

1 **The use of carer perspectives and expert consensus to define key**  
2 **components of a biopsychosocial support intervention for stroke carers.**

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4 Laura Condon PhD\*, Penny Benford PhD, Eirini Kontou PhD DCLin Psy,  
5 Shirley Thomas PhD and Marion Walker PhD

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7 *<sup>a</sup>Division of Rehabilitation and Ageing, University of Nottingham, B Floor, The Medical*  
8 *School, Queens Medical Centre, Nottingham, NG7 2UH.*

9 *\*Corresponding Author: [laura.condon@nottingham.ac.uk](mailto:laura.condon@nottingham.ac.uk)*

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11 Objective: To identify the key components of a biopsychosocial support intervention to  
12 improve mental wellbeing for informal stroke carers within the first year post-stroke  
13 based on the combined perspectives of experts in the field of psychological care after  
14 stroke and informal stroke carers themselves. Methods: After reviewing the existing  
15 literature a cross-sectional mixed-methods design was adopted comprising 1) focus  
16 groups with informal stroke carers about their psychological support needs, and 2)  
17 nominal group technique with academic and clinical stroke care experts to reach  
18 consensus on intervention priorities. Transcripts were thematically analysed and  
19 combined with the ranked priorities from the nominal group to identify key  
20 components for intervention content. Results: Key themes for informal stroke carers  
21 were associated with: 1) changes in relationships, roles, and dynamics; 2) emotional  
22 impact and acceptance; 3) drawing on inner resources; 4) looking for information,  
23 solutions, and explanations; 5) support from others. The expert nominal group placed  
24 priority on eight ranked areas: 1) acknowledging “normal” emotions; 2) education  
25 about the effects of a stroke; 3) reactions to loss and adjustment; 4) recognising signs of  
26 symptoms of not coping; 5) knowing how and when to access practical and emotional  
27 support; 6) strategies for taking care of own health; 7) dealing with difficult emotions;

28 and 8) problem solving skills. Conclusions: Themes from the informal carer focus  
29 groups, and ranked priority areas will inform the development of a biopsychosocial  
30 support intervention for stroke carers to be tested in a feasibility randomised controlled  
31 trial.

32 Keywords: stroke, carers, biopsychosocial, nominal group technique, focus groups.

### 33 **Introduction**

34 According to figures published in February 2018 there are approximately 1.2 million stroke  
35 survivors in the UK and around 100,000 new strokes each year, with two thirds of which are  
36 living with a disability<sup>1</sup> and are cared for by family members and friends. An informal carer  
37 is defined as, ‘a person of any age who provides unpaid help and support to a relative, friend  
38 or neighbour who cannot manage to live independently without the carer’s help due to frailty,  
39 illness, disability or addiction.’<sup>2</sup> Therefore, they play a vital role in the rehabilitation and  
40 long-term care and deal with many practical, personal and emotional care needs<sup>3</sup>.

41 The sudden event of a stroke denies family members the time to prepare themselves  
42 for the caring role or the nature of the care they will need to provide. Some people find the  
43 role a positive experience, however, the demands of caring for a relative can increase stress  
44 and lower levels of mental and physical wellbeing<sup>4-8</sup>. Previous research has reported that the  
45 psychological impact of caring can result in increased frequency of anxiety and depressive  
46 episodes<sup>9,10</sup> negatively affect relationships both within and external to the family, and reduce  
47 ability to participate in leisure activities or paid employment<sup>11,12</sup>.

48 A wellbeing survey of UK stroke carers revealed that many experience negative  
49 psychological effects as a consequence of caring, namely anxiety (79%), frustration (84%),  
50 sleeping disturbances (60%), depression (56%), and stress (57%).<sup>13</sup> Given the lack of  
51 provision of psychological support services for stroke carers, it is unsurprising that declines  
52 in psychological and physical health of the carer can negatively impact the care provided to

53 the survivor<sup>13, 14</sup>. However, research to develop effective support interventions for stroke  
54 carers has had limited success<sup>15, 16</sup>. For example, a systematic review of interventions for  
55 informal caregivers of stroke survivors found that non of the interventions included showed  
56 positive effects on all outcomes of carer wellbeing, which included caregiver burden,  
57 depression and anxiety, family functioning and quality of life. The interventions that focussed  
58 on providing the caregiver with information about stroke and available resources were least  
59 likely to have an impact on caregiver outcomes. However, those that included multiple  
60 intervention components such as stroke education, problem solving, emotional support and  
61 psychological support were more likely to show an early effect on the outcome of carer  
62 wellbeing.<sup>17</sup> Therefore, in order to have a positive effect upon carer wellbeing it is important  
63 to consider the multiple sources of support needed by stroke carers when developing such  
64 interventions.

65 The biopsychosocial model of health and illness acknowledges the joint influence of  
66 biological (physical health), psychological (thoughts, emotions and behaviours) and social  
67 (relationships and roles) factors upon mental and physical wellbeing and emphasises that  
68 support interventions should focus on reducing negative symptoms and maintaining  
69 psychobiological health in order to be effective<sup>18</sup>. However, to ensure that they are fit for  
70 purpose in the context of stroke care it has been argued that involvement of the stroke carer  
71 perspective using a co-production approach, whereby stroke carer views and perspectives are  
72 used to inform the intervention content alongside those of other stakeholders such as  
73 clinicians or academics, is needed<sup>19</sup>. Also, involvement of experts in stroke care and stroke  
74 research can provide a complimentary perspective of the needs of the stroke carer population.

75 Therefore, the aim of the present study was to identify the key components of a  
76 biopsychosocial support intervention to improve mental wellbeing for stroke carers within the

77 first year post-stroke based on the combined perspectives of experts in the field of  
78 psychological care after stroke and stroke carers themselves.

## 79 **Methods**

### 80 *Research Design*

81 A mixed-methods cross-sectional design was adopted comprising: (i) Carer focus  
82 groups. These were conducted to give a ‘lived experience’ detailed picture of the support  
83 needs and priorities of stroke carers and (ii) a nominal group technique<sup>20-22</sup>. This method was  
84 used to reach consensus among stroke experts on priorities for intervention content. Written  
85 informed consent was obtained from all participants and ethical approval for the study was  
86 gained from the local research ethics committee (Nottingham 2 Research Ethics Committee,  
87 REC Ref: 14/EM/1264). This manuscript and the reporting of the study findings conform to  
88 the COREQ Guidelines<sup>23</sup> (see Supplementary Material). The research team were all female  
89 academics with a background in stroke research.

90 A participatory approach involving stroke carers was adopted as the theoretical framework  
91 for the study. Cornwall & Jewkes (1995) described the approach as having four phases:  
92 Contractual (whereby participants consent to take part in research), Consultative (participants  
93 are consulted on their opinions), Collaborative (participants work with academic researchers  
94 on research project controlled by the researchers), and finally Collegiate (participants work  
95 alongside the academic researchers)<sup>24</sup>. The advantages of the participatory approach are that  
96 by working collegiately with the key stakeholder group their experiences and views yield  
97 better designed research studies with outcomes that hold greater relevance to their real-world  
98 experience. As such the study protocol and research objectives were developed in  
99 consultation with an expert group of stroke survivors and carers who advise on local and  
100 national research, The University of Nottingham Stroke Research Partnership Group

101 (NSRPG). In line with the collegiate phase of the approach two members of the group were  
102 also involved in data collection procedures, management of the consultation groups and  
103 discussion of the study findings.

104

## 105 *Data collection & Analysis*

### 106 *Carer focus groups*

107 Carers were recruited from community stroke support and partnership groups in  
108 Nottinghamshire and were included in the study if their experience of being an informal  
109 stroke carer was < 1 year. We did not exclude based upon stroke characteristic of the survivor  
110 but we did exclude carers from taking part in the study if they were paid to undertake the care  
111 of the stroke survivor which would not have defined them as an informal carer. Ethical  
112 considerations were taken into account when constructing the sampling framework to ensure  
113 that a range of caring experiences were sampled and that the sample was not weighted  
114 towards i) one type of stroke, ii) the same type of post-stroke caring responsibilities, iii)  
115 family relationship to the survivor, or iv) employment status of the carer. All of which we felt  
116 were important sampling characteristics that could affect the experiences of the carer towards  
117 their caring role. Another consideration was whether it was ethical to collect data from stroke  
118 carers in a focus group format (ie. which would leave the stroke survivor without their carer),  
119 however all carers were eager to take part in the groups and arranged for the survivor to be  
120 looked after while they attended the group of their choice.

121 The carers could choose to attend only one out of a choice of three focus groups,  
122 which took place on different dates at the University of Nottingham, and were facilitated by  
123 the chief investigator (MW) and two other members of the research team (EK, PB) who  
124 assisted and took field notes. A topic guide was used to inform the group discussions and was

125 constructed following a review of the literature on stroke caregiver support interventions up  
126 to and including the year 2016. s The topic guide focussed on the biopsychosocial impact of  
127 being a stroke carer as well as practical issues to facilitating a support intervention (see  
128 Supplementary Material). Each group lasted for ~60 to 90 minutes and discussions were  
129 audio-recorded and transcribed verbatim. The data was organised using QSR NVivo 11  
130 (QSR International Pty, Ltd) and inductively thematically analysed (PB, ST, EK) following  
131 the procedure detailed by Braun & Clarke<sup>25</sup>. An interpretive approach was taken to explore  
132 contextual, consequential, and hierarchical connections, and any discrepancies were resolved  
133 by discussion.

#### 134 *Expert nominal group*

135 The Nominal Group Technique is one of the most common techniques used to obtain  
136 views and gain consensus on a given topic. Methodologically it belongs to the same family of  
137 techniques as the Delphi method, however unlike a Delphi it is conducted face-to-face with  
138 several ‘rounds’ of consensus gathering taking place with the same group of participants, in  
139 the same place, and at the same time until a final list of consensus priorities are agreed upon<sup>20</sup>

140 In the present study purposive sampling through stroke research networks and  
141 clinical networks was used to identify nationwide research and/or clinical experts.  
142 Participants were included if they had experience in psychological care or clinical carer after  
143 stroke and had experience relating to stroke carers. Participants were excluded if their  
144 experience did not relate to stroke or if they had no experience of working with stroke carers.  
145 Those experts who were eligible to take part who were then invited to participate in the face-  
146 to-face expert nominal group with the aim of generating priorities for key components of a  
147 group intervention for the psychological care of stroke carers.

148           The nominal group was facilitated by MW who set out the objectives and processes  
149 involved in the expert nominal group at the University of Nottingham and asked participants  
150 to individually generate ideas in response to the question ‘What elements should be included  
151 in a biopsychosocial support intervention for informal carers of stroke survivors?’ This was  
152 followed by a ‘round robin’ sharing of ideas. Each participant in turn contributed one idea  
153 which was recorded on a flip chart without discussion. This was followed by a group  
154 discussion in which the facilitator ensured that all group members had the opportunity to  
155 contribute, and that all items were valid to the research question. Where appropriate, new  
156 items could be added, or amalgamated, but none were eliminated.

157           The meeting ended with each participant anonymously selecting and ranking their top  
158 priorities from the list, which were then collated to form the final list of rankings.

159

## 160 **Results**

### 161 *Carer Focus Groups*

162 A convenience sample of 16 stroke carers (12 female; 8 spouses) took part in the 3 focus  
163 groups; 5 carers attended Group 1, 5 carers attended Group 2, and 6 carers attended Group 3.

164 The carers were aged between 47 and 79 years old (mean 57.5 years) and at the time of the  
165 study their time as a carer ranged from 6 months to 10 years (median = 3 years).

166 The themes outlined below represent recurring topics of discussion between the three focus  
167 groups.

168           *Changes in Relationships, Roles and Dynamics:* Carers across each group described  
169 how there had been quite immediate and pervasive changes in the dynamics of their

170 relationship with the survivor following the stroke. Many described how tensions had arisen  
171 between the carer and the stroke survivor due to the consequences of the stroke:

172           “I think the problem is...for us, he feels very vulnerable and he feels less of a man because  
173 he’s got these physical problems...and I think that puts a strain on the relationship.” (Focus Group 3,  
174 Carer 3, Wife).

