PEER REVIEW HISTORY

ARTICLE DETAILS

TITLE (PROVISIONAL)	What helps and hinders the provision of healthcare that minimises treatment burden and maximises patient capacity? A qualitative study of stroke health professional perspectives
AUTHORS	Kyle, John; Skleparis, Dimitris; Mair, Frances; Gallacher, Katie I

VERSION 1 - REVIEW

REVIEWER	Carole Parsons Queen's University Belfast
REVIEW RETURNED	07-Oct-2019

GENERAL COMMENTS	This is an interesting study of healthcare professional perspectives regarding minimising treatment burden and maximising patient capacity. The aims and methods have been well described, and the results clearly presented and discussed in the context of previous work in the field. Future work has also been clearly outlined. The COREQ criteria for reporting qualitative research should be used and included in the supplementary files to illustrate where each of the criteria have been met.

REVIEWER	Jacqueline Morris University of Dundee United Kingdom
REVIEW RETURNED	30-Oct-2019

GENERAL COMMENTS	This study addresses treatment burden, an important topic in post-stroke care, that is increasingly been seen as problematic for stroke survivors. The authors explore the views of a range of health professionals to identify the barriers and facilitators to minimising treatment burden. The strength of this study is that it identifies pragmatic issues in the organisation of healthcare services that influence patient experiences of care after stroke. The main limitations are the description and justification of methods, which is scant in places, and the largely descriptive presentation of the data. Given the range of participants and contexts from which they were recruited, the richness and explanatory power of the study could have been stronger. Abstract

	The abstract identifies the key themes identified within the study, but does not mention the barriers, facilitators and solutions, that were the stated aim of the study. Introduction The authors provide a definition of “treatment burden” and describe it as being the self-management workload experienced by stroke survivors. The authors imply that treatment burden relates to the work that is imposed by healthcare guidelines and systems and discuss difficulties in adherence to prescribed care. They appear to conflate treatment burden with self-management, without really defining what self-management is. I would argue that self-management is the actions and decisions people make themselves to manage their own health, with or without support from healthcare providers, and in the light of the information and knowledge that they have about their condition. This is qualitatively different from the idea of burden imposed by healthcare treatments and deficiencies in the healthcare pathway described in the introduction. I suggest the authors revisit this section and reconsider their use of the term self-management in this context or define more fully what they mean by it. Methods The methods are described in scant detail in places. It is not clear how participants were identified and recruited, by whom and in what contexts. The criteria and rationale for purposive sampling – maximum variation, theoretical, convenience etc are not described and there are no details about how the criteria were operationalised as the study progressed, or by whom. Was a sampling frame used? The authors mention that data collection and analysis occurred concurrently – how did that influence the sampling strategy? Context is extremely important for interpretation of qualitative data and more detail should be provided. There should be more detail about how the interview schedule was derived. There is no description of any conceptual of theoretical basis for the study, therefore clear information about decisions on the structure and content of the interview schedule should be provided. Similarly the ontological and epistemological basis for the study is not provided, and should be described to provide readers with a sense of where the authors are positioned on these matters. The approach to ensuring coding reliability is rigorous, however it is less clear how the coding framework was derived. The authors discuss inductive and deductive coding, but do not describe how each approach was applied. As they were not using a theoretical framework to guide analysis, a description and distinction between deductive concepts and those that were inductively derived should be provided, to indicate how the final themes were arrived at. Why was thematic analysis selected as the analytical approach? As there are many analytical methods in qualitative research, it is important to specify why one approach was selected over another, and this should probably be seen to relate to the philosophical approach adopted for the study. Results The findings are clearly presented, but descriptive, as opposed to conceptual and explanatory. I would like to have seen more interrogation of the data to explore how and why the barriers and facilitators occurred in different settings and from the perspective of different participants. The idea of purposeful sampling is to identify a range of views so that contextual factors that influence experiences or perceptions can be explored. A range of

