-based stroke coordinators when using the CAT-S	Semistructured interviews with stroke family caregivers in North West England. Staff feedback forms that were completed as part of the CAT-S pilot	As above during the pilot

4. Procedure and Results

4.1. Consultation Exercise (Pre-Exploratory Phase). This comprised 29 key stakeholders as follows: stroke family caregivers, community-based stroke coordinators, managers, staff from a national stroke charity, and staff working on a stroke unit (doctors, therapists, and nurses) in London and the North West of England. Data were collected through three face-to-face meetings, multiple telephone conversations, and e-mail communications. This exercise confirmed the need for the study and highlighted the wide variation in practice where caregiver assessment tools were being utilised.

4.2. Phase 1: Item Generation (Exploratory Phase)

4.2.1. Recruitment. Purposive sampling [31] was utilised to recruit participants for this phase of the study as illustrated in Table 1. Community-based stroke coordinators assisted with recruitment by informing stroke family caregivers (defined as any family member who was active in supporting the stroke survivor in any way) about the study. The inclusion criteria for this phase are provided in Figure 1. Study information packs containing an invitation letter, participant information sheet, and local support services were handed out to family caregivers. Interviews were conducted in the participants' homes or the venue of their choice. An interview guide was developed from existing literature [32] and refined by VAG members. A broad range of questions was included (see Table 2). All participants described themselves as White British. Table 3 provides a summary of participants in this phase of the study.

4.2.2. Data Analysis. Thematic analysis as advocated by Braun and Clarke [33] was followed due to its flexible and pragmatic approach [34]. The themes were required to understand the local context in line with action research but also to form the content of the questionnaire for the next phase. Findings from this phase are described in detail in a previous publication [35]. Two main themes identified as factors contributing to the burden when supporting individuals following a stroke were the effects of caregiving and family caregivers' unmet needs. Additionally, participants reported positive views about the original CAT, however, they highlighted some missing items and the inappropriateness of some questions in this context.

4.3. Phase 2: Item Selection (Exploratory Phase)

4.3.1. Delphi Development. The themed factors identified in phase 1 as contributing to the burden when supporting individuals following a stroke were developed into a two-round Delphi survey. As stated earlier, the original CAT was created in the context of end-of-life care. However, findings from the qualitative interviews in phase 1 of the current study [35] highlighted key differences between the experiences and needs of family caregivers of stroke survivors and those providing care to someone dying at home. The purpose

Inclusion criteria	Exclusion criteria
(i) Stroke family caregivers residing at the same address with the stroke survivor	(i) Stroke family caregivers not residing at the same address with the stroke survivor
(ii) Aged over 18 years	(ii) Aged under 18 years
(iii) English speaking	(iii) Non-English speaking

FIGURE 1: Inclusion and exclusion criteria for participants in phase 1.

of the Delphi survey was, therefore, to rate the items identified in phase 1 and the literature and reach a consensus on the priority items to include in the CAT-S. Studies that employ the Delphi technique use individuals who have knowledge of the topic being investigated, which McKenna p.1221 [36] defines as a "panel of informed individuals." Participants in this phase were stroke family caregivers and staff working within various stroke services in the UK. The eight topics utilised in the development of the original CAT [26] were reviewed as a starting point to map findings from the literature and the interviews in phase 1. The items (questions) under each topic were discussed with VAG members. The survey comprised of 43 items under eight topics for the first round of the Delphi survey. The survey was created in the following two formats: paper and electronic via Survey Monkey®. Prior to launching the survey, a small pilot ($n = 6$) was completed to check readability and minor modifications were made following feedback received. A summary of the number of items under each topic is provided in Table 4.

4.4. Recruitment

4.4.1. Family Caregivers. Purposive sampling was adopted [31]. The inclusion criteria for family caregivers in this phase were the same as in phase 1 (see Figure 1). Flyers advertising the study were distributed to a total of seven sites; three sites that participated in phase 1 and an additional four sites of the same organisation. Furthermore, the study was advertised on the website of a national stroke charity and on their Twitter account to allow stroke family caregivers to participate at a national level.

4.4.2. Staff. Similarly, purposive sampling was used to recruit staff. The Delphi survey was distributed electronically (via e-mail link) to staff working within various stroke services in the UK. Staff needed to be in post for 6 months or more to allow them to draw upon their experiences. Figure 2 provides a summary of the inclusion and exclusion criteria for staff.

