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**The long-term unmet needs of informal carers of stroke survivors at home: a systematic review of qualitative and quantitative studies**

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## **Abstract**

**Aim:** To synthesise research describing the long-term unmet needs of carers who are providing care to a stroke survivor at home who is at least three months post-discharge.

**Methods:** A systematic review with narrative synthesis of the English-language qualitative and quantitative studies identified from MEDLINE, CINAHL, PsycINFO, EMBASE, AMED, and Scopus was undertaken.

**Results:** Five quantitative studies, seven qualitative studies, and one mixed-method study were included in the review. Five themes of unmet needs were identified from the synthesis: (1) Obtaining adequate information, (2) Taking care of oneself, (3) Service accessibility, (4) Emotional and psychological, and (5) Relationship. Commonly reported needs across the 13 final studies included the need for support from health care and/or service providers, help with self-care, and help with coping and managing emotions. Variables associated with unmet needs included the severity of the stroke that the stroke survivor experienced and length of hospital stay.

**Conclusions:** Evidence from this review suggests that carers are experiencing a range of long-term unmet needs, particularly in education and training, coping and managing their own emotions, and accessing much-needed services. Recommendations to support carers at home include continuing engagement, assessment, and support from health care providers and services to meet the needs of carers throughout the stroke recovery process.

## **IMPLICATIONS FOR REHABILITATION**

- Carers of stroke survivors experience complex long-term unmet needs around managing the recovery process of the stroke survivor when they have been discharged from hospital and returned home.
- Evidence suggests that continuing engagement and support from health care providers and services may assist carers in meeting their unmet needs.
- Healthcare professionals should provide help in accessing training and services.
- Support is required to help carers cope and to manage their emotions.

Keywords: Carers, caregivers, stroke, needs, systematic review

## Introduction

Defined as “the spouse or partner, family members, friends or significant others who provide unpaid physical, practical or emotional support to someone after their stroke event”<sup>1</sup>, carers have an essential role in the recovery of stroke survivors from rehabilitation, to returning home and their eventual return to the community<sup>2 3</sup>. The term, “carer”, is used throughout this systematic review, although it is recognised that different countries may prefer other terminology. Seven studies included in the review use the term “caregiver”<sup>4-10</sup>, and six studies use the term, “carer”<sup>11-16</sup>, to interchangeably refer to family, friends and others who provide informal care for someone who has experienced a stroke. The experiences of providing care among stroke carers are diverse, with research providing evidence of positive and negative experiences associated with caregiving<sup>17-19</sup>. For example, positive aspects such as pride, strengthened relationships, progress in the care recipients’ recovery and feeling appreciated have emerged in studies exploring the caregiving experience<sup>17</sup>. However, research has also demonstrated that providing care to a stroke survivor can have a negative impact on the well-being of the carer, such as increased burden and strain<sup>20 21</sup>. Individual studies have reported that carers who are helping to manage the recovery process of stroke survivors at home may have unique long-term unmet needs, compared to carers who are within the rehabilitation and early discharge periods<sup>20 22-24</sup>. Identifying the unmet needs of carers of stroke survivors and the variables associated with unmet needs may provide information on where support deficiencies exist, and offer insight as to how services may improve to safeguard the health and well-being of carers.

The term, “needs”, describes issues and/or actions that are deemed necessary by carers to manage their own wellbeing, and to provide the best quality of care for the stroke survivor. Needs are considered to be “unmet” when supports and services to assist with the issue and/or actions are not received<sup>25-27</sup>. One example of an unmet need is the need to

adequately prepare carers to manage the physical health of survivors once they have been discharged from the hospital setting<sup>12</sup>. Identifying the self-reported unmet needs of carers of stroke survivors can provide insights into areas for health improvement from the carers' perspectives; however, there is limited research investigating the needs of carers at different points during the stroke survivors' recovery.

In previous research, Greenwood et al.<sup>20</sup> reported that one major limitation of research into the experiences and needs of carers of stroke survivors is that carers at different stages of caring are not distinguished as such, and are included in the same study simply as "carers". Therefore, it is difficult to identify needs of carers at specific time points in the caring process, and provide recommendations for appropriate support for carers at different stages of care. It is important to provide evidence of the changing and complex needs of carers of stroke survivors at varied and defined periods of providing care to provide insights into areas of support for carers during the entire caregiving trajectory.

Previous research provides some evidence of carers' needs during specific time points throughout the caregiving trajectory. A systematic review of the experiences, needs and preferences during the rehabilitation period has been conducted<sup>28</sup>, and has found unmet needs specific to this period, such as support for managing the transition home from hospital and navigating the culture and environment of the hospital setting. However, no reviews have specifically examined the long-term unmet needs of carers of stroke survivors who are providing care at home and beyond the early discharge period, and what needs may be specific to longer-term carers. For example, individual studies have found that increased dependence on the carer may limit opportunities for the carer to engage in self-care activities<sup>10</sup>. The period when the carer and stroke survivor have been home for several months is of particular interest, as this is when the needs of the carer are often difficult to anticipate and meet<sup>20 22-24</sup>. For example, after leaving the hospital setting, carers may

experience unanticipated adverse health-outcomes, such as increased physical and mental ill-health. Additionally, resources and health care providers that were available during the rehabilitation setting are much less accessible once the stroke survivor has returned home<sup>20 22-24</sup>. As a result carers may develop different adaptive and coping strategies to manage their own needs, in addition to the changing needs of stroke survivors.

Specifically investigating the unmet needs of carers of stroke survivors who provide care at home will provide rich insights into: (1) the experiences of carers regarding the services they desired/needed to receive to support their caregiving role when stroke survivors had returned home for at least three months; and (2) the variables associated with unmet needs. Synthesis of qualitative and quantitative studies that investigate and examine the long-term unmet needs of carers of stroke survivors, in particular, has not been conducted before. This review provides robust data and evidence to guide the development of interventions and services to support carers of stroke survivors by:

- (i) Developing analytical themes related to the long-term unmet needs of carers of stroke survivors at home from analysis of both quantitative and qualitative studies utilising a needs-led framework;
- (ii) Examining quantitative data to report the prevalence of long-term unmet needs of carers of stroke survivors providing care to stroke survivors at home;
- (iii) Thematically analysing qualitative data to report meaningful patterns and themes of long-term unmet needs of carers of stroke survivors who are providing care to stroke survivors at home;
- (iv) Defining the variables associated with long-term unmet needs of carers of stroke survivors at home.

## Method

### Study design

Guidelines for the reporting of systematic reviews (PRISMA)<sup>29</sup> were followed. A protocol for this review was registered with PROSPERO International Prospective Register of Systematic Reviews (Trial registration number: CRD42017067391). The methodology for this systematic review is described in detail in Denham et al.<sup>1</sup>

### Search strategy

A systematic search using Medical Literature Analysis and Retrieval System Online (MEDLINE), Cumulative Index of Nursing and Allied Health Literature (CINAHL), PsycINFO, EMBASE, Allied and Complementary Medicine Database (AMED), and Scopus was conducted for eligible studies until July 2019. Further information regarding the development of the search strategy and methodology of the database searches is described in Denham et al.<sup>1</sup> The search terms used in the MEDLINE database are available in Table 1.

**Table 1. MEDLINE Search Strategy**

No.	Search Strategy
1	(cva\$ or stroke\$ or poststroke\$ or post-stroke\$ or post stroke\$ or transient isch?emic attack\$ or TIA\$ or ministroke\$ or ministroke\$ or mini stroke\$).mp.
2	(cerebrovascular\$ or cerebral vascular).tw.
3	(cerebral or cerebellar or brain\$ or vertebrobasilar) adj5 (infarct\$ or isch?emi\$ or thrombo\$ or apoplexy or emboli\$).tw
4	(cerebral or intracerebral or intracranial or brain\$ or cerebellar or subarachnoid) adj5 (accident\$ or h?emorrhag\$).tw
5	1 or 2 or 3 or 4
6	Need.mp.
7	Needs.mp.
8	6 or 7
9	Support person.mp.
10	Wife.mp.
11	Wives.mp.
12	Husband*.mp.
13	Close relative*.mp.
14	Next of kin*.mp.
15	Significant other*.mp.
16	Relative*.mp.



No.	Search Strategy
17	Caregiver*.mp.
18	Carer*.mp.
19	Famil*.mp.
20	9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19
21	5 and 8 and 20
22	limit 21 to (English language and humans)

### **Inclusion and exclusion criteria**

The original inclusion and exclusion criteria for the database search, as outlined in Denham et al.<sup>1</sup>, are as follows:

- Manuscripts must be published in peer-reviewed journals and report primary data on the self-reported unmet needs of carers of stroke survivors.
- English language qualitative, quantitative and mixed-methods studies will be included.
- Intervention studies will be included if they report the baseline estimates of carers' unmet needs.
- The needs of carers reported by others (such as the stroke survivors or by health professionals) will be excluded.

In previous research, it has been reported that carers of stroke survivors have unique unmet needs around managing the recovery process of stroke survivors when they have been discharged from hospital and returned home<sup>20 22-24</sup>. As the needs of carers of stroke survivors in the rehabilitation period have been investigated previously<sup>28</sup>, this current review will focus on the long-term needs of carers of stroke survivors at home, with care being provided at least three months post-discharge. Consequently, additional inclusion and exclusion criteria from the original protocol were added to this systematic review.

In addition to the original inclusion criteria<sup>1</sup>, studies were included if their aims specifically reported primary data on the needs of carers of stroke survivors who were

providing care to stroke survivors living at home (not inpatients or those in institutional care) and were at least three months post-discharge.

In addition to the original exclusion criteria<sup>1</sup>, studies were excluded if: (1) the study exclusively investigated the needs of carers of stroke survivors who were less than three months post-discharge; and (2) the needs of carers of stroke survivors at home providing care to stroke survivors who were at least three months post-discharge could not be extracted separately from the needs of carers of stroke survivors at other stages of caring.

### **Data extraction**

As outlined in the protocol for the systematic review<sup>1</sup>, two reviewers independently assessed all abstracts (AMJD and a research assistant) and full text studies (AMJD and AT). Data from the included journal articles were extracted into summary tables independently by one reviewer (AMJD) and were checked for accuracy by a second reviewer (ML). Discrepancies were resolved via discussion and consensus.