	professionals were interviewed, yet their distinctive perceptions were not really brought out. Whilst many issues would have been shared, the authors could have taken the analysis to a higher level by comparing and contrasting the views of different professional groups within different setting to explore the discussed phenomena in a more nuanced and richer fashion. For example, it would have been interesting and important to explore and compare within the dataset how the different professionals understand complex post-stroke difficulties experienced by patients. How complexity influences the treatment they provide or recommend, and its impact on burden could have been explored more fully to give a more in-depth explanation of the reasons for burden. Although the themes make sense, overall this reads a bit like a service evaluation, relevant to a particular service. Although qualitative research cannot be generalised, it often seeks to add conceptual or theoretical clarity, that can be examined more broadly beyond the specific setting. This is not a piece of work that can currently add much to broader conceptual understanding of burden because many issues are so service specific, but it could. I am sure if the authors took a more comparative approach to exploring how perspectives of participants agree or differ, and explored how context influenced them, they could provide a richer and more conceptual evaluation of why the burden occurs and hence more detailed exploration of solutions. The barriers, facilitators and solutions given within the tables are simply listed, and not defined or discussed within the text, and this is a limitation. Discussion The discussion summarises the findings well and addresses some of the strengths and limitations. However the authors state that data saturation was reached, but do not define what they mean by saturation, nor how this judgement was made. The authors state that person-centered care is fundamental but do not define what they mean by this. Person-centeredness is a complex philosophical approach to care that has various elements that most certainly vary contextually and between professions, should therefore be more fully discussed – the reference to it is currently a bit glib. Better aligning the issue of person-centeredness to study findings and the barriers/facilitators and solutions would also strengthen the argument for its provision.

VERSION 1 – AUTHOR RESPONSE

Reviewer: 1

Reviewer Name: Carole Parsons

Institution and Country: Queen's University Belfast

This is an interesting study of healthcare professional perspectives regarding minimising treatment burden and maximising patient capacity. The aims and methods have been well described, and the results clearly presented and discussed in the context of previous work in the field. Future work has also been clearly outlined.

The COREQ criteria for reporting qualitative research should be used and included in the supplementary files to illustrate where each of the criteria have been met.

Many thanks for your supportive comments. We did include an SRQR checklist with our paper, which is very similar to COREQ, and included as one of the options on the BMJ Open website as a checklist for qualitative research. We hope this is suitable.

Reviewer: 2

Reviewer Name: Jacqueline Morris

Institution and Country: University of Dundee

Please leave your comments for the authors below

This study addresses treatment burden, an important topic in post-stroke care, that is increasingly been seen as problematic for stroke survivors. The authors explore the views of a range of health professionals to identify the barriers and facilitators to minimising treatment burden.

The strength of this study is that it identifies pragmatic issues in the organisation of healthcare services that influence patient experiences of care after stroke. The main limitations are the description and justification of methods, which is scant in places, and the largely descriptive presentation of the data. Given the range of participants and contexts from which they were recruited, the richness and explanatory power of the study could have been stronger.

Abstract

The abstract identifies the key themes identified within the study, but does not mention the barriers, facilitators and solutions, that were the stated aim of the study.

Thank you for this comment. The key themes were reported in the abstract but as this was not clear, we have changed the wording to:

‘Barriers and facilitators to the provision of healthcare that minimises treatment burden and maximises patient capacity were reported under five themes: healthcare system structure e.g. care co-ordination and autonomous working; resources e.g. availability of ward nurses and community psychologists; knowledge and awareness e.g. adequate time and materials for optimal information delivery; availability of social care e.g. waiting times for home adaptations or extra social support; and patient complexity e.g. multimorbidity.

Introduction

The authors provide a definition of “treatment burden” and describe it as being the self-management workload experienced by stroke survivors. The authors imply that treatment burden relates to the work that is imposed by healthcare guidelines and systems and discuss difficulties in adherence to prescribed care. They appear to conflate treatment burden with self-management, without really defining what self-management is. I would argue that self-management is the actions and decisions people make themselves to manage their own health, with or without support from healthcare providers, and in the light of the information and knowledge that they have about their condition. This is qualitatively different from the idea of burden imposed by healthcare treatments and deficiencies in the healthcare pathway described in the introduction. I suggest the authors revisit this section and reconsider their use of the term self-management in this context or define more fully what they mean by it.

Many thanks for your interesting comments. It was not our intention to conflate the concepts of treatment burden and patient capacity, although these ideas are closely related they are certainly distinct from one another. We accept the current heterogeneity in the use of the term self-management in the medical literature and that using this term may be confusing to some readers. We have therefore removed this term from the introduction.

Methods

The methods are described in scant detail in places. It is not clear how participants were identified and recruited, by whom and in what contexts. The criteria and rationale for purposive sampling – maximum variation, theoretical, convenience etc are not described and there are no details about how the criteria were operationalised as the study progressed, or by whom. Was a sampling frame used? The authors mention that data collection and analysis occurred concurrently – how did that influence the sampling strategy? Context is extremely important for interpretation of qualitative data and more detail should be provided.