(1) Round 1. Two surveys were developed as follows: one for family caregivers and one for staff. Both comprised three sections, with Sections A and B containing the same questions for both cohorts. Section A comprised 43 items under eight topics as described earlier (Table 4). Participants were asked to rate the importance of each of the 43 items for

Table 2: Phase 1 topics and questions in the interview guide.

Topic	Questions
Demographics	(a) Please state the box that best describes your age. 18–25 ☐ 25–35 ☐ 36–45 ☐ 46–55 ☐ 56–65 ☐ 66–75 ☐76+ ☐ (b) Employment status—current, previous, reasons for stopping work, how long ago stopped work (c) Ethnicity (d) Gender (e) Relationship with the person currently caring for
Current caring role	(a) How long have you looked after . . . .;? (b) Can you describe some of the things that you do for. . .? (Physical, social, psychological) (c) Have there been any occasions when you have found caring to be challenging? (Examples and context, what was the most challenging and why? Is the emotional impact of stroke an issue?) (d) What helps you to cope with the challenges? (what helps most, least)
	(a) What support or help have you received whilst caring for . . .? (b) Is there any help or support you feel you might have benefited from but did not receive? (c) Did you or. . . . . .have the 6 months follow-up? (d) Have you had any assessments since you started caring for . . ..? (Prompts: Did those assessments result in any additional support?) (e) What are your thoughts on regular assessments of stroke carers' needs? (Prompts: Any particular areas that you feel need to be assessed?) (f) How would you feel being asked about your needs on a regular basis by someone who comes into your home regularly, such as a district nurse or stroke coordinator? (Any other professional you would prefer?)
Support and assessments	
The Carers' Alert Thermometer (CAT) (participants are shown the original CAT)	(a) Looking at the items on the CAT, are they appropriate? (Prompts: Are there any items missing? Any examples?)
Open-ended question	Is there anything else you'd like to add to what you've said today?

Table 3: Summary of participants in phase 1.

Characteristics	Number $n = 16$
Age	
35–45	1
46–55	0
56–65	4
66–75	8
76+	3
Gender	
Male	5
Female	11
Employment	
Employed	2
Unemployed	4
Retired	10
Duration of caregiving in years	
Less than 1 year	7
1-2 years	4
3–5 years	1
6 years or more	4

Table 4: Number of items under each topic.

Topic	Number of items
Topic 1 caring situation	7
Topic 2 caring role	8
Topic 3 relationship with health and social care professionals	3
Topic 4 respite and emergency care	3
Topic 5 financial support and assessments	7
Topic 6 carer's health and well-being	7
Topic 7 support for the carer	5
Topic 8 end of life and planning	3
Total number of items	43

Inclusion criteria	Exclusion criteria
(i) Staff who have direct contact with stroke survivors and their families as part of their role	(i) Staff working in administrative roles or managerial positions without direct contact with stroke survivors and their families
(ii) Staff in post for 6 months or more	(ii) Staff in post for less than 6 months

Figure 2: Inclusion and exclusion criteria for staff.

inclusion in the CAT-S using a five-point Likert scale from 1 "not at all important" to 5 extremely important. Additionally, under each topic, they were asked to select the most important item that should be included in the CAT-S. A comment box was also provided. In Section B, views were sought on the development of the CAT-S and its potential use in practice. Participants were also asked to rank the eight topics in order of priority from one "most important topic" to eight "least important topics." In Section C, the participants were asked to provide anonymous demographic information. Family caregivers provided information regarding their caregiving experience, whilst staff commented on their professional experience. The last page of the family caregivers survey contained useful contacts of national support organisations. Implied consent was assumed upon survey completion [37].

Round 1 was completed by 101 staff (electronic) and 12 family caregivers (electronic $n = 3$; paper $n = 9$). The same analysis methods were used for both electronic and paper surveys. Family caregivers were mostly female ($n = 9$) and over the age of 55 ($n = 7$). One staff participant did not provide demographic information, therefore, a summary of the characteristics of the 100 staff without missing data is presented in Table 5. Qualitative data from the comments box were analysed using a thematic analysis approach [33].