175           For some carers changes had also taken place in their relationships with the wider  
176 family unit as family members assumed new roles so relationships had to be renegotiated.  
177 Carers spoke about how these new dynamics could result in instances of families either  
178 pulling together or bringing additional tensions which caused strain on these relationships:

179           “... if I’d have not had my sister, I don’t know what I would’ve done quite honestly...my  
180 brother then felt left out, you know and then commented on that...that was frustrating.” (Focus Group  
181 3, Carer 1, Daughter)

182           Carers talked about the reactions to the survivor’s stroke from members of their social  
183 circle which elicited feelings of disappointment in close members who had distanced  
184 themselves from them and failed to accommodate their change in circumstances. However,  
185 they also experienced feelings of surprise when ‘peripheral members’ of the social circle  
186 offered help. In this way the carer’s social support network could become restructured with  
187 members switching roles and social support often being provided from unexpected sources:

188           “...the strange thing is that some people you didn’t know that well start getting really  
189 interested in you. And other people who you knew really well...kind of move away because they’re  
190 worried about what they’ll find sort of thing” (Focus Group 2, Carer 2, Husband)

191           *Emotional Impact and Acceptance:* Alongside the challenges of their new role carers  
192 were simultaneously having to deal with their own emotional response to the event and



193 aftermath of the stroke as well as managing the emotions of the stroke survivor. This  
194 inevitably could cause considerable tensions:

195 “you know, she cries all the time and constantly will say ... I wish I were dead.. I wish this  
196 had never happened... and that’s really upsetting.” (Focus Group 3, Carer 2, Husband)

197 Carers revealed feeling a sense of loss for the previous relationship with the stroke  
198 survivor and the life they once had together which was characteristic of the grief response,  
199 including anger, frustration, loneliness, despair and depression:

200 “I’ve been angry a lot of the time... basically that this has happened to us, you know... I used  
201 to go downstairs and I used to sob my heart out ‘cos it was just...devastating really. This wasn’t going  
202 to be fixed.” (Focus Group 3, Carer 4, Wife).

203 Over time they adapted to the new situation and there was a point of acceptance in  
204 coming to terms with how their lives had changed:

205 “When your life is completely sort of knocked sideways, what you want is to get it back to  
206 where it was. I think it’s all about learning to accept that that’s not gonna happen.” (Focus Group 2,  
207 Carer 2, Husband)

208 *Drawing on Inner Resources:* Assuming this new role daunted some of the carers and  
209 there was a sense of feeling unprepared for the added responsibilities they had to undertake  
210 and many carers discussed how they felt a need to be strong and self-reliant. For some, this  
211 was out of necessity due to their family situation, for others it was a natural coping  
212 mechanism. There were also feelings of protectiveness towards the survivor and some carers  
213 were unwilling to accept help instead feeling that they should just be “getting on with it”:

214 “But I... but I wasn’t very open to offers of help at that stage, no. Because I just thought...  
215 you know, I can deal with this. This is my husband and I’ll sort it out.” (Focus Group 3, Carer 4,  
216 Wife)

217           *Looking for Information, Solutions, Explanations:* There was a need to gain a better  
218 understanding of what had happened from very early on following the stroke, to gather  
219 information and look for solutions. Carers felt concern about what had caused the stroke and  
220 the chances of recurrence, and sought information about how to access formal care support,  
221 and how best to practically support the stroke survivor:

222           “...we just thought about ways that we could help dad and mum at home ...every single issue  
223 that she had, we as a family tried to source information about.” (Focus Group 1, Carer 1, Son)

224           *Support from others:* Practical and emotional support from others, particularly friends  
225 and family, was seen by the carers as being key to their wellbeing and to provide relief from  
226 their situation. Contact and interaction from other carers who might empathise and give the  
227 benefit of their own experiences was raised as something they would value:

228           “...because of [wife’s name]’s rehabilitation there’s an awful lot of families and partners who  
229 sort of hang around there. And you do...you find yourself having conversations with them... you  
230 become an informal little support group.” (Focus group 2, Carer 4, Husband)

231           There were varying degrees of input from health and social care agencies experienced  
232 by the carers across all of the groups. Typically the most input came at the early stages  
233 immediately post stroke and then gradually reduced. The withdrawal of input was described  
234 as being a difficult period and left some carers feeling abandoned:

235           “After hospital pretty much you get on with it and see what you can find out. Ring people that  
236 you think can help. I found no help whatsoever and I work for the NHS! I found that really difficult”  
237 (Focus group 3, Carer 6, Wife)

238 *Expert nominal group*

239 Ten experts consented to take part in the group; 4 came from a clinical background, 5  
240 came from an academic background, and 1 had a dual clinical academic role . All of the  
241 expert had over 15 years of experience in their respective roles (see Table 1)

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Table 1 About Here

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246 Table 2 shows the long-list of 30 ideas generated by the expert group and the total scores  
247 given for each item. This was then reduced to eight ranked priority areas during subsequent  
248 rounds of the nominal group technique and comparison with areas of agreement with the  
249 focus group findings.

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Table 2 About Here

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254 The ranked priorities from the expert nominal group identified the psychological,  
255 biological, and social effects of stroke on the carer along with practical considerations for  
256 delivering interventions and techniques that can be used within the intervention.

257 Areas of agreement were identified between the ranked priorities and the carer  
258 perspectives namely: acknowledging “normal” emotional reactions to the caring role,

259 learning more about the biological basis of what a stroke was and how it impacts the  
260 survivor; developing problem solving skills to deal with caring situations; dealing with  
261 difficult emotions; loss reactions and dealing with adjustment; recognising the symptoms of  
262 not coping; knowing when and how to access practical and emotional support (see Appendix  
263 1 for conceptual map of areas of agreement).

264           Ranked priorities that were not in agreement with carer perspectives were related to  
265 the practicalities of intervention delivery: setting sessional boundaries (eg. session start/finish  
266 times, session duration, session frequency); setting tasks between sessions; knowledge and  
267 skill level of the facilitator on biological and psychological effects of stroke; and encouraging  
268 participants to form a social support network.

269           Other ranked priorities that were not identified in the carer perspectives related to  
270 therapeutic techniques to encourage the stroke carer's self-reflection, increased self-  
271 awareness and thinking about the future, namely; using pictorial aides as prompts (ie. the  
272 stroke stress thermometer); acknowledging variation in previous life/relationship situations;  
273 acknowledge that carer and stroke survivor may have different perspectives on recovery;  
274 maintaining the carer's future goals; developing strategies for taking care of their health such  
275 as self-monitoring; developing a wellbeing toolbox for the skills that they would learn during  
276 the group sessions (Table 3)

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Table 3 About Here

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281 **Discussion**

282 This study sought to identify the key components for a biopsychosocial support intervention  
283 for stroke carers. To our knowledge this is the first study to use a nominal expert group  
284 technique alongside focus groups with stroke carers to identify joint priorities for a  
285 biopsychosocial support intervention. The findings of this study have highlighted important  
286 areas of agreement between expert priorities and carer perspectives which fall within the  
287 domains of the biopsychosocial model of health and illness, namely: learning more about  
288 what a stroke was and how it impacts the survivor (biological & psychological); developing  
289 problem solving skills to deal with caring situations (psychological); exploring normal  
290 emotional responses to the caring role (psychological); dealing with difficult emotions  
291 (psychological); loss reactions and dealing with adjustment (psychological); drawing on inner  
292 emotional resources (psychological); recognising the symptoms of not coping (biological &  
293 psychological); knowing when and how to access practical and emotional support  
294 (psychological & social).

295 Educating carers on the aetiology of a stroke and the physical, emotional and  
296 cognitive effects is in line with recommendations made by previous research<sup>26 27 28</sup>. For  
297 example, post-intervention accounts have reported carers gaining confidence by learning  
298 about the aetiology of a stroke<sup>27</sup> and a systematic review of systematic reviews<sup>16</sup> concluded  
299 that carer interventions that include information provision are effective in improving stroke  
300 carer quality of life.

301 Drawing on inner coping resources such as resilience and problem solving skills  
302 emerged from our carer focus groups as a priority for support and have been adopted as a  
303 coping strategy by stroke carers in other studies<sup>26, 29-31</sup>. Furthermore, a recent systematic  
304 review and meta-analysis<sup>31</sup> concluded that the inclusion of problem solving and stress-

305 coping as intervention components had a positive effect on stroke carers' psychosocial  
306 wellbeing and reduced their use of healthcare resources<sup>15</sup>.

307         The findings of the present study have also highlighted points of deviation in the  
308 expert ranked priorities and the carer perspectives. Practical aspects for intervention delivery  
309 were ranked as priorities by the experts but were not highlighted by the carers. The experts  
310 also gave priority to techniques that the carers could use to encourage self-reflection and  
311 increase self-awareness and self-monitoring of their own emotional health and wellbeing,  
312 which also relate to the biological and psychological domains of the biopsychosocial model  
313 of health and illness. These may not have been identified as priorities by the carers because  
314 they are 'unknown unknowns' for them in terms of techniques they can use to monitor their  
315 emotional health and wellbeing because they have not been exposed to them before and so do  
316 not know about them, or that they do not know that they can be used as formal techniques.

317         The process of adjusting to the caring role and the need to explore difficult emotions  
318 were reflected in the focus group discussions among the carers in our study. The clinical  
319 implications drawn from qualitative studies of carer experiences support the adjustment  
320 response and associated emotional difficulties as priorities for the psychological health of  
321 stroke carers<sup>26, 32, 33</sup>. As noted by Backstrom et al<sup>32</sup> '...intervention strategies need to include  
322 awareness of the long-term impact of the changes in the relationship and the losses  
323 experienced by the spouses. Even if the partner is still alive, there are losses to grieve and to  
324 be understood and it is an important part of the transition in the relationship...' (p226). The  
325 stroke carers in our study didn't report a need to learn techniques to help them cope with this,  
326 however they did report often having to deal with difficult emotions but coped with them  
327 alone without seeking professional psychological support or having any offered to them as  
328 part of standard care. Previous research highlights the negative implications of stroke carers  
329 suppressing emotions<sup>34</sup> and the implications on adjusting to the caring role<sup>35</sup>, along with

330 emotional suppression being potentially detrimental to carers' long-term physical and  
331 emotional health<sup>35</sup>. This was supported by the accounts described by the carers in the present  
332 study.

333 Overall the joint findings of the stroke carer focus groups and the expert nominal  
334 group have identified key component for a support intervention for stroke carers which fits  
335 the biopsychosocial model of health and illness. Many of the priorities highlighted by both  
336 the carers and the experts related to the biological and psychological domains, and the  
337 priority identified relating to knowing when and how to seek support related to the social  
338 domain of the model. This resonates with the findings of previous research which has shown  
339 that interventions that include elements of peer support can be effective in helping carers  
340 cope and have positive effect on their wellbeing<sup>36</sup> This conceptual model will be used to  
341 develop the sessional plan of a biopsychosocial support intervention that can be delivered to  
342 stroke carers within the first year of caring.

### 343 **Strengths and limitations**

344 While this study provided data on the support needs of stroke carers, as well as expert  
345 consensus of ranked priorities, the findings should be considered in relation to the purpose of  
346 the study which was to inform the development of a biopsychosocial intervention. The data  
347 therefore underwent validation by two independent researchers to mitigate any interpretation  
348 bias. Furthermore, adopting a participatory design approach and conducting the study with  
349 stroke carers as co-researchers ensured that the study procedures were acceptable and  
350 applicable to its target population. Finally, to enhance the validity of our interpretations they  
351 are presented and discussed in the context of previous research in this area.

352 However, a limitation of our approach was that the overall study findings did not undergo a  
353 further collaborative consultation process held simultaneously to include both the carers and

354 experts after the initial individual consultation process. This provides an opportunity for  
355 future research on the needs of informal stroke carers to gain enhance the findings.

## 356 **Conclusion**

357 This study combined stroke carer perspectives and ranked priorities of expert stroke  
358 researchers and clinicians to identify key components for a biopsychosocial support  
359 intervention for stroke carers. Agreement of priorities between stroke carers and experts  
360 related to learning more about what a stroke is and how it impacts the survivor; developing  
361 problem solving skills to deal with caring situations; exploring normal emotional responses to  
362 the caring role; dealing with difficult emotions; loss reactions and dealing with adjustment;  
363 drawing on inner emotional resources; recognising the symptoms of not coping; knowing  
364 when and how to access practical and emotional support. There were also areas of difference,  
365 or areas that were highlighted by the experts only, which are also important to include as key  
366 components of a biopsychosocial support intervention for stroke carers, such as: defining  
367 sessional boundaries (ie. session start/finish times, times, session duration, session frequency),  
368 acknowledging variation in previous life/relationship situations, acknowledging differences  
369 in perspectives and expectations between the carer and survivor, developing strategies that  
370 carers can use to look after their own health and wellbeing, and encouraging carers to form  
371 social support networks. These key components will be taken forward to develop the  
372 biopsychosocial support intervention for stroke carers which will be tested in a feasibility  
373 randomised controlled trial.