### **Risk of bias in quantitative, qualitative and mixed-method studies**

Quality assessment adhered to the protocol for the systematic review and was independently performed by two reviewers (AMJD and ML)<sup>1</sup>. Qualitative studies were assessed using the 32-item Consolidated Criteria for Reporting Qualitative Research (COREQ)<sup>30</sup>. Quantitative studies were assessed using a six-item measure (score range 0–6) developed for a similar review<sup>20</sup>. Further information on how these measures were used to assess quality is detailed within the published protocol of this systematic review<sup>1</sup>.

### **Data synthesis**

Variations in study methodology and outcome measures precluded a meta-analysis, and thus a narrative synthesis was undertaken. Information such as the caregiving time point (providing care for a stroke survivor  $\geq 3$  months post-discharge at home), setting and study sample were reported. A summary of descriptive information for the included quantitative

studies can be found in Supplementary Table 1, and a summary of descriptive information for studies included in the qualitative synthesis can be found in Supplementary Table 2.

## Results

### Search results

After duplicates were removed, 9,288 records were identified from electronic searches, and two additional records were identified through manual searches of reference lists of identified articles. Of those, 297 were assessed for eligibility criteria (Figure 1). In the final analysis, 13 studies were included in the review: five quantitative studies<sup>4-7 11</sup> seven qualitative studies<sup>8-10 12-14 16</sup>, and one mixed-method study<sup>15</sup>. However, only qualitative primary data could be extracted from the mixed-method study<sup>15</sup> that met the inclusion criteria of the review. Thus, critical appraisal of the methodological quality of the study was only conducted on the qualitative strand of the study<sup>31</sup>.

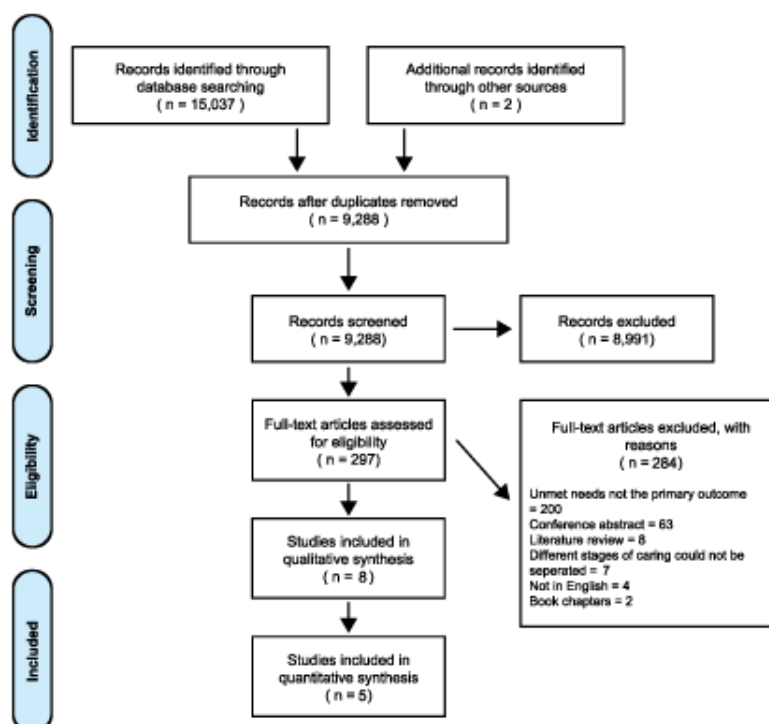


Figure 1. PRISMA Chart, database search results

### **Study characteristics**

The five quantitative studies were published between 2004<sup>11</sup> and 2014<sup>7</sup>, and reported sample sizes ranging from nine<sup>11</sup> to 276<sup>5 6</sup>. Four of the five quantitative studies reported more female than male participants<sup>4 5 7 11</sup>, and one quantitative study did not report the gender of the carers who participated in the study<sup>6</sup>. Two studies reported spouses as taking the majority of carer responsibility<sup>4 11</sup>, one study reported adult children (sons and daughters) as the carers<sup>7</sup>, and the remaining two studies did not report the relationship of the carer to the stroke survivor<sup>5 6</sup>. Where mean carer age was reported, it ranged between M=44.2 years (SD = 13.08)<sup>7</sup> and M=69.9 years, (SD=9.4)<sup>11</sup>. Three quantitative studies originated from the United States<sup>4-6</sup>, one was from Australia<sup>11</sup> and one from Taiwan<sup>7</sup>. Three quantitative studies reported the race and/or ethnicity of carers within the sample; these studies allowed carers to identify as White, African American, Latino, or Other. Carers were then further categorised depending on whether they resided on the United States Mainland or on the island of Puerto Rico<sup>4-6</sup>.

The seven qualitative studies and one mixed-method study included in the qualitative synthesis were published between 1998<sup>13 16</sup> and 2007<sup>10</sup>, and reported sample sizes ranging from seven<sup>12</sup> to 93<sup>15</sup>. Most studies included a majority of female participants; one study did not report the gender of the carers who participated<sup>16</sup>. All studies reported spouses/partners as the most prevalent relationship to the stroke survivor; one did not report the relationship of the carer to the stroke survivor<sup>16</sup>. Where reported, mean carer age ranged from M=56.7 years (SD =14.7)<sup>15</sup> to M=70 years (SD not reported)<sup>10</sup>. Mean carer age was not reported in four of the included studies<sup>12-14 16</sup>. Five of the studies in the qualitative synthesis originated from the United Kingdom<sup>12-16</sup>, one study was from Hong Kong<sup>9</sup>, one was from the United States<sup>10</sup>, and one was from Canada<sup>8</sup>. Two studies in the qualitative synthesis reported the race and/or ethnicity of the sample: one study included primarily white carers<sup>15</sup>, while another included only Chinese carers<sup>9</sup>.

### **Quality assessment of quantitative studies**

The results of the quality assessment of quantitative studies are presented in Supplementary Table 3. No study was rated as a six on the quality assessment measure developed by Greenwood et al.<sup>20</sup>: two studies received a moderate score of three<sup>4 11</sup> (n=2, 40%), and three studies achieved a high score of four or more<sup>5-7</sup> (n=3, 60%). Overall, the quality of the quantitative papers was high.

### **Quality assessment of qualitative studies**

The results of the quality assessment of qualitative and mixed-method studies are presented in Supplementary Table 4. Overall, the quality of studies was moderate, with studies meeting between 12<sup>15</sup> and 18<sup>8</sup> of the 32 items reported in the domains of the COREQ. The majority (n=7, 87.5%) of the studies included in the qualitative synthesis failed to meet any items in the first Domain of the COREQ, Researcher Team and Reflexivity<sup>8 9 12-16</sup>. All studies provided information on their study design in Domain 2 and analysis and findings in Domain 3 of the COREQ.

### **Synthesis of analytical themes**

The development of themes and categories was based on Pini et al's needs-led framework<sup>32</sup> for understanding how providing care impacts on carers' fulfilment of needs. Working within Pini et al's needs-led framework<sup>32</sup>, AMJD reviewed and coded the content from the original studies, including extracts of quotes, themes and categories, to identify patterns across the studies. Unmet needs items in quantitative studies were also coded and synthesised within these categories. The analysis and synthesis of qualitative and quantitative data resulted in the development of five themes (1) Obtaining adequate information; (2) Taking care of oneself; (3) Service accessibility; (4) Emotional and psychological; and (5) Relationship, which contained 12 categories. ML reviewed the content and coding of these themes and categories, and any discrepancies were resolved by discussion and agreement. After complete agreement had been reached, the qualitative themes and categories were

finalised, and the prevalence for each quantitative category was reported and calculated.

Table 2 shows the themes/categories, a definition of each, and a representative quote for each category from studies in the qualitative synthesis.

Qualitative data extraction is presented in Table 4. The need for coping and managing emotions emerged across all qualitative studies

**Table 2. Unmet needs themes, categories, definitions, and representative quotes**

No.	Theme/category	Definition	Representative studies/quote
1.0	<b>Obtaining adequate information</b>	Carers report unmet needs for preparation for the caregiving role at any time.	
1.1	The need for carer education and training	Carers describe the need for formal education and training as a much-needed service for preparing carers to take on the caregiving role. This may include but is not limited to: (1) information about the stroke itself; (2) secondary prevention of the stroke; (3) basic nursing training, and/or (4) personal hygiene training.	<i>“Then, only a couple of days ago, a nurse just happened to be there when my Mom was getting out of bed. So she showed me the easier way for my mother to get out of bed. And just yesterday, the easier way to get her out of the wheelchair... so I would have appreciated knowing all that, at the beginning. Like if somebody – because I spend a lot of time here – if somebody had taken the trouble to say, “Look, we can see that you’re helping your Mom. This is like the basic things that she’s doing on a regular basis during the day, this is how to do them.” I think it would have definitely benefited me and my Mother... because I would have been doing the things.” (C9)<sup>8</sup></i>
1.2	The need for support from health care and/or service providers	Carers express a lack of a supportive relationship with healthcare professionals. This includes but is not limited to: (1) poor or rude communication with the carer; (2) the carers feeling unsupported by staff; (3) deliberately ignoring carer concerns for the stroke survivors needs; and/or (4) deliberately ignoring carer concerns for their own needs.	<i>“I didn’t have the support I needed from staff; I was helpless, scared.”<sup>15</sup></i>
2.0	<b>Taking care of oneself</b>	Carer expresses difficulty in separating and managing their own needs from caregiving. This may include their mental and physical health, or a need for respite and time off from caregiving.	