Quantitative data were entered into IBM SPSS Statistics for Windows, version 25 for analysis [38]. Descriptive statistics were used to explore the measures of central tendency (median) and dispersion (interquartile range) (IQR) to identify the ratings of both staff and caregiver cohorts separately then the combined sample for rating individual items and ranking of topics [39]. In a classical Delphi approach, statements that have reached consensus tend to be set aside at this stage, only retaining those where consensus has not been reached for further consideration in subsequent rounds [40]. A modification to this approach was adopted where items with clear disagreement according to the preset criteria were removed. This was done to refine and reduce the priority items to be included in the CAT-S to ensure a short screening tool [25, 41, 42]. A summary of the

TABLE 5: Characteristics of staff in round 1.

(N = 100, missing = 1 where no characteristics shared)	
Gender N (%)	
Male	7 (7%)
Female	93 (93%)
Profession group	
Nursing	14 (14%)
Physiotherapists	42 (42%)
Occupational therapists	31 (31%)
Speech and language therapists	1 (1%)
National stroke charity staff	12 (12%)
Age range	
18–25	1 (1%)
26–35	24 (24%)
36–45	33 (33%)
46–55	27 (27%)
56–65	15 (15%)
Region	
Yorkshire and Humber	6 (6%)
East Midlands	8 (8%)
West Midlands	11 (11%)
North West	15 (15%)
South West	10 (10%)
London	9 (9%)
South East	14 (14%)
East of England	9 (9%)
Scotland	17 (17%)
Other	1 (1%)
Length of time in the role	
6 months to less than 1 year	6 (6%)
1-2 years	10 (10%)
3–5 years	19 (19%)
6–8 years	21 (21%)
9 years or more	44 (44%)

(i) Criterion for accepting an item	-	At least 70% of the caregiver and professional cohort rated an item as (4) 'important' or (5) 'extremely important'.
(ii) Criterion for re-rating an item	-	If 70% of one cohort or the total sample rated an item as (4) 'important' or (5) 'extremely important' but the other panel did not, suggesting disagreement between the panels.
(iii) Criterion for rejecting an item	-	Any items that did not meet the 70% criterion in either the panel or the total sample.

FIGURE 3: Summary of the predetermined criteria used in this study to accept, rerate or reject an item.

predetermined criteria used in this study to accept, rerate or reject an item is presented in Figure 3.

Responses in Round 1 showed a high level of consensus on the rated items. Twenty out of 43 items met the criterion for acceptance, 13 items were retained for rerating due to disagreement between cohorts and 10 items were rejected. Consequently, 33 items were included in Round 2.

(2) Round 2. The sampling strategy and data collection methods used in Round 1 were replicated in this round. In view of the low level of participation of family caregivers in Round 1, various strategies were employed to increase participation in Round 2. This involved attending local family caregiver events and meetings and talking to staff to raise awareness of the study at the recruitment sites [41]. Subsequently, two further sites participated in Round 2.

The Round 2 survey also contained three sections but comprised fewer items than in Round 1 (33 items). The median group rating given to each of the 33 items in Round 1 was presented to participants (whether an item was rated

4 "very important" or 5 "extremely important"). Participants were invited to consider the median group ratings and then rerate each item under the eight topics on a five-point Likert scale, as in Round 1, and to rank the eight topics in order of priority. A comment box was provided. Participants also completed Section B to provide their views on the future CAT-S as well as their demographic data in Section C. Data analysis replicated Round 1.

The survey Round 2 survey had 136 participants; 117 staff (electronic) and 19 family caregivers (electronic $n = 2$; paper $n = 17$). The consensus criterion applied to items in Round 1, was replicated in Round 2. Out of the 33 items, 15 met the acceptance criteria, three were rejected. There was disagreement on 15 items between the staff and family caregiver cohorts and as a result, these items had to be included for rerating. The analysis in Round 2 resulted in 30 items. The number of family caregivers in Round 2 remained considerably low in comparison to staff. The overall analysis was undertaken at this stage [39] and involved calculating the mean in addition to the median, which was used to give feedback to participants between the two rounds. The mean and standard deviation for each item was, therefore, calculated in both cohorts (staff and family caregivers) and the total sample. The total sample mean was used to rank the items from the most important to the least important, thus allowing the top 10 items for inclusion in the CAT-S to be determined [40]. The rationale for having 10 items was pragmatic, to avoid overburdening staff and family caregivers when completing the CAT-S.