Thank you for this comment. We have updated the 'recruitment of participants' section to clarify that a combination of convenience and purposive sampling was used to identify potential study participants. The methods section now reads as follows:

'A combination of convenience and purposive sampling was used to select participants involved in the planning, management or delivery of healthcare to stroke survivors in one area of Scotland (NHS Greater Glasgow and Clyde Health Board). For inclusion, participants had to have worked within a relevant role in the past five years, be able to provide informed consent and be able to participate in a face to face interview. Initially potential participants were identified via their participation in the Scottish National Advisory Committee for Stroke, the Glasgow Stroke MCN, the Scottish Stroke Nurses Forum and the Scottish Stroke AHP forum. Potential participants were then contacted via email and those who expressed an interest were screened via telephone to ensure they met our inclusion criteria. During recruitment we continually monitored participant roles to ensure a balanced variety of healthcare professionals from throughout the stroke survivor journey were included. Analysis and recruitment were conducted as an iterative process with arising themes prompting recruitment of certain types of health professional. For example, our finding that psychology resources were limited prompted recruitment of a stroke psychologist.'

There should be more detail about how the interview schedule was derived. There is no description of any conceptual of theoretical basis for the study, therefore clear information about decisions on the structure and content of the interview schedule should be provided.

Thank you. Our work was underpinned by theory and on reflection we did not make this clear in our paper. We have added a sentence on Burden of Treatment Theory to the introduction:

'Burden of Treatment Theory is a formal theory that models the relationship between patients, their social networks and healthcare services.'

We have also clarified in the paper that our interview schedule was developed from the conceptual model and taxonomy of treatment burden we developed in our previous published work, as well as Burden of Treatment Theory:

'The interview schedule was underpinned by our conceptual model and taxonomy of stroke survivor treatment burden from previous work and by Burden of Treatment Theory.'

Similarly the ontological and epistemological basis for the study is not provided, and should be described to provide readers with a sense of where the authors are positioned on these matters.

Thank you. We have added the following to address this comment:

‘Indeed, we chose thematic analysis among other qualitative methods for its flexibility, while we position our study within the social constructionist epistemological tradition, according to which patterns of meaning and experience are socially produced and reproduced’.

The approach to ensuring coding reliability is rigorous, however it is less clear how the coding framework was derived. The authors discuss inductive and deductive coding, but do not describe how each approach was applied. As they were not using a theoretical framework to guide analysis, a description and distinction between deductive concepts and those that were inductively derived should be provided, to indicate how the final themes were arrived at.

Thank you for this comment. We have amended our methods section to add more detail as follows:

‘As a first step, eighteen broad thematic categories (nodes) were deductively generated and formed the code manual which can be found in Appendix 4. Each node contained two sub-categories (sub-nodes): ‘facilitators’; and ‘barriers’ and then a third sub-category ‘improvements’ was added inductively during analysis due to participants commonly suggesting potential improvements to services. The second step involved the testing of the reliability of the coding template. A researcher (DS) with considerable experience of qualitative data analysis but not of health-related research coded all transcripts. NVivo software was used to aid this process. Then four transcripts were also coded independently by another author (JK), an academic GP who had some prior knowledge about the topic being researched through his clinical experience. Any differences between coding were discussed. No major conflicts arose. The third step involved the recoding of the entire dataset using NVivo software. Analysis of the interview transcripts at this stage was guided, but not limited, to the initial codes. Inductive codes were assigned to parts of data that described a new theme observed in the text. These new codes were either separate from or expanded a code from the original template. The final step focused on connecting the codes and identifying and clustering the main themes that emerge within the dataset. These broad thematic categories were further clustered into overarching themes and were assigned succinct descriptions that captured the essence of each theme. Coding clinics were also held between DS, JK, KG and FM to discuss coding and to shape overarching themes. In order to ensure that the final clustered themes were representative of the initially assigned codes, preceding stages were carefully scrutinised before proceeding to the interpretation of the coded text.’

Why was thematic analysis selected as the analytical approach? As there are many analytical methods in qualitative research, it is important to specify why one approach was selected over another, and this should probably be seen to relate to the philosophical approach adopted for the study.

Thank you. As stated above, we have added the following sentence into your methods section:

‘Indeed, we chose thematic analysis among other qualitative methods for its flexibility, while we position our study within the social constructionist epistemological tradition, according to which patterns of meaning and experience are socially produced and reproduced’.