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462

## 1 **The use of carer perspectives and expert consensus to define key** 2 **components of a biopsychosocial support intervention for stroke carers.**

3 Objective: To identify the key components of a biopsychosocial support intervention to  
4 improve mental wellbeing for informal stroke carers within the first year post-stroke  
5 based on the combined perspectives of experts in the field of psychological care after  
6 stroke and informal stroke carers themselves. Methods: After reviewing the existing  
7 literature a cross-sectional mixed-methods design was adopted comprising 1) focus  
8 groups with informal stroke carers about their psychological support needs, and 2)  
9 nominal group technique with academic and clinical stroke care experts to reach  
10 consensus on intervention priorities. Transcripts were thematically analysed and  
11 combined with the ranked priorities from the nominal group to identify key  
12 components for intervention content. Results: Key themes for informal stroke carers  
13 were associated with: 1) changes in relationships, roles, and dynamics; 2) emotional  
14 impact and acceptance; 3) drawing on inner resources; 4) looking for information,  
15 solutions, and explanations; 5) support from others. The expert nominal group placed  
16 priority on eight ranked areas: 1) acknowledging “normal” emotions; 2) education  
17 about the effects of a stroke; 3) reactions to loss and adjustment; 4) recognising signs of  
18 symptoms of not coping; 5) knowing how and when to access practical and emotional  
19 support; 6) strategies for taking care of own health; 7) dealing with difficult emotions;  
20 and 8) problem solving skills. Conclusions: Themes from the informal carer focus  
21 groups, and ranked priority areas will inform the development of a biopsychosocial  
22 support intervention for stroke carers to be tested in a feasibility randomised controlled  
23 trial.

24 Keywords: stroke, carers, biopsychosocial, nominal group technique, focus groups.

### 25 **Introduction**

26 There According to figures published in February 2018 there are approximately 1.2 million  
27 stroke survivors in the UK and around 100,000 new strokes each year, with two thirds of  
28 which are living with a disability<sup>1</sup> and are cared for by family members and friends. An  
29 informal carer is defined as, ‘a person of any age who provides unpaid help and support to a  
30 relative, friend or neighbour who cannot manage to live independently without the carer’s

31 help due to frailty, illness, disability or addiction.<sup>2</sup> Therefore, they play a vital role in the  
32 rehabilitation and long-term care and deal with many practical, personal and emotional care  
33 needs<sup>3</sup>.

34 The sudden event of a stroke denies family members the time to prepare themselves  
35 for the caring role or the nature of the care they will need to provide. Some people find the  
36 role a positive experience, however, the demands of caring for a relative can increase stress  
37 and lower levels of mental and physical wellbeing<sup>4-8</sup>. Previous research has reported that the  
38 psychological impact of caring can result in increased frequency of anxiety and depressive  
39 episodes<sup>9, 10</sup> negatively affect relationships both within and external to the family, and reduce  
40 ability to participate in leisure activities or paid employment<sup>11, 12</sup>.

41 A wellbeing survey of UK stroke carers revealed that many experience negative  
42 psychological effects as a consequence of caring, namely anxiety (79%), frustration (84%),  
43 sleeping disturbances (60%), depression (56%), and stress (57%).<sup>13</sup> Given the lack of  
44 provision of psychological support services for stroke carers, it is unsurprising that declines  
45 in psychological and physical health of the carer can negatively impact the care provided to  
46 the survivor<sup>13, 14</sup>. However, research to develop effective support interventions for stroke  
47 carers has had limited success<sup>15, 16</sup>. For example, a systematic review of interventions for  
48 informal caregivers of stroke survivors found that non of the interventions included showed  
49 positive effects on all outcomes of carer wellbeing, which included caregiver burden,  
50 depression and anxiety, family functioning and quality of life. The interventions that focussed  
51 on providing the caregiver with information about stroke and available resources were least  
52 likely to have an impact on caregiver outcomes. However, those that included multiple  
53 intervention components such as stroke education, problem solving, emotional support and  
54 psychological support were more likely to show an early effect on the outcome of carer

55 wellbeing. <sup>17</sup> Therefore, in order to have a positive effect upon carer wellbeing it is important  
56 to consider the multiple sources of support needed by stroke carers when developing such  
57 interventions.

58 The biopsychosocial model of health and illness acknowledges the joint influence of  
59 biological (physical health), psychological (thoughts, emotions and behaviours) and social  
60 (relationships and roles) factors upon mental and physical wellbeing and emphasises that  
61 support interventions should focus on reducing negative symptoms and maintaining  
62 psychobiological health in order to be effective <sup>18</sup>. However, to ensure that they are fit for  
63 purpose in the context of stroke care it has been argued that involvement of the stroke carer  
64 perspective using a co-production approach, whereby stroke carer views and perspectives are  
65 used to inform the intervention content alongside those of other stakeholders such as  
66 clinicians or academics, is needed <sup>19</sup>. Also, involvement of experts in stroke care and stroke  
67 research can provide a complimentary perspective of the needs of the stroke carer population.

68 Therefore, the aim of the present study was to identify the key components of a  
69 biopsychosocial support intervention to improve mental wellbeing for stroke carers within the  
70 first year post-stroke based on the combined perspectives of experts in the field of  
71 psychological care after stroke and stroke carers themselves. ~~to use the existing literature base~~  
72 ~~along with stroke carer perspectives, and priority rankings from academic and clinical experts~~  
73 ~~in stroke care to identify key components to develop a biopsychosocial support intervention~~  
74 ~~for stroke carers.~~

75

76 **Methods**

77 ~~A participatory approach was adopted as the theoretical framework for the study and it was~~  
78 ~~developed in consultation with an expert group of stroke survivors and carers who advise on~~  
79 ~~local and national research, The University of Nottingham Stroke Research Partnership~~  
80 ~~Group (NSRPG). Two members of the group were involved in data collection procedures,~~  
81 ~~management of the consultation groups and discussion of the study findings.~~

82 **Research Design**

83 A mixed-methods cross-sectional design was adopted comprising: (i) Carer focus  
84 groups. These were conducted to give a ‘lived experience’ detailed picture of the support  
85 needs and priorities of stroke carers and (ii) a nominal group technique<sup>20-22</sup>. This method was  
86 used to reach consensus among stroke experts on priorities for intervention content. Written  
87 informed consent was obtained from all participants and ethical approval for the study was  
88 gained from the local research ethics committee (Nottingham 2 Research Ethics Committee,  
89 REC Ref: 14/EM/1264). This manuscript and the reporting of the study findings conform to  
90 the COREQ Guidelines<sup>23</sup> (see Supplementary Material).

91 A participatory approach involving stroke carers was adopted as the theoretical framework  
92 for the study. Cornwall & Jewkes (1995) described the approach as having four phases:  
93 Contractual (whereby participants consent to take part in research), Consultative (participants  
94 are consulted on their opinions), Collaborative (participants work with academic researchers  
95 on research project controlled by the researchers), and finally Collegiate (participants work  
96 alongside the academic researchers)<sup>24</sup>. The advantages of the participatory approach are that  
97 by working collegiately with the key stakeholder group their experiences and views yield  
98 better designed research studies with outcomes that hold greater relevance to their real-world  
99 experience .-As such the study protocol and research objectives were~~t was developed in~~  
100 consultation with an expert group of stroke survivors and carers who advise on local and

101 national research, The University of Nottingham Stroke Research Partnership Group  
102 (NSRPG). In line with the collegiate phase of the approach ¶two members of the group were  
103 also involved in data collection procedures, management of the consultation groups and  
104 discussion of the study findings.

105

## 106 *Data collection & Analysis*

### 107 *Carer focus groups*

108 ~~A convenience sample of 16 stroke carers (12 female; 8 spouses) Carers werewas~~ recruited  
109 from community stroke support and partnership groups in Nottinghamshire and were  
110 included in the study if their experience of being an informal stroke carer was < 1 year. We  
111 did not exclude based upon stroke characteristic of the survivor but we did exclude carers  
112 from taking part in the study if they were paid to undertake the care of the stroke survivor  
113 which would not have defined them as an informal carer. Ethical considerations were taken  
114 into account when constructing the sampling framework to ensure that a range of caring  
115 experiences were sampled and that the sample was not weighted towards i) one type of  
116 stroke, ii) the same type of post-stroke caring responsibilities, iii) family relationship to the  
117 survivor, or iv) employment status of the carer. All of which we felt were important sampling  
118 characteristics that could affect the experiences of the carer towards their caring role. Another  
119 consideration was whether it was ethical to collect data from stroke carers in a focus group  
120 format (ie. which would leave the stroke survivor without their carer), however all carers  
121 were eager to take part in the groups and arranged for the survivor to be looked after while  
122 they attended the group of their choice. - Participants were aged between 47 and 79 years old  
123 ~~(mean 57.5 years) and at the time of the study their time as carers ranged from 6 months to 10~~  
124 ~~years (median = 3 years).~~

125 ~~Participants~~ The carers could choose to attend only one out of a choice of three focus  
126 groups, which took place on different dates, and were attended one of three focus groups  
127 facilitated by the chief investigator (MW) and two other members of the research team (EK,  
128 PB) who assisted and took field notes. A topic guide was used to inform the group  
129 Discussions and was constructed were informed by following a review of the literature on  
130 the research literature on stroke caregiver support interventions up to and including the year  
131 2016. searing and The topic guide focussed on the biopsychosocial impact of being a stroke  
132 carer as well as practical issues to facilitating a support intervention (see Supplementary  
133 Material). Each group lasted for ~60 to 90 minutes and discussions were audio-recorded and  
134 transcribed verbatim. The data was organised using QSR NVivo 11 (QSR International Pty,  
135 Ltd) and inductively thematically analysed following the procedure detailed by Braun &  
136 Clarke<sup>25</sup>. An interpretive approach was taken to explore contextual, consequential, and  
137 hierarchical connections, and any discrepancies were resolved by discussion.

### 138 *Expert nominal group*

139 The Nominal Group Technique is one of the most common techniques used to obtain  
140 views and gain consensus on a given topic. Methodologically it belongs to the same family of  
141 techniques as the Delphi method, however unlike a Delphi it is conducted face-to-face with  
142 several ‘rounds’ of consensus gathering taking place with the same group of participants, in  
143 the same place, and at the same time until a final list of consensus priorities are agreed upon<sup>20</sup>

144 In the present study Ppurposive sampling through stroke research networks and  
145 clinical networks was used to identify nationwide ~~experts with~~ research and/or clinical  
146 experts. Participants were included if they had experience in psychological care or clinical  
147 carer after stroke and had experience relating to stroke carers. Participants were excluded if  
148 their experience did not relate to stroke or if they had no experience of working with stroke



149 carers. Those experts who were eligible to take part who were then invited to ~~take~~  
150 ~~part~~participate in the face-to-face expert nominal group with the aim of generating priorities  
151 for key components ~~elements~~ of a group intervention for the psychological care of stroke  
152 carers. ~~Ten experts consented to take part in the group; 4 came from a clinical background, 5~~  
153 ~~came from an academic background, and 1 had a dual clinical-academic role.~~

154 The nominal group was facilitated by MW who set out the objectives and processes  
155 involved in the expert nominal group exercise and asked participants to individually generate  
156 ideas in response to the question ‘What elements should be included in a biopsychosocial  
157 support intervention for informal carers of stroke survivors?’ This was followed by a ‘round  
158 robin’ sharing of ideas. Each participant in turn contributed one idea which was recorded on a  
159 flip chart without discussion. This was followed by a group discussion in which the facilitator  
160 ensured that all group members had the opportunity to contribute, and that all items were  
161 valid to the research question. Where appropriate, new items could be added, or  
162 amalgamated, but none were eliminated.

163 The meeting ended with each participant anonymously selecting and ranking their top  
164 priorities from the list, which were then collated to form the final list of rankings.