A review of the top 10 items ranked by mean in each cohort (family caregivers and staff) was undertaken to ensure equal consideration was given to the views of both groups. It was noted that seven items were top-ranked by staff and family caregivers (Topic 1: two items, Topic 2: four items, and Topic 4: one item). For the remaining three items, family caregivers selected items from topic 3 (Relationship with health and social care professionals, two items) and topic 7 (support for the carer, one item). Staff on the other hand selected items from topic 1 (caring situation, two items) and topic 2 (caring role, one item). Furthermore, a review of the top 10 items ranked by the total sample mean revealed that five items originated from topic 2 (caring situation), four originated from topic 1 (caring role), and one from topic 4 (respite and emergency care). To ensure the inclusion of items from all eight topics, the top two items ranked according to the total sample mean under each of the eight topics were selected resulting in 16 items. This approach enabled the views of family caregivers to be retained as the plan was to have an equal number of staff and family caregivers during the consultation with expert consultation. The two highly ranked topics were topic 6: carer's health and well-being followed by topic 1: the caring situation.

4.5. Phase 3: Consultation with an Expert Panel (Exploratory Phase). The 16 items across eight topics identified following a final analysis in Round 2 were used to develop a short questionnaire and sent to an expert panel. The panel consisted of eight members of the VAG and three additional family caregivers who participated in phase 1 ($n = 11$; five staff and six family caregivers). Panel members were asked to rank their final top 10 items for inclusion in the CAT-S from the 16 items and were further invited to provide comments or highlight any issues that they felt were missing. Items were ranked "1" as the highest ranked item; thus, items ranked highest have the lowest mean [26, 40]. Overall, a high level of agreement was observed within the staff and family caregiver cohorts with each ranking seven similar items in their top 10. The panel's (total sample) top 10 ranked items are provided in Table 6. Interestingly, there were two items from topic 1 (caring situation), two from topic 2 (caring role), two from topic 3 (relationship with professionals), two from topic 4 (respite and emergency care), and one item each from topic 5 (financial support and assessment), and topic 6 (carer's health and wellbeing). There were no items from topic 7 (support for the carer) and topic 8 (end of life and planning).

Findings from the consultation exercise were shared with VAG members and discussed with members of the wider research team. An unexpected finding from the Delphi survey was the absence of the item on emotional support for family caregivers which was strongly expressed by participants during the interviews in phase 1 but was not rated highly in the survey. Since emotional support was identified as a missing item during the consultation with the expert panel, a decision was made to include this item on the CAT-S for the pilot. Additionally, VAG members decided to retain the item regarding end-of-life planning which is present on the original CAT but was not highly rated in this study. This decision was based on taking an inclusive approach across the stroke care pathway as the question may be relevant when supporting family caregivers looking after stroke survivors approaching the end of their life. This resulted in 12 items (The top 10 ranked items presented in Table 6 and two items identified as important by the expert panel).

4.5.1. Creation of the CAT-S for Pilot. A draft version of the CAT-S was created using the 12 items prioritised by the expert panel in phase 3. Seven sections were created as shown in Table 7.

The draft version of the CAT-S was shared electronically with VAG members. They were enthusiastic, particularly with the colour, design, and picture of the thermometer. Minor modifications were suggested in Sections 1 and 2 of the CAT-S and incorporated following consultation with the

Table 6: Top 10 ranked items by the expert panel.

Topic	Items	Rank	Mean (SD)
T1	. . .If the carer has other demands on their time in addition to their caring role? (e.g. working, volunteering, studying, young family, and caring for grandchildren)	1	3.28 (3.19)
T2	. . .If the carer feels able to manage and cope with the behaviour of the person they care for?	2	3.77 (2.58)
T1	. . .If the carer understands the expected recovery from stroke for the person they are caring for?	3	4.22 (3.07)
T6	. . .If the carer would like help to cope with any aspects of their caring role?	4	4.50 (3.53)
T2	. . .If the carer needs any training to provide care safely, such as lifting, and handling or equipment use training?	5	5.20 (2.16)
T5	. . .If the carer has had a carer's assessment?	6	5.33 (4.03)
T4	. . .If the carer would like support with a break from caring such as using a sitting service in their home for a few hours or to use respite care for a longer break?	7	5.40 (1.94)
T3	. . .If the carer feels they are receiving the support they need from professionals at the time they need it?	8	5.42 (2.76)
T4	. . .If the carer has planned what should happen in an emergency if they were unable to provide care e.g. if they become ill or go into hospital?	9	5.60 (2.54)
T3	. . .If the carer feels that professionals involve them in decision-making by seeking their knowledge and expertise about the care needed by the person they care for?	10	5.77 (3.52)

Table 7: Sections of the CAT-S for the pilot.

