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

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

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

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

Introduction

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

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

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

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

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

Methods

Research Design

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

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

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

Data collection & Analysis

Carer focus groups

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

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

Expert nominal group

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

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

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

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

Results

Carer Focus Groups

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

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

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

> "I think the problem is...for us, he feels very vulnerable and he feels less of a man because he's got these physical problems…and I think that puts a strain on the relationship." (Focus Group 3, Carer 3, Wife).

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

> "… if I'd have not had my sister, I don't know what I would've done quite honestly…my brother then felt left out, you know and then commented on that...that was frustrating." (Focus Group 3, Carer 1, Daughter)

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Expert nominal group

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

Table 1 About Here

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

Table 2 About Here

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

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

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

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

Table 3 About Here

Discussion

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

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

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

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

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

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

Strengths and limitations

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

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

Conclusion

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

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Introduction

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

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

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

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

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

Methods

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

Research Design

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

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

Data collection & Analysis

Carer focus groups

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

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

Expert nominal group

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

In the present study ~~P~~purposive sampling through stroke research networks and clinical networks was used to identify nationwide ~~experts with~~ research and/or clinical experts. Participants were included if they had experience in psychological care or clinical carer after stroke and had experience relating to stroke carers. Participants were excluded if their experience did not relate to stroke or if they had no experience of working with stroke carers. Those experts who were eligible to take part who were then invited to ~~take part~~participate in the face-to-face expert nominal group with the aim of generating priorities for key components ~~elements~~ of a group intervention for the psychological care of stroke carers. ~~Ten experts consented to take part in the group; 4 came from a clinical background, 5 came from an academic background, and 1 had a dual clinical academic role.~~

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

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

Results

Carer Focus Groups

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

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

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

> "I think the problem is...for us, he feels very vulnerable and he feels less of a man because he's got these physical problems…and I think that puts a strain on the relationship." (Focus Group 3, Carer 3, Wife).

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

> "… if I'd have not had my sister, I don't know what I would've done quite honestly…my brother then felt left out, you know and then commented on that...that was frustrating." (Focus Group 3, Carer 1, Daughter)

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Expert nominal group

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

Table 1 About Here

Table 2~~1~~ shows the long-list of 30 ideas generated by the expert group and the total scores given for each item. This was then reduced to eight ranked priority areas during subsequent rounds of the nominal group technique and comparison with areas of agreement with the focus group findings.

Table 2~~1~~ About Here

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

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

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

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

Table 3 About Here

Discussion

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

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

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

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

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

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

Strengths and limitations

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

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

Conclusion

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

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

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

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

Introduction

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

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

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

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

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

Methods

Research Design

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

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

Data collection & Analysis

Carer focus groups

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

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

Expert nominal group

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

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

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

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

Results

Carer Focus Groups

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

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

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

> "I think the problem is...for us, he feels very vulnerable and he feels less of a man because he's got these physical problems…and I think that puts a strain on the relationship." (Focus Group 3, Carer 3, Wife).

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Expert nominal group

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

Table 1 About Here

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

Table 2 About Here

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

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

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

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

Table 3 About Here

Discussion

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

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

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

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

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

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

Strengths and limitations

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

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

Conclusion

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

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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

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

<u>Additional Comments from the Editor in Chief:</u>

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].

Acknowledgements

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Additional contributions: The authors wish to thank all of the study participants for their time and the members of the Nottingham Stroke Research Partnership Group for their contributions to the participatory study design. They would also like to thank the members of the expert nominal group for their contributions. Thanks go to Dr Joanna Fletcher-Smith and Dr Christine Cobley for their assistance with data collection and input into the study design, and to Helen Taylor for assistance with transcription.

Disclosure statement: No conflict of Interest is declared.

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

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.
Domain 1: Research team and reflexivity			
Personal characteristics			
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
Relationship with participants			
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
Domain 2: Study design			
Theoretical framework			
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
Participant selection			
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
Setting			
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
Data collection			
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	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	No
Domain 3: analysis and findings			
Data analysis			
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
Reporting			
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.