165

## 166 **Results**

### 167 *Carer Focus Groups*

168 A convenience sample of 16 stroke carers (12 female; 8 spouses) took part in the 3 focus  
169 groups; 5 carers attended Group 1, 5 carers attended Group 2, and 6 carers attended Group 3.  
170 The carers were aged between 47 and 79 years old (mean 57.5 years) and at the time of the  
171 study their time as a carer ranged from 6 months to 10 years (median = 3 years).

172 The themes outlined below represent recurring topics of discussion between the three five  
173 focus groups.

174 *Changes in Relationships, Roles and Dynamics:* Carers across each group described  
175 how there had been quite immediate and pervasive changes in the dynamics of their  
176 relationship with the survivor following the stroke. Many described how tensions had arisen  
177 between the carer and the stroke survivor due to the consequences of the stroke:

178 “I think the problem is...for us, he feels very vulnerable and he feels less of a man because  
179 he’s got these physical problems...and I think that puts a strain on the relationship.” (Focus Group 3,  
180 Carer 3, Wife).

181 For some carers changes had also taken place in their relationships with the wider  
182 family unit as family members assumed new roles so relationships had to be renegotiated.  
183 Carers spoke about how these new dynamics could result in instances of families either  
184 pulling together or bringing additional tensions which caused strain on these relationships:

185 “... if I’d have not had my sister, I don’t know what I would’ve done quite honestly...my  
186 brother then felt left out, you know and then commented on that...that was frustrating.” (Focus Group  
187 3, Carer 1, Daughter)

188 Carers talked about the reactions to the survivor’s stroke from members of their social  
189 circle which elicited feelings of disappointment in close members who had distanced  
190 themselves from them and failed to accommodate their change in circumstances. However,  
191 they also experienced feelings of surprise when ‘peripheral members’ of the social circle  
192 offered help. In this way the carer’s social support network could become restructured with  
193 members switching roles and social support often being provided from unexpected sources:

194 “...the strange thing is that some people you didn’t know that well start getting really  
195 interested in you. And other people who you knew really well...kind of move away because they’re  
196 worried about what they’ll find sort of thing” (Focus Group 2, Carer 2, [Husband](#))

197 *Emotional Impact and Acceptance:* Alongside the challenges of their new role carers  
198 were simultaneously having to deal with their own emotional response to the event and  
199 aftermath of the stroke as well as managing the emotions of the stroke survivor. This  
200 inevitably could cause considerable tensions:

201 “you know, she cries all the time and constantly will say ... I wish I were dead.. I wish this  
202 had never happened... and that’s really upsetting.” (Focus Group 3, Carer 2, [Husband](#))

203 Carers revealed feeling a sense of loss for the previous relationship with the stroke  
204 survivor and the life they once had together which was characteristic of the grief response,  
205 including anger, frustration, loneliness, despair and depression:

206 “I’ve been angry a lot of the time... basically that this has happened to us, you know... I used  
207 to go downstairs and I used to sob my heart out ‘cos it was just...devastating really. This wasn’t going  
208 to be fixed.” (Focus Group 3, Carer 4, [Wife](#)).

209 Over time they adapted to the new situation and there was a point of acceptance in  
210 coming to terms with how their lives had changed:

211 “When your life is completely sort of knocked sideways, what you want is to get it back to  
212 where it was. I think it’s all about learning to accept that that’s not gonna happen.” (Focus Group 2,  
213 Carer 2, [Husband](#))

214 *Drawing on Inner Resources:* Assuming this new- role daunted some of the carers and  
215 there was a sense of feeling unprepared for the added responsibilities they had to undertake  
216 and many carers discussed how they felt a need to be strong and self-reliant. For some, this  
217 was out of necessity due to their family situation, for others it was a natural coping

218 mechanism. There were also feelings of protectiveness towards the survivor and some carers  
219 were unwilling to accept help instead feeling that they should just be “getting on with it”:

220 “But I... but I wasn’t very open to offers of help at that stage, no. Because I just thought...  
221 you know, I can deal with this. This is my husband and I’ll sort it out.” (Focus Group 3, Carer [4](#),  
222 [Wife](#))

223 *Looking for Information, Solutions, Explanations:* There was a need to gain a better  
224 understanding of what had happened from very early on following the stroke, to gather  
225 information and look for solutions. Carers felt concern about what had caused the stroke and  
226 the chances of recurrence, and sought information about how to access formal care support,  
227 and how best to practically support the stroke survivor:

228 “...we just thought about ways that we could help dad and mum at home ...every single issue  
229 that she had, we as a family tried to source information about.” (Focus Group 1, Carer [1](#), [Son](#))

230 *Support from others:* Practical and emotional support from others, particularly friends  
231 and family, was seen by the carers as being key to their wellbeing and to provide relief from  
232 their situation. Contact and interaction from other carers who might empathise and give the  
233 benefit of their own experiences was raised as something they would value:

234 “...because of [wife’s name]’s rehabilitation there’s an awful lot of families and partners who  
235 sort of hang around there. And you do...you find yourself having conversations with them... you  
236 become an informal little support group.” (Focus group 2, Carer [4](#), [Husband](#))

237 There were varying degrees of input from health and social care agencies experienced  
238 by the carers across all of the groups. Typically the most input came at the early stages  
239 immediately post stroke and then gradually reduced. The withdrawal of input was described  
240 as being a difficult period and left some carers feeling abandoned:

241 “After hospital pretty much you get on with it and see what you can find out. Ring people that  
242 you think can help. I found no help whatsoever and I work for the NHS! I found that really difficult”  
243 (Focus group [3](#), Carer [6](#), [Wife](#))

244 ***Expert nominal group***

245 Ten experts consented to take part in the group; 4 came from a clinical background, 5  
246 came from an academic background, and 1 had a dual clinical academic role . All of the  
247 expert had over 15 years of experience in their respective roles (see Table 1)

248 

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249 Table 1 About Here

250 

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251

252 Table [21](#) shows the long-list of 30 ideas generated by the expert group and the total scores  
253 given for each item. This was then reduced to eight ranked priority areas during subsequent  
254 rounds of the nominal group technique and comparison with areas of agreement with the  
255 focus group findings.

256 

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257 Table [21](#) About Here

258 

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259

260 The ranked priorities from the expert nominal group identified the psychological,  
261 biological, and social effects of stroke on the carer along with practical considerations for  
262 delivering interventions and techniques that can be used within the intervention.

263 Areas of agreement were identified between the ranked priorities and the carer  
264 perspectives namely: acknowledging “normal” emotional reactions to the caring role,  
265 learning more about the biological basis of what a stroke was and how it impacts the  
266 survivor; developing problem solving skills to deal with caring situations; dealing with  
267 difficult emotions; loss reactions and dealing with adjustment; recognising the symptoms of  
268 not coping; knowing when and how to access practical and emotional support (see Appendix  
269 1 for conceptual map of areas of agreement).

270 Ranked priorities that were not in agreement with carer perspectives were related to  
271 the practicalities of intervention delivery: setting sessional boundaries (eg. session start/finish  
272 times, session duration, session frequency); setting tasks between sessions; knowledge and  
273 skill level of the facilitator on biological and psychological effects of stroke; and encouraging  
274 participants to form a social support network.

275 Other ranked priorities that were not identified in the carer perspectives related to  
276 therapeutic techniques to encourage the stroke carer’s self-reflection, increased self-  
277 awareness and thinking about the future, namely; using pictorial aides as prompts (ie. the  
278 stroke stress thermometer); acknowledging variation in previous life/relationship situations;  
279 acknowledge that carer and stroke survivor may have different perspectives on recovery;  
280 maintaining the carer’s future goals; developing strategies for taking care of their health such  
281 as self-monitoring; developing a wellbeing toolbox for the skills that they would learn during  
282 the group sessions (Table 3)-

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284 Table 3 About Here

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287 **Discussion**

288 This study sought to identify the key components for a biopsychosocial support intervention  
289 for stroke carers. To our knowledge this is the first study to use a nominal expert group  
290 technique alongside focus groups with stroke carers to identify joint priorities for a  
291 biopsychosocial support intervention. The findings of this study have highlighted important  
292 areas of agreement between expert priorities and carer perspectives which fall within the  
293 domains of the biopsychosocial model of health and illness, namely: learning more about  
294 what a stroke was and how it impacts the survivor (biological & psychological); developing  
295 problem solving skills to deal with caring situations (psychological); exploring normal  
296 emotional responses to the caring role (psychological); dealing with difficult emotions  
297 (psychological); loss reactions and dealing with adjustment (psychological); drawing on inner  
298 emotional resources (psychological); recognising the symptoms of not coping (biological &  
299 psychological); knowing when and how to access practical and emotional support  
300 (psychological & social).

301 Educating carers on the aetiology of a stroke and the physical, emotional and  
302 cognitive effects is in line with recommendations made by previous research<sup>26 27 28</sup>. For  
303 example, post-intervention accounts have reported carers gaining confidence by learning  
304 about the aetiology of a stroke<sup>27</sup> and a systematic review of systematic reviews<sup>16</sup> concluded  
305 that carer interventions that include information provision are effective in improving stroke  
306 carer quality of life.

307 Drawing on inner coping resources such as resilience and problem solving skills  
308 emerged from our carer focus groups as a priority for support and have been adopted as a  
309 coping strategy by stroke carers in other studies<sup>26, 29-31</sup>. Furthermore, a recent systematic  
310 review and meta-analysis<sup>31</sup> concluded that the inclusion of problem solving and stress-  
311 coping as intervention components had a positive effect on stroke carers' psychosocial  
312 wellbeing and reduced their use of healthcare resources<sup>15</sup>.

313 The findings of the present study have also highlighted points of deviation in the  
314 expert ranked priorities and the carer perspectives. Practical aspects for intervention delivery  
315 were ranked as priorities by the experts but were not highlighted by the carers. The experts  
316 also gave priority to techniques that the carers could use to encourage self-reflection and  
317 increase self-awareness and self-monitoring of their own emotional health and wellbeing,  
318 which also relate to the biological and psychological domains of the biopsychosocial model  
319 of health and illness. These may not have been identified as priorities by the carers because  
320 they are 'unknown unknowns' for them in terms of techniques they can use to monitor their  
321 emotional health and wellbeing because they have not been exposed to them before and so do  
322 not know about them, or that they do not know that they can be used as formal techniques.

323 The process of adjusting to the caring role and the need to explore difficult emotions  
324 were reflected in the focus group discussions among the carers in our study. The clinical  
325 implications drawn from qualitative studies of carer experiences support the adjustment  
326 response and associated emotional difficulties as priorities for the psychological health of  
327 stroke carers<sup>26, 32, 33</sup>. As noted by Backstrom et al<sup>32</sup> '...intervention strategies need to include  
328 awareness of the long-term impact of the changes in the relationship and the losses  
329 experienced by the spouses. Even if the partner is still alive, there are losses to grieve and to  
330 be understood and it is an important part of the transition in the relationship...' (p226). The  
331 stroke carers in our study didn't report a need to learn techniques to help them cope with this,



332 however they did report often having to deal with difficult emotions but coped with them  
333 alone without seeking professional psychological support or having any offered to them as  
334 part of standard care. Previous research highlights the negative implications of stroke carers  
335 suppressing emotions<sup>34</sup> and the implications on adjusting to the caring role<sup>35</sup>, along with  
336 emotional suppression being potentially detrimental to carers' long-term physical and  
337 emotional health<sup>35</sup>. This was supported by the accounts described by the carers in the present  
338 study.

339 Overall the joint findings of the stroke carer focus groups and the expert nominal  
340 group have identified key component for a support intervention for stroke carers which fits  
341 the biopsychosocial model of health and illness. Many of the priorities highlighted by both  
342 the carers and the experts related to the biological and psychological domains, and the  
343 priority identified relating to knowing when and how to seek support related to the social  
344 domain of the model. This resonates with the findings of previous research which has shown  
345 that interventions that include elements of peer support can be effective in helping carers  
346 cope and have positive effect on their wellbeing<sup>36</sup> This conceptual model will be used to  
347 develop the sessional plan of a biopsychosocial support intervention that can be delivered to  
348 stroke carers within the first year of caring.

### 349 **Strengths and limitations**

350 While this study provided data on the support needs of stroke carers, as well as expert  
351 consensus of ranked priorities, the findings should be considered in relation to the purpose of  
352 the study which was to inform the development of a biopsychosocial intervention. The data  
353 therefore underwent validation by two independent researchers to mitigate any interpretation  
354 bias. Furthermore, adopting a participatory design approach and conducting the study with  
355 stroke carers as co-researchers ensured that the study procedures were acceptable and

356 applicable to its target population. Finally, to enhance the validity of our interpretations they  
357 are presented and discussed in the context of previous research in this area.