Section number	Details of information contained under each section
Section 1	Demographic information (including age and relationship to the stroke survivor)
Section 2	12 items prioritised by an expert panel
Section 3	Picture of the original CAT to record the number of medium and high alerts
Section 4	Suggested next steps providing guidance to staff for addressing each item scoring a medium or high alert in Section 2
Section 5	Space to document up to four priority alerts requiring action together with boxes for staff to record any immediate action taken, next steps, name of the person responsible for the following up action, and a date for when the action would be followed up
Section 6	Space for when and who would conduct the next review
Section 7	Space for staff to record the amount of time taken to complete the CAT-S

VAG. For instance, the two items ranked 8th and 10th concerning professionals (as shown in Table 6) were rephrased and combined into a single question on the CAT-S. Additionally, the item regarding carers assessment ranked 6th, was shifted to Section 1 to be completed at the beginning of the conversation as a yes or no question. No changes were proposed to the remaining Sections 3 to 7.

4.6. Phase 4 and 5: CAT-S Pilot (Intervention and Evaluation). Although this study's phases are presented separately (Table 1), in practice, action research phases tend to overlap, allowing researchers to flexibly respond to dynamic changes in reality [27, 43]. The CAT-S pilot was, therefore, conducted as part of both the implementation and evaluation phases. Gatekeepers at a national stroke charity in the North West of England were invited to take part in the pilot to test the readability and usability of the CAT-S with staff (community stroke coordinators) and stroke family caregivers. The inclusion criteria for family caregivers in this phase were the same as for phases 1 and 2 (Figures 1 and 2).

Staff ($n = 4$) were provided with a guidance sheet and short training on how to complete the CAT-S. They completed a feedback form comprising of nine closed questions and three open-ended questions immediately after administering the CAT-S with family caregivers. Semistructured interviews were conducted with family caregivers ($n = 5$) approximately a month after completing the CAT-S to explore their experiences of using it. The one-month gap was to allow time for any referrals and support to be initiated. Quantitative data from the CAT-S and closed questions on the staff feedback forms were subjected to quantitative data analysis. Frequency distributions were used to present information regarding the number of alerts identified, the time taken to complete the CAT-S, and staff feedback [44, 45]. The open comment sections of the staff feedback forms plus data from the semistructured interviews with family caregivers were analysed using content analysis [46].

4.7. Results of the Pilot and Further Consultations. Evaluation of the feedback indicated that the CAT-S was highly valued by staff. They reported that the instructions and questions on the CAT-S were easy to follow and read. Staff also suggested the CAT-S could be completed electronically. Similarly, family caregivers welcomed the CAT-S and provided some positive comments regarding the time taken to complete the CAT-S and its usefulness. Overwhelmingly, family caregivers expressed positive views regarding regular assessment with the CAT-S. Although some did not specify the frequency of completing the CAT-S, two participants identified every three months as the appropriate frequency for completing the CAT-S.

During the pilot, the CAT-S identified various alerts. Subsequent actions included a referral to the emotional support service, provision of information regarding stroke, and a referral to the community stroke team for further equipment training. The mean completion time of the CAT-S was 25 minutes. Following the pilot, further consultations with staff and family caregivers at the national stroke charity were undertaken to refine the CAT-S. Changes to the layout of information on the CAT-S were suggested including a numerical scoring system for the items in Section 2 of the CAT-S as opposed to the total needs score. The questions are jointly scored by stroke family caregivers and staff on a scale of zero to three with 0 indicating no risk alert, 1 low-risk alert, 2 medium-risk alert, and 3 high-risk alerts as illustrated in Table 8. Other recommendations made included adding an item concerning financial support. Furthermore, a question regarding the ability of the family caregiver to continue providing care which is present on the original CAT was added to the CAT-S (Question 11). Evidence suggests that the needs of family caregivers and their resilience to continue caring need to be explored concurrently [25, 47]. The CAT-S is being used by other community stroke teams following a local evaluation study. A larger feasibility study delayed due to the global pandemic is currently underway with community stroke teams in the North West of England using the CAT-S. A copy of the CAT-S v3 is provided in the supplementary material section. Any updated versions of the CAT-S will be made freely available on the CAT website once the study is completed.