Results

The findings are clearly presented, but descriptive, as opposed to conceptual and explanatory. I would like to have seen more interrogation of the data to explore how and why the barriers and facilitators occurred in different settings and from the perspective of different participants. The idea of purposeful sampling is to identify a range of views so that contextual factors that influence experiences or perceptions can be explored. A range of professionals were interviewed, yet their distinctive perceptions were not really brought out. Whilst many issues would have been shared, the authors could have taken the analysis to a higher level by comparing and contrasting the views of different professional groups within different setting to explore the discussed phenomena in a more nuanced and richer fashion. For example, it would have been interesting and important to explore and compare within the dataset how the different professionals understand complex post-stroke difficulties experienced by patients. How complexity influences the treatment they provide or recommend, and its impact on burden could have been explored more fully to give a more in-depth explanation of the reasons for burden. Although the themes make sense, overall this reads a bit like a service evaluation, relevant to a particular service. Although qualitative research cannot be generalised, it often seeks to add conceptual or theoretical clarity, that can be examined more broadly beyond the specific setting. This is not a piece of work that can currently add much to broader conceptual understanding of burden because many issues are so service specific, but it could. I am sure if the authors took a more comparative approach to exploring how perspectives of participants agree or differ, and explored how context influenced them, they could provide a richer and more conceptual evaluation of why the burden occurs and hence more detailed exploration of solutions.

Thank you. We agree that the aim of qualitative research is not to produce generalisable, reproduceable findings, but to conduct and in-depth exploration of a topic with a rich description of key aspects of the context from which the findings emerge to allow the reader to make judgements about the extent to which they may be applicable to other contexts. We acknowledge this in our limitations section:

‘Qualitative research does not aim to be representative therefore the small sample size and purposive sampling technique should not be viewed as a limitation. However, findings should be considered as explorative and not definitive, and as all participants were employed in one geographical area, it would be beneficial to additionally study a group of health professionals from another locality.’

In acknowledgment of the reviewer’s comments, we have conducted additional data analysis as suggested in order to explore potential differences between type of health professionals and different contexts. We have added findings to our results such as:

‘ This issue was particularly raised by interviewees who work in the hospital setting, who seem to be more in need of more structured communication procedures, for example between health and social care’

‘ This opinion was expressed by more senior health professionals (i.e. 5+ years in the job)’.

‘In this regard, many participants from both settings argued for the enhancement of social network support, particularly for those with weak social networks, acknowledging their crucial role in the rehabilitation of stroke survivors.’

All additional sentences are clearly visible in the ‘marked up’ version of our paper.

The barriers, facilitators and solutions given within the tables are simply listed, and not defined or discussed within the text, and this is a limitation.

Thank you. In Tables 2 and 3 we detail the barriers and facilitators to providing care that minimises burden and maximises capacity within each overarching theme. In the text we describe and discuss in more detail pertinent factors that were commonly reported by participants. We feel this is a suitable way to present the data. We decided to report potential solutions in Table 4 only as there were less data to present in this category and we wanted to avoid unnecessary duplication in the text. Identification of potential solutions was not in our original aim, however collection and analysis of this type of data was added inductively due to many participants making useful and interesting suggestions about potential improvements to stroke services. This is made clearer in our methods section:

‘Each node contained two sub-categories (sub-nodes): ‘facilitators’; and ‘barriers’ and then a third sub-category ‘improvements’ was added inductively during analysis due to participants commonly suggesting potential improvements to services.’

We have added a little more detail about potential solutions in the discussion section and hope you find this suitable:

‘One example was the implementation of a named discharge co-ordinator who could facilitate a smooth transition into the community, improve communication between health and social services and act as a contact for patients. Another example was initiation of routine follow up reviews for more complex, multimorbid patients after discharge into the community, in order to deal with issues such as medicine reconciliation.’

Discussion

The discussion summarises the findings well and addresses some of the strengths and limitations. However the authors state that data saturation was reached, but do not define what they mean by saturation, nor how this judgement was made.

Thank you. We have clarified this in our methods section:

‘No further interviews were conducted once data saturation had been reached i.e. no new themes arose during analysis.’

The authors state that person-centered care is fundamental but do not define what they mean by this. Person-centeredness is a complex philosophical approach to care that has various elements that most certainly vary contextually and between professions, should therefore be more fully discussed – the reference to it is currently a bit glib. Better aligning the issue of person-centeredness to study findings and the barriers/facilitators and solutions would also strengthen the argument for its provision.

Thank you. We have added an explanation of what we mean by person centred care:

‘Person-centred care is healthcare that is tailored towards an individual’s circumstances and preferences, with flexibility in how care is delivered and shared decision between patient and health professional. Person-centred care prioritises the needs and wants of the patient taking careful consideration of their physical, psychological and social circumstances at the point in time when care is being delivered.’

VERSION 2 – REVIEW

REVIEWER	Jacqueline Morris University of Dundee
REVIEW RETURNED	10-Jan-2020

GENERAL COMMENTS	The authors have dealt with previous comments comprehensively, and there is a much clearer sense of the views and perceptions of the professions involved. i have no further comments.