358 However, a limitation of our approach was that the overall study findings did not undergo a  
359 further collaborative consultation process held simultaneously to include both the carers and  
360 experts after the initial individual consultation process. This provides an opportunity for  
361 future research on the needs of informal stroke carers to gain enhance the findings.

## 362 **Conclusion**

363 This study combined stroke carer perspectives and ranked priorities of expert stroke  
364 researchers and clinicians to identify key components for a biopsychosocial support  
365 intervention for stroke carers. Agreement of priorities between stroke carers and experts  
366 related to learning more about what a stroke is and how it impacts the survivor; developing  
367 problem solving skills to deal with caring situations; exploring normal emotional responses to  
368 the caring role; dealing with difficult emotions; loss reactions and dealing with adjustment;  
369 drawing on inner emotional resources; recognising the symptoms of not coping; knowing  
370 when and how to access practical and emotional support. There were also areas of difference,  
371 or areas that were highlighted by the experts only, which are also important to include as key  
372 components of a biopsychosocial support intervention for stroke carers, such as: defining  
373 sessional boundaries (ie. session start/finish times, times, session duration, session frequency),  
374 acknowledging variation in previous life/relationship situations, acknowledging differences  
375 in perspectives and expectations between the carer and survivor, developing strategies that  
376 carers can use to look after their own health and wellbeing, and encouraging carers to form  
377 social support networks. These key components will be taken forward to develop the  
378 biopsychosocial support intervention for stroke carers which will be tested in a feasibility  
379 randomised controlled trial.

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468

# 1 **The use of carer perspectives and expert consensus to define key** 2 **components of a biopsychosocial support intervention for stroke carers.**

3 Objective: To identify the key components of a biopsychosocial support intervention to  
4 improve mental wellbeing for informal stroke carers within the first year post-stroke  
5 based on the combined perspectives of experts in the field of psychological care after  
6 stroke and informal stroke carers themselves. Methods: After reviewing the existing  
7 literature a cross-sectional mixed-methods design was adopted comprising 1) focus  
8 groups with informal stroke carers about their psychological support needs, and 2)  
9 nominal group technique with academic and clinical stroke care experts to reach  
10 consensus on intervention priorities. Transcripts were thematically analysed and  
11 combined with the ranked priorities from the nominal group to identify key  
12 components for intervention content. Results: Key themes for informal stroke carers  
13 were associated with: 1) changes in relationships, roles, and dynamics; 2) emotional  
14 impact and acceptance; 3) drawing on inner resources; 4) looking for information,  
15 solutions, and explanations; 5) support from others. The expert nominal group placed  
16 priority on eight ranked areas: 1) acknowledging “normal” emotions; 2) education  
17 about the effects of a stroke; 3) reactions to loss and adjustment; 4) recognising signs of  
18 symptoms of not coping; 5) knowing how and when to access practical and emotional  
19 support; 6) strategies for taking care of own health; 7) dealing with difficult emotions;  
20 and 8) problem solving skills. Conclusions: Themes from the informal carer focus  
21 groups, and ranked priority areas will inform the development of a biopsychosocial  
22 support intervention for stroke carers to be tested in a feasibility randomised controlled  
23 trial.

24 Keywords: stroke, carers, biopsychosocial, nominal group technique, focus groups.

## 25 **Introduction**

26 According to figures published in February 2018 there are approximately 1.2 million stroke  
27 survivors in the UK and around 100,000 new strokes each year, with two thirds of which are  
28 living with a disability <sup>1</sup> and are cared for by family members and friends. An informal carer  
29 is defined as, ‘a person of any age who provides unpaid help and support to a relative, friend  
30 or neighbour who cannot manage to live independently without the carer’s help due to frailty,

31 illness, disability or addiction.<sup>2</sup> Therefore, they play a vital role in the rehabilitation and  
32 long-term care and deal with many practical, personal and emotional care needs<sup>3</sup>.

33 The sudden event of a stroke denies family members the time to prepare themselves  
34 for the caring role or the nature of the care they will need to provide. Some people find the  
35 role a positive experience, however, the demands of caring for a relative can increase stress  
36 and lower levels of mental and physical wellbeing<sup>4-8</sup>. Previous research has reported that the  
37 psychological impact of caring can result in increased frequency of anxiety and depressive  
38 episodes<sup>9, 10</sup> negatively affect relationships both within and external to the family, and reduce  
39 ability to participate in leisure activities or paid employment<sup>11, 12</sup>.

40 A wellbeing survey of UK stroke carers revealed that many experience negative  
41 psychological effects as a consequence of caring, namely anxiety (79%), frustration (84%),  
42 sleeping disturbances (60%), depression (56%), and stress (57%).<sup>13</sup> Given the lack of  
43 provision of psychological support services for stroke carers, it is unsurprising that declines  
44 in psychological and physical health of the carer can negatively impact the care provided to  
45 the survivor<sup>13, 14</sup>. However, research to develop effective support interventions for stroke  
46 carers has had limited success<sup>15, 16</sup>. For example, a systematic review of interventions for  
47 informal caregivers of stroke survivors found that non of the interventions included showed  
48 positive effects on all outcomes of carer wellbeing, which included caregiver burden,  
49 depression and anxiety, family functioning and quality of life. The interventions that focussed  
50 on providing the caregiver with information about stroke and available resources were least  
51 likely to have an impact on caregiver outcomes. However, those that included multiple  
52 intervention components such as stroke education, problem solving, emotional support and  
53 psychological support were more likely to show an early effect on the outcome of carer  
54 wellbeing.<sup>17</sup> Therefore, in order to have a positive effect upon carer wellbeing it is important

55 to consider the multiple sources of support needed by stroke carers when developing such  
56 interventions.

57         The biopsychosocial model of health and illness acknowledges the joint influence of  
58 biological (physical health), psychological (thoughts, emotions and behaviours) and social  
59 (relationships and roles) factors upon mental and physical wellbeing and emphasises that  
60 support interventions should focus on reducing negative symptoms and maintaining  
61 psychobiological health in order to be effective<sup>18</sup>. However, to ensure that they are fit for  
62 purpose in the context of stroke care it has been argued that involvement of the stroke carer  
63 perspective using a co-production approach, whereby stroke carer views and perspectives are  
64 used to inform the intervention content alongside those of other stakeholders such as  
65 clinicians or academics, is needed<sup>19</sup>. Also, involvement of experts in stroke care and stroke  
66 research can provide a complimentary perspective of the needs of the stroke carer population.

67         Therefore, the aim of the present study was to identify the key components of a  
68 biopsychosocial support intervention to improve mental wellbeing for stroke carers within the  
69 first year post-stroke based on the combined perspectives of experts in the field of  
70 psychological care after stroke and stroke carers themselves.

## 71 **Methods**

### 72 ***Research Design***

73         A mixed-methods cross-sectional design was adopted comprising: (i) Carer focus  
74 groups. These were conducted to give a ‘lived experience’ detailed picture of the support  
75 needs and priorities of stroke carers and (ii) a nominal group technique<sup>20-22</sup>. This method was  
76 used to reach consensus among stroke experts on priorities for intervention content. Written  
77 informed consent was obtained from all participants and ethical approval for the study was  
78 gained from the local research ethics committee (Nottingham 2 Research Ethics Committee,

79 REC Ref: 14/EM/1264). This manuscript and the reporting of the study findings conform to  
80 the COREQ Guidelines<sup>23</sup> (see Supplementary Material). The research team were all female  
81 academics with a background in stroke research.

82 A participatory approach involving stroke carers was adopted as the theoretical framework  
83 for the study. Cornwall & Jewkes (1995) described the approach as having four phases:  
84 Contractual (whereby participants consent to take part in research), Consultative (participants  
85 are consulted on their opinions), Collaborative (participants work with academic researchers  
86 on research project controlled by the researchers), and finally Collegiate (participants work  
87 alongside the academic researchers)<sup>24</sup>. The advantages of the participatory approach are that  
88 by working collegiately with the key stakeholder group their experiences and views yield  
89 better designed research studies with outcomes that hold greater relevance to their real-world  
90 experience . As such the study protocol and research objectives were developed in  
91 consultation with an expert group of stroke survivors and carers who advise on local and  
92 national research, The University of Nottingham Stroke Research Partnership Group  
93 (NSRPG). In line with the collegiate phase of the approach two members of the group were  
94 also involved in data collection procedures, management of the consultation groups and  
95 discussion of the study findings.

96

## 97 ***Data collection & Analysis***

### 98 *Carer focus groups*

99 Carers were recruited from community stroke support and partnership groups in  
100 Nottinghamshire and were included in the study if their experience of being an informal  
101 stroke carer was < 1 year. We did not exclude based upon stroke characteristic of the survivor  
102 but we did exclude carers from taking part in the study if they were paid to undertake the care



103 of the stroke survivor which would not have defined them as an informal carer. Ethical  
104 considerations were taken into account when constructing the sampling framework to ensure  
105 that a range of caring experiences were sampled and that the sample was not weighted  
106 towards i) one type of stroke, ii) the same type of post-stroke caring responsibilities, iii)  
107 family relationship to the survivor, or iv) employment status of the carer. All of which we felt  
108 were important sampling characteristics that could affect the experiences of the carer towards  
109 their caring role. Another consideration was whether it was ethical to collect data from stroke  
110 carers in a focus group format (ie. which would leave the stroke survivor without their carer),  
111 however all carers were eager to take part in the groups and arranged for the survivor to be  
112 looked after while they attended the group of their choice.

113           The carers could choose to attend only one out of a choice of three focus groups,  
114 which took place on different dates at the University of Nottingham, and were facilitated by  
115 the chief investigator (MW) and two other members of the research team (EK, PB) who  
116 assisted and took field notes. A topic guide was used to inform the group discussions and was  
117 constructed following a review of the literature on stroke caregiver support interventions up  
118 to and including the year 2016. s The topic guide focussed on the biopsychosocial impact of  
119 being a stroke carer as well as practical issues to facilitating a support intervention (see  
120 Supplementary Material). Each group lasted for ~60 to 90 minutes and discussions were  
121 audio-recorded and transcribed verbatim. The data was organised using QSR NVivo 11  
122 (QSR International Pty, Ltd) and inductively thematically analysed (PB, ST, EK) following  
123 the procedure detailed by Braun & Clarke<sup>25</sup>. An interpretive approach was taken to explore  
124 contextual, consequential, and hierarchical connections, and any discrepancies were resolved  
125 by discussion.

126 *Expert nominal group*

127           The Nominal Group Technique is one of the most common techniques used to obtain  
128 views and gain consensus on a given topic. Methodologically it belongs to the same family of  
129 techniques as the Delphi method, however unlike a Delphi it is conducted face-to-face with  
130 several ‘rounds’ of consensus gathering taking place with the same group of participants, in  
131 the same place, and at the same time until a final list of consensus priorities are agreed upon<sup>20</sup>

132           In the present study purposive sampling through stroke research networks and  
133 clinical networks was used to identify nationwide research and/or clinical experts.  
134 Participants were included if they had experience in psychological care or clinical carer after  
135 stroke and had experience relating to stroke carers. Participants were excluded if their  
136 experience did not relate to stroke or if they had no experience of working with stroke carers.  
137 Those experts who were eligible to take part who were then invited to participate in the face-  
138 to-face expert nominal group with the aim of generating priorities for key components of a  
139 group intervention for the psychological care of stroke carers.

140           The nominal group was facilitated by MW who set out the objectives and processes  
141 involved in the expert nominal group at the University of Nottingham and asked participants  
142 to individually generate ideas in response to the question ‘What elements should be included  
143 in a biopsychosocial support intervention for informal carers of stroke survivors?’ This was  
144 followed by a ‘round robin’ sharing of ideas. Each participant in turn contributed one idea  
145 which was recorded on a flip chart without discussion. This was followed by a group  
146 discussion in which the facilitator ensured that all group members had the opportunity to  
147 contribute, and that all items were valid to the research question. Where appropriate, new  
148 items could be added, or amalgamated, but none were eliminated.

149           The meeting ended with each participant anonymously selecting and ranking their top  
150 priorities from the list, which were then collated to form the final list of rankings.