**Table 2. Unmet needs themes, categories, definitions, and representative quotes**

No.	Theme/category	Definition	Representative studies/quote
2.1	The need to balance own needs with caregiving duties	Unmet needs that involve the impact of caregiving on lifestyle and schedule, may include impact on free-time, work, hobbies or seeing friends.	<i>Q: Were there some things that you felt you had to give up?</i> <i>A: Yes. Pleasures. My own pleasures. I gave up working with the volunteers in the Nearly New Shop. Then I used to go to a thing called Circle in the mornings, there would be lectures; I had to give that up. I used to be a member of the Luncheon Club, I gave that up. I have given everything up except what was important. But what was important; just going shopping really and seeing to his needs" (Margaret)<sup>13</sup></i>
2.2	The need for self-care	Carer describes their own diminishing mental and physical health as a result of providing care for the stroke survivor. This includes negative outcomes such as anxiety and depression, and also aspects such as being unable to exercise any more.	<i>"Wife: I lost an awful lot of sleep because of getting up and taking care of him during the night...I was so exhausted, I would just sit at the desk and cry, from my whole body was just exhausted...I didn't get a break...I was just exhausted."</i> <sup>10</sup>
2.3	The need for financial support and security	Carer describes lack of knowledge of information on where to get more financial support, such as through benefits. This also includes the impact of purchasing stroke care related services/products.	<i>"Everything was right except getting him upstairs and I said I wanted to see a social worker. They said, "Well what do you want to see a social worker for?" I said, "I want a chair lift for *** to go up and down stairs" and someone said, "Oh you'll get no help with that", so when they said he was coming home, I went and ordered one."</i> <sup>12</sup>
3.0	<b>Service accessibility</b>	Carers describe a lack of understanding regarding the health care services and/or government benefits that they can access as a carer of a stroke survivor at any time during the caregiving trajectory.	
3.1	The need for accessing appropriate services	Carers describe a lack of co-ordination of needed services for themselves or the stroke survivor, particularly from rehabilitation to the initial return home.	<i>"I think we should have been told sooner about what was available and what we could apply for... I would have thought on a disabled ward they'd have all these things off pat... they could do with a sort of small</i>



**Table 2. Unmet needs themes, categories, definitions, and representative quotes**

No.	Theme/category	Definition	Representative studies/quote
			<i>directory showing the numbers to ring and the numbers to get in contact with.” (Female, aged 68, wife of stroke patient, longer-term post-discharge group)<sup>16</sup></i>
3.2	The need for services to provide ongoing support	Carers describe the lack of co-ordination of physical and emotional care for themselves and/or stroke survivor. This may happen at any stage of care.	<i>[Carer L: female; husband] He’s no keen on going in anywhere [respite care]. What I would really like is for someone to come to the house to let me out for a few hours . . . that would make a big difference.<sup>14</sup></i>
4.0	<b>Emotional and psychological</b>	Unmet needs that involve the emotional and psychological aspects of providing care to the stroke survivor.	
4.1	The need for coping and to manage emotions	Carer expresses emotional distress (e.g. anger, guilt, sadness, anxiety, depression, exhaustion), and a need to seek support to manage their emotional distress.	<i>“[Carer E: male; wife] What you need is people like yourself where I can sit and talk about it. Where I can get it out of my system. It’s helpful to get it all out. I cannae talk to my son, he’s a worrier. But people like yourself, you can talk to a stranger better. You can put your feelings out. I don’t want to burden my son, he’s got his own problems.”<sup>14</sup></i>
4.2	The need for managing personality and/or emotional changes in the stroke survivor	Carer expresses lack of knowledge on how to provide emotional or psychological support for the stroke survivor. This includes but is not limited to: (1) communication/language issues post-stroke; (2) mood change post-stroke; and/or (3) personality changes post-stroke.	<i>They could have warned me about emotional things. It’s very frustrating when she can’t communicate. She was very weepy and thinking she was a burden to me and things like that. (Male, aged 73, husband of stroke patient)<sup>16</sup></i>
4.3	The need for certainty for the future	Carer expresses fear or uncertainty for the future of the stroke survivor, and/or fears about the stroke survivors’ condition worsening.	<i>“I’ll tell you the thing that frightens me most, I had a really bad tummy ache the other day and I thought, ‘what happens if I’ve got appendicitis, and I am rushed in, who will look after Terry’. That sort of</i>

**Table 2. Unmet needs themes, categories, definitions, and representative quotes**

No.	Theme/category	Definition	Representative studies/quote
5.0	<b>Relationship</b>	Unmet needs that involve the relationships changes involved with providing care to the stroke survivor.	<i>thing really is quite frightening, if you stop to think about it” (Sarah)<sup>13</sup></i>
5.1	The need for support to manage changes in the role and relationship with the stroke survivor	Carers express difficulty in coming to terms with the changes in the relationship with their partner who has suffered a stroke. This may include but is not limited to reminiscing on the life with the stroke survivor before the stroke event.	<i>Wife: All the responsibilities of everything. I mean all the decisions and I don’t know, it just seems like sometimes it is overwhelming because everything.... It seems like always something happens when you just think you’ve got something settled and something happens...And uh, he had a few accidents, and didn’t get to the bathroom in time and had problems getting up and down out of a chair.<sup>10</sup></i>
5.2	The need for social support from friends, family and the community	Carers express difficulty in communicating with family, friends and others about their caregiving experience. Carers may express a need to connect with other people outside of the caregiving role.	<i>[Carer Q; female; father] My family has suffered. There have been arguments and lots of stress. You are getting pulled in different directions. It can cause a lot of friction.</i>  <i>[Carer V: male; father] I mean I have a wife and a new baby, I feel guilty but I have to be there for my family as well.<sup>14</sup></i>

**Table 3. Data extraction of quantitative studies**

First Author (Year), Country	Obtaining adequate information		Taking care of oneself		Service accessibility	Emotional and psychological		Relationship	
	Education and training for carers	Support from health care and/or service providers	Self-care	Financial Stability	Accessing appropriate services	Coping and managing emotions	Managing personality and emotional changes in the stroke survivor	Changes in relationship with stroke survivor	Social support from friends, family and the community
Hinojosa (2007) <sup>6</sup> , USA	12-35/120 (10–29)			20/120 (17)			32/120 (27)	17/120 (14)	17/120 (14)
Hinojosa (2009) <sup>5</sup> , USA	48–137/276 (17–50)			97/276 (28)			99/276 (36)	64/276 (23)	76/276 (24)
Hinojosa (2012) <sup>6</sup> , USA	41–166/276 (15–60)			94– 138/276 (34–50)			69–144/276 (25–52)	47–72/276 (17–26)	50–80/276 (18–29)
Hoffmann (2004) <sup>11</sup> , AU	0–3/9 (0–33)			0/9 (0)	1/9 (11)		1/9 (11)	2/9 (22)	
Tsai (2014) <sup>7</sup> , Taiwan	6–56/60 (10–93)	45/60 (75)	36/60 (60)	7/60 (12)	5– 10/60 (8– 17)	13–18/60 (22-30)			36–43/60 (60–72)
Total n (%)	107–397/741 (14–54)	45/60 (75)	36/60 (60)	218– 262/741 (29–35)	6–11/69 (9–16)	13–18/60 (22-30)	201–276/681 (30–41)	130–155/681 (19–23)	179–216/732 (25–30)

**Note:** Many studies used multiple items which were interpreted to assess this need. “–” denotes the range of prevalence reported on the items which mapped on to this need

**Note:** Hinojosa et al. 2007<sup>4</sup>, 2009<sup>5</sup> and 2012<sup>6</sup> used the same unmet needs measure developed by the authors for investigating Caregiver Health Information Needs across studies

**Note:** Hoffmann et al. 2004<sup>11</sup> used a unique unmet needs surveys compared to other studies to assess unmet needs; Tsai et al. 2014<sup>7</sup> used a modified version of the Family Needs Questionnaire (FNQ)<sup>38</sup>

**Table 4. Data extraction of qualitative and mixed-method studies**

<b>First Author (Year), Country</b>	<b>Obtain adequate information</b>		<b>Take care oneself</b>			<b>Service accessibility</b>		<b>Emotional and psychological</b>			<b>Relationship</b>	
	<b>Education and training for carers</b>	<b>Support from health care and/or service providers</b>	<b>Balance own needs with caregiving duties</b>	<b>Self-care</b>	<b>Financial support and security</b>	<b>Accessing appropriate services</b>	<b>Services to provide ongoing support</b>	<b>Coping and managing emotions</b>	<b>Managing personality/emotional changes in the stroke survivor</b>	<b>Certainty for the future</b>	<b>Support to manage the changes in role and relationship with stroke survivor</b>	<b>Social support from friends, family and the community</b>
Brereton (2000) <sup>12</sup> , UK	✓	✓	✓	✓	✓	✓	✓	✓				
Cameron (2013) <sup>8</sup> , CAN	✓	✓				✓	✓	✓				✓
Denman (1998) <sup>13</sup> , UK	✓	✓	✓		✓	✓	✓	✓		✓	✓	✓
Kerr (2001) <sup>14</sup> , UK		✓	✓	✓	✓	✓	✓	✓		✓		✓
King (2006) <sup>15</sup> , UK	✓		✓	✓	✓			✓	✓		✓	
Lee (2004) <sup>9</sup> , HK	✓		✓	✓				✓			✓	✓
Lutz (2007) <sup>10</sup> , USA		✓	✓	✓		✓	✓	✓			✓	✓
Wiles (1998) <sup>16</sup> , UK	✓	✓				✓		✓	✓	✓		

## ***Theme 1: Obtaining adequate information***

*1.1 The need for education and training for carers.* The need for education and training for carers was examined in all included quantitative studies<sup>4-7 11</sup>, with the prevalence of unmet needs in education and training for carers varying across studies (N across studies=107–397, 14–54%). Education and training for carers was one of the most reported unmet needs across studies in the qualitative synthesis, and appeared in six studies<sup>8 9 12 13 15 16</sup>. Carers needed education, information and training across a variety of topics, including general information about the stroke itself, particularly short-term and long-term outcomes of the stroke event such as aphasia<sup>12 13 16</sup>, the practical and emotional aspects of caring for a stroke survivor at home<sup>8 9 16</sup>, and the need to be educated on the signs and symptoms in order to prevent future stroke events<sup>16</sup>. This information is needed to gain understanding of the management of symptoms and complications that the stroke survivor experiences as a result of the stroke event<sup>16</sup>, to enhance the stroke survivor's function and to have opportunities to provide rehabilitation at home<sup>15 16</sup>.

*1.2. The need for support from health care and/or service providers.* The need for support from health care and/or service providers was only examined in one quantitative study (n=45, 75%)<sup>7</sup>. Six studies in the qualitative synthesis<sup>8 10 12-14 16</sup> explored the need for support from health care and/or service providers. The vast majority of carers discussed the need to receive support from different types of health care professionals<sup>8</sup>, more open communication with medical staff<sup>8 10 13 14 16</sup> and the appropriate type and intensity of support through the caregiving trajectory<sup>8 12 14 16</sup>.

## ***Theme 2: Taking care of oneself***

*2.1. The need to balance own needs with caregiving duties.* The need for the caregiver to balance their own needs with caregiving duties was identified in six studies in the qualitative synthesis<sup>9 10 12-15</sup>. Carers discussed the need to have capacity to engage with their usual

recreational activities and hobbies<sup>9 13-15</sup>, and their need for the capacity/ability to work<sup>9 10 12 15</sup>.