5. Discussion

This paper has reported on the development of an evidence-based screening tool to identify and support the needs of stroke family caregivers. The CAT-S was developed by incorporating the perspectives of staff and family caregivers throughout each phase of the process. The insights provided by this wider group from various regions of the UK make the development of the CAT-S unique compared to other tools that tend to exclude family caregivers in their development which is an additional value of the design. Additionally, the active involvement of service users in research can have a positive impact on outcomes by ensuring its relevance [48] and can aid in the adoption by those involved in the development of the tool.

The items on the CAT-S are presented under the following two main overarching themes: understanding the current caring situation and the carer's health and wellbeing. The two topics were also highly ranked in the current study by family caregivers and staff highlighting the importance of the two topics when providing support to family caregivers of stroke survivors. The findings concur with those from the original CAT [25, 26] and other caregiver populations [49]. National stroke guidelines in the UK recognise that family caregivers have their own needs and further identify them as partners in the provision of care; recommend that they are supported in this role [12]. Findings from the current study complement these assertions and further support the advocating of considering the position of family caregivers as equal partners in the care process or coworkers and as coclients having their own needs and aspirations [50, 51]. Since these two topics are included in the CAT-S, it can be argued that utilising it with stroke family caregivers will facilitate the recommendations made by the national guidelines to be achieved.

Despite the similarities mentioned above, there are also some notable differences between the items included on the original CAT [25] and the CAT-S under the two main topics. The support required to manage the difficult behaviours of the stroke survivor, an item under the current caring situation, was identified as a priority and included on the CAT-S but is absent on the original CAT. This is unsurprising as patients approaching the end of their life may exhibit different symptoms with the progression of the disease including physical deterioration, thus, placing different demands on family caregivers [52].

Another key difference between the original CAT and the CAT-S is the item regarding the emotional well-being of the family caregivers. There is overwhelming evidence in the literature including findings from phase 1 of this study [35] regarding the effects of caregiving on the emotional well-being of stroke family caregivers. The sudden onset and chronic nature of stroke compared with other progressive illnesses have been highlighted as a contributing factor to the high prevalence of psychological distress among stroke family caregivers [5, 53]. Findings from a national survey by the Stroke Association revealed that 69% of those who had been caring for seven years or more reported stress compared to 48% who had been providing care for up to three years [54]. In phase 1 of the current study, some family caregivers were providing care for up to ten years, which further reflects the chronic nature of stroke disease [5].

Even with the wide range of roles among participants, there was a high level of consensus and agreement on items to be included in the CAT-S. The importance of these items is highlighted in existing literature [55–57]. It is important to note that two items regarding family caregivers' views of their relationship with professionals were highly rated in this study (ranked 8th and 10th, respectively) (Table 6). As explained earlier, the two questions were rephrased into one question by VAG members. The prominence of the two items in this study suggests the relationship between professionals and family caregivers is an important area that must be considered when supporting stroke family

Table 8: Questions from section 2 of the CAT-S.

		0	1	2	3
PART A: THE CURRENT CARING SITUATION	1) Do you currently have any needs or concerns about providing care or your own health and well-being? (*please circle one*) Yes No Unsure				
	How much support do you need:-				
	2) …with any information about the person's stroke condition and their expected recovery?	N	L	M	H
	3) …with any training or support to provide care safely? (*e.g. lifting and handling training, equipment use*)	N	L	M	H
	4) …to manage any changes in the behaviour of the person? (*e.g. wandering, aggression*)	N	L	M	H
	5) … to know who to call in an emergency, or out-of-hours, to discuss any concerns about the person?	N	L	M	H
	6) …to feel involved in the decision making and listened to by professionals about the care needed by the person (*Consider if the person requires power of attorney*)	N	L	M	H
PART B: CAREER HEALTH AND WELL-BEING	7) …about financial, legal or work issues?	N	L	M	H
	8) …to take a break from caring during the day or overnight? (*e.g. sitting service, respite*)	N	L	M	H
	9) …to balance your own needs with the demands of caring? (*e.g. attend own health appointments, social activities, caring for others*)	N	L	M	H
	10) …to manage any feelings or worries that you may have? (*e.g. a 'listening ear' or having someone to talk to*)	N	L	M	H
	If appropriate include: Do you know the person's wishes and preferences for end of life care? (*If known, have they been written down and shared, e.g. advance care planning (ACP) document*)	N	L	M	H
	Sub-total scores for low, moderate and high needs				

	Not very Able				Very Able
11) How able do you feel to continue providing care at the current level for the person? (*please circle one number on the scale*)	1	2	3	4	5

caregivers. Furthermore, having positive relationships between stroke family caregivers and professionals has been highlighted as important in previous research [58, 59].