151

## 152   **Results**

### 153   *Carer Focus Groups*

154   A convenience sample of 16 stroke carers (12 female; 8 spouses) took part in the 3 focus  
155 groups; 5 carers attended Group 1, 5 carers attended Group 2, and 6 carers attended Group 3.

156   The carers were aged between 47 and 79 years old (mean 57.5 years) and at the time of the  
157 study their time as a carer ranged from 6 months to 10 years (median = 3 years).

158   The themes outlined below represent recurring topics of discussion between the three focus  
159 groups.

160           *Changes in Relationships, Roles and Dynamics:* Carers across each group described  
161 how there had been quite immediate and pervasive changes in the dynamics of their  
162 relationship with the survivor following the stroke. Many described how tensions had arisen  
163 between the carer and the stroke survivor due to the consequences of the stroke:

164           “I think the problem is...for us, he feels very vulnerable and he feels less of a man because  
165 he’s got these physical problems...and I think that puts a strain on the relationship.” (Focus Group 3,  
166 Carer 3, Wife).

167           For some carers changes had also taken place in their relationships with the wider  
168 family unit as family members assumed new roles so relationships had to be renegotiated.

169   Carers spoke about how these new dynamics could result in instances of families either  
170 pulling together or bringing additional tensions which caused strain on these relationships:

171           “... if I’d have not had my sister, I don’t know what I would’ve done quite honestly...my  
172 brother then felt left out, you know and then commented on that...that was frustrating.” (Focus Group  
173 3, Carer 1, Daughter)

174           Carers talked about the reactions to the survivor’s stroke from members of their social  
175 circle which elicited feelings of disappointment in close members who had distanced  
176 themselves from them and failed to accommodate their change in circumstances. However,  
177 they also experienced feelings of surprise when ‘peripheral members’ of the social circle  
178 offered help. In this way the carer’s social support network could become restructured with  
179 members switching roles and social support often being provided from unexpected sources:

180           “...the strange thing is that some people you didn’t know that well start getting really  
181 interested in you. And other people who you knew really well...kind of move away because they’re  
182 worried about what they’ll find sort of thing” (Focus Group 2, Carer 2, Husband)

183           *Emotional Impact and Acceptance:* Alongside the challenges of their new role carers  
184 were simultaneously having to deal with their own emotional response to the event and  
185 aftermath of the stroke as well as managing the emotions of the stroke survivor. This  
186 inevitably could cause considerable tensions:

187           “you know, she cries all the time and constantly will say ... I wish I were dead.. I wish this  
188 had never happened... and that’s really upsetting.“ (Focus Group 3, Carer 2, Husband)

189           Carers revealed feeling a sense of loss for the previous relationship with the stroke  
190 survivor and the life they once had together which was characteristic of the grief response,  
191 including anger, frustration, loneliness, despair and depression:

192           “I’ve been angry a lot of the time... basically that this has happened to us, you know... I used  
193 to go downstairs and I used to sob my heart out ‘cos it was just...devastating really. This wasn’t going  
194 to be fixed.” (Focus Group 3, Carer 4, Wife).

195 Over time they adapted to the new situation and there was a point of acceptance in  
196 coming to terms with how their lives had changed:

197 “When your life is completely sort of knocked sideways, what you want is to get it back to  
198 where it was. I think it’s all about learning to accept that that’s not gonna happen.” (Focus Group 2,  
199 Carer 2, Husband)

200 *Drawing on Inner Resources:* Assuming this new role daunted some of the carers and  
201 there was a sense of feeling unprepared for the added responsibilities they had to undertake  
202 and many carers discussed how they felt a need to be strong and self-reliant. For some, this  
203 was out of necessity due to their family situation, for others it was a natural coping  
204 mechanism. There were also feelings of protectiveness towards the survivor and some carers  
205 were unwilling to accept help instead feeling that they should just be “getting on with it”:

206 “But I... but I wasn’t very open to offers of help at that stage, no. Because I just thought...  
207 you know, I can deal with this. This is my husband and I’ll sort it out.” (Focus Group 3, Carer 4,  
208 Wife)

209 *Looking for Information, Solutions, Explanations:* There was a need to gain a better  
210 understanding of what had happened from very early on following the stroke, to gather  
211 information and look for solutions. Carers felt concern about what had caused the stroke and  
212 the chances of recurrence, and sought information about how to access formal care support,  
213 and how best to practically support the stroke survivor:

214 “...we just thought about ways that we could help dad and mum at home ...every single issue  
215 that she had, we as a family tried to source information about.” (Focus Group 1, Carer 1, Son)

216 *Support from others:* Practical and emotional support from others, particularly friends  
217 and family, was seen by the carers as being key to their wellbeing and to provide relief from

218 their situation. Contact and interaction from other carers who might empathise and give the  
219 benefit of their own experiences was raised as something they would value:

220 “...because of [wife’s name]’s rehabilitation there’s an awful lot of families and partners who  
221 sort of hang around there. And you do...you find yourself having conversations with them... you  
222 become an informal little support group.” (Focus group 2, Carer 4, Husband)

223 There were varying degrees of input from health and social care agencies experienced  
224 by the carers across all of the groups. Typically the most input came at the early stages  
225 immediately post stroke and then gradually reduced. The withdrawal of input was described  
226 as being a difficult period and left some carers feeling abandoned:

227 “After hospital pretty much you get on with it and see what you can find out. Ring people that  
228 you think can help. I found no help whatsoever and I work for the NHS! I found that really difficult”  
229 (Focus group 3, Carer 6, Wife)

230 ***Expert nominal group***

231 Ten experts consented to take part in the group; 4 came from a clinical background, 5  
232 came from an academic background, and 1 had a dual clinical academic role . All of the  
233 expert had over 15 years of experience in their respective roles (see Table 1)

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235

Table 1 About Here

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238 Table 2 shows the long-list of 30 ideas generated by the expert group and the total scores  
239 given for each item. This was then reduced to eight ranked priority areas during subsequent

240 rounds of the nominal group technique and comparison with areas of agreement with the  
241 focus group findings.

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243

Table 2 About Here

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245

246 The ranked priorities from the expert nominal group identified the psychological,  
247 biological, and social effects of stroke on the carer along with practical considerations for  
248 delivering interventions and techniques that can be used within the intervention.

249 Areas of agreement were identified between the ranked priorities and the carer  
250 perspectives namely: acknowledging “normal” emotional reactions to the caring role,  
251 learning more about the biological basis of what a stroke was and how it impacts the  
252 survivor; developing problem solving skills to deal with caring situations; dealing with  
253 difficult emotions; loss reactions and dealing with adjustment; recognising the symptoms of  
254 not coping; knowing when and how to access practical and emotional support (see Appendix  
255 1 for conceptual map of areas of agreement).

256 Ranked priorities that were not in agreement with carer perspectives were related to  
257 the practicalities of intervention delivery: setting sessional boundaries (eg. session start/finish  
258 times, session duration, session frequency); setting tasks between sessions; knowledge and  
259 skill level of the facilitator on biological and psychological effects of stroke; and encouraging  
260 participants to form a social support network.

261 Other ranked priorities that were not identified in the carer perspectives related to  
262 therapeutic techniques to encourage the stroke carer's self-reflection, increased self-  
263 awareness and thinking about the future, namely; using pictorial aides as prompts (ie. the  
264 stroke stress thermometer); acknowledging variation in previous life/relationship situations;  
265 acknowledge that carer and stroke survivor may have different perspectives on recovery;  
266 maintaining the carer's future goals; developing strategies for taking care of their health such  
267 as self-monitoring; developing a wellbeing toolbox for the skills that they would learn during  
268 the group sessions (Table 3)

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Table 3 About Here

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272

## 273 **Discussion**

274 This study sought to identify the key components for a biopsychosocial support intervention  
275 for stroke carers. To our knowledge this is the first study to use a nominal expert group  
276 technique alongside focus groups with stroke carers to identify joint priorities for a  
277 biopsychosocial support intervention. The findings of this study have highlighted important  
278 areas of agreement between expert priorities and carer perspectives which fall within the  
279 domains of the biopsychosocial model of health and illness, namely: learning more about  
280 what a stroke was and how it impacts the survivor (biological & psychological); developing  
281 problem solving skills to deal with caring situations (psychological); exploring normal  
282 emotional responses to the caring role (psychological); dealing with difficult emotions  
283 (psychological); loss reactions and dealing with adjustment (psychological); drawing on inner



284 emotional resources (psychological); recognising the symptoms of not coping (biological &  
285 psychological); knowing when and how to access practical and emotional support  
286 (psychological & social).

287         Educating carers on the aetiology of a stroke and the physical, emotional and  
288 cognitive effects is in line with recommendations made by previous research<sup>26 27 28</sup>. For  
289 example, post-intervention accounts have reported carers gaining confidence by learning  
290 about the aetiology of a stroke<sup>27</sup> and a systematic review of systematic reviews<sup>16</sup> concluded  
291 that carer interventions that include information provision are effective in improving stroke  
292 carer quality of life.

293         Drawing on inner coping resources such as resilience and problem solving skills  
294 emerged from our carer focus groups as a priority for support and have been adopted as a  
295 coping strategy by stroke carers in other studies<sup>26, 29-31</sup>. Furthermore, a recent systematic  
296 review and meta-analysis<sup>31</sup> concluded that the inclusion of problem solving and stress-  
297 coping as intervention components had a positive effect on stroke carers' psychosocial  
298 wellbeing and reduced their use of healthcare resources<sup>15</sup>.

299         The findings of the present study have also highlighted points of deviation in the  
300 expert ranked priorities and the carer perspectives. Practical aspects for intervention delivery  
301 were ranked as priorities by the experts but were not highlighted by the carers. The experts  
302 also gave priority to techniques that the carers could use to encourage self-reflection and  
303 increase self-awareness and self-monitoring of their own emotional health and wellbeing,  
304 which also relate to the biological and psychological domains of the biopsychosocial model  
305 of health and illness. These may not have been identified as priorities by the carers because  
306 they are 'unknown unknowns' for them in terms of techniques they can use to monitor their

307 emotional health and wellbeing because they have not been exposed to them before and so do  
308 not know about them, or that they do not know that they can be used as formal techniques.

309         The process of adjusting to the caring role and the need to explore difficult emotions  
310 were reflected in the focus group discussions among the carers in our study. The clinical  
311 implications drawn from qualitative studies of carer experiences support the adjustment  
312 response and associated emotional difficulties as priorities for the psychological health of  
313 stroke carers<sup>26, 32, 33</sup>. As noted by Backstrom et al<sup>32</sup> ‘...intervention strategies need to include  
314 awareness of the long-term impact of the changes in the relationship and the losses  
315 experienced by the spouses. Even if the partner is still alive, there are losses to grieve and to  
316 be understood and it is an important part of the transition in the relationship...’ (p226). The  
317 stroke carers in our study didn’t report a need to learn techniques to help them cope with this,  
318 however they did report often having to deal with difficult emotions but coped with them  
319 alone without seeking professional psychological support or having any offered to them as  
320 part of standard care. Previous research highlights the negative implications of stroke carers  
321 suppressing emotions<sup>34</sup> and the implications on adjusting to the caring role<sup>35</sup>, along with  
322 emotional suppression being potentially detrimental to carers’ long-term physical and  
323 emotional health<sup>35</sup>. This was supported by the accounts described by the carers in the present  
324 study.

325         Overall the joint findings of the stroke carer focus groups and the expert nominal  
326 group have identified key component for a support intervention for stroke carers which fits  
327 the biopsychosocial model of health and illness. Many of the priorities highlighted by both  
328 the carers and the experts related to the biological and psychological domains, and the  
329 priority identified relating to knowing when and how to seek support related to the social  
330 domain of the model. This resonates with the findings of previous research which has shown  
331 that interventions that include elements of peer support can be effective in helping carers

332 cope and have positive effect on their wellbeing<sup>36</sup> This conceptual model will be used to  
333 develop the sessional plan of a biopsychosocial support intervention that can be delivered to  
334 stroke carers within the first year of caring.

### 335 **Strengths and limitations**

336 While this study provided data on the support needs of stroke carers, as well as expert  
337 consensus of ranked priorities, the findings should be considered in relation to the purpose of  
338 the study which was to inform the development of a biopsychosocial intervention. The data  
339 therefore underwent validation by two independent researchers to mitigate any interpretation  
340 bias. Furthermore, adopting a participatory design approach and conducting the study with  
341 stroke carers as co-researchers ensured that the study procedures were acceptable and  
342 applicable to its target population. Finally, to enhance the validity of our interpretations they  
343 are presented and discussed in the context of previous research in this area.