As providing care had put restrictions on meeting these needs, carers indicated that trusted options for respite could help them address this need<sup>10 13 14</sup>.

*2.2. The need for self-care.* The need for self-care was reported in one quantitative study (n=36, 60%)<sup>7</sup>, and in five of the studies in the qualitative synthesis<sup>9 10 12 14 15</sup>. Across studies, carers usually expressed difficulty in separating and managing their own needs in addition to those of the persons that they cared for<sup>10 12 14</sup>. Poor management of their pre-existing conditions and current physical and mental health was commonly discussed by carers<sup>9 10 12</sup>, and carers also described a decline in their mental and physical health as a result of providing care<sup>9 10 12 14</sup>. Common indicators of unmet needs for self-care included a lack of energy<sup>9 10 14</sup>, sleeping difficulties<sup>10</sup>, and continually enduring mentally frustrating experiences<sup>10 14</sup>. Again, respite was proposed as an option to help meet the last need<sup>10 12 14</sup>.

*2.3. The need for financial support and security.* The need for financial support and security was reported across all five quantitative studies (N across studies=218–262, 29–35%)<sup>4-7 11</sup>. The need for financial stability also emerged in four studies in the qualitative synthesis<sup>12-15</sup>. These costs were related to needed equipment or support to provide the required/necessary care to the stroke survivors, such as aids to deal with incontinence<sup>12</sup>. Unmet financial needs were exacerbated by the lack of formal referral and assessment for carers to receive the financial support from benefits that they were entitled to<sup>12-14</sup>.

### ***Theme 3: Service accessibility***

*3.1 The need for accessing appropriate services.* The need for accessing appropriate services was assessed in two quantitative studies (N across studies=6–11, 9–16%)<sup>7 11</sup>, and also emerged in six studies in the qualitative synthesis<sup>8 10 12-14 16</sup>. Carers reported the need to understand and identify the services and resources that existed, and if they were eligible for

such services<sup>8 10 12 14</sup>. Carers discussed the need for increased awareness and knowledge on how to access services, resources and support provided by the community or government<sup>10 13</sup>. Some carers described receiving assistance with accessing and co-ordinating health services; however, most carers received inadequate support to access support services<sup>8 12-14</sup>. Examples of these services include professional psychological/emotional support<sup>8 13 14</sup> and physical support care for the stroke survivor<sup>12</sup>. In an attempt to meet these needs, carers often sought information on services from “word of mouth”, such as through friends, family, and support groups<sup>12 14</sup>.

*3.2 The need for services to provide ongoing support.* The need for services to provide ongoing support emerged in five studies in the qualitative synthesis<sup>8 10 12-14</sup>. Across studies, carers expressed feeling on their own when they returned home with the stroke survivors, and needed to know who to contact when their situations changed throughout the stroke caregiving trajectory<sup>8 10 12 14</sup>. Carers described how the needs of a carer and a stroke survivor change over time, and the dynamic nature of the needs often led to confusion about the most appropriate services and where to find relevant information<sup>8 13</sup>. Examples of ongoing services that carers needed included transitioning services<sup>10</sup> and respite services<sup>10 12 14</sup>.

#### ***Theme 4: Emotional and psychological***

*4.1 The need for coping and managing emotions.* The need for coping and managing emotions was assessed in one quantitative study (n=13–18, 22-30%)<sup>7</sup>. The need for coping and managing emotions was explored in all eight studies in the qualitative synthesis<sup>8-10 12-16</sup>. Carers described how they needed support, as they struggled to cope and manage a range of emotions, with recurring negative emotions such as worry, stress and/or anxiety<sup>8 10 14</sup>, anger, frustration<sup>14</sup>, and feeling overwhelmed<sup>9 10 12-16</sup>. The carers’ awareness of their knowledge gap in caring<sup>12 16</sup> and lack of readiness to care<sup>12 16</sup> were identified across studies as contributing to carer emotional distress.

#### *4.2 The need for managing personality and/or emotional changes in the stroke survivor.*

Managing personality and/or emotional changes in the stroke survivor was assessed in four quantitative studies (N across studies=201–276, 30–41%)<sup>4-6 11</sup>, and this need also emerged in two studies in the qualitative synthesis<sup>15 16</sup>. Carers discussed needing support to provide emotional support and manage cognitive and behavioural changes in the stroke survivors<sup>15 16</sup>. In particular, carers needed support in managing the often out-of-character and unpredictable strong negative emotions that the stroke survivors presented (such as mood swings, anger, frustration and depression)<sup>16</sup>.

*4.3 The need for certainty for the future.* The need for certainty for the future was an unmet needs category that was explored in three studies in the qualitative synthesis<sup>13 14 16</sup>. Many carers reported they continually had to adjust to new expectations around the future for themselves and the stroke survivors and that this caused uncertainty. Carers felt the need to address and resolve uncertainty in changing situations such as during the decision-making making process for any further stroke-related needs, for example in the event of a recurrent stroke<sup>16</sup>, and identifying who would provide care for the stroke survivors if their own health was to decline<sup>13 14</sup>.

### ***Theme 5: Relationship***

#### *5.1 The need for support to manage changes in the role and relationship with the stroke survivor.*

The need for support to manage changes in the role and relationship with the stroke survivor was assessed in four quantitative studies (N across studies=130–155, 19–23%)<sup>4-6 11</sup>, and emerged in four studies in the qualitative synthesis<sup>9 10 13 15</sup>. Carers often expressed a need for support in their new roles and duties as they struggled taking on the roles/responsibilities that the stroke survivor primarily used to do, such as managing household chores or finances, in addition to adapting to new caregiving responsibilities<sup>9 10 13 15</sup>. The relationship between



the carer and stroke survivor was often significantly impacted by stroke-related outcomes, including aphasia<sup>13</sup> and communication difficulties<sup>9</sup>.

*5.2 The need for social support from friends, family and the community.* The need for social support from friends, family and the community was measured in four quantitative studies (N across studies=179–216, 25–30%)<sup>4-7</sup>, and was further explored in five studies in the qualitative synthesis<sup>8-10 13 14</sup>. Most carers expressed unmet needs for social relationships and support, including imposed social restrictions<sup>9 10 13</sup> as a result of providing care. This often resulted in changes in relationships with friends, family and the community<sup>8 9 14</sup> and feelings of abandonment and/or isolation<sup>14</sup>. Most carers needed and recognised their desire for more support from friends, family and the community<sup>8 13 14</sup>.

### **Defining the variables associated with unmet needs of carers of stroke survivors**

Three quantitative studies<sup>4 6 7</sup> examined variables that were significantly associated with unmet needs. The factors most related to unmet needs were associated with the stroke survivor, such as: (1) burden/number of Activities of Daily Living (ADL) that the carer assists with<sup>6</sup>; (2) physical dependency of the stroke survivor (measured by the Barthel Index)<sup>7</sup>; (3) severity of stroke at admission<sup>7</sup>; and (4) length of stay during the hospitalisation period<sup>7</sup>. Psychosocial factors associated with unmet needs included the carers' reported positive aspects of caregiving<sup>6</sup>, caregiver depression<sup>6</sup>, and caregiving coping scores<sup>6</sup>. The demographic variable associated with increased unmet needs was ethnicity; both studies indicated that Puerto Rican carers were more likely to report unmet information needs than carers who resided in the United States Mainland<sup>4 6</sup>.

### **Discussion**

This is the first study to specifically focus on the unmet needs of carers of stroke survivors living at home beyond the early discharge period. The findings from this systematic review demonstrate that carers of stroke survivors experience a range of unmet needs, including that

of obtaining adequate information, taking care of their mental and physical health, accessing appropriate services, supporting and managing emotional and psychological needs, and meeting relationship needs such as role changes with the stroke survivors and support from friends, family and the community. The evidence suggests that carers of stroke survivors need support in skill-building, not only in preparation for the caregiver role, but also to meet new problems as they evolve. Health care providers and services who aim to support carers of stroke survivors need to increase their awareness of how information is delivered and presented, in addition to the appropriate timing of the support to best assist carers.

Four of the five quantitative studies included in the systematic review exclusively measured information needs<sup>4-6 11</sup>, suggesting that there is scope for further quantitative exploration on a broad range of unmet needs experienced by carers of stroke survivors in the longer term. These findings suggest that it may also be difficult to quantitatively explore and quantify unmet needs which are better explored in studies using qualitative methods, such as the need for certainty in the future. Future research should utilise both forms of qualitative and quantitative measurement to capture the richness of the longer-term unmet needs of carers of stroke survivors, as some themes are missed if only quantitative data are collected.

Improving initial and ongoing support, resources and services for carers of stroke survivors at home has the potential to mitigate several identified long-term unmet needs. The themes of Obtaining adequate information, Service accessibility, and the Emotional and psychological themes were connected. Furthermore, these prevalent needs, particularly emotional and psychological support and appropriate information, were consistent with literature on the needs and experiences of carers within the rehabilitation period<sup>28</sup>. Carers often turned to health care providers prior to their return home as providers of knowledge to provide emotional and physical support for the stroke survivors at home. Additionally, evidence from the rehabilitation period indicates that how prepared carers felt to take on the

caring role were primarily influenced by available information, support from family and clinicians, and access to services/resources to support the transition home<sup>28</sup>. When carers of stroke survivors returned home, their needs were much more difficult to anticipate, and ongoing and open communication and support between carers and health care providers may help to meet these often unpredictable and complex needs. Health care providers and services should aim to provide initial support, followed by continuing engagement, information and resource provision, and needs assessment to the carer and stroke survivor when they return home.

Unmet needs within the themes of Taking care of oneself and Relationship were often intertwined. Many carers expressed feeling isolated and alone due to the deterioration in and/or lack of quality of their social relationships and support following their care recipients' return home. Carers described how their relationships with friends and family, and community support were impacted post-stroke. Our findings were consistent with previous research that identified that friends of the carer and stroke survivor may avoid contact because stroke survivors have problems communicating, mood changes, or a reduced interest in socialising<sup>33 34</sup>. A previous systematic review of the quantitative studies on the factors influencing carers of stroke survivors raised the issue that there is limited investigation in quantitative research around negative life events such as role change, lifestyle change, and financial stability, factors which have been identified through previous research as influencing carers of stroke survivors<sup>20</sup>. We similarly found these results: lifestyle changes such as the need to balance own needs with caregiving duties and the need for certainty for the future were not investigated in any quantitative studies; however, all of these unmet needs commonly arose in qualitative studies. It is apparent that carers of stroke survivors who have returned home need support in developing and utilising networks and self-care strategies in

order to maintain the caregiver role longer term without suffering a decline in mental and/or physical health.