Questions (7–10) under the carer's health and well-being focus on financial and work-related issues, having a break from caring and balancing own needs with caring and emotional support. Similarly, these findings are supported by existing literature [10, 55, 60]. Although not highly rated, the question regarding end-of-life care e.g. advance care planning (ACP) is included on the CAT-S as an optional question for use if appropriate following consultation with VAG members. Providing high-quality end-of-life care remains a priority for most national and international stroke guidelines and the importance of ACP has been highlighted in these guidelines [12, 61]. There is currently a dearth of stroke-specific studies that have examined the effectiveness of ACP, however, benefits including improved communication and awareness of the stroke survivors' end-of-life

wishes were reported in Australia [62]. Furthermore, significantly reduced levels of stress, anxiety, and depression were observed in studies where family members were involved in ACP and end-of-life discussions, compared to the studies where these conversations did not occur [63, 64]. Most importantly the patient's end-of-life wishes were achieved [64]. The inclusion of the ACP item on the CAT-S is thus, justifiable and could allow discussions regarding ACP to be initiated sooner.

A recurring theme throughout the development of the CAT-S was the importance of having regular assessments for stroke family caregivers. This is particularly important as their needs may change over time [65]. Based on these findings, it can be argued that utilising a screening tool such as the CAT-S in clinical practice offers opportunities for staff to identify the needs of stroke family caregivers and for a detailed assessment to be undertaken if required [25, 26]. As established from the pilot, the CAT-S can easily be

completed by staff and volunteers such as community-based stroke coordinators, thus making the assessment of stroke family caregivers' needs more accessible and structured. Since the CAT-S offers suggestions for further action, this can trigger appropriate referrals being made and result in family caregivers receiving timely support. It should be acknowledged that the provision of support services for family caregivers varies widely across the UK, even more so since the impact of the pandemic. However, the routine investigation of stroke family caregivers' needs will assist in providing evidence to inform policy and commissioning of services.

6. Strengths and Limitations

There were a low number of stroke family caregivers who participated in both rounds of the modified Delphi survey. It is possible that this may have influenced the final selected items. Having an expert panel with more family caregivers than staff, however, strengthens the study's findings. Additionally, the pilot study and subsequent evaluation phase had a small sample, and this may limit the ability to draw definite conclusions and global recommendations regarding the usability of the CAT-S in practice. Piloting of the CAT-S with a large number of stroke family caregivers was delayed due to the pandemic but is currently underway to establish its reliability and validity. Nonetheless, the wide geographical spread of participants in the Delphi survey enhances the generalisability of findings. Three frameworks were utilised during the development of the CAT-S to support and evaluate the quality and rigour of how the study was conducted and reported. These include the consolidated criteria for reporting qualitative research (COREQ) [66], guidance on conducting and reporting Delphi studies (CREDES) [67], and finally the questions regarding rigour in action research studies as proposed by Koch and Kralik [68].

7. Conclusion

Most stroke survivors rely on their family caregivers for support to continue living at home. Supporting stroke family caregivers is vital to prevent inappropriate hospital admission, institutionalisation, and distress for caregivers and stroke survivors. Shortfalls in existing approaches to identifying and supporting the needs of stroke family caregivers are apparent. The CAT-S is a short, easy-to-use, screening tool that has the potential to underpin person-centred care by enabling the identification and provision of vital support to all stroke family caregivers.

Data Availability

The anonymised data that support the findings of this study are available from the corresponding author upon reasonable request.

Disclosure

Some information contained in this manuscript was previously presented as a doctoral thesis of the main author at

Conflicts of Interest

The authors declared no potential conflicts of interest with respect to the research, authorship, and publication of this article.

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Supplementary Materials

Original CAT v1.1 (2014) CAT-S v3. (*Supplementary Materials*)

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