344 However, a limitation of our approach was that the overall study findings did not undergo a  
345 further collaborative consultation process held simultaneously to include both the carers and  
346 experts after the initial individual consultation process. This provides an opportunity for  
347 future research on the needs of informal stroke carers to gain enhance the findings.

### 348 **Conclusion**

349 This study combined stroke carer perspectives and ranked priorities of expert stroke  
350 researchers and clinicians to identify key components for a biopsychosocial support  
351 intervention for stroke carers. Agreement of priorities between stroke carers and experts  
352 related to learning more about what a stroke is and how it impacts the survivor; developing  
353 problem solving skills to deal with caring situations; exploring normal emotional responses to  
354 the caring role; dealing with difficult emotions; loss reactions and dealing with adjustment;  
355 drawing on inner emotional resources; recognising the symptoms of not coping; knowing

356 when and how to access practical and emotional support. There were also areas of difference,  
357 or areas that were highlighted by the experts only, which are also important to include as key  
358 components of a biopsychosocial support intervention for stroke carers, such as: defining  
359 sessional boundaries (ie. session start/finish times, times, session duration, session frequency),  
360 acknowledging variation in previous life/relationship situations, acknowledging differences  
361 in perspectives and expectations between the carer and survivor, developing strategies that  
362 carers can use to look after their own health and wellbeing, and encouraging carers to form  
363 social support networks. These key components will be taken forward to develop the  
364 biopsychosocial support intervention for stroke carers which will be tested in a feasibility  
365 randomised controlled trial.

366

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454

## Topic Guide for Focus Groups with Carers

1. Can you share your experience and what life was like following the stroke?

2. In what ways did life change for you?

Prompts:

- Did your social life change in anyway? Hobbies and leisure activities?
- Did roles and relationship change? Feelings toward the stroke survivor?
- Work life?
- New responsibilities?

3. What types of psychological difficulties did you experience (stress, anxiety, depression etc) if any following the stroke?

Prompts:

- How did you cope and manage these emotions?
- Did you speak to anyone? Receive any support for management of mood difficulties?

4. What were the most difficult or challenging aspects of life for you following the stroke?

5. Did you receive any support following the stroke?

Prompts:

- What form?
- Who from?
- Whether and why it was of benefit?

6. What additional support do you feel would have been of benefit?

7. What topics would be important for a support programme for stroke carers to cover?

8. If you had been offered a support programme what do you think would have been the barriers to you taking part? What would have helped you to take part?

Re-submission date: 18 April 2019

**Address to Editors:**

Elliot J. Roth, MD  
Editor-In-Chief  
Topics in Stroke Rehabilitation

Dear Prof Roth

RE: **Manuscript Ref: TSR1135 | Reply to Reviewer's Comments |**

We are pleased to receive both the reviewer and Associate Editor's comments on our manuscript entitled:

"The use of carer perspectives and expert consensus to define key components of a biopsychosocial support intervention for stroke carers"

We would like to take this opportunity to thank both the reviewers and the Associate Editor for their time in reviewing our manuscript and providing such useful feedback. We noticed that Reviewer 2 did not include any numbering of their comments so we have taken the liberty of doing so in order to make the itemization of the comments in the track changed manuscript easier to identify.

Please find enclosed 1) a copy of the revised manuscript with track changes, 2) a final formatted revised version, and 3) detailed itemized line by line responses to the reviewer's comments. Please do not hesitate to contact me should you need anything further in support of our manuscript.

We look forward to hearing from you.

Sincerely,

**Dr Laura Condon**

School of Medicine, University of Nottingham, UK

Email: [laura.condon@nottingham.ac.uk](mailto:laura.condon@nottingham.ac.uk)



Comments from the Editor and Reviewers:

Reviewer #1:

Abstract

1. The authors provide a concise summary of research study.
2. The objective stated in the abstract does not match the aim of study described in the introduction, namely the timeframe of "within the first year post-stroke"

**Response: We have amended the text in the introduction section to ensure that the aim and objective are consistent between the abstract and the introduction section. [Text amended: Pg 3 lines 69-70]**

Introduction

1. Authors clearly outline the significance of a support intervention to improve the mental wellbeing of stroke carers and the need to include both the perspectives of stroke carers and experts to develop such an intervention.
2. More information should be included about previous interventions and subsequent outcomes to better outline the gap in current research.

**Response: We have now included this information [Pg 2 line 47 – Pg 3 line 57].**

3. Page 2, Line 44-45: Why haven't past support interventions been successful? This is important information to include.

**Response: We have now included this information [Pg 2 line 47 – Pg 3 line 57].**

Methodology

1. The authors' state 'a participatory approach was adopted as the theoretical framework' but do not explain this theory, its' relation to the study, or include a citation for it.

**Response: We have now included much more detail about the participatory approach and its relevance to this study and have provided a reference for this [Pg 4 line 91 – Pg 5 line 104]**

2. Informed consent was obtained from patients but IRB approval was not mentioned.

**Response: We have now included the details of IRB approval and stated the approval reference allocated to the study [Pg 4 line 88-89].**

3. The authors state 'existing literature base' used to identify key components to be included in an intervention but this information is not reported and it is unclear if this is a date source for this study.

**Response: We have now included the date source for the review of the existing literature [Pg 6 line 131].**

4. Inclusion/exclusion criteria for both stroke carer and expert participants not described.

**Response: We have now included the inclusion and exclusion criteria for both the stroke carer and expert participants for clarity in the 'Methods' section [Pg 5 line 110-113 & Pg 6 line 146-148].**

5. Demographics of participants are included in 'Methods' rather than 'Results'

**Response: We have now moved the information on demographics to the 'Results' section [Pg 7 line 168-171 & Pg 11 line 245-247].**

6. Were there questions that guided the focus group discussions with stroke carers?

**Response: Yes, there was a topic guide for the focus group discussions with stroke carers. We have now provided a description of this in the manuscript and a copy of the full topic guide as supplementary material. [Pg 6 line 128]**

7. How many stroke carers participated in each focus group?

**Response: We have now included these details in the manuscript [Pg 7 line 168-169].**

8. No explanation of 'nominal group technique'. Recommend authors' expound on this method especially since this is described as part of the novelty of the study.

**Response: We have now included much more detail about the Nominal Group Technique and provided a reference for this [Pg 6 line 139-143].**

#### Results/Discussion

1. The authors present data that is relevant to their research aim and provide great quotations to support their findings. They also do a good job of discussing their results in relation to studies on similar topics.
2. Demographics of experts are not included.

**Response: We have now included the demographic details of the experts in Table 1.**

3. Background of experts is vague. What are their specific roles?

**Response: We have now provided the details of the specific roles of the experts in Table 1**

4. In the 'Methods', the authors state 3 focus groups were conducted but in the 'Results' a total of 5 focus groups are described

**Response: We thank the reviewer for this comment and have amended the 'Methods' section to state more clearly that there were three focus groups, not five as previously stated. [Pg 6 line 125-126]**

5. A total of 16 stroke carers participated in 1 of 3, or 5, focus groups but exemplary quotes show quotes from carers at multiple focus groups. For example, quotes are included from Carer 2 in Focus groups 2 and 4. Were carers allowed to attend more than one focus group? Please make the protocol for attendance clear in the 'Methods'.

**Response: Again, we must thank the reviewer for this comment as upon reflection we realized that this was confusing for the reader. There were three focus groups held on different dates and the carers could choose to attend only one of the groups. We have now amended the Methods section with this information for clarity. [Pg 6 line 125-126]**

6. Suggest including demographics of each carer since participants are referenced as Carer 1, Carer 2, etc. with their quotes.

**Response: We have added the demographics of each carer with their quotes [Pg 7- 11 line 168-243].**

7. Explanation of conceptual model is needed as well as how it will be used in next steps of intervention development.

**Response: We have now included the detail of how the conceptual model will be used in the next steps of intervention development [Pg 15 line 346-348].**

8. Recommend adding an additional figure/chart to display comparison of findings from stroke carers and experts to better showcase areas of agreement and differences between the two groups as current 'listing' approach used by the authors is difficult to follow.

**Response: We thank the reviewer for this comment and agree that this is helpful for the reader. We have now added an extra table (Table 3) to display this comparison in a clearer way**

9. No connection of findings to the biopsychosocial model of health and illness

**Response: We have now provided clearer connection of the how the findings connect with the biopsychosocial model of health and illness [Pg 14 line 318-322 & Pg 15 line 339-348].**

10. More discussion of the deviation between the stroke carers and experts perspectives is needed as this is an interesting finding as well as an area for additional research.

**Response: We have now provided more discussion of the deviation between the stroke carers and experts perspectives [Pg 14 line 318-322].**

11. There was no mention of the limitations of this study.

**Response: We have now added more detail about the limitations of the study to the section 'Strengths and limitations' [Pg 16 line 358-361].**

#### Conclusion

1. Need clarity around what the 'key components' were determined to be. Conclusion reads as though only the areas of agreement between stroke carers and experts were determined to be the key components that will be the basis of the support intervention. If this is correct, why not also include areas that differed between the two groups?

**Response: We thank the reviewer for this comment as have added more detail to the conclusion section to explain more fully that areas of disagreement are also to be included as key components of the intervention [Pg 16 line 370-377]**

#### Reviewer #2:

If you have any further comments or questions for the EDITOR, you may enter them here.

This is an important area of research and it is good to see a study that is examining the perspectives of informal carers and clinical experts to inform the development of a supportive intervention.

In order to strengthen the article the following needs to be addressed:

1. Inclusion of 'informal' carer in abstract so it is clear the focus of the study is on informal carers.

**Response: We have included 'informal' throughout the abstract to ensure that the readership are clear that the focus of the study is on informal carers. [Pg 1, lines 4, 6, 8, 12, 20]**

2. Include dates to justify data presented (line 25 pg. 1)

**Response: We have now added in the date of publication of these statistics to justify the data presented. [Pg 1, line 26]**

3. Review punctuation and grammar throughout paper.

**Response: We thank the reviewer for this helpful comment. We have conducted a punctuation and grammar check throughout the whole manuscript and have now amended these errors.**

4. Explanation required for 'co-production' approach ( line 52 pg.2)

**Response: We have now given a fuller explanation to the co-production approach in the context of stroke carer research [Pg 3 line 64-66].**

5. Ethical considerations needs to be included in the paper

**Response: We have now included our ethical considerations in the manuscript [Pg 5 line 113-122].**

6. Further explanation regarding the participatory action approach as a theoretical framework and include appropriate references.

**Response: We have now included much more detail about the participatory approach and it's relevance to this study and have provided a reference for this [Pg 4-5 line 91-104]**

7. Research design and research methods needs to be explained more clearly with the design stated first followed by the methods

**Response: We have now restructured this section so that the design is stated first followed by the study methods.**

8. Additional detail regarding focus groups is required to identify the number of participants in each focus groups and to identify if the 12 female and spouses attended the same groups. This could be reworded to state " pairs of family members" etc

**Response: We have now reworded this section to provide more clarity on the structure of the focus groups [Pg 6 lines 125-126].**

9. Additional detail is also required to identify if an interview schedule was utilised and if not the broad areas of discussion should be stated.

**Response: Yes, there was a topic guide for the focus group discussions with stroke carers. We have now provided a description of this in the manuscript and a copy of the full topic guide as supplementary material.[Pg 6 line 128-133].**

10. Clarification is required to identify if the focus groups discussed strategies to support their needs in a similar way to the expert nominal group "who ranked ... practical considerations for delivering interventions and techniques...". If this was not included as part of the fgi discussion this needs to be stated as a limitation.

**Response: We have now added more detail in the manuscript for clarity and have provided a copy of the full topic guide for the focus groups as supplementary material [Pg 6 line 128-133].**

11. Additional detail is required to identify the professional groups included in the expert nominal groups and to identify if the groups were conducted face to face.

**Response: We have now provided the details of the specific roles and the demographics of the experts in Table 1. We have also clarified in the manuscript that the groups took place face-to-face [Pg 6 line 141 & Pg 7 line 150].**

12. The inclusion of additional exemplars for each theme in the findings from the informal carer group would strengthen the results section.