As only three quantitative studies assessed the factors associated with unmet needs of carers of stroke survivors at this stage of care, it is difficult to draw conclusions about the sociodemographic, socioeconomic and cultural factors which may influence unmet needs. Stroke survivor factors gave the greatest indication of which carers may be at risk of experiencing unmet needs. Carers of stroke survivors who have experienced a more severe stroke event (determined by NIHSS scores), have higher physical needs, and require more ADL support may need increased information provision and further support. Individual factors such as ethnicity, and psychosocial factors such as carer depression, could also be taken into consideration by health care providers when assessing if a carer may be more at risk of experiencing long-term unmet needs.

Given the findings of ongoing social isolation and information needs, recommendations for the development of future services and interventions are to provide carers with a platform to connect with health care providers, other carers, family, friends and peers once the carers and stroke survivors have returned home. The ability to connect with others for particular purposes may assist carer physical and mental health and well-being, and increase support networks. This support may provide opportunities for easily accessible pragmatic care, such as respite or care in a group setting with relaxed social restrictions, that may allow carers to manage their mental and physical health. An online platform may be a way to address these needs; previous research has identified that online resources may also be helpful for information and support for carers of stroke survivors<sup>35</sup>. To implement a strategy using online resources, it is imperative that health care providers are aware of and up to date on current online resources available for carers of stroke survivors to meet the needs of the carers. Lutz et al.<sup>35</sup> suggested that health care providers could facilitate skill-building for

online searches for carers of stroke survivors, providing that they have access to and a willingness to use the internet.

### **Strengths and limitations**

A strength of this systematic review is that it is the first review to investigate the long-term unmet needs of carers of stroke survivors who are providing care to stroke survivors who are at least three months post-discharge at home. Quantitative and qualitative data on these needs were analysed in a systematic method, which facilitates reliable conclusions and recommendations based on the evidence provided in this review. However, systematic reviews are limited by the quality of the included studies. Three of the five quantitative studies<sup>4,6</sup> were produced by the same lead author, which may lead to bias in these studies. Furthermore, seven of eight studies in the qualitative synthesis did not meet any criteria in the Reflexivity domain of the COREQ<sup>30</sup>. Therefore, these included studies may be subjected to ethical issues and personal biases during the collection and analysis of the research presented. It is also possible that relevant non-English studies were not included in this review. Therefore, these findings may not be generalisable to non-English-speaking populations, in which there may be differing cultural unmet needs of carers of stroke survivors.

A further consideration is how unmet needs are defined across studies; therefore, measures which use an operationalised definition of needs, which can adequately capture the caregiver experiences, are needed. Studies included in this review specifically included the word, “needs”, in the objective of the included manuscripts. This means that some studies which use other language/terminology such as “difficulties,” “concerns”, “problems” and “issues” to potentially describe the same concept as needs were excluded. As a result, the reported prevalence of unmet needs may be underestimated. As ‘Needs’ (compared to terms such as “difficulties” and “problems”) may imply a construct with more direct and explicit implications for health services delivery, there is a requirement to refine the definition of

needs across studies and needs instruments, rather than viewing these terms as interchangeable with one another.

### **Recommendations for future research**

There is a need for measurement of unmet needs over time, and for further exploration of the factors associated with unmet needs. There were no quantitative longitudinal studies that examined longer-term needs of carers of stroke survivors. Hoffman et al.<sup>11</sup> compared the hospitalisation period and the six-month follow-up, and Tsai et al.<sup>7</sup> compared needs at three times during the hospitalisation period, and once three-months post-discharge. No included studies in the qualitative synthesis conducted follow-up interviews with carers in the longer-term, though their experiences during the rehabilitation period were often described. This suggests that the unmet needs of carers of stroke survivors over time and beyond the rehabilitation period still require exploration, and mixed-methods research should be utilised to capture the richness of the longer term unmet needs of carers of stroke survivors over time. As only three quantitative studies assessed the factors associated with unmet needs of carers of stroke survivors at this stage of care, it is difficult to draw conclusions about the factors which may influence unmet needs. Further research is needed to assess the prevalence of these unmet needs over time in carers of stroke survivors and the factors associated with these unmet needs, so that services and interventions may be developed to address these needs at an appropriate time.

The last study included in the review was published in 2015<sup>7</sup>. There are several possible reasons for this. Firstly, there is evidence that recruiting carers for research is challenging, as informal carers are particularly time poor due to juggling many duties and tasks alongside their caregiving responsibilities<sup>36-38</sup>. An individual study has found that while there are benefits for carers of stroke survivors to be involved in research, there were also many negatives, including painful emotions being drawn out in interviews, the time-

consuming nature of research involving, and the relationship strain between the stroke survivor and the carer, as the stroke survivor would wonder if the carer was talking about them during interviews<sup>38</sup>. Specific to longitudinal studies, carers also identified that the relationship with the researcher is difficult to end<sup>38</sup>. These findings suggest that further research is needed to develop strategies and protocols to increase the engagement of carers of stroke survivors in long-term and longitudinal research, so that further perspectives, insights and evidence may be provided to support the development of appropriate services and support.

Additionally, further research needs to be conducted into the unmet needs of carers of stroke survivors in other countries, as their unmet needs may be influenced by the country of origin and access to support and services within their health care systems. Studies included in this review were primarily from the United Kingdom and United States; thus, some experiences of English-speaking caregivers were not able to be explored. For example, no qualitative evidence met the inclusion criteria of this review to investigate the longer-term unmet needs of carers of stroke survivors who reside in Australia, and no quantitative evidence of the longer-term unmet needs of carers who reside in Canada or the United Kingdom were explored. Furthermore, identification of carer race and/or ethnicity was limited in the included studies, as only five studies identified this characteristic within their sample. This suggests that further research is needed to assess the unmet needs of carers of stroke survivors across countries and within racial/ethnic groups to identify possible common and unique unmet needs, and provide recommendations on how these needs could be addressed.

## **Conclusions**

This systematic review synthesises the evidence of the long-term unmet needs of carers of stroke survivors at home to provide new insights into the development of services and

interventions to support carers of stroke survivors. The evidence suggests that carers of stroke survivors experience a range of unmet needs, and that several of these needs could be met through intervention by health care providers and services. Raising awareness so that carers of stroke survivors may access much-needed services such as respite care is a further recommendation of this review. There is much scope for developing support services and interventions in this area. Mixed-methods and longitudinal studies should be conducted to further identify and explore the unmet needs of carers of stroke survivors, to develop services and interventions which can provide continuing support carers over time.

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**Supplementary Table 1. Systematic review of the unmet needs of carers of stroke survivors – quantitative summary table**

First Author (Year), Country	Study Aims	Caregiving time point; and Setting	Carer Sample Information	Type of survey; response rate	Outcome measure Unmet needs domains; (number of items in each domain)	Unmet needs domain, items (prevalence)	Analysis and statistically related factors to unmet needs (test statistic)
Hinojosa (2007), USA	Explore the information resources and needs of stroke caregivers both in Puerto Rico and the Mainland United States	All carers were recruited in the previous three financial years, and eligibility criteria included that the stroke survivor must live in the community*; Caregiver identified by stroke survivor contacted through Veteran Integrated Service Network  <i>*This study is part of a larger study conducted in Hinojosa (2009) and Hinojosa (2012); on average, carers were providing care for between two and four years to</i>	Overall 120; Mainland group (n = 78) Puerto Rico group (n=42)  Female: Overall (n=111, 92.5%); Mainland group (n= 70, 89.7%) Puerto Rican group (n=41, 97.6%)  Age: Overall 61.6 years old (SD = 11.6); Mainland group (M = 61.2, SD = 11.0) Puerto Rican group (M=62.4, SD = 12.7)  Overall caregiver group: Spouse/Partner (n=88, 73.3%); Child (n=8, 6.7%); Parent (n=5, 4.2%); Sibling (n=3, 2.5%);	Telephone survey; the response rate of Mainland caregivers was 78%, the response rate of Puerto Rican caregivers was 85.7%; the overall response rate was 81.9%	Measure developed for this study based on and literature review (unnamed); focuses on Caregiver Information Needs  Two domains; 13 items  Clinical Aspects of Stroke Caregiving; eight items  Social Aspects of Stroke Caregiving; five items	<b>Clinical Aspects of Stroke Caregiving 9.5% - 28.9%</b> Stroke, Risk of Second Stroke (14.6%) (Table 3); average frequency of unmet needs between the two groups is 51.55% (Table 4) Mainland Group (50.7%) Puerto Rican Group (52.4%)  Help with Communication (11.8%); average frequency of unmet needs between the two groups is 19.4% (Table 4) Mainland Group (16.7%) Puerto Rican Group (22%)  Managing Behaviour (falling etc) (28.9%); average frequency of unmet needs between the two groups is 42.2% (Table 4) Mainland Group (23.4%) Puerto Rican Group (61%)  Managing Privacy Issues (9.5%); average	A chi-square analysis showed that ethnicity was statistically correlated with the two items Managing Behaviour (falling etc) (p<.001) and Safety at Home (p<.001)

First Author (Year), Country	Study Aims	Caregiving time point; and Setting	Carer Sample Information	Type of survey; response rate	Outcome measure Unmet needs domains; (number of items in each domain)	Unmet needs domain, items (prevalence)	Analysis and statistically related factors to unmet needs (test statistic)
		<i>a stroke survivor at home</i>	Other Family (n=1, .8%); Other (n=15; 12.5%); Mainland group Spouse/partner (n=54, 69.2%); Child (n=5, 6.4%); Parent (n=1, 1.3%); Sibling (n=2, 2.6%); Other Family Member (n=1, 1.3%) Other (n=15, 19.2%); Puerto Rican group Spouse/partner (n=34, 81%) Child (n=3, 7.1%) Parent (n=4, 9.5%) Sibling (n=1, 2.4%)  Education: High School Graduate Overall (n=83, 69%) Mainland group high school graduate (n=63, 81.3%) Puerto Rican high school graduate (n=20, 47%)  Hours per week spent caregiving:			frequency of unmet needs between the two groups is 15.7% (Table 4) Mainland Group (14.3%) Puerto Rican Group (17.1%)  Moving or Lifting (9.6%); average frequency of unmet needs between the two groups is 15.2% (Table 4) Mainland Group (16.0%) Puerto Rican Group (14.3%)  Functional Changes (9.6%); average frequency of unmet needs between the two groups is 62.8% (Table 4) Mainland Group (28.6%) Puerto Rican Group (34.2%)  Prescriptions/Medications (12%); average frequency of unmet needs between the two groups is 42.1% (Table 4) Mainland Group (39.0%) Puerto Rican Group (45.2%)	