Figure

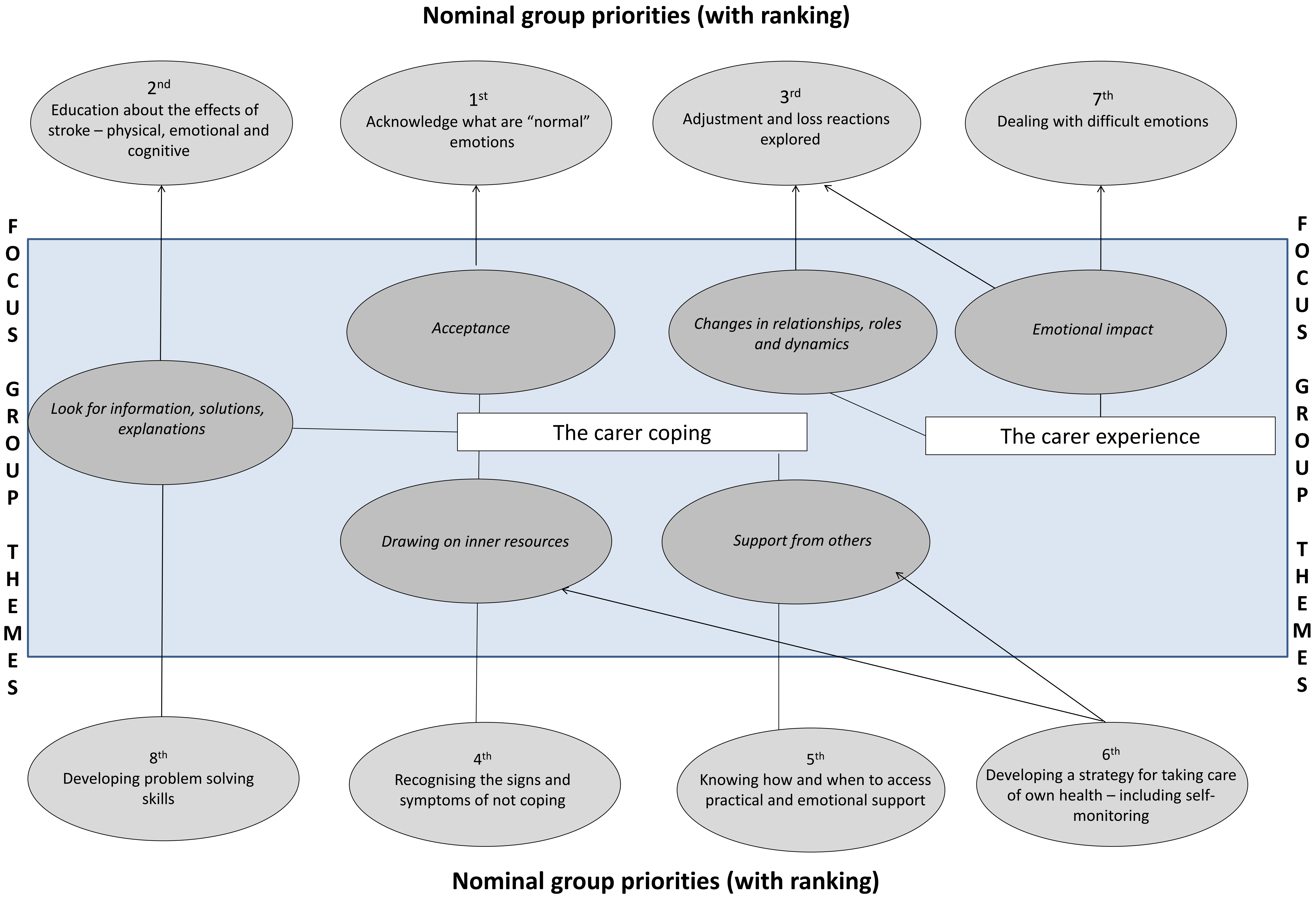
Nominal group priorities (with ranking)
2nd Education about the effects of stroke – physical, emotional and cognitive
1st Acknowledge what are "normal" emotions
3rd Adjustment and loss reactions explored
7th Dealing with difficult emotions
FOCUS GROUP THEMES
Acceptance
Changes in relationships, roles and dynamics
Emotional impact
Look for information, solutions, explanations
The carer coping
The carer experience
Drawing on inner resources
Support from others
FOCUS GROUP THEMES
8th Developing problem solving skills
4th Recognising the signs and symptoms of not coping
5th Knowing how and when to access practical and emotional support
6th Developing a strategy for taking care of own health – including self-monitoring
Nominal group priorities (with ranking)

Table 1: Stroke Expert Characteristics

Expert Role	**M/F**	**Nominal Group Perspective**	**Years in Role**
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

Support Needs Generated	Score	Ranking
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.

Areas of Agreement	**Areas of Difference**
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.	

Areas of Priority Identified By Experts, But Not By Carers
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).