**Response: We thank the reviewer for this comment. We do feel that we have presented the most representative quotes in the manuscript.**

13. The term "setting sessional boundaries" in the results section of experts needs explanation.

**Response: We have now added more explanation of this term and agree with the reviewers comment that the initial term needed more explanation. [Pg 12 line 271-272].**

14. The lack of collaborative consultation with both groups together after the individual consultation needs to be recognised as a limitation or included as an opportunity for further research as part of the development of the intervention.

**Response: We thank to reviewer for this comment and have now included this important limitation of our work and have included a statement for further research in the area to use this method to enhance their findings. [Pg 16 line 358-361].**

15. The references should be reviewed to ensure inclusion of more current literature. Interesting to note there are no references to peer support programs (PSP) and are reported as a useful strategy to support not only stroke survivors but also for informal carers.

**Response: We have now included more current references to peer support programs [Pg15 line 344-348].**

16. The diagrammatic representation of the fgi themes requires refinement as it could be presented more clearly.

**Response: We have now amended the diagram in Appendix 1 to present the focus group themes more clearly**

#### Additional Comments from the Editor in Chief:

Like many journals, Topics in Stroke Rehabilitation requires that manuscripts conform to the EQUATOR guidelines (Enhancing the QUALity and Transparency Of health Research, <http://www.equator-network.org>), which for this manuscript requires using the "Consolidated criteria for reporting qualitative research" (COREQ) Guidelines.

Therefore, it is necessary that you:

- Insure that your manuscript conforms to the COREQ Guidelines;
- State in the Methods section that your manuscript conforms to the COREQ Guidelines; and
- Include a completed checklist demonstrating that your manuscript conforms to the COREQ Guidelines, available at:

Tong A, Sainsbury P, Craig J: Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups, International Journal for Quality in Health Care, Volume 19, Issue 6, 1 December 2007, Pages 349–357, <https://doi.org/10.1093/intqhc/mzm042>.

**Response: We have reviewed our manuscript and completed a checklist demonstrating how it meets the COREQ guidelines. We have then submitted the checklist as Supplementary Material along with the revised manuscript and have also stated these details in the 'Methods' section.[Pg 4 line 89-90].**

1 **Acknowledgements**

2 **Financial support/disclosures:** This study was funded by the National Institute for Health Research  
3 (Research for Patient Benefit Programme, Biopsychosocial Intervention for Stroke Carers (BISC),  
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6 **Additional contributions:** The authors wish to thank all of the study participants for their time and  
7 the members of the Nottingham Stroke Research Partnership Group for their contributions to the  
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10 assistance with data collection and input into the study design, and to Helen Taylor for assistance with  
11 transcription.

12 **Disclosure statement:** No conflict of Interest is declared.

13 **Ethical approval:** The study protocol was reviewed and approved by the Nottingham 2  
14 Research Ethics Committee (REC Ref: 14/EM/1264).

15

16 **Trial Registration Number:** ISRCTN15643456

### COREQ (CONsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	Pg 6
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	Title Page
Occupation	3	What was their occupation at the time of the study?	Pg 4
Gender	4	Was the researcher male or female?	Pg 4
Experience and training	5	What experience or training did the researcher have?	Pg 4
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	No
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	None
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Pg 4
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Pg 4
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Pg 6
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	Pg 5 Pg6
Sample size	12	How many participants were in the study?	Pg7 Pg11
Non-participation	13	How many people refused to participate or dropped out? Reasons?	None
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	Pg 6 Pg 7
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	No
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	Pg8 Pg11
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Pg 6
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	None
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	Pg 6
Field notes	20	Were field notes made during and/or after the inter view or focus group?	Pg 6
Duration	21	What was the duration of the inter views or focus group?	Pg 6
Data saturation	22	Was data saturation discussed?	No



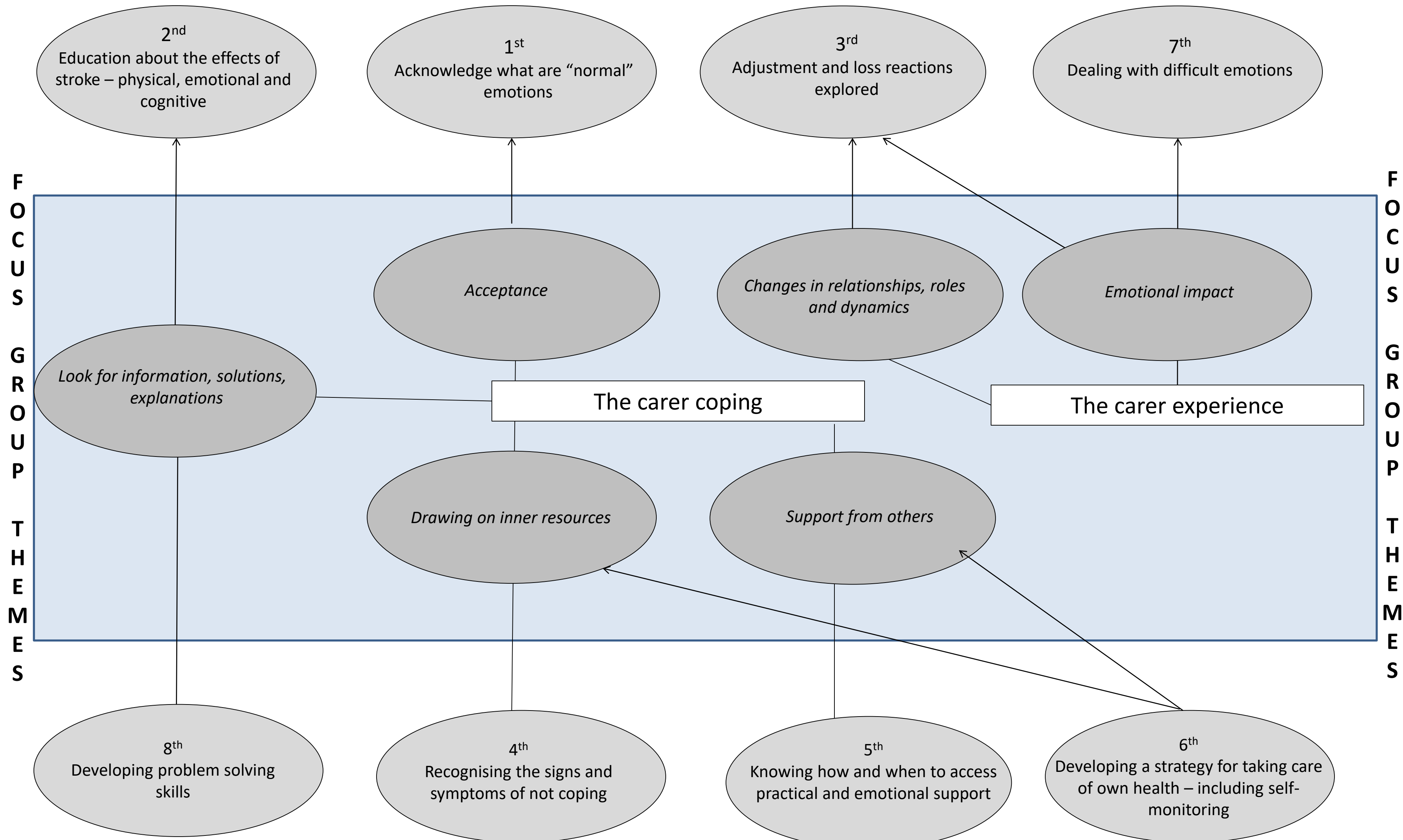
Transcripts returned	23	Were transcripts returned to participants for comment and/or	
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Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	No
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	Pg6
Description of the coding tree	25	Did authors provide a description of the coding tree?	No
Derivation of themes	26	Were themes identified in advance or derived from the data?	Pg6
Pg6	27	What software, if applicable, was used to manage the data?	Pg 6
Participant checking	28	Did participants provide feedback on the findings?	No
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Pg8-11
Data and findings consistent	30	Was there consistency between the data presented and the findings?	Pg8 -17
Clarity of major themes	31	Were major themes clearly presented in the findings?	Pg 8-11
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	Pg 8-11

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

**Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.**

### Nominal group priorities (with ranking)



### Nominal group priorities (with ranking)

Table 1: Stroke Expert Characteristics

<b>Expert Role</b>	<b>M/F</b>	<b>Nominal Group Perspective</b>	<b>Years in Role</b>
1. Academic (Clinical Psychology & Stroke)	F	Academic	>35
2. Clinical (Mental Health Specialist Nurse – Stroke)	M	Clinical	>30
3. Academic (Stroke Nursing & Psychology)	F	Academic	>25
4. Academic (Stroke Nursing)	F	Academic	>30
5. Academic (Speech & Language, Stroke)	F	Academic	>30
6. Clinical (Stoke clinician)	F	Clinical	>30
7. Clinical (Clinical Psychology)	M	Clinical	>25
8. Academic (Clinical Psychology & Stroke)	M	Academic	>35
9. Academic (Clinical Psychology & Stroke)	F	Clinical & Academic	>20
10. Clinical (Stoke clinician)	M	Clinical	>30

Table 2: Full list of ranked scores of support needs as identified by the expert nominal group

<b>Support Needs Generated</b>	<b>Score</b>	<b>Ranking</b>
1. Acknowledge what are “normal” emotions	64	1*
2. Education about the effects of stroke – physical, emotional and cognitive	60	2*
3. Adjustment and loss reactions explored	55	3*
4. Recognising the signs and symptoms of not coping	51	4*
5. Knowing how and when to access practical and emotional support	39	5*
6. Developing a strategy for taking care of own health – including self-monitoring	32	6*
7. Dealing with difficult emotions eg sadness, guilt, resentment	31	7*
8. Developing problem solving skills	28	8*
9. Exploration of strengths and difficulties for carer and survivor	23	9
10. Development of communication skills and active listening	21	10
11. Coping styles and reappraisal strategies	19	=11
12. Maintaining and having own goals for future	19	=11
13. Discussion around common themes: social participation, roles, identities, relationships	18	12
14. Direction to resources for relaxation and mindfulness	16	13
15. Make clear at induction the scope and limitations of the intervention	12	14
16. Planning for a different future	9	=15
17. Use of stroke stress thermometer to identify/explain issues	9	=15
18. Acknowledging variation in previous life/relationship situations – residential situation, pre-existing mental health issues	8	16
19. Carer and survivor may have different perspectives on recovery	7	=17
20. Individualised tasks to try between sessions	7	=17
21. Encourage group members to form own social support network	6	=18
22. Risk taking and how to manage it	6	=18
23. Group ground rules/aims for session to facilitate interaction	5	19
24. Developing a tool box of skills learnt throughout the group	2	20
25. Something physical to take away as prompt/reminder	1	=21
26. Matching what is to be delivered to the skills of the psychologist delivering it	1	=21
27. Components should be those for which there is evidence of effectiveness	0	=22
28. CBT strategies to address anxiety and depression	0	=22
29. Flexibility of session depending on problems identified in session	0	=22
30. Ability for each session to be self-contained (to allow non-attendance)	0	=22

= denotes joint ranking; \* indicates final list of top priority areas identified

Table 3: Areas of agreement compared to areas of difference between the stroke carer views and the expert views.

<b>Areas of Agreement</b>	<b>Areas of Difference</b>
Acknowledge what are “normal” emotional reactions to the caring role	Defining sessional boundaries (ie. session start/finish times, times, session duration, session frequency)
Learning more about the biological basis of what a stroke is.	Setting tasks between sessions.
How the stroke impacts the survivor.	Knowledge of the session facilitator on biological and psychological effects of stroke
Developing problem solving skills to deal with caring situations.	Encouraging carer to form social support networks.
Dealing with difficult emotions.	
Dealing with loss reactions and adjustment.	
Recognising the symptoms of not coping.	
Knowing when and how to access practical and emotional support.	
<b>Areas of Priority Identified By Experts, But Not By Carers</b>	
Using pictorial aides as prompts for self-reflection (ie. the stroke stress thermometer).	
Acknowledging variation in previous life/relationship situations.	
Acknowledging that the carer and survivor may have different perspectives and expectations on the survivor’s recovery.	
Maintaining the carer’s future goals.	
Developing strategies for taking care of their own health (carer) such as self-monitoring.	
Developing a “wellbeing toolbox” of different strategies for taking care of their own health (carer).	