First Author (Year), Country	Study Aims	Caregiving time point; and Setting	Carer Sample Information	Type of survey; response rate	Outcome measure Unmet needs domains; (number of items in each domain)	Unmet needs domain, items (prevalence)	Analysis and statistically related factors to unmet needs (test statistic)
			Overall (M=35.8, SD=41.4); Mainland group (M=25.2, SD = 19.5); Puerto Rican group (M=54.8, SD=60.0)			Safety at Home (23.6%); average frequency of unmet needs between the two groups is 39.5% (Table 4) Mainland Group (19.5%) Puerto Rican Group (59.5%)	
			Income not reported			<b>Social Aspects of Stroke Caregiving 13.9% - 26.7%</b> Protecting Veteran (21.9%) average frequency of unmet needs between the two groups is 28.9% (Table 4) Mainland Group (22.1%) Puerto Rican Group (35.7%)	
						Managing Emotional Ups and Downs (26.7%); average frequency of unmet needs between the two groups is 37.8% (Table 4) Mainland Group (31.67%) Puerto Rican Group (43.9%)	
						Getting Financial Help (16.7%) average frequency of unmet needs between the two groups is 30.5% (Table 4)	

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						Mainland Group (29.9%) Puerto Rican Group (31.0%)  Changes in Relationship with Veteran (13.9%); average frequency of unmet needs between the two groups is 43.2% (Table 4) Mainland Group (23.7%) Puerto Rican Group (19.5%) Changes in Veteran Relationship with Family (13.9%); average frequency of unmet needs between the two groups is 7.6% (Table 4) Mainland Group (10.3%) Puerto Rican Group (4.8%)	
Hinojosa (2009), USA	To examine the association between health education needs and physical injury sustained as a result of activities related to the caregiving role, in orde to assist in the recovery process at home	Caregivers had spent an average of 2.74 years providing care; Caregiver identified by stroke survivor contacted through Veteran Integrated Service Network	n = 276  Female: n=251, 90.9%  Age: M=65.5, SD=10.51  Education: Completed high school n=188, 68.1%	Structured interview; response rate not reported	Measure developed for this study based on and literature review (unnamed); focuses on Caregiver Information Needs	<b>Physical Aspects of Stroke Caregiving</b> Managing Behaviour (falling etc) Total (38.6%) Caregiver Injury Group (53.8%) No Caregiver Injury Group (34%)  Safety at Home Total (34.8%) Caregiver Injury Group (49.2%) No Caregiver Injury Group (30.4%)	The study investigated the impact of needs on caregiver injury rather than caregiver characteristics associated with increased unmet needs, therefore prevalence is only reported

First Author (Year), Country	Study Aims	Caregiving time point; and Setting	Carer Sample Information	Type of survey; response rate	Outcome measure Unmet needs domains; (number of items in each domain)	Unmet needs domain, items (prevalence)	Analysis and statistically related factors to unmet needs (test statistic)
			Average time spent caregiving in years (M=2.74, SD=2.07)		Two domains; 13 items	Managing Privacy Issues Total (17.2%) Caregiver Injury Group (19.7%) No Caregiver Injury Group (16.4%)	
			Caregivers identified themselves as White, African American, Latino, or Other (mainly Asian American or Native American), and were further categorised if they lived on the U.S. Mainland or on the island of Puerto Rico. (count not provided)		Clinical Aspects of Stroke Caregiving; eight items	Moving or lifting Total (19.6%) Caregiver Injury Group (30.8%) No Caregiver Injury Group (16.2%)	
			Carer group and income not reported		Social Aspects of Stroke Caregiving; five items	Functional Changes Total (31.6%) Caregiver Injury Group (57.8%) No Caregiver Injury Group (23.5%)	
						<b>Social Aspects of Stroke Caregiving</b> Help with Communication Total (22.3%) Caregiver Injury Group (33.3%) No Caregiver Injury Group (18.9%)	
						Protecting Veteran Total (27.6%) Caregiver Injury Group (47%)	

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						No Caregiver Injury Group (21.6%) Managing Emotional Ups and Downs Total (36%) Caregiver Injury Group (53.8%) No Caregiver Injury Group (30.6%)	
						Getting Financial Help Total (23.1%) Caregiver Injury Group (39.1%) No Caregiver Injury Group (18%)	
						Changes in Relationship with Veteran Total (23.1%) Caregiver Injury Group (39.1%) No Caregiver Injury Group (18%)	
						Changes in Veteran Relationship with Family Total (23.9%) Caregiver Injury Group (43.1%) No Caregiver Injury Group (17.9%)	
						Stroke, Risk of Second Stroke	



First Author (Year), Country	Study Aims	Caregiving time point; and Setting	Carer Sample Information	Type of survey; response rate	Outcome measure Unmet needs domains; (number of items in each domain)	Unmet needs domain, items (prevalence)	Analysis and statistically related factors to unmet needs (test statistic)
						Total (49.8%) Caregiver Injury Group (71.9%) No Caregiver Injury Group (43.3%)  Prescriptions/Medications Total (46.7%) Caregiver Injury Group (68.8%) No Caregiver Injury Group (40.1%)	
Hinojosa (2012), USA	Primary aim is to identify the educational and information needs of stroke caregivers with regard to managing the stroke recovery process at home	Caregivers had spent an average of two – four years providing care; Caregiver identified by stroke survivor contacted through Veteran Integrated Service Network	n = 276  Age: Puerto Rico group M=61 years, (SD = 12.94) Mainland (White) group M=61.86 years, (SD = 12); Mainland (Black) group M=55.63 years, (SD = 13.50) Mainland (Other) group M=66 years, (SD=11.76)  Completed high school Puerto Rico group (n=37, 50%) Mainland (White)	Structured interview; 71% response rate	Measure developed for this study based on and literature review (unnamed); focuses on Caregiver Health Information Needs  Two domains; 13 items  Clinical Aspects of Stroke	<b>Clinical Aspects of Stroke Caregiving 15% - 59.2%</b> Stroke, Risk of Second Stroke Puerto Rican Group (54.2%) Mainland (White) Group (43.9%) Mainland (Black) Group (32.5%) Mainland (Other) Group (53.9%)  Help with Communication Puerto Rican Group (29.6%) Mainland (White) Group (21%) Mainland (Black) Group (15%) Mainland (Other) Group (23.1%)  Managing Behaviour (Falling Etc)	A one-way ANOVA showed that Ethnicity across all groups was correlated to the items “Managing Behaviour (Falling Etc)” (p<.001) and “Moving or Lifting” (p<.001)  A Poisson regression analysis showed that the following factors were related to health information needs: (1) Ethnicity (Puerto Rico group) (p <.05); (2) Desire to institutionalize (p<.01); (3) Positive aspects of caregiving

First Author (Year), Country	Study Aims	Caregiving time point; and Setting	Carer Sample Information	Type of survey; response rate	Outcome measure Unmet needs domains; (number of items in each domain)	Unmet needs domain, items (prevalence)	Analysis and statistically related factors to unmet needs (test statistic)
			group (n=62, 43%); Mainland (Black) group (n=17, 41%); Mainland (Other) group (n=6, 48%)		Caregiving; eight items	Puerto Rican Group (56.3%) Mainland (White) Group (36.6%) Mainland (Black) Group (12.8%) Mainland (Other) Group (38.5%)	(p<.05); (4) Caregiver depression (p<.01); Caregiver coping (p<.01); and (5) ADL burden/number of ADLS (p<.01)
			Average time spent caregiving in years Puerto Rico group (M=2.44, SD=1.72); Mainland (White) group (M=2.89, SD=1.65) Mainland (Black) group (M=2.35, SD=1.38) Mainland (Other) group (M=4, SD=1.83)		Social Aspects of Stroke Caregiving; five items	Managing Privacy Issues Puerto Rican Group (17.8%) Mainland (White) Group (16.2%) Mainland (Black) Group (22.5) Mainland (Other) Group (15.4%)  Moving or Lifting Puerto Rican Group (15.3%) Mainland (White) Group (21%) Mainland (Black) Group (25%) Mainland (Other) Group (23.1%)  Functional Changes Puerto Rican Group (35.3%) Mainland (White) Group (32.4%) Mainland (Black) Group (25%) Mainland (Other) Group (33.3%)  Prescriptions/Medications Puerto Rican Group (49.3%) Mainland (White) Group (46.9%) Mainland (Black) Group (46.2%) MI (33.3%)	
			Caregivers identified themselves as White, African American, Latino, or Other (mainly Asian American or Native American), and were further categorised if they				

First Author (Year), Country	Study Aims	Caregiving time point; and Setting	Carer Sample Information	Type of survey; response rate	Outcome measure Unmet needs domains; (number of items in each domain)	Unmet needs domain, items (prevalence)	Analysis and statistically related factors to unmet needs (test statistic)
			lived on the U.S. Mainland or on the island of Puerto Rico.			Safety at Home Puerto Rican Group (59.2%) Mainland (White) Group (22.5%) Mainland (Black) Group (30%) Mainland (Other) Group (46.2%)	
			Race/ethnicity: U.S. Mainland sample White (73%) African American/black (20.4%) Latino (2.6%) Other (4.1%)			<b>Social Aspects of Stroke Caregiving 17.5% - 53.9%</b> Protecting Veteran Puerto Rican Group (34.3%) Mainland (White) Group (24.7%) Mainland (Black) Group (17.5%) Mainland (Other) Group (53.9%)	
			Race/ethnicity: Puerto Rico sample Latino (67.1%) White (29.5%) African American/black (5.5%) Other (5.5%)			Managing Emotional Ups and Downs Puerto Rican Group (52.1%) Mainland (White) Group (34%) Mainland (Black) Group (25%) Mainland (Other) Group (15.4%)	
			Gender, carer group and income not reported			Getting Financial Help Puerto Rican Group (33.8%)	

First Author (Year), Country	Study Aims	Caregiving time point; and Setting	Carer Sample Information	Type of survey; response rate	Outcome measure Unmet needs domains; (number of items in each domain)	Unmet needs domain, items (prevalence)	Analysis and statistically related factors to unmet needs (test statistic)
						Mainland (White) Group (33.1%) Mainland (Black) Group (50%) Mainland (Other) Group (30.8%)  Changes in Relationship with Veteran Puerto Rican Group (17.1%) Mainland (White) Group (26.2%) Mainland (Black) Group (20%) Mainland (Other) Group (33.3%)  Changes in Veteran Relationship with Family Puerto Rican Group (28.6%) Mainland (White) Group (24.5%) Mainland (Black) Group (17.5%) Mainland (Other) Group (25%)	
Hoffmann (2004), AU	To determine the current practice of in the provision of written information to stroke survivors and their carers. Also aimed to explore their information	Six months after hospital interview; Interviews at hospital and home	<b>*Results only reported at the six months after hospital interview time point</b>  Sample: n = 9	Structured interview; 75% follow-up rate	Measure was developed for the study	<b>*Results only reported at the six months after hospital interview time point</b>  Items identified by carers requesting more information What is a stroke? (n=1, 11%)	Only prevalence reported; needs were not compared to any other factors

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	needs while in hospital and six months later		<p>Female: (n = 7, 77%)</p> <p>Age: M = 69.9 years, (SD=9.4)</p> <p>Carer group: Spouse/partner (n=9, 100%)</p> <p>Education: M=8.7 years, (SD=1.9)</p> <p>Race/ethnicity, income and average time spent caregiving not reported</p>			<p>Causes of stroke (n=2, 22%)</p> <p>Risk factors of stroke (n=2, 22%)</p> <p>Treatment available after stroke (n=0 ,0%)</p> <p>Recovery after a stroke (n=0, 0%)</p> <p>Medications prescribed after a stroke (n=1, 11%)</p> <p>Physical effects of a stroke (n=0, 0%)</p> <p>Emotional/psychological effects of stroke up (n=1, 11%)</p> <p>Cognitive effects of stroke (n=3, 33%)</p> <p>Communication effects of stroke (n=0, 0%)</p> <p>Continence following stroke (n=0, 0%)</p> <p>Behavioural effects of stroke (n=0, 0%)</p>	

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						Effects of stroke on family and/or marriage (n=2, 22%)	
						How to prevent further strokes (n=6, 67%)	
						Community services available for stroke patients (n=1, 11%)	
						Stroke support groups (n=1, 11%)	
						Legal information following stroke (n=1, 11%)	
						Financial information following stroke (e.g. benefits) (n=0, 0%)	
						Equipment and aids necessary after stroke (n=0, 0%)	
						Information about exercise/activities to do after stroke (n=0, 0%)	
						Information about healthy living (e.g. tips for exercising) (n=0, 0%)	

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						Where to obtain further support/information (n=3, 33%)	
						Tips for performing self-care tasks (n=0, 0%)	
						Tips for performing household tasks (n=0, 0%)	
						Returning to community activities (n=0, 0%)	
						Returning to driving (n=0, 0%)	
						Helpful tips for carers (n=2, 22%)	
Tsai et al. (2014) Taiwan	This study aimed to explore the changing needs of family caregivers of stroke patients and factors related to the needs in four stages, before the transfer from intensive care unit to neurological unit, before discharge, two weeks post- hospitalization, and three months post- hospitalization	Recruited consecutive family caregivers of the patients admitted to a stroke ICU in Northern Taiwan during 2009– 2010	n = 60  Female: (n=35, 58.3%)  Age: M = 44.25 years, (SD = 13.08)  Son (n=19, 31.7%); Daughter (n=16, 26.7%); Spouse (n=16, 26.7%); Daughter- in-law (n=4,	Cross-sectional survey; 95.2% response rate	Family needs of stroke patient questionnaire (FNQ): This questionnaire was based on the needs questionnaire for family caregivers by Kreutzer and Marwitz and translated by Chung[1].	<b>*Results only reported at the three months post- hospitalization time point</b>  <b>Health information (43.3%)</b>  Respect the patient when performing education, treatment or rehabilitation (35%)  Providing information on disease progress (33%)  To have my question answered honestly (32%)	Severity of stroke at admission (national institutes of health stroke scale; NIHSS) (p<0.01)  Length of stay: ICU; neurological unit; total length of stay; (all p's<0.01)  Physical dependency (Barthel index); (p<0.01)

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			6.7%); Parents (n=2, 3.3%); Siblings (n=2, 3.3%); Grandchildren (n=1, 1.7%)  Education reported as Illiterate (n=1, 1.7) Literature (n=59, 98.3%)  Race/ethnicity, income and average time spent caregiving not reported		Items were added based on the previous research findings and researcher's clinical experience  Six domains; 42 items  Health information; 13 items  Community support network; four items  Professional support; four items  Instrumental support; nine items  Emotional support;	To have information on medication and treatment (87%)  To have information on the patient's physical problems (88%)  To have information on the patient's rehabilitation progress (23%)  To be assured that the best possible medical care is being (35%)  To be informed about all changes in the patient's medical (23%)  To be informed about the exams and laboratory results daily (10%)  To have explanations from professionals given in terms I can understand (30%)  To have information on the patient's thought problems (38%)	



First Author (Year), Country	Study Aims	Caregiving time point; and Setting	Carer Sample Information	Type of survey; response rate	Outcome measure Unmet needs domains; (number of items in each domain)	Unmet needs domain, items (prevalence)	Analysis and statistically related factors to unmet needs (test statistic)
					eight items		
					Involvement with patient care; five items	<p>To have information about dying and hospice care when the patient disease reaches the end (20%)</p> <p><b>Community support network</b> (69.3%)</p> <p>Conveying advice with the help of professionals (75%)</p> <p>To have other family members understand the patient's problems (67%)</p> <p>To have support from family and friends (75%)</p> <p>To discuss my feelings about caring for the patient with other friends or family (60%)</p> <p><b>Professional support</b> (72.0%)</p> <p>Being informed of how to handle the medical emergencies of the patient (93%)</p> <p>To have comprehensive information for the patient eg,</p>	

First Author (Year), Country	Study Aims	Caregiving time point; and Setting	Carer Sample Information	Type of survey; response rate	Outcome measure Unmet needs domains; (number of items in each domain)	Unmet needs domain, items (prevalence)	Analysis and statistically related factors to unmet needs (test statistic)
						<p>rehabilitation programmes, physical therapy (53%)</p> <p>Being informed on what to do when the patient became upset or acted strange (88%)</p> <p>To discuss with health care workers on how much the patient can do independently (53%)</p> <p><b>Instrumental support (33.9%)</b></p> <p>To have help from other members of the family in taking care of the patient (72%)</p> <p>To get enough rest or sleep (60%)</p> <p>To have information about financial assistance, eg, physical and mental disability benefits, medical expenses, catastrophic illness benefits, hospital care in seriously ill low-income subsidy (12%)</p> <p>To get a break from my problems and responsibilities (60%)</p>	

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						To have time to spend with friends (60%)	
						To have information about homecare (eg, home rehabilitation, day care, respite care) (17%)	
						To have information about assistive devices (eg, beds, wheelchairs, oxygen, suction machine, ventilator) (0%)	
						To have information on patients' long-term care (eg, nursing home, respiratory care center) (8%)	
						To have help keeping the house (eg, shopping, cleaning, cooking, etc.) (17%)	
						<b>Emotional support</b> (32.8%)	
						Help remaining hopeful about the future (42%)	
						To be encouraged to ask others to help out (40%)	

First Author (Year), Country	Study Aims	Caregiving time point; and Setting	Carer Sample Information	Type of survey; response rate	Outcome measure Unmet needs domains; (number of items in each domain)	Unmet needs domain, items (prevalence)	Analysis and statistically related factors to unmet needs (test statistic)
						To express my feelings about the patient with someone who has gone through the same experience (20%)	
						To have my partner or friends understand how difficult it is for me (58%)	
						Help in getting over my doubts and fears about the future (27%)	
						To have time to go to temple or church (23%)	
						To be reassured it is usual to have strong negative feelings about the patient (30%)	
						To discuss my feelings about the patient with a professional, eg, anxious, worry, sad, feeling guilty, anger (22%)	
						Involvement with patient care (18.0%)	
						To learn how to help patients stand up, shift and rehabilitation techniques (32%)	
						To help patients deal with physical care to make patients	

First Author (Year), Country	Study Aims	Caregiving time point; and Setting	Carer Sample Information	Type of survey; response rate	Outcome measure Unmet needs domains; (number of items in each domain)	Unmet needs domain, items (prevalence)	Analysis and statistically related factors to unmet needs (test statistic)
						<p>more comfortable, eg, grooming, bathing and massage (33%)</p> <p>To learn how to prepare meals for patients (12%)</p> <p>To learn nasogastric tube and urinary catheter care (8%)</p> <p>To learn patients' wound care (5%)</p>	

**Supplementary Table 2. Systematic review of the unmet needs of carers of stroke survivors – qualitative and mixed-methods summary table**

<b>First Author (Year), Country</b>	<b>Study Aims</b>	<b>Caregiving time point; and Recruitment</b>	<b>Carer Sample Information</b>	<b>Interview schedule/ discussion guide</b>	<b>Type of analysis</b>	<b>Domains*,Categories *Domains/themes that reflected unmet needs developed by the original authors</b>
Brereton (2000), UK	To interview a number of experienced carers of stroke survivors and to ask them to recount the way in which they had become carers, what their initial needs were and how these had evolved over time	Providing care for at least two years; The researcher gained permission from the Stroke Association to approach a local stroke and carers' club	n = 7  Female: (n=5, 71.4%)  Age: M, SD not reported - between 65 and 84 years of age  Spouses (n=7, 100%)  Providing care for at least two years  Race/ethnicity, education and income not reported	Carers were asked to recount the way in which they had become carers, what their initial needs were and how these had evolved over time	Four cognitive processes suggested by Morse (1995)[2]	<b>What's it all about?'</b> <b>`Going it alone'</b> <b>`Up to the job'</b> <b>`What about me?'</b>
Cameron (2013), CAN	The objectives of this qualitative study were to: (1) explore the support needs over time from the perspective of carers, (2) explore the support needs over time from the perspective of health care professionals	Carers were interviewed 1-134 months post-stroke; Carers were purposively sampled from three sources (1) an inpatient rehabilitation center; (2) a community based aphasia program and (3) a community care organization serving a rural population	n = 24  Female: (n=17, 70.8%)  Age: M=65.5 years, SD not reported; Age ranged between 36 – 77 years  Spouse (n=18, 75%) Child (n=6, 25%)  Race/ethnicity not reported	Caregivers were asked to discuss their personal needs for emotional, informational, and instrumental (e.g. caregiver training and hands on assistance) support at different times	Framework analysis	<b>The Type and Intensity of Support Needed</b>  <b>Primary Focus of Care</b>  <b>Who Provides Support and the Method of Providing Support*</b>

First Author (Year), Country	Study Aims	Caregiving time point; and Recruitment	Carer Sample Information	Interview schedule/ discussion guide	Type of analysis	Domains*,Categories *Domains/themes that reflected unmet needs developed by the original authors
	(HCPs), and (3) compare and contrast caregivers' and HCPs' perspectives	<i>*Only the needs of carers in the Adaptation stage have been extracted. The needs in the Adaptation stage follow the Preparation and Implementation phases. These phases reflect the needs of the carer during the immediate transition period when the stroke survivor and carer first return home (Preparation phase), and the first few months post-discharge at home (Implementation phase).</i>				
Denman (1998), UK	To identify the needs of spouses caring for someone who has communication difficulties due to a stroke and to determine what solutions they felt would have helped to alleviate the difficulties they described	All carers in this study are defined as "Established carers", who have been providing care to the stroke survivor at home for a number of months and have learned to adapt and cope with the initial changes experienced by "Novice carers"; A letter was sent out to all carers who met the criteria for the study; participants	n = 9  Female: (n=6, 66.7%)  Spouses (n=9, 100%)  Race/ethnicity, age, education, income, are not reported	The interview schedule covered five main areas. These were: (1) The carer's perception of their needs; (2) The carer's perception of the help available; (3) Information	Not reported; common themes were identified from the transcripts	<b>Support</b> Support from the family Support from friends and neighbours Support from outside agencies Lack of support  <b>Information</b> Types of information Methods of accessing information Consequences of the provision of relevant information

First Author (Year), Country	Study Aims	Caregiving time point; and Recruitment	Carer Sample Information	Interview schedule/ discussion guide	Type of analysis	Domains*,Categories *Domains/themes that reflected unmet needs developed by the original authors
		were contacted if they were known to the Stroud Locality Community Speech and Language Therapist		about the carer's actual access to The carer's satisfaction with the levels of service; (4) Services that the carer feels they would like or would have liked		<b>Role change</b> Patient 's relative Novice carer Chronic carer  <b>Training</b> No help Lack of explanation Learning on the job  <b>Day and respite care</b> The need to have time off to themselves The need to have a break from each other The need to have respite back-up in case of illness or emergency  <b>Possible solutions</b> Access to someone in an advisory role Regular reassessments Involvement with carers groups Access to somebody to call on in emergencies Access to support services for carers  <b>Provision of co-ordinated information</b>



<b>First Author (Year), Country</b>	<b>Study Aims</b>	<b>Caregiving time point; and Recruitment</b>	<b>Carer Sample Information</b>	<b>Interview schedule/ discussion guide</b>	<b>Type of analysis</b>	<b>Domains*,Categories *Domains/themes that reflected unmet needs developed by the original authors</b>
Kerr (2001), UK	To provide informal carers of stroke patients with a voice, presenting information that health care professionals can use to inform their practice – such as the perceived needs of informal carers	Carers who had been providing care for at least one year; Stroke patient-carer 'pairs' were recruited through two hospital sites in the west of Scotland	<p>n = 22</p> <p>Female: (n=13, 59.1%)</p> <p>Age: M,SD not reported; median 61.0 IQR 41.0-69.2</p> <p>Spouse (n=14, 63.6%); Partner (n=1, 4.5%); Son (n=1, 4.5%); Daughter (n=5, 22.7%); Daughter-in-law (n=1, 4.5%)</p> <p>Race/ethnicity not reported</p>	The interview guide focused on the carers' experiences during their relative's stay in hospital (both acute care and rehabilitation), in the early weeks following discharge, and in the months that had followed. Carers were also asked to comment on what they anticipated their future needs might be	Analysed thematically	<p><b>Preparation for discharge/feelings about discharge</b></p> <p><b>Early weeks/months at home</b></p> <p><b>A year of caring</b></p> <p><b>The future</b></p>
King (2006), UK	To identify the most difficult times, unmet needs and advice of carers during the first two years of caregiving and to examine resource use and perceptions of resource importance	Providing care over the first two years post-discharge; Carers were recruited/interviewed during 32 months from consecutive patients admissions to five hospital rehabilitation units and a rehabilitation hospital	<p>n = 93</p> <p>Female: (n=60, 64%)</p> <p>Age: M=56.7 years, (SD =14.7)</p> <p>Spouse (n=83, 89%) Other (n=10, 11%)</p> <p>Education reported as: Completed high school (n=75, 80%) Other (n=18, 20%)</p>	Semi-structured questions were used to collect data on the most difficult times, contributing factors, unmet resource needs and advice	Content analysis	<p><b>Preparing for caregiving</b></p> <p><b>Enhancing the stroke survivor's emotional and physical function</b></p> <p><b>Sustaining the self and family</b></p>

First Author (Year), Country	Study Aims	Caregiving time point; and Recruitment	Carer Sample Information	Interview schedule/ discussion guide	Type of analysis	Domains*,Categories *Domains/themes that reflected unmet needs developed by the original authors
		<i>*Qualitative data extracted only as quantitative data were not available for longer-term unmet needs</i>	Race/ethnicity: White (75%), remainder not reported  Income and average time spent caregiving not reported			
Lee (2001), HK	To explore the experiences of Chinese family members caring for relatives who have been diagnosed with stroke, and to identify the perceived needs of carers	Carers had more than six months' caregiving experience in a home setting; two stroke wards in two hospitals and two stroke support groups in the community of Hong Kong	n = 15  M=62, SD not reported. Age ranged between 27 and 87 years of age  Wives (n=7, 46.7%), husbands (n= 5, 33.3%), daughters (n=3, 20%)  Race/ethnicity: Chinese (100%)  Education, income and average time spent caregiving not reported	Interview/ discussion guide not discussed	Content analysis	<b>Learning to cope with new demands</b>  <b>Managing one's own emotional responses</b>  <b>Appraising kinship and community support</b>  <b>Maintaining a balance between caregiving needs and one's own needs</b>
Lutz (2007), USA	To identify post-discharge needs of veterans with stroke and their carers and to identify how to design a care coordination/home-telehealth (CC/HT) program to address these needs	Post-discharge from hospital; Veteran and carers were interviewed in their homes; They were recruited from the Florida/South Georgia Veterans Health Service	n = 10  Female: (n=10, 100%)  Age: M=70 years, SD not reported. Age ranged between 57 - 86 years  Spouse (n=10, 100%)	An interview guide was used to ask stroke survivors and carers about their experiences with stroke, their post-discharge stroke recovery needs, and their	Grounded dimensional analysis	<b>Assessing and managing the residual effects of stroke</b>  <b>Shifting roles and responsibilities</b>

First Author (Year), Country	Study Aims	Caregiving time point; and Recruitment	Carer Sample Information	Interview schedule/ discussion guide	Type of analysis	Domains*,Categories *Domains/themes that reflected unmet needs developed by the original authors
			Race/ethnicity, education, income and average time spent caregiving not reported	experiences with the Veterans Administration's existing CC/HT program		
Wiles (1998), United Kingdom	To identify the information needs of stroke survivors and their informal carers at various stages post-stroke with the aim of developing a database from which individualized information packages could be provided	Multiple time points; Interviewees were either in-patients identified by staff at one general hospital, or were living in the community, and identified from discharge lists by staff at other local hospitals	<p><b>*Up to one year post-discharge group</b> n = 8</p> <p>Age, gender, carer group, education, income, and average time spent caregiving not reported</p>	The topic guide was developed from a literature review, and included questions on current problems, types of support/services currently received, and aspirations/need for support	Thematic analysis; a constant comparison method	<p><b>Psychological and emotional problems</b> Recognising limitations and developing coping strategies Fear of another stroke Anxiety and emotional consequences Stigma and isolation</p> <p><b>Information needs</b> The need for information</p> <p><b>Contact with services</b> Support for carers The role of primary care Social services and home care.</p>

**Supplementary Table 3. Quality appraisal of quantitative studies**

<b>First Author (Year), Country</b>	<b>Scoring (Greenwood et al, 2008): 1 Point if the criteria was met</b>						<b>Total</b>
	<b>Inclusion of inclusion and or exclusion criteria for carers</b>	<b>Clear hypotheses/ hypothesis</b>	<b>Response rate reported or possible to calculate</b>	<b>Multivariate analyses/control for possible confounders</b>	<b>Full definition of carer provided (including spouse as the definition)</b>	<b>Timing of assessment similar for all participants</b>	
Hinojosa (2007), USA	1	1	1	0	0	0	3
Hinojosa (2009), USA	1	1	1	1	0	1	5
Hinojosa (2012), USA	1	0	1	1	0	1	4
Hoffmann (2004), AU	1	0	1	0	0	1	3
Tsai (2014), Taiwan	1	0	1	1	0	1	4

**Supplementary Table 4. Quality appraisal of qualitative and mixed-method studies**

<b>First Author (Year), Country</b>	<b>COREQ (Tong et al, 2007) Scoring: 1 Point for Each Reporting Criteria Met</b>			
	<b>Domain 1 (8 items) Researcher Team and Reflexivity</b>	<b>Domain 2 (15 items) Study Design</b>	<b>Domain 3 (9 items) Analysis and Findings</b>	<b>Total (32)</b>
Brereton (2000), UK	0	7	5	12
Cameron (2013), CAN	0	10	8	18
Denman (1998), UK	0	10	5	15
Kerr (2001), UK	0	10	7	17
King (2006), UK	0	6	6	12
Lee (2001), HK	0	10	6	16
Lutz (2007), USA	1	9	6	16
Wiles (1998), UK	0	11